



Masculinity as Defined by Males Self-Advocates with Intellectual Disabilities: A Focus Group Research Report

Katarzyna Ćwirynkało* , Beata Borowska-Beszta ** & Urszula Bartnikowska *** ^{15,2}

¹ *Katarzyna Ćwirynkało, Assistant Professor, University of Warmia and Mazury Poland,
k.cwirynkalo@uwm.edu.pl, katarzyna2710@wp.pl

**Beata Borowska-Beszta, Associate Professor, Nicolaus Copernicus University, Poland borbesz@umk.pl,
borbesz@wp.pl

***Urszula Bartnikowska, Associate Professor, University of Warmia and Mazury, Poland,
u.bartnikowska@uwm.edu.pl, ubartnikowska@tlen.pl

2 Article was written as part of the scientific activities by Members of the Special Adult Education Team functioning at the Unit of Special Education in the Committee of Educational Sciences of the Polish Academy of Sciences

Abstract

The paper presents the report analysis of the research undertaken in collaboration with male self-advocates with the usage of a focus group methodology. In the explanatory study the researchers explore topics of masculinity conceptualization of 9 males with intellectual disabilities. The main research question was: how do males with intellectual disabilities conceptualize masculinity? The main themes that emerged from the data collected in the interviews include: the males' identification with masculinity, their perceptions of masculinity, male role models and roles associated with it.

Keywords : Masculinity, intellectual disability, self-advocates, qualitative research, focus research

Introduction

In social constructionism identity is considered to be a socially produced phenomenon that arises out of our interactions with others (Burr 2003). Constructing one's identity involves his or her life experiences, relationships and connections with others (Dowling, 2011). Therefore people's identities are not stable – they are rather ever-changing and multifaceted (Azzopardi-Lane, Callus, 2015). Furthermore, their construction is based on our own perceptions, other people's perceptions of us, and our perceptions of others' perceptions (Mead 1934, in: Azzopardi-Lane, Callus, 2015). People with intellectual disabilities have often been seen, treated and called in a derogative way (Barnes, Mercer, 2008). Their social image is associated with such features as helplessness, vulnerability, unsuccessfulness, dependency and being 'eternal children' (Głodkowska, 2005; Ostrowska, 2015). These characteristics are in contrast with a commonly used, hegemonic perception of masculinity which is connected with institutional power and cultural ideal (Rushbrooke, Murray, Townsend, 2014). Although there is a growing interest of researchers in the area of masculinity and in the area of adulthood of people with intellectual disabilities, there is still little research on issues of gender in disability studies (Ćwirynkało, Borowska-Beszta, Bartnikowska, 2016). In this article we will try to contribute towards filling this gap by presenting research results on masculinity as perceived by males with intellectual disabilities.

Literature review

Self-advocacy and Disabilities

Self-advocacy of people with disabilities is a kind of disability activism. This may become a way to gain or improve some life-useful skills like: understanding one's disability, knowing one's abilities, limitations and needs, being aware of human rights, skills of effective communication of one's needs, teaching a new role. People with an intellectual disability learn to make choices, speak up for their rights, be confident, independent and responsible for their lives (Stalker, 1997, Goodley, 1998, Preston, 1998, Garcia-Iriarte, Kramer, Kramer, Hammel, 2009, Podgórska-Jachnik, Tłoczkowska, 2009, Beart et al., 2004, Gilmartin, Slevin, 2009, Roberts et al., 2014, Wamsley, 2014).

There is a growing interest in research (especially qualitative) connected with self-advocacy. Researchers show groups of self-advocates as groups which have positive impact on people with intellectual disability, their families, communities and even on policy

(Gilmartin, Slevin, 2009, Tilley, 2013, Hole, Stainton, Wilson, 2013, Frawley, Bigby, 2011). Some of the research show how intellectually disabled people define and experience themselves in the context of their self-advocacy, e.g. sexual and relationship self-advocacy (Azzopardi-Lane, Callus, 2015, Friedman, Arnold, Owen, Sandman, 2014, Owen, Arnold, Friedman, Sandman, 2016), health and aging in the context of self-advocacy (Feldman, Owen, Andrews, Hamelin, Barber, Griffiths, 2012, Hole, Stainton, Wilson, 2013), leadership and self-advocacy (Caldwell, 2010).

Theoretical Framework of Focus Group Research

Focus groups belong to the tradition of non-positivist qualitative research. They come from the ground of sociology (Morgan, 1988; Freitas, Oliveira, Jenkins, Popjoy, 1998; Barbour 2011), especially medical sociology (Kitzinger, 1994). For the first time academics mentioned their conduct in 1920 (Kitzinger, 1994, p. 103) and in 1950 Merton (1952) made use of them. Focus group studies, according to Barbour (2011), are widely used in health sciences and social sciences. Sometimes, according to this author they are used in sociological research, particularly medical sociology (Thomas, Taylor, 2001; Cox et al., 2003), psychological research (Wilkinson, 2003), business and marketing research (Blackburn, Stokes, 2001; Maison, 2001), in the areas of interpersonal communication and analysis of public relations (Kidd, Parshal, 2000 and others). Focus research is also carried out in education (Vilson, 1997), health education (Branco, Kaskutas 2001), special education and in disability studies (Holis, Openshaw, Goble, 2002; Gajdzica, 2013; Drzażdżewska, 2014; Kowalska 2015). This type of study is, according to Kitzinger (1994), a discussion of focus groups “organised to explore a specific set of issues such as people's views and experiences” (Kitzinger, 1994, p. 103). Morgan (1988) writes, that “crucially, focus groups are distinguished from the broader category of group interviews by 'the explicit use of the group interaction' as research data” (Morgan, 1988, p. 12). According to Krueger (1994) focus groups may be appropriate in projects involving small research.

Focus Group as Method or Technique

The research involving focus groups tends to be variously defined: 1) as a group conversation with a prepared script (Gawlik, 2012), 2) a method (Barbour, 2011) or 3) a technique (Morgan, 1988). According to Barbour (2011), focus group is a qualitative and comprehensive research method that allows to go beyond description and gain a deeper explanation (Barbour, 2011). According to Flick (2010) focus group is both an analytical method and a comparative study with the participation of a group of people, where a group discussion is lead on a specific topic (Flick, 2010). Freitas et al. (1998) write that „depending on the research objective, the focus group can be used alone or in conjunction with other methods” (Freitas, Oliveira, Jenkins, Popjoy, 1998 p. 6). Morgan (1997) writes “my own preference (Morgan, 1996) is for a more inclusive approach that broadly defines focus groups as a research technique that collects data through group interaction on a topic determined by the researcher. In essence, it is the researcher's interest that provides the focus, whereas the data themselves come from the group interaction” (Morgan, 1997 p. 6).

In this project, and the research report the authors adopted Morgan’s (1997) definition of the focus research, as a technique of data collection, which might be part of a broader research e.g. involving team work, inter-paradigmatic and interdisciplinary work. Furthermore, Morgan (1988), Greenbaum (1993), Krueger (1994) defines focus research in the context of their use in wider projects, taking into account the quantitative research. These authors suggest three ways of connecting data collection techniques in focus groups and quantitative research. They all suggest that focus group research can precede a quantitative

research method, can be used at the same time as quantitative research method, can follow a quantitative research method” Morgan, (1988); Greenbaum, (1993); Krueger, (1994).

Ethical Consideration of Data Collection

As any research in social sciences, this study was also bound to raise ethical issues, which need to be addressed. In this case they related mostly to the involvement of people with intellectual disabilities and the subject of the research, which was sensitive and deeply personal (Borowska-Beszta, 2015). According to Hammersley, Atkinson (2000), Denzin, Lincoln (2009), Flick (2010), Angrosino (2010), Barbour (2011), Jamielniak (2012), Ciuk (2012), the Ethics and ethical data collection is a key part of data collection. Rapley (2010) indicates the basic rules that must be adopted by a researcher. Flick (2010) writes about the problems broader. "Informed consent means that one should not take part in the research, without knowing it and without being able to express refusal. Researcher should avoid the hidden participant observations or providing participants with false information about the purpose of research. Researcher should respect the privacy of subjects and guarantee them full confidentiality (and keep his/her word). The accuracy of the respondents and their interpretation should put principle guiding research, and therefore are not allowed to conscious omissions or manipulation in the course of data collection and analysis. Care should be taken to study without harm considered. It should be fairly balanced the benefits and burdens binding for respondents from participating in the research."(Flick, 2010, p.123). The authors of the research accepted and implemented all ethical suggestions expressed by the above mentioned social scientists.

Data Analysis: Coding and Categorization Steps

In the analysis, the authors have used the technique of coding and categorization according to Flick (2010), Kvale (2010), Gibbs (2011). Flick (2010) writes that the aim of this technique is to find important items and then make their analysis by combining with other data and the naming and classification. The final stage of this process is a comprehensive grasp of the topic (Flick 2010). Encoding is an essential part of the analysis of the text. Analyses were carried out according to significance-oriented analysis of coding and categorization (Kvale, 2010), using the following steps:

- coding by assigning labels (basic words or group of words) as certain fragment of verbatim expression in order to later identify the expression of a subject;
- encoding process involving the segmenting of the data, comparing and conceptualizing the data segments in focus interviews
- generating the general categories (from the transcriptions) related to response to the main and detailed research questions
- categorization involving the cutting of the text (focus interviews transcriptions) into fragments entered in the research questions
- written presentation of results

Research Framework

Summary of Project

Focus groups were conducted in Poland in June 2016 in Occupational Therapy Workshops with 9 males (Peter, Andrew, Matthew, George, Damian, John, Conrad, Keith, Paul) with mild (2) and moderate (7) intellectual disabilities. The aim of the research was to find focus replying to one main research question and six detailed research questions concerning 9 males' conceptualization

of masculinity. The discussion was designed to gather information from the participants of the focus group with regard to the following outcomes:

1. What concept of masculinity do the members of the focus group have?
 - 1.1. How do the members of the focus group define themselves as males?
 - 1.2. What is their sense of masculinity?
 - 1.3. When, in their opinions, does one become a male?
 - 1.4. What are the qualities of good male?
 - 1.5. Who are the role models for the participants?
 - 1.6. What roles of males do the participants fulfill?

The participants of the focus group provided information in one way, as oral responses in group discussion.

Purposive Sample

Freitas et al. (1998) write, that “the general characteristics of the Focus Group are people's involvement, a series of meetings, the homogeneity of participants with respect to research interests, the generation of qualitative data, and discussion focused on a topic, which is determined by the purpose of the research.”(Freitas, Oliveira, Jenkins, Popjoy, 1998 p. 2) Overall, 9 self-advocates took part in the focus group research. The group consisted of males only (which was one of the criteria the researchers decided on). Their age varied from 22 to 58. Five of participants were in their twenties, one in his thirties, two in their forties and one in his late fifties. All of them were characterized as having intellectual disabilities. Although level of disability was not a formal criterion for purposive sampling, the resulting sample of participants had mild-to-moderate intellectual disabilities, sometimes accompanied by physical problems (two people on wheelchairs), and visual disability (one person – blind). All the participants used verbal communication.

The self-advocacy group involved in carrying out this research work within the Polish Association on People With Intellectual Disabilities. The meetings of self-advocates usually take place once a week in the day support center called Occupational Therapy Workshops (all of them attend the OTW every day). The entire self-advocacy group consists of twenty-five adults (males and females) with a moderate or even severe intellectual disabilities. The ages of the self-advocates vary from 21 to 58. Some of them are in part-time employment on the open market, usually with the assistance of an employee from the Occupational Therapy Workshops. The regular meetings of self-advocates are planned and led by a support member with a cooperation of the leader of the group who is a person with intellectual disability elected by the members themselves.

Data Collection

The focus group, consisting of 9 members, had undertaken meetings on three days in June 2016 (17/06/16, 23/06/16, 24/06/16). The venue was a day centre for people with intellectual disabilities (Occupational Therapy Workshops, OTW) located in a small town in north-eastern Poland, region called Warmia-Mazury where the participants regularly meet. The place of focus group meetings was a spacious room with a round table and chairs around it so that all the participants could keep an eye-contact with one another. Each session lasted approximately 60 to 90 minutes and was audio recorded.

Ethical Consideration

The participation in the focus group research was voluntary and all adult males were asked for and had to give their written consent to participate in it prior to the sessions.

Therefore, not every self-advocacy member who was invited, decided to take part. All of the members of the focus group were informed about the general research aims, and assured about guaranteed anonymity and confidentiality of their personal data. Their first names were encrypted and changed in this report. Participants of the focus group agreed about the issue that coded and transcribed data from focus meetings will be published in the research report. The male self-advocates we interviewed do not constitute a statistically representative sample so only internal generalization is possible.

Written Consent Form Content

Below we attach the content of the written consent form presented to the signing to the 9 adult males self-advocates:

- I hereby consent to participate in focus research, anonymous interviews for research tit. "Masculinity as Defined by Males with Intellectual Disabilities: A Focus Group Research Report"
- I agree to the recording and transcription of interviews in the belief that my personal data will be treated as confidential material and stored in such a way that only a person dedicated to the research project would have access to them. I understand that the original recordings will be destroyed within six weeks of making transcription.
- I agree to place the transcription of entire encrypted and anonymized interviews and posting them in the report focus
- I am aware that at any time I can withdraw from the study without giving a reason.

Results

Outcome 1.1: Understanding what personal definitions of themselves as males are held by the members of the focus group

When asked who they are, several men from the focus group explained that they fulfill two roles: of a participant of the Occupational Therapy Workshops and of a self-advocate, but – which is worth noting – they also mentioned that they ‘belong’ to a particular therapist (which can be associated with belonging to a certain theme workshop, like carpenter’s or sculptor’s):

"... I'm at Mrs. Anna's..." (Peter)

"... *I am with Mrs. Sylvia...*" (Andrew)

"I'm at the Occupational Therapy Workshop with Mr. Martin" (Matthew)

For two participants passion (acting, singing) appeared to be an important factor shaping the men’s identity. One of them emphasized his achievements associated with it: *"Recently, there was a song contest in Warsaw and I sang very nicely. I did a good job and got the prize. I won the first prize"* (Andrew)

In two other cases filling the specific role turned out to be connected with the participants’ state of health. This state determines the role - for them it was a limiting determinism, or rather deterioration of health that has become a barrier to fulfill a specific role:

"Unfortunately they suspended me on the practices because of health reasons" (George)

The participants’ self-identity turns out to be related to *places* where they spend time (e.g. Occupational Therapy Workshops), *people* they keep in touch with (mainly therapists, but also a group of self-advocates, a group of actors), and *their state of health*. Interestingly

enough, the feeling of ‘being someone’ is not necessarily dependent on the overall ability or disability of the body, but rather on experienced additional health problems.

None of the participants stated clearly that they were ‘men’, but – as it turned out later – they associated many features of a man with the features of a self-advocate and when asked directly whether they felt they were ‘males’, they all confirmed they did.

Outcome 1.2: Understanding what personal sense of maleness is held by the members of the focus group

The analysis of the participants’ statements shows that they perceived themselves as men because of certain behaviors which they considered to be typical of men. These behaviors were associated with being active as opposed to being passive.

It is noticeable that the participants connected being a man with various activities: helping others, appropriate behavior (e.g. towards women) and taking on responsible tasks (e.g. looking after animals). The respondents usually referred to activities that required a relationship with another person – which might imply that they construct their identity as men through relationships with others.

It is also clear that being a self-advocate and a participant of the Occupational Therapy Workshops where they meet people in need (e.g. people moving on wheelchairs), gives a lot of other opportunities to strengthen the participants’ sense of being men. The category of ‘helping’ appears here in the context of their own involvement and maleness:

"There are some colleagues on a wheelchair. I help them, and I feel like a man " (Peter)

"I feel as the guy, because I like to help, I like standing up for someone if they're in trouble" (George)

Since the key category that confirm someone’s masculinity in the opinions of the respondents was ‘helping’, we can conclude that it is the environment that enhances their feeling of being men. In some cases, their family home is another living space where they can confirm their identity as men. However, the condition is that they fulfill tasks which they consider to be male and responsible there:

"I help at home. I will feed rabbits. I'll give them drink" (Conrad)

"I also help my sister with the housework" (Damian)

The category of being a man implies a great deal of activity and responsibility. In the case of our participants the feeling of being a man is – in many ways – dependent on others – to what extent the environment responds correctly to their willingness to engage and will allow them to feel like men.

"In here it's us – the guys – who prepare the room" (John)

"We go to conferences and to all the people, and fight for our rights (...) We must set an example for others. Good example. As self-advocates we need to be an example here (...) A self-advocate must know his rights and must also be familiar with the rights of others and follow the rules (...) We help a lot. We help to carry the wheelchairs of our colleagues" (Peter)

"I also fight. Everyone is fighting for their rights. I don't give up" (George)

Although the participants had no doubts about the fact that they were men, in their life they experienced certain barriers that made it difficult for them to feel like ones. In particular, the lack of a female partner seemed to be crucial:

“The man is worthless without this, I think. I think that a man is worthless when he’s without a woman, for example” (Andrew)

“Yeah, we’re missing these partners. Definitely missing. Being alone is damned bad. When there’s a woman, you can sit and talk to her, go for a walk to church (...) And when you’re all by yourself? I’m all alone and what do I do? Nothing. (...) It’s good to have a friend. But you lack a woman” (Peter)

Being with a woman is presented here (especially in Andrew’s words) as the value which creates the overall value of a man. This is the element they all miss.

Outcome 1.3: Understanding the conditions of becoming a male in the opinion of the focus group members

According to the participants there are two main elements which confirm that someone became a man: reaching the age of 18 and receiving an identity card. In other words, becoming a man equals reaching a certain age by males. They perceived it as a universal principle. It is also worth noting that the self-advocates emphasized the similarities between the process of becoming a man with the process of becoming a woman. In both cases, as they argued, a teenage girl or boy becomes a woman or a man when they attain the age of maturity (18) as specified by law. Becoming an adult was also perceived in terms of gaining ‘your rights’ and the seriousness that from this moment seems to be a necessary feature of a person. Such an opinion is clearly visible in Peter’s statement:

“When you’re in your teenage years, it is not yet. Only when you are 18 years of age, you have your rights, your own ID. When a girl is 14 or 12, then no, but when she is 18 years old, she’s already an adult.” (Peter)

Outcome 1.4: Understanding the qualities of a good male in the opinion of the focus group members

Among the qualities of a man mentioned by the participants there are features connected with 1) manners: politeness, modesty, courtesy, 2) appearance: being clean and well-dressed, 3) relationships with others: taking care of others, being able to make them (especially women) feel accepted or happy, 4) attitude towards life: being a long-life learner, and 5) practical skills.

“He must be polite, modest, caring. He must be careful about his look. And he must be very clean. He must take care of himself, his look. He must pay attention so that a woman looked at him” (Peter)

“I can also say – as my friend mentioned – that when a guy says something, someone must feel accepted – to make a woman happy” (George)

“You can say that he that he teaches. He is a teacher and a learner – because he teaches others but also learns himself throughout the lifetime” (Keith)

“Well, every man should know how to do things. To do them. I learnt to... for example to paint the walls, to fix a table...” (John)

What is characteristic here is the fact that the participants talked about features they can also associate with themselves. An ideal man, in their point of view, does not have to be able-bodied, strong, confident or successful at work. Instead, he should be clean, modest and caring.

Outcome 1.5: Understanding the significant masculine role models in the opinion of the focus group members

An interesting theme that emerged in the interview was a model of a man – someone the participants wanted to follow. Two of our participants claimed that did not have such a model. Others spoke about it willingly and – in comparison to other parts of the interview – in a more vivid and engaged way. The statements of these participants indicate that usually close family members (e.g. brothers, fathers, stepfathers, grandfathers) served as such models. These were men that they had an intimate relationship with. The closeness of this relationship seemed to play a dominant role, because it allowed to experience the activities of a ‘significant other’ and to follow their pattern. Two elements seemed to be crucial: 1. engagement of the model man in a relationship with the participant and 2. helping the model man. These activities were accompanied by commitment and kindness (although the relationships could be rough and strict sometimes).

The respondents emphasized the importance of common activities they got involved in with the ‘model men’. These activities included leisure time activities (“*We go cycling together and to the swimming pool and things like that*”, Mathew), teaching a disabled boy / man new knowledge and skills (some participants highlighted that these were typically male activities), as well as the introducing to the social world (“*My father took me to conferences. He took care of me and taught life*”, Paul). An important element of this relationship was the opportunity to obtain physical and psychological support from the significant other, which is illustrated in the following statements:

“For me, it was my father, although now I live with two brothers. He taught me a lot of things, showed me how you can do it. He taught me so that I could put parts together to make a cabinet, how to fix a table” (John)

“... for me it was my brother. Cause he was such a heart for me... Really...” (Damian)

“I loved my father. He always supported me. He helped me a lot. Also emotionally. I was more attached to my dad than mum” (Paul)

Not all of the relationships described continued. Some ceased with the death of a ‘significant other’, others – after certain events in their life (e.g. moving out, divorce), but the impact on the respondents is still clear and highlighted by them:

“We no longer live together. He has his a family” (Damian)

“For me it was the grandfather. And now, after his death, it is... well... I miss him” (George)

Outcome 1.6: Understanding the masculinity roles that are already implemented by the focus group members

In one of the focus group meetings the men had a chance to say how they perceived important male roles, including the role of a father and a woman's partner. The analysis of the participants’ statements shows that – according to them – features of an ideal partner and an ideal father of a child are the same. The man in these roles should be: sensitive, understanding, kind, polite, eloquent, hard-working, committed and active (to serve home, family). The ability to ‘educate the family’, ‘feed the family’, ‘be the head of the family’ was emphasized.

The comparison of the role of a man and a woman in a relationship and family on the one hand shows the similarity of characteristics associated with a good partner, irrespective of their sex (a woman-partner should be: caring, compassionate, intelligent, nice, polite), on the

other it also shows a stereotypical differentiation (she should be ‘a diligent homemaker’, be neat in dress and appearance). This is well illustrated in Keith’s summary:

“[A man] must feed his family, work, support everyone in the family so that nothing was lacking. Simply the head of a family (...) women are more for washing, cooking and taking care of a child. And guys are more for work” (Keith)

Not all participants, however, shared Keith’s opinion. Some expressed their strong opposition to these stereotypical beliefs. Two of them, giving examples from their personal experiences in family life, talked about the possibility of sharing responsibility (or co-responsibility) for the family and relationship by a man and a woman. Others noted that nowadays there are no universal standards for men and women both on the basis of family and professional life (*“But women also work. I know such cases (...) [a woman] can also be a breadwinner”*, Peter). The characteristic element which indicates that the participants recognized a greater responsibility of men than women in the family is, however, an opinion expressed by a few self-advocates that men should ‘raise a family’, while women should ‘raise children’.

Outcome 1.6a: Understanding the conceptualization of being a partner of a female by the members of the focus group

A male as a partner of a female

Out of the three participants who had some experience of being in a relationship with a woman, for two of them these were negative experiences (Peter and Keith). One caught his girlfriend cheating on him, the other does not know how to interpret the ambiguous behavior of women: “... but to me, damn, [women] make a fool of me. They trick me. Simply, they make a fool of guys” (Keith). These experiences make the men reluctant to speak about their relationships.

Nonetheless, the desire to have a partner / wife was declared by all the respondents. The purpose of such a relationship may be two-fold: 1) having someone to do the housework, which is stereotypically believed to be intended for a woman (e.g. washing, cleaning, cooking, taking care of a man: “Well, it seems I can clean the flat myself and do some things, but a woman could cook dinner or supper”, Peter; “She is useful... for the cleaning, cooking”, Robert), 2) accompanying the man and undertaking joint activities (“... to go out for a walk and talk together, eat dinner together, watch TV, when there’s a good movie”, Andrew).

Outcome 1.6b: Understanding the conceptualization of being a father by the members of the focus group

A male as a father

None of the self-advocates who took part in the research was a father, but everyone declared their willingness to become one (although some – especially the younger ones – admitted that they would rather wait with the decision). Their visions in which they saw themselves as future fathers were based on the observations of their family of origin and situations in close environment. The men, however, seemed to realize that in order to be fathers, they need to fulfill certain requirements, including having a job.

The participants’ statements indicate that there are two main reasons why they want to be fathers: 1) the need to fulfill oneself in a new role as well as checking whether they would cope to do it, 2) the need to provide care for themselves when they grow old.

Andrew’s statement is the illustration of the first reason: *“I would like to taste fatherhood a little bit... To see how it tastes, whether it is hard or easy. And to ensure the best*

possible welfare for children so that they had an apartment, for example. And to work... Simply, to raise them to be good people, right?"

Peter's opinion can serve as an example of the second approach: *"I would take a child from an orphanage for example. I'd ensure prosperity and jobs for them. And I'd also work and help, and raise them to be good people so that when I'm in my old age... I could have someone to take care of me."*

The analysis of the men's opinions reveals that, on the one hand, fatherhood is regarded as a challenge, on the other hand, it can be perceived as a kind of "investment" for the future. Peter expects reciprocal relationships with potential children. What is also worth noting, he introduces the topic of adoption. It turns out that the aim of being a father does not necessarily have to be connected with transferring one's genes, but 'raising for oneself' a carer for their old age. Adoption and biological fatherhood became the subject of the participants' further reflections. Some of the self-advocates opted for biological fatherhood rather than fatherhood in general. In their statements, one might notice some uncertainty about the transmission of genes: *"But these [children] may, for example... You don't know what they'll be like, what they'll do..."* (Keith).

Others argued that it does not really matter whether a child was adopted or biological as what the child would be like is dependent mainly on their parents. Therefore every child should be loved in the same way.

To sum up, trying to understand the conceptualization of masculinity by the members of the focus group, we discovered that:

- the participants' self-identity is usually connected with places they stay in (e.g. OTW), people they spend time with (e.g. their therapists or trainers at Workshops), activities they are involved in (e.g. acting, singing, self-advocacy), and their state of health;
- all the participants perceive themselves as males and are aware of the features that make them 'males', e.g. being active, helpful, responsible;
- according to the participants, a boy becomes a man when he reaches the age of 18 and receives an ID;
- the distinctive features of males, in the focus group members' opinion, include characteristics connected with manners (e.g. politeness, modesty), appearance (e.g. being clean), relationships with others (e.g. taking care of others), attitude towards life, and practical skills;
- most of the participants claimed that they did have male models in their lives – usually close family members they had close, engaging and supportive relationship with;
- according to the focus group members important roles of a male are those of a partner and a father and a man fulfilling such roles should be: sensitive, understanding, polite, eloquent, hard-working, committed and active.

Discussion

A person's identity can be linked to a variety of factors, including gender, racial and cultural heritage, age, social class or sexual preference and is constructed both by the person and through the environment (early socialization and expectations from family, friends and community) (Dowling 2011). In the present study we proved that intellectual disability does not have to be a dominant feature determining a person's self-identity. Rather, while defining who they were, the participants referred to their activities (being a self-advocate, an employee in the Occupational Therapy Workshops), places they spend time in, people they have close relationship with, and their state of physical health. Also, being a male was a significant part

of the self-advocates' identity. This masculinity, however, can be argued as a *reliant masculinity* which is the antonym of hegemonic masculinity (Wilson et al., 2013). Although they did consider themselves as active, helpful, engaged (features they associated with both being a male and a self-advocate), they also felt some constraints connected with the desire to fulfill the roles typical of males. Being a female's partner ("You're not fully a man without a woman", Andrew) and a child's father can be described here as *possible masculinity*, which is a future-oriented goal for males' identities that is based mainly on what they want to be in the future (Davies, Shen-Miller & Isaco, 2010).

Despite the benefits, the study definitely had some limitations as well. It was limited by a small sample size and as with all qualitative research its results are not generalizable. Although participants were diverse as far as their age and abilities are concerned, they were all from an organization situated in a small town in northern Poland and lived either in the town or in rural areas. It is possible that the results would be different in large urban settings with lower unemployment rates and better access to cultural facilities.

Conclusion

The findings of the study reflect a diversity of the self-advocates' views with respect to masculinity. Becoming an adult can open up a great deal of opportunities for any person, also the one with an intellectual disability. The participants of the focus group described in the study consider themselves as males for several reasons. First, they are all over 18 years of age and own their identification card. Second, they believe they can be characterized by features typical of males: being active, helpful and taking responsibility for serious tasks. According to the members of the group an ideal male should be polite, modest, courteous (good manners), clean and neatly-dressed (the right appearance), skillful (practical skills) and take care of others (good relationships). What is also worth noting is the fact that these are the features the participants associate themselves with so, in a sense, their perception of self is that they are masculine. There are some constraints, however, as they (usually) do not fulfill the roles which they consider to be important for males, i.e. the role of a female's partner and a child's father. Most of the participants did not have partners at the time of the interviews, although all of them expressed their desire to have one. Also, none of the participants was a father and everyone declared the willingness to be one. The self-advocates believed that males fulfilling such roles should be characterized by such features as sensitivity, politeness, eloquence, diligence, commitment and activeness. These features are similar to the ones associated with the participants' role models: significant males (usually close family members – fathers, grandfathers, stepfathers) they would like to follow. Exploring this topic showed deeply personal opinions of the group on their self-identity as males and needs to fulfill the roles to maximum of their potential.

References

- Angrosino, M., (2010). *Badania etnograficzne i obserwacje*. Warszawa: PWN.
- Azzopardi-Lane, C. & Callus, A.-M. (2015). Constructing sexual identities: people with intellectual disability talking about sexuality. *British Journal of Learning Disabilities*, 43(1), 32-37.
- Barbour, R., (2011). *Badania fokusowe*. Warszawa: PWN.
- Barnes, C., Mercer, G. (2008). *Niepełnosprawność*, Warszawa: Sic!

- Beart, S., Hardy, G., Buchan, L. (2004). Changing selves: a grounded theory approach of belonging to a self-advocacy group for people with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities*, 17 (2), 91-100.
- Blackburn, R. & Stokes, D. (2000) Breaking Down the Barriers: Using Focus Groups to Research Small and Medium-sized Enterprises, *International Small Business Journal*. 19(1): 44–67.
- Branco, E. I. & Kaskutas, L.A. (2001). “If it burn going down...”: How focus groups can shape Fetal Alcohol Syndrome (FAS) prevention. *Substance Use and Misuse*, 36 (3), 333-345.
- Borowska-Beszta B., (2015). Methodological Issues Related to the Rapport and Data Collection while Qualitative Researches in Special Andragogy Areas. *International Journal of Business and ICT*, 1(3-4), 1-11.
- Burr, V., (2003). *Social constructionism*, 2nd edn. London: Routledge.
- Caldwell, J. (2010). Leadership development of individuals with developmental disabilities in the self-advocacy movement. *Journal of Intellectual Disability Research*, 54, 1004–1014.
- Ciuk S., Latusek-Jurczak D., (2012). *Etyka w badaniach jakościowych* (w:) Jamielniak D., (2012). *Badania jakościowe. Metody i narzędzia*, T.1., Warszawa: PWN s. 23-40.
- Cox, H., et al. (2003). Learning to take charge: Women's experiences of living with endometriosis. *Complementary Therapies in Nursing and Midwifery* 9(2): 62-8.
- Ćwirynkało, K., Borowska-Beszta, B., Bartnikowska, U. (2016). Masculinity and Intellectual Disability: A Review of Theoretical Concepts and Research. *International Journal of psycho-educational studies*, 5(12), 36-50.
- Davies, J. A., Shen-Miller, D. S. & Isacco, A. (2010) The men’s center approach to addressing the health crisis of college men. *Professional Psychology: Research and Practice*. 41. pp. 347–354.
- Denzin, N. & Lincoln Y., (2009) *Metody badań jakościowych*, T., 1, 2. Warszawa: PWN
- Dowling S.J. (2011). *Constructing Identity. Identity Construction*. Thesis. Georgia State University. Retrived from: http://scholarworks.gsu.edu/cgi/viewcontent.cgi?article=1089&context=art_design_theses (24/10/2016)
- Drzażdżewska, K., (2014). *Jak przedszkolaki rozumieją niepełnosprawność? Badanie fokusowe*. Niepublikowana praca magisterska napisana po kierunku dr hab. B. Borowskiej-Beszty, Prof. UMK
- Feldman, M.A. & Owen, F. , Andrews, A., Hamelin, J., Barber, R., Griffiths D. (2012). Health self-advocacy training for persons with intellectual disabilities. *Journal of Intellectual Disability Research*, 56, 1110–1121.
- Gibbs, G., (2011). *Analiza danych jakościowych*. PWN, Warszawa
- Głodkowska, J. (2005). Między integracją a izolacją – jedność w zróżnicowaniu a oddzielenie w odmienności. In: M. Orłowska (Ed.), *Skazani na wykluczenie* (pp. 109-119). Warszawa: APS.

- Goodley D. (1997). Supporting people with learning difficulties in self-advocacy groups and models of disability. *Health and Social Care in the Community*, 6(6), 438–446.
- Flick, U., (2010). *Projektowanie badania jakościowego*. Warszawa: PWN.
- Francis, D. J., Rivera, M., Lesaux, N., Kieffer, M., & Rivera, H. (2006). *Practical guidelines for the education of English language learners: Research-based recommendations for instruction and academic interventions*. Texas: Center on Instruction.
- Frawley, P. & Bigby Ch., (2011) Inclusion in political and public life: The experiences of people with intellectual disability on government disability advisory bodies in Australia. *Journal of Intellectual & Developmental Disability*, 36(1), 27-38.
- Freitas, H., Oliveira, M., Jenkins, M., Popjoy, O., (1998). The Focus Group, A Qualitative Research Method. Isrc, Merrick School Of Business, University Of Baltimore (Md, Eua), Wp Isrc No. 010298, 22 P. – tu nie mamy miejsca wydania
- Friedman, C., Arnold, C.K., Owen, A.L., Sandman, N. (2014). ‘Remember Our Voices are Our Tools:’ Sexual Self-advocacy as Defined by People with Intellectual and Developmental Disabilities. *Sexuality and Disability*, 32, 515–532.
- Gajdzica, Z., (2013). *Kategorie sukcesów w opiniach nauczycieli klas integracyjnych jako przyczynek do poszukiwania koncepcji edukacji integracyjnej*. Kraków: Wyd. Impuls”
- Garcia-Iriarte, E., Kramer, J.C., Kramer, J.M., Hammel, J. (2009). ‘Who Did What?’: A Participatory Action Research Project to Increase Group Capacity for Advocacy. *Journal of Applied Research in Intellectual Disabilities*, 22, 10–22.
- Gawlik, K., (2012). Badania fokusowe. In: D. Jamielniak (Ed.), *Badania jakościowe. Metody i narzędzia. T 2*. Warszawa: PWN
- Gibbs, G., (2011). *Analiza danych jakościowych*. Warszawa: PWN.
- Gilmartin, A., Slevin, E. (2009). Being a member of a self-advocacy group: experiences of intellectually disabled people. *British Journal of Learning Disabilities*, 38, 152-159.
- Gilmartin, A., Slevin, E. (2009). Being a member of a self-advocacy group: experiences of intellectually disabled people. *British Journal of Learning Disabilities*, 38, 152–159.
- Greenbaum, T. L., (1993). *The Handbook Goes Focus Group Research*. New York: Lexington Books
- Hammersley, M., Atkinson P., (2000). *Metody badań terenowych*. Poznań: Zysk i S-ka.
- Hole, R.D., Stainton, T., Wilson, L. (2013). Ageing Adults with Intellectual Disabilities: Self-advocates’ and Family Members’ Perspectives about the Future. *Australian Social Work*, 66, 4, 571-589.
- Hollis, V., Openshaw, S & Goble, R., (2002). Conducting focus groups: Purpose and practicalities. *British Journal of Occupational Therapy*, 65(1): 2-7.
- Jamielniak, D., (2012). *Qualitative Researches, Methods and Tools*, Warsaw: PWN.
- Kitzinger, J., (1994). The methodology of focus groups: the importance of interaction between research participants, *Sociology of Health* 16 (1): 103-21.
- Kowalska, H., (2016). *Co wiedzą o niepełnosprawności uczniowie klasy II szkoły odstawowej? Badania fokusowe*. Niepublikowana praca magisterska napisana po kierunku dr hab. B. Borowskiej-Beszty, Prof. UMK

- Kidd, P., S. & Parshall, M., B., (2000). Getting the focus and the group: enhancing analytical rigor in focus group research, *Qual Health Res.* May;10 (3):293-308.
- Krueger, R. A., (1994). *Focus Groups: The Practical Guide Goes Applied Research.* Thousand Oaks: Sage Publications, 2nd. Ed.,.
- Kvale S., (2010). *Prowadzenie wywiadów.* Warszawa: PWN
- Lederer, J. (2000). Reciprocal teaching of social studies in inclusive elementary classrooms. *Journal of Learning Disabilities, 33*, 91-106.
- Maison D., (2001). *Zogniskowane wywiady grupowe. Jakościowa metoda badań marketingowych,* Warszawa: PWN
- Mead, G.,H. (1934). *Mind, self, and society.* Chicago, IL: University Chicago Press.
- Morgan, D., L. (1996). *Focus Groups. Annu. Rev. Sociol. 22:*129-52.
- Morgan, D. L., (1997). *Focus Groups As Qualitative Research* Portland: State University
- Ostrowska, A., (2015). *Niepełnosprawni w społeczeństwie 1993-2013.* Warszawa: IFiS PAN.
- Owen, A., Arnold, K., Friedman C., Sandman, L. (2016). Nominal Group Technique: An accessible and interactive method for conceptualizing the sexual self-advocacy of adults with intellectual and developmental disabilities. *Qualitative Social Work, 15*(2), 175-189.
- Podgórska-Jachnik, D., Tłoczkowska D. (2009). Ruch self-advokatów jako rozwijanie kompetencji w zakresie rzecznictwa własnego osób z niepełnosprawnością intelektualną. In: D. Podgórska-Jachnik (Ed.), *Problemy rzecznictwa i reprezentacji osób niepełnosprawnych* (pp. 177-189). Łódź: WSP.
- Preston, A. (1998). Developing Self Advocacy Skills in Adults with Learning Difficulties and Challenging Behaviour. *British Journal of Learning Disabilities, 26*, 27-36.
- Rapley T. (2010). *Analiza konwersacji dyskursu i dokumentów.* Warszawa: PWN.
- Roberts, E.L.& Ju, S., Zhang, D. (2014). Review of practices that promote self-advocacy for students with disabilities. *Journal of Disability Policy Studies, 26* (4), 209-220.
- Rushbrooke, E., Murray, C. & Townsend, S. (2014). The Experiences of Intimate Relationships by People with Intellectual Disabilities: A Qualitative Study. *Journal of Applied Research in Intellectual Disabilities, 27*(6), 531-541; DOI: 10.1111/jar.12091.
- Stalker, K.,(1997). Choices and voices: a case study of a self-advocacy group. *Health & Social Care in the Community, 5* (4), 246-254.
- Thomas, V., J. Taylor L., M. (2002). The psychosocial experience of people with sickle cell disease and its impact on quality of life: Qualitative findings from focus groups, *Br J Health Psychol.:*7(Part 3):345-363.
- Tilley, E., (2013). Management, Leadership, and User Control in Self-Advocacy: An English Case Study. *Intellectual and Developmental Disabilities, 51*, 6, 470-481.
- Wamsley, J., (2014). Telling the History of Self-Advocacy: A Challenge for Inclusive Research. *Journal of Applied Research in Intellectual Disabilities, 27*, 34-43.
- Vilson, V.,(1997). Focus Groups: A Useful Qualitative Method for Educational Research? *British Educational Research Journal* Vol. 23, No. 2 (Apr., 1997), pp. 209-224

- Wilson, N.J., Parmenter, T.R., Stancliffe, R.J. & Shuttleworth, R.P. (2011). Conditionally Sexual: Men and Teenage Boys with Moderate to Profound Intellectual Disability. *Sexuality and Disability*, 29, 275-289.
- Wilkinson, S., (2003). Focus Groups. In J., A. Smith, *Qualitative Psychology: A Practical Guide to Research Methods*, London: Sage pp. 184-204.