

ARTYKUŁY I ROZPRAWY

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POLISH RESEARCHERS’ THEORETICAL AND EMPIRICAL APPROACH TO DISABILITY: FROM THE PERSPECTIVE OF DISABILITY STUDIES

Introduction

In view of the constantly changing social reality – also in the area of scientific research on the phenomenon of disability – new trends in theoretical analyses are becoming increasingly prominent. There is also a growing interest in the issue of disability shown by the representatives of various scientific disciplines which goes far beyond the traditional medical model. Certainly, the perspective of the humanistic, social conception of disability creates a new interdisciplinary cognitive space. Researchers emphasize the strengths, potential and developmental power of people with disabilities more and more clearly. From this perspective, disability is not perceived as an individual problem only. There is a need to perform in-depth and multidimensional empirical diagnoses that take into account the social, cultural and political contexts of the functioning of people with disabilities. In the second half of the 20th century, a new interdisciplinary trend in research on disability appeared, namely Disability Studies. It has profoundly enriched the area of research on disability, going beyond the approaches of individual disciplines, including psychology, pedagogy, sociology, philosophy, anthropology or medicine.

The importance of the new perspective of Disability Studies in designing and providing activities for people with disabilities should also be indicated. It can be expected that comprehensive and interdisciplinary theoretical and empirical

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analyses will provide a solid foundation for building a new social space that will be free from stereotypes and prejudices. The mechanisms of marginalization, stigmatization, and social exclusion will also end. At the same time, the real lives of people with disabilities will be created according to the ideas of normalization, integration, and social inclusion.

The aim of this article is to present Polish researchers' theoretical and empirical approach to disability from the perspective of Disability Studies. At the beginning of this study, the strategy of higher education development in Poland is presented as an important source of scientific search, also in the area of disability. According to the concept of this article, the following areas will be discussed: historical and contemporary approaches to disability (facts – leading representatives; general current trends – paradigm formulation; Disability Studies a scientific discipline and a field of study), an interdisciplinary empirical analysis of the phenomenon of disability (research analysis in the positivist orientation and in the humanistic orientation, methodological pluralism), selected constructs in the approach to the phenomenon of disability (personalistic perspective, perspective of the normalization of life of people with disabilities, cultural construct).

Strategy for the development of higher education

According to the Regulation of the Minister of Science and Higher Education of October 1, 2011, a new scheme of areas, fields and disciplines was introduced. Referring to the theme of this article, the main focus is on the area of the humanities, social sciences, medical sciences and health sciences. The field of the humanities includes philosophy, cultural studies, family studies and management science, and the field of social sciences includes media studies, political science, the science of cognition and communication, pedagogy, psychology and sociology (see no. 1 in netography). In Poland, research and development work is mainly conducted by universities, the Polish Academy of Sciences (PAN), and research and development units. Research is funded with a grant for the development of research capacity, awarded on a competitive basis to public academic and research universities and to research projects submitted by teams located in schools of any type. Analyses carried out by the UNESCO Institute for Statistics showed that expenses for research and the development of research capacity in Poland constituted 0.90 percent of GDP in 2012, which placed Poland 38th in the world. It has been the highest GDP value in Poland since 2003 (0.54 percent of GDP) to 2012. Polish researchers constitute about 5 percent of all EU researchers. Academic research is becoming increasingly internationalized. Over the last 20 years, we have doubled the number of joint international publications of authors from different countries. The percentage of Polish researchers who publish work together with authors from EU countries (25.2%, 2003) is larger than the EU average (22.9%). The main partners of Polish researchers are researchers

from Germany (23.4% of publications with a foreign co-author) (see no. 2 in netography). The level of research funding from international funds (including the European Union budget) has also increased.

In 2010, a strategy for the development of higher education in Poland by 2020 was developed (see no. 3 in netography). Pursuant to the provisions of this document, actions need to be undertaken to increase the quality of all academic areas and the entire system of higher education. It is expected that universities will compete for grants for both teaching and research more intensely.

National reports documenting the phenomenon of disability

In Poland, at least two definitions of people with disabilities are used. The first is the definition arising from law and the legal basis for being acknowledged as disabled. The second, a much broader one, is used in the statistics of the Central Statistical Office (GUS). The definition for the statistics includes not only people who are legally classified as disabled, but also people who do not have a certificate of disability, but claim that they have limitations in the performance of selected activities (“biological disability”). Data on people with disabilities relate directly to existing Polish disability legislation.

Representative survey research on the health of Poles was conducted by the Central Statistical Office twice – in 1996 and in 2004. It was carried out based on the recommendations of international organizations dealing with health statistics. The data from 2004 indicated that there were 6.2 million people with disabilities in Poland, of which 4.8 million people were legally disabled (with a disability certificate) (see no. 4 in netography). In 2009, the European Health Interview Survey (EHIS) (see no. 5 in netography) was conducted in Poland for the first time. According to Eurostat methodology, there were 8.1 million people with disabilities in Poland at the end of 2009 (nearly 4.2 million Polish people had a legal disability certificate or its equivalent). The incidence of disability increases with biological age – rapidly after 50 years of age (it is nearly 25 percent in the adult population). The survey was also conducted in 2014 (see no. 6 in netography). As indicated by the results, 4.9 million Polish citizens are disabled, including more than 3.8 million with a legal disability certificate or its equivalent – every fifth person with a disability does not have the certificate or the legal disability status. Every tenth resident of Poland has a certificate of disability.

In the project *From a comprehensive diagnosis of the situation of people with disabilities in Poland to a new model of social policy towards disability*, the authors sought a “new opening” for the state policy towards disability by making a comprehensive diagnosis of the situation of people with disabilities in Poland (see no. 7 in netography). Recommendations were developed indicating directions for the modification of social policy which would make it possible to include people with disabilities into the mainstream of various areas of social

life, to improve the effectiveness of institutions supporting these people and to increase the empowerment of the community of people with disabilities by their participation in the shaping of social policy.

Polish membership in the EU involves participation in the implementation of the *European Disability Strategy 2010–2020: A Renewed Commitment to a Barrier-Free Europe*. It should be supposed that the implementation of this strategy in Poland should also lead to a number of changes, in particular with regard to education, work, and political and social participation. The noticeable increase in the activity of organizations for people with disabilities, which are expressing the need for substantial modification of institutional support mechanisms more and more clearly, is an important reason for institutional reform.

Historical and contemporary approach towards disability

Facts – leading representatives. The forerunner of the scientific approach to disability was Maria Grzegorzewska (1888–1967), who initiated the development of special education in Poland according to the idea “There is no cripple – there is a person.” In 1922, she established the Institute of Special Education in Warsaw (now The Maria Grzegorzewska University), which undertook research on disability and the preparation of teachers – specialists in the education of students with disabilities. Professor Maria Grzegorzewska, a Sorbonne graduate, is the creator of special education in Poland, she created its scientific basis and undertook systematic research on all the subdisciplines of special education – particularly, on issues relating to people with visual impairments (education of people with visual impairments, psychology of people with visual impairments). Her achievements fit into global special education and international research on disability. Between 1958 and 1960, she led the Department of Special Education – the first one in Poland – at the University of Warsaw. The academic status of special education in Poland dates back to that time.

At the Institute of Special Education, Maria Grzegorzewska gathered outstanding educators, psychologists, doctors, professionals working with children with special needs. Janusz Korczak (1878–1942), a physician, educator, writer, journalist and social activist was a lecturer at the Institute. Józefa Jotejko (1866–1928) worked together with Maria Grzegorzewska to establish special education in Poland. She was a psychologist, educator and physiologist, president of the Belgian Neurological Society and a multiple prizewinner of the French Academy of Sciences. Janina Doroszewska (1900–1997) was a professor at the National Institute of Special Education and at the University of Warsaw. She dealt with the issues of therapeutic pedagogy, prophylaxis and medical, psychological and pedagogical treatment. Alexander Hulek (1916–1993) was a strong supporter and promoter of social integration. Władysław Dykcik (1942–2013) was a special teacher; he published numerous works in the field of special education, social

education and sociology of education. Jan Pańczyk (1937–2007) was the author of numerous scientific, theoretical and research works. He helped to organize Polish terminology in special education. He was an ardent advocate of the creation of special education identity and of giving it the status of a scientific discipline.

General current trends – Paradigm formulation. There are a few trends that determine how the phenomenon of disability is being built in Poland. To a large extent, the way disability is presented results from special education's search for paradigms. Inspiring and still valid are the paradigms developed 30 years ago by Irena Obuchowska (1987). The author formulated ten paradigms: a biographical paradigm (integration and a social rather than a medical approach), a positive orientation (assessment and rehabilitation which highlight the strengths of people with disabilities), a self-rehabilitation paradigm (individuality, self-conduct), a help-the-helper paradigm (prevention of burnout burning power syndrome), a paradigm of subjectivity (identity, autonomy, agency), a paradigm of prophylaxis and integration in the family (family support in the sense of its autonomy), an anti-stigmatic paradigm (action against stigma, labeling, marginalization), a conceptual paradigm (names that are not offensive to the dignity of people with disabilities), an ignored paradigm (concerning the sexual life of people with disabilities), and an existential paradigm (sanctioning the right of people with disabilities to normal participation in social and economic life). In the first decade of the 21st century, Amadeusz Krause (2010) outlined four paradigms of special education: (1) a social paradigm of disability, (2) a paradigm of normalization, (3) an emancipatory paradigm, and (4) a qualitative paradigm. In this perspective, special education, and thus the phenomenon of disability, were clearly situated in the context of the social model, which undeniably refers to normalization, participation, self-determination and inclusion of people with disabilities in the mainstream of social life. The paradigms formulated – as specific patterns of thinking about disability – determine the perspective from which the different areas of the image of people with disabilities are presented in terms of: terminology (definitions, classifications), the model of disability (social model), assessment (inclusion and development of qualitative, interpretive research), and rehabilitation (positive rehabilitation, based on the developmental potential, strengths of people with disabilities), and in terms of creating appropriate living conditions (normalization, participation, self-determination) (Głodkowska, 2012). It should also be emphasized, as Janusz Kirenko stated (2006), that disability is a challenge for those who are marked with it, but also for people without disabilities that accompany the life of people with disabilities. Different faces of disability are shaped by personal experience and public perception, which determines the change in the image of people with disabilities from stigma, rejection and marginalization to the creation of a climate of social acceptance.

Disability Studies a scientific discipline, a field of study. Currently, Disability Studies do not have the status of a scientific discipline in Poland. Special

education, the source of which dates back to the early 20th century, is not a scientific discipline now either, although special educators are increasingly seeking its academic privilege. Today, without a doubt, a broad and rich area of concepts, research and reflection can be built with focus on the phenomenon of disability. For almost a century, Polish scientists have been creating a theoretical and empirical spectrum of knowledge which falls within the scope of the international trend of multifaceted disability research.

The university's tradition and the continuity of Maria Grzegorzewska's idea build the mission of the university, also in the scientific exploration of people with disabilities and in seeking opportunities to provide them with the rights other members of society enjoy. The university is involved in increasing cooperation with foreign research centers and universities that focus on disability and people with disabilities. For many years, The Maria Grzegorzewska University Institute of Special Education has been encouraging the initiative aimed at personalistic, interdisciplinary approach to disability (Głodkowska, 2015). Since 2003, regular international "PERSON" conferences have been organized. The conferences are scientific meetings, whose purpose is multifaceted discussion and exchange of experience in the field of studying the phenomenon of disability. In 2016, the conference participants addressed the issue of early intervention for children with various disorders. In 2005, the university created the scientific journal "Man – Disability – Society," which tackles the issue of disability from an interdisciplinary perspective. In 2013, the portal Forum of Special Education was created as a tool to document and spread knowledge in the area of disability (<http://www.efps.pl/>). The university promotes the idea of the social integration and inclusion of people with disabilities by carrying out numerous research projects from an interdisciplinary perspective. They analyze the subjectivity, identity and dignity of people with disabilities, normalization of their lives, processes of integration and social support, as well as family life and social exclusion.

In 2016, The Maria Grzegorzewska University in Warsaw created the first Polish training course "Interdisciplinary Disability Studies." We based the development of this program on many international models and concepts. Interesting and inspiring for us were, among others, elaborations by Barnes, Oliver and Barton (2002), Brown (2002), Ferguson and Nusbaum (2012), Taylor, Shoultz and Walker (2003), and Rembis and Pamula (2016). We analyzed a lot of programs provided in universities which conduct Disability Studies. In our program, we prepare professionals – leaders, advocates, specialists, researchers – dealing with disability and people with disabilities. The course gives students a practical opportunity to design actions aimed at people with disabilities and their environments. It lets them acquire interdisciplinary knowledge, abilities and social skills necessary to understand and explain disability, and to act for the benefit of people with disabilities and their families.

Interdisciplinary empirical analysis of the phenomenon of disability

Research analysis in the positivist orientation. A strong record of research on disability in Poland uses the proven and effective principles and methods of the natural sciences. The description and explanation of the processes under investigation, and the verification of hypotheses and theorems are the objectives of empirical inquiry undertaken within this orientation. Authors of reports, following the cause-and-effect or correlation regularities they discover, *formulate regularities, theorems and laws concerning the reality of people with developmental disorders, the sick and people with disabilities they study* (Oleniacz, 2009, p. 95). This reality is the subject of research in many scientific disciplines, including sociology, psychology, pedagogy, philosophy, anthropology, and medicine. Selected examples of empirical analyses shall be shown below.

Sociological studies focus on the social consequences of being disabled, as well as on explaining the mechanisms of self-determination and identity formation in people with disabilities develops in social situations (Ostrowska, Sikorska, Gąciarz, 2001; Wiszejko-Wierzbicka, 2008; Sikorska, 2002; Gustavsson, Zakrzewska-Manterys, 1997; Błęzyńska, 2001). The issue of social identity formation in people with disabilities was also the subject of Krystyna Błęzyńska's research (2001). The author, taking into account the aspect of self-categorization, highlighted the importance of social identity in the process of integrating people with disabilities in social life and the specifics of its formation in a situation of reduced mobility. Adopting a quantitative research strategy, she used elements of the monographic and survey method. As a result, she described the categories of social belonging which most of people with disabilities identify with and pointed to the relationship between belonging and social identity. Błęzyńska (2001) states that the specific nature of the mental and physical functioning of people with disabilities is not a key factor in the formation of their social identity. More significant is variation within the psychosocial context of experiencing the situation of disability, especially in the style and content of socialization (*ibid.*, p. 305).

A lot of space in psychological research is devoted to the issues of personal identity formation when a person experiences disability. Anna Brzezińska and Konrad Piotrowski (2011) undertook the issue of identity formation in people with disabilities reaching adulthood and early adulthood. They performed a comparative analysis of the process of identity formation in people with reduced abilities and nondisabled people. The authors emphasize that a sense of independence has special importance for identity formation in people with disabilities reaching adulthood. Its low level can be an important predictor of social and occupational activities for people with disabilities. Konrad Piotrowski (2013) presented a study on the personal identity of people with physical disabilities compared with their nondisabled peers. As the author emphasizes, the identity built by people with disabilities is clear and consistent. They have a clearer vision

of the future than their nondisabled peers. At the same time, they represent less exploration in fulfilling the roles of adulthood (employee, partner). The author suggests that this may be a causative factor of reduction in the variety and flexibility of their personal identity and the low level of resistance to changes in life circumstances (*ibid.*, p. 160).

Numerous empirical analyses of the phenomenon of disability seek to ascertain the correctness of the process of adaptation, both psychologically and socially. An example is Mariusz Korczyński's research (2009). The author presented a comparative analysis of the system of instrumental and ultimate values in people with disabilities and in nondisabled people, and pointed to the relationships between the system of values and the level of social and psychological adaptation in the subjects. As the analysis revealed, there are only slight differences between the value system of people with disabilities and nondisabled people. In terms of social adaptation, people with disabilities show a higher level of social maturity, responsibility, independence of thought and a greater freedom and sense of humor than people without disabilities. People without disabilities, however, are characterized by a higher level of balance, confidence, and ability to affect others than people with disabilities (*ibid.*, p. 188–189). It was also found that people with disabilities present a more favorable profile of coping with difficult situations than people without disabilities (*ibid.*, p. 191). As pointed out by Korczyński (2009), commitment and social activity are factors determining the quality of the system of values preferred by people with disabilities (*ibid.*, p. 192).

The issue of psychosocial adaptation in people with disabilities was also studied by Piotr Majewicz (2012). The author, referring to the principles of positive psychology, took into account not only negative but also positive aspects of social adaptation, including: the level of satisfaction with life, the ability to see problems and strategies used to deal with them, and the ability to use restorative and creative behaviors aimed at achieving life objectives. He described the psychosocial adaptation of people with physical disabilities in three stages: early, middle and late adulthood, and demonstrated the importance of socio-demographic factors, factors associated with disability and personality factors for this process. Majewicz (2012), on the basis of the research presented, carried out empirical verification of the model of psychosocial adaptation in people with physical disabilities, in which self-esteem and coping strategies are paramount (*ibid.*, p. 290–291).

In psychological and pedagogical literature, a lot of space is given to studies which refer to the ways in which people with disabilities (and their families) perceive and experience their disabilities and deal with the hardships of everyday life (e.g.: Palak, Lewicka, Bujnowska, 2006; Parchomiuk, Byra, 2006; Sadowska, 2006; Otrębski, 2007; Chodynicka, Rycielski, 2008; Smoczyńska, 2010; Wiszejko-Wierzbička, 2010; Zawisłak, 2011). An example of this research area are empirical analyses by Monika Parchomiuk and Stanisława Byra (2006),

whose aim was to assess the quality of life in the context of disability types. The study involved people with intellectual and physical disabilities, and visual and hearing impairments. Parchomiuk and Byra (2006) stress that whatever disability type, their need for independence, action and decision-making in situations that differ in terms of importance is a significant predictor of perceived quality of life in people with disabilities (p. 32). This conclusion is extremely important because it shows how much these people value the opportunity to create their own development and life.

Anna M. Chodyncka and Piotr Rycielski (2008) described selected areas of the reality of people with disabilities in the context of the living conditions of the Polish population and the population of selected European countries (Great Britain, France, Sweden). The authors analyzed the mechanisms conditioning the quality of life of people with disabilities. They presented a comparative analysis of social policy towards people with disabilities and conditions for making public space free from barriers and prejudices. The analysis of the social situation in the selected countries was shown in the light of two concepts: (1) aid that complies with the principle of subsidiarity, and (2) cultural concepts of the independent self and the interdependent self. As a result, a cultural and subsidiary model of the quality of life of people with disabilities was presented, showing interactions between cultural dimensions and the principle of subsidiarity applied in the creation of support for people with disabilities, and their standard of living and the quality of their lives (*ibid.*, p. 85).

The quality of life of people with disabilities was also the subject of research carried out by Karolina Smoczyńska (2010) and Dorota Wiszejko-Wierzbička (2010). The studies were conducted as part of a nationwide survey on the situation, needs and abilities of people with disabilities under the direction of Anna Brzezińska and colleagues (2010). The studies included: the co-occurrence of other disabilities and the legal status of the people surveyed (biological disability or certificate of disability) (Smoczyńska, 2010), housing conditions, the network and scope of support from the closest people, respondents' age and sex (Wiszejko-Wierzbička, 2010). As a result, the level and factors determining the quality of life of people with disabilities in Poland were identified.

Research analyses in the humanistic orientation. Speaking about the human in terms of subjectivity creates the need to reach for humanistic methodology and the interpretive paradigm of qualitative research in research projects. Testing through common experience, a characteristic of the quality strategy, creates the possibility of a deeper and more personalized examination of the reality of people with disabilities and intentions and meanings we attribute to it (Wyka, 1993; Kosakowski, 2001). Qualitative research makes it possible to adopt various perspectives on disability that will take into account different consequences of disability, ways of experiencing it and the social and situational context of life of people with disabilities. Disability issues in research also mean exploring inten-

tional behaviors and unique experiences. Humanistic methodology is used also by those authors who focus their research around the life situation of people with limited communication skills, with a lower level of autonomy or consciousness, or coming from different social backgrounds. In these analyses, the assessment of the subjects' situation is most frequently made by direct participant observation, narrative interviews or document analysis.

Beata Borowska-Beszta (2012) applied humanistic methodology as a significant source of anthropological and ethnographic knowledge of the reality of people with disabilities. The concept of cultural relativism used served as the basis of ethnographic research which enabled the author to build a picture of the lifestyle of adults with developmental disabilities with the dominant dysfunction in the intellectual sphere. Borowska-Beszta defined an empirical phenomenon, i.e. a unique pattern of the lifestyle of people with disabilities and their families. She recognized that cultural anthropology makes it possible to understand modern humans from the point of view of their life problems, at least in the context of inequality, discrimination and exclusion. She adopted the characteristic position of ethnographic research, which is based on contact, participation and in-depth interviews in the cultures of people with disabilities. The interpretive paradigm applied made it possible to identify, describe and explain different pictures of the complex reality of people with disabilities.

The qualitative research strategy was also adopted by Beata Cytowska (2012); the subject of her empirical investigations is the situation of adults with intellectual disabilities in Poland. She used the methodology of Kathy Charmaz's constructivist grounded theory and Adele E. Clarke's situational analysis, which served to build a theory describing the process of adaptation of people with intellectual disabilities to the challenges of contemporary, postmodern society. The author, referring to the research participants' biographies, describes the way in which they experience the process of social adaptation and which of their competences, developed through socialization, education and therapy, are crucial for the social roles they play (*ibid.*, p. 148). Based on the analysis of narrative interviews, she describes three key categories emerging from the biographical material collected: (1) the process of "person adventitia" identity formation, (2) the formation of the foundations of responsibility as a result of becoming independent, and (3) subjectivity experienced by people with intellectual disabilities in "objectifying socialization" (*ibid.*, p. 351–356). She set her empirical analyses in a widely analyzed situational and social context of the life of people with intellectual disabilities in Poland.

Agnieszka Woynarowska (2010), using the interpretive paradigm of qualitative research, undertook the issue of constructing intellectual disability in public discourse and in the biographies of people with disabilities. The author, using a biographical strategy and a critical analysis of the discourse present in social narratives, presented a holistic approach to the issues. Her analyses made

it possible to distinguish two parallel discourses of understanding the issues of intellectual disabilities. The first is the discourse of negation and exclusion, in which negative meanings of dependence, helplessness, suffering, misery and sadness are attributed to people with intellectual disabilities. The second refers to perceiving people with intellectual disabilities as full members of society and to ensuring their right to self-determination, self-realization and self-reliance. Agnieszka Woynarowska (*ibid.*) defines the latter discourse as the discourse of normalization, ordinariness, discourse for differences, and emancipation discourse (*ibid.*, p. 299–300).

A qualitative analysis of the phenomenon of disability was also conducted by Urszula Bartnikowska and Agnieszka Żyta (2007). The authors analyzed the life situation of adults with sensory, physical or intellectual disabilities. Using the dialogue method and the biographical method, they defined the life situations of adults with different types and degrees of congenital and acquired disabilities. Referring to the respondents' autobiographies, they described various individual and social consequences of disability and the problems people with disabilities face every day in Poland. They analyzed subjective assessments concerning the respondents' abilities, participation in the process of rehabilitation, social integration, plans and life goals, and opportunities and threats for their implementation. The authors also analyzed pro-integration activities undertaken in Poland. They pointed out the difficulties experienced by people with disabilities in adolescence and adulthood, life crises, negative aspects of integrated education and limitations to full social integration. At the same time, they extensively analyzed the functional abilities of the people with disabilities in the study, their goals in life and hierarchy of values. They pointed to their cognitive and task activity, creative attitude, communication skills and constructive strategies of coping with their difficult life situation and limited efficiency.

Methodological pluralism. Undertaking disability issues in scientific research often requires delving into complementary research. Such studies are used to examine the issues interesting to the researcher in the fullest possible, multifaceted way. Ewelina J. Konieczna (2010) applied complementary research to identify the relationship between disability and a sense of purpose in life in people with disabilities. The author searched for answers to questions about demographic factors determining purpose in life in people with physical disabilities. The study also took into account the categories of personal values, acceptance of disability, a sense of self-efficacy and a sense of optimism in life. The study's interesting results helped to identify the level of perceived quality of life in people with disabilities and individual determinants.

In the area of psychology, Ewa Zasepa and Agnieszka Wołowicz (2010) applied a quantitative and qualitative orientation as a source of knowledge of the quality of life in families with children with intellectual disabilities. Using their own adaptation of the Family Quality of Life Survey – a general version, they

determined the quality of life in the families surveyed in nine dimensions: family health, financial situation, family relationships, support from others, support within the framework of specialized services and social assistance, system of values, career and preparing for a career, leisure time and recreation, and social interactions. The authors used a research tool which takes into account both the subjective and objective aspects of perceived quality of life. It also enables the quantitative and qualitative assessment of the individual dimensions adopted. As a result, they presented a comparative analysis of subjective and objective dimensions of quality of life and personal satisfaction in families with children with disabilities and families with children without disabilities. They also identified the factors that determine the level of quality of life in the groups studied.

A complementary sociological theoretical and empirical study on the issues of the social marking of people with congenital disabilities was undertaken by Beata Pawlica (2001). The author searched for answers to questions about the causes of stigmatization, self-marking and the feeling of being inferior, as well as self-image in the perception of adolescents with congenital disabilities and their nondisabled peers. She attempted to identify the impact of congenital defects on the subjective experiences of young people with limited efficiency, on their self-esteem, interpersonal relationships and life plans.

An example of interdisciplinary and complementary empirical research on the phenomenon of disability is the in-depth and wide-ranging study on the situation and needs of people with disabilities and their opportunities, which covers the period from 2008 to 2010. It was conducted by Anna Brzezińska and colleagues (2010). The aim of the study was to develop recommendations for the National Strategy for Increasing the Social and Vocational Activity of People with Disabilities, Including People With Multiple and Rare Disabilities. The multi-module expert evaluation included both surveys and individual and group interviews. Empirical analyses prepared for the project concerned selected areas of the functioning of people with disabilities. Interdisciplinary reports raised questions from different areas of the social sciences. The project was carried out by a team of psychologists of different specialties, sociologists and methodologists. Consultations were held in the area of rehabilitation psychology, sociology of health, psychiatry, geriatrics, social gerontology and cognitive science. The research resulted in the following: (1) statistical characteristics of the group of people with disabilities in the study were presented, also in terms of sociodemographic variables and the causes of disability, (2) conditions that affect the quality of life of the respondents with disabilities and their quality of life perceptions were set out, (3) risk factors and factors protecting against marginalization and exclusion were isolated, (4) the factors hindering and supporting the inclusion of people with disabilities were determined, and (5) recommendations for constructing programs that support people with disabilities in the labor market were developed (Brzezińska et al., 2010; Brzezińska, Kaczan, Rycielski, 2010a, 2010b; Piotrowski, 2010).

Selected constructs in the approach to the phenomenon of disability

Personalistic perspective. A humanistic and subjective approach to disability changes the optics of the perception of people with disabilities. It is also an important aspect of the examination of this person activities, which not only are organized by the environment, but they also run with its participation and consent, with the ability to participate and make choices. Maria Grzegorzewska (1964) stressed the importance of boosting the potential of people with disabilities, inducing their initiative, creativity, enthusiasm for work and willpower to overcome difficulties.

Czesław Kosakowski (1997) stresses that subjectivity is the transfer of responsibility for oneself in the hands of the person with disability within the limits of his or her ability. Creating conditions to experience subjectivity by people with disabilities is both showing opportunities and assistance in creating and expressing oneself, in struggling with the contradictions inherent in the environment and one's own weaknesses. The author recognizes that the subjectivity of people with disabilities expresses their awareness of agency, ability to influence their own life and taking responsibility for it.

In Polish special education, the issue of subjectivity has been a significant domain of theoretical studies for many years (Kosakowski, 1997; Wojciechowski, 2002; Mikrut, 2009; Podgórska-Jachnik, 2009; Rzeźnicka-Krupa, 2011, 2012; Głodkowska, 2014b). Also empirical reports concerning subjective aspects in the functioning of people with disabilities can be referred to. Bernadeta Szczupał (2008) considers the subjectivity of people with disabilities in relation to dignity, thanks to which humans have autonomy in selecting their values and choosing how they realize them. Hanna Żuraw (2008) analyzes the participation of people with disabilities in society as an important manifestation of their subjectivity. Jolanta Rzeźnicka-Krupa (2011, 2012) makes an inspiring recommendation – she suggests that the categories of subject and identity be given the cardinal importance of the sources of “paradigm change” in special education, as well as the sources “that constitute its research area” (Rzeźnicka-Krupa, 2012, p. 7). Researchers' recent focus on issues relating to the subjectivity of people with disabilities and the search for reasons for the paradigm change may be considered to demonstrate the legitimacy of changes “in the area of constructing the field of interest in special education” (ibid., p. 7).

Clearly marked is a trend in which researchers perform analyses that present disability as a source of strength in forming identity, experiencing subjectivity and building authorship of their own lives in people with disabilities (after Głodkowska, 2014a, 2014b, 2014c, 2014d). Experiencing disability is often associated with the need, and sometimes the necessity, to constantly modify one's own identity, as well as to make an effort to become the author of one's own life. In the literature of the last decades, extensive scientific search for the potential,

strengths, and developmental power of people with disabilities in various aspects of their lives can be noted. To be the author is to be the creator of one's inner world, to get to know oneself and create oneself. It is also to offer something to others and create the world around them (Głodkowska, 2014a). The issue of self-determination, independence and people with disabilities being the authors of their own lives did not appear suddenly in special education. In the scientific sense, it developed gradually as the idea of every person's inalienable right to freedom, to decide on his or her development, to make choices and to create his or her life strengthened in the humanistic and social disciplines.

The models of the development of people with disabilities began to expose the aspects of health, well-being, personification and inclusion in social life. In this way, the idea was born to provide people with disabilities with the right to a shared experience of the world and "shared existence." The need for the fullest possible approximation of the living conditions of people with disabilities to the living standards of nondisabled people was formulated. At the same time, research on disability undertaken in line with positive psychology showed the need to identify the optimal functioning of people with disabilities and the factors that lead to human "flourishing" (Głodkowska, 2013).

The search connecting different theoretical concepts has led to the development of the construct of people with disabilities being authors of their own lives (Głodkowska, 2015). The theoretical foundations of this construct take into account: (1) positive psychology, (2) personalistic pedagogy, (3) the theory of optimal functioning, (4) the theory of developmental tasks, and (5) the theory of social support. Building a theoretical basis was an inspiring impulse for the reflections of the author (*ibid.*) about the merging of the ideas of humanities and social sciences, as well as the merging of researchers' thoughts identifying and explaining the phenomenon of disability. A holistic approach helped to see the construct of people with disabilities being the authors of their own lives in a positive perspective of welfare, subjectivity, self-determination, optimal functioning, fulfilling age-appropriate developmental tasks and experiencing social support. The construct takes into account several aspects: eudaimonic, personalistic, functional, temporal and assistive aspects. Głodkowska emphasizes that it would be interesting to use the construct to design research on personalistic, interdisciplinary investigation of the phenomenon of disability. Giving one's own life self-made qualities is a value and an inalienable right of every person with disability.

A personalistic, humanistic approach to disability also refers to normalization as a process which makes it possible to consider the lives of people with disabilities in the dimensions of self-creation, their sense of identity, quality of life, self-determination and subjectivity (Głodkowska, 2014d). In general, normalization leads to the creation of such conditions of support that will activate a person, his or her need for participation and self-realization. The adoption of the concept of

people with disabilities as subjects builds new research perspectives (e.g.: Sidor-Rządowska, 2000; Szawarski, 2000; Przyłuska-Fischer, 2003; Szczupał, 2008).

In special education, such conceptual categories as dignity, autonomy, identity, subjectivity, self-determination and the authorship of their own lives in people with disabilities are essential components in building the image of people with disabilities (Dykcik, 1996; Szczupał, 2008; Głodkowska, 2015). They result from humanistic ideas, which have influenced both the practice and the shape of the theoretical and empirical basis of the phenomenon of disability in special education since its inception.

Perspective of the normalization of life of people with disabilities. In the perspective of normalization, essential threads of the consideration of disability are indicated by Stanisław Kowalik's analysis (2007). The author uses the term "dysfunctional" to show the disparities between the requirements of normal life situations and the activity of a person with disability. He shows that in the case of dysfunction, such activity is insufficient for the person with disability to be able to independently cope with life and overcome obstacles. Dysfunctional forces increased effort which must be put in by people with disabilities to overcome these obstacles. The researcher adds that the dysfunctionality of the body is a necessary condition but not sufficient for the diagnosis of disability in a person – neither is non-compliance with imposed social tasks.

"Quality of life" is a central concept in the scientific approach used to determine the conditions for the normalization of life of people with disabilities. This category is sometimes reduced to objective factors, such as health, family situation, education level, income level, possessions or rights, close and lasting relationships with other people. A subjective evaluation of various aspects of one's situation which is expressed in certain emotional states and beliefs, expectations and hopes is considered a particularly important criterion and indicator of the quality of life. Currently, numerous research projects on the quality of life of people with disabilities can be seen (e.g. Palak, Lewicka, Bujnowska, 2006).

Today, the issue of the normalization of life of people with disabilities is relatively well-presented in Polish literature. The authors consider, among others, the normalization of the living environment (Kosakowski, Krause 2005) and the normalization of the social environment (Krause, Żyta, Nosarzewska, 2010). Detailed discussion of the process of normalization is covered, among others, in publications analyzing the issues of social integration and inclusion processes, as well as presenting theoretical and empirical search for the quality of life of people with disabilities, their social participation or autonomy. There are also studies in which authors somehow reorient their thinking of normalization, introducing meanings that have been marginalized so far to the understanding of this process.

In numerous publications, authors probe social relationships as sources of subjective treatment and vital signs of changes in public consciousness that lead

to overcoming prejudices, restricting stereotypes or promoting the idea of integration and inclusion (e.g.: Gustavson, Zakrzewska-Manterys, 1997; Sadowska, 2005; Żuraw, 2008). The researchers emphasize that approaching disability in a broader social and cultural perspective makes it easier to understand people with disabilities in the individual, subjective dimension.

The repeated research explorations of normalization are a sign of the continuity of this idea, but they also make one understand that it has not been fully realized yet. It turns out that after almost 50 years, discussions on the course of normalization and its expected effects are still valid (after Głodkowska, 2014a). The manifestations of normalization can be perceived in many different areas of the functioning of people with disabilities: their lives in an open environment, support with their participation, identifying and activating their developmental potential, building dialogue relationships with them and their subjective treatment or increasing their quality of life and recognizing their right to happiness and prosperity in life (Głodkowska, 2012, p. 91).

Making normalization and the authorship of one's life real requires that both social environment and people with disabilities perform tasks. Social environment's task is to create conditions which will enable people with disabilities to take causative actions; performing life tasks, they become responsible for their fate. Giving one's life the characteristics of authorship is a challenge for people with disabilities, who – guided by their needs, abilities, aspirations and dreams – create themselves – give their lives a unique, subjective value.

Władysław Dykcik (1996) argues that it is a common misconception that any ability that is impaired in a human reduces, limits or blocks cognitive and practical activity and requires constant external control. The author also notes that excessive support and protection can cause secondary, learned helplessness and consequently hinder the full use of his or her developmental potential by a person with disability. The right to freedom of choice and autonomy, as an important dimension of the subjectivity of people with disabilities, is increasingly prominent in both the theory and practice of special education. It is the right of every human being, including people with disabilities, which enables them to manage their own lives and be responsible for them.

Cultural construct. Polish researchers' achievements which document the culture of people with disabilities can be referred to five main pillars after Beata Borowska-Beszta (2008, 2012): (1) perceiving disability as a distinct culture, (2) perceiving disability as a cultural construct (3) perceiving the culture-forming dimension of the culture of people with disabilities, (4) getting to know the culture of people with disabilities and studying it scientifically, (5) learning the universal, dominant culture by the culture of origin of people with disabilities (2012, p. 67). The author points out that belonging to disability culture can be implemented in two ways: (1) it can be imposed by the dominant culture due to external specialist medical, psychological or social classifications (connected with the diagnosis

of disability) or (2) it can be voluntary, being the choice of people engaged in disability issues (connected with non-obligatory entanglement in the lives of people with disabilities) (*ibid.*, p.70–71). As pointed out by the author, disability cultures are heterogeneous. They have their own language (e.g.: sign language, gesture or picture systems), writing (e.g.: Braille, PCS, pictograms), lifestyles, their own customs, rituals or models. They may experience various difficulties and mental or physical barriers which characterize the dominant culture (*ibid.*, p. 68). The author, on the basis of numerous studies in the field of the culture of people with disabilities, presented a concept of the cultural habilitation of adults with developmental disabilities. In this concept, she provided a comprehensive presentation of the relations that exist between the dominant culture and the culture of people with disabilities (the culture of origin), recognizing disability as a culture in the dominant culture and a construct of the dominant culture. She pointed to two important processes: (1) learning the dominant, universal culture by people with disabilities and (2) co-creating disability culture and the dominant culture (Borowska-Beszta, 2012, p. 222). The scientific understanding of disability culture emphasizes the need to go beyond best practices in quantitative research and to include the interpretive paradigm of qualitative research (Chodkowska, 1993; Żuraw, 1999; Borowska-Beszta, 2005, 2008, 2012).

A lot of space in Polish literature is devoted to the influence of culture on the formation of social attitudes towards people with disabilities (Chodkowska, 1994; Kossewska, 2003; Walecka-Matyja, 2013). Joanna Kossewska (2003) emphasizes that growing up in a particular culture and a system of values cherished by society significantly influences the attitude towards people with disabilities. Also cultural diversity, which promotes greater tolerance for otherness, and society's hierarchy of values are not without significance. Katarzyna Walecka-Matyja (2013) points out that the culture of each society consists of many elements that shape attitudes towards disability, including, among others: scientifically documented statements about reality, beliefs and myths, ideologies, social norms, styles of behavior and role models. Maria Chodkowska (1994) analyzed religious, moral and cultural determinants of attitudes towards people with disabilities, pointing to the special role of ancient models in the formation of the attitude to disability in European culture. The author emphasizes that it is necessary to make a change in social attitudes aimed at eliminating stereotypes and prejudice against people with disabilities, which still exist in Polish society. Władysław Dykcik (2007), by making certain conclusions about attitudes towards disability from a historical and cultural point of view, points to three main orientations: (1) strategies of other controllable, permanent, ostracizing regulation of human behaviors, (2) too liberal strategies, and (3) strategies of inner controllable, emancipatory, humanistic, partnership-based influence on attitudes.

Numerous publications analyze the culture-forming dimension of the culture of people with disabilities (Dykcik, 2001; Wojciechowski, 2001, 2004; Jutrzyzna,

2002, 2003; Borowska-Beszta, 2008; Ploch, 2014). Hanna Źuraw (2001) sees the opportunity for empowering the process of rehabilitation in the cultural activity of people with disabilities (p. 165). At the same time, the author points to rehabilitative functions of participation in culture: (1) culturally synchronizing functions (making the living conditions of people with disabilities approximate to the living conditions of nondisabled people), (2) existentially empowering functions (making people with disabilities aware of the possibility of autonomous and independent actions), (3) community functions (integration of people with disabilities), (4) compensating and cathartic functions (compensation for gaps in everyday life associated with reduced abilities), (5) creative functions (encouraging self-realization and creative skills), (6) cognitive functions (learning about one's predisposition and abilities), and (7) hedonistic and relaxing functions (the entertaining dimension of participation in culture) (ibid., p. 166–170). Władysław Dykcik (2001), analyzing the therapeutic importance of culture techniques and art therapy in stimulating the development of people with disabilities, highlights the wider importance of their participation in culture. In this context, he sees the cultural activity of people with disabilities *as creating a different lifestyle, organizing the environment and cultural experiences of individuals within their cognitive and emotional relationships with their immediate surroundings and the whole world* (p. 33). The author emphasizes that because of various difficulties, dysfunctions and restrictions, this activity still has a subcultural, marginal, individual, intimate and religious dimension (ibid., p. 32). Also Leszek Ploch (2014) sees the opportunity to protect people with disabilities against marginalization and exclusion in their cultural activity. Beata Borowska-Beszta (2008), analyzing various forms of art therapy and therapy by narratives and writing, indicates that they perform rehabilitative functions: (1) give the possibility for creative expression and establishing interactions in the course of operations, (2) shape a sense of coherence and, (3) add a creative dimension to everyday life of people with disabilities (p. 111). Andrzej Wojciechowski (2001) indicates that artistic work makes it possible to see people with disabilities cooperating and participating with others. It becomes an opportunity for them to satisfy their need for development and to become included in the community.

Conclusion

The article presents the phenomenon of disability as seen by Polish researchers from historical, contemporary, theoretical and empirical perspectives. It presents multifaceted empirical examinations relating to various areas of the life of people with disabilities. We hope this article will, at least partially, outline and bring closer the achievements of Polish researchers in the phenomenon of disability.

Abandoning the perception of disability only from the perspective of the medical model (individual model) in favor of the social model creates an inspiring, interdisciplinary research space for the social sciences. This idea is depicted

in this article. The theoretical and empirical analyses performed aim at learning about the personal, social, cultural, legal and economic dimensions of disability. They are the basis of critical discourse on the place of people with disabilities in society and the role of society in creating the situation of people with disabilities. Currently, Disability Studies do not have the status of a scientific field in Poland, and available scientific publications approach disability from the perspective of individual disciplines. Nevertheless, the theoretical and empirical experiences presented in this article may indicate a solid foundation for building this discipline in the Polish scientific perspective.

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POLISH RESEARCHERS' THEORETICAL AND EMPIRICAL APPROACH TO DISABILITY: FROM THE PERSPECTIVE OF DISABILITY STUDIES

Abstract

The article presents Polish researchers' scientific approaches to the phenomenon of disability in a historical perspective and in view of modern interdisciplinary theoretical and empirical studies. Humanistic and social approaches to disability create a new, interdisciplinary cognitive space. Researchers highlight the strengths, potential and developmental power of people with disabilities more and more clearly. From this perspective, disability is not perceived as an individual problem only. It is becoming apparent that it is necessary to carry out detailed and multidimensional empirical investigations that take into consideration the social, cultural and political context of how people with disabilities live. The article looks at Polish researchers' achievements that fit in with the trend dating from the second half of the 20th century – Disability Studies. The authors review and analyze paradigms of disability to show positivist and humanistic research orientations, methodological pluralism and an interdisciplinary approach to the phenomenon of disability.

Key words: Disability Studies, person with disability, paradigms of disability, positivist orientation, humanistic orientation, methodological pluralism, normalization, disability culture

TEORETYCZNO-EMPIRYCZNE UJĘCIE ZJAWISKA NIEPEŁNOSPRAWNOŚCI PRZEZ POLSKICH BADACZY. Z PERSPEKTYWY STUDIÓW NAD NIEPEŁNOSPRAWNOŚCIĄ

Abstrakt

Artykuł prezentuje naukowe ujęcia polskich badaczy zjawiska niepełnosprawności w perspektywie historycznej i współczesnych interdyscyplinarnych opracowań teoretyczno-empirycznych. Humanistyczne i społeczne rozpatrywanie fenomenu niepełnosprawności tworzy nową, interdyscyplinarną przestrzeń poznawczą. Badacze coraz wyraźniej akcentują mocne strony, możliwości i siły rozwojowe osób z ograniczoną sprawnością. Z tej perspektywy niepełnosprawność nie jest postrzegana wyłącznie jako problem jednostkowy. Uwidacznia się potrzeba podejmowania pogłębionych i wielowymiarowych rozpoznań empirycznych uwzględniających społeczny, kulturowy oraz polityczny kontekst funkcjonowania osób z niepełnosprawnością. Artykuł ukazuje osiągnięcia polskich badaczy, wpisujące się w nurt z drugiej połowy XX w. – Disability Studies. Autorki prowadzą analizy przeglądowe w zakresie paradygmatów niepełnosprawności, ukazania pozytywistycznej i humanistycznej orientacji badawczej, pluralizmu metodologicznego oraz interdyscyplinarnego ujęcia fenomenu niepełnosprawności.

Słowa kluczowe: Disability Studies, osoba z niepełnosprawnością, paradygmaty niepełnosprawności, orientacja pozytywistyczna, orientacja humanistyczna, pluralizm metodologiczny, normalizacja, kultura niepełnosprawności