

## LEGAL AND ECONOMIC CONDITIONS FOR THE PARTICIPATION OF PARENTS OF CHILDREN WITH DISABILITIES IN THE LABOR MARKET IN POLAND

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### ABSTRACT

**Aim:** The main aim of the study was to identify the determinants of career decisions among caregivers of children with disabilities, including the role of care allowance regulations, perceptions of recent legal changes, and the significance of paid employment. **Methods:** The study employed a qualitative approach based on primary qualitative data collected through a proprietary online survey (CAWI) of 25 parents of children with disabilities carried out in 2025. The survey questionnaire was developed following a review of relevant legal regulations, an analysis of online discussion fora and Facebook support groups for caregivers of children with disabilities, as well as exploratory semi-structured interviews conducted with three mothers receiving the care allowance in 2025. **Results:** Findings of the study demonstrate that the career decisions of mothers caring for children with disabilities are shaped by interacting legal, economic, and social factors. Recent changes to the care allowance system have diversified caregivers' employment strategies while creating new challenges and uncertainties. Caregivers also perceive the current system as requiring further improvements, particularly regarding flexibility, continuity of support, and adaptation to individual family circumstances. **Conclusions:** It is necessary to elaborate more flexible support mechanisms that facilitate labor market participation among caregivers of children with disabilities without compromising the quality of care provided. An effective social policy should better accommodate the diverse and changing circumstances of caregiving families. Future policy reforms should be designed in close consultation with parents and caregivers of children with disabilities and should take into account their identified needs and lived experiences.

**Key words:** parents of children with disabilities, caregivers, employment, social policy support

**JEL codes:** I14, J22, I18

### INTRODUCTION

Every person's right to work has been established by Article 23 of the Universal Declaration of Human Rights as one of the most important social rights. It guarantees a minimum level of economic security, 'ensuring for (everyone) and his family an existence

worthy of human dignity, and supplemented, if necessary, by other means of social protection' (UN, 1948).

The fundamental motive for a person taking up work is to acquire material goods necessary to ensure the basic conditions of existence. However, work is not merely a source of income – it also fulfills the need for a sense of belonging and recognition

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and enables the formation of interpersonal bonds. As a particularly significant part of life, work plays a key role in fulfilling people's psychological, physiological, and social needs, while also enabling personal and professional development. Achieving these provides a sense of contentment and satisfaction, as well as a sense of fulfillment of one's duty toward one's family, group, or society (Kotarbiński, 1965).

A large body of literature has highlighted that having children worsens parental labor-market outcomes and imposes severe constraints or even makes achieving the above impossible. This phenomenon is recognized and called 'child penalty' (Goldin, 2014). As children with disabilities require more support, care, and attention, the child penalty may be significantly increased in case of their parents or caregivers (Brown & Clark, 2017; Asuman et al., 2025).

Raising a child with a disability is an experience that radically affects the daily life and employment choices of the whole family (Brennan et al., 2020). The sudden accumulation of tasks undertaken by parents following the diagnosis of their child's disability – a series of procedures to document the child's health, specialist medical appointments, rehabilitation, extraordinary caregiving responsibilities, and the purchase of necessary equipment – places a significant burden on them (Komorowska, 2017). Parents often have to give up their previous way of life in order to meet the specific demands arising from the child's health. At first, the focus shifts to the child and the support of their development (Komorowska, 2017). A parent of a child with a disability, in a sense, takes on another, unpaid, and extremely demanding job – that of providing care for the child. This entails a range of challenges, not only emotional and social, but also economic, as once a child's disability is established, a family member – most often the mother (Porterfield, 2002; Dizaho et al., 2016) – has to give up the paid job or reduce working hours (Wołowicz & Zasępa, 2010).

However, after adapting their environment to their child's special needs and adjusting their daily routine to caregiving responsibilities, many parents of children with disabilities adapt to this new reality and find stability. In such a situation, they are often ready and willing to take up employment, as alongside the opportunity to increase the household budget –

which, in addition to daily living expenses, must cover the higher costs incurred due to the disabled child's needs – work is also seen as providing non-financial benefits that positively influence their psychosocial well-being. These benefits include rest, respite from the caregiving role, the establishment and expansion of social ties, a sense of agency and recognition, the development of interests and skills, and even the attainment of a desired social status (Giddens, 2008; Bakalarczyk, 2020). Unfortunately, parents and caregivers of children with disabilities may face a number of external barriers to employment, such as employers' reluctance, gaps in their employment history, or the inability to adapt working hours to their personal schedules.

The pressure from work and caregiving responsibilities leads to work-to-family conflict, depending, among other things, on government social policies aimed at supporting families of children with disabilities and the corresponding welfare system (Wondemu et al., 2022). The study by Israeli et al. (2026) concludes that a significant disability penalty is observed in Poland, where a full-time labor market is combined with traditional gender norms in the private sphere and offers minimal state support for family caregiving, compared to other analyzed European countries. Parental labor market disruptions and financial hardship caused by having a child with a disability may negatively affect the circumstances of both the household (Shahat & Greco, 2021) and the development of the child (Stabile & Allin, 2012), if not prevented rightly.

For this reason, the state, as the entity responsible for supporting the society, particularly those requiring special assistance, has introduced a system of benefits and financial support to parents of disabled children in Poland. They are currently supported based on the rules either of the Act of 28 November 2003 on Family Allowances (*Ustawa z dnia 28 listopada 2003 r. o świadczeniach rodzinnych*) or on the Act of 28 November 2003 on Family Allowances significantly amended by the Act of 7 July 2023 on the Support Allowance (*Ustawa z dnia 7 lipca 2023 r. o świadczeniu wspierającym*).

Despite a broad discussion on this topic, little is known about how general and targeted family

policies laid down in these acts shape employment patterns of Polish families with disabled children in practice and thus how they are perceived by these families. This knowledge gap provides a rationale for undertaking this study, which investigates a family perspective on legal and institutional support for parents of disabled children in Poland as the main factors determining their participation in the labor market.

## CONCEPTUAL FRAMEWORK AND LITERATURE REVIEW

### Definition and the role of work in human life

Work is a multidimensional phenomenon that finds its place in many fields of science, such as sociology, philosophy, history, and economics. Each of these perspectives enables an understanding of the diverse functions and meanings of work in the life of the individuals and society. The most significant aspect in the context of this paper, however, is the economic dimension.

Tomaszewski (1984) defines work as ‘human activity organized socially in such a way as to lead to socially valuable outcomes and to improve the quality of life of the individuals performing it.’ The multifaceted role of work in people’s lives means that it is closely linked to Maslow’s (1943) hierarchy of needs. Work – or more specifically, the pay it provides – is a source of the funds allowing people to meet their basic needs such as food, shelter, and healthcare. Satisfying basic human needs enables the utilization of the secondary aspects of work, which, alongside material wealth, also determines an individual’s social standing. In turn, the sense of personal fulfillment and satisfaction in other areas of life may depend on these factors. Work therefore influences the values held by the individual, their attitude toward themselves, and toward the social reality surrounding them (Bejma, 2015). Job security, social benefits, and insurance provided by the company relate to the need for safety. On the other hand, the opportunity to work in a friendly environment and with a close-knit team fosters the fulfillment of the need for social belonging. Recognition from superiors, promotions, bonuses, and awards contribute to the fulfillment of the need for esteem. In turn, professional development, the realization of ambitious ideas, and the opportunity to study

in a preferred field support employees’ self-actualization (Szejniuk, 2017). Work is also a place that enables the formation of social bonds, the forging of relationships, and the creation of communities within which a person can integrate with others who share similar views, thereby fulfilling the need for affiliation. Achievements, promotions, or skills acquired at work satisfy the need for recognition and respect and also enable personal development and fulfill the need for self-actualization. People devoid of work lack all accomplishments it provides and may experience negative consequences of such situation.

### Definitions and classifications of disability

Disability is a particularly multifaceted, diverse, and dynamic phenomenon. Depending on the discipline under consideration, there are many definitions and criteria used to describe it (Gielda, 2015). In economics, disability refers to a limited ability to generate income; in medicine, it denotes reduced physical functioning; while in sociology, it indicates difficulties in social adaptation (Garbat, 2013).

In order to create an integrated, standardized language and framework for describing health and health-related conditions, the World Health Organization established the International Classification of Functioning, Disability and Health (WHO, 2001). Taking into account a person’s state of health, the WHO introduced the concept of disability in three dimensions:

1. Impairment: a loss of function or an abnormality in the structure or functioning of the body, whether psychological, psychophysical, or anatomical.
2. Disability: a limitation or inability (resulting from a disability) to lead an active life in a manner or to an extent considered typical for a person.
3. Handicap: a person’s impairment resulting from a disability or functional limitation that restricts or prevents the full fulfillment of a social role appropriate to their age and gender, and consistent with social and cultural norms.

In addition, the United Nations (UN, 2006) Convention on the Rights of Persons with Disabilities defines persons with disabilities as those who have long-term physical, mental, intellectual, or sensory

impairments which, in interaction with various barriers, may hinder their full and effective participation in society on an equal basis with others.

Under the Polish law, matters relating to people with disabilities are governed by the Act of 27 August 1997 on the Vocational and Social Rehabilitation and Employment of People with Disabilities. It applies to people whose disability has been confirmed by a decision: (1) ‘classifying them by the adjudicating authorities into one of the three degrees of disability specified in Article 3, or (2) of total or partial incapacity for work on the basis of separate regulations, or (3) of disability, issued before the age of 16’ (Ustawa z dnia 27 sierpnia 1997 r. o rehabilitacji zawodowej i społecznej oraz zatrudnianiu osób niepełnosprawnych).

In the case of minors, the Act stipulates that persons under the age of 16 who have been diagnosed with a permanent or long-term physical or mental impairment (expected to last for more than 12 months) are classified as persons with disabilities. Another key concept regarding people with disabilities is the inability to live independently, defined in the Act as a limitation of bodily function to such an extent that assistance from others is required to meet basic life needs, such as personal hygiene, mobility, or interacting with the environment.

Disability is directly linked to the need for support. Under Polish law, it is defined as the absence or impairment of the capacity for independent functioning in the physical, mental, intellectual, or sensory spheres. When assessing an individual’s need for support, consideration is given to their ability to perform daily activities independently, taking into account their age and the nature of their disability. Based on this assessment, the type and extent of support required are determined. The level of support required is determined by a score on a scale of 0 to 100.

Given the need for ongoing support in daily life for people who are unable to live independently, people with disabilities and their caregivers may apply for social assistance benefits, which, in accordance with the Act of 12 March 2004 on Social Assistance (Ustawa z dnia 12 marca 2004 r. o pomocy społecznej), support individuals and families in their efforts to meet essential needs and enable them to live in conditions befitting human dignity.

### **Social security benefits for caregivers of children with disabilities in Poland**

The upbringing and education of children with disabilities entail significant additional costs, both financial and non-financial, associated with compensating for various impairments (Olcoń-Kubicka & Kubicki, 2012). In their study on the economic effects of child’s disability, Stabile and Allin provide evidence on three kinds of costs resulting from it: direct costs, incurred as a result of the child’s disability; indirect costs incurred by the family as it decides how best to cope with the child’s disability; and long-term costs associated with the child’s future economic performance (Stabile & Allin, 2012).

The Polish system of support and allowances for parents and caregivers of children with disabilities is intended to partially cover the costs associated with caring for a child and to enable families to ensure an adequate standard of living and meet educational, therapeutic, and health needs. However, it offers different solutions to parents and caregivers of disabled children depending on the time of application for the allowance (Table 1).

Those who applied for and received the care allowance until December 31, 2023, based on the rules laid down in the Act of 28 November 2003 on Family Benefits could not continue or take up any paid employment, as the allowance was meant to serve as compensation for lost income. The compensation provides a minimum level of financial security equivalent to the minimum wage and is paid for only one child with a disability in the family. However, the allowance is also payable after the disabled child has reached the age of 18 and becomes an adult.

In January 2024, the newly enacted Support Benefit Act came into effect, amending the rules governing the award of the care allowance. Unlike the previous rules, the new ones allow recipients to combine paid work with receipt of the allowance. Furthermore, the benefit can be paid for each eligible child with a disability in the family, while the old rules allowed the care allowance to be claimed for a maximum of one child with a disability. Despite these positive changes, the amendment has also introduced a restriction: under the rules effective from January 2024, the care allowance is payable only until the child reaches the age

**Table 1.** The main principles of granting the care allowance for children with disabilities until December 31, 2023 and since January 1, 2024

| Specification                                                 | Care allowance for children with disabilities                                                                                                                                                                                                                                                                                                                                                                                                                                                                               |                                                                                                                                                                                                                                                               |
|---------------------------------------------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Legal basis                                                   | Until 31 December 2023<br>The Act of 28 November 2003 on Family Allowances                                                                                                                                                                                                                                                                                                                                                                                                                                                  | Since 1 January 2024 amendments to the Act of 28 November 2003 on Family Benefits based on the Act of 7 July 2023 on the Support Allowance                                                                                                                    |
| Required documentation of the child's disability              | A disability certificate (for persons under 18 years of age) including indications of the need for permanent or long-term care or assistance of another person in connection with a significantly limited ability to lead an independent life (Point 7) and of the need for the permanent daily participation of the child's guardian in the process of treatment, rehabilitation, and education (Point 8).<br>A certificate of significant disability (for persons over the age of 18) including an indication of Point 7. |                                                                                                                                                                                                                                                               |
| Recipient of the care allowance for a child with a disability | Mother or father<br>Child's <i>de facto</i> guardian<br>Kinship foster family<br>Persons with maintenance obligations (except those with severe disabilities)                                                                                                                                                                                                                                                                                                                                                               | The same as until 31 December 2023, plus:<br>• Spouse<br>• Foster family, person in charge of a family children's home, director of a foster care facility, director of a regional care and therapy facility, director of an intervention pre-adoption center |
| Recipient participation in the labor market                   | The requirement to refrain from undertaking or to resign from paid employment or any other paid activity.                                                                                                                                                                                                                                                                                                                                                                                                                   | The possibility of combining paid employment with receiving the allowance.                                                                                                                                                                                    |
| Age criterion for a child with a disability                   | No age limits apply.                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                        | Granted up to the age of 18 for a child holding a disability certificate.                                                                                                                                                                                     |
| Number of allowances                                          | Paid only to one child holding a valid disability certificate in a family.                                                                                                                                                                                                                                                                                                                                                                                                                                                  | Paid to all eligible children with disability.                                                                                                                                                                                                                |
| Protection of acquired rights                                 | Individuals who acquired the right to the care allowance before December 31, 2023, may continue to receive it under the previous regulations. However, if they are caring for a dependent under the age of 18 and wish to receive the allowance under the new rules, they must submit a new application for the benefit along with a declaration of resignation from the previously received 'old' allowance.                                                                                                               |                                                                                                                                                                                                                                                               |

Source: Authors' elaboration based on the Act of 28 November 2003 on Family Benefits (Ustawa z dnia 28 listopada 2003 r. o świadczeniach rodzinnych) and the Act of 7 July 2023 on the Support Allowance (Ustawa z dnia 7 lipca 2023 r. o świadczeniu wspierającym).

of 18. Upon reaching the age of majority, an adult with a disability can apply for the support allowance. However, it is subject to certain restrictions – its amount, as well as its award, depends on a decision by the competent committee, based on the number of points awarded on the support needs scale. This means that individuals who fail to obtain the required number of points will not qualify for the benefit, while a score

considered inadequate by the person concerned may result in a lower-than-expected benefit.

In accordance with the protection of acquired rights, parents and caregivers who received the care allowance under the rules in force until December 31, 2023, have a choice: they may either remain under the previous rules or switch to the new ones. However, this is an irreversible one-time decision.

These changes raise questions regarding the views of those directly involved – parents and caregivers of children with disabilities. Although the amendment introduces many useful improvements, it also entails restrictions that may raise concerns among caregivers of children with disabilities. It is therefore particularly important to understand the views, personal experiences, and perspectives of those who receive the care allowance under both the old and the new rules.

## AIMS AND METHODS

The main objective of the study was to identify legal and economic conditions for the participation of parents of children with disabilities in the labor market, as stated in the title of the paper. The specific objectives of the study were to identify the following:

- the motivations and barriers influencing the career decisions of caregivers of children with disabilities;
- the impact of legal provisions governing the granting of care allowances on the career decisions of caregivers of children with disabilities before December 31, 2023, and since January 1, 2024;
- the views of caregivers of children with disabilities regarding the legal changes; and
- the significance of paid employment for parents and caregivers of children with disabilities.

In the theoretical part of the research, a critical literature review and analysis of legal acts was carried out, together with the analysis of publications and reports on the situation of people with disabilities and their caregivers, made available by the Institute of Labor and Social Affairs (IPiSS), the Statistics Poland (GUS), and the World Health Organization (WHO).

Four theoretical groups of respondents were defined based on the legal rules in Poland:

- Group 1. Recipients of the care allowance granted before December 31, 2023, and paid under the previous rules,
- Group 2. Recipients of the care allowance granted before December 31, 2023, who decided to opt for the care allowance under the new rules in force since January 1, 2024,
- Group 3. Recipients of the care allowance granted after January 1, 2024, under the new rules (not eligible under the previous rules),

- Group 4. Recipients of the care allowance granted before December 31, 2023, who are currently not receiving any allowance.

The empirical investigation draws on the analysis of primary quantitative and qualitative data obtained through a proprietary online survey created in Google Forms in accordance with the principles of the CAWI (computer-assisted web interview) method. To develop questions included in the survey, a review of legal acts relating to the phenomenon in question was first conducted. Next, it was followed by a review of the content of online fora and closed discussion groups that bring together parents and caregivers of people with disabilities on Facebook. Based on the analysis of this content, face-to-face and telephone interviews were conducted with three parents (mothers) of children with disabilities who were receiving a care allowance in 2025, using partially standardized interview techniques. The interviewees were asked four general, filter questions to determine their eligibility as respondents:

1. Do you receive the care allowance under the new or the old rules?
2. Following the changes, did you decide to switch to the new rules, and why?
3. Do you think the new rules are more favorable than the previous ones?
4. What is your opinion on the new rules of granting the care allowance?

They served as a starting point for the rest of the conversation. The semi-open character of the interviews and the opportunity for the interviewees to share their own experiences and views allowed us to gain preliminary insight into personal perspectives and reasons for the employment decisions of parents of children with disabilities.

Based on this triangulation of information sources – legal acts, literature, and interviews, we formulated 30 questions in total for the questionnaire survey. The questionnaire included 4 filter questions designed to identify eligible respondents and to assign them into one of the four aforementioned groups, while branching questions directed respondents to different sections of the questionnaire based on their answers. Some questions were optional. In general,

the questionnaire included questions of three types: closed-ended (with a specific set of options to choose from), open-ended (allowing the respondent to express themselves freely), and semi-open-ended (combining multiple-choice answers with the option to add their own response).

In the next stage the questionnaire was shared within the aforementioned closed groups on Facebook, as well as among other private groups bringing together parents of children with disabilities. All addressees were informed about the purpose of the survey and assured about the anonymity of the published results.

The survey provided qualitative data, which was analyzed using the standard Qualitative Data Analysis (QDA) methods. However, several responses were exceptionally rich in information and conveyed a distinct emotional content that could have been lost through the use of QDA only. Therefore, they have been reproduced in this article in full, as they represent particularly valuable research material and insight into the investigated matter.

## RESULTS

Ultimately, 25 parents and caregivers of children with disabilities who receive or have received the care allowance took part in the survey. Although the survey was addressed to all, regardless of their gender, all respondents were women, residents of 11 out of 16 Polish voivodships. Most of the respondents live in cities with over 500,000 inhabitants (24%), in towns with populations between 20,000 and 50,000 inhabitants (20%), and in rural areas (20%). Another 36% live in towns of other population sizes, and the remainder live in towns of varying population sizes.

The vast majority (88%) of respondents indicated that they were employed before the birth of their children with a disability, while 12% did not work. Additionally, 80% of respondents indicated that their husbands worked, while 20% were single mothers raising a child or children with a disability. Their children with disabilities were aged between 1 and 17 years.

### **Group 1. Recipients of the care allowance granted until December 31, 2023, and still paid under the previous rules**

These respondents (48% of all) were mothers of children with disabilities aged between 6 and 17. Two of them indicated that they were caregivers to two children with disabilities – aged 7 and 16, and 8 and 16. They all had been working before their children were born, of whom: 17% stated that they gave up work because it was required to receive the allowance, while 83% stated that they gave up work both because it was required to receive the allowance, and because they had to take care of the disabled child totally dependent on them.

The motivation behind the decision to remain under the previous rules, and not opt for the new ones included: child's lack of independence in daily life and the need for assistance (50% of respondents), the early stage of implementation of the new rules and uncertainty regarding the future of the amended regulations (25%), uncertainty regarding the future of the child when they are 18 and reach the age limit for receiving the allowance (17%).

Respondents' attitudes to the new rules were expressed by the fact that 42% had no intention of switching to the new rules in the future, 25% were considering opting for the new regulations because they allow recipients to take a job, and 33% were undecided justifying their stand by uncertainty regarding the rules of granting the allowance (quote: 'I also do not know how my child's ability would be assessed; I doubt the good intentions of those making the decisions, so I fear that the benefit amount under the new rules would be inadequate.').

Half of the respondents in group 1 would take a job if it were possible under the old rules, reasoning: (1) 'I would like to feel like the majority of society, earn my own living, and have contact with a social circle other than one associated with disability.' (2) 'The lack of paid work leads to withdrawal from the labor market and makes it difficult to return to it if the opportunity arises; moreover, I suspect that a long break in employment is a disadvantage in recruitment processes. I would like not to lose the opportunities gained through years of work while studying

and to be secure in terms of future employment in the event of unforeseen, difficult life situations.’ and (3) ‘The issue of income – supporting a child with a disability is very costly. However, work also offers intangible benefits such as social connections, personal development, and maintaining a healthy work-life balance.’ The other half would reject such possibility as their children require constant assistance with self-care activities.

Half of the respondents think that the new rules for the care allowance are not more favorable than the previous ones. One respondent shared her personal observations: ‘At first glance, it seems it might be more beneficial for my daughter, but parents’ opinions on the assessors’ evaluations vary, so I’m afraid to take the risk.’. Next, 17% believe that the amended rules are more favorable than the previous ones, and 25% did not respond to the question.

Asked what should be changed or improved regarding the care allowance, the respondents pointed at ‘The option to work and remain under the old rules.’, ‘an incentive (tax relief) for employers to hire parents of children with disabilities.’, ‘The option to return to caring for the child if their health deteriorates. At the moment, it’s a one-way street. (...) Parents have to make a serious decision to give up work to care for their child without taking up any paid employment.’ ‘Once the child reaches the age of majority, it should be possible to revert to the old rules if necessary.’ ‘It is absurd to have to appear before a (medical) committee every year or two in the case of a permanent condition, such as a genetic disorder with no prospect of improvement. It is downright humiliating for both the child and the parent.’ ‘There is no legal provision regarding what happens when a parent of retirement age is left alone (if the child passes away first). If a mother gives birth at a young age, between 23 and 30, she has no chance of a decent pension. This is a major problem (...)’.

In response to the next question, respondents indicated that support should address needs they are able to identify themselves, as both children and their disabilities vary. These articulated needs include: (1) An assistant to help at home or at school’, (2) ‘Access to care for a child with a disability when they are not at school or nursery’, (3) ‘Respite care, a respite assistant,

and a rehabilitation center with the option of a day care center (my child attends the center for 4 hours a day and returns home; how could I take up employment under such conditions?)’, (4) ‘Above all, psychological support right at the start of the journey with a disabled child.’, (5) ‘Disability certificates should not have an expiry date but should instead be based on assessments by committees to confirm that the situation remains unchanged – thereby maintaining existing benefits (without risking a break in payments), granted privileges (such as a parking permit or a sub-account with charities), and avoiding the need to queue for committee appointments, which risks a gap in the certificate’s validity. A precise definition of the minimum documentation required by the committees – due to insufficient information provided by the center’s staff, in my case the process of submitting documentation was delayed by almost two weeks. Adjusting the specializations of the medical assessors on the committees – the situation of a person with a non-genetic condition should not be decided by, for example, an ophthalmologist. Speeding up the appeals process so that parents affected by incorrect decisions do not have to wait several years for the award of a compensatory benefit while lacking the means to support themselves. Extending the period for awarding the one-off ‘living’ benefit (before the age of 12 months, many disabled children do not even have a diagnosis yet due to the diagnostic odyssey).’, (6) ‘There needs to be greater understanding within society – but not pity. Sometimes it’s the small but practical gestures that count, like holding the stairwell door open. Our wheelchairs really are heavy.’

The respondents shared their views on selected forms of support for caregivers of children with disabilities, as well as other experiences: (1) ‘If a parent devotes their entire life to this, the benefit should be the national average, not the subsistence minimum. The state shifts the entire burden of caring for a sick child onto the family. The child should be able to receive care at a center or school so that the parent can take up employment. And after finishing school, a sheltered workshop or some other form of support should be provided. Aggressive individuals never get anywhere; they are stuck at home and lose the skills they acquired through the education system. (...)’, (2) ‘(...) within the community of caregivers for people with disabilities, there is a very negative trend, namely the harsh criticism of those who take on work

and receive child benefits by people who do not have that option. It is often argued that this is unfair to those who cannot do so as their child requires round-the-clock care (...). As a result of this phenomenon, I observe a massive amount of hate – naturally, on social media. I believe that caring for a child with a disability is a very difficult task, and I absolutely disagree with the criticism that is being spread. I believe that the community of caregivers for people with disabilities is in desperate need of campaigns and programs promoting an end to hate and mutual acceptance. (...) to provide better psychological and psychiatric care for those who, as a result of their own difficulties, exhibit negative behavior, nevertheless, promoting mutual support, curbing hate, and emphasizing understanding and greater respect for one another could bring about at least a small change that might support caregivers' mental health and their ability to cope with the difficult situation that a child's illness represents.' (3) 'Don't be under any illusion: if you have a child with a severe disability at home, you won't be making a fortune. A chronic, terminal illness seeks to destroy not only the child's body but also, in the process, family relationships. It takes a great deal of effort, strength, and determination not to give in to it. Any form of support in this situation is important, whether it comes from a charity, a hospice, or other support programs.'

The respondents shared the following thoughts and experiences relating to both their professional and personal lives as caregivers of children with disabilities: (1) 'It also happens that parents are unable to undertake further training because the local job centers in small towns do not organize courses. There are also cases of anonymous complaints being sent to the Social Welfare Center alleging that a parent is training on their own.', (2) 'We're always short of money; we're always having to give up holidays or other pleasures to pay for our child's therapy. The residential therapy stays are so expensive that even with funding from PFRON, we can't afford to go. Prices reach up to PLN 16,000, whereas a parent and child receive around PLN 5,000 in funding. You have to fight for everything. At the social services office, the staff just discourage us rather than talking about ways to help. We're socially excluded; our family is ashamed to invite us over because of our child's socially unacceptable behavior. There's nothing harder in life than raising a disabled child. Constant wran-

gling with the PPP for assessments and opinions, then with MZON/PZON/WZON, or fighting for our rights in court. A child psychiatrist is overbooked and appointments are horribly expensive at PLN 600, whereas I receive PLN 3,200 per child in total – so what am I supposed to live on? And how am I supposed to pay for a dentist or an orthodontist, for example? The state should provide subsidies to parents for therapy/care, etc., rather than making them beg for money from the 1.5%. It is simply degrading.', (3) 'I believe that people who received their child's diagnosis at a stage in their lives when they were already well-established in their careers are better able to cope with the challenges of keeping their jobs. For someone like me, whose child's diagnosis came at the very start of my professional career, the limitations on career development and work make returning to the profession extremely difficult. Furthermore, it is very hard to balance care with employment – illnesses, trips to rehabilitation centers, and medical appointments leading to absences are, of course, highly undesirable for employers. (...) Problems with finding care for people with disabilities are a huge obstacle. Holidays are also often a time when childcare options run out, requiring the caregiver to use all their annual leave for caregiving. (...) Enabling caregivers to work is costly, but I believe it could bring many benefits that outweigh the costs. Unfortunately, our decision-makers are not sufficiently aware of the situation faced by caregivers. (...), when shaping our country's policies, they should conduct proper public consultations with the people who will be affected by the legislation.', (4) 'Parents who receive benefits are often called good-for-nothings, lazybones, fraudsters, or scroungers. Our work, which ends with the death of a child, goes unnoticed and is looked down upon. Please remember that not everyone has the support needed to take on work for even a few hours a week. Dreams are one thing, reality another.'

## **Group 2. Recipients of the care allowance granted before December 31, 2023 who decided to opt for the care allowance under the new rules in force since January 1, 2024**

They made 24% of all respondents of the survey. Children in their care were aged between 1 and 11 years. Three respondents indicated that they were caregivers to two children with disabilities – aged 7 and 11, next

1 and 5, and 4 and 8. The majority (83%) of respondents in this group were employed before the birth of their children, while 17% were not.

The respondents were asked about the motivation behind their decision to switch to the amended regulations in a semi-closed question. Choosing from the pre-selected answers or providing their own answers, the respondents explained that they switched from the previous to the new rules because: (1) of the possibility to take up employment, (2) they had more than one child with a disability, and they could get the care allowance for each disabled child.

The majority (67%) of respondents in this group took up a job after switching from previous to the new rules and receiving the right to the allowance, while 33% did not. Only 33% of respondents who decided to take up employment after the changes did not have any difficulties in re-entering the labor market in their situation. Another 33% indicated ‘problems related to the long-term exclusion from the labor market’ and ‘a gap in professional resume due to childcare as a difficulty in finding employment’, as well as the lack of part-time employment offers. Some respondents could not take up a job because of ‘hospital stays, rehabilitation, and doctors. My son is under the constant care of 16 specialists. I previously worked professionally, but after maternity leave, I didn’t return to work.’

Respondents noted that a series of state-funded meetings with professionals who facilitate access to education and training opportunities, while also providing psychological support and encouragement, would be of considerable assistance. They further emphasized the need for greater state support for childcare and more effective assistance from employment services. Respondents also pointed out that the improved support should include a higher allowance to those who need more equipment that PFRON and PCPR cannot provide them with when needed, a facility where they can go for psychological support, job search assistance, or help with selecting doctors for a child with a disability, and most of all ‘Actual access to specialists and rehabilitation services under the National Health Fund (NFZ), not with yearly deadlines, because we have to obtain most therapies and doctors privately due to the deadlines and limited number of therapy hours under the NFZ.’

One respondent concluded by sharing her personal feelings about the daily lives of parents of children with disabilities: ‘The lives of parents of children with disabilities are a constant struggle for a better tomorrow. We feel left to our own devices. We fight for jobs, doctor’s appointments, and constantly seek funds for rehabilitation. All this makes us less confident in ourselves and our abilities. We are tired of the constant struggle and begin to forget about each other and our own needs. The government doesn’t focus enough on providing support to these families, both financially, medically, and psychologically.’

### **Group 3. Recipients of the care allowance granted after January 1, 2024, not eligible for it under the previous rules**

This group consisted of 6 respondents (24% of all respondents of the survey), who were granted the care benefit under the regulations in force since January 1, 2024, and therefore did not have the opportunity to choose between the previous and the amended system. Thus, their observations, assessments, and comments related to the new support model. These mothers were caregivers to children and adolescents with disabilities, aged 2 to 17. Two respondents, of whom one was a single mother, indicated that they had two children with disabilities – aged 2 and 5, and 15 and 17.

83% of them are currently professionally active, and 17% are unemployed. Respondents appreciate that the care benefit under the new rules allows them to: work (67%) and to receive the benefit for more than one child with disabilities (33%).

Two respondents indicated no barriers to employment, explaining ‘I was working before, so when the new rules came into effect, I was granted the care benefit.’ and ‘I worked before my pregnancy, and after returning to work, I work in the same position, only remotely.’ Another respondent considered giving up the job ‘because the number of visits, rehabilitation, and work with the child is difficult to reconcile with work, and the facilities failed us.’ One also mentioned employers’ reluctance to hire someone raising a child with a disability.

Respondents emphasized that parents of children with disabilities would be greatly supported by: (1) ‘Workplaces where remote work or flexible work-

ing hours are possible. Although the law allows parents to request such working conditions, few parents are aware of this.’, (2) ‘Support in finding employment.’, and (3) ‘Easier access to vacation/sick leave for appointments (I know this is difficult in some industries). Places where you can safely leave your child, or find someone specializing in care (which is difficult).’

Most (67%) of respondents believe that the new rules for care benefits are more favorable than the previous ones, and 17% had no opinion about it. However, although it’s appreciated that the new rules allow the recipients to work, the age limit of 18 for receiving the benefit is perceived as their key disadvantage.

Asked about the welcome changes and improvements regarding care services, respondents highlighted: ‘Sometimes it’s not about money, but about access to places, facilities, specialists, medications, and a bit of respite. Money, while helpful, doesn’t solve everything. There’s also the issue of divisions and commissions – it’s difficult to describe all disabilities with a single metric.’ The things that would help them in everyday life are: (1) ‘Psychological support for parents raising children with disabilities.’ and (2) better organization of medical services ‘Sometimes it would be nice not to waste so much time on travel and delayed appointments (once we waited 5 hours for an orthopedist). Just because a disability isn’t visible doesn’t mean it doesn’t exist. My son copes well, but he often falls, things fall out of his hands, and people look at him strangely. I think it’s a matter of low awareness and acceptance of differences in people. There’s a lack of appropriate facilities and those worth recommending – we’ve encountered two, and the reviews are rather unfavorable, as we’re not a good fit for either ‘very’ special children or healthy ones.’

At the end of the survey, respondents were encouraged to share their personal feelings, thoughts, or experiences related to their professional and life situations as caregivers of children with disabilities, to which they responded: (1) Even though it’s difficult for me to combine work, childcare, and rehabilitation, I work because I want all benefits, such as the care allowance, or the 800+ program, to be truly spent on the child and their needs, not on maintenance. Therefore, what I earn goes toward food, hygiene products, clothing, bills, etc., while what the child receives from bene-

fits goes toward all doctor’s visits, rehabilitation, and orthopedic equipment.’, (2) ‘By being able to receive benefits, one feels cared for by the State.’ and (3) ‘Life changes forever, but on the other hand, experience allows one to see the world and surroundings differently.’

#### **Group 4. Recipients of the care allowance granted before December 31, 2023, who are currently not receiving any allowance**

This group includes one woman who currently does not receive the care benefit but previously received it under the old rules and participated in the study. She is the mother of a 16-year-old teenager with a disability. She did not work before the child’s birth, but is currently employed, as her son is quite independent and no longer requires much of her care. When asked about her potential decision to pursue employment in the past, if it had been possible to combine it with the care benefit, she answered that she would definitely have worked while her son was at school.

In the respondent’s opinion the amended care benefit rules are more favorable than the old ones. However, significant improvement should be introduced because ‘The care benefit should count toward the length of service for retirement. I received the benefit for 12 years under the old rules and now I’ve learned that it doesn’t count toward my retirement. It’s sad.’ Although local authorities pay contributions to pension and disability insurance for the benefit recipients, the time over which the benefit is paid, is not included in the retirement count. Consequently, individuals providing long-term care for a disabled child and receiving the care benefit for this purpose do not acquire a number of employee rights, such as: the right to holiday leave, seniority allowance, anniversary bonus, or retirement and disability severance pay.

The respondent remarked that both the benefits and the care allowances should be higher, especially for children with the greatest needs.

Sharing her personal feelings, thoughts, and experiences, both in terms of professional activity and daily life as a parent of a child with a disability, the respondent said: ‘After 12 years of receiving benefits, it’s very difficult for me to find a job because I have no experience. I’d never worked before. I became a mother

at a young age and didn't have the opportunity to work after school. My child needed me. After the benefit was rejected, I started my own business, which made it easier for me to adjust my schedule to accommodate the constant trips with my child to therapy. However, it's very difficult to maintain my own business. Parents of children with disabilities should have access to free courses or internships to help them start work more easily and ensure that their benefits count toward their retirement years.'

## DISCUSSION

The findings of the study proved that motivations influencing the career decisions of caregivers – here mothers – of children with disabilities depend largely on the interplay between the legal framework to which they are subject and their professional, family, and economic situation. Those who were granted the allowance under the rules in force until December 31, 2023 exhibit two main attitudes: (1) those who have chosen to remain under those rules and do not intend to change their status in the future, as they are either unable to undertake paid employment due to their child's condition or experience uncertainty arising from the amended regulations, particularly regarding the age limit for eligibility for the allowance; and (2) those who decided to opt for the new rules because they wanted to take up paid employment and/or had more than one disabled child and thus could receive the care allowance for each. No matter which attitude they represent, they call for more flexible arrangements enabling transitions between the previous and the current support schemes in the event of, e.g., a change in the child's health condition, as it would help them to adjust to changing and often unpredictable conditions. Another group are those, who were granted the allowance after January 1, 2024 and have no other option than the new rules.

Respondents mostly agree on the strengths and especially on the weaknesses of the previous and current rules of granting the allowance. They advocate for incorporating certain elements of the former regulations into the rules in force since January 1, 2024, and also suggest numerous improvements to the system support-

ing children with disabilities, elaborated in collaboration with parents and caregivers of children with disabilities.

Barriers influencing the career decisions and everyday lives of mothers of children with disabilities include not only the aforementioned legal constraints, but also economic and social factors. In cases of exclusion from the labor market – whether due to the child's condition, legal requirements, or a lack of suitable job opportunities – respondents experience the well-documented negative consequences identified in the existing literature (Goldin, 2014; Bakalarczyk, 2017; Brown & Clark, 2017; Asuman et al., 2025; Israeli et al., 2026), while being deprived of the benefits associated with paid employment (Giddens, 2008; Bakalarczyk, 2020; Tokić et al., 2023).

## CONCLUSIONS AND LIMITATIONS

This study shows that the career decisions of mothers caring for children with disabilities are determined by a complex interaction of legal, economic, and social factors. Changes introduced to the care allowance system have diversified caregivers' strategies and preferences, while also creating new challenges and uncertainties. The findings highlight the importance of developing more flexible support mechanisms that can respond to changing family circumstances and facilitate labor market participation without compromising the quality of care provided to children with disabilities.

The study also provides evidence that caregivers perceive the current support system as requiring further adjustments, particularly in terms of flexibility, continuity of support, and responsiveness to individual family situations. These findings may contribute to future discussions on social policy reforms aimed at improving the balance between caregiving responsibilities and professional activity.

The limitations of this study arise from the unintended gender homogeneity of the sample, which comprised exclusively mothers of children with disabilities, as well as from the relatively small number of interviews conducted. These constraints may limit the transferability of the findings. Accordingly, future research should include fathers and male caregivers of children with disabilities, as well as partici-

pants living in small towns and rural areas, in order to capture a broader range of caregiving experiences and socio-spatial contexts.

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## PRAWNE I EKONOMICZNE UWARUNKOWANIA UCZESTNICTWA RODZICÓW DZIECI Z NIEPEŁNOSPRAWNOŚCIAMI W RYNKU PRACY W POLSCE

### STRESZCZENIE

**Cel:** W Głównym celu badania była identyfikacja determinant decyzji zawodowych opiekunów dzieci z niepełnosprawnościami, w tym roli przepisów dotyczących świadczenia pielęgnacyjnego, percepcji ostatnich zmian prawnych oraz znaczenia pracy zarobkowej. **Metody:** W badaniu zastosowano podejście jakościowe oparte na pierwotnych danych jakościowych zebranych za pomocą autorskiego badania online (CAWI) przeprowadzonego w 2025 roku wśród 25 rodziców dzieci z niepełnosprawnościami. Kwestionariusz badawczy opracowano na podstawie przeglądu obowiązujących regulacji prawnych, analizy internetowych forów dyskusyjnych oraz grup wsparcia na Facebooku dla opiekunów dzieci z niepełnosprawnościami, a także eksploracyjnych wywiadów częściowo ustrukturyzowanych przeprowadzonych z trzema matkami pobierającymi świadczenie pielęgnacyjne w 2025 roku. **Wyniki:** Respondentkami badania okazały się wyłącznie matki dzieci z niepełnosprawnościami. Wyniki badania wykazują, że ich decyzje zawodowe są kształtowane przez interakcje czynników prawnych, ekonomicznych i społecznych. Ostatnie zmiany w systemie świadczenia pielęgnacyjnego doprowadziły do zróżnicowania strategii zatrudnienia, jednocześnie utworzyły nowe wyzwania i obszary niepewności. Respondentki postrzegają obecny system jako wymagający dalszych usprawnień, zwłaszcza w zakresie elastyczności, ciągłości wsparcia oraz dostosowania do indywidualnych sytuacji rodzinnych. **Wnioski:** Konieczne jest opracowanie bardziej elastycznych mechanizmów wsparcia, które ułatwią opiekunom dzieci z niepełnosprawnościami uczestnictwo w rynku pracy, bez obniżania jakości świadczonej opieki. Skuteczna polityka społeczna powinna lepiej uwzględniać zróżnicowaną i zmieniającą się sytuację rodzin sprawujących opiekę. Przyszłe reformy tej polityki powinny być projektowane w ścisłej konsultacji z rodzicami i opiekunami dzieci z niepełnosprawnościami oraz uwzględniać ich doświadczenia życiowe i zidentyfikowane potrzeby.

**Słowa kluczowe:** rodzice dzieci z niepełnosprawnościami, opiekunowie, zatrudnienie, wsparcie polityki społecznej