

Polish Parents with Intellectual Disabilities: A Case Study Report

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Abstract

The purpose of the study is the attempt to present the empirical aspects of raising children by parents with intellectual disabilities. The author describes the methodology of qualitative case study and the research report and results after analysis of 5 Polish parents (3 females and 2 males) with mild intellectual disabilities (IQ 70-50). The main research question was: What are the concepts of parenthood held parents with intellectual disabilities? How do intellectually disabled adults' function in their roles of parents?

Keywords: Parenthood, intellectual disability, qualitative research, case study.

Introduction

People occupy certain roles in a society from an early age. These roles may result from people's own choices or they may be associated with social tasks which people are supposed to accomplish at a certain stage of their lives.¹ Adulthood involves taking up special roles of spouses and parents.² Stelter³ by referring to Levinson's theory highlights that starting a family, together with professional commitments, constitutes the basis for the human's whole life structure whereas the fact of becoming a father/ mother strengthens family ties and serves as a basis for the spouses to take actions that aim at providing the family with all relevant goods.⁴

In intellectually disabled people's adulthood, there is also a need for loving someone as well as for being loved not only by the parents.⁵ According to Janiszewska-Nieścioruk⁶ and Borowska-Beszta⁷, a desire for having a spouse and being a parent is very often emphasised by intellectually disabled people. However, as noticed by Parchomiuk², marriages and procreation in the case of intellectually disabled people still meet with social resistance and lack of approval. Żyta⁸ adds that negative social attitudes as well as a legal basis and the lack of relevant assistance and support provided to the intellectually disabled make them fail to take on the roles of spouses or parents. It is therefore beyond doubts that it is incredibly important and significant to raise the issues concerning the problems that affect intellectually disabled people, especially the problems relating to marriages and procreation.

Based on source literature, empirical issues concerning procreation and marriages of intellectually disabled adults in Poland have been studied by M. Kościelska⁹, Zawiaślak^{10,11}, Żyta⁸, Lizoń-Szlapowska¹², Wołowicz- Ruskowska¹³,

Bartnikowska, Ćwirynkało and Chyla¹⁴, Nowak-Lipińska¹⁵, Grütz¹⁶, Kijak¹⁷ and others.

Research Design

This qualitative research report – a case report – focuses on discovering and studying the concept of own parenthood in people with intellectual disabilities. Moreover, the studies aimed at learning how intellectually disabled adults' function with regard to their roles of fathers and/or mothers. The research problem has been identified with reference to the social problem as well as theoretical and empirical scientific analyses concerning taking on the roles of spouses and parents by intellectually disabled people in Poland that have been conducted in the field of social sciences.

Kornas-Biela¹⁸ states that regarding the Polish scientific discourse, “marital and family roles together with procreation constitute the most frequently overlooked problems, next to spirituality and religiousness, with regard to intellectually disabled people, in both source literature as well as everyday life and various measures undertaken in their favour” whereas Żyta⁸ believes that “for many years the issue of intellectually disabled people getting married or becoming parents has been absent in scientific research. If addressed, it was considered in terms of minimising the probability of the occurrence of such events rather than searching for the ways of support.”

For the above reasons, it seems justified to undertake further educational studies that would expand our knowledge on marriages and procreation of intellectually disabled people.

Methods

In terms of epistemology, the studies have been based on interpretive paradigm whereas the project has been defined as qualitative research according to the assumptions of the following authors: Denzin and Lincoln¹⁹, Borowska-Beszta²⁰, Flick²¹, Jemielniak²² and Kubinowski²³. A case report served as a scientific strategy in the studies. An interviewing technique was used to collect the research material. The data collected through interviews were analysed in terms of areas and images according to Spradley in Borowska- Beszta²⁰.

The research project aimed at gaining information on how intellectually disabled adults perceive themselves in their roles of parents and what concepts of parenthood they have as well as finding the answers to the following research questions: What are the concepts of parenthood held parents with intellectual disabilities? How do intellectually disabled adults' function in their roles of parents?

Purposive Sample: In the research, 5 parents with intellectual disabilities (3 adult mothers with and 2 adult fathers) participated. All participants have mild intellectual disability (IQ 70-50). Two of them are also physically disabled. Their age ranged between 29 and 58 years. The personal data of the participants were encoded during the research process. The selection of the participants for this qualitative research was purposive. I used the following criteria while selecting the targeted sample: first of all – availability of the informants, in accordance with U. Flick's²¹ guidelines (2010); and second of all – the fact of being an intellectually disabled adult parent.

Data Collection: The studies were conducted for 13 months between November 2016 and December 2017 due to difficulties to get access to proper informants with mild intellectual disabilities who are parents. Verbal data were gathered through 5 interviews. First step in this research project was to locate the informants. Once two informants (married) had given their initial consent, I visited them at their place of residence to conduct interviews. Thanks to the courtesy of the above-mentioned informants, I got contact information and initial declarations on study participation from the rest of my informants. Just before I entered the research area, I had prepared the interview matrix.

While conducting this research project, I aimed at taking actions that would respect ethical principles. Therefore, just before I entered the research area, I had analysed Rapley's²⁴ approach and prepared my informed consent form on its basis. The prepared written informed consent form included detailed information about the interview. It included, among others, the information that the interview would be individual and free. Moreover, I included the information that by signing the informed consent the participant gives his/her consent to recording and making a transcript of the interview as well as encoding his/her personal data. What is more, the informed consent included the information that the informant might withdraw his/her consent for study participation at any time without providing reasons for resignation. All informants gave their written consent to take part in the study by signing the consent form.

In order to make research reliable, I used triangulation. Denzin defines triangulation as “a combination of different research methods in the study of the same phenomenon”.²⁵ Research involved data triangulation; I used different sources of information as I gathered data from different informants.

Data Analysis: Verbal data gathered at the research area were analysed with regard to analytical categories called images – a term by Borowska-Beszta²⁰.

The analytical process started with forming the research questions as follows: “What are the concepts of parenthood in people with intellectual disabilities? How do intellectually disabled parents' function in their roles of fathers or

mothers?” Then I encoded the personal data of the participants. I named my informants with adjectives that described their characters. I used the following codes: cheerful, creative and talkative for women and shy and reserved for men. Then, following guidelines of Borowska-Beszta²⁰, I familiarised myself in detail with the collected research material in order to differentiate analytical areas.

I distinguished the following categories (images):

- **IMAGE 1 – “Being a parent means...”**
1a – “motherhood/fatherhood for me means...”
1b – “I would like my parenthood to be...”
- **IMAGE 2 – “Me and my child...”**
2a – “My day with my child...”
2b – “Parental difficulties and problems...”

IMAGE 1 – “Being a parent means...”

Image 1a – “motherhood/fatherhood for me means...”

Intellectually disabled adults believe that being a parent is the most beautiful thing people may experience in their lives. It is a unique experience for every parent. For all the informant, being a mother/father is a meaning and fulfilment of life. It is great love. The participants stress that a real family is a family with children. What is more, the participants most importantly highlight that parenthood is not only happiness, but also responsibility for another life. It is a duty that changes the current life.

“for sure a fulfilment and meaning uhm in terms of starting a family (3.0) (CHEERFUL);

“great love (2.0), but... also great responsibility (3.0), because... when a family wants a child... they must (2.0) realize that it will be a great... responsibility (3.0) – that... a child changes everything (4.0) and needs to be taken care of (2.0) so that it feels needed (4.0) and loved” (CREATIVE);
“I am really happy (2.0), I like being a mother (3.0), uhm, I am happy with it (2.0), I love my children very much (3.0), but sometimes it is so difficult (3.0), because they must have a bath (2.0), they must be... helped with everything (3.0), washed... and, when I don't have the strength for it, my husband washes them (2.0), you know... you must do something with them all the time” (TALKATIVE);

“yeah, it is great to be a dad (3.0), you have somebody... to live for, it is a pleasure when I come back home and there are children (2.0), but when they were younger I had to have two jobs because we needed more money (2.0) and there is always something to do with them, because they are ill so, you know, uhm we must look after them” (RESERVED);

“being a dad is really wonderful (2.0), uhm I am happy that I have my J. (3.0) although I know that I need... to take care of her” (SHY).

Image 1b – “I would like my parenthood to be...”

Parenthood has always been perceived as something special, wonderful by the informants. The participants emphasize that they have dreamt of being a mother/father since their childhood and despite many misfortunes and difficulties they have believed that one day they will fulfil this dream. All the participants stress that they would like to be good parents. Two concepts of parenthood may be distinguished from the participants' utterances. Two female informants are very indulgent towards their children, they fulfil all their expectations and needs, doing many activities for them and devoting all their time to the child. The other informants stress that the main idea of parenthood is a desire to teach them responsibility and conscientiousness, introducing household chores since an early age.

“it was such a dream (3.0), it seems that since I became aware... that I would also like to be a mother (2.0) and when I became a mother, I decided that I would be the best mother in the world (...), I want... my children not to lack anything, so they have everything they want (2.0), uhm, I let them do anything so that they do not feel worse that they have such a mother” (CHEERFUL);

“I have always wanted to have a baby (2.0), but... I was afraid that I would not make it (3.0), I've prayed and believed that... God will give me a baby. When I got it, I knew that I need to be good for her (2.0), I buy her everything what she wants (2.0), we take her to many different places. So that she can have what other children have or even more... (2.0)” (CREATIVE);

“uhm yeah I really wanted to be a mother (3.0), when I had, I was, I always said that I want to give birth to children (2.0), I myself allow my children to do a lot, but they also need to know that there are things you don't do. They also have some chores that they have to do at home. So that they are not too spoiled” (TALKATIVE);

“when I was like I don't know... maybe seventeen, I wanted to have children, Of course, children are nice, but they have to know that they can't do everything. And... you have to teach them to work and... go to school. Because if I do everything for them, I will worry about their lives later” (RESERVED);

“I have always dreamt of having children (3.0), but... they told me at home that I would not have them (3.0). It's nice that I have J., that it happened. I try to be a good father for her, I spoil her (2.0), but not so much as A. (2.0), she allows her to do everything, I want her to be well-behaved when she goes to school and can do different things (2.0), so that other children don't laugh at her” (SHY).

IMAGE 2 – “Me and my child...”

Image 2a – “My day with my child...”

These are mainly mothers who take care of children. The men spend time with their children on non-working days. The participants spend most of their time with children in the

same way. There is a routine notable in their everyday life. Sundays and other public holidays are exceptions. However, the informants every day try to spend their time with children in an interesting way.

“most of our days is the same... in the morning the children go to kindergarten (2.0) and when they come back home, we eat dinner (2.0), in the evening there is supper and when the dad comes back from work we often go out (3.0), the girls really like going to the playground (2.0), climbing... wall, swings, slides... and of course to the... sandpit (3.0); when there are holidays we meet our family” (CHEERFUL);

“J. doesn't go to school yet so we are together at home (2.0), because my husband works (3.0), we cook together, clean... and play (2.0), we like puzzles most (2.0), I mean jigsaw or building blocks (3.0), we... also like going to the playground (2.0). J. likes swings (3.0), J. also likes drawing (we draw together) (3.0), or we listen to music (3.0), then she watches cartoons (3.0), we play... board games (.), play with a ball” (CREATIVE);

“we spend all our time at home (because there is no place to go out) and we always have something there (ha ha) (3.0), and... yeah they like watching television (2.0), some jigsaw puzzles. I used to go with them for walks, there, to the palace (because it's close) (3.0), they also like when the music is playing and then they dance and sing (4.0), nothing more” (TALKATIVE);

“now I work less so I can spend more time with them (2.0), but... then we stay at home or go to the palace for a walk uhm (2.0) and so we walk (3.0), there are... birds, there are... ducks, there are... fish (2.0), we do these puzzles uhm, they also draw sometimes (3.0) and yeah they also like songs in television (they dance and sing then) (3.0)” (RESERVED);
 “when I come back from work after 5 p.m. we go for a walk every day (3.0), uhm we play with blocks too (4.0), we also draw” (SHY);

Image 2b – “Parental difficulties and problems...”

Intellectually disabled adults encounter many difficulties and problems in their lives just like other parents. The prevailing problem among the participants is a financial issue as only one spouse in the informants' families is professionally active. The parents also mentioned difficulties with nursing and care activities in the first years of their children's lives. Another significant problem enumerated by the disabled relates to their relationships with the closest family, which in many cases are difficult. Moreover, the parents are worried by the fact that their children could be harassed because of their parents' disabilities. They worry that the children may feel distress and may encounter difficulties which would be new to them. “we had most difficulties when the children were small (2.0), how to do everything with an infant and don't do any harm (3.0), now no, but my only my husband works so we also worry about money (3.0), I worry that they may be viewed

in a negative light some day because of my disability, but...uhm I try to be with them when I can (2.0)” (CHEERFUL);

“most of our difficulties are connected with money because only D. works and he doesn’t earn much and it is not always enough (2.0) and when it comes to the child, we do well, but at the beginning it was difficult (2.0), of course, I’m... afraid (3.0), I think about it from the very beginning (3.0), when she starts going to school, other children will point their fingers at her (3.0), laugh at her that she has such parents (2.0)” (CREATIVE);

“well, when they were young, I had problems with washing them, dressing them and changing napkins. Now when they are older, the only problem is to ensure that they have something to eat, that there is enough money because my husband doesn’t work anymore and disability pension is low” (TALKATIVE);

“yes, they don’t do many things themselves (3.0), I worry about them (3.0), so that there is enough money, so that they have something to eat and wear (3.0), I am a father so I worry” (RESERVED);

“there are always some problems, with health, not enough money, but I guess everybody experiences that?” (SHY).

Results

The conducted studies show that intellectually disabled mothers/fathers perceive parenthood as one of the most crucial tasks of adulthood. All the informants find the fact of being a mother/father a dream come true; a dream that seemed unreal when they were adolescents. Parenthood is a meaning of life, love that may be experienced. Two concepts of parenthood may be differentiated among the intellectually disabled participants. The first one is characterised by a total commitment to a child, fulfilling all its expectations and desires. A willingness to provide the child with everything it dreams about whereas the second one is marked by the idea of teaching responsibility and self-reliance.

The main difficulties experienced by the intellectually disabled parents are associated mostly with financial issues, problems with work, lack of knowledge on possible forms of support and professional assistance. Moreover, the participants experienced some difficulties with caring for the child in the first years of the child’s life. The informants’ utterances reveal a care for the children’s future. They especially worry that the children may experience negative social attitudes because of their parents’ disabilities.

Conclusion

The results of the presented case report with the participation of 5 intellectually disabled parents show that parenthood is the most important experience in the participants’ lives. The research question raised in the context of the concept of parenthood in the intellectually disabled adult participants is embodied in the following terms: excessive care,

overprotectiveness (2 informants) and responsibility, self-reliance, autonomy (3 informants).

Moreover, the verbal data collected as an answer to the second research question revealed that intellectually disabled parents try to provide their children with a decent life. They try to fulfil all their needs and provide them with many entertaining activities in their everyday lives. What is more, it may be noted that the difficulties and problems that intellectually disabled parents encounter in their everyday lives do not always result from their intellectual disabilities. Data collected confirms the previous studies conducted by other authors e.g. Zawiaślak¹¹, Lizoń- Szłapowska¹², Bartnikowska, Chyła and Ćwirynkało¹⁴ and others on the difficulties related to motherhood/fatherhood of intellectually disabled parents.

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