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Beata CYTOWSKA*

The meaning of professional work in the lives of adults with intellectual disabilities in the opinion of their parents

Znaczenie pracy zawodowej w życiu dorosłych osób z niepełnosprawnością intelektualną w opinii ich rodziców

Abstract

Introduction. Taking up a job is one of the determinants of adulthood. The employment of people with intellectual disabilities (ID) is becoming more and more accepted, especially among their families and people in their immediate environment; There is also a growing understanding of the positive impact of professional activity on their independence, self-determination, self-development and social inclusion.

Aim. To find out the opinions of parents of adult children with ID on the importance of professional work in the lives of their daughters and sons.

Methods and materials. A semi-structured interview was used to collect data and was conducted with 18 parents of unemployed adults with ID (10 mothers, 8 fathers) and 14 parents of working people with ID (10 mothers, 4 fathers).

* e-mail: beata.cytowska@uwr.edu.pl

University of Wrocław, Faculty of the Historical and Pedagogical Sciences,
Institute of Pedagogy, Dawida 1, 50–527 Wrocław, Poland

Uniwersytet Wrocławski, Wydział Nauk Historycznych i Pedagogicznych,
Instytut Pedagogiki, Dawida 1, 50–527 Wrocław, Polska

ORCID: 0000-0002-4884-2608

Results and conclusion. In their statements, the respondents indicated: the reasons for their adult children with ID being unemployed, the limitations and opportunities for them to take up work, the benefits of taking up and continuing work, the difficulties they encounter at work and the opportunities for them to become independent. According to parents, work is an important aspect of the lives of their adult children with ID, and most would like them to enter and/or maintain employment. Although the respondents saw many benefits resulting from their sons and daughters fulfilling professional duties, only a few admitted that employment was another stage in the process of their child achieving greater autonomy. Some parents downplayed the importance of the work of their adult children with ID, relating their opinion to the social context.

Keywords: parents, supported employment, structured interview, adults with intellectual disabilities, importance of work, self-reliance and autonomy.

Abstrakt

Wprowadzenie. Podjęcie pracy jest jednym z wyznaczników dorosłości. Zatrudnianie osób z niepełnosprawnością intelektualną (NI) jest coraz bardziej akceptowane, szczególnie wśród ich rodzin i osób z najbliższego otoczenia; rośnie też zrozumienie pozytywnego oddziaływania aktywności zawodowej na niezależność, samostanowienie, samorozwój i włączenie społeczne osób z NI.

Cel. Poznanie opinii rodziców dorosłych dzieci z NI na temat znaczenia pracy zawodowej w życiu ich córek i synów.

Metody i materiały. Do zgromadzenia danych został wybrany wywiad częściowo ustrukturyzowany, który przeprowadzono z 18 rodzicami niezatrudnionych dorosłych osób z NI (10 matek, 8 ojców) i 14 rodzicami pracujących osób z NI (10 matek, 4 ojców).

Wyniki i wnioski. W wypowiedziach badani wskazywali na: przyczyny pozostawiania bez pracy przez ich dorosłe dzieci z NI, ograniczenia i możliwości podjęcia przez nie pracy, korzyści z podjęcia i kontynuowania pracy, trudności, jakie napotykają w pracy, oraz szanse dotyczące ich usamodzielnienia się. Zdaniem rodziców praca jest ważnym aspektem życia ich dorosłych dzieci z NI, a większość chciałaby, aby podjęły zatrudnienie i/lub je utrzymały. Choć badani dostrzegali wiele korzyści płynących z wypełniania obowiązków zawodowych przez swoich synów i swoje córki, tylko nieliczni przyznali, że zatrudnienie stanowi kolejny etap w procesie osiągnięcia przez ich dziecko większej autonomii. Część rodziców umniejszała znaczenie pracy ich dorosłych dzieci z NI, odnosząc swoją opinię do społecznego kontekstu.

Słowa kluczowe: rodzice, dorośli z niepełnosprawnością intelektualną, znaczenie pracy, wywiad ustrukturyzowany, usamodzielnienie i autonomia, zatrudnienie wspomagane.

Introduction

Human adulthood is a key concept considered in the field of social and biological sciences. Whether analysed in scientific discourse or in relation to everyday practice, it is currently considered an ambiguous and complex phenomenon, especially when it concerns people with disabilities, primarily intellectual disabilities (ID). This is due to the stereotypical perception of this social group through the lens of cognitive deficits (including the ‘perpetual children’ syndrome) (Cytowska, 2012; Priestley, 2003).

The development and maturation of people with ID are the result of a continuous interaction between problems arising from their dysfunction and environmental barriers, especially those related to social attitudes (*Konwencja* [Convention], December 19, 2023). Therefore, their adulthood is entangled in a complex socio-cultural context and should not be evaluated in terms of developmental tasks assigned to typical adults in the community. A growing body of research on the adulthood of people with ID portrays this period of their lives as a time of developing many of the skills and social competences that they failed to acquire in school and adolescence (*cf.* Cytowska, 2009; Southward, Kyzar, 2017; Strandova, Evans, 2015; Wolska, 2015).

In describing adulthood for people with ID, it is important to emphasise that, as with any human being, it represents a certain stage in their social and personality development. It is usually valued, desired, determined by authority (parental and formal) and sanctioned by social norms. And although the transition from an earlier stage, youth, to adulthood is smooth and a certain process, every person, including those with ID, perceives and empirically confirms the qualitative difference between these stages (Malewski, 2010) in all spheres of life: biological, psychological, socio-cultural (Dubas, 2005; Gurba, 2004).

One of the most important indicators of adulthood is paid employment. For every person, work is an important aspect of life because it allows them to experience development, increased self-esteem and social usefulness, independence and effectiveness in decision-making – essential for full independence, and expanded social contacts. For people with ID, the benefits of work are similar. They are most often observed in three areas: existential – work as a source of livelihood and satisfaction of needs related to daily existence; social – work as a source of a sense of participation in a work group and building new interpersonal relationships; psychological – work as an opportunity to use one’s skills and satisfy higher-order needs such as self-realisation and self-development. In addition, professional work shapes a person’s socio-professional identity (*cf.* Cytowska, 2012; Wehmeyer, Garner, 2003).

Employment of people with intellectual disabilities

In Poland, the employment of people with ID is regulated by the Act on Vocational and Social Rehabilitation and Employment of Persons with Disabilities of 1997, as amended. Currently, the work of this social group can be based on competitive conditions on the open labour market – the same rules apply to every candidate for a given position – and on special conditions on the protected labour market, i.e. organised workplaces, selected and adapted to the needs of people with disabilities (*Ustawa [Act]*, 2003).

The two systems offer different solutions. In the sheltered labour market, there are sheltered workshops [*zakłady pracy chronionej*] (ZPCh) and increasingly popular occupational activity establishments [*zakłady aktywności zawodowej*] (ZAZ). The requirements to be met by a workplace in order to obtain the status of ZPCh or ZAZ are set out in the above-mentioned Act, in particular with regard to medical care and support and rehabilitation services, as mainly people with moderate and severe disabilities are employed there. It should be emphasised that both forms of employment increasingly comply with the requirements of the European Union, indicating that they should be regarded only as an intermediate stage on the way to employment in companies on the open labour market. These establishments, through vocational and social rehabilitation, prepare people with disabilities for an active working life at the level of their individual capabilities.

Employment and labour market participation of people with disabilities in the open labour market can take the following forms (Cytowska, Wołowicz–Ruszkowska, 2013):

- social employment, which consists in providing support of a counselling and financial nature in maintaining professional activity enabling one to take up employment or socially useful work, establish or join a social cooperative or take up economic activity (*Ustawa [Act]*, 2004);
- Supported employment, defined by the World Association for Supported Employment (WASE) as “gainful employment in an integrated environment in the open labour market, with ongoing support provided to the disabled worker. Gainful employment means the same payment for the same work as for a non-disabled worker” (Majewski, 2006, p. 15). A preliminary definition of supported employment in Poland was proposed in May 2011 (in line with the perspective of the European Union of Supported Employment, EUSE): “providing support to persons with disabilities or other groups at risk of exclusion in obtaining and maintaining paid employment on the open labour market” (Cytowska, Wołowicz–Ruszkowska, 2013, p. 22). Supported employment was developed on the basis of the “training through work” method for people with ID, taking into account their individual needs. The previous, traditional model – train

and place – has been replaced by a new approach: place – train – maintain (Hotny, 2011). Supported employment includes help and support from a job coach or assistant whose activities aim to provide the most targeted support possible. Job coaches combine the functions of professional teachers, career counsellors, occupational therapists and coaches (Kamp, Lynch, 1993; McInnes, Ozturk, McDermott, & Mann, 2010).

Problems experienced by parents of people with intellectual disabilities

In the process of raising children from ID to adulthood, parents are accompanied by a constant fear for the future of their offspring and anxiety triggered by daily threats. Over time, they may also feel frustrated by failures in their children's upbringing and education, making them less willing to take on new challenges, losing confidence in their child's ability to succeed. On the other hand, stagnation or lack of significant progress in children's development results from caregivers' underestimation of their child's small and sometimes evident successes, especially if they believe in the social message that their daughter or son has limited usefulness in the family and society and that her or his work represents unnecessary and undesirable effort. Parents adopting similar attitudes perceive their parenting as a personal failure, especially when faced with sacrificing their own professional and personal aspirations. Due to the daily challenges and difficulties of raising a child with ID, they doubt whether they have exhausted all possibilities for therapy, support and education for their children (*cf.* Bakiera, Stelter, 2010; Davies, Beamish, 2009; Dobson, Middleton, & Beardsworth, 2001; Stelter, 2013; Suwalska-Barancewicz, & Malina, 2013; Twardowski, 2008).

In Polish society, professional expectations of people with disabilities are rarely formulated. They are usually perceived to be poorly prepared to work both in schools, in occupational therapy workshops and in the home environment.

Bearing in mind the role of work in the lives of people with ID, as well as the problems of the family environment in raising children with ID towards adulthood and preparing them for the developmental tasks associated with entering employment, the main aim of this study was to present parents' views on the importance of work in the lives of their adult children with ID. These issues are pertinent as they relate to those with more profound ID who may experience particular setbacks in seeking and entering employment and in maintaining employment.

Both in the Polish and English-language literature, this issue has been poorly recognised. The author of the present study conducted research on a similar topic in 2016 (Cytowska, 2017). The results obtained, although satisfactory, required a change in the research approach, hence situating the research in the qualitative stream in the in-

terpretative paradigm.

Data collection method

A semi-structured interview, which has a scenario in the form of issues, but allows for any order of questions to be asked, as well as additional questions if there is a need to develop the respondent's statements (Kvale, 2011), was used to gather research material. Parents were asked similar questions, but given the opportunity to deepen their statements by asking about more interesting or less developed themes. Issues raised in the interview included: their son or daughter with ID entering paid employment (location, position, work activities, employment process), reasons for not being employed (when the adult child remains in a WTZ-type institution), benefits of employment perceived in their adult daughters and sons with ID and any difficulties reported by them, emotions surrounding the employment process and support given to the person with ID during this period, independence and autonomy of adults with ID.

Research participants

Interviews were conducted with two groups of parents: 10 mothers and 8 fathers of people with ID who are not yet in work (participants in the WTZ), and 10 mothers and 4 fathers of people in the supported employment programme (with the support of a job coach). The participants came from a large Polish city. The research was carried out in the premises of the WTZ, a place attended by the adult children of the parents surveyed, which also hosted support groups for people in the supported employment programme. All parents consented to participate in the study. Data on the adult children of the parents surveyed are included in Table 1.

Table 1

Characteristics of parents surveyed, highlighting data on their adult children

Data on respondents and their children	Adult children with ID employed	Adult children with ID not employed
Mothers	10	10
Fathers	4	8
Gender of the adult child		
male	8	10
female	6	8

Data on respondents and their children	Adult children with ID employed	Adult children with ID not employed
Age of the adult child		
18–23	0	1 (M), 1 (K)
24–29	3 (M), 2 (K)	4 (M), 3 (K)
30–35	4 (M), 2 (K)	3 (M), 2 (K)
36–41	2 (K)	1 (M), 1 (K)
42–48	1 (M)	1 (M), 1 (K)
Residence of adult children		
jointly with parent(s)	13	18
independently	1	0
Degree of ID of the adult child		
light	2	1
moderate	10	10
significant	2	7
deep	0	0
Degree of disability adult child		
light	0	0
moderate	3	12
significant	11	6
Seniority of son/daughter		
up to 1 year	3 (M), 2 (K)	
2–3 years	2 (M), 2 (K)	
4–6 years	2 (M), 2 (K)	
9 years	1 (M)	

Note: The degree of disability is assessed by the City or County Disability Assessment Boards on the basis of the Act of 27 August 1997 on Vocational and Social Rehabilitation and Employment of Persons with Disabilities Act, 1997. Declared disability has a legal character and indicates, among other things, the possibility and type of employment.

Source: Author's own study.

Data analysis method

The interviews collected were transcribed and subjected to *thematic analysis* (TA), which focuses on identifying recurring themes and patterns in the data. The themes represent the results of the analyses developed during the creative coding work. They re-

flect in-depth analytical work and are actively created by the researcher at the interface of data, analytical process and subjectivity. Themes do not passively emerge from either the data or the code; they are not “in” the data and waiting to be identified and retrieved by the researcher. Themes are creative and interpretive stories about the data, emerging at the intersection of the researcher’s theoretical assumptions, the researcher’s resources and analytical skills, and the data themselves. The reflective quality of TA is not about following procedures but about the researcher’s thoughtful engagement with the process of analysing the collected data. Participants’ experiences, perspectives and narratives are carefully explored, allowing the researcher to understand the scale and diversity of their perspectives (Braun, Clarke, 2019). While some of the themes of analysis identified overlapped with the questions posed during the interviews, the majority stemmed from recurring themes containing respondents’ reflections and thoughts.

The following themes were identified in the analysis of the interviews with parents of non-workers:

- making excuses for not working for adult children with ID,
- criticism of the lack of work readiness of people with ID expressed by parents,
- parents’ attitudes towards the possible employment of their adult children with ID,
- The benefits of an adult child with ID attending a WTZ,
- perspective on the independence of an adult child with ID.

The themes identified during the analysis of interviews with parents of employed adults with ID are as follows:

- work activities carried out by working children with ID,
- job satisfaction noted in an adult child with ID,
- difficulties experienced by a son or daughter with ID at work,
- the importance of the job coach in the employment process,
- reflections on the empowerment of the working adult child with ID.

Thematic analysis of the data collected – from parents of non-workers

Justifying for not working for adult children with ID

Parents of non-working adults with ID, participants in WTZs, explained their lack of employment in predictable ways. First and foremost, they referred to the decision of the County Disability Assessment Committee, which determines the possibility of gainful employment. Most of the sons and daughters of the persons interviewed had a severe degree of disability, which implied, according to the decision, that the person was not able to work (“the degree of disability does not allow it,” “she is simply dis-

abled”). However, parents elaborated on this theme and concretised the impediments preventing their children from gainful employment. They mentioned health problems, including epilepsy, cerebral palsy and difficulties related to intellectual disabilities, quoting: “She lacks abstract thinking, has no time management skills, does not feel the value of money” (mother of a 27-year-old participant in the training centre), “She does not read, write, needs help with bathing, is practically not independent in anything” (mother of a 24-year-old participant in the training centre), “She has problems with concentration, understanding orders given by superiors” (mother of a 40-year-old participant in the training centre).

Another category of reasons indicated by those surveyed as hindering their employment concerned the psychosocial functioning of a child with ID: “He lacks independence in making life decisions” (father of a 25-year-old participant in the WTZ), “He is unable to function independently, separately, only with his parents” (father of a 38-year-old participant in the WTZ), “He communicates poorly, which results in closure to the social environment” (father of a 27-year-old participant in the WTZ).

Although parents provided extensive reasoning to justify their child’s unemployment due to their disability, they also expressed opinions regarding the labour market – “lack of job opportunities” and “no offers on the labour market” – which may indicate that the person with ID or their parents, or other relatives, have attempted to look for work but, they say, unsuccessfully.

Critics on the lack of work readiness of people with ID expressed by parents

Among the statements analysed, there were highly critical, even negative, opinions about the willingness of people with ID to work:

- “I can’t imagine her working because she works for an hour and is tired, so she rests” (mother of a 40-year-old WTZ participant);
- “My daughter has difficulty pronouncing complex sentences, she has difficulty choosing clothes, she doesn’t know what to wear. She is disturbed by someone in the yard. She is aggressive, stubborn. She likes to watch fairy tales, buy fairy tales. She doesn’t like someone advising her what to buy” (mother of a 37-year-old WTZ participant);
- “She has the mind of a 5-year-old [...], I don’t know what kind of work she would do, probably in a kindergarten playing with children” (father of a 24-year-old WTZ participant);
- “There is no option for her to take up any work, she will starve and she will not work” (father of a 38-year-old WTZ participant);
- “I don’t think he can cope at work, no independence” (mother of a 28-year-old WTZ participant).

The quoted statements express many negative emotions: bitterness, disappointment, frustration and even anger. There were also opinions about people with no additional handicaps, including those with a declared disability of a moderate degree, without finding it impossible to work. Of course, one can try to get to the bottom of this lack of readiness to work perceived by respondents in their children. Parents tended to stay with the statement that it was a matter of disability, of accumulated “inabilities,” sometimes pointing to their adult children’s bad will or unwillingness to work. Actually, interestingly, they did not blame the system – educational, supportive or therapeutic.

Parents’ attitudes towards the possible employment of their adult children with ID

Despite a number of factors preventing people with ID from taking up employment, a positive attitude towards this option emerged from some of the parents interviewed:

- “I am in favour of employing people with disabilities so that they have contact with other people” (father of a 30-year-old WTZ participant);
- “I would be in favour. The person interested in employment would have to be patient” (mother of a 32-year-old WTZ participant).

Parents also pointed to certain conditions to be fulfilled for their adult child to be employed, such as supervising the work, checking on performance, building a sense of security and providing support. One father stated that “the only condition to be fulfilled is to just get healthy.” Such a statement is indicative of the scepticism that was prevalent in the interviews (“there is no such option,” “lack of independence,” “not responsible”), and coincides with criticisms of the work readiness of people with ID and the enumeration of impediments not conducive to their taking up employment.

The benefits of an adult child with ID attending a WTZ

The majority of the respondents, i.e., 18 people, are parents of female and male WTZ participants. These establishments have the task, among others, of preparing people with ID to take up employment. Their activity, in a way, complements vocational education, introduces into the work environment, activates a young person after graduating from an adaptive school to take up activities at a specific position or in a specific workplace. WTZ is a link in the process of preparing a person with ID for employment in the sheltered or open labour market. Practice shows, however, that many of the WTZ participants remain in the institution for a long time (this is indicated, for example, by the age of the children of the parents surveyed – most are over 30). This was also pointed out by the interviewees themselves, indicating as a reason the poor possibilities of the labour market to absorb this group of workers.

During the interviews, themes emerged regarding the participation of adult children with ID in activities or work organised in the occupational therapy workshop. Almost

all statements indicate a positive evaluation of the facility:

- “He enjoys participating in the art therapy classes, he helps with the cleaning, with the carpentry work, he is very happy with his stay at the WTZ” (mother of a 32-year-old WTZ participant);
- “He commutes to the workshop on his own and attends photography, cooking and English classes” (father of a 32-year-old WTZ participant);
- “She actively participates in organised activities and is happy to help with the work being done. He is happy to go to workshops. He enjoys the computer group the most but is happy to work in the others too” (father of a 28-year-old man).

What shines through, both from the statements quoted above and from the others, is the concept of WTZ as a safe, well-liked place where people with ID spend useful time. Few parents, however, drew attention to the primary purpose of the place, namely to practice activities that are useful in the workplace. Only two parents mentioned that apprenticeships are organised at the WTZ in companies on the open labour market, and these people expressed the hope that their children would be employed.

Perspective for the empowerment of the adult child with ID

The topic concerning the independence of sons and daughters attending WTZ was prompted by the question: how do you see the possibility of your son/daughter becoming independent? The answers were mostly sceptical and related to the previously raised issue of the readiness of a person with ID to work. Usually a statement such as “I don’t see such possibilities,” “this type of disability excludes full independence” or “at the moment there is no such chance” was made, followed by an elaboration with arguments similar to those cited earlier, e.g. “I don’t see such a possibility.”

- “She can’t cope on her own, she’s afraid of storms, fire, she’s childish” (mother of a 36-year-old WTZ participant);
- “At his current age, there is no chance of independence anymore. That’s why I’m very afraid of what will happen when I’m gone” (mother of a 45-year-old WTZ participant);
- “There is no chance of full independence. The only thing left is to live in a centre for the disabled” (father of a 34-year-old WTZ participant).

Continuing on this theme, respondents pointed to a number of conditions and circumstances that would need to exist for their adult child to become independent:

- “If D... doesn’t take a job, and he won’t, I don’t see any chance of living separately. As long as we are alive, it is best with us. After we die, she needs to be under the supervision of some charity or other, as she will not be able to cope with life on her own. Life is a hard struggle for survival, which she cannot win”

- (father of a 37-year-old WTZ participant);
- “He would have to have a flat adapted for a wheelchair user and an adequate income that would be enough for him to function independently” (mother of a 29-year-old WTZ participant);
 - “My son requires a third person, he needs a lot of help. He tries to do a lot of things, but under control” (mother of a 30-year-old male WTZ participant);
 - “A big influence on my daughter’s independence is ‘residential training,’ which she has benefited from twice” (mother of a 27-year-old WTZ participant);
 - “She needs long training: financially – spending and saving, taking care of her diet, her health; supervision is needed for her rapid fatigue” (father of a 27-year-old WTZ participant).

Only a small proportion of those who spoke recognised their own educational failings in preparing their daughters and sons for adulthood; most saw the fault as being with the child themselves, their illness, their disability.

Thematic analysis of the data collected – from parents of working people

Occupational activities carried out by working children with ID

People with profound ID are able to carry out jobs that are uncomplicated and not physically exhausting. These usually include cleaning jobs in the catering, in the garden, in the office and in the shop. Most parents mentioned in the interviews the work activities performed by working children with ID. Some described them in quite some detail:

- “She works in a hypermarket, where she places goods on the shelves or adds missing goods, keeps the shop clean, washes the shelves and the floor, as well as the baskets for customers, labels the goods, tidies up the trolleys for customers” (mother of a 30-year-old man with five years of work experience);
- “It is a lobby job. Cleaning the hall, toilets, washing the dishes, putting the dishes in the dishwasher and taking the clean dishes out” (mother of a 39-year-old man with 2 years of work experience);
- “Her job is to watch the cameras on her laptop” (mother of a 36-year-old woman with four years of work experience);
- “She is preparing the restaurant for opening. Her duties include sweeping the floor, mopping it, taking the chairs off the tables, wiping the dust, vacuuming the rugs, cleaning the bathroom” (mother of a 33-year-old woman with one year of work experience);
- “She works in a social cooperative... as a quality controller, checking and packaging cosmetic sachets” (mother of a 24-year-old woman with 4 years

of work experience).

Sometimes respondents briefly described the work activities undertaken by their children, especially when it involved cleaning (e.g. “it’s kind of a housekeeping job there,” “he just cleans”). More important to them was the place of employment, they were keen to mention that their child works in a well-known pizzeria, café or restaurant by name.

Job satisfaction perceived in an adult child with ID

Parents of those in work (the longest length of service was nine years and the shortest six months) valued their children’s commitment to work. Mothers were more likely to appreciate attitudes towards work and its importance in developing positive qualities in their adult sons and daughters:

- “She likes her job, she enjoys it when she can help a customer find goods, when she can handle a new challenge” (mother of a 30-year-old woman with five years of work experience);
- “She really enjoys her job; she is happy to get to know her colleagues. Her self-esteem is slowly improving, and the support she receives in a friendly atmosphere teaches my daughter self-awareness in communicating with other employees and teamwork skills, which enables her to cope at work” (mother of a 39-year-old woman with two years of work experience);
- “He works diligently and with precision. He is a calm and likeable worker, which gives him joy” (mother of a 25-year-old man with one year of work experience). The father added: “He is dutiful and disciplined. He does his job properly, for which he is appreciated, which gives him joy, satisfaction and motivates him to continue his efforts.”

The parents surveyed mostly perceived their children’s maturation to be influenced by their work responsibilities and varied social contacts.

Difficulties experienced by the son or daughter at work

Parents describing the work activities and work environment of their adult children with ID highlighted a number of difficulties that they complained about. Some of these stemmed from the problems previously identified, linked to intellectual disability:

- “He has difficulty remembering recipes and ingredients [to prepare salads]” (mother of a 31-year-old man with nine years of work experience);
- “Her biggest problem is the disruption of her daily work rhythm. She is very much affected by critical remarks about her work” (mother of a 27-year-old woman with five years of work experience);
- “Difficulties arise from not understanding the behaviour of those around him,

hence his moods are sometimes volatile” (father of a 30-year-old man with three years of work experience);

- “The biggest difficulty is related to communication, he speaks unclearly” (father of a 33-year-old man with one year of work experience).

Adults with ID may perceive their work as strenuous and tiring, regardless of whether they enjoy it. This is due to the nature of the work, i.e. performing basic, physically demanding, repetitive, monotonous activities. Parents highlighted this issue:

- “Cleaning the toilets depresses and tires her a bit, but she has the satisfaction of knowing that it is clean” (mother of a 25-year-old woman with seven months of work experience);
- “She complains when she has to carry bags of potatoes, apples etc. Sometimes she doesn’t know how to manage so that she can fit everything in” (mother of a 30-year-old woman with 5 years of work experience).

The mother of one of the men and the father of another stressed that the current job did not meet the expectations of their adult children:

- “He likes his job, but has ambitions to do another job someday, not physical. He’s great on the computer, it’s not just games, and he dreams of a change” (mother of a 25-year-old man with three years of work experience);
- “He likes his work moderately, he is happy to earn money, he would most like to work in a hotel” (father of a 31-year-old man with nine years of work experience).

Parents have encouraged their sons to change employment. Interviews with job coaches are underway and the search for satisfactory employment positions is ongoing.

The importance of the job coach in the employment process

Most of the adult children of parents surveyed were working in the open labour market, most often in a supported employment programme. Parents emphasised the importance of job coaches in getting and keeping a job. Some even stressed that it was only with the support of a coach that their son or daughter was able to take up gainful employment, learn how to do it quickly and go through a smooth adaptation process to it:

- “If there was no such programme, my daughter would not be working. My personal attempts in this direction were unsuccessful. A person with a disability needs this kind of help both in finding a job and in preparing for his/her job duties” (mother of a 30-year-old woman with 5 years of work experience);
- “This form of employment is great, without it, it would be much more difficult for him to take up a job... So that there are always enough finances for the most

- committed coaches, which is what my son is lucky enough to have” (mother of a 25-year-old with three years of work experience);
- “Great project, very much needed, tremendously developing young people” (mother of a 43-year-old man with six years of work experience);
 - “I evaluate this form of employment positively. The coach helps to find a job, my son also has help in dealing with difficult situations in the workplace and help with training” (father of a 31-year-old son with nine years of work experience).

All respondents were asked about their knowledge of the supported employment programme. It turned out that some of them did not know about such a possibility or, at the mention of a job coach, answered in the affirmative (on the basis of “I have heard something”), but without knowing the principles of this form. However, this was mainly the case for parents of adults with ID attending WTZ.

Reflections on the empowerment of the working adult child with ID

During the course of the interviews, themes of empowerment emerged for those who had taken on the role of worker. Achieving this dimension of adulthood is, in a way, the trigger for making plans related to expanding personal autonomy. The respondents’ statements varied, although the majority indicated little chance of independence, a dimension of which is living separately or entering into an intimate relationship with a partner. The most surprising were those in which it was categorically stated that the achievements to date in terms of employment and job retention do not contribute to triggering the next steps in the process of becoming independent:

- “It’s impossible. Her dysfunction is too strong to function independently” (father of a 25-year-old woman with six years of experience);
- “Given the nature of my son’s illness, he has no chance of being independent” (mother of a 39-year-old man with eight years of experience);
- “There is no such chance, no conditions to be met will remedy this” (mother of a 36-year-old woman with four years of experience).

There were also more cautious voices in the interview with parents of those already in employment, indicating the hope that there is still time to develop many of the skills that will ultimately prepare their son or daughter for greater autonomy. Parents of those younger and with more seniority spoke in this way:

- “I would love it to be possible, but I have a lot of concerns. He would need to be accompanied by a life coach of sorts to help sort things out. My daughter does well in constant, predictable conditions; any change throws her off balance, she gets lost...” (mother of a 30-year-old woman with 5 years of experience);
- “I think he would have a hard time, mainly dealing with the maze of different

- regulations, but I don't prejudge, maybe he could do it because he's ambitious" (father of a 31-year-old man with nine years of experience);
- "I don't know that yet, but I would love to... She would have to become more responsible for her actions, less trusting" (mother of a 25-year-old woman with one year of experience).

Several parents were more optimistic about their adult child's plans for independence:

- "I think there is a chance to live separately in the near future... The biggest problem could be with finances, i.e. paying bills, cooking..." (mother of a 31-year-old man with nine years of experience);
- "He has a chance, but with the help of his family" (father of a 25-year-old man with three years of experience);
- "I think she could become independent, but under control, because these people are trusting and can be easily taken advantage of, they can be hurt" (father of a 27-year-old woman with 4 years of experience).

The sample parental statements presented above were characterised by concern and hope, but also a great deal of fear and uncertainty. Difficult emotions emanated from all the statements concerning the autonomy and independence of adults with ID, and there was a sense of caution in the parents' messages about their plans for the future.

Discussion

The thematic analysis of the collected material allowed us to capture similarities and differences in the statements of the two groups of parents interviewed. The themes addressed by the interviewees reveal their thoughts on an important sphere of life, namely work, and its importance for their adult children with ID.

The first observation from the interviews was that mothers were more open to speaking about their adult children. Respondents gave more detailed information, were more insightful and explained their thoughts on the fly. Interviews with fathers were more of a reporting nature, based on facts, interviewees were less likely to deepen or develop more difficult themes. The mothers' and fathers' opinions on the common child (two cases each in both groups) were rather consistent, although fathers (generally) were more critical of their daughters and sons, regardless of their gender. These findings are not surprising, as confirmed by other interview-based studies (*cf.* Cytowska, 2012; Żyta, 2011).

The most significant problem that could be identified already during the interview with the parents, and later during the analysis of the interviews, was the restriction

of their children with ID to try to face the challenges of adulthood. Beata Górnicka (2016) notes that disability often causes severe limitations in terms of life independence, so that the adult child has difficulty becoming independent and in the eyes of the family still remains a child.

The parents interviewed, when giving arguments to justify their adult children with ID not having paid employment, linked them primarily to the diagnosis of intellectual disability by the assessment body. They supplemented this diagnosis with a rather extensive list of additional, co-occurring or derived difficulties or deeper problems. This was also how many of them justified the unwarranted pursuit of independence (for themselves) for their sons and daughters with ID. A number of studies show that intellectual ability has no significant impact on either self-determination or autonomous functioning for this group of individuals. Instead, the ability to make choices and the environmental conditions that enable it are more important (*cf.* Mill, Mayes, & McConnell, 2010; Strandova, Evans, 2015; Wehmeyer, Garner, 2003).

The fears articulated by respondents about their sons/daughters' possible entry into the workforce, or the constant disbelief that a person who has already entered the role of worker and is comfortable in it can go further in the process of building autonomy, show that parents participate in a social process of control and incapacitation of their adult children with ID. Other researchers elaborate on the issue of people with ID remaining in constant dependence on the care of the family, showing the consequences for the formation of their identity. Such people do not have the opportunity to develop their own competences, defence mechanisms, build up their self-esteem, which in later life may result in a strong fear of being harmed by those around them, thus there is a withdrawal from most social relationships, which in turn may affect the achievement of full maturity, including social maturity. Remaining under the influence of the family blocks their desire for social participation and involves remaining in the circle of closest people unconditionally accepting their relatives with ID (Chruściak, Michalczyk, Sijko, Wiszejko-Wierzbicka, & Życzyńska-Ciołek, 2008; Cytowska, 2012; Gumienny, 2016; Twardowski, 1996).

Among the parents of the WTZ participants, especially the older ones (over 35), resignation and even frustration could be perceived when the conversation turned to the possibility of their sons and daughters being employed and becoming more independent than before. The respondents understood that their adult child, who is past his or her youth and most active in life, was not in a position to change dramatically. Consequently, they were reconciled to the vision of seeing a person with ID as a beneficiary of supportive or therapeutic institutions where he or she would be able to count on care and support, i.e. they accepted the perspective of his or her total dependence on others (*cf.* Marciniak-Madejska, 2013; Ryan, Taggart, Truesdale-Kennedy, & Slevin, 2013).

Parents of working people, on the other hand, recognise the importance of work

in their adult children's lives and appreciate their efforts and attitudes towards work responsibilities. They consider the benefits of people with ID taking up work in terms of becoming more independent, expanding their social contacts and being satisfied with their lives, but they do not consider that entering the role of a worker is a marker of their adulthood and an opening to the next challenges of social maturity (*cf.* Brown, Schalock, & Brown, 2009; Chadwick et al., 2012; Cytowska, 2012; Grant, Ramcharan, 2002; Mill, Mayes, & McConnell, 2010; Pisula, 2008; Wolska, 2015; Zakrzewska, 2021). Only a few of this group of respondents felt it was important to recognise their children's needs in this area and to support them in becoming adults.

The analysis and interpretation of the collected material reveal a complex picture of the adult with ID in the family context. It would seem that the realisation of the important challenge of adulthood, i.e., entering the role of a worker, will create an opportunity for this group of people to achieve further markers of adulthood, among them the most important one – autonomy. Although parents recognise the importance of work in the lives of their daughters and sons, relating it to the development of a number of important adult characteristics, such as independence, responsibility, self-discipline, the ability to make professional challenges and decisions, these correlate poorly – in the view of mothers and fathers – with the ability of their adult children to achieve an increasing degree of autonomy.

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