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## **Persons with Moderate and Severe Intellectual Disabilities – the Specific Needs of Adulthood**

<http://dx.doi.org/10.12775/PBE.2019.020>

### **Abstract**

People with intellectual disabilities (ID) are perceived as helpless, dependent, and unable to fulfil social roles assigned to the so-called able-bodied<sup>1</sup> people. As a consequence, the entrance of the said group into adulthood is impeded and delayed. It is not for the lack of will on the part of the subject or as a consequence of intellectual disability, but rather as a result of the existing social situations which create barriers hindering the fulfilment of needs. A person with ID has a right to have needs and fulfil them. Among them there are specific needs – shaped by individual human characteristics, experiences, and development changes – which are related to the particular stage of the individual's development. The aim of this research was to diagnose the specific needs of adults with intellectual disabilities at a moderate and severe level, while the main research problem consists of the following questions: what are the specific needs of adults with intellectual disabilities at a significant level (moderate and severe) between the ages of 18 and 35? Which of the indicated needs are being met by the research participants? The research was conducted by employing a quantitative strategy, using the author's self-designed survey questionnaire. 96 people with intellectual disabilities were surveyed – the participants of the occupational therapy workshop (OTW). An analysis was conducted on the needs which, according to Erikson, most commonly manifest in adulthood

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<sup>1</sup> The term “so-called able-bodied” was used as dictated by the social paradigm of disability. Every person can be, at different times in their life, disabled and experience the full spectrum of related difficulties (Krause, 2011).

(between the ages of 18 and 35). The test results reveal the actual state of their occurrence and fulfilment.

**Key words:** needs, specific needs, intellectual disability, arranging life, adulthood.

## Introduction

Entering the adult stage of life begins around the age of 20 and lasts approximately 10 years (Arnett, 2000; Furstenberg, 2000; Bańka, 2006). However, this process may lengthen, and it is difficult to indicate standards associated with a particular age (Helson, Mitchell, Moane, 1984). The period of emerging adulthood<sup>2</sup> is the period of new life decisions related to, among other things, independence, professional work, starting a family, and choosing a new place of residence. The perception of being an adult and the level of needs being fulfilled can differ among excluded or threatened by social exclusion groups, such as people with ID. Marisa Forte conducted a study that confirmed the thesis that the social functioning of people with ID is associated with isolation and stigmatization (Forte 2009 for: Brzezińska and others, 2011, p. 96). As such, performing the role of an adult in society by a person with ID is more difficult. An online video<sup>3</sup> which denies, in an unconventional manner, that people with ID have any kind of specific needs was the inspiration for the author's research and the writing of the article. According to the video's author, the needs of people with ID are not unusual.

Fulfilling needs is a prerequisite for living and maintaining a person in a state of normal and proper functioning (Obuchowski, 1983; Sobol, 1993; Kupisiewicz, 2013). In contrast, unfulfilled needs lead to frustration (Kupisiewicz, 2013, p. 277). There are many types and classifications of needs, among them biological (basic), social (derived), cultural, educational, and physiological needs, as well as, needs related to feeling of security, affiliation, affection, and recognition [Abraham Maslow's hierarchy of needs] (Kupisiewicz, 2013, p. 277). The subject of the article are specific needs related to a particular mo-

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<sup>2</sup> According to J. J. Arnett, the period of emerging adulthood falls between the ages of 18 till 25. According to A. Bańka, it lasts longer – till the age of 30.

<sup>3</sup> <https://www.youtube.com/watch?v=kNMJaXuFuWQ&feature=youtu.be> (date of access 8th February 2017).

The video, which was part of a social campaign, breaks stereotypes that people with intellectual disabilities have special needs. Research also disproved them. It proves that research participants with ID have special needs corresponding to the special needs of people with standard intellectual abilities.

ment in human development. The path of development is shaped by individual life experiences and developmental changes determined by the pressures of the social environment (Brzezińska at al., 2014, p. 37). Not every person enters the next phase of development at the same stage of life. At the beginning of every new phase, a person learns to recognise their new needs and name them. Only then do they learn how to fulfil them (Brzezińska, Jabłoński, Ziółkowska, 2014, p. 40). Not all development needs and tasks for a given development period are realised during it. It is possible to find justification for this phenomenon in Anna I. Brzezińska's concept of punctual and non-punctual events (2010). According to the author, it is difficult to pinpoint the most appropriate moment for a person to fulfil a particular need associated with, for instance, adulthood. She writes that "it is impossible to judge, in an objective and external to the individual manner, whether a need appears at the right time – punctual or not at the right time – non-punctual" (Brzezińska, 2010, p. 86). This lack of punctuality may be associated with current socio-cultural changes or human individuality.

There are three conditions for the fulfilment of specific needs by the individual: optimisation, selection, and compensation. The first of these pertains to ensuring the best conditions to meet the needs and improving already-developed techniques to meet them. The second concerns the selection of methods to fulfil needs, accounting for the existing life situation (Brzezińska at al., 2014, p. 42). The third "involves the necessity of temporarily limiting the fulfilment of some needs in order to reach higher levels of development which, by offering new means to fulfil needs, compensate for these limitations over time" (Brzezińska at al., 2014, p. 42).

The ability to plan, decide, and make independent decisions regarding the fulfilment of specific needs, allows people with intellectual disabilities to increase their autonomy. As a result, this social group can manage and arrange their life<sup>4</sup>. It is a process which allows an individual to acquire skills to organise their life in the most optimal conditions (Kowalik, 2018, p. 195). In reality, all too frequently the parents, legal guardians, teachers, tutors, therapists and other specialists impact the managing and arranging of life of adults with intellectual disabilities, especially for those determined to have a significant level of intellectual disability; and make the decisions for them. They forget that meeting basic needs of adulthood supports their autonomous fulfilment of the role of an adult in society.

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<sup>4</sup> The term "arranging life" is derived from sociology. It was introduced into social sciences by Michael Foucault (2010) [original: art of managing life]. According to the author, "all social life is organised by the state by forcing specific principles of social interaction upon a given community, as established by the law" (Kowalik, 2017, p. 193).

Fulfilling needs in the period of adulthood should depend on the person's own activity (Jabłoński, 2009, p. 76). That activity should focus on the realisation of the key needs of the given development phase, e.g. in early adulthood – the need to establish and maintain relationships with people (Jabłoński, 2009). It should be noted, however, that not all specific needs related to adulthood will be realised by persons with significant ID (on account of their real capabilities or the specificity of the activity related to the manifestation of certain needs).

## Methods

The research was conducted by means of quantitative strategy. Its aim was to diagnose the specific needs of adults with intellectual disabilities at a moderate and severe level<sup>5</sup>.

The research focused on answering the following questions: what are the specific needs of adults with intellectual disabilities at a significant level (moderate and severe) between the ages of 18 and 35? Which of the indicated needs are being met by the research participants?

The following hypotheses were proposed before the research project commenced:

1. According to Erikson's concept, the needs of affection, intimacy, forming of relationships, starting a family, taking up employment, and education are specific needs that the research participants (between the ages of 18 and 35) with intellectual disabilities at a significant level possess.
2. Not all of the needs diagnosed by the research are being met by the research participants.

The author's self-designed survey questionnaire, consisting of eight questions, was a tool used to collect data. Two of the questions were open-ended, and the participants were free to give any response they liked, while the remaining six required *yes, no, I don't know* responses. Three charts are presented in this article. The categories presented in Graph 1 were determined by analysing the data collected from the research participants. The data was coded and then

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<sup>5</sup> According to the latest reports, the level of intellectual disability does not have a significant impact on an individual's social functioning. People with intellectual disabilities at a moderate and severe level are the research group for this research. Because of the similar level of intellectual and social functioning of people with particular levels of ID, no division into particular levels is made in the assessment of collected research results.

In the article, intellectual disability is understood in the social dimension of the contemporary concept of intellectual disability (Kazanowski, 2015).

formulated into categories. Graph 2 presents categories of specific needs corresponding to those found in the survey questionnaire (the survey included the following needs: learning, acquiring new skills through course participation, taking up employment, having a partner, forming a relationship, getting married, and having children). Graph 3 includes the same categories as Graph 2 as those were the only ones indicated by research participants as specific needs being fulfilled.

Table 1. Profile of research participants

	N research participants	Number of women	Number of men
N = 96 adults	96	43	56
Intellectual disability at a moderate and severe level	96	X	X
Participants of OTWs:			
– in kujawsko-pomorskie voivodeship	69	31	38
– in warmińsko-mazurskie voivodeship	27	12	15
Participants of OTWs:			
– in towns up to 30 000 inhabitants	69	31	38
– in towns over 30 000 inhabitants	27	12	15

Source: Author's researches.

The participants of this research were adults (according to Erikson – young adults – aged 18–35)<sup>6</sup> with ID at a moderate and severe level, communicating verbally and being the participants of an occupational therapy workshop<sup>7</sup>. The selection of that institution was intentional since the researched social group at the indicated age can typically be found there in Polish reality. Next, the selection of the sample involved the random selection of 5 occupational therapy workshops from the randomly selected voivodeships: kujawsko-pomorskie and warmińsko-mazurskie. The selection of research participants from particular workshops was deliberate. All participants that met the selection criteria (intel-

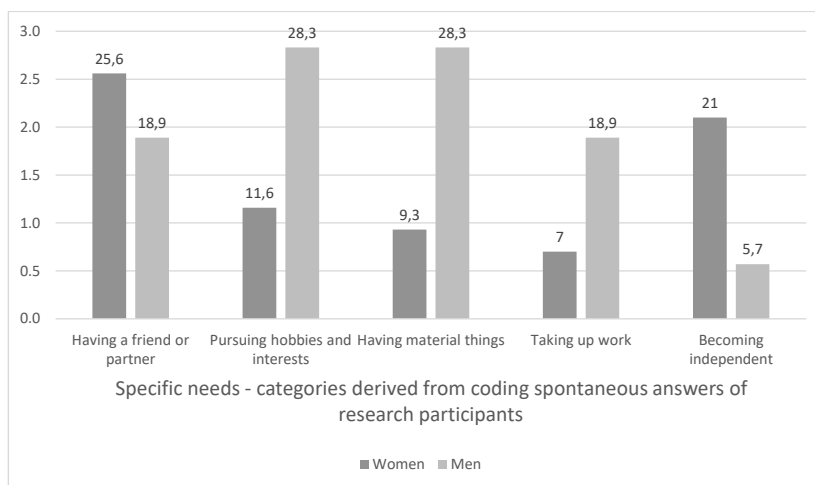
<sup>6</sup> The classification of adulthood stages according to E. H. Erikson (1968) is used for this research.

<sup>7</sup> According to the Act of 27 August 1997 on vocational and social rehabilitation, and employment of disabled people “a workshop means an institution that is separated organisationally and financially and creates an opportunity for disabled people incapable of taking up work to rehabilitate socially and professionally insofar as restoring skills essential to taking up employment” (Journal of Laws from 1997, No. 123, item. 776, paragraph 10a).

lectual disability level, age, verbal communication) were selected from among those who wished to participate in the research. In total, 96 people – 43 women (W) and 56 men (M) participated in the research. The survey questionnaire was filled out with every research participant individually by the researcher, as mandated by the research participants' illiteracy. Using IBM SPSS Statistics 22 software, the collected data was analysed. The distribution of the variable value was estimated (only one variable was taken into account – sex – while ignoring intellectual disability level, age, and town size).

## Results

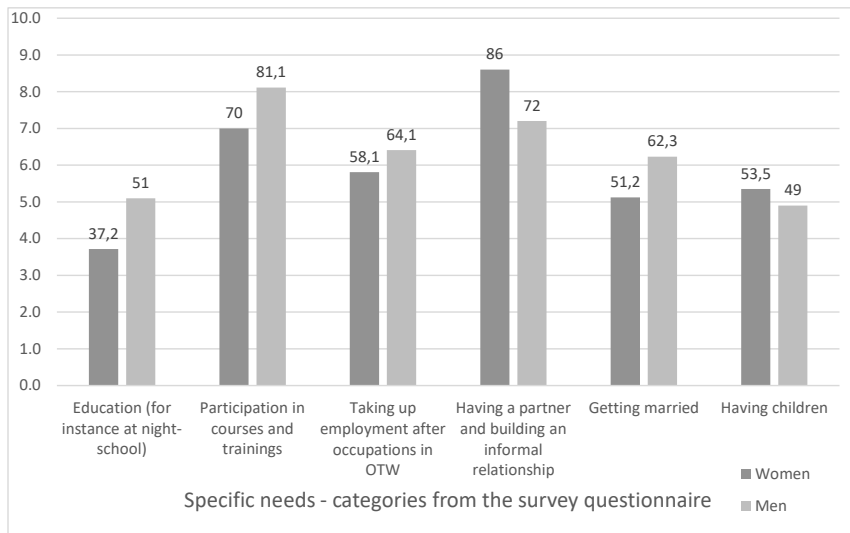
The research analysed the needs that, according to Erikson, manifest most frequently in adulthood between the ages 18 and 35. At this stage, young adults take up their first professional work and raise their qualifications. They seek friends and love. They face the task of starting a family, as well as, engage in intimate relations that give them satisfaction. There are many of these kinds of needs in the life of every person. These research results determine the actual state of their occurrence and fulfilment. The sum of answers in the graphs does not equal 100. It results from the possibility of choosing multiple answers by the research participants.



Graph 1. The specific needs of people with intellectual disabilities – research participants' spontaneous responses

Source: Author's researches.

The overall conclusion to be drawn from research participants' spontaneous responses is that the most frequently indicated need is that of having a friend or partner (18,9% M; 25,6% W). Next, the having and pursuing of personal hobbies and interests (28,3% M; 11,6% W), the possession of material things (28,3% M; 9,3% W), the taking up of work (18,9% M; 7,0% W) and that of becoming independent (5,7% M, 21,0% W). Some participants also indicated the need to be healthy, helping others, and participating in OTWs as well as, sexual and educational needs. As a result of data analysis, significant differences between men and women can be noted in terms of experiencing needs related to pursuing hobbies (15 M; 5 W), possessing material things (15 M; 4 W), and becoming independent (3 M; 9 W).

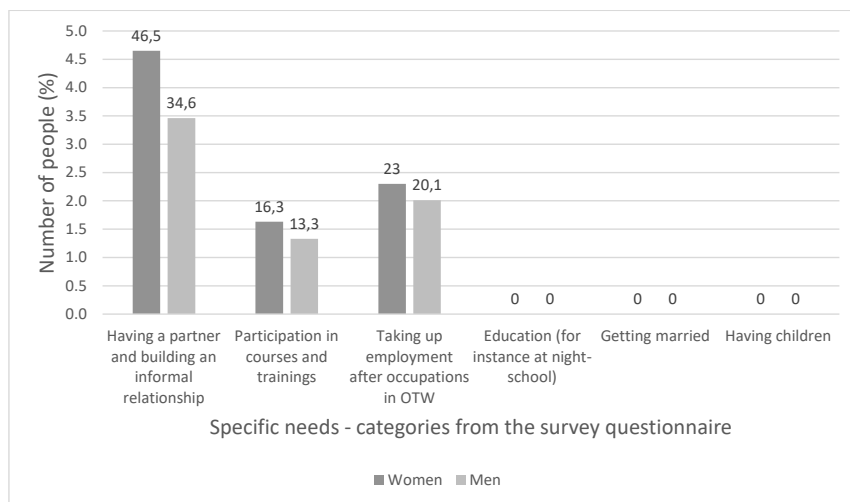


Graph 2. The specific needs of people with intellectual disabilities – research participants' declaration

Source: Author's researches.

It follows from the data presented that more men (51%) than women have a need to learn (37,2%), for instance in the form of graduating from new schools. Research participants with ID experience the need to acquire new practical skills by participating in courses and training (81,1% M; 70,0% W). The respondents also demonstrate the need to take up employment (64,1% M; 58,1% W). However, they consider having a partner and forming a relationship as the most

crucial need (72,0% M; 86% W), which is also associated with the need to get married (62,3% M; 51,2% W) and have children (49,0% M; 53,5% W).



Graph 3. The specific needs of people with intellectual disabilities – research participants’ declaration related to fulfilment of needs

Source: Author’s researches.

The respondents also answered which of these needs are being met. Almost 24% of research participants did not describe them and answered *I don’t know*. The largest amount of respondents are, however, fulfilling the need to have a partner and form informal relationships (34,6% M; 46,5% W). The spontaneous experiencing of the need to have a partner is low, whereas the fulfilment of this need is at an average level. Voluntary and declaratory responses do not reflect the actual state of the other needs being met. Despite the high or average results of needs, which the research participants have, being declared, only a small percentage of them endeavours to fulfil them:

- 14 people (13,3% M; 16,3% W) participated in a course or training,
  1. 12 people (20,1% M; 2,3% W) undertook extra work outside of that at OTW,
  2. none of the research participants fulfil the need to educate themselves, get married or have children.



## Discussion

The period of early adulthood is when the necessity of fulfilling some human needs intensifies. However, in the case of people with ID, acting as an adult, as well as, performing all the functions and tasks associated with this period can be difficult (state of functioning, the attitudes of excessive protectiveness from the environment, social stereotype). Sometimes, because of the surrounding environment, people with ID are not able to be adults. They are deprived of the tasks that are an integral part of adulthood (Marciniak-Madejska, 2013). The first of hypotheses formulated by this research is thus confirmed. According to Erikson's conception, young adults (aged 18–35) seek the company of family and friends, and love and intimacy. They form relationships and get married, as well as, begin individual careers by, for example, taking up employment (Erikson, 1968). By contrast, the conclusions of the research report do not confirm the second hypothesis. Not all of the diagnosed needs of individuals with ID are being met. It comprises the existential problem of the researched group. This issue can be caused by numerous factors. The lack of fulfilment may result from, among other things, legal conditions (legal restrictions) that are in place in Poland, or from attitudes present within the environment where an individual functions. People with intellectual disabilities have the potential to meet their needs (for example, making choices and decisions). All they need is to be supported in order to prevent them from being deprived of the opportunity to fulfil the most human needs, such as having a partner in a formal relationship or having children. People who support adults with intellectual disabilities should help them arrange their life rather than exclude them from such. The effect of the aforementioned arranging of one's life should be effective adaptation and full satisfaction in subsequent life periods. Meeting one's own needs is predicated upon suitable life conditions being secured (Kowalik, 2018, p. 195). The life of people with intellectual disabilities in conditions of normalization (also in the realization of the needs of an adult person) is the basis of autonomous adult life.

In order to increase the opportunities to fulfil needs by people with intellectual disabilities, it is important to create suitable conditions and to equip them with proper skills. Based on these stipulations, they will be able to meet the requirements of adult life. The cooperation of families and people coexisting with an individual is crucial in this process. According to Władysława Pilecka, "the support of the immediate family, friends, and other disabled people is the most significant factor that unleashes motivation to work on oneself" (Pilecka 2014, 17). However, this support cannot be limited to assuming control over

a person with ID, depriving them of their dignity (Pilecka 2014, p. 17). Actions taken should be complex and tailored to the individual, and only their personal needs should be taken into consideration.

This research is not representative of people with intellectual disabilities at a significant level in Poland. The research conclusions concern only the research group. Exploration is the prelude to further scientific research related to the issue of specific needs of adults with intellectual disabilities. One of the ideas for the next research project is to seek the answer to the question: what are the conditions for selected needs not being fulfilled by an individual.

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