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**INSTITUTIONALIZED CHAOS
INSTEAD OF INDEPENDENT LIVING.
FORCED MODERNIZATION
AND ASSISTANT SERVICES IN POLAND**

Personal assistance for people with disabilities in Poland is not available as part of a comprehensive state policy; it is instead a dispersed, fragmented service based on projects. There is a lack of both a national strategy for independent living (including solutions for personal assistance as a key tool) and a plan for deinstitutionalisation of support services. A disabled person as an independent entity seems to be invisible to legislators, despite the postulates regarding “tailor-made” services or “profiling of help” present in public discourse. At the same time, uncoordinated changes are taking place regarding support for people with disabilities, including assistance services. They are partly forced by Poland’s ratification (2012) of the Convention on the Rights of Persons

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with Disabilities, and partly due to grassroots social innovations of non-governmental organizations. In the article, the authors analyse the factors responsible for the current state of affairs in the context of the theory of imposed modernization, emphasizing the superficiality of institutional changes. They will refer to critical research of public policies (so-called street level bureaucracies) analysing the daily practices of public officials and the social consequences for their recipients. The limitations of the model of personal assistance services as services including disabled people in the mainstream of social life will also be discussed.

Keywords: personal assistance, disabled person, imposed modernization, independent life strategy, deinstitutionalisation of services, Poland

INTRODUCTION

Personal assistance is now recognized as one of the basic instruments enabling the inclusion of people with disabilities¹ into the mainstream of social life. This service is derived from the right to an independent life understood as the right of disabled people to exercise control over their own lives and to make all decisions that affect them. In many Western countries, the institution of personal assistant is an important element of public policy related to the implementation of rights enshrined in the UN Convention on the Rights of Persons with Disabilities (UN CRPD 2006/2008²). The support of personal assistants enables disabled people to enjoy full and equal access to all human rights and fundamental freedoms. The implementation of personal assistance services is not a simple process and it faces many difficulties, both in countries where these services already exist (e.g. in Norway) and in those that are just introducing them (e.g. in Poland). There are tensions at the macro-, meso- and micro-levels.

In Poland, the development of personal assistance services has been partly forced by Poland's ratification (2012) of the Convention on the Rights of Persons with Disabilities, and partly by grassroots social innovations of NGOs. This service is not currently available as a comprehensive state policy. It is instead dispersed, fragmentary, and available on the basis of projects (Błaszczak-Banasiak and Kubicki 2017: 6). The main public sources of financing for this type of service are: The State Fund for the Rehabilitation of the Disabled (PFRON), and the Solidarity Fund for the Disabled (SFWON), which was launched at the beginning of

¹ In this article we use interchangeably the terms “disabled people”, “the disabled” and “people with disabilities”. We are aware of the fact that in Poland the politically correct term is the term “person with a disability”, which is supposed to focus the attention on the person, rather than their disability. However our decision to use the above-mentioned terms synonymously is due to 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 disability from a person (Sztobryn-Giercuskiewicz 2017: 34) (2) the use of these two terms is increasingly nuanced, reserving the phrase “persons with disabilities” 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” (Raćlaw 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 its 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, mental or intellectual.

² UN CRPD was adopted on 13 December 2006, entered into force on 3 May 2008.

2019. At universities, assistance services are financed by the Ministry of Science and Higher Education and university funds.

In the article we will deal with the issue of the determinants of the current state of affairs, using the findings of the theory of convergence and modernisation, neo-modernisation and neo-convergence. This allows us to emphasize the superficiality of institutional changes. We will refer to critical research of public policies (so-called street level bureaucracies) analysing the daily practices of public officials and the social consequences for their recipients. The limitations of the model of personal assistance services as services including disabled people in the mainstream of social life will also be discussed.

1. THEORIES OF MODERNIZATION AND SOCIAL CHANGE

Modernization is a bundle of economic, political, social, and cultural processes. Its result is the transformation of underdeveloped (less developed) countries into developed (more developed) countries (Morawski 2010: 18). In analysis of the modernization process, sociologists focus mainly on the transformation of traditional societies into modern ones. Much attention is devoted to people as individuals and communities, focusing on national communities, societies and their culture, attitudes, and behaviour. Their analyses are significant because involving people in the processes of socio-cultural modernization occurs more slowly than in technological and economic modernization. The so-called “soft cultural and social tissue” is highly likely to generate conflicts, and the choice of the path of modernization depends on many factors. Indeed Eisenstadt argues that the best way to explain the history of modernity is to “see it as a story of continual constitution and reconstitution of a multiplicity of cultural programs” (Eisenstadt 2000: 2). These reconstitutions are carried out by a variety of actors who hold a variety of views as to what makes a society modern, which ultimately leads to unique expressions of modernity.

Modernization processes can be viewed from three perspectives: structuralist, constructivist and institutional, and configurational (Morawski 2010: 23):

- the structural perspective, dominating in the socio-economic sciences, assumes that structures (economic, political, social and cultural) are decisive for the modernization process; the aim of the activities is to adapt to the requirements of the existing structure–system of developed countries;
- the constructivist perspective assumes that the decisive factor for the modernization process are agencies (actors and entities: individual people, companies, cities, universities, countries, etc.) which, guided by their values, set goals and means to change their positions in the structure;
- the institutional and configuration perspective is a kind of bridge between structures and agencies; modernization is the result of seeking configurations (agencies’ intentional interactions with structures) and, on the other hand, non-intentional, spontaneous, unplanned processes, which are accompanied by side effects that are opposite to those intended by the agencies or planned structural changes.

In this third sense, as Morawski emphasizes, modernization is partly marked by fate, but it is increasingly the result of conscious choices (a *sui generis* process). This perspective seems to be useful in ongoing analyses of the implementation of personal assistance services in Poland.

Another group of analyses of modernization indicates the specificity of changes introduced by specific countries in specific historical contexts. For example Piotr Sztompka emphasizes that post-communist countries survived the so-called “false modernization”, implemented top-down by the authorities (Sztompka 2005: 137). Its core is an incoherent, disharmonious and contradictory combination of three components: imposed modernity in some areas combined with the tradition of other spheres, which was masked by a symbolic façade imitating western modernity (Sztompka 2005: 137).

The experience of Eastern European countries has allowed verification of assumptions of the theory of modernization and the theory of convergence (Sztompka 2005: 138–140). Studies on the transformation of post-communist countries have highlighted the need to focus analysis on “grassroots” forces for change (e.g. social movements, charismatic leaders) and to appreciate human aspirations, growing along with the possibility of confronting patterns drawn from so-called First World countries. The importance of exogenous forces in introducing changes in a given area was recognised. Their importance is growing in the era of globalization (the availability of flowing capital and ideas in the global system). A better understanding of “traditions of modernisation” which can legitimize changes based on references to values and patterns that already exist, has led to the recognition of diverse visions and models of modernisation.

We consider the contribution of the theory of neo-modernization and neo-convergence to the recognition of the importance of the psychological significance of the aspiration factor, aroused – as Sztompka claims – by the “demonstration effect” of Western patterns (Sztompka 2005: 141) to be particularly important. “It was not the socialist countries that were technologically modernized, but rather their backward technologies turned out to be unbearable for people living in conditions of global competition and windows open to the world (thanks to the flow of information, people and ideas)” (ibid). In the perspective of the analyses undertaken in our article, this means the possibility of “grass-roots” modernization, when the aspirations of disabled people regarding independent living, awakened by observations of activity and changes introduced in other countries, will become the *spiritus movens* of transformations in the support system in Poland. However, we also take into account the institutionalized experiences of “false modernization”. We are afraid that the introduction of modern ideas into circulation while maintaining traditional elements in a medicalised support system for people with disabilities (Kubicki 2017: 69–80) will create a façade of independent life and not the real conditions for its implementation.

2. PERSONAL ASSISTANCE AS A SOCIAL SERVICE IN THE MODEL OF INDEPENDENT LIFE

Personal assistance derives from the right to an independent life understood as the right of persons with disabilities to exercise control over their own lives and make all the decisions that affect them. One of the instruments for exercising the right to independent living

is the availability of the services of a personal assistant for a person with a disability, which is enshrined in the Convention on the Rights of Persons with Disabilities. In article 19 on living independently and being included in the community, under point b, it is written that:

“Persons with disabilities have access to a range of in-home, residential and other community support services, **including personal assistance** (emphasis by the authors) necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community”.

The change in the approach to disability and the image of people with disabilities is associated with the emergence of the Independent Living movement in the USA and its development in other countries, and their union under the name ENIL (European Network on Independent Living)³. In the early 1970s, there was a political mobilization of disabled people and an increase in social protests: “People with impairments argued that they were subjected to a battery of disabling attitudes and barriers – from education to employment, through housing and transport, to sexuality and reproduction. Campaigns ‘took off’ around the world” (Barnes, Mercer and Shakespeare 2005: 11). The involvement of people with disabilities initiated a key transformation in the approach to and understanding of the phenomenon of disability – from the individual medical model to the social problem.

Activists, initiators of the Independent Living movement, which over time has evolved into an international network, are considered “heroes”. By undertaking numerous activities to promote the idea of independent life (while struggling with their own limitations), they refuted the myth about the passivity of people with disabilities, their low expectations and inability to lead an ordinary life. They broke common stereotypes and inspired subsequent generations to follow in their footsteps and continue their work (Bolling and Farren : 2017: 4).

The idea of independent living has become not only the axiological basis of the social movement (gradually institutionalizing), but also the “paradigm” setting the directions of changes in the practical and political sphere (DeJong 1979: 442). Thanks to this the goals of support offered to people with disabilities have changed, as they had been previously determined by the rehabilitation paradigm. The emphasis on the importance of self-care, mobility, and employment has been replaced by a wider perspective recognizing the importance of living arrangements, consumer assertiveness, outdoor mobility, and out-of-home activity (DeJong 1979: 444). This changed the axiological justifications for support and caused the need to rethink the tools used, because self-care was no longer the ultimate goal of actions taken for the sake of the disabled. “The fact that disabled person needs more support from a human helper does not necessarily imply that he/she is more dependent. If a person can get dressed in 15 minutes with human assistance and then be off for a day of work, that person is more independent than the person who takes 2 hours to dress and remains home-bound” (DeJong 1979:444). Blind faith in the necessary rehabilitation of a disabled person has been replaced by the search for solutions enabling their inclusion into society taking into account the specificity of the disability. Personal assistance has thus become an instrument of inclusion and independence as well as a kind of mediated agency.

³ The founders of the Independent Living movement in the USA are Eda Roberts and Judith Heumann; the pioneer of bringing Independent Living to Europe was Adolf Ratzka, the founder of ENIL.

In many Western countries, the development of personal assistance services is the result of many years of struggle of disabled people for autonomous and independent live. It also involves the processes of de-institutionalization of care and support and the overall paradigm shift from the medical model of disability to the social model. This instrument is increasingly being introduced into public policies in Central and Eastern European countries. Of course, the level and scale of assistance services are different in different societies. This is illustrated by the results of pilot assessment of assistance services carried out in eight European countries: Belgium, Bulgaria, Ireland, Serbia, Slovenia, Spain, Sweden, and the United Kingdom (Mladenov et al. 2019). The best results regarding independent living by disabled people using personal assistance were obtained in Sweden: there, compared to other countries analyzed, people who use personal assistance can make the most decisions about their lives, and the personal assistants' interests are strongly protected by trade unions and labour law.

The least favourable was the situation in Bulgaria, where assistants are paid a low salary (less than 2 euros per hour), which discourages candidates from providing such services. In Bulgaria, the main support comes from families of people with disabilities, which limits the free choice and independent life of people with disabilities (Mladenov et al. 2019: 11). In many countries surveyed, a tendency to cut public costs was observed, which translated into a reduction in the availability of assistance services. This was even noted in the Swedish case (considered to set international standards). Recently Sweden introduced stricter eligibility criteria and redefined "basic needs", which led to the rejection of 80% of new personal assistant applications (Mladenov et al. 2019:11).

However, the institution of personal assistant is an important element of public policy enabling people with disabilities to enjoy full and equal access to all human rights and fundamental freedoms. "The support of a personal assistant is not treated as a form of social assistance, but as a right of a disabled person to a dignified life on an equal footing with a non-disabled person" (Błaszczak-Banasiak and Kubicki 2017: 21).

3. PUBLIC POLICY TOWARDS DISABLED PEOPLE IN POLAND

Demands for the reconstruction of public policy towards people with disabilities in Poland intensified after UN CRPD was adopted and ratified by Poland (2012). Earlier, the postulates for independent living had been disseminated by the disabled and the NGOs or expert communities representing them. Ratification of the convention imposed on public authorities the obligation to implement its provisions, or at least to develop a plan for their implementation. These tasks overlapped with earlier unsuccessful attempts, undertaken since the 1990s, to introduce changes in social policy towards people with disabilities. The failures associated with the reconstruction of public policy towards the disabled were of a complex nature. The reasons we want to draw attention to and which had an impact on the course of modernization processes are: 1. inefficiency of the bureaucratic apparatus and resistance to change, 2. limited agency of disabled people and their weak social capital, 3. slow changes in attitudes towards disabled people at the level of the whole society.

Public administration, as a result of a wider context of its functioning, turned out to be ineffective in the face of such a complex phenomenon as disability. Public administration in Poland after 1989 was subjected to many significant changes characterized by selectivity and a lack of consistency and vision of the target model. This resulted in unsatisfactory quality of the process of creating and implementing public policies and programs, problems in the sphere of coordination processes, inadequate quality of the assessment of the activities undertaken, and poor quality of regulatory policy (Mazur, Hausner, 2010: 396). These features are also attributed to other countries from Central and Eastern Europe, often referred to as “weak states”. They share a common heritage of the region, remaining in the zone of Soviet influence and the realities of the socialist economy, as well as transformational experiences. These features of the context, other than in the stable democracies of Western Europe, translate into the quality of the institutional environment. Among others this means extensive legislation leading to over-regulation of the social and economic environment, and limited institutional capacity of the state leading to a gap between legislation and effective implementation of adopted law, which are visible signs of insufficient monitoring and evaluation of public policies (Mering 2018: 179). It is worth emphasizing that the ability to accumulate knowledge about cause-effect relationships and building institutional memory in organizations are considered a *sine qua non* condition for accurate programming and effective implementation of public policies (Mazur and Hausner 2010: 397).

The aforementioned issues of the malfunction of the bureaucratic apparatus have resulted in poor internalization of the demands for integration and activation of social policy in the whole environment of people with disabilities. People with disabilities have been and are part of a society characterized by a relatively low agency. Studies of the Polish society in the first decade of transformation pointed to the weak development of civil society, electoral apathy, limited involvement of citizens in the preparation and implementation of life plans and strategies focused on deliberate actions resulting in social effects desired by the individual. Terms such as “agency”, “social efficiency”, being “an actor”, “internal location of control”, and “endurance”, derived from various theories, were not often used to characterise Polish society (Mach 2010: 357). The next decade also failed to show a systematic and significant increase in the importance of individuals as subjects. Poles were not so much subjects as objects of the transformation process, but there have been clear “upward” and “downward” changes at the individual level. The higher level of subjectivity in society was favoured by higher levels of education and earnings, which translated into an increase in social inequalities and strengthened the division into beneficiaries and of transformations (Mach 2010: 377). People with disabilities in Poland have fewer opportunities than other members of society to mobilize and accumulate social capital (Masłyk 2019). These people are characterized by a relatively low social status measured by the income and material level of the household, so they have limited possibilities to meet diverse needs. A deficit of personal resources does not constitute a basis for the accumulation of social capital. In addition, the professional and educational passivity of the majority of disabled people limits their access to positional resources in the social structure (such as social positions related to profession, organizational functions), which weakens their ability to accumulate social resources (Masłyk 2019: 353). Weak social capital and limited agency make it difficult to enforce the social rights of disabled people.

Persistent prejudices and stereotypes that dominate the entire society can also be a barrier to including disabled people in the mainstream of social life. Antonina Ostrowska draws attention to this while discussing the results of comparative studies carried out at an interval of twenty years (1993–2013). The author pointed towards positive changes in this area, but also to the persistence of some beliefs regarding, among others, the conditions of employment and remuneration for the disabled, and the lack of favourable changes regarding their promotion and professional development. She emphasized that despite the removal of many architectural, institutional and legal barriers in recent years, persistent mental and awareness barriers impede the actual integration introduced by social policy institutions (Ostrowska 2015: 12).

The described complex combination of factors at the levels of the administrative apparatus, the community of disabled people and the whole society led to the failure of modernization processes. Experts have for many years pointed to the need to change the paradigm of public policy towards disability (Gaćiarz 2014; Dudzińska 2015; Kubicki 2017).

The attempts to implement the UN Convention in Poland are an illustration of the concept of conducting public policy through managing failure (Kubicki 2017: 175). Public policy in the context of expected failure can take place according to three scenarios: permanent failure (permanent failure, co-occurrence of small achievements combined with high expectations as a result of “inhibiting” the process of change by institutional actors), successful failure (successful failure, delegating sensitive and socially difficult problems to non-governmental organizations, with low expectations for their resolution) and so-called “fracasomania” (continuous opening and diagnosis of the problem without final implementation) (Mica and Nys 2014).

The concept of management through failure applied to the implementation of independent life policy in Poland. On the one hand there were great expectations related to the adoption of the Convention and the effects of its implementation, while on the other there have been limited and small changes which correspond to the concept of permanent failure. (Kubicki 2017: 175). The adoption of the Convention, including the postulates for independent living and personal assistance services, encountered many barriers and was not internalized at the levels of the bureaucratic apparatus, the disabled, or the entire society.

4. ASSISTANCE SERVICES AS AN EXAMPLE OF FORCED MODERNIZATION

Personal assistance for disabled people in Poland is not available as part of a comprehensive state policy. A disabled person as an independent entity seems to be invisible to legislators, despite the postulates regarding “tailor-made” services or “profiling of help” present in public discourse. At the same time, uncoordinated changes are taking place regarding support for people with disabilities, including assistance services. Below we discuss the main areas in which personal services supporting disabled people are being developed. We will discuss the system of education and certification of assistants in Poland, the functioning of personal assistance in the social assistance system at universities and in the labour market, and assistance programs developed by non-governmental organizations.

4.1 THE SYSTEM OF EDUCATION AND CERTIFICATION OF ASSISTANTS

In Poland, two different functions should be distinguished: a disabled person's assistant (*asystent osoby niepełnosprawnej*) and a personal assistant of a disabled person (*asystent osobisty osoby niepełnosprawnej*), whose scope of activities may partly overlap, but which have completely different ideological, institutional and legal bases, including in terms of the education and certification system, and the right to practice. Due to their similar names, these functions are sometimes confused.

A disabled person's assistant is one of the helping professions of social work and assistance professions (profession symbol 346 [02]). Such an assistant mobilizes for action, helps, supports, advises, co-creates rehabilitation or activation programs, and diagnoses the barriers faced by a disabled person, whereas the personal assistant of a disabled person is the executor of the disabled person's will, which defines the scope of the assistant's activities in carrying out everyday activities.

The legal and organizational aspects of training disabled persons' assistants are presented in detail by Ilona Fajfer-Kruczek (2013). Vocational training lasts a year and takes place in a post-secondary vocational school. The vocational training program is defined by the vocational core curriculum approved by the Ministry of National Education in 2001 and regularly updated since then. The current core curriculum was updated in 2017. Obtaining the title of a disabled person's assistant requires passing an exam confirming professional qualifications (Journal of Laws of 2005, No. 66, item 580). A single qualification has been distinguished in the profession of disabled person's assistant: "Providing assistance and organization of support to a disabled person", with the qualification symbol from the core curriculum MS.08. Post-secondary vocational education is focused on practical skills and knowledge in the area of care and support systems for people with disabilities (Fajfer-Kruczek 2013).

The vocational training program for disabled person's assistant qualifications reflects its location in the context of professions related to social assistance and social work. The learning outcomes are in line with the assistance and caring professions, but they diverge from the ethos of the disabled person's assistant developed in the context of the idea of Independent Living. The list of learning outcomes – in terms of supporting the subjectivity, agency, and independence of people with disabilities – is internally contradictory and inconsistent. It even seems to assume that the decision-making and agency of a disabled person is limited in some way. Among the learning outcomes are entries such as "analyses the causes and methods of solving social and personal problems of a disabled person" or "organizes free time for a disabled person using the resources of the local environment" (Centralna Komisja Egzaminacyjna 2017: 20–22).

The function of personal assistant for a disabled person is not yet entered in the government register of professions and is not combined with a formal qualification awarded by the Central Examination Board. However, there are various courses for personal assistants of people with disabilities. These courses are organized and conducted by private vocational training centres, local development agencies, non-governmental organizations, and local governments and related institutions, such as district family support centres (PCPR – Powiatowe Centra Pomocy Rodzinie). Some training courses are financed from EU and state funds.

Training for a Personal Assistant of a Disabled Person may include the following elements: 1) A course for a personal assistant for a disabled person (130h), 2) Premedical help (10h), and 3) An emotions management course (16h) (for example <http://trzcianka.naszepcpr.pl/tablica-ogloszen/ogloszenie-o-naborze-kandydatow-do-przeszkolenia-i-zatrudnienia-asystent-osobisty-osoby-niepelnospprawnej>, [10.03.2020])⁴. In this particular case the people trained were to be employed by the districtfamily support centre that trained them.

4.2 PERSONAL ASSISTANCE IN SOCIAL ASSISTANCE

In the system of public social assistance in Poland, assistance – as a service directed to the marginalized or groups in need of support – is becoming very popular. Assistance supplements other care and assistance services. However, there is no clear definition of assistance in relation to its axiological foundations, methods and tools used, which is confirmed by experts and practitioners of social assistance.

The Act on social assistance (Journal of Laws 2018, item 1508) does not include a definition of assistance services for people with disabilities. Neither is there any direct use of the terms “supporting services”, “personal assistance” or “assistance of people with disabilities” (as a service provided in a local environment). The profession of assistant for a disabled person is mentioned only in the aspect of employment in specific support facilities (e.g. in shelters or public nursing homes). However, elements of assistance are “inscribed” in specialist care services and social and vocational rehabilitation services.

References to assistance can be found in executive acts to the Act. The provisions on specialist care services include tasks of assisting in everyday activities, in contacts with employers and in budget management, and they indicate that these can be performed by, among others, assistants for the disabled (Regulation of the Minister of Social Policy of 22 September 2005 on specialist care services, Journal of Laws of 2005, No. 189, item 1598, as amended). On the other hand, in another executive act referring to outsourcing of social assistance tasks, the provision of services supporting these persons in independent life in the form of personal assistance is explicitly included (). (Regulation of the Minister of Labour and Social Policy of 7 February 2008 regarding the objectives of occupational and social rehabilitation for disabled persons with respect to foundations and non-governmental organizations Journal of Laws of 2016, item 1945). Therefore, while social assistance units provide assistance as part of care services (which is a contradiction: independent life movement activists fought against the notion of care in relation to themselves), they can outsource it to civic entities in relation to the assumptions of rehabilitation.

In practice, various models of assistance services for disabled persons in social assistance units are encountered in Poland, although they are extremely rare in the model form (hybrid versions are more common). On the one hand, services closer to care are offered, mainly intended for people with intellectual disabilities and mental disorders (assistant tasks require care, support in decision-making processes, accompanying in official matters and involvement in the multi-faceted rehabilitation process) (Mirewska 2010); on the other hand there are services closer to personal assistance, addressed to people without intellectual disability, supporting them in social roles (in the workplace, college, the office, and everyday activities).

The latter often take the form of social and vocational rehabilitation services (Trajańska 2010).

In Poland, organizations representing people with disabilities report difficulties in accessing assistant services from the public social assistance system. The growth dynamics of assistant services is very low. Data from a decade ago regarding tangible and intangible social assistance benefits indicate little interest in this type of services on the part of social assistance organizational units (Szarfenberg 2011). This is probably due to the perception of disabled people by social assistance employees as passive charges and not clients in need of activation (see *Włączający system edukacji i rynku pracy...* 2014). In addition, disabled rural residents experience increased difficulties in accessing assistance, as rural areas are poorer in socio-technical infrastructure and local authorities and administrations usually have smaller financial budgets for the development of specific services (see Kutek-Składek 2010).

As well, research carried out several years later by the Office of the Ombudsman confirms the poor development of assistant services and the negative consequences of limiting them to specialist social assistance services (Błaszczak-Banasiak and Kubicki 2017). They also confirm that social assistance units are not prepared to provide personal assistance, and nor are they ready to accept this service on the side of beneficiaries and their families. Nevertheless, people with disabilities expect the development of personal assistance services. In their opinion, it should be a service easily available in the municipality, tailored to individual needs, flexible in its scope of tasks, and of duration determined by the recipient.

4.3 ASSISTANCE SERVICES AT HIGHER EDUCATION INSTITUTIONS

Tasks related to creating conditions for full participation in the education process for students and doctoral students who are disabled are set out in the Act on Higher Education and Science (Article 11.1 item 6, Article 365 item 6 and Article 409.1 item 2 of the Act on July 20, 2018 – Law on Higher Education and Science, Dz.U.2018.0.1668).

On its basis, universities create regulations supporting the process of educating students and doctoral students (which are separate documents or part of general study regulations). The creation of such documents had already been permitted by earlier statutory solutions. Financial resources from the state budget and university funds may be used to support people with disabilities. Universities finance or co-finance many different forms of support, including the assistance of a disabled person's assistant.

The presence of assistants at universities is an important instrument supporting the process of educating students with disabilities. The model of educational assistant at universities enables them to participate more fully in the education process: "He/she performs both supporting and compensating functions. Satisfactory completion of the tasks of an assistant permits one to study, follow a program of studies, develop one's own interests, obtain material and financial support, take advantage of various forms of student activities, establish social contacts, and participate in student social life" (Chrzęszcz 2018: 172).

The presence of assistants at universities is varied. At some universities the service is unknown, while at others there are several to several dozen assistants (Chrzęszcz 2018: 175). The University of Warsaw is an example of a university where assistant services are provided for students with disabilities. Candidates are informed of the opportunity to use this type of

service. Students report their needs for assistant services (number of hours, type of support needed) to the Disabled People's Office (BON). The office conducts a continuous campaign of recruiting candidates for assistants (e.g. places ads on its website). The assistants are often other UW students or graduates. Currently 13 assistants are employed. They assist with note-taking and transportation. The office employs a person who coordinates the work of assistants, prepares work schedules, and reacts to problematic situations on a regular basis (e.g. exceeding the working time limits / tasks of the assistant). According to information obtained from BON UW, the demand for this type of services is growing and BON plans to increase their provision.

The idea of support at the level of higher education, as emphasized by Janina Filek (2015), raises many ethical problems related to the "phenomenon of assistance" and its institutionalization, which results in many negative phenomena such as loss of contact with those in need, disproportionate or unjust distribution of support combined with growth of controversy around forms of assistance, suspected lack of competence, inappropriate use of resources, and dishonesty. Research among students with disabilities at Polish universities conducted in the 2015/2016 academic year (Chrzęszcz 2016), shows that young people expect their assistants to both "prosthetize" them in terms of their own limitations (e.g. help in taking notes, help in moving around, translating didactic materials for students with sensory disabilities, helping to organize work or translating into sign language), as well as accompany them in social situations (e.g. when establishing contacts with a peer group or support in conflict situations). This means that students need personal and sometimes supportive assistance. Hence the question is asked whether the assistance of an assistant, with a large range of supportive assistance, does not create a barrier to the development and maintenance of students' own resourcefulness.

4.4 ASSISTANCE SERVICES ON THE LABOUR MARKET

In Poland, the services of a job coach and an assisting employee are also located in the field of supporting disabled people on the labour market. Elements of assistance can also be found in the time-limited programs of the State Fund for the Rehabilitation of the Disabled (PFRON).

Work assistance services are sometimes referred to as vocational assistance services. The tasks of this type of assistant are not the same as the work of a personal assistant for a disabled person. The role of a work assistant is to facilitate the entry of a disabled person into the labour market and support them in the performance of their duties (Błaszczak-Banasiak and Kubicki 2017: 6), while the main task of a personal assistant is to support a disabled person in playing social roles.

A vocational assistant, sometimes called a job coach, support assistant, vocational instructor, or specialist in assisted employment, works in the area of assisted employment, providing support to both disabled employees and employers (Łuczak et al. 2007). A vocational assistant should be able to diagnose the skills and work ability of a disabled person, evaluate their qualifications, provide career counselling and assist in the field of broadly

understood job placement, as well as in the adaptation of the workplace to the needs of a disabled person. He/she should also be able to support the integration of the client in the workplace.

Legal changes related to the services of a job coach are currently expected. The Ministry of Family, Labor and Social Policy has prepared a draft law on supported employment (<https://bip.kprm.gov.pl/kpr/bip-rady-ministrow/prace-legislacyjne-rm-i/prace-legislacyjne-rady/wykaz-prac-legislacyjny/r429173561,Projekt-ustawy-o-zatrudnieniu-wspomaganych.html>, accessed 31.12.2019 r.). The target group of beneficiaries of the new regulations are to be people with mental illnesses, intellectual disabilities, pervasive developmental disorders, sight impairments, voice and speech disorders, hearing disorders, and epilepsy. The purpose of the draft act is to ensure stable financing of supported employment, unification of service provision standards and a definition of the time frame for individual stages of assisted employment, determination of the conditions to be met by a candidate for a job coach, and harmonization of the job coach's work standards. The conducted analyses regarding the target group of supported employment programs show that without the constant and stable support of a job coach, these people quickly lose employment and return to the ranks of the unemployed or the inactive. The planned entry of the act in 2019 has not been met.

On the other hand, in the open labour market, it is possible for PFRON to reimburse employers for the costs of employing employees supporting disabled people. The purpose of the supporting employee is to assist a disabled person in communication with the people around him/her and in activities impossible or difficult for independent performance by a disabled employee in the workplace. Assistance may not exceed 20% of the working time of the supporting employee.

Employment of an assisting employee and submission of an application for reimbursement of costs is the responsibility of the employer, not the person in need of assistance. The method of calculating refunds reflects the low value attributed to assistant services, which may demotivate highly qualified personnel from undertaking assistant tasks.

Non-governmental organizations acting for the benefit of the disabled also indicate that the conditions and qualifications that must be met by a supporting employee have not been specified. The employer may designate this function to a work colleague of a person with a disability, which is embarrassing in the case of performing certain hygienic activities. In addition, the difficulty of complaints procedures is emphasized when an employer fails to provide real support to a disabled person (e.g. employers do not enforce the tasks of a supporting employee, being satisfied only with their presence on paper). Usually, disabled employees give up on their rights to seek support (see ⁹ <https://www.integralia.pl/porada-pracodawca/asystent-niepelnospawnego-pracownika-pomoc-dodatkowy-obowiazek/> [31.12.2019]).

Elements of assistance (as support for professional activation of disabled people) also appear in other programs of the State Fund for the Rehabilitation of the Disabled. Currently, several such initiatives have been launched, including the "Graduate", (*Absolwent*) "Work-Integration" (*Praca-Integracja*) and "Stable employment" (*Stabilne Zatrudnienie*) programs. In these programs, assistant services are offered only at the initial stage of activation and

employment of the project beneficiary. They have the character of both personal assistance (e.g. support in commuting to work) and the activities of a job coach, and the duration of their provision is short (3 or 6 months).

4.5 ASSISTANCE SERVICES PROVIDED BY NON-GOVERNMENTAL ORGANIZATIONS

Assistant support services as an instrument leading to an independent life, preventing social exclusion, and supporting the agency of a disabled person are offered primarily by non-governmental organizations financed under temporary grants (Błaszczak-Banasiak and Kubicki 2017: 6).

In accordance with the provisions of art. 36 of the Act of 27 August 1997 on professional and social rehabilitation and employment of disabled people (Journal of Laws of 2019, item 1172, as amended) tasks in the field of professional and social rehabilitation of disabled people can also be implemented by non-governmental organizations commissioned by PFRON, as well as those commissioned by the voivodship or district self-government – from PFRON funds transferred according to an algorithm.

Tasks are commissioned following an open competition, which is announced in accordance with the Act of 24 April 2003 on public benefit activities and volunteering (Journal of Laws of 2019, item 688, as amended). The types of tasks that can be outsourced to NGOs are indicated in the Regulation of the Minister of Labour and Social Policy of February 7, 2008 on the types of tasks in the field of vocational and social rehabilitation of disabled people commissioned to foundations and NGOs (Journal of Laws of 2016 item 1945). The task referred to in §1 point 13) of the regulation regarding the provision of support services that are designed to enable or support the independent life of people with disabilities, in particular personal assistance services (hereinafter task 13), was introduced by the amending regulation of October 22, 2015 (Journal of Laws from 2015, item 1778). For the first time, task 13 was commissioned in competition No. 2/2016 “Course for independence”, announced on October 18, 2016 by PFRON, regarding projects implemented from January 1, 2017. Projects which declared task 13 exclusively or among other things were implemented by 18 non-governmental organizations in 2017, 28 organizations in 2018, and 37 organizations in 2019 (Department for Programs of the State Fund for the Rehabilitation of Disabled People (PFRON)). Projects implemented earlier (i.e. since the first call for proposals for commissioning tasks in 2009) could provide for the provision of assistance services for people with disabilities among other declared forms of support, but they had to primarily deal with the implementation of the tasks specified in the regulation (in the wording before October 22, 2015).

In relation to assistantship, NGOs operate in a project mode, so the services are insecure and financially and temporally unstable. The time limit for financing of assistant services, whether funded by PFRON or the EU, significantly reduces their functionality and leads to professional and social instability of both the disabled person and his or her family, and it makes it difficult to recruit and employ candidates for personal assistants who are also looking for stable employment. The time-limited method of financing assistant services for people with disabilities does not take into account that disability lasts a lifetime and requires long-term and stable support (Błaszczak-Banasiak and Kubicki 2017: 68). Also, it does not take into

account the importance of the relationship that arises between a disabled person and his or her assistant. Another problem related to the implementation of assistance services by NGOs is that these organizations operate primarily in large cities, which significantly limits access to assistance services for disabled people living in villages and smaller towns (Błaszczak-Banasiak and Kubicki 2017: 68).

5. DISCUSSION

Summing up the presented results of the analysis, we can say that personal assistance in Poland is not available as a comprehensive state policy; it is instead a dispersed, fragmented and project-based service. There is a lack of both a national strategy for independent living (including solutions for personal assistance as a key tool) and a plan for deinstitutionalisation of support services. Deinstitutionalization is often treated as family care and not personal assistance in connection with the control of services by the user – a disabled person.

There is no definition of assistance as a social policy institution, including social assistance and social work institutions. It is defined contextually in relation to a problematic phenomenon or group of recipients. There are many types of assistance:

- in social assistance: personal assistant of a disabled person and assistant of a disabled person; they are educated at various levels, from certified courses to postgraduate studies at universities; elements of assistance also appear in care services and specialist care services;
- in education: assistant of a disabled student;
- in employment: job coaches, support workers, project assistants.

The low level of development of assistant services is evident in local communities (mainly limited to specialist social assistance services) and in the workplace. The proposed solutions do not take into account the basic assumptions underlying the independent living policy: the allocation of personal assistance services does not result from the social rights of individuals, but from their civil rights (the right to an independent life guaranteed by the CRPD) and should not be limited to situations requiring social protection.

The result is a low level of use of services by people with disabilities. It results from the small scale of real assistance services provided in the local environment and in the workplace. Meanwhile, research indicates existing expectations of disabled people in Poland regarding a high supply of assistance services. Therefore, one may wonder whether there is a non-take up (*non-recours*) situation in relation to assistance services. It consists in the non-use of social rights by authorized persons and is the subject of research in some EU countries (see Sztandar-Sztanderska 2018: 19–20). For example, in France there is a special research institution, the Observatoire des non-recours aux droits et services (Odenore), which deals with analyzing the multiple and multi-faceted effects of this phenomenon. *Non-recours* are considered to be all situations (regardless of the reason) in which a person does not use his or her material and intangible benefits.

Karolina Sztander-Sztanderska (2018) emphasizes that in the case of Poland, the reasons for the failure to implement the rights of individuals are “transparent” and rarely analysed, as are their social and political consequences. This is due to the focus of Polish researchers on the “attitude of entitlement” of beneficiaries of the social security system, bypassing analyses of informal rules that hinder individuals from enforcing their social rights and analyses of their lack of preparation for the use of benefits (Sztandar-Sztanderska 2018: 20). Meanwhile, it is often not the legal status that matters, but the extra-legal criteria related to the resources of social and cultural capital and personal skills of the beneficiary or client of the given office.

In the case of disabled people in Poland, the phenomenon of non-take up has not been studied. This requires long-term observation of clerical and administrative activities in individual executive units in the field of social security. It can be assumed that non-take up takes place in the area of assistance services. This may be due to the stereotypical perception of people with disabilities. There are no reasons to believe that the so-called first contact officials with discretionary power are guided by different premises for assessing the phenomenon of disability than “average” members of society. Sociologists dealing with disability report this, as we mentioned in earlier parts of the text.

In contemporary Polish society, there is a recomposition of the stereotype of people with disabilities. The negative image of people with disabilities that emphasizes passivity, weakness, clumsiness, addiction, and dissatisfaction with their lives disappears (Ostrowska 2015: 222). A decade ago society more often perceived individuals with impairments as “normal “ (just like us, i.e. non-disabled). However, the socially constructed stereotype still connects disability with poverty or lack of confidence. Ostrowska sees a relationship between respondents’ declarations with the dominant equality-based rhetoric of discourse dealing with disabled people. It may prompt respondents to give “politically correct” declarations, with the social distance still persisting (Ostrowska 2015: 222).

In conclusion, assistance services are a tool rarely used to support people with disabilities because of: 1) the construction of the social security system, in which assistance services have been omitted as a tool for exercising civil rights, (2) routine bypassing of the implementation of forms of such assistance by employees of entities implementing legal system assumptions, and (3) (un-)awareness of rights and the limited possibility of their implementation on the side of people with disabilities.

We also take into account the institutionalized experiences of “false modernization”. The example of Bulgaria shows that post-socialist countries have difficulties in implementing modern services for cultural and economic reasons (public finances). Rich countries like Sweden also face such problems. Polish solutions often refer to the idea of personal assistance in name only, based on free choice and subjective agency. An assistant for a disabled person (*asystent osoby niepełnosprawnej*), an assisting employee or a job coach are help services. Their directive and lack of consideration for securing the needs of confidentiality and self-determination do not correspond to the axiological foundations of independence in the spirit of ENIL. On the other hand, personal assistance services are difficult to access, temporary or – oddly – provided as elements of social assistance services. Therefore, referring to the concept of modernization cited in the first part of the article, we believe that the introduction

to the debate and public policy of modern ideas such as the postulates of independent living and personal assistance services, while maintaining the traditional elements of the medical approach in the system of supporting people with disabilities, create a façade of independent life, and institutionalized chaos.

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ZINSTYTUCJONALIZOWANY CHAOS ZAMIAST NIEZALEŻNEGO ŻYCIA.
PRZYMUSOWA MODERNIZACJA A USŁUGI ASYSTENCKIE W POLSCE

Asysta osobista dla osób niepełnosprawnych w Polsce nie jest dostępna jako kompleksowa polityka państwa, jest to raczej rozproszona, fragmentaryczna usługa realizowana na bazie projektów. Brakuje krajowej strategii niezależnego życia (w tym rozwiązań dla pomocy osobistej jako kluczowego jej narzędzia) i planu deinstytucjonalizacji usług wsparcia. Osoba niepełnosprawna jako niezależny podmiot zdaje się niewidzialna dla ustawodawców, mimo obecnych w dyskursie publicznym postulatów dotyczących usług „szytych na miarę” czy „profilowania pomocy”. Jednocześnie dokonują się nieskoordynowane zmiany dotyczące wsparcia osób z niepełnosprawnością, w tym usług asystenckich. Częściowo są one wymuszone ratyfikowaniem przez Polskę (2012) konwencji o prawach osób niepełnosprawnych, częściowo zaś wynikają z oddolnych innowacji społecznych organizacji pozarządowych. W artykule autorki analizują czynniki odpowiedzialne za obecny stan rzeczy w kontekście teorii modernizacji narzuconej, akcentując powierzchowność zmian instytucjonalnych. Podjęta też zostanie dyskusja dotycząca ograniczeń modelu usług asysty osobistej jako usług włączających osoby niepełnosprawne w główny nurt życia społecznego.

Słowa klucze: Polska, osoba niepełnosprawna, asysta osobista, modernizacja narzucona, strategia niezależnego życia, deinstytucjonalizacja usług

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