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Ideologies and Policies for Independent Life and Disability: Personal Assistance Services Supporting the Employment of People with Disabilities in Norway and Poland

Abstract: In this article we consider the concept of “independent life” for people with disabilities, and attempts to implement the idea in Norway and Poland, especially in relation to the employment of people with disabilities. Assistant services appear to be so crucial in this regard that they are mentioned in the UN Convention on the Rights of Persons with Disabilities (the CRPD, adopted on December 13, 2006). However, the organization of such services in these countries reveals strains resulting in part from misconceptions of what it means to have a disability and what is meant by “independent living.”

Keywords: independent living, disabled person, personal assistance, Norway, Poland

Introduction

The idea of “independent living,” which has been popularized and put into practice by the movement of persons with disabilities,¹ is, as Colin Barnes emphasizes, a concept rooted in ideological, cultural, and pragmatic traditions of Western society based on human and civil rights (Barnes 2004). “Independent living” is a radical concept because it poses

¹ In this article we use the terms “disabled people,” “the disabled,” and “people with disabilities” interchangeably. We are aware of the fact that in Poland and elsewhere the politically correct term is “person with a disability,” which is supposed to focus the attention on the person rather than their disability. However, we decided to use the above-mentioned terms synonymously for two reasons: (1) the term “person with a disability” is criticized by representatives of critical theory of disability as apolitical, individualizing, and inappropriate due to the separation of the disability from a person (Sztobryn-Giercuszkiwicz 2017: 34), and (2) the use of these two terms is increasingly nuanced, with the phrase “persons with disabilities” being reserved for visible disability (due to the greater ease of marking a distance between the person and their “disability,” and “disabled people” for people with hidden/invisible disabilities (usually such people are perceived as disabled, i.e., a person and their disability form an “inseparable whole” (Raćław and Szawarska 2018). Because both of these terms are criticized, including by advocates of change to the paradigm for defining disability, and there is no consensus about their adequacy, we assume that those terms are “neutral” with respect to the model for defining disability and describe a person who is not fully functional, i.e., has some impairment, visible or invisible: physical or sensory, psychological or intellectual.

a direct challenge to the conventional thinking about disability represented by the medical approach, which treats a disabled person as an object of care and rehabilitation. People with disabilities have existed in all societies in the world—only their position and the reactions of society to their impairments have changed. As Colin Barnes points out in reference to the works of other authors, despite the differences in terminology among disabled activists and their allies, there is general agreement that the philosophy of “independent living” has four basic assumptions:

1) that all human life, regardless of the nature, complexity and/or severity of impairment is of equal worth; 2) that anyone whatever the nature, complexity and/or severity of their impairment has the capacity to make choices and should be enabled to make those choices; 3) that people who are disabled by societal responses to any form of accredited impairment—physical, sensory or cognitive—have the right to exercise control over their lives; and 4) that people with perceived impairments and labelled ‘disabled’ have the right to participate fully in all areas, economic, political and cultural, of mainstream community living on a par with non-disabled peers (Barnes 2004: 10).

The idea of independent living assumes the equal participation of disabled people in society and its institutions. It combines both ideological and practical solutions for everyday problems encountered by disabled people and their families. One such problematic area is the labor market: access to work, the work environment, and the opportunity to pursue a professional career. Industrial societies have marginalized people with disabilities, treated them as unproductive, or pushed them into sheltered workplaces. The contemporary social approach, which is derived from the idea of independent life, emphasizes the right of disabled people to work on an equal basis with other people. The new ideology has changed the methods of supporting the employment of people with disabilities. Such methods include personal assistance services, which as far as possible enable “independent” functioning in various spheres of social life, including work.

In this article, we will discuss the development of assistant services in Norway and Poland, with particular attention to the sphere of employment. The two countries are at different stages of implementing the ideology of independent living in practice. They have varying experiences in employing people with disabilities and their state entities have different practices in approaching the ideology of independent living and independent-living conditions for people with disabilities. We will show the strengths of the solutions developed and the areas that create tension in practice. In conclusion, we will address the ideological, cultural, and practical implications of these changes.

Disability and Labor Policies and Ideologies

There is a limited amount of scholarly literature on the work of people with disabilities in different historical periods and geographical areas. One of the first was Vic Finkelstein’s study *Attitudes and Disabled People: Issues for Discussion* (1980). Using the approach of historical materialism and phases of economic and technological development, it analyzes labor relations and the position of people with disabilities in pre-industrial, feudal society, industrial capitalism, and post-industrial society. This approach was further developed in Mike Oliver’s work *The Politics of Disablement* (1990). In the analyses of both authors,

a significant place in the perception of disability is attributed to ideology. Olivier defines ideology as a set of values or beliefs that form the basis for social practices involving work processes, medical intervention, or the provision of welfare services (Oliver 1990: 43). The primary function of work ideology “is to stabilize the social order by providing all categories of society with an ‘obvious’ justification of their place in society” (Marody, Lewicki 2010: 91). As Barnes and Mercer emphasize, discrimination against people with disabilities is a simple reflection of the interests of capitalists or ruling classes (Barnes, Mercer 2003).

The exclusion of people with disabilities from the labor market, as the above-mentioned authors stress, is very strongly linked to the emergence of industrial capitalism in nineteenth-century Europe and North America. It has weakened the traditional values characteristic of feudal societies and the related support possibilities based on local communities and family (Barnes, Mercer 2003). The “productivity revolution” initiated at the turn of the nineteenth and twentieth centuries by Taylor led to an increase in the purchasing power of workers and improved living standards, which significantly mitigated industrial conflicts (Marody, Lewicki 2010: 94). At the same time, capitalism, which is based on a free market economy, paid work, and mechanized production systems, has led to the removal of disabled people from employment as less productive workers (Barnes, Mercer 2003).

Two researchers of left-wing orientation, Marta Russell and Ravi Malhotra (2002), stress that industrial capitalism has created not only a class of proletarians but also a new “disabled class.” The category of disability derives from labor relations. It is a product of the exploitative economic structure of capitalist society, which creates and then oppresses “disabled bodies.” As a result, the “disabled class,” whose bodies do not conform to the standard body pattern of the workforce, has been excluded from paid work. People with disabilities became a social problem; they were excluded from mainstream society and directed to special institutions such as workhouses, hospitals, or special schools (Russell, Malhotra 2002: 213).

In post-industrial societies we observe a change of trends in the approach to the phenomenon of disability. Focusing on the subjectivity and rights of people with disabilities has directed the attention of researchers and practitioners to the labor market. Attention has been drawn to the new opportunities offered by economic and social changes in post-industrial societies using computerized information and communication technologies, which Manuel Castells has described as “network society” (1996). New technologies, thanks to technical and communication solutions, have created previously impossible opportunities on the labor market for people with disabilities: new opportunities to engage in paid work on an equal footing with others and thus to lead an independent life.

The changes in ideology and labor policies in regard to people with disabilities can also be seen from the perspective of the transformation of modern capitalism toward “disorganized capitalism” (Lash, Urry 1993), which is characterized by the division of the labor market into a “core” and “peripheral” areas. People with disabilities often supply the periphery of the labor market; they are a category of the precariat, and the status of “others” assigned to them means that their life choices are often limited to so-called precarious possibilities (Standing 2012). At the same time, researchers highlight the role

of the cultural transformations of “new capitalism,” which involves new opportunities for work, the development of talent, and consumption (Bartkowski 2018). However, according to Sennett, these need not translate into the expansion of individual freedom. Changes in the sphere of work in “flexible capitalism,” which is characterized by the discontinuity of employment, can become a source of suffering and enslavement, leading to a “corrosion of character” and not providing individuals with a sense of anchorage (Sennett 2006).

Marcin Garbat published historical and review papers on the perception of disability and forms of support (2015) and on employment and rehabilitation in Europe (2012). In his analyses, he emphasizes that the “productivity” of people with disabilities is still an important issue in assessing their place in the social division of labor, especially in countries where the medical model is dominant. In the twentieth century there were changes in the approach to the vocational rehabilitation and employment of people with disabilities. Most countries are moving away from the practice of isolating and segregating people with disabilities in special workplaces, which were previously considered to be the best place for them to live and earn money. An open labor market is now being promoted and protected employment is being replaced by supported employment and social employment. Nevertheless, economic support for employers, to compensate for the lower “productivity” of workers with disabilities, is still a factor determining their employment in most European countries (Garbat 2012: 515–517). In most European countries, including Poland, the so-called quota model is in force: it requires employers who do not employ a fixed number of people with disabilities to contribute to a separate fund (in Poland, the State Fund for the Rehabilitation of Disabled People, [PFRON]). It should be stressed, however, that approaches based on civil rights and equality policy are becoming increasingly important (e.g., in Norway), as well as mixed, so-called hybrid approaches. These systems are based on the right to work and the prohibition of discrimination against people with disabilities, with the enforcement of constitutionally guaranteed rights. This approach refers to shared values of equality and freedom in post-modern societies. The growing importance of social and civil rights, as well as the emergence of a new social issue (e.g., as a result of an increasing labor supply with a decreasing demand for labor), is prompting states to look for new solutions in social policy (Rymsza 2015). In recent decades, both convergence processes and the hybridization of national policies have influenced the remodelling of welfare-state forms in European countries (Golinowska 2018: 139), including changes in ideologies, employment policies, and approaches to the work of people with disabilities.

Independent Living as an Ideology and Practical Paradigm

As we mentioned in the introduction, the right to an independent life is understood as the right of people with disabilities to control their own lives and make all the decisions that affect them. It derives from fundamental ideas of creating equal opportunities for people with disabilities to access civil rights and of obliging societies to remove barriers to these rights, and it involves the duty to see people with disabilities holistically, beyond the prism of their impairment and failure (“our biology is not our destiny”) (Morris 2004: 428). Currently, such an approach to independent life is sanctioned by the Convention on the

Rights of Persons with Disabilities (especially Article 19 concerning living independently and being included in the community).

The idea of independent living (IL) was first connected with the Independent Living Movement in the USA, whose origins can be traced back to the 1960s. It was then adopted by organizations of people with disabilities in other countries, which led to the institutionalization of activities and the creation of the European Network on Independent Living in 1989 (Giermanowska, Greniuk 2019). However, the political mobilization of people with disabilities has been visible since the beginning of the 1970s (Barnes, Mercer and Shakespeare 2005: 11), which has resulted in a change of understanding disability in favor of a social model.

The idea of independent living appeared at a time when representatives of consumer, de-institutionalization, de-medicalization, civil rights, self-help, and normalization movements articulated their postulates and put forward claims in Anglo-Saxon countries and Western Europe. They co-shaped the assumptions of the independent-life movement and the model of life promoted by this movement, which was soon defined as the new paradigm (DeJong 1979: 438). In defining the social problem, seeking its sources, proposing solutions, locating social control, and perceiving social roles for people with disabilities (DeJong 1979: 443) it differed from the previous, medical approach (in the spirit of rehabilitation). According to the new approach, independent life is the result of a process in which there is a release from dependence on professionals, relatives, or other people who provide care for/control a disabled person. It is lived outside 24-hour care institutions, in the local environment (it corresponds to the postulates of de-institutionalization) and a disabled person acts as an active consumer of services, exercising control over them, and speaking on his/her own behalf (DeJong 1979: 443).

The paradigm of independent life initiated changes in the practical and political spheres (DeJong 1979: 442). There has been a departure from the importance of self-care, mobility, and employment as goal determinants in social service organizations. These determinants have been replaced by a wider perspective, involving recognition of the importance of living arrangements, consumer assertiveness, outdoor mobility, and out-of-home activities (DeJong 1979: 444). Over time, activists for independent living have identified 12 “basic needs” whose satisfaction is key to achieving IL. These are full access to the environment, a fully accessible transport system, technical aids (equipment), accessible adapted housing, personal assistance, inclusive education and training, an adequate income, equal opportunities for employment, appropriate and accessible information, advocacy and self-advocacy, counselling, and the provision of appropriate and accessible health care (Morris 2004: 428–429).

As a result, under pressure from IL activists, governments have revised their support tools. Faith in the necessary rehabilitation of a disabled person has been replaced by the search for solutions enabling their inclusion in society that take into account the specificity of disability. Instead of the provision of care for disabled people, personal assistance as a civil right is indicated (Ahlstom, Wadenstein 2012: 113). It is emphasized that assistance is related to the empowerment of people with disabilities, who decide for themselves who will assist them, when, and in what activities, and the assistant becomes the “hands, legs, senses” of the person with a disability, while the person with a disability retains control over

the support process. However, there are research reports that reveal the difficult nature of the assistant's work, especially in the emotional sphere. Ahlstrom and Wadenstein (2012: 116) link them to the "difficulties of being in a subordinate position" resulting from the nature of work. In this respect, the researchers stress the importance of a subjective rather than objective treatment of assistants, as then the assistants will be more capable of furthering the empowerment of persons with disabilities as recipients of the service.

The problem of empowering assistants in relations with a disabled person is raised in emancipation research based on the social model of disability and the philosophy of independent living. A 2018 survey of members of the independent-living movement in Europe and people with disabilities using personal assistance (PA) identified those features of PA that were considered to be enabling factors for choice and control, those that were perceived as barriers, and those on which there was no consensus (Mladenov 2020). From the viewpoint of users of PA services, it is important that such services should not be imposed by the provider and should be in line with the suggestions of PA users and members of the independent living movement (this includes the possibility of choosing the assistant, the possibility of appealing an assessment of need for assistance services, and ensuring good working conditions for assistants). The results of the survey indicate that full consensus is lacking among the respondents in regard to some features of PA services, such as providing access to PA regardless of the degree of disability, limiting the recruitment of family members as assistants, the requirement for a medical certificate when applying for PA, and the instrumental treatment of assistants by users. The latter issue results from the dual role of assistants, who enter into friendly, quasi-family relationships on the one hand, and are in an employee relationship on the other: "Yet whilst PA relationships involve characteristics features [sic] of friendship (such as emotional attachment and shared interests) they also retain fundamental qualities of the employer-employee relationship" (Shakespeare, Porter, and Stöckl 2017: 5). The solution could be the "dialogical" model of PA, although the choice of the relationship model may also be an individual issue depending on preferences or lifestyle (Mladenov 2020: 17).

Personal Assistance Services Supporting the Employment of Disabled People

Information on the project and research methodology

The empirical material used in the article was obtained as part of the research grant "Policies for Independent Living in Poland and Norway on the Example of the Policy of Professional Activation and Employment of Disabled Students and Graduates of Universities." The project is implemented through the Bilateral Cooperation Fund, the European Economic Area Financial Mechanism, and the Norwegian Financial Mechanism 2014–2021 (operator—the Ministry of Funds and Regional Policy). Our research tasks involved, *inter alia*, conducting semi-structured in-depth interviews with selected experts and personal assistants of disabled people in Poland and Norway. The analysis presented in the article concerns data collected during interviews with Polish experts (13 interviews) and Norwegian experts (9 interviews). They represented various institutions and organizations,

including public agencies. Among the respondents were also representatives of non-governmental organizations, and activists. Some of the interviews were conducted face-to-face, others—due to the pandemic—remotely. These were synchronous interviews (Sullivan 2012), conducted mainly on the Zoom.com platform. An additional source of data was the information contained in reports prepared by our Norwegian project partners (Askheim 2019a, 2019b; Uloba 2019a, 2019b) and data provided during a seminar organized in Warsaw in February 2020 with the participation of guests from Norway.

The selection of experts for the research was based on the snowball method. While we had no difficulty in reaching representatives of selected institutions in Poland, in Norway we had to use recommendations and so-called doorkeepers, who facilitated our access. We are not sure whether we exhausted the pool of competent persons, but we treated the expert knowledge of experienced practitioners as one of several sources of information. This knowledge is different from scientific knowledge in that it depends on the definitions of the actors themselves, their views and interests, and has its own institutional context of production and characteristics such as content or procedural requirements (Pawlak 2012: 111).

Remote interviews are an increasingly common way of obtaining data in sociology, and the first methodological studies on the subject have already been developed (Sullivan 2012; Brompton and Cowton 2002; Grzeszczyk 2009; Jemielniak 2018). For our research team, this was not a planned strategy but the result of adapting to a sudden and unpredictable event—the Covid-19 epidemic. In the course of our research, we did not encounter technical difficulties or aversion to videoconferencing. However, we are aware that there are certain advantages and disadvantages to this way of conducting interviews and new ethical dilemmas arise, such as safeguarding the privacy and confidentiality of the interlocutor in a situation where the owner of the platform has access to the interlocutor's data (cf. Sullivan 2012; Grzeszczyk 2009). However, we agree with Sullivan that “The potential of videoconferencing as a research tool is almost unlimited. (...) Although there are some drawbacks, the benefits strongly outweigh them. With all of this in mind, further research on the use of videoconferencing as a method of data collection and interviewing in particular is needed” (Sullivan 2012: 60). In our case, it enabled us to talk to people who were geographically dispersed and/or isolated in their homes because of their health.

Another difficulty was to interview Norwegian experts in English. The methodological literature stresses that the “difficulty” of research can be understood in various ways: as the application of complex methods and techniques (with a high level of complexity); as the study of secret, inaccessible phenomena or social problems; and as inaccessible research areas (such as total institutions or specific subcultures) (Męcfal 2012: 157). In our case, the difficulty arose in a double sense: as inaccessible research areas due to bans on domestic and foreign travel caused by the Covid-19 epidemic, and as inaccessible research areas due to having to gather information from experts in Norway in English. English was not the mother tongue of either the researchers or their Norwegian interlocutors, and thus there was a risk that the content of the message would be simplified, statements would be shortened, or there would be mutual misunderstanding.

The literature on ethnographic research raises the problem of conducting interviews in a non-native language, as “Language and communications issues are clearly critical

in cross-cultural qualitative research” (Hennik 2008: 32). Using a non-native language can lead to misunderstandings due to an inability to ask the right question and a lack of understanding of the lexical choices of the research participants, resulting in the relative powerlessness of the researcher (Winchitz 2006: 86). However, if, as Winchitz argues, the researcher does not focus on his or her lack of language skills and trusts his or her interlocutor, communicating clearly and openly about the problem, the interview can be fruitful (Winchitz 2006: 93–94). We believe that this level of trust was achieved in our interviews and resulted in a considerable amount of meaningful content.

The NVivo12 program was used in analysis of the interviews with experts (transcripts) and enabled the generation of the required analytical categories. The interviews were a source of knowledge for us about the individual experiences of the experts—information that was embedded in a cultural and institutional reality and reconstructed in the course of interaction. Our approach is close to that of the interactionists, who do not perceive statements made in an interview in terms of truth and falsehood but use narratives to understand subjective attitudes and feelings. As Silverman writes, “We need not hear interview responses simply as true or false *reports* on reality. Instead, we can treat such responses as *displays* of perspectives and moral forms” (Silverman 1995: 107).

Norway—personal assistance services and support for the employment of disabled people

Norway’s system of personal assistance services and the related policy are under review as this article is being written. The normalization principle which guides the current policy and which placed assistance services within the responsibilities of municipalities, appears to have backfired, causing a number of issues, about which we write below.

In Norway about 17% of the population lives with a disability (https://bufdir.no/en/English_start_page/Disabilities_in_Norway/). According to the most recent data (03/09/2020) of the Norwegian Bureau of Statistics, 40.06% of people with a disability are employed, in comparison to 73.4% of employed people in the total population aged 15–66. Of employed people with disabilities, 43.6% work part time. This is roughly twice as many part-time workers as in the total employed population (23.7%). In the population of disabled people aged 25–39, 48.4% are employed, and 39.9% in the 15–24 age range are employed. There is thus a significant need for services supporting people with disabilities both in everyday living activities and in the context of employment.

The normalization principle, which holds that there should be no unnecessary divisions between disabled people and other citizens in terms of medical care, employment, education, welfare, and so forth, has a long history in Norway, as it was first introduced in the 1960s (Askheim 2019a). The principle was later supplemented by legislation strengthening organizational integration, with the idea that ordinary welfare services should have full responsibility for all inhabitants, regardless of disability status or specific needs. As welfare provision in Norway is the responsibility of municipalities, these are the institutions obliged to provide and finance all the necessary services (Romoren 2018). This fact, coupled with the principle of social integration which is also implemented in Norway, means that people with a disability should be able live and work in the community just as non-disabled people do. Overall, Norway appeared to be well prepared for implementation

of the UN Convention on the Rights of Persons with Disabilities, which it ratified in 2013. Furthermore, the governmental “Action Plan for Disabled People” (1994–1997) proposed that people with disabilities, as both consumers of services and citizens with democratic rights, should have stronger user control over the services they use (Askheim 2019a). This has paved the way for the introduction of citizen-controlled personal assistance as a municipal service and in some cases a civil right. User-controlled personal assistance [UPA] was contained in the Social Services Act in 2000, as one of the services that municipalities are obliged to offer (Askheim 2019a).

At first glance, UPA appears to be the perfect tool for the implementation of the ideology of independent living. It is the users, or—as some organizations such as Uloba would call them—work leaders, who manage the service, recruit the assistants, and make decisions regarding the use of allocated hours. Moreover, it is a solution that is not part of the rehabilitation paradigm. The assistant does not play any advisory or therapeutic role. He or she is there to perform the task assigned by the person with a disability.

UPA has definitely contributed to the greater self-determination and participation in society of people with disabilities and reduced their marginalization. However, it is not without some problems in its present form. On the one hand, people with long-standing and high need for personal assistance consider it their civil right, on the other its allocation depends on a discretionary estimation of the user’s needs, both in terms of qualifying for the service and the number of hours allocated. Because the decision is discretionary, the law may be interpreted differently in different municipalities, as is in fact the case. One reason might be that municipalities must ensure they have the funds for all the services they are obliged to provide and not just the UPA. However, Norway was criticized by the UN for a lack of uniform interpretation of the law and the resulting unpredictability in implementing services and the rights of people with disabilities (UN 2020: 6).

Currently, in accord with the 2015 Patient and User Rights Act, people with long-standing (over two years) and high need for personal assistance have the right to be granted UPA. A “major need” was defined as a service requirement of at least 32 hours per week. However, at the same time it was noted that people with disabilities and UPA needs of at least 25 hours per week should also have the right to services organized as UPA if a municipality can afford it. Moreover, the right to the service was restricted to those under the age of 67 for new applicants—as if the notion of independent living did not apply to senior citizens.

One of the major problems with UPA is that, according to the Social Services Act which regulates its implementation, time and activities spent in organized areas not covered by the Social Services Act are not included in UPA. In other words, UPA hours cannot be allocated to the time the user spends at educational institutions or at work. There the person with a disability is supposed to take advantage of other services. This, in particular, is a problem for people with severe disabilities who are attending educational institutions, especially in higher education. While universities provide note-taking services and other academic support, people supporting students with disabilities within this framework cannot assist them with eating or going to the toilet.

The absence of UPA from the work environment is partially redeemed by the functional assistance provided by NAV, which is a service similar to that of UPA, but in the work

environment. However, in comparison to UPA, functional assistance NAV is not widely used (in 2020 only 337 people benefited from functional assistance). This being said, access to UPA is beneficial in the areas of education and employment because people with disabilities can, for example, spend less time and effort dressing and getting ready, which gives them more time and strength to deal with learning or working. Moreover, being a work-leader for a PA teaches a person valuable skills in time management, prioritizing, communication, and so forth, which may be useful in the work environment.

Poland—personal assistance services and support for the employment of disabled people

In Poland, social policy on disability is incoherent as it is based on mutually exclusive concepts of the scope and fulfilment of the state's caring functions. The essence of the inconsistency lies, on the one hand, in the declarative recognition of fundamental objectives such as professional activation and social integration, and on the other hand, in "maintaining institutional mechanisms and instruments of social policy which serve only to carry out compensation functions and social provision at a minimum level" (Gąciarz 2017: 85). Among other things, the discrepancy between declarations and reality concerns implementation of the UN Convention by which the state has undertaken to ensure the rights of every person with disabilities to, *inter alia*, dignity, equality, freedom, self-determination, work, support, and housing. Nevertheless, many of the provisions relating to disability in Poland are still not in line with the Convention, and the conduct of the policy is referred to as "managing failure." (Kubicki 2017: 175). One of the basic and unresolved problems relates to the employment of disabled people: the system of support in the open labor market is inefficient (Gąciarz 2017: 89).

In Poland, the employment of disabled people has been at a low level for many years. According to the Central Statistical Office's LFS study (average annual data for 2019), the employment rate for people with disabilities (with a certificate of legal disability) of working age (women of 18–59 years of age, men up to 64 years of age) is 26.8%, the economic activity rate is 28.8%, and unemployment rate is 7.2%. Despite the existence of various forms of support for employers employing disabled people, the vast majority of employers pay contributions to PFRON for not employing the required share of disabled employees (in PL it is 6% for employers employing at least 25 people, 2% for public and non-public universities, schools, kindergartens, crèches, and other care institutions). The most popular forms of support from PFRON for employers are subsidies for salaries and reimbursement of social security contributions. Other forms of support include subsidies for adapting and equipping new and existing workplaces for the disabled, support for training and professional development, and the removal of architectural and communication barriers.

Personal assistance services, especially in the workplace, are not a comprehensive service in Poland offered to a disabled person on their own terms and according to the ideology of independent living (Giermanowska, Raclaw, Szawarska 2020). Currently, they are difficult-to-access services which are often provided within the framework of a special project, with the risk of the service's being discontinued or of not being receiving on time or in the form that the person with a disability expects. This contradicts the ideal of providing

personal assistance through the implementation of civil rights. Contrary to the provisions of the Convention on the Rights of Persons with Disabilities, which Poland ratified in 2012, assistance services are still interpreted as social services and are related to the realization of social rights.

This state of affairs causes frustration among people with disabilities (as evidenced by data from interviews with Polish experts—activists for the rights of people with disabilities), especially as people with disabilities have a growing awareness of their rights and the resulting solutions. In Poland, personal assistance services are organized both by local governments (often as part of social welfare projects but also from PFRON funds) and by non-governmental organizations (also using PFRON funds).

In the workplace, there are services similar to personal assistance, i.e., the services of a work coach and an assistant. The job coach assists people with disabilities in supported employment by introducing the employee to their duties and providing counselling and integration services during the first months of work. On the open labor market, however, it is possible for an employer to apply to have the costs covered of the services of an employee assisting a person with a disability in the workplace (PFRON funds). However, the assistance services provided in such a case cannot exceed 20% of the employee's working hours per month. There are criticisms of this solution because the qualifications needed to assist a person with a disability have not been defined and it can be embarrassing to appoint a co-worker, especially in situations involving assistance with hygienic activities.

In addition, some special PFRON programs include elements of personal assistance or job-coach services. These are provided for a maximum of six months of the program. Moreover, the services provided by NGOs are neither long term nor stable due to the project system, and as these organizations operate primarily in large cities, access is restricted for people living outside of such areas.

As previously highlighted, there are virtually no workplace assistance services except for the project activities described above. Furthermore, the demand for assistance services in the work environment is not one of the most frequently expected forms of support among disabled people who do not work. In PFRON research, non-working and disabled people most often mentioned, as expected forms of support, appropriate adaptation of the workplace, vocational courses to raise qualifications, and appropriate working conditions (e.g., no noise, breaks) (*Badanie potrzeb osób niepełnosprawnych*. PFRON 2017, N = 750, excluding people who declared that they are unfit for work or do not want to work, p. 214). The help of an assistant in the disabled person's commute to work was mentioned as very important or crucial by 22% of the respondents and as important by 26%. In turn, the constant help of an assistant in the performance of professional work was mentioned as very important or crucial by 19% of the respondents and as important by 29%. There was variation in the kind of assistance expected. The help of an assistant in commuting to work was more often mentioned by persons with sight impairment and persons with movement impairment (an average of 2.5 on a scale of 1–5). The desire for the permanent help of an assistant in the performance of professional work was most often reported by people with motor dysfunction (an average of 2.5 on a scale of 1–5, *Badanie potrzeb osób niepełnosprawnych*. PFRON [Survey of the Needs of Disabled People, PFRON 2017]), N = 750, excluding people who declared they were unfit for professional work or do not

want to work, 2017, p. 216). Personal assistance services are a practically unavailable form of support in the workplace, but it can be assumed that their widespread use could activate certain categories of currently unemployed disabled people.

These multiple restrictions on access to personal assistance services in the area of everyday functioning for people with disabilities, including in the workplace, lead to a situation where independent living becomes—as Magdalena Kocejko (2019) puts it—a “rationed product.”

Norway and Poland: expert opinions on independent living

Interviews with experts from Norway and Poland provided considerable information about national public policies for people with disabilities, socio-economic contexts, and social practices of assistance. In one of the questions, the respondents were asked to define the concept of independent living as they themselves understood it.

The literature raises the issue of multiple definitions of IL, which differ in content due to the socio-cultural context of individual societies. Differences in the understanding of independent living can occur even among collective actors operating at the same historical time and within the same territory (Yang 2014). “Using the same vocabulary, some accounts comply with concepts proposed by the IL movement, whereas others differ in their outlook” (Yang 2014: 674). With this awareness, we show here the similarities and differences in the understanding of independent living, while taking into account the variable of national affiliation. Due to space limitations, we do not indicate the subtle differences of definition within expert groups in the two countries.

An analysis of the material showed that both Polish and Norwegian experts built their definition of independent living in opposition to social and institutional paternalism in regard to people with disabilities. This is significant, as in both cases the majority of experts rejected the Western vision of independence as being self-supporting and self-reliant (cf. Christensen 2009). Definitions emphasizing this kind of independence as a component of IL were rare:

For me, an independent life is a life that I can live without having to support myself with other people, institutions, and external services (...). Without any special improvements or facilities from others. For me, “independent” in some way means “self-reliant” (W_PL_J).

Most often the interviewees from both countries referred to the ideal of the IL movement, emphasizing equal civil rights with non-disabled persons and gaining control of everyday life (Christensen 2009: 119). Anti-paternalism, which was the axis of the definition, was a structure composed of elements such as:

- free choice on the part of people with disabilities,
- the self-determination of people with disabilities,
- the independence of people with disabilities.

In the case of respondents from both Norway and Poland, these components were related to assistance services and break with the care approach to people with disabilities:

You can recruit instead, you can choose who should help you, what you need help with, when, and where, which is very important for feeling in control of your own life (W_N_K).

And for someone—and this is the real life story of a deaf-blind person—whose mother always sweetened his tea, it is a matter of drinking the tea without sugar—a preference the person was able to communicate only when the assistant appeared. And that is the independence that was possible there at the time. That he could finally drink that tea the way he liked it. And here, without this assistant, that would not have happened. So self-determination and control is what matters (W_N_M).

In this context, the importance of the assistant as a service leading to this independence was stressed:

For me, assistance is the extra arms and legs which, as I usually say, are the bridge between my disability and the rest of the world because, if you can imagine the model of a gap, assistants fill this gap for me. They enable me not only to live with my disability but also to be a person who is part of society (W_N_I).

(...) as for me, of all services relating to people with disabilities, this is the most important one. Without personal assistance services for a significant proportion of people with disabilities, it will simply not be possible to provide an independent life (W_PL_A).

However, in the statements of the respondents, there was a dialectic referring to assistance. On the one hand, they stressed its importance as a service derived from the anti-paternalistic vision of supporting people with disabilities and stemming directly from civil rights. On the other hand, the independent life of people with disabilities required the objectification of the assistant and de-personalization of his or her work. He or she became a tool for the activity of the main actor—the person with disabilities:

I use the metaphor of robots. Maybe someday in the future you will have robots that will be your arms and legs. This is it (W_N_O).

(...) the assistant is simply a kind of tool, just like a sign-language interpreter. (...) I feel that the assistant is a bit of a shadow, of course with full recognition of his or her work (W_PL_B).

In this context, the surveyed experts, both Norwegian and Polish, did not indicate the limitations of the accepted anti-paternalistic understanding of independent living. These are associated with negating or minimizing the dependence of disabled people on PA, which in turn is determined by the organization of local service systems. In fact, independence is interdependence, as Karen Christensen (2009) has brilliantly demonstrated with examples from the British and Norwegian systems.

Among Polish experts, definitions of independent living contained references to the law and to guarantees of equal human and civil rights, which are the essence of this ideology:

I think that independent life is a guarantee of fundamental rights that a person should have influence on, i.e., respect, dignity, access to the world of culture, to the world of sport, to the world of politics, social policy (...) human rights (W_PL_S).

For me, independent living is the possibility for people with disabilities to decide, on equal rights (...) on equal terms with other people to do the same things that other people can do (W_PL_A).

And this independent life is to guarantee that these needs and these rights are satisfied to an equal extent with other citizens, and also on the basis of such a democracy (W_PL_K).

This emphasis on the principle of equal rights by Polish experts may result from the fact that in Poland the ideology of independent life is poorly established, even though its

development was stipulated by the UN Convention, which Poland ratified in 2012. In the experts' statements, the use of legal arguments is intended to confirm the validity of the definitions provided, as well as to justify the expected social change.

On the other hand, one element that was observed among Norwegian experts did not appear in the statements of respondents from Poland. The category of "independent person" was used as a brand/brand of a service accessible to people with disabilities, associated with a specific provider:

Yes, I associate independent life with the ideology of independent life represented by Uloba [an organization providing assistance services founded by people with disabilities—ed. own.], which is the main goal of Uloba's activity. There are different types of pillars, deinstitutionalization, de-medicalization, de-professionalization and empowerment (W_N_K).

It is just a word, but as Uloba is one of many providers of the same services, so I guess they kind of grabbed the word or took the word for themselves. (...) It is like McDonald's, which has its brand and other things. It's like it's their brand as a recognition that BPA [system of personal assistance services] means independent living and that's true for Uloba (W_N_A).

Below, we compare the defining elements that appeared among the respondents from both countries with the components of the IL paradigm indicated by DeJong (1979: 443) and discussed in the previous subsection (Table 1).

Table 1

**Own definitions of independent life from experts in Poland and Norway
in the context of the Independent Life Paradigm**

Item	DeJong's independent-life paradigm	Concepts used by Polish and Norwegian interviewees
Definition of problem	Dependence on professionals, relatives, etc.	Dependence on professionals, relatives, etc. (for Polish and Norwegian interviewees)
Locus of problem	In the environment: in the rehabilitation process	In the medical model of public policy (Polish interviewees); In the social construct of disability (Norwegian interviewees)
Solution to problem	Peer-counselling, advocacy, self-help, consumer-control, removal of barriers	Introduction of Personal Assistance as a civil right (Polish interviewees); consolidation of support, such as Personal Assistance for persons with disabilities (Norwegian interviewees)
Social roles (of a person with disabilities)	Consumer	Self-independent actor (Polish interviewees); consumer and work leader (Norwegian interviewees)
Who controls? (role of the person with disabilities in controlling the assistance process—own note)	Consumer	Self-independent actor (Polish interviewees); consumer and work leader (Norwegian interviewees)
Desired outcomes	Independent life	Independent life (Polish interviewees); independent life (Norwegian interviewees)

Source: Own compilation based on DeJong (1979: 443) and results from interviews with Polish and Norwegian experts.

The differences in aspects of the IL concept indicated in the compilation can of course be explained by cultural differences and the historical moment captured in analyses and research (the moment of implementation of IL as a justification for practical solutions in national public policies). In the USA in the 1970s, the consumer movement was inspired by a relatively less developed social security system than in the countries of Northern and Western Europe. In the twenty-first century, Norway incorporated the IL paradigm into its system, the ideological base of which is egalitarianism. In Norway, equality of rights is an unquestionable goal of the political system and social security. Poland is at the beginning of the road. Experts emphasize that the success of implementing the IL ideology depends on abandoning the medical model, which is visible in the Polish legal and social security system (Kubicki 2017: 69–80), in favor of the actual implementation of a model based on civil and human rights.

The implementation of independent living requires the de-institutionalization of public policy. In Poland, as in other post-communist countries in Central and Eastern Europe, the process of the de-institutionalization of support for people with disabilities is shaped “by legislative, political and funding agendas set by EU bodies and supported by human rights discourses, particularly the CRPD [Convention on the Rights of Persons with Disabilities]. However, these ‘external’ forces have been mediated by two ‘internal’ historical factors characterizing the current situation in the CEE region—state socialist legacy and postsocialist neoliberalization” (Mladenov, Petri 2019: 16). The result of these overlapping conditions is the occurrence of re-institutionalization, which is an attempt to maintain institutions while making superficial changes to public policies and without reflecting on the similarity between the “new services” and “old institutions” (Mladenov, Petri 2019: 17). Furthermore, as argued by Ratzka, service providers offering conventional forms of support based on treating, training, guiding, and protecting people with disabilities, often end up withholding rights to independent living as a result of their administrative culture and framework (Ratzka 2007 after Power 2013: 205). This, we would argue, is also the case in Poland. For example, the assistants of disabled people in Poland are part of conventional social services, which has very little space for the agency of people with disabilities. It most certainly is not a user-driven form of support.

Conclusion

The ideology of independent living, at its base, was not geared toward the professional activation of disabled people. Its main objectives were to improve the quality of life and dignity of people with disabilities by recognizing their human and civil rights and increasing their autonomy, choice, control over their own lives, and participation in the life of the community, including the independent fulfilment of their duties, for example, as parents. Personal assistance services were intended to support people with disabilities in leading an autonomous and, where possible, independent life.

At the same time, there were changes in the ideologies and policies of work related to disability. The right of people with disabilities to work on an equal basis with others was sanctioned by the UN Convention and involves the development of an open labor market.

At the same time, new employment opportunities for disabled people have opened up in post-industrial societies as a result of technological progress. However, changes in law and technology have not resulted in a radical change in the professional activity of disabled people, while new threats have emerged in connection with their marginal position on the labor market (in the form of precarious employment).

Personal assistance services are one of the forms of support that can increase the professional activity of disabled people. The development of these services in Norway and Poland indicate that the two countries are at different stages. In Norway, the right to assistance is developing in an objective and subjective way: in addition to personal assistance, there has begun to be assistance in the workplace; assistants are assigned to the parents of minors with disabilities, which improves the functioning of the family and enables adults to work. In Norway, assistance services have not been implemented seamlessly: local variations in their supply are being discussed, as well as difficulties in accessing services due to local authorities' diagnosis of the needs of people with disabilities, and the medicalization of assistance as a result of its transfer to the health sector.

In Poland, on the other hand, we have not gone beyond the phase of short-term projects implemented by local governments or non-governmental organizations. Receiving assistance services requires being well oriented with the system and laborious work on coordinating support. The issue of assistance in the workplace has not been solved. The important fact that assistance service requires the disabled person to be prepared to receive it and the assistant to be prepared to provide it is not taken into account.

The experience of Norway, however, is very instructive for Polish planners: it shows that assistance must be treated as one of many support services, because disability is not a static condition. A flexible approach in organizing this type of service, taking into account changes in the health and fitness of the recipient, is needed, and it is often difficult to separate care and nursing activities from the tasks of the assistant. We cannot hope that independent life can be guaranteed solely by the introduction of universal assistance services. It will be implemented, among other things, thanks to this type of service, but there must be a warning against over-ideologizing assistance and turning it into an IL indicator, which may encourage the objectification of human work and the alienation of the assistant.

References

- Ahlstrom, G., Wadstein, B. 2012. Enjoing Work Or Burdened by it? How Personal Assistants Experience and Handle Stress at Work, *Journal of Social Work & Rehabilitation* 11(2): 112–127.
- Askheim, O. 2019a. The Norwegian system of supporting people with disabilities in independent living, including assistant services, report for Warsaw University, Lillehammer: Høgskolen and Innlandet.
- Askheim, O. 2019b. Personal assistance services and other public measures for people with disabilities in the work environment and in higher education in Norway, report for Warsaw University, Lillehammer: Høgskolen and Innlandet.
- Badanie potrzeb osób niepełnosprawnych. Raport końcowy. 2017. PFRON. Available at: <https://www.pfron.org.pl/instytucje/badania-i-analzy-naukowe/raport-koncowy-z-badania-potrzeb-osob-niepelnosprawnych/>
- BAEL G U S. 2019. Dane średnioroczne, Biuro Pełnomocnika Rządu ds. Osób Niepełnosprawnych. Available at: <http://niepelnosprawni.gov.pl/index.php?c=page&id=80&pdf=1>

- Barnes, C. 2004. *Independent Living, Politics and Implications*. Available at: <https://disability-studies.leeds.ac.uk/wp-content/uploads/sites/40/library/Barnes-Janes-paper.pdf>
- Barnes, C., Mercer, G. 2003. *Disability*. Cambridge: Polity Press & Blackwell Publishers Ltd.
- Barnes, C., Mercer, G., Shakespeare, T. 2005. *Exploring Disability. A Sociological Introduction*. Cambridge: Polity Press.
- Bartkowski, J. 2018. Polityka w epoce postpracy, in: J. Czarzasty, Cz. Kliszko (eds.), *Świat (bez) pracy. Od fordyzmu do czwartej rewolucji przemysłowej*. Warszawa: Oficyna Wydawnicza SGH.
- Bompton, R., Cowton, Ch.J. 2002. The E-Interview, *Forum Qualitative Sozialforschung/Forum: Qualitative Social Research* 3(2), Art. 9.
- Castells, M. 1996. *Rise of the Network Society*. Hoboken, New Jersey: Blackwell Publishing Ltd.
- Christensen, K. 2009. In(ter)dependent lives, *Scandinavian Journal of Disability Research* 11(2): 117–130.
- DeJong, G. 1979. Independent Living: From Social Movement to Analytic Paradigm, *Archives of Physical Medicine and Rehabilitation* 60: 435–446.
- Finkelstein, V. 1980. *Attitudes and Disabled People: Issues for Discussion*. New York: World Rehabilitation Fund.
- Garbat, M. 2012. *Zatrudnianie i rehabilitacja zawodowa osób z niepełnosprawnościami w Europie*. Zielona Góra: Oficyna Wydawnicza Uniwersytetu Zielonogórskiego.
- Garbat, M. 2015. *Historia niepełnosprawności. Geneza i rozwój rehabilitacji, pomocy technicznych oraz wsparcia dla osób z niepełnosprawnościami*. Gdynia: Novae Res.
- Gąciarz, B. 2017. Polityka społeczna wobec niepełnosprawności. Zarządzanie problemem czy strategia empowerment?, in: A. Karwacki, M. Rymśa, B. Gaciarz, T. Kaźmierczak, B. Skrzypczak, *Niezatrudnieniowe wymiary aktywizacji. W stronę modelu empowerment*. Toruń: Wydawnictwo Naukowe Uniwersytetu Mikołaja Kopernika.
- Giermanowska, E., Greniuk, A. 2019. Wchodzenie w dorosłość i niezależne życie osób niepełnosprawnych na przykładzie European Network on Independent Living, in: B. Szluz (ed.), *Doświadczenia niepełnosprawności w rodzinie*. Rzeszów: Wydawnictwo Uniwersytetu Rzeszowskiego.
- Giermanowska, E., Raclaw, M., Szawarska, D. 2020. Institutionalized Chaos Instead of Independent Living. Forced Modernization and Assistant Services in Poland, *Studia Humanistyczne AGH* 19(3): 73–92.
- Golinowska, S. 2018. *Modele polityki społecznej w Polsce i Europie na początku XXI wieku*. Warszawa: Fundacja im. Stefana Batorego.
- Grzeszczyk, E. 2009. Jak pochwyć rozmówcę w sieci, czyli wywiady przeprowadzane przez Internet jako technika socjologii jakościowej użyteczna w badaniu życia codziennego, in: M. Bogunia-Borowska (ed.), *Barwy codzienności. Analiza socjologiczna*. Warszawa: Wydawnictwo Naukowe Scholar.
- Hennik, M.M. 2008. Language and Communication in Cross-Cultural Qualitative Research, in: P. Liamputtong (ed.), *Doing Research in a Cross-Cultural Context: Methodological and Ethical Challenges*. Dordrecht: Springer, pp. 21–33.
- Jemielniak, D. 2018. Socjologia 2.0: o potrzebie łączenia Big Data z Etnografią cyfrową, wyzwaniach jakościowej socjologii cyfrowej i systematyzacji pojęć, *Studia Socjologiczne* 2(229): 7–29.
- Kocejko, M. 2019. Niezależne życie — produkt reglamentowany. W Polsce dramatycznie brakuje usług asystencji osobistej. Available at: <https://oko.press/niezalezne-zycie-produkt-reglamentowany-w-polsce-dramatycznie-brakuje-uslug-asystencji-osobistej/?fbclid=IwAR13K0OOLvag4vtbQ3LtcGAuv4he2vCgOzZdcyqrAaXRJx5GQzD-AiN3WSs>.
- Kubicki, P. 2017. *Polityka publiczna wobec osób z niepełnosprawnościami*. Warszawa: Oficyna Wydawnicza SGH.
- Lash, S., Urry, J. 1993. *The End of Organized Capitalism*. Cambridge: Polity Press.
- Marody, M., Lewicki, M. 2010. Przemiany ideologii pracy, in: J. Kochanowicz, M. Marody (eds.), *Kultura i gospodarka*. Warszawa: Wydawnictwo Naukowe Scholar.
- Męćfal, S. 2012. Problemy badań terenowych — wybrane kwestie metodologiczne, praktyczne oraz etyczne przy badaniu zjawisk „trudnych”, *Przegląd Socjologiczny* 61(1): 156–178.
- Mladenov, T. 2020. What is good personal assistance made of? Results of a European survey, *Disability & Society* 35(1): 1–24, doi: 10.1080/09687599.2019.1621740.
- Mladenov, T., Petri, G. 2019. Critique of deinstitutionalisation in postsocialist Central and Eastern Europe, *Disability & Society* 1–24, doi: 10.1080/09687599.2019.1680341.
- Morris, J. 2004. Independent living and community care: a disempowering framework, *Disability & Society* 19(5): 427–442.
- Oliver, M. 1990. *The Politics of Disablement*. London: Palgrave.

- Pawlak, M. 2012. Wykorzystanie wiedzy naukowej i eksperckiej w kształtowaniu polityki integracji imigrantów w Polsce po 2004 roku, *Normy, Dewiacje i Kontrola Społeczna* 13: 105–138.
- Power, A. 2013. Understanding the complex negotiations in fulfilling the right to independent living for disabled people, *Disability & Society* 28(2): 204–217, doi: 10.1080/09687599.2012.699280.
- Ratzka, A. 2007. Independent living for people with disabilities: From patient to citizen and customer. GLADNET Collection Paper 424. Ithaca, NY: GLADNET, Cornell University, ILR School.
- Russell, M., Malhotra, R. 2002. Capitalism and Disability, in: L. Panitch, C. Leys (eds.), *A World of Contradictions*. Vol. 38: Socialist Register: 211–228. Available at: <https://socialistregister.com/index.php/srv/issue/view/439>.
- Rymsza, M. 2015. Polityka społeczna wobec kwestii społecznej w XXI wieku, in: E. Giermanowska, M. Raćlaw, M. Rymśza (eds.), *Kwestia społeczna u progu XXI wieku. Księga jubileuszowa dla Profesora Józefiny Hryniewicz*. Warszawa: Wydawnictwa Uniwersytetu Warszawskiego.
- Sennett, R. 2006. *The Culture of the New Capitalism*. Yale University Press.
- Shakespeare, T., Porter, T., and Stöckl, A. 2017. Personal Assistance Relationships: Power, Ethics and Emotions. Report on ESRC Project ES/L007894/1. Norwich: University of East Anglia. Available at: <https://www.thekkingarmidstod.is/media/frettir/PA-Report-final-copy.pdf>.
- Silverman, D. 1995. *Interpreting Qualitative Data. Methods for Analysing Talk, Text and Interaction*. London: SAGE Publications.
- Standing, G. 2011. *The Precariat: The New Dangerous Class*. London: Bloomsbury Academic.
- Sullivan, J.R. 2012. Skype: An Appropriate Method of Data Collection for Qualitative Interviews?, *The Hilltop Review* 6(1), Article 10: 54–60.
- Sztobryn-Giercuskiewicz, J. 2017. Krytyczna teoria niepełnosprawności jako rama teoretyczna w badaniach nad niepełnosprawnością, in: J. Niedbalski, M. Raćlaw, D. Żuchowska-Skiba (eds.), *Oblicza niepełnosprawności w teorii i praktyce*. Łódź: Wydawnictwo Uniwersytetu Łódzkiego.
- Ułoba. 2019a. Information materials on the functioning of assistant services in Ułoba, Information Materials for Warsaw University. Drammen: Ułoba.
- Ułoba. 2019b. Information materials on local cooperation in the area of assistant services. The case of Ułoba, Information Materials for Warsaw University. Drammen: Ułoba.
- Winchitz, M.R. 2006. Fieldworker or Foreigner?: Ethnographic Interviewing in Nonnative Languages, *Field Methods* 18(1): 83–97.
- United Nations. 2020. *Visit to Norway. Report of the Special Rapporteur on the rights of persons with disabilities*. United Nations, A/HRC/43/41/Add.3.
- Yang, Ch. 2014. Being independent from whom? Analysing two interpretations in the paradigm of ‘independent living’, *Disability & Society* 29(5): 671–684, doi: 10.1080/09687599.2013.844098.

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