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## Introduction

### (on the rights of people with disabilities and on the academics with disability – the educational dimension of a certain event)

In the autumn of 2017, while undertaking the commitment to prepare volume 27 of the journal *Problems of Education, Rehabilitation and Socialization of the Disabled* (2/2018), I wondered what slogan should be the leading one for potential authors of the articles. My interests are focused on the women's issues (or, more broadly, gender issues), which I try to combine with social pedagogy, while practicing *gender-sensitive social pedagogy*, therefore I decided it is worth following through in this direction. However, there was an immediate doubt about what topic to choose: women or femininity – in connection with disability. The difference is important. Without getting into detailed explanations, I will promptly say that my choice was the former – women. The reason behind making this decision was the realization of the confluence of dates: 2018 and 1918. The year 2018 is the hundredth anniversary of the Polish women having been granted their rights to vote and stand in elections, obtaining the status of equal citizens. The presented volume of the journal is to be a tribute to women. Those who are citizens,<sup>1</sup> regardless of whether they are fully abled or with some impairment or disabilities, whether they freely pursue their individual reflexive identity projects<sup>2</sup> or em-

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<sup>1</sup> Assuming that they have full legal capacity as citizens. For instance, in the era of migration, it is clearly visible that the citizenship of a given country can be a very desirable good (especially in the context of the European Union citizenship) and not given to everyone; it also has an exclusive character.

<sup>2</sup> On life policy, which is a lifestyle policy, self-realization in a reflexively ordered environment, see Giddens, 2001.

broiled in a relationship of concern,<sup>3</sup> traditionally fulfilling their obligations and meeting expectations ascribed to their role. It is fully justified, therefore, to celebrate the hundredth anniversary of regaining independent statehood in 2018, as well as the centenary of the civil rights won by Polish women.

Instantly, however, a reflection appeared: Was the equal rights of women tantamount to creating conditions allowing them, on an equal footing with men, to use their statutory rights and freedoms? In each and every society, there is a constant struggle between conflicting forces and interests. The interests of women are not always synonymous with the interests of men, and the interests of women from the privileged classes with the interests of women from lower social strata. An example can be the sphere of health care, especially concerning reproductive health.<sup>4</sup> Advertisement campaign for Viagra – the “blue pill” improving men’s sexual potency, produced 20 years ago, which is said to have revolutionized sexual life around the world – does not go hand in hand with the advertisement of a contraceptive pill (still anachronistic). What is more, until today, a contraceptive pill for men has not been invented, even though work has been going on for many years. In corporations managed by men, there is no economic interest in the search for a drug that would limit the sexual freedom of men, impose on them the duty to control their own sexual potency and responsibility for procreation. This responsibility rests almost exclusively on women, and the consequences of the lack of contraception and sexual education in Poland are borne by women, mostly those from the lower social classes. Issues regarding basic women’s rights, their dignity, for example, access to epidural anaesthesia during childbirth, also differs based on social class (access to private medical care or lack thereof).

Creating a comprehensive narrative that would encompass all females, as opposed to all males, is difficult, but not unfounded.<sup>5</sup> Within the category of women there are subcategories (“minorities within the minority”), for example women and girls with disabilities, singles mothers,<sup>6</sup> especially those raising children with disabilities, caregivers of elderly family members with disabilities.

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<sup>3</sup> See Górnikowska-Zwolak, 2015.

<sup>4</sup> See Górnikowska-Zwolak, 2009.

<sup>5</sup> See Mayer Hacker, 1982. “Woman is a Nigger of the World” – a clear slogan, and at the same time the title of the song written by John Lennon and Yoko Ono in 1969 (from the record *Some Time in New York City* of 1972) draws attention to the subordination of women in the masculine, patriarchal world.

<sup>6</sup> These mothers are often classified as single parents, parents raising a child/children alone. But the term single parent can be and is often misleading, as is the concept of a parent. The “parent” category is gender-neutral. What are the proportions of mothers and fathers raising their children alone? How does the material status of mothers and fathers change after divorce? Who uses the parental leave? Whose (which parent’s?) career is determined by having a child? – this type of questions reveal the issue of gender (culturally-shaped expectations towards women and men), which disappears from our view when we use the term parent.

As sociological research show, in Poland the largest social group complaining about the lack of equal treatment are people with disabilities. There are still too many people suffering from violence in the family, with 90% of adult victims of domestic violence being female.<sup>7</sup> It happens that these factors (disability and violence) overlap, leading to an increased risk of threats to the empowerment and security of girls and women – in the absence of legal and institutional protection. Each of the difficult matters, which have a systemic basis, and not an individual character, is bound together with the processes of socialization and education (the missing part thereof – concerning human rights, tolerance, and lessons preparing for life in the family). That is why, teacher trainers, academics representing fields pertaining to upbringing and education, have the responsibility to recognize, identify, diagnose, and submit solutions to problems, as well as to monitor the effectiveness of these solutions. There is a wide range of possible cooperation between social pedagogues, special pedagogues, sociologists, and social politicians. For the benefit of the general population, the key factors, due to their character – both “exclusionary or inclusive”<sup>8</sup> – are institutions and non-institutional social forces that can exert pressure on the elites (intellectual, political, economic), express social expectations, demand taking into consideration different postulates.<sup>9</sup>

Deciding at the beginning of 2018 that the volume should be devoted to women and propounding the title “Women with disabilities and facing disabilities. The issues of education and socialization”, I could not have known that the said year would be marked by the protest of women – mothers of people with disabilities (parents, Parents of Disabled People, hereinafter RON), a protest that the media would call the longest strike of the Fourth Polish Republic (meaning: the longest under the currently governing party). And it would not be a glorious record commemorating the anniversary of obtaining citizens’ rights, although it is exactly about citizenship here. About the recognition of the rights of adults with disabilities and their caregivers (mainly female) to a dignified life in society, about the possibility of functioning according to the same rules and similar conditions as other citizens. The protest began on April 18 and ended on May 27, 2018, lasting 40 days. The place of protest was

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<sup>7</sup> See “Napełn na błędne koła. Rozmowa z dr Sylwią Spurek, zastępczynią rzecznika praw obywatelskich, o tym, czy sto lat po wywalczeniu praw wyborczych dla kobiet wciąż jest o co walczyć” (2018).

<sup>8</sup> Institutions were indicated by the economists from the Massachusetts Institute of Technology, James A. Robinson and Daron Acemoglu, in their famous book entitled *Why Nations Fail*, published in 2012, as a key factor in the success or fall of a nation. Asking about the nature of the institution, either exclusionary or inclusive, they showed the importance of social promotion, possible or difficult (impossible) due to the mechanisms of functioning of dominant classes. See Rafał Woś, 2018.

<sup>9</sup> See Bolton, 2018.

the main hall of the parliament, 18 parents (17 mothers and one father) and their children with disabilities participated in it. As announced, it was the renewal of the protest from 2014.<sup>10</sup> Two main demands and five additional ones were put forward.<sup>11</sup>

The leading figures of the protest were women: its leader – Iwona Hartwich, mother of 24-year-old Kuba, and Anna Glinka, mother of 22-year-old Adrian. Young men, their sons, became ambassadors of the community of people with disabilities.

This 40-day protest campaign was a great lesson for the entire society about the rights of people with disabilities, about their dignity, and also about freedom of speech, the longest lasting and most eminent lesson that took place in the contemporary Poland. As noted by Piotr Zawadzki on the official website of the Stowarzyszenie Strefa Wenus z Milo (the Venus de Milo Zone Association), the occupation of the parliament by people with disabilities and their carers (RON) led to a breakthrough in understanding who the people with disabilities are, changing their image that has been hitherto disseminated (of a disabled superhero athlete or person affected by fate).<sup>12</sup> A voice was given to people who, on a daily basis, face similar problems as the parents who went on strike. Similar stories were told in the mainstream media and heard by those who wanted to hear them and submitted to those who did not want to listen, did not have and still do not have time to take concrete actions.

Although a significant part of the protesters' demands have not been answered to, the effort to perpetuate the protest did not go in vain – it had a powerful educational value. During the protest, all of us – as Polish society, as representatives/members of various groups and environments, and as individuals, free in our decision making and responsible for actions or lack of action – we had the opportunity to reflect on ourselves in this protest action. The image that has emerged is multidimensional, ambiguous, but generally speaking – not very encouraging.

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<sup>10</sup> See timeline of the protest until its 38th day: *Nie odpuścimy. Rozmawia Barbara Jagas*, 2018.

<sup>11</sup> The main demands were: 1. introducing a rehabilitation supplement for people with disabilities, unable to live independently after the age of 18, in the amount of PLN 500 per month without the income criterion, the supplement would not be included in the income of a person with disability; 2. equating the amount of the social pension with the lowest ZUS (the Polish Social Insurance Institution) pension for total incapacity to work, along with a gradual increase of this amount to the equivalent of the subsistence minimum calculated for a household with a person with disability. The content of additional postulates – see *Ibid.*, p. 9. On the policy of the state towards the family in Poland, the social determinants of the introduction (in 2004) of a new social benefit – the caretaker's benefit, which has the character of benefits supporting a family with a child/children with disabilities, writes Bożena Kołaczek. See Kołaczek, 2015.

<sup>12</sup> See <http://www.strefawenusznilo.org/art,76,moje-refleksje-nt-protestu-ron> [access: 27.09.2018].

It is positive and worth emphasizing that the protesting mothers received support from feminist circles. Women's solidarity, so often ridiculed, was visible. It is the solidarity that Maria Janion spoke about in her lecture inaugurating the Warsaw Women's Congress in 2009 as our collective duty. The key here was the awareness of belonging to a community created by women, on whose shoulders falls the burden of caring for persons with various disabilities, the burden of responsibility for the life of their daughter or son. The people in power, driven by the principles of neoliberalism, do not feel the obligation to support mothers and fathers concerned about the fate of their adult children with disabilities. It should also be clearly stated that this community has been consistently disregarded in the political programmes of all factions in power after 1989.

Sister Małgorzata Chmielewska,<sup>13</sup> who fights for the dignity of the excluded, commenting on the protest of mothers of people with disabilities,<sup>14</sup> noticed that it showed not only the "class of the political class," but also the moral level of the society. If the politicians did not feel the public support, they would behave differently. In her opinion, Polish society is not willing to help, the stronger are willing to objectify the weaker. Adult men with disabilities are called children. "We have pushed the weakest people to the margin, giving them a bowl, and a very modest one. However, we do not give them the opportunity to live" – she stressed.<sup>15</sup>

It is not (it cannot be) my intention here to settle accounts with the political elites that are currently in power or in opposition, or the economic elites connected with them. I just want to draw attention to the attitudes of the intellectual elites. And to narrow it down – to the attitudes of the representatives of the academic world, to which I belong, especially that part of it which teaches about sensitivity to human harm on a daily basis, educates about it. I am interested in the voice of social and special pedagogues.

Tadeusz Pilch, currently the honorary Chairman of the Social Pedagogues Group at the Pedagogical Sciences Committee of the Polish Academy of Sciences, the initiator and co-organizer of the Social Pedagogues Congress in 2013, stated powerfully: "If the slogan of social justice is used today in social discourse with a degree of shyness as a category aligned with unrealistic idealism [...] then this situation must be regarded as alarming, requiring rapid opposition and correction of public awareness."<sup>16</sup> Two years later, with passion and zeal, he called for rejection of indifference, for commitment to change –

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<sup>13</sup> The superior of the Catholic community "Bread of Life," in the past she used to work as a catechist to blind children in Laski and in the pastoral care of the blind in Warsaw, she also organized help for women from the prison at Rakowiecka Street in Warsaw.

<sup>14</sup> Statement on the information programme TVN24 of 27 May 2018.

<sup>15</sup> See <http://www.tvn24.pl> [access: 23.07.2018].

<sup>16</sup> Pilch, 2013, p. 25.

repairing a badly functioning world. It is obvious to him that the fight against all evil is a moral duty of the social pedagogy.<sup>17</sup> By perceiving social pedagogy as a system of moral convictions and practical actions, he saw the urgent need to transcend the university halls, to incorporate it into the stream of repair and to build a better world.<sup>18</sup> In May 2018, Pilch, the Chairman of the “Socially Engaged Pedagogues Movement” Association, in the association’s bulletin no. 6(8), addressed the teachers and educators with a dramatic call: “Our voice cannot be muted in the matter of the parents with adult children with disabilities protesting in the parliament. Our voice of solidarity with the suffering, our respect for the legitimate determination of their caregivers, our support for the right of their demands cannot be missing.”<sup>19</sup> The author stated clearly that we must not remain silent in the face of the drama which is taking place in front of the entire country. He paid attention to the indifference and helplessness: “two sides of the same society suffering from a deficit of subjectivity, devoid of the need to engage, less and less sensitive to the evil and harm of the weaker and disaccustomed from reactions and defence mechanisms of civil society.”<sup>20</sup> He reminded us that it is the teachers and educators who build the future through the minds and social forces of the pupils. And that in times of trial we must not be silent, “for whoever keeps silent – agrees; who does not protest – supports it.”

And yet there was silence about the RON strike – which was still ongoing when a large national scholarly conference<sup>21</sup> under the patronage of the Pedagogical Sciences Committee took place – that was the reaction to the drama in the parliament. During the conference debates, in the plenary part with the participation of luminaries of pedagogical sciences, no reference was made to the event, there were no expressions of solidarity or support.

Zbigniew Kwieciński, who has been observing the Polish academic world for years, offers his diagnosis: “[...] in social science environments, there has been profound loss of traditional ethical sensitivity to social issues, issues of social inequality, developmental threats.”<sup>22</sup> Like other pedagogues and social scientists, he notices that the problem of social justice has become less important. Kwieciński speaks of the epidemic scope of indifference of the civic

<sup>17</sup> Pilch, 2015, p. 2.

<sup>18</sup> See Pilch, Sosnowski, 2016, pp. 91–101.

<sup>19</sup> The appeal was posted on the site of ngo.pl, see <http://wiadomosci.ngo.pl/wiadomosc/2177518.html#>

<sup>20</sup> Ibidem.

<sup>21</sup> Ogólnopolska Konferencja Naukowa „Edukacja dla rozwoju – edukacja w rozwoju – teoria i praktyka. Osiągnięcia – ważne perspektywy” (Nationwide Academic Conference “Education for development – education in development – theory and practice. Achievements – important prospects”). Cieszyn, 24–25 May 2018.

<sup>22</sup> Kwieciński, 2012, pp. 271.

academic environment (including youth). According to him, the civil indifference falls into one of three epidemics prevailing in this environment.<sup>23</sup>

An interesting but depressing experience for me was the failure to try to provoke discussion even in a small team composed of a few people. A letter I sent to my colleagues via e-mail on the 33rd day of the strike, accompanied by the bulletin of the Association “Socially Engaged Pedagogues Movement” (containing the appeal by Pilch) and an article about, among others, attitudes of academic teachers, social and special pedagogues, in the face of disturbing phenomena in Polish public life,<sup>24</sup> remained unanswered. The reaction to it was consistent silence. In response to a question asked face-to-face concerning the reasons for this state of affairs, I was offered a few words that would misrepresent the meaning of my own words. The issue of civic involvement was identified with politics and received in categories of private whims, which made taking a stance in this matter unnecessary.

We are ready, bluntly speaking, to “jump on the bandwagon of protest” to take advantage of a loud, compelling topic, but we are not ready to speak out in public. We have separated academic work from life so much that when we see harm being done, we ensure that we are just observing, objectively, conceptualizing the research topic, looking for tools to measure this harm, ways of learning about its subjective perception and preventing adverse phenomena (of which we will make a practical-implementation goal). Polish academics have chosen, in fact, their own position – outside. If we do not want to speak out due to fear that we will become partial in a dispute (by becoming politically involved), then we cannot be surprised that hardly anybody is interested in our opinion, does not invite us to debate about society, which, by the way, seems to worry only a few. People employed in the academic sector in Poland – because it would be difficult to use the term “intellectuals” in relation to the entire environment, let alone “engaged intellectuals” – so busy with navel-gazing, applying for funding projects, and earning points, became silent, mute, and more accurately deaf-mute. They have acquired this disability willingly.

The opinion expressed by the author of a blog signed as socioblogger, on the ethos of researcher, lifestyle and the values of the environment of academic teachers seems justified.<sup>25</sup> Perhaps the name that would describe them more appropriately is employees of the bureaucratic scholarly machine?

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<sup>23</sup> The other two are the commodification of all academic relations and mediatization, that is, the dominance of electronic media over real life.

<sup>24</sup> Górnikowska-Zwolak, 2019.

<sup>25</sup> In his speech entitled *Ethos or ethics of a researcher* (referring to the “Code of ethics of a researcher” adopted by the General Assembly of the Polish Academy of Sciences on December 13, 2012), he notes that researchers “are creating a separate, autonomous environment to a lesser and lesser extent, instead they are more and more similar to the number

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In the presented collection of texts there are no direct references to current social events, but the issues of socialization of people with disabilities are broadly presented – in a modern society, with the dominating discourse of neoliberal economics. There is a deep insight into the content of the Bible (its chosen themes) which is a source of God's law, binding the members of the Christian community, which is also referred to by those who establish public policy rules, the rights of male and female citizens. The cultural message regarding the accepted image of women, on which there is a lot in this collection, is, at the same time, key and oppressive for those who, due to illness, its visible symptoms or effects (physical and mental scars resulting from the treatment of breast cancer) or disability, struggle with a lack of physical attractiveness. Constructing a positive identity is particularly difficult under these conditions.

Relations with medical staff, family members, and a wider milieu are, in turn, some of the issues related to the sphere of education – needed by women with their own disabilities (when dependent on caregivers, may be exposed to violence) or to their pupils: children, including adult children, or foster children, patients of social welfare homes.

The vast majority of the contributions were written by the “academic youth,” both young in terms of age and “younger” in the sense of position in the academic hierarchy. It is worth emphasizing that all those who took part in the project decided to devote their time and energy despite the lack of a measurable award in the form of points for publication. In today's era it is a matter of difficult ethical choice. That is why I am sincerely and deeply grateful to them.

I would like to thank the referees who have made the effort to read and carefully evaluate the texts submitted, indicate fragments requiring alternations or minor corrections, thanks to which the presented articles have improved in their quality.

In closing, I would like to thank the participants of the debate entitled “Rebellion is our duty. Strike of Parents of Disabled People – a strike by women?,” which took place on 22 September 2018 in Kraków, during the conference “Women's Utopia in Action. 100 years of women's electoral rights (1918–2018),” in particular Alicja Jochymek who, along with her daughter, 20-year-old Kinga, took part in the RON protest campaign – for their testimony of struggle for empowerment, dignity, autonomy, and independence. I am grateful to the members of the Venus de Milo Zone Association for empowering girls and women with disabilities, especially for educational work.

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of subjects managed by administrators and bureaucratic structures.” The statement was published on March 9, 2013. <https://socjobloger.wordpress.com/2013/03/09/etos-czy-etyka-naukowca>; <https://socjobloger.wordpress.com/2013/03/09/etos-czy-etyka-naukowca/> [access: 25.09.2018].

I hope that the Readers of this issue of the journal *Problems of Education, Rehabilitation and Socialization of the Disabled* will consider reading it to be interesting, maybe even inspirational.

Elżbieta Górnikowska-Zwolak

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