



Polish Disability Studies: Inspiring Scientific Area and General Academic Profile of Study

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Abstract

This article presents general assumptions of an innovative, first in Poland master's degree – Interdisciplinary Studies on Disability (in the world called Disability Studies). Authors built the theoretical and empirical context of this general profile of studies, using knowledge about international experiences and Polish researches on the phenomenon of disability. Master's degree Interdisciplinary Studies on Disability were established in 2016 year in The Maria Grzegorzewska University in Warsaw. The establishment of studies was the result of a response to the changing social situation (an increase in social movement for people with disabilities), the increasing need for initiating, designing and implementation of integrated support systems and the need to prepare comprehensive professionals prepared to work with people with disabilities and their families – leaders, researchers, specialists. Authors present also scientific sources as the foundation of initiation and development of a new higher education field of study and opportunity.

Keywords :disability studies, interdisciplinary studies on disability, personalization normalization, culture of disability

Introduction

About forty years ago originated the world trend, called *Disability Studies*. Although already emerged stirrings of interests to researchers a specific, no medical, approach to disability. *Disability Studies* is an academic interdisciplinary endeavor that analyzes disability and the lived experiences of people with disabilities from the perspective of the humanities, social sciences, and arts, not the medical fields that sees it in more negative and individualizing terms, as a deficit or defect that must be cured, or eliminated in order for an individual to function “normally” in society (Rembis, Pamula, 2016). Undercurrent this is built on a social model of disability, which accentuates the interactions in the world of people with disabilities and in the world around them. *Disability Studies* has its political and intellectual roots in the disability rights movement.

The aim of the article is to present an innovative, first in Poland field of education at major degree – *Interdisciplinary Studies on Disability* (in the world called *Disability Studies*) in the context of the Polish researches on the phenomenon of disability and international teaching experience in the implementation of studies in this field. *Interdisciplinary Studies on Disability* were established in 2016 year. This is the faculty which arose as a response to the changing social situation – an increase in social movement for people with disabilities, the increasing need for initiating, designing and implementation of integrated support systems and the need to prepare comprehensive professionals prepared to work with people with disabilities and their families – leaders, researchers, specialists. These objectives can be achieved through the use of knowledge, resources and research solutions used in a variety of research disciplines. Hence, designed in The Maria Grzegorzewska University study, is interdisciplinary and clearly focused around disability as a social phenomenon.

According to data published in the report *European Disability Strategy 2010–2020*, one in six Europeans is a person with disabilities. Altogether in Europe, there are approximately 80 million people with various kind of disability. Figures suggest that the number in Poland is slightly lower than the European average. In the report edited by Kryńska (2013) according to the results of the National Census of Population and Housing from 2011 the number of people with disabilities in Poland amounted to approximately 4,7 million, which means about 12,2% of the total population. Among them there were approx. 3131.9 thousand legally disabled people (with disability certificate), and there were 1656.6 thousand

biologically disabled people (who do not have legal documents certifying disability, but sentient its physical effects). These data indicate a decrease in the number of people with disabilities in Poland – in the previous census in 2002 people with various forms of disability accounted for approx. 14.3%. The most common causes of disability are – according to the report by the *Office of the Government Plenipotentiary for Persons with Disabilities* – cardiovascular, locomotor and neurological disorders. It is worth noting that despite the relatively lower percentage of people with other kind of disability (disability of sight, hearing, intellectual, etc.), it is a significant part of society, requiring adaptation of the conditions of local environment, education, labour market, etc., to their needs.

Review of Literature

Disability Studies in the World

Disability Studies are a new field of study in Poland, but in the world it is well-known and has had a long tradition. Its origin dates from the 80s of the twentieth century – in 1982 *The Society for Disability Studies (SDS)* was founded, the oldest academic organization for interdisciplinary research on disability (initially the organization was called *Section for the Study of Chronic Illness, Impairment and Disability (SSCIID)*). A few years later, the SDS began issuing *Disability Studies Quarterly (SDQ)* – it was the first scientific publication devoted to *Disability Studies*. History of *Disability Studies* as a field of academic training began in 1992, when on Syracuse University first training program in this regard appeared. Although it was not very popular, the number of universities opening courses of I, II or III degree in this area began to grow fairly quickly. Initially, this faculty was introduced to training in higher education institutions in the US and the UK, and later in Canada and Australia and other countries in Europe, the Americas and even Asia (Rembis, 2010). Ferguson and Nusbaum (2012) note, however, that the theoretical origins of *Disability Studies* are much earlier and are associated with individual research projects, as well as individual approach of specific scientists to the phenomenon of disability.

Origins

Searching for the origins of *Disability Studies* as a field of academic education, Ferguson and Nusbaum (2012) go back to the beginnings of movements for the rights of people with disabilities, and therefore to the 70s of the twentieth century (and even – in socio-anthropological terms – to the early 60s of the twentieth century). Similarly – to the mid-twentieth century, as to the time of the beginning of *Disability Studies* – point Barnes (1997), Rembis (2010), Albrecht, Seelman and Bury (2001), Brueggemann (2013). The creation of *Disability Studies* as a field of academic education was associated therefore with a new approach to people with disabilities as well as disability as a phenomenon. This meant changing the perception of disability model – the transition from medicalization towards a social, humanistic, positive model.

Ferguson and Nusbaum (2012) indicate the characteristics defining and specifying *Disability Studies* in this approach. These are: (1) a social model – the perception of disability in social, cultural, historical context; (2) treating disability as one of the fundamental differences (such as gender or race); (3) interdisciplinarity – analyzing the phenomenon of disability from the perspective of different disciplines; (4) participation in studies of people with disabilities; (5) basing the study and research on the system of values. According to the authors, application of these criteria to *Disability Studies* is necessary so that these studies as well as the research within them gave the effect of the form: to create and disseminate alternative perception of people with disabilities and disability (*imagine disability otherwise*), to create a cultural and social space for the support system and inclusive education of people

with disabilities, to implement programs to prepare for teaching of the disabled and about disability, but also to create a critical yet at the same time reflective scientific community.

Legal Grounds

Also, we cannot suppress in development of *Disability Studies* the legal basis for the implementation of the social model of disability. The legal situation of people with disabilities is regulated by many documents of national, as well as European and global character. One of the most important international documents defining the rights and status of people with disabilities is the UN Convention on the Rights of People with Disabilities. This document was adopted by the United Nations General Assembly on December 13, 2006. The Polish government signed it on March 20, 2007, while its full ratification took place on September 6, 2012. “The aim of the Convention is to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities and to promote respect for their inherent dignity”. It applies to all aspects of social life and devotes particular attention to equality of people with disabilities and able-bodied and pays attention to the responsibilities of the state to ensure people with disabilities a full implementation of citizens’ rights. The convention is based on eight basic principles. These are: (1) respect for inherent dignity, individual autonomy, including the freedom to make choices, and respect for the dignity of the person, (2) non-discrimination, (3) full and effective participation and inclusion in society, (4) respect for otherness and acceptance of people with disabilities being of human diversity and humanity, (5) equality of possibilities, (6) accessibility, (7) equality of men and women, (8) respect for the developing capacities of children with disabilities and respect for the rights of children with disabilities to preserve their identities. In particular, the convention clearly emphasizes the multidimensionality and multidimensional phenomenon of disability and the necessity to adapt the existing legal and physical solutions to needs of people with disabilities.

Disability Studies in Poland

The beginning of the new century clearly show the changes in the perception of man in the social sciences, including changes in the perception of people with disabilities (Głodkowska 2014a, p. 75). The source of these changes Głodkowska (2014a) sees inter alia to premises of humanistic psychology and messages of vital philosophy of Jose Ortega a Gasset. There is clearly apparent, that a new space for scientific diagnoses of the phenomenon of disability is also built by a departure from the perception of it only through the prism of medical model to a socio-cultural perspective. Interdisciplinary theoretical and empirical analysis tend to learn the personal, social, cultural, legal and economic dimension of disability. In the Polish scientific literature, you can identify the different areas and the perspectives explanation of the phenomenon of disability. In the context of the subject matter of this article we set three constructs down: (1) the personalist construct, (2) the construct of normalization and (3) the cultural construct.

Personalist Construct

With the personalist construct of the approach of disability involve directly issues subjectivity, sense of identity, self-determination, autonomy. In special education problem of subjectivity for many years has been a significant domain of Polish studies (including Kosakowski, 1997; Wojciechowski, 2002; Dykcik, 2007; Szczupał, 2008; Mikrut, 2009; Podgórska-Jachnik, 2009; Rzeźnicka-Krupa, 2011; Głodkowska, 2014b). “Subjectivity is manifested in the fact that man is someone, that has a specific identity, that has more or less distinct individuality distinguishing him from the others, that his activity depends largely on himself”(Tomaszewski, 1985, p. 72). According to Kosakowski (1997) realization of the postulate of subjectivity in special education is expressed in making people with disabilities

aware of their agency, ability to influence their own lives and taking responsibility for themselves. Dykciak (2007) analyzes the cardinal principles of *cooperation and coexistence* in the changing social reality as the superior one shows the principle of personalization, which refers to the protection of personal relationships of people with disabilities, their dignity and personal identity as inalienable rights of every human being irrespective of the scope of the dysfunction or disability (p. 75). As an important dimension of subjectivity he perceives the right of people with disabilities to freely make choices and autonomous actions. In this context, he defines autonomy as a value, right and privilege of individuals to build a unique shape of their own self and their own personal version of life (p. 365). Szczupał (2008) subjectivity of people with disabilities considers in relation to the dignity by which a person has autonomy in the selection and the manner of realizing value. Głodkowska (2014b) examines subjectivity, as a dimension integrating human functioning, giving them identity and individuality in relations with the environment (p. 109). Sources of such understood subjectivity are found in the currents of humanistic psychology, whose representatives see man as an autonomous being, able to control their own behaviour and accepting responsibility for them (p. 94). The author sees a person with a disability, as a being creating themselves and the world around them, but also acting in specific relationships designated by circumstances of life (p. 91). The author refers to such characteristics of a person-entity as: causativeness, decision-making, initiating, a sense of identity, individuality, independence, control, autonomy, self-determination, welfare, quality of life (p. 106). She considers speaking about the person with a disability as an entity to be an imperative to special education. In the analysed issues Głodkowska (2014a, 2014b, 2014c) undertakes numerous analyzes endearing disability as a source of strength in shaping identity, experiencing subjectivity and the possibility of being the author of one's own life.

The humanistic methodology enables understanding of what is most important to study the humanities, and so knowledge of man and the meaning and value of what a man gives to events and activities (Lindyberg, 2001, p. 203). Personalist, humanistic vision of man is also apparent in the methodology of empirical research that is used by Polish researchers for recognition of the phenomenon of disability (including Obuchowska, 1987; Żuraw, 1999; Rzeźnicka-Krupa, 2009; Mikrut, 2009; Podgórska-Jachnik, 2009; Borowska-Beszta, 2012). In the 80s of the twentieth century Obuchowska (1987, p. 31) among the current paradigms of special education points to "paradigm of subjectivity in methods" giving suitable importance to qualitative research, that let you penetrate the essence of experiencing life by persons with disabilities. Rzeźnicka-Krupa (2009) in the interpretative paradigm of qualitative research puts the possibility of the realization of the subjective treatment of subjects postulate, emphasizing their uniqueness and the treatment of persons with disabilities as unique in their diversity (p. 181). According to Mikrut (2009) return to the methods of the quality serves knowing what lies deep in the psyche of a subject, what is personal, intimate, hidden and unique – in short, what constitutes such, not other experiencing their situation (p. 156).

Normalization Construct

The personalist construct is directly related to the construct for normalization, because normalization is a process, that get authorship features the life of people with disabilities, awake of their sense of identity, self-determination, the needs to improve the quality of their life. All of these qualities and activity therefore be considered in connection with identity of person with disability, that is, in terms of the personalist construct (Głodkowska, 2014c). Today, the issue is already relatively rich in Polish literature.

Stochmiątek (2002) sees normalization as a process of approximation of the living conditions of people with disabilities, including their living conditions, social status, or role-

life experiences to those of the general public (p. 53). Kosakowski and Krause (2005) focused their attention on the normalization of the living environment of people with disabilities. In the cited monograph they entered into multidimensional problems of the normalization process. They have taken into account the context of education, rehabilitation, family and society. Doroba (2010) refers to the normalization of key experiences in life cycle of humans, such as experience of self-creation, leaving the family home, empowerment, acquiring professional qualifications, creating their own way of life (p. 8). Krause, Żyta and Nosarzewska (2010) undertook the issues of normalization of the social environment of people with intellectual disabilities. In the theoretical dimension they drew attention to the context in which people with disabilities function in institutional and family environment. They gave empirical verification of the basic areas of normalization of life of adults with disabilities, including the housing situation, work situation and social situation (family life, interpersonal relationships and the development of leisure time).

According to Głodkowska (2012) manifestations of normalization can be perceived in many different areas of people with disabilities: their lives in an open environment, support with their participation, recognition and activation of their development potential, taking up with them the relationship of dialog and subjective treatment, or improvement of quality of their lives and recognition of their right to happiness and prosperity in life (p. 91). The author analyzes the ideas of normalization from the perspective of “authorship of their own lives of people with disabilities” (Głodkowska, 2014a). In this sense, the author sees normalization “as the goal and the process of fulfilling the rights of people with disabilities to build their own path of life – to create the best of their capabilities, their author life”(p. 86). In the theoretical foundations of the construct by their own life the author shows: (1) positive psychology, (2) educational personalism (3) the theory of optimal functioning, (4) the theory of developmental tasks, (5) the theory of social support (Głodkowska, 2015). She takes into account eudaemonist, personalist, functional, temporal aspect of authorship of their own lives (p. 117). According to the author, the opportunity to be an author of one’s own life is a value and an inalienable right of every person with a disability (p. 128).

The central category around which conditions of the normalization of life of people with disabilities are examined is the *quality of life*. In scientific terms, this category was the subject of many theoretical analyzes and empirical investigations (including Parchomiuk, Byra, 2006; Palak, Lewicka, Bujnowska, 2006; Sadowska, 2006; Otrębski, 2007; Chodyncka, Rycielski, 2008; Smoczyńska, 2010; Wiszejko-Wierzbička, 2010; Zawiaślak, 2011). The multiplicity undertaken analysis takes into account both objective and subjective dimension of quality of life of people with disabilities. Objective measures come down to health, education level, income, ownership of goods or rights, sustainability and proximity of relationships with other people. Especially important in assessing the quality of life of people with disabilities, however, are the dimensions that relate to the subjective assessment of various aspects of their life situations, including the level of satisfaction with family life, career, and social participation.

Cultural Construct

Increasingly, and commonly accented phenomenon not only in rehabilitation practice dimension but also in dimension of theoretical and empirical diagnoses of various scientific disciplines is the participation of people with disabilities in culture as a manifestation of their inclusion and social integration. Seeing a man in cultural terms of interdisciplinary diagnoses of disability studies can be referred after Borowska-Beszta (2012, p. 67) to six pillars: (1) perception of disability as a distinct culture, (2) perception of disability as a construct of cultural heritage (3) perception of culture-creating dimension of people with disabilities (4)

knowledge of the culture of people with disabilities and its scientific research, (5) learning the dominant culture by culture of origin of people with disabilities.

Culture of disability was the subject of empirical analysis of many authors (including Chodkowska, 1993; Żuraw, 1999; Borowska-Beszta, 2008, 2012, 2013). Chodkowska (1993) by locating her research in qualitative research orientation presented socio-pedagogical empirical study of the situation of women with disabilities. Żuraw (2008) as the subject of her empirical diagnoses made styles of social participation of people with reduced abilities and factors determining them. Borowska-Beszta (2012), reaching to ethnographic research identified an empirical phenomenon, which is a unique design of style of life of adults with disabilities and their families.

Undertaken theoretical analysis also applies to the recognition of disability as a cultural construct (including Chodkowska, 1994; Kossewska, 2003; Wałęcka-Matyja, 2013). Chodkowska (1994) points to two trends being a source of attitudes towards disability in European culture: (1) religious-cultural, and (2) the cultural-moral. Making their characteristics she emphasizes that the basis of any modifications to the negative attitudes and prejudices should be constituted by integrative model of social functioning of people with disabilities (p. 126). Kossewska (2003) analyzes the attitude of Polish society towards people with disabilities referring to socialization-acculturation process of transmission of values and rooted in a culture stereotypes and prejudices. She points to the intergenerational transmission of culture as a reason for moving stereotypes and labelling people with reduced abilities. She also takes into account cultural diversity, nationality, as well as the type of dysfunction as factors determining the direction of expressed attitudes. Wałęcka-Matyja (2013) indicates specific to a given culture claims about reality, beliefs and myths, ideologies, social norms, styles of behaviour personal patterns as determinants of attitudes and behaviours towards disability. The author analyzes religious-cultural and cultural-moral factors determining the attitude of non-disabled persons to persons with disabilities.

Many Polish authors in their publications have taken the issues of culture-creating dimension of culture of people with disabilities (including Dykcik, 2001; Żuraw, 2001; Wojciechowski, 2001, 2004; Jutrzyzna, 2002, 2003; Borowska-Beszta, 2008, 2013). Dykcik (2001) sees the cultural activities of disabled people “as the creation of a different lifestyle, organizing environment and cultural experiences of individuals within their cognitive and emotional relationships with their immediate surroundings and the whole world” (p. 33). Żuraw (2001) emphasizing the integration and inclusive nature of participation of people with reduced abilities in culture points to the functions: (1) cultural-synchronization, (2) existentially-subjective (3) of community, (4) compensating-cathartic, (5) creative (6) cognitive, and (7) hedonistic and relaxation (pp. 166–170). Borowska-Beszta (2008) indicates that the participation of people with disabilities in culture has *habilitation functions*, thus it creates the possibility of creative expression, creates the feeling of coherence and gives the everyday life of people with disabilities a creative dimension (p. 111).

Interdisciplinary Disability Studies in Poland

Historical Ground

The major study in special education, called *Interdisciplinary Studies on Disability* was constituted in The Maria Grzegorzewska University in 2016 year. The Maria Grzegorzewska University was established in 1922 as the National Institute of Special Education (PIPS). It was the first Polish university, whose task was not only the training of teachers working with children with disabilities, but also conducting research in the area of special education. The founder and first director of the Institute was the precursor of Polish special education – Maria Grzegorzewska. Among the lecturers and associates of PIPS were

the most outstanding educators of that time – Janusz Korczak, Józefa Jotyeko, Tytus Benni, Janina Doroszevska, Natalia Han-Iglewicz and others. Initially PIPS trained teachers working with four groups of pupils: intellectually disabled, morally neglected, deafblind and blind. Until the outbreak of World War II 660 teachers completed PIPS (Kulbaka, 2012, p. 24), the vast majority were teachers of children with intellectual disabilities (Gasik, 1990, p. 170). During the post-war period gradually another specialty teachers were introduced. They were created in response to public demand (the need to train teachers working with students with a particular type of disability) and as a consequence of the implementation of new research ideas in the field of special education. In 1950, PIPS was transformed into the National College of Special Education (PSPS), then (1976) into the College of Special Education (WSPS) and in 2000 The Maria Grzegorzewska Academy of Special Education (APS) was founded. Since 2011, the English version of the name of the Academy is The Maria Grzegorzewska University.

The activity of University, from its beginning, was a double track: it educated teachers of schools and special institutions but it also conducted research in the field of special education. Thus, University was the first teaching – research institution having actual impact on the shape and scope of the Polish special education. Starting in the academic year of 2016/2017 *Interdisciplinary Studies on Disability* is a continuation of the activities of the school in this area.

General Academic Profile of Study

Starting *Interdisciplinary Studies on Disability* at The Maria Grzegorzewska University is one of the ways to implement the mission of the university – combining educational, scientific activity and ideas of supporting communities in need. This mission is concluded in, representing the motto of the university, words of Maria Grzegorzewska “*There is no crippled – there is the human*”. *Interdisciplinary Studies on Disability* is an independent study of the master degree. It is addressed to graduates of humanities and social sciences of the first degree interested in taking broadly defined practical action aimed on the environment of people with disabilities, as well as considering a career in research in the field of *Disability Studies* and planning to undertake doctoral studies in this area. Graduates of this course can therefore be both a scientist who will create new research constructs in the area of broadly understood research on disability, as well as a practitioner implementing ideas of interdisciplinary understanding of this phenomenon. They will be prepared to undertake discussions on disability in a variety of contexts – educational, legal, social, and will have the power to create and implement solutions aimed at the improvement and normalization of the situation of people with disabilities, and as a consequence – to work towards equality and social inclusion. Graduates will be able to be advocates defending the rights of disabled people, the leaders of introducing and promoting new solutions for people with disabilities, employees of the media, whose actions will affect the social image of people with disabilities and disability specialists working in local communities. The study program uses the long tradition of the university – combining the practical and research issues, taking into account current research constructs.

Modules

Profile of education in *Interdisciplinary Studies on Disability* is created on the basis of six modules: theoretical, medical, research, language, teaching and optional. The issues that form the basis for developing a detailed profile of the faculty, as well as the program of activities, refer to the current state of knowledge in social and health sciences and humanities, they also take into account the relationships between them. A very important objective of this field of study is far-reaching individualization of education. This objective is to be achieved

by creating favourable conditions for making research activities in line with the interests of students, in individual contact with teaching staff. It seems particularly important in the implementation of this assumption to use in classroom tutoring methods (planned for the end of the theoretical module). An innovative solution, which also aims to the process of individualization of studies, is the requirement of submitting by students finishing college – next to thesis – an individual, created through the whole period of study portfolio. Portfolio is to include the effects of the student's work, projects carried out during classes, as well as reflections, thoughts and conclusions resulting from the study. At the same time, in addition to efforts to individualize the learning process, emphasis in the curriculum is located on the shaping of social skills: ability to work in a team, developing communication skills, using skills in working directly with people with disabilities. These activities are aimed at preparing graduates in the most comprehensive way to work for people with disabilities and their communities after graduation.

Conclusion

The article presents an innovative, first in Poland field of education, masters degree – *Interdisciplinary Studies on Disability* in the context of international origins and development of *Disability Studies* and selected constructs of Polish scientific recognition of disability. In the presented and selected constructs of scientific recognition of disability – personalist, normalization and cultural constructs – a new academic approach to disability can be noticed. The authors hope, that expanding the area of scientific knowledge by social, cultural, economic and legal reality of people with disabilities builds a promising perspective for the development of interdisciplinary studies on disability in Poland. This perspective is also built by the establishment of a new general profile of study at The Maria Grzegorzewska University – *Interdisciplinary Studies on Disability*.

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