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Protests of People with Disabilities as Examples of Fledgling Disability Activism in Poland

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Abstract

The article outlines the causes, course and consequences of the protests of people with disabilities and their carers that took place in Poland in 2014 and 2018 respectively. Said protests took a form of occupation of the Polish parliament building. This was intended to draw attention to the considerable difficulties people with disabilities face, as well as to advocate for raising social benefits. We also describe the process of people with disabilities gaining subjectivity and the role of non-governmental organisations and various experts, including but not limited to academics. Moreover, the article demonstrates circumstances to be considered with regards to disability activism. We argue that the systemic transformation that Poland underwent in 1989 and the following years pertained chiefly to matters relating to improving the country's economic situation. This led to civic matters being treated as less of a priority. Subsequently, people with disabilities became one of the marginalised groups. Their incomplete emancipation has hindered the proper application of the principles of the CRPD. The article was co-written by persons with disabilities, who draw on their experiences, and their non-disabled colleagues in academia who are actively engaged in supporting disability activism.

Keywords: persons with disabilities, Poland, activism, protests, disability policy

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Introduction

In recent years disability matters have become increasingly important in Poland. It is likely so because of the social and demographic changes typical of western societies. In particular, we mean the ageing of the population, which goes hand in hand with the higher proportion of people with disabilities, as well as increasing cost of long-term care. Another factor is the diminished care potential of families, which means that they are less able or willing to provide care that they traditionally provided. All of this causes the increase in the cost of disability, both in terms of the expenses incurred and covered directly by families, as well as public spending. It is estimated that direct spending on disability constitute 1.2% of worldwide GDP, while indirect costs of having a disability, although difficult to count, are several times higher (World Health Organization & World Bank 2011, 42–44). In comparison, the overall cost of disability in Poland for the year 2010 was estimated to be between 4.6 and 5.3% of GDP (Marska-Dzioba 2013; Piętka-Kosińska 2012). This drew politicians' attention.

Yet, the economic dimension of disability is not the only important aspect of the discussed phenomenon. The socio-cultural aspect of disability, relating to the definition thereof, as well as the position of people with disabilities in societies cannot be overlooked. In countries like the UK, initiatives intended to alter perceptions of disability are dated as early as the 1970s (UPIAS 1976). Poland, in turn, took 20 years to join the countries of the West in a very gradual and often difficult process of shifting from the medical model of disability

towards the social model thereof (Oliver 2013), or its alternatives (Degener 2014; Shakespeare 2013, 72–91). However tardy and slow this process might be, it is an important one, as it moves from the narrative of individuals' impairments and deficits, to one emphasising disabled people's right to have the same opportunities and enjoy the same privileges as the non-disabled majority.

It is important to note the relative lack of power of grass roots organisations of disabled people in Poland, where these organisations are few and far between and as such have had limited impact on public debate. These organisations have, however, exerted indirect influence, typically by working alongside other institutions, or exposing cases of gross negligence towards people with disabilities. More influential in making change in Poland were the non-governmental organisations *for* disabled people - rather than organisations led by and employing people with disabilities, and policy changes. Some of the latter resulted from Poland being a member of the European Union. On the one hand, these factors allowed to partly make up for Poland's delay, as well as ratify the CRPD in 2012. Still, on the other hand, they meant that the minority of roughly 4.7 million people¹ with disabilities in Poland, as per the National Census published by Statistics Poland (Główny Urząd Statystyczny) in 2013 has not produced any organisations that were strong and financially stable enough to represent said minority as equals in dialogue with the government. NGOs have been a party that has a considerably weaker position in this dialogue, as they depend on government funding, and have few experts backing them.

The purpose of this article is to analyse two sit-in protests of people with disabilities and their carers to explore the reasons behind the relatively weak position of the community of people with disabilities. The manuscript is divided into three main parts. The first part reviews the historic conditions, as well as the impact of ratifying the CRPD. The second part is a fairly detailed outline of the protests taking part respectively in 2014 and 2018 and the differences between those protests. The third and final part is discussion. We believe that the most important elements of our paper are: exploration of a) the newest developments in the perceptions of disability matters; b) the change of the model of disability from the medical to one based on human rights; c) the role of grass roots activism in that process.

¹ 12.2% of the population.

People with Disabilities in Poland - Between Socialism and the CRPD

The second decade of the 21st century in Poland has seen more protests from people with disabilities and their families than ever before. In fact, we do not just mean protests as separate events within the space of time. Instead, one could say that a protest movement - or movements - emerged. They led to a variety of actions, such as recurring street demonstrations², the sit-in protests in the Polish parliament building in 2014 and 2018, and a protest of carers of adults with disabilities outside the parliament building. Aside from those well-publicised events, a lot of smaller actions have been taken. These included many petitions, statements, attempts at advocacy, education and consolidation of people with disabilities movement by means of the Internet and social media. However, the sit-ins and their sister protests outside the parliament in 2014 and 2018 were most momentous. Due to their dramatic course - children and young adults with disabilities spending a number of days at a time on cold floors to try to draw attention to the adversity of their situation - as well as thanks to media coverage, the people who had neither experience nor knowledge of the hardship faced by people with disabilities and their families, became aware of it.

It is important that the main focus of the protests in 2014 was securing the parents / carers financial stability. The later protests emphasized the rights of people with disabilities and the need for greater financial support afforded to people with disabilities themselves. The protests were also interwoven with the instances of more or less confrontational dialogue between disability advocates and the government (Bakalarczyk 2016). Those attempts of advocacy pertained to various aspects of life of people with disabilities and their families. Aside from financial security, another important theme having been advocated for were educational rights (Kubicki 2016). The dynamics of dialogue and protests was also affected by institutions that shape public policy but are independent from the government. In particular we mean the Constitutional Tribunal and its verdicts. The verdicts deemed some provisions around the social security benefits for carers of people with severe disabilities as breaching the constitution. Thus, the advocates endeavoured partly to fix the faulty provisions

² These were particularly numerous in the 7th term of the parliament, when a Civic Platform and Polish People's Party coalition was in power. Yet, they continued with lesser intensity into the 8th term of the parliament.

(Bakalarczyk 2015), which would in itself alleviate some of the adversity suffered by people with disabilities and their families.

The situation of people with disabilities in Poland is a resultant of historic factors, relating to the country's socialist past (Rasell i Jarskaja-Smirnova 2016) on the one hand and an economic and systemic transformation of 1989, with the neoliberal reforms that it engendered on the other. Postsocialist disability matrix (Mladenov 2017, 2015) is relevant here. Yet we are adding to Mladenov's two analytical dimensions of state socialist legacy and postsocialist neoliberalization a third one. Namely the growing influence of ratifying the CRPD in 2012. Said ratification affected public discourse, regulations as well as the ways in which upholding the rights of people with disabilities is monitored. Reports on the implementation of the CRPD form one example of such monitoring (Zadrożny 2015; Biuro Rzecznika Praw Obywatelskich 2015; Kubicki 2017, 120–25; McRae, Szarota 2018). Crucial to the successful practical application of the CRPD were regulations on disbursing EU subsidies in a fashion that is non-discriminatory and allows equal opportunities. These rules emanate directly from the CRPD itself (Daniłowska i in. 2015). It seems that particularly in the context of the EU member states, the CRPD provided people with disabilities with new options to articulate their needs, so this is by no means specific to Poland (Sturm i in. 2017; Waldschmidt i in. 2017).

The most recent "tool" for exerting influence on the Polish government, in relation to implementing the CRPD is the document by the Committee on the Rights of Persons with Disabilities, entitled *Concluding observations on the initial report of Poland* and published on 29 October 2018³. In it, the committee offers a number of valuable insights, such as: pointing out the lack of strategy for implementing CRPD; the lack of relevant statistics; the need for: i. paradigm shift from a charity model to the human-rights model of disability; ii. closer cooperation with the community of people with disabilities; iii. changes to disability adjudication system and iv. clear endorsement of deinstitutionalisation. Still, at present it is difficult to predict whether said paper would bring about a breakthrough in disability policy or rather remain one of the many documents outlining the appropriate course of action. Another

³ CRPD/C/POL/CO/1,

https://tbinternet.ohchr.org/_layouts/treatybodyexternal/Download.aspx?symbolno=CRPD%2fC%2fPOL%2fCO%2f1&Lang=en

useful analytical framework is that of three-dimensional social justice (Fraser 2013). This refers to the following dimensions of participation in public life: economic, cultural and political. In this context, the trajectory of disability could also be seen as the trajectory of social exclusion, understood as a threefold deprivation: of assets, of rights and of participation. Significantly, deprivation of one of these aspects, leads to decreased availability of the other two (Karwacki 2014, 233–34). In turn, fulfilling one's needs to the greatest possible extent in all of these three aspects would allow for both attaining social justice and breaking the trajectory of social exclusion relating to disability.

The main aspect of the state socialist legacy (see also table 1) is the domination of institutional care, which segregates and thus separates people with disability from the non-disabled majority. Notably, many non-disabled experts and professionals, as well as politicians making decisions about supportive measures available to people with disabilities tend to equate supporting this group with such segregated institutionalisation and thus think it the most appropriate way of containing the issue of disability.

That is not to say that the process of deinstitutionalisation and supporting independent living has not started, but it is very gradual, which means that the main conclusions of the 2011 report are still relevant: The problem with the current provisions is very complex. Firstly, the government does not implement "(...) *modern solutions like personal budgets, direct payments, individual budgets, respite services.*" (Wapiennik 2009, 2), to name but a few. Secondly, it is often argued that the provisions that are already in place lack synergy. Thirdly, while there are NGOs which endeavour to support people with disabilities, they are few and far between. This, in turn, means that whether a person with a disability gets the support s/he needs will depend on where s/he lives. Consequently, many people with disabilities in Poland have no viable alternatives to living in an institution.

In relation to economic distribution, the CRPD effect is still largely declarative and has had little if any impact on the everyday life of people with disabilities. Yet, one can see a slow move away from both segregation and neoliberal attitudes. As a matter of fact, retrenchment policy has never been as robustly implemented in Poland as in other countries. It appears, however, that the main obstacle to applying the principles of CRPD is *not* the state socialist legacy, or the liberal economic transformation, but familialism of Polish social policy (Szelewa 2017). Such an approach proposes that the family is the main unit responsible for the welfare of its members and it should be the primary provider of care. This is at odds with

the values of the convention, which emphasises the individual rights of people with disabilities. Thus, a gap can be observed in the support system: between the family and the segregating institutions providing the round-the-clock care.

The medical model of disability is especially prevalent in disability adjudication system. The main purpose of said system is to deem people unfit for work and, in some cases, independent functioning (Radlińska, Bażydło, i Karakiewicz 2014). It is worth noting, that the adjudication system was set to undergo changes in the last quarter of 2018. Still, as of January 2019 its final form remains unknown. Conversely, the aspect of the experience of having a disability that has been most influenced by the new attitudes based on human rights and the social model of disability, is cultural recognition. This was particularly visible in the protest of 2018, which raised the profile on disability matters and challenges faced by people with disabilities to an unprecedented level. We expand on that in the next part of the manuscript.

Table 1. Postsocialist Disability Matrix

	State socialist legacy	Postsocialist neoliberalization	CRPD effect
Economic Redistribution	Segregated service provision: <ul style="list-style-type: none"> • Sheltered workshops • Residential institutions 	Restructuring and reducing social support: <ul style="list-style-type: none"> • Decentralization • Benefit cuts • Workfare 	Pointing out subjectivity and right to choose; emphasis on employment in the open market, but also support for independent living
Cultural Recognition	<ul style="list-style-type: none"> • Medical-productivist understanding of disability (codified in disability assessment systems) • Denial of disability (on the everyday level) 	<ul style="list-style-type: none"> • Stigmatization of social assistance and 'dependency' accompanied by promotion of self-sufficiency • Responsibilization 	Social model of disability; pointing out the barriers that people with disabilities face in everyday life as the disabling factors,
Political Representation	Weak civil society – suppression of counter publics and counter discourses	Depoliticization through: <ul style="list-style-type: none"> • Restriction of civil society to service provision 	Presence of people with disabilities in the public debate; "nothing about us without us" attitude; attempts to influence legislation

		• Token (quasi-corporatist) participation	
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Source: (Mladenov 2017, 113), with the addition of CRPD effect by the authors

It is important to note that even though the CRPD and the protests led to increased political involvement on the part of people with disabilities, such involvement remains relatively low overall. This might be partially caused by the fact that in Polish there is no distinction between politics and policy. Thus, campaigning for one's rights is often frowned at and wrongly viewed as engaging in political games, intended to further the agenda of either the government or the opposition. In line with that, the protesters of 2014 and 2018 had actually had to face such accusations. Therefore, while the need for the political involvement of people with disabilities is paramount, it is more declarative than factual. In this way, the situation in Poland is very different than the UK or the USA, where people with disabilities are a leading force in bringing about the needed changes: *Avoiding politics might be possible if disability were an exclusively private affair. But it is fundamentally a public concern, affecting everyone directly or indirectly and revealing our obligations to one another as members of a democratic society. Issues of accessibility can be fully addressed only through public institutions and collective effort. For the disability community, there is no answer but politics.*⁴ It seems that little involvement of NGOs in politics relates to both being financed from the public purse and service provision being their main purpose. They are only indirectly involved with disability rights. As a result, the consensus model of NGOs is dominant, not the conflict-based, rights model of disability activism. That has not changed significantly since a 2008 review of NGO activity in central and eastern Europe (Holland 2008), where the above-mentioned classification of NGOs was proposed. Significantly, Holland's review pre-dates the ratification of the CRPD by Poland. Still, it remains relevant, as there are, sadly, no reasons to believe that there could be any changes for the better in the near future.

⁴ Ruckelshaus, J. (2017). The Non-Politics of Disability, *New York Times*, https://www.nytimes.com/2017/01/18/opinion/denouncing-trump-wont-help-disability-rights.html?_r=0, accessed: 24 July 2018.

The 2014 Protests of People with Disabilities and Their Carers

One could view the protests that took place in Poland in 2014 and 2018 from two distinct perspectives. The first perspective is that of parents fighting for their children's rights (Walmsley et al. 2017; Burke et al. 2018). The other is that of somewhat forcibly getting the government to consult the provisions for people with disabilities. The latter pertains to article 4 of the CRPD. The protest of 2014 started when some of the parents and carers of people with disabilities decided to remain in the parliament building after a press conference held on 19 March 2014. Their decision was motivated by the fact that lengthy negotiations to increase the carer's allowance had been unsuccessful⁵ (Bakalarczyk 2015). The main focus of the protest was financial. Yet, protesters had a variety of demands⁶, such as ratifying the optional protocol to the CRPD. In the end, only one demand was met: increasing the carers allowance for carers of children with disabilities, and other persons whose disability occurred before they turned 18 - or 25, if they continued their education. This was secured in an act amending the act on family benefits, of 24 April 2014 (Journal of Laws from 2014, item 559).

Shortly after the protest inside the parliament building started, carers of adults with disabilities began a demonstration⁷ outside the parliament - because they would not be let inside. Despite similar demands, to increase the social security benefits they were receiving, their manifestation did not garner comparable attention from the media or the politicians. In fact, the demands of the carers of adults with disabilities had not been met in 2014 or later. This is interesting in terms of the process of shaping public policy and putting the problem on political and media agendas. Invoking multiple streams framework, (Kingdon 1995), one could say that these streams - the protests within and outside the parliament - met very briefly, and the window of opportunity closed particularly quickly.

The 2014 occupation of the parliament had both direct and indirect results. The former included increasing the carers allowance for the carers of minors with disabilities. The latter

⁵ Importantly, adults with disabilities supported the carers of children with disabilities in said negotiations.

⁶ The first draft of the document comprised of 29 demands and it was created in 2015 on the basis of the demands of the March 2014 protest. In 2016 the list was edited, and similar demands were merged. Thus, the number was reduced to 21. The protesters of 2018 raised the same demands again, but the media and the public focused on the demands that were crucial to ending the protest. <https://www.facebook.com/notes/ron-rodzice-os%C3%B3b-niepe%C5%82nosprawnych/postulaty-cz%C4%99%C5%9Bci-%C5%9Brodowiska-os%C3%B3b-niepe%C5%82nosprawnych-w-stopniu-znacznym/944130795670067/>

⁷ See: <http://www.niepelnosprawni.pl/ledge/x/181182> (accessed on 24 July 2018)

consisted chiefly of initiating a more consistent dialogue between the government and representatives of the families of people with disabilities. Another consequence of the protest was sensitising the public to the dire situation of those families. Expectations of at least part of this community with regards to the amounts paid out in social security benefits became widely known, thanks to this protest (Kończak 2014).

In turn, the self-proclaimed protest of the excluded carers of adults with disabilities focused heavily on the central demand: increasing their carer's allowance. While the demands voiced by the protesters within the parliament were also echoed, they were never items in their negotiations with the government. One could then say that and the aim of the group protesting outside did not relate to disability matters nor the rights of people with disabilities. Instead, they accentuated the loss of previously acquired rights, social injustice and the need for equal treatment of people in similar circumstances. In this particular context we mean carers whose loved ones acquired a disability at different stages of their lives. Other issues raised were the social exclusion of carers of adults with disabilities and inadequate funds to support themselves and their families. Thus, they demanded mainly two things. Firstly, the restoration of eligibility for carers allowance, which they had previously held, but lost in 2013. Secondly, in relation to the first point, they stipulated that all carers should be eligible for benefits, regardless of when their charges acquired a disability.

Polish regulations have differentiated the amount of the benefit available and the eligibility criteria depending on whether a disability occurred before or after the person with a disability turned 18 - or 25 if they remain in school. Similarly, if a person was forced to take early retirement to care for his or her child with a disability, they would not be eligible for the carer's allowance. Thus, the reference point for the carers of adults with disabilities was the level and conditions of support enjoyed by carers of people with disabilities whose disability started during childhood. Both protests were not only akin to one another in some respects, but also related. The fact that they started at similar points in time was not accidental either. The carers of adults with disabilities started their improvised tent site thanks to the encouragement provided by the sit-in protest that was already taking place within the parliament. Another factor that emboldened them, was the attention from the media and the politicians. In fact, the then-PM, Donald Tusk, promised the original protesters that the carer's allowance would, over a period of a few years, be brought into line with the minimum wage (Bakalarczyk 2015).

As we have pointed out before, the protesters outside the parliament did not receive analogous assurances. It could be that the sheer occurrence of two protests at the same time and the fact that their leaders have, at times, confronted one another, hindered the resolving of the issues raised by means of the second protest. Arguably, there were factors other than the order and place the protests occurred that influenced the results of said protests. The protest of parents and carers of children with disabilities could have garnered more attention, because problems of children tend to be perceived as more moving than those faced by adults and / or elderly people. Moreover, the first protest had the main demand that was easier to articulate and explain to the media and public opinion: it was about bringing the carer's allowance into line with the minimum wage. Conversely, to understand the aim of the second protest, one had to look more closely at the differences within the community of families and carers of people with disabilities. These differences seem counter-intuitive, especially considering that they are *not* based on the age of a person with disability, *but* the age they were when they acquired the disability, as well as other factors, e.g. whether or not a carer of a person in question opted for early retirement. This differentiation is lasting to this day, despite the fact that in 2014, after the protests, the Constitutional Tribunal deemed it to be in breach of the constitution and requiring amendment (case no. K 38/13).

Aside from influencing public opinion and campaigning for new regulations, the protests led to a new format of dialogue on disability matters. This took a form of regular meetings between the representatives of the government and people with disabilities, their families and organisations speaking on their behalf. These meetings were entitled "Round-table on supporting people with disabilities". They featured five panels based on different themes. The community representation included both the representatives of the two protesting groups, as well as e.g. advocacy and self-help organisations. Many tensions surfaced during these meetings and not just between the government and the community. There were marked differences in perspectives and expectations within the community representation. The differences did not only occur between the carers of adults and children, but also with other parties. Neither did the round-table discussions follow a road map nor was there a genuine political will to implement changes, so there was little hope for this process to produce any tangible results.

The community representation, and in particular members of academia involved in the process, voiced a number of reservations about the way in which those meetings proceeded.

Said reservations included: lack of synergy between the five panels; difficulties the members of these panels had in accessing the work of other panels; lack of transparent reports on the proceedings and / or conclusions from the individual meetings (Bakalarczyk 2016). The round-table discussions ended with the change of government in late 2015, even though new themes for potential discussions emerged, e.g. relating to the consultations⁸ on the "Pro-life" government programme (MRPiPS, 2016). However, the programme itself, adopted by the resolution of the lower chamber of parliament in late 2016, was not concerned with supporting people with disabilities or their carers in a sustained fashion. As such, it did not address the issues previously brought up by the protesters.

The 2018 Protest of People with Disabilities and Their Carers

The 2018 protest proved to be another crucial event. There have not been many scholarly or expert reports on it, because it was recent. Yet, even during the protest, there were plenty of media comments. This protest centred around two main demands: 1) bringing the social allowance into line with the lowest rate of the full incapacity allowance⁹; 2) introduction of a monthly rehabilitation allowance of 500 PLN to adults whose disabilities have been assessed as severe. The protests of 2014 and 2018 are alike in terms of focusing primarily on financial demands. Still, the differences between those protests are also noteworthy. These differences were partly due to the structure of the demands, but also due to other factors.

In 2014 it was the carers perspective and experiences that were at the forefront. That held true for both the protests within and outside the parliament building. Conversely, in 2018, the input of the protesters with disabilities was as important as their carers'. Not only was this difference visible in the content of the protest, but also in who took the floor. In 2018, unlike before, people with disabilities spoke about the demands and problems they faced. Different

⁸ <http://www.zazyciem.mrpips.gov.pl/>

⁹ In Poland there are two different benefits that people with disabilities can claim depending on their circumstances. If their disability occurred before the age of 18 - or 25 if they remain in education - they would claim "renta socjalna" (social allowance). If they had been in employment before their disability occurred and their disability prevents them from doing any work, they would be eligible for "renta z tytułu całkowitej niezdolności do pracy" (full incapacity allowance). The amount of the latter allowance is proportional to their social insurance contributions, but always higher than the social allowance

issues were accentuated in the protest of 2018 as well. Active participation of people with disabilities allowed for framing the demands in terms of the rights of people with disabilities. The dispute between the government and the protesters concerned the mode of delivery of this additional support. The government suggested in kind support, by means of priority access to doctors and other specialists, which points to the fact that the government's approach to disability is still based on the medical model of disability. This also raises a number of questions, relating e.g. to whether or not the government would actually be able to fund the services suitably for them to be able to cope with increased demand, but even more importantly to the subjectivity and agency of people with disabilities.

The 2018 protest had had an unprecedented public support and impact on public debate. There were numerous support events, both in Warsaw, outside the parliament building, in other cities and towns, as well as in the social media. It seems that the response from the public was considerably higher in 2018. This could be partly due to somewhat different political and media landscapes, compared to 2014. These support events were also attended by people with disabilities, but they were mostly organised by people, organisations, and groups that are not ordinarily involved in disability activism. Feminist groups such as All-Poland's Women Strike and Warsaw's Women Strike were among the chief organisers of these support events¹⁰. A play entitled "Rewolucja której nie było", meaning „Revolution that did not happen” could serve as an example of artistic continuation of the dialogue kickstarted during the protest. Authors of the performance asserted that said performance is not a mere reconstruction of events. Rather than that it is a play upon the meanings and emotions invoked by the protest in the parliament. The protest, followed by entire Poland, left us not only with disillusionment and proof of the marginalization of people with disabilities, but also with physical artefacts, such as banners, letters and postcards written both to and by the protesters. These will be utilised in the “Revolution that did not happen” to pose questions about the image of people with disabilities in Poland, but also to explore whether the community of people with disabilities can come together to fight for their common goal.¹¹

¹⁰ <http://warszawa.wyborcza.pl/warszawa/7,54420,23359191,protestuja-pod-sejmem-wspierajac-strajk-okupacyjny-ron-rzad.html?disableRedirects=true>

¹¹ <http://teatr21.pl/en/spektakle/rewolucja-ktorej-nie-bylo>, “Teatr 21 [Theatre 21] was created in 2005 from drama workshops at the Community Special School Complex “Dać szansę” [Give a chance] in Warsaw. The team of actors consists primarily of students and alumni of the school complex who have Down syndrome and autism. What started off as playing at theatre has since become gainful employment.”

Table 2. Selected differences between 2014 and 2018 protests

	Protests of 2014	Protest of 2018
Protesting group	Parents of people with disabilities, with their children (the protest inside the parliament building) Carers of adults with disability (the protest outside the parliament building)	People with severe disabilities and their parents
Key demands	<ul style="list-style-type: none"> a) Bringing the carer's allowance into line with the minimum wage (the protest inside the parliament) b) Equating the amount of carers allowance regardless of when the carers' dependants acquired their disabilities (the protest outside the parliament) 	<ul style="list-style-type: none"> a) Bringing the social allowance into line with the lowest full incapacity allowance; b) Introduction of rehabilitation allowance at 500 PLN per month for adults with severe disabilities
Nature of demands	Financial: allowances for carers	Financial: allowances for people with severe disabilities
Extent of realisation of demands	<ul style="list-style-type: none"> a) Gradual realisation of the main demand of those protesting within the parliament b) Demands of the protesters from outside the parliament not realised at all 	<ul style="list-style-type: none"> a) Realisation of the first demand b) Lack of satisfactory realisation of the second demand.
Level of interest from the media and politicians during the protests	High (the protest inside the parliament), limited (the protest outside the parliament)	Very high

Source: authors' own work

Discussion

The 2014 and 2018 protests of people with disabilities and their carers show the extent of the influence they can exert on public policy in Poland. At the same time, assessing the scale of the impact depends on its definition. On the one hand, if it means something tangible, such as legislative change, impact is very limited. On the other hand, if it means social changes, such as a difference in attitudes towards disability and people with disabilities, the impact is considerable. This is particularly impressive if one takes into account limited

resources at the disposal of people with disabilities. The protests, as well as the actions of their participants between the protests, have likely been important in creating the movement demanding changes to support available to people with disabilities.

It seems that the dissonance between the failure to bring about legislative changes and the successful influencing of attitudes, lies in the fact that people with disabilities, and the organisations that represent them have limited resources to communicate their suggestions and needs to the government. Thus, the only way to open the window of opportunity or, more specifically, garner the political will to improve the situation of people with disabilities is to protest. This focuses the attention of the media and the public and forces politicians to respond.

Other actions are less effective. This is partly due to the fragmentation and isolation of the community of people with disabilities and partly because of them being preoccupied with tackling their everyday problems. Organisations of experts working on behalf of people with disabilities and academics are relatively strongest. The former, however, do not always include people with disabilities in their ranks. Furthermore, both experts and academics "can afford" to offer a more distanced perspective on disability matters because they have the human, social and economic resources not to worry about the barriers routinely faced by the majority of people with disabilities. Because of that they tend to think in a way that is cross-sectional and strategic.

Yet, both those groups have limitations of their own. NGOs for people with disabilities are heavily dependent on state funding, which means that they are afraid to start an open conflict with government or local authorities, for fear of losing their income and not being able to function. The non-existence of advocacy and watchdog organisations resembling Disability Rights UK¹² in the character, but especially the scale of operations is starkly visible. In turn, what hinders the members of academia from taking a more active part in influencing the status quo is their conviction that they should not conflate policy with politics. In other words, they advocate detachment from their research subject and limiting their work to describing problems, and possibly recommend solutions. Direct involvement, and / or lobbying is usually outside the scope of their interests. It is worth noting, however, that this distancing on the part of the academics is gradually changing. More and more

¹² <https://www.disabilityrightsuk.org/>

academics have been admitting either to having a disability or identifying as allies of people with disabilities. For example, a recent issue of "Studia de Cultura" academic journal consisted, in its entirety, of articles written by representatives of disability studies and the movement of people with disabilities (Pamuła, Szarota, Usiekiewicz, 2018).

At the same time, the mode of the protest - a sit-in - meant that both the demands and the opportunity for dialogue with the government were limited. This was because protesters had to rely on the opposition MPs, who were the only people who could move around the parliament freely. The reliance on the opposition MPs allowed the government to present the protest as a cynical attack on the ruling party and it affected the media discourse. This is significant, because Polish public feels deep hostility towards politics and party games or political tactics intended to score points¹³. Paradoxically, then, a sit-in was the only way to get the attention of the government, but at the same time it made academics, politicians, and NGOs uncomfortable - as they were forced to react and unable to maintain detachment. Such coercion resulted in the dialogue only relating to isolated demands, rather than working towards a long-term strategy or a systemic plan for improving the situation of people with disabilities.

One could say that the communities of people with disabilities are in the state of unfinished emancipation. This is partly a result of the economic and systemic transformation of 1989, but it was mostly affected by the ratification of the Convention on the Rights of People with Disabilities. The Convention brought about an understanding of disability based on human rights. However, what the CRPD did not accomplish, was introducing an adequate institutional base. This was because most institutions were created, and experts acquired their expertise at a time, when the medical model of disability was dominant. Moreover, for many of the people with disabilities in Poland, a relatively dignified life is synonymous with the support provided by their family, which further reinforces the familialism of the social policy. Consequently, the portion of disability activists who live independently is relatively small. At

¹³ In this context, it is significant, that in the autumn of 2018, one of the protesters, Jakub Hartwich, ran a successful campaign to become a member of Toruń's city council. This caused backlash from other protesters, because some of them did not want to be associated with any political party. Talking to TVN24, Hartwich said "The forty-day long protest made me realise that I want to have real say on what is happening in my city, in the local authorities (...) I am glad that Civic Coalition gave me that opportunity, I am thankful to them that they enabled me to advocate for people with disabilities, change their lives for the better". He also claimed, however, that being on this particular party's electoral ticket was of lesser importance to him than being able to exert his influence (see <https://wiadomosci.wp.pl/protestowal-w-sejmie-jakub-hartwich-zostal-radnym-6309029686294657a>)

the same time, the disparity between the declarations, as well as regulations derived from the CRPD and the daily life of people with disabilities keeps growing, leading to conflicts. Thus, one can expect more protests of people with disabilities, but one can also pessimistically assume that they are not likely to bring about a tangible improvement to the lives of people with disabilities.

Looking for an optimistic conclusion, it is worth pointing out that the upcoming parliamentary elections, scheduled for autumn 2019, will test the effects of the protests. It is possible that the topic of disability will be a talking point of the nearing campaign. More importantly, it is also possible that people with disabilities will be spoken about in a more subjective manner that would be in line with the social model of disability. If that proves to be the case, one will be able to say that the impact of the protests was much bigger and more important than it would seem from focusing chiefly on the failure to bring about legislative change.

References

- Biuro Rzecznika Praw Obywatelskich. 2015. Realizacja przez Polskę zobowiązań wynikających z Konwencji o prawach osób niepełnosprawnych. Sprawozdanie Rzecznika Praw Obywatelskich. Warszawa: Biuro Rzecznika Praw Obywatelskich.
- Bakalarczyk, Rafał. 2015. „Polityka wsparcia rodzin z osobami niepełnosprawnymi. W cieniu wyroków Trybunału Konstytucyjnego RP i protestów społecznych”. *Studia z Polityki Publicznej* 1(5): 63–80.
- Bakalarczyk, Rafał. 2016. Dialog i konflikt rządu z nieformalnymi opiekunami osób niepełnosprawnych. Zybala A. (ed.) *Polska w dialogu. Tradycja. Zmiany. Porównanie. Perspektywy*, Centrum Partnerstwa Społecznego, Warszawa.
- Burke, Meghan M., Linda Sandman, Beatriz Perez, Meghann O’Leary. 2018. „The Phenomenon of Legislative Advocacy among Parents of Children with Disabilities”. *Journal of Research in Special Educational Needs* 18 (1): 50–58.
<https://doi.org/10.1111/1471-3802.12392>.
- Daniłowska, Sylwia, Agata Gawska, Bartosz Kostecki, Justyna Kosuniak, Piotr Kowalski, Paweł Kubicki, Joanna Miela et al.. 2015. *Realizacja zasady równości szans i niedyskryminacji, w tym dostępności dla osób z niepełnosprawnościami. Poradnik dla realizatorów projektów i instytucji systemu wdrażania funduszy europejskich 2014-2020*. Warszawa: Ministerstwo Rozwoju.
- Degener, Theresia. 2014. „A human rights model of disability”. *Disability Social Rights*.
- Fraser, Nancy. 2013. *Fortunes of feminism: from state-managed capitalism to neoliberal crisis*. Brooklyn, NY: Verso Books.
- Główny Urząd Statystyczny. 2013. *Ludność: stan i struktura demograficzno-społeczna: Narodowy Spis Powszechny Ludności i Mieszkań 2011*. Warszawa: Zakład Wydawnictw Statystycznych.
- Holland, Daniel. 2008. „The Current Status of Disability Activism and Non-governmental Organizations in Post-communist Europe: Preliminary Findings Based on Reports from the Field”. *Disability & Society* 23 (6): 543–55.
<https://doi.org/10.1080/09687590802328337>.
- Karwacki, Arkadiusz. 2014. „Usługi reintegracji społecznej. Istota, procedury, problemy”. [in:] *Reintegracja: aktywna polityka społeczna w praktyce*, przez Arkadiusz Karwacki, Tomasz Kaźmierczak, and Marek Rymśza. Warszawa: Fundacja Instytut Spraw Publicznych.
- Kingdon, John W. 1995. *Agendas, alternatives, and public policies*. 2nd ed. New York: Longman.
- Kołaczek, Bożena. 2014. Świadczenia pielęgnacyjne dla opiekunów dzieci niepełnosprawnych - funkcje społeczne i ekonomiczne, *Polityka społeczna*, 4: 21-27.
- Kubicki, Paweł. 2016. „Między włączaniem a segregacją - szkoły w Polsce wobec uczniów z niepełnosprawnościami”. *Niepełnosprawność. Dyskursy Pedagogiki Specjalnej* 22: 107–118.

- Kubicki, Paweł. 2017. *Polityka publiczna wobec osób z niepełnosprawnościami*. Warszawa: Oficyna Wydawnicza SGH Szkoła Główna Handlowa.
- Marska-Dzioba, Natalia. 2013. *Racjonalność wydatków publicznych przeznaczonych na integrację osób niepełnosprawnych w Polsce*. Szczecin: volumina.pl Daniel Krzanowski.
- McRae, Amanda., Szarota, Magdalena., (2018). Shadow report about the situation of the Polish girls and women with disabilities for the UN CRPD Committee https://tbinternet.ohchr.org/_layouts/treatybodyexternal/Download.aspx?symbolno=INT%2fCRPD%2fCSS%2fPOL%2f31934&Lang=en
- Mladenov, Teodor. 2015. "Neoliberalism, Postsocialism, Disability". *Disability & Society* 30 (3): 445–59. <https://doi.org/10.1080/09687599.2015.1021758>.
- . 2017. „Postsocialist Disability Matrix”. *Scandinavian Journal of Disability Research* 19 (2): 104–17. <https://doi.org/10.1080/15017419.2016.1202860>.
- Oliver, Mike. 2013. „The Social Model of Disability: Thirty Years On”. *Disability & Society* 28 (7): 1024–26. <https://doi.org/10.1080/09687599.2013.818773>.
- Pamuła, Natalia., Szarota, Magdalena., Usiekniewicz, Marta. (red.) (2018). *Studia de Cultura*, 10 (1). <http://studiadecultura.up.krakow.pl/issue/view/337>
- Piętka-Kosińska, Katarzyna. 2012. „Koszty niepełnosprawności”. *Polityka Społeczna*, 2T: 57–61.
- Radlińska, I, M Bażydło, B Karakiewicz. 2014. „The rights of persons with disabilities in Poland”. *Journal of Public Health, Nursing and Medical Rescue* 121 (2014_4): 25–30.
- Rasell, Michael, Elena R. Jarskaja-Smirnova, ed. 2016. *Disability in Eastern Europe and the Former Soviet Union: History, Policy and Everyday Life*. 1st issued in paperback. BASEES - Routledge Series on Russian and East European Studies 94. London New York: Routledge.
- Shakespeare, Tom. 2013. *Disability Rights and Wrongs Revisited*. 2nd edition. London; New York: Routledge.
- Sturm, Andreas, Anne Waldschmidt, Anemari Karačić, Timo Dins. 2017. „Exercising influence at the European level: Political opportunity structures for disability rights advocacy and the impact of the UN CRPD”. *The Changing Disability Policy System: Active Citizenship and Disability in Europe* 1: 159–76.
- Szelewa, Dorota. 2017. „From Implicit to Explicit Familialism: Post-1989 Family Policy Reforms in Poland”. W *Gender and Family in European Economic Policy*, zredagowane przez Diana Auth, Jutta Hergenhan, i Barbara Holland-Cunz, 129–51. Cham: Springer International Publishing. https://doi.org/10.1007/978-3-319-41513-0_7.
- UPIAS, From. 1976. „Fundamental principles of disability”. Reprinted in edited form in M. Oliver, *Understanding Disability: From Theory to Practice*, 19–29.
- Waldschmidt, Anne, Andreas Sturm, Anemari Karacic, Timo Dins. 2017. „Implementing the UN CRPD in European countries: A comparative study on the involvement of

organisations representing persons with disabilities". *The Changing Disability Policy System: Active Citizenship and Disability in Europe* 1: 177–95.

- Walmsley, Jan, Liz Tilley, Sue Dumbleton, Janet Bardsley. 2017. „The Changing Face of Parent Advocacy: A Long View”. *Disability & Society* 32 (9): 1366–86.
<https://doi.org/10.1080/09687599.2017.1322496>.
- Wapiennik, Ewa. 2009. „ANED country report on the implementation of policies supporting independent living for disabled people Country: Poland.” ANED.
<https://www.disability-europe.net/downloads/512-pl-8-aned-2009-request-07-task-5-request-template-approved-by-author-to-publish-to-ec>.
- World Health Organization, World Bank, red. 2011. *World report on disability*. Geneva, Switzerland: World Health Organization.
- Zadrożny, Jacek, red. 2015. „Alternative Report on the Implementation of the UN Convention on the Rights of Persons with Disabilities”. Foundation KSK.
https://tbinternet.ohchr.org/Treaties/CRPD/Shared%20Documents/POL/INT_CRPD_NGO_POL_21651_E.doc.