

Persons with Intellectual Disabilities, their Right to Human Rights: Personal Assistant's Work Context

Osoby z niepełnosprawnością intelektualną, ich prawo do praw podstawowych.
Instytucja asystenta osobistego

Ditta Baczała

Nicolaus Copernicus
University in Toruń,
Poland

ORCID

0000-0002-2761-2897

ditta.baczala@gmail.com

Klaudia Chruszczewska

Nicolaus Copernicus
University in Toruń,
Poland
klaudiachruszczewska@
icloud.com

Received: 5 Dec 2024

Revised: 9 Aug 2025

Accepted: 30 Sep 2025

Published: 31 Dec 2025

Abstract: Background: The fundamental rights of individuals with intellectual disabilities are being restricted, including the right to work, housing and cultural participation. This situation can be changed by developing personal assistance. Objective of the study: To find out the extent to which people with intellectual disabilities realize their basic rights with the support of a personal assistant. Methods: The study involved 13 adults (11 in early adulthood and 2 in middle adulthood) with intellectual disabilities. The study was designed using an interpretive approach and a focus interview method. Participants answered questions related to work and employment, housing and cultural participation in the context of personal assistance. Results: Participants felt that a personal assistant is essential in finding work and employment, using assisted housing and enabling and facilitating participation in cultural life. Conclusions: Personal assistance enables individuals with intellectual disabilities to execute their fundamental rights, and the results can help state agencies prepare comprehensive strategies to support this social group.

Keywords: persons with intellectual disability, human rights, personal assistant, support

Abstrakt: Kontekst: Podstawowe prawa osób z niepełnosprawnością intelektualną są ograniczane, w tym prawo do pracy, mieszkania i uczestnictwa w kulturze. Sytuację tę można zmienić poprzez rozwój asystentury osobistej. Cel badania: Poznanie zakresu realizacji praw podstawowych przez osoby z niepełnosprawnością intelektualną przy wsparciu asystenta osobistego. Metody: W badaniu wzięło udział 13 osób dorosłych (11 młodych dorosłych i 2 w średniej dorosłości) z niepełnosprawnością intelektualną. Badanie zostało zaprojektowane przy użyciu podejścia interpretacyjnego i metody wywiadu fokusowego. Osoby badane odpowiadały na pytania związane z pracą i zatrudnieniem, mieszkaniem i uczestnictwem w kulturze przy wsparciu asystenta osobistego. Wyniki: Osoby badane uważały, że asystent osobisty jest niezbędny w znalezieniu pracy i zatrudnienia, korzystaniu z mieszkań wspomaganych oraz umożliwianiu i ułatwianiu uczestnictwa w życiu kulturalnym. Wnioski: Asystent osobisty umożliwi osobom z niepełnosprawnością intelektualną realizację ich podstawowych praw, a wyniki badania mogą pomóc agendum państwowym w przygotowaniu kompleksowych strategii wspierania tej grupy społecznej.

Słowa kluczowe: osoby z niepełnosprawnością intelektualną, prawa człowieka, asystent osobisty, wsparcie



This article is an open-access article distributed under the terms and conditions of the Creative Commons Attribution (CC BY) license (<https://creativecommons.org/licenses/by/4.0>).

INTRODUCTION

Fundamental human rights are the rights inherent to a person by virtue of being a human being (Hersch 1986, 132). They gained universal recognition only after World War II (Weston 1984). The history of humanity is filled with numerous examples of violations of these rights (slavery, racial discrimination, genocide, religious and political persecution, gender-based violence). The deprivation of fundamental rights can occur on a mass and systematic scale. The fundamental human rights constitute one of the most important principles of the organization of a civilized state. They are the foundation of enacted law and a just public order, and their respect should be a prerequisite for any public action.

The Universal Declaration of Human Rights (*Universal Declaration of Human Rights* 1948) constitutes a collection of human rights and principles for their application. Every individual has the right to: equality before the law, freedom of speech, religion, movement, work, education and health care. The concept of human rights is based on the belief that every person, regardless of gender, religion, health condition or nationality, has a set of basic rights, which should be guaranteed by the state (Klug 2000).

In all societies, there have been and still are individuals or groups experiencing social exclusion, which is a blatant violation of their rights. One such group is persons with intellectual disabilities, who experience restrictions in exercising fundamental rights, discrimination, abuse, segregation, barriers in access to education, work or culture. The American Association on Intellectual and Developmental Disabilities (AAIDD) defines people with this type of disability not only as a group with a lower-than-average intellectual functioning and limitations in adaptive behaviour, but above all as a group requiring support (Schalock, Luckasson, & Tassé 2021). “Systems of supports: (a) are characterized by being person-centred, comprehensive, coordinated and outcome oriented; and (b) encompass choice and personal autonomy, inclusive environments, generic supports, and specialized supports” (Schalock, Luckasson, & Tassé 2021, 4). The lack of support for this social group will result in a negative impact on various areas of their lives: safety, health, employment, intimate relationships, self-determination, well-being and quality of life (Ditchman et al. 2016).

The situation of people with intellectual disabilities requires state intervention, which should guarantee them the right to equality, dignity and autonomy in accordance with the human rights model (Degener 2014). This model enables the creation of coherent social structures that promote the development of both individuals and the community. It emphasizes the importance of individual preferences and choices, granting people the right to full participation in social life (Lawson & Beckett 2021). It rejects the assumption that disability can in any way limit the enjoyment of human rights and clarifies that people should not be judged solely on the basis of their usefulness, but rather on their inherent personal dignity, which is theirs from birth (Degener 2016). This model is substantively related to the

United Nations Convention on the Rights of Persons with Disabilities (2006, CRPD), which sets standards for states to ensure social justice for individuals with disabilities (including those with intellectual disabilities) and their equal participation in various areas of social life (Lawson & Beckett 2021). People with intellectual disabilities must have the opportunity to express their opinions, participate in public life, make decisions about their personal lives and access public services and goods on an equal basis with all citizens, including employment and work, housing and participation in cultural life. This would be in line with Article 19 of the CRPD “Living independently and being included in the community”, which establishes the right of people with disabilities to independent living and social inclusion.

Personal assistance (PA) is a support model for people with intellectual disabilities and a condition for their independent living. It also helps in the realization of the fundamental rights of this social group (Mladenov 2020). Availability of personal assistant services is crucial for the process of deinstitutionalization and for respecting the rights of an individual to self-determination, including the choice of a person – a potential personal assistant (Porter, Shakespeare & Stöckli 2020). A civilized state should have a comprehensive system of personal assistance services, developed with the involvement of its beneficiaries (Riobóo-Lois et al. 2024). This would align with the provisions of the CRPD, which states that all solutions concerning people with disabilities should be developed with their participation and genuine consideration of their opinions. Decisions relating to people with disabilities should be made in accordance with the principle of participation, especially if they concern the implementation of fundamental rights, for example the right to work, housing and access to cultural goods.

For people with intellectual disabilities as well as for everyone else, work facilitates social interaction, gives life meaning and builds self-esteem. It is a means of supporting oneself and one’s family, enabling a dignified life. Work also allows for personal development, increases the chance of social participation and significantly improves the quality of life of this group (Kocman & Weber 2018). People with intellectual disabilities, however, require support in obtaining and maintaining employment, as well as within the workplace (Cheng et al. 2018). Such support should be provided by a personal assistant, acting as an advocate and trusted representative of the person with intellectual disabilities. A personal assistant should also help coworkers understand how a person with intellectual disabilities functions (Brennan et al. 2015).

Participation in culture influences cognitive development and compensatory-rehabilitation processes, providing a sense of pleasure and satisfaction (Nowak 2015). It helps develop and shape one’s identity. Through exploration of various areas of culture, persons with intellectual disabilities can discover their interests, preferences and strengths. Active participation in culture contributes to the social independence of these people and to their empowerment. Participation in cultural life is an individual, personalized matter. In the absence of an inclusive cultural environment, personal assistantship becomes essential for people with intellectual

disabilities. The role of a personal assistant is to accompany a person with this disability in selecting cultural areas that align with their individual interests and to support them in these choices. Fulfilling this role requires the personal assistant to possess the awareness and skills necessary to avoid limiting the individual's autonomy (Romer & Walker 2013).

Housing is a fundamental human right and represents having a place where an individual or group of people can fulfil their basic needs. It plays a significant role in a person's well-being and sense of security. It is a private space that shapes identity and creates a personal, intimate world. For people with intellectual disabilities, housing forms the foundation of independent living and is of great importance for social inclusion. The realization of the right to housing is possible through personal assistance. The primary goal of supported housing is to assist individuals with intellectual disabilities in leading independent lives (Wiesel 2014).

1. OBJECTIVE OF THE STUDY

In our research, we aimed to understand (in line with the research questions below) the experiences of adults with intellectual disabilities in exercising their fundamental rights (employment and work, housing and participation in cultural life) with the support of a personal assistant.

1. How does a personal assistant support a person with an intellectual disability in exercising their right to work?
2. How does a personal assistant support this person in the process of employment in the open labour market?
3. How does a personal assistant support this person in exercising their right to participate in cultural life?
4. How does a personal assistant support this person in exercising their right to housing?

We considered it important to learn about the experience of the institution of a personal assistant for young adults from this social group. In pursuing such a goal of the study, our aim was to listen to people with intellectual disabilities, to learn about their voices. The goal of the study, set in this way, fits in with the human rights-based model of disability. We assumed that achieving our research objective would enrich the subject literature and contribute to expanding research on problems of personal assistance within the interpretative and participatory paradigms.

2. METHODS

2.1. Project

The interpretive approach is applied in research conducted in a qualitative strategy (Cohen, Manion & Morrison 2011). For interpretive researchers, the starting point is an individual and the goal of the research is to explore and understand their interpretation of the surrounding world. In our research, we decided to focus on

adults with intellectual disabilities to learn about their personal experiences, needs and perspectives. We wanted to understand the role of a personal assistant as an indispensable tool in enabling this group to exercise their fundamental rights and participate fully in society. The research project received a positive decision from the Research Ethics Committee of the Faculty of Philosophy and Social Sciences (No. 36/2024).

2.2. Participants

The selection of the research sample (13 individuals: 11 in early adulthood and 2 in middle adulthood) in the study was done in a purposeful manner (purposive sampling), because “qualitative samples are deliberately purposeful, not random (Kuzel 1992; Morse 1989)” (Miles & Huberman 2000, 28). The criteria we used in selecting the sample were as follows: all participants were adults with diagnosed intellectual disability of moderate or severe degree, used verbal communication, and attended a day care institution for adults focusing on social and professional rehabilitation. They self-reported on a fully voluntary basis. The purposeful selection of the sample enabled a more in-depth understanding of the phenomenon under study. However, it should be noted that the use of this method does not guarantee the representativeness of the sample, and thus no inferences can be drawn about the wider population. Consequently, it was necessary to be prudent in interpreting the context in which the data were obtained to minimise errors in their analysis.

2.3. Materials

In the study, we applied the focus group interview method, during which each participant had the right to express themselves freely. The researcher acted as a moderator, recording the discussion on an audio device. The interview was conducted on the basis of a questionnaire consisting of eighteen questions, previously reviewed by competent judges recruited from representatives of both science and practice (DeVellis 2017). Each participant was clearly informed about the following: the voluntary nature of their participation in the study and the right to withdraw at any stage, the requirement to give informed consent to participate in the study, the researcher’s coding of their identity and the deletion of their data after its use for analysis. The survey took place at the institution that the subjects attended, in a setting that was friendly and familiar to the subjects. Each interview lasted approximately two hours. The interviews were conducted over six weeks. The study was conducted on the legal basis – the Mental Capacity Act of 2005, ensuring the right to exercise legal capacity as outlined in Article 12 of the CRPD.

2.4. Procedure

Each participant provided verbal informed consent to participate in the research. This was done after several detailed explanations. We had to ensure that each person studied understood the information that was relevant for making a decision and received appropriate practical support from us, under Principle 2 of the MCA

(Harding 2021). During the focus group interviews, certain issues occurred such as inconsistencies between the questions and responses or participants straying from the core topics of the interviews. After repeating the question several times, participants returned to key issues.

2.5. Analysis

The stages of data analysis include data reduction, representation and verification. The collected data were coded substantively line by line. Substantive coding began with an open approach, in which the text was analysed from multiple perspectives, allowing for the identification of as many analytical categories as possible. The next step was selective coding, which involved choosing only those categories that best reflected the research problem for further theoretical analysis. After completing the open coding process, the codes that were directly related to the research topic were selected. The selected codes formed the basis for the representation of the collected data (cf. Babbie 2003).

In Table 1, we present a comparison of the research questions and those selected from the interview questionnaire.

Table 1. Comparison of research questions with selected questions from the interview questionnaire.

Research question	Question from interview questionnaire
How does the personal assistant support a person with intellectual disabilities in exercising their right to work?	What does work mean to you?
	What is important to you in a job?
How does the personal assistant support this person in the process of employment in the open labour market?	Did the personal assistant help you find a job? If so, how?
How does the personal assistant support this person in exercising their right to participate in cultural life?	What cultural events have you attended?
	How does the personal assistant encourage you to participate in cultural events?
How does the personal assistant support this person in relation to their right to housing?	Is it better to live independently?
	Would you like to live independently?

Source: own study.

In Table 2, we present examples of questions from the interview questionnaire, responses and selected analytical categories.

Table 2. Data coding examples.

Questions from the interview questionnaire	
What is culture for you?	
Sample answers	Analytical categories
“For example, if you see elderly or disabled people on the tram, or those with strollers or walkers, you should be even more polite and understanding towards such people. It says a lot about a person how they behave in such situations.”	Personal culture Empathy
“Culture to me means showing respectful behaviour towards others, such as saying good morning, good evening, please, thank you, excuse me – these are basic, everyday courtesies. That is what my mother always taught me.”	Respect in interactions with others Respectful behaviour
“Of course, proper personal attire such as dressing elegantly when needed, and personal hygiene like bathing daily, taking care of your teeth and keeping your hair looking neat and tidy. This is also culture.”	Personal hygiene Appearance

Source: own study

3. RESULTS

Personal assistant provides comprehensive support in job searching and employment.

The first research question required analysing data obtained from responses to five questions in the interview questionnaire. Twelve participants were employed in the sheltered labour market, which provides adapted positions for employees with disabilities. Only one person worked in the open labour market. Three persons obtained employment before receiving support from a personal assistant. The remaining participants consistently stated that their assigned personal assistant comprehensively engaged in actions aimed at finding a suitable job offer and prepared them for the selected job position. The personal assistant's strategies related to job search began with assessing the individual's competences, as well as their interests and preferences related to future employment.

I remember that we simply started with conversations about what I like to do or where I would like to work. We also talked about my interests and where I would see myself, in what job. (KA – f)¹

My assistant asked me to complete several tests, where I had to mark an answer. He read them to me, and I told him which answer to mark. It helped me understand what jobs might interest me most and in which would be good. (A – m)

¹ The uppercase letter indicates the initial of the name, and the lowercase letter indicates the metric gender. The transcript of the statement is original.

The personal assistant presented career options and used tests to examine vocational predispositions, which further helped in understanding the expectations of the beneficiaries and developed an action plan aligned with their competence profile.

Work means, for example, arriving on time. The purpose of work is to do it, not to come and be lazy. I am already an adult, so I have a job, and I go to work. I try to do everything properly, carefully. I know what I have to do and I do it. Everyone has their own tasks. When I've completed everything, I feel satisfied with myself. (B -f)
I used to give some of the money to my mother, and she was happy when I brought it home. She was proud of me, and I felt so happy then. I can say that I was proud of myself for being able to do it. (K -f)

Having a job means having some means to simply accomplish something. It means being independent. (D - m)

Work serves as a means of acquiring new skills, which strengthens self-esteem and effectiveness. Work provides money, which is the basis for economic independence from family or the social welfare system. People with intellectual disabilities view work as a collection of diverse activities, which contributes to a sense of competence and helps in structuring their daily routine.

I like going to work. I know what to do. In the morning, I get up, get ready for work, then when I finish, I have time for myself. I like knowing what to do when and having my day planned out. (KA - f)

Respondents emphasized the significant role of personal assistants in maintaining employment. Assistants support them with organizational matters, prepare them for work and teach them how to handle daily tasks. They help adapt their beneficiaries to professional tasks and the work environment.

The assistant did not help me find a job, but they did help me adjust to it. They introduced me to this job, prepared me and reminded me about punctuality and my responsibilities. (A - m)

Assistants also offer emotional support, which is crucial in the process of maintaining employment. They help their beneficiaries cope with stressful situations related to performing work, thus motivating them to keep going.

I was very nervous, but my assistant was with me the whole time and comforted me. She said that everything would be fine. Having her by my side was important to me. (A - f)

People with intellectual disabilities feel more confident in previously unfamiliar conditions thanks to assistants.

My Marcin was with me almost from the beginning of this job. He helped me there when I didn't know something and also when I got nervous, when things weren't going well. He always calmed me down and said that I would definitely manage and then I felt better. (P - m)

Personal assistant helps in every aspect of supported employment on the open labour market.

The second research question required analysis of data obtained in responses to two questions from the interview questionnaire. Supported employment for individuals with intellectual disabilities on the open labour market involves cooperation between employers, employees, job coaches and other people involved in the process. The participants confirmed that assistants play a crucial role in the process of acquiring vocational skills and in handling employment-related formalities.

He helped me. He found this job, this place and helped me fill out the paperwork, he completed the documents with me. Then he helped me there too, because this was a new place for me. (D – m)

Assistants facilitate adaptation to new job conditions. The interviews indicate that the first stage is often training, during which the assistant introduces the person to specific tasks that they will perform at the selected job position.

He showed how to perform all the duties, showed what to do in this job. (D – m)
Operating machinery, observing safety rules, or time management at work. (A – m)

In addition to direct training, assistants can also provide support in developing interpersonal relationships in the workplace and communicating with other employees, which creates a friendly professional environment. They educate employers about the functioning, needs and possibilities of individuals with intellectual disabilities.

My assistant helped me make friends at work and that girl is still my friend and we meet often. It's important to also like the people you work with. (KA – f)
I also know that my assistant talked to my boss about me and what I can do, what problems I sometimes have. I think that it helped a little, because my boss was more understanding and nicer to me afterwards. We worked well together. I remember it well. (A – m)

Assistants also represent the interests of their clients regarding the scope of duties, hours and working conditions including remuneration. They monitor their clients' progress and adjust their support depending on their needs.

My assistant always checked how I was doing. It was very nice because if I was struggling with something, she would ask if she could help me in any way and she would always explain something and assisted me if I wanted. (KA – f)

Personal assistant encourages participation in various cultural events.

The third research question required analysing data obtained from the responses to seven questions from the interview questionnaire. The responses were extremely varied. For the participants, the concept of culture encompasses a wide range of behaviours and practices from personal hygiene, appearance, respect for others to social behaviours that reflect their daily lives.

Culture, for me, is respectful behaviour towards others like saying good morning, good evening, please, thank you, excuse me. These are basic, everyday courtesies. That's what my mother always taught me. (K – f)

Of course, proper attire such as dressing elegantly when needed, personal hygiene, like taking care of yourself, bathing daily and keeping your hair looking neat and tidy, is also part of culture. (A – f)

This indicates that the participants understand that different situations require appropriate forms of presentation and behaviour. Appropriate behaviour towards others in public places and elsewhere is perceived by the respondents as synonymous with personal culture.

For example, if you see elderly or disabled people on the tram, or those with strollers or walkers, you should be even more polite and understanding towards such people. It says a lot about a person how they behave in such situations. (K – m)

Caring for others, empathy and assistance are seen as integral components of culture, which highlights its social dimension. Culture, in the respondents' statements, occupies an important place in their personal space and in defining its boundaries.

The same with touch. We can't pet, hug, squeeze or touch everyone. Then you can treat the other person inappropriately if they don't wish for it. Everyone has their own boundaries, and you have to respect that, being cultured and polite. (KA – f)

For the respondents, culture is also a form of participation in various cultural events: concerts, film screenings, festivals, theatre performances.

For example, I once went to this cinema, a sort of art house cinema, to see the film *Where Are You, Anne?* It was a Jewish film. I absolutely love going to the cinema. It gives me a lot of joy to be able to go out somewhere. (K – f)

The assistant encourages the participants to take part in various cultural events and accompanies them during such outings.

For example, when there was an event in big town with some concerts, the assistant took me there. It's nice to be among people, to walk around and be with strangers, not to stay at home or at least go for a walk and take a leisurely stroll. Well, but I probably wouldn't have dared to do it if it weren't for the assistant. I would have been afraid, but with her I feel much more confident because she introduces me to everything. (K – f)

One of the respondents emphasizes how important the presence of an assistant is in overcoming barriers and fears of the unknown. The assistant enables safe exploration of public spaces.

Yesterday I went to the cinema with my assistant. I freshened up, washed, dressed a bit nicer because I wanted to feel better. I go out with my assistant for various things like that. (KA – f)

Going to cultural events can provide an opportunity to express oneself through appearance and proper preparation. Choosing suitable clothing, make-up or accessories allows individuals to express their individuality and feel more comfortable around other people. All participants agree that activities related to cultural life are a significant element of their social interactions.

When you stay at home all the time, it's the worst. You have to go out to meet people so you're not so lonely. Talk to someone or something. You can get bored to death otherwise. That's why I'm glad I have this assistant. (KA – f)

Personal assistants supporting people with intellectual disabilities in accessing various forms of culture use various strategies and methods. The assistant not only presents the available options but also discusses them in detail.

My assistant always asks me what I would like to see or what event I would like to participate in. Together, we browse information about events, and my assistant helps me choose the ones that interest me the most. (P – m)

Before every outing, we go through flyers and event websites together. The assistant helps me understand what exactly is going to happen, who will perform, for example, or how long it will last. (E – f)

This approach builds the autonomy of people with intellectual disabilities, enabling them to make informed and independent decisions. Many respondents emphasized that assistants often prepare various offers that are tailored to the individual's level of understanding and sensory accessibility. Arranging transportation and ensuring the destination is fully accessible is also important.

The assistant always makes sure that the place we are going to is safe for me. For example, whether there are wheelchair ramps or if the staff working there are prepared properly. (A – m)

When we go to a concert, the assistant always finds a place where it is a bit quieter so that I can enjoy the music without too much noise. (E – m)

At the venue, assistants act as mediators, helping with communication between staff and participants, which is especially important for people with communication difficulties.

When we were at the exhibition, my assistant explained how best to talk to me. I feel better when someone speaks a little louder and a little slower too. (K – f)

The role of the assistant also includes support in independent travel. They not only accompany outings, but also teach how to get around the city, which significantly increases the participant's independence.

I simply want to say that I would go to the cultural centre with the assistant. I went to see beautiful monuments and paintings. We went to the cinema to various film premieres. Then, I would go for a walk with my assistant. I learned how to ride the bus with them, and now, thanks to them, I travel on my own. (A – f)

Personal assistant means independence in living.

The fourth research question required analysis of data obtained in the responses to three questions from the interview questionnaire. All thirteen individuals live with their parents and most of them have never lived independently. This living arrangement results from their health condition and the need for permanent support (including economic), which, apart from the assistant, is also provided by their family.

I live with my parents, but that's because of my illness. Of course, my assistant helps me with that too, but they are not with me all the time. Sometimes I wake up at night and then my mother comes to help me take the right medication or gives me an inhaler. If I were alone, I wouldn't be able to cope with it. (A – f)

I live and get along well with my mom. I'm attached to my mother; we're like two friends. My mother is about 80, so obviously, that's quite an age. I don't want to think about it, but I know that I might be on my own soon. I'll have to manage. It's good that my assistant helps me with household chores now. She is teaching me many things that my mother can't show me anymore. My assistant often talks to me about how important it is that I can function on my own, without my mother. (E – f)

In the housing context, it is important to ensure emotional stability, which is often achieved by living with loved ones.

My parents are already elderly. I help them a little too and sometimes even my assistant helps. Well, but I enjoy living with them. I wouldn't want to move out, but I know they're getting older. (A – m)

Some of the respondents expressed a desire to live independently or live with a partner without parents or caregivers.

I would also like to live without my parents. (A – m)

Me too, I want to live with someone, but not with my parents, not with my mom. (K – m)

The statements indicate a desire for independence among the participants. While the motivations may be different, the denominator is the wish to become independent from parents or caregivers.

That's really true, it's about becoming independent. But also, when you reach a certain age, you want to stand on their own. You want to be independent, and that's how it should be. It's the natural order of things. (Z – f)

For the respondents, becoming independent is a natural stage in a person's life. They indicate the need to be independent not only in the physical sense, but also emotionally and socially.

Only two respondents used the support of a personal assistant in supported living. They indicated that the actions taken by the assistants aimed to adapt the living space to the specific needs of the residents.

I lived in a supported apartment twice. Once in the summer, once in the winter. When I was there for the first time, I had a barrier when it came to speaking. A kind of block. The assistant helped me by showing me cards with sentences on them, like

wanting to go to the bathroom or something. I used those for a while, and then I gained confidence and started speaking normally. (B – f)

Assistants work with their residents to develop skills: cooking, cleaning, managing finances or shopping.

Overall, it was great in that apartment later on. My assistant suggested various things to me, we were always doing something. Sometimes shopping, other times cooking or playing games. (B – f)

My assistant told me that it was important to open up to others. She said that if I have someone to talk to, it will always be easier for me and that, if necessary, I can ask someone for help or help someone myself. (B – f)

4. DISCUSSION

“People with intellectual and developmental disabilities (IDDs) around the world experience stigma that can limit social inclusion” (Jansen-van Vuuren & Aldersey 2020, 163). This situation can be counteracted by the personal assistance support model. It depends on the socio-cultural and economic factors of a given country. Personal assistance for persons with intellectual disabilities is a condition for their independent living, empowerment and choice in terms of work, type of housing and participation in cultural life.

Having a job can bring life-changing benefits. The work of people with disabilities, including supported employment and open employment, translates into contentment, satisfaction, independence and social inclusion of people with intellectual disabilities (Robertson et al. 2019). Personal assistants play a key role in supporting this social group in realizing their fundamental right – the right to work. Support includes psychological and practical preparation for employment and work, help in coping with the position, support in interpersonal contacts in the workplace and education of employers and co-workers related to the specifics of social functioning of people with intellectual disabilities. Assistants not only support in acquiring professional skills, but also in building self-esteem. The experiences of the respondents and research by other authors (Nevala et al. 2019) clearly indicate that work is perceived by people with intellectual disabilities not only in the economic context, but also as an important factor in personal development and fulfilling their professional aspirations.

Participation in cultural life for people with intellectual disabilities is not only one of the fundamental rights, but also a considerable challenge for personal assistants. It requires assistants to identify the individual needs and preferences of each person with this type of disability, to awaken their interest in culture and to select appropriate, satisfying cultural events. The role of the assistant also involves accompanying the person under their care, ensuring their safety during cultural events, always with respect for their dignity and autonomy.

The right to housing is a very important fundamental right, as it provides a sense of security and intimacy. Housing is a right that allows every person to meet their needs in a private space, to spend time with loved ones and

individuals important to them. People with intellectual disabilities have varying housing experiences, ranging from living with a family to living independently, in sheltered or supported housing (Douglas et al. 2022). These latter forms of housing for people with intellectual disabilities provide greater independence while securing the necessary support. Living with a family involves emotional support and familiar routines that are well-known to the individuals. The role of a personal assistant is to aid with daily activities in the family home and making architectural, sensory, and technological adjustments in supported housing. Personal assistants play a multifaceted role in the lives of people with intellectual disabilities, in the context of housing. Their support extends from life skills education to adapting living spaces to meet individual needs.

Personal assistance affects the well-being of people with intellectual disabilities and improves their quality of life (Anderson 2021). It is important that personal assistance forms a part of a broader movement toward emancipation of this group (Tschanz 2018). Personal assistance plays an important role in the lives of people with intellectual disabilities in realizing all of their fundamental rights. “The last decades have been marked by a shift in thinking. From viewing disability as a personal problem that needs to be cured (the medical model), we have come to see the source of the problem: the society’s attitude towards persons with disabilities. This means that we have to act collectively as a society in order to remove the barriers that hinder persons with disabilities from living among us and contributing to our society, and to fight against their isolation in institutions or in the back-rooms of family homes” (Hammarberg 2011, 639).

Proper understanding of the mechanisms and effectiveness of personal assistance support is crucial for improving the quality of these services. The study focused on identifying specific fundamental rights such as the right to work, housing and participation in culture with the aim of providing a comprehensive overview of the situation of people with intellectual disabilities in these areas. Their analysis allows for an understanding of the support provided by personal assistants in helping people with intellectual disabilities exercise their fundamental rights. This enhances the knowledge about personal assistance as a tool enabling full participation of people with intellectual disabilities in society and can contribute to the preparation of comprehensive and effective support strategies by state agencies.

It was very difficult to select a sample for the study. These difficulties resulted from the institutions’ reluctance to conduct any research on their premises (fear of its functioning being assessed), and the selection of participants (the institutions wanted to select the participants for the study). The sample of our study was small, so the possibility of generalisation is limited. In this study, the experiences of people with intellectual disabilities were used to learn about the role of a personal assistant in supporting this group in employment and work, housing and participation in cultural life. These experiences may differ from the experiences of other adults with this disability. Further research is needed to explore how the current findings may apply, for example, in the work environment. The findings from the presented studies

can be transferred to a wider population (Maxwell & Chmiel 2014; Maxwell 2019) and may become a new perspective for the state building a system of assistance.

CONCLUSIONS

The study showed the importance of professional activity, access to culture, and individually adapted housing in the lives of people with intellectual disabilities. For the study participants, employment is not only a guarantee of economic stability but also a source of self-realization, self-esteem, and social inclusion. In this context, the role of personal assistants is invaluable. An important conclusion from the data analysis is the need to develop more integrated support strategies that would enable people with intellectual disabilities to successfully enter the open labour market. Only one out of thirteen people participating in the study was employed in the open labour market. Comprehensive cooperation between personal assistants and employers, as well as education about the needs and abilities of people with intellectual disabilities, is necessary to foster more accessible employment opportunities.

Personal assistants, by supporting the study participants in creating art and participating in cultural events, contribute to the social inclusion and personal development of this social group. Creating and presenting their artwork provides an opportunity for self-expression and contributes to the development of self-confidence.

Personal assistants support people with intellectual disabilities in adapting to independent living. This support includes carrying out daily tasks, managing finances, and developing the skills necessary for independent living. Unfortunately, the vast majority of the surveyed individuals live with their parents, and only two out of thirteen used assisted housing services. Therefore, there is a need to develop accessible forms of housing support that will enable more people with intellectual disabilities to lead independent lives.

In the interviews conducted, respondents did not report negative experiences with personal assistant services, as presented by some studies (Wadensten & Ahlström 2009; Stårek 2020).

It is crucial to create a comprehensive and coherent support system, also based on personal assistance, that considers the diverse needs and abilities of people with intellectual disabilities. Only in this way can this marginalized and discriminated social group be ensured full participation in social, professional, and cultural life, which forms the foundation of social inclusion and equal opportunities. At the same time, it will fulfil Article 19 of the United Nations' Convention on the Rights of Persons with Disabilities (UNCRPD) (cf. von Granitz et al. 2017).

Funding: This research received no external funding.

Institutional Review Board Statement: Not applicable.

Conflicts of Interest: The author declares no conflict of interest.

REFERENCES:

- Anderson, Bridget. 2021. "Capability, care, and personal assistance: Making connections." *Open Gender Journal* 5:1-20. DOI: <https://doi.org/10.25595/2287>.
- Babbie, Earl. 2003. *Badania społeczne w praktyce*. Warszawa: Wydawnictwo Naukowe PWN.
- Brennan, Ciara et al. 2016. "Negotiating independence, choice and autonomy: experiences of parents who coordinate personal assistance on behalf of their adult son or daughter." *Disability & Society* 31(5): 604-621. doi.org/10.1080/09687599.2016.1188768.
- Cohen, Luis, Lawrence Manion, & Keith Morrison. 2011. *Research Methods in Education*. Routledge.
- Davidson, Joyce. 2010. "It cuts both ways: A relational approach to access and accommodation for autism." *Social Science & Medicine* 70: 305-312. <https://doi.org/10.1016/j.socscimed.2009.10.017>.
- Convention on the Rights of Persons with Disabilities*. 2006. Available from: <https://www.ohchr.org/en/instruments-mechanisms/instruments/convention-rights-persons-disabilities>.
- Cheng, Chi-Wai et al. 2018. "What constitutes effective support in obtaining and maintaining employment for individuals with intellectual disability? A scoping review." *Journal Intellectual & Developmental Disability* 43(3): 317-327. <https://doi.org/10.3109/13668250.2017.1327040>.
- Degener, Teresa. 2014. *A human rights model of disability*. Routledge handbook of disability law and human rights.
- Degener, Teresa. 2016. "Disability in a Human Rights Context." *Laws* 5(3): 7-43. <https://doi.org/10.3390/laws5030035>.
- DeVellis, Robert. 2017. *Scale Development: Theory and Applications*. Sage.
- Ditchman, Nicole et al. 2016. "How stigma affects the lives of people with intellectual disabilities: An overview." In *Intellectual disability and stigma: Stepping out from the margins*, edited by K. Scior, & S. Werner, 31-47. Palgrave Macmillan.
- Douglas, Jacinta et al. 2022. "Moving into new housing designed for people with disability: preliminary evaluation of outcomes." *Disability and Rehabilitation* 45(8): 1370-1378. <https://doi.org/10.1080/09638288.2022.2060343>.
- Hammarberg, Thomas. 2011. "Disability Rights: From Charity to Equality." *European Human Rights Law Review* 6: 638.
- Harding, Rachel. 2021. "Doing research with intellectually disabled participants: reflections on the challenges of capacity and consent in socio-legal research." *Journal of Law and Society* 48, 51: 528-543. <https://doi.org/10.1111/jols.12331>.
- Hersch, Jeanne. 1986. *Human Rights in Western Thoughts*. In A. Diemer et al., *Philosophical Foundations of Human Rights*, 131-148. Paris.
- Jansen-van Vuuren, Joe-Anne, & Heather Aldersey. 2020. "Stigma, Acceptance and Belonging for People with IDD Across Cultures." *Current Developmental Disorders Reports* 7: 163-172. <https://doi.org/10.1007/s40474-020-00206-w>.
- Klug, Francesca. 2000. *Values for a Godless Age: The Story of the United Kingdom's New Bill of Rights*. Penguin.
- Kocman, Alenka, & Gustav Weber. 2018. "Job satisfaction, quality of work life and work motivation in employees with intellectual disability: a systematic review." *Journal Applied Research Intellectual Disability* 31(1): 1-22. DOI: 10.1111/jar.12319.

- Kuzel, Anton. 1992. "Sampling in qualitative inquiry." In *Doing qualitative research*, edited by B.F. Crabtree & W.L. Miller. Sage.
- Lawson, Anna, & Elizabeth Beckett. 2021. "The social and human rights models of disability: towards a complementarity thesis." *The International Journal of Human Rights* 25(2): 348-379. DOI: 10.1080/13642987.2020.1783533.
- Maxwell, Joseph, & Maria Chmiel. 2014. "Notes toward a theory of qualitative data analysis." In *The Sage handbook: Qualitative data analysis*, edited by U. Flick. SAGE.
- Maxwell, Joseph. 2020. "The Value of Qualitative Inquiry for public Policy." *Qualitative Inquiry* 26(2): 177-186. <https://doi.org/10.1177/1077800419857093>.
- Mental Capacity Act*. 2005. Available from: <https://www.legislation.gov.uk/ukpga/2005/9/resources>.
- Miles, Matthew, & Michael Huberman. 2000. *Analiza danych jakościowych*. Trans Humana.
- Mladenov, Teodor. 2020. "What is good personal assistance made of? Results of a European survey." *Disability & Society* 35(1): 1-24. <https://doi.org/10.1080/09687599.2019.1621740>.
- Morse, Janice. 1989. *Qualitative nursing research: A contemporary dialogue*. Sage.
- Nevala, Nina et al. 2019. "The Effectiveness of Rehabilitation Interventions on the Employment and Functioning of People with Intellectual Disabilities: A Systematic Review." *Journal of Occupational Rehabilitation* 29(4): 773-802. DOI: 10.1007/s10926-019-09837-2.
- Nowak, Anna. 2015. „Uczestnictwo osób niepełnosprawnych w kulturze.” *Chowanna* 44(1): 91-102.
- Porter, Tom, Tom Shakespeare, & Alexandra Stöcki. 2020. "Performance management: a qualitative study of relational boundaries in personal assistance." *Sociology of Health & Illness* 1: 191-206. DOI: 10.1111/1467-9566.12996.
- Riobóo-Lois, Beatriz et al. 2024. "Personal assistance, independent living, and people with disabilities: An international systematic review (2013-2023)." *Disability and Health Journal* 17(4): 1-16. doi: 10.1016/j.dhjo.2024.101630.
- Robertson, Jan et al. 2019. "The association between employment and the health of people with intellectual disabilities: a systematic review." *Journal Applied Research Intellectual Disability* 32(6): 1335-1348. <https://doi.org/10.1111/jar.12632>.
- Romer, Lisa, & Paula Walker. 2013. "Offering Person-Centered Supports on a Daily Basis: An Initial Appreciative Inquiry into the Relationship between Personal Assistants and Those Seeking Support." *Research and Practice for Persons with Severe Disabilities* 38(3): 186-195. <https://doi.org/10.1177/154079691303800305>.
- Schalock, Robert, Ruth Luckasson, & Marc Tassé. 2021. *Intellectual disability: Definition, diagnosis, classification, and systems of supports* (12th Edition). Washington, DC: American Association on Intellectual and Developmental Disabilities. Available from: https://www.researchgate.net/publication/349409269_Schalock_R_L_Luckasson_R_Tasse_M_J_2021_Intellectual_disability_Definition_diagnosis_classification_and_systems_of_supports_12th_Edition_Washington_DC_American_Association_on_Intellectual_and_Developm.
- Stárek, Lumir. 2020. "Ethical Aspects at Work of Personal Assistants." *International Journal of Arts Humanities and Social Sciences Studies*. V.5(19): 151-162.
- Tschanz, Caroline. 2018. "Theorising disability care (non-)personalisation in European countries: comparing personal assistance schemes in Switzerland, Germany, Sweden, and the United Kingdom." *Social Inclusion* 6(2): 22-33. <https://doi.org/10.17645/si.v6i2.1318>.

- Universal Declaration of Human Rights*. 1948. Available from: <https://www.un.org/en/about-us/universal-declaration-of-human-rights>.
- von Granitz, Henrik et al. 2017. "Do personal assistance activities promote participation for persons with disabilities in Sweden?" *Disability and Rehabilitation* 39(24): 2512-2521. doi: 10.1080/09638288.2016.1236405.
- Wadensten, Barbro, & Gerd Ahlström. 2009. "Ethical values in personal assistance: narratives of people with disabilities." *Nursing Ethics* 16(6): 759-74. doi: 10.1177/0969733009341913.
- Weston, Burns. 1984. "Human Rights." *Human Rights Quarterly* 6(3): 257-283.
- Wiesel, Ilan. 2015. "Housing for People with Intellectual Disabilities and the National Disability Insurance Scheme Reforms." *Research and Practice in Intellectual and Developmental Disabilities* 2(1): 45-55. <https://doi.org/10.1080/23297018.2014.992037>.