

Protests of Parents of Persons with Disabilities in Poland: The Results of a Qualitative Study Among the Participants and Supporters

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Abstract: The paper tackles the phenomenon of a protest organized by parents, care providers, persons with disabilities, and supporters in the building of the Polish Parliament in 2018. It was held for 42 days and supported regular protests organized in front of the building as well as, occasionally, in several Polish cities. It was the second nationwide protest by the movement of parents of people with disabilities in the Polish Parliament, and the first one took place in 2014. The article also refers to those events.

The paper aims at presenting and discussing the protest phenomenon in 2018 at two levels. At the micro-level, we reconstruct the protest's meaning for its participants and supporters. Here, we present individual motivations, attitudes toward the protest, and the subjective perception of the whole action, as well as its place in the participants' and supporters' lives. At the second level (collective), we locate the protest among other activities carried out by formal and informal groups and organizations of people with disabilities, or acting on their behalf. We also identify gains and losses of the protest, especially from the subjective perspective of the participants.



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We applied a qualitative approach that included conducting individual in-depth interviews with protest participants and supporters. The participants were selected in a purposive sampling scheme.

A general overview of the results shows that whereas there are no meaningful differences in carers' opinions on the protest's necessity, there are diverse opinions about how it was held. The protest proved that the community of carers of persons with disabilities is heterogeneous. The brief literature review demonstrates no clarity on whether it was parents' or persons' with disabilities protest. This confusion shows that there is still a tendency to perceive parents (as carers) and a person with a disability as an inseparable whole despite protests.

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Introduction

In this paper, we present and discuss the motivations and goals of the protest held in 2018 by parents of persons with disabilities in the Sejm building in Warsaw. The protest has been the most spectacular parents' mobilization ever since. In the first part, we briefly describe its background and present parents' and carers' previous actions. Then, we provide a basic literature overview to find out how it discussed the protest. After an informative methodological sketch, we present and discuss the study results. The paper closes with concluding remarks.

The protest's background

The situation of two social groups – i.e. people with disabilities and carers of children with disabilities – had been difficult before the ratification of the UN Convention on the Rights of Persons with Disabilities in 2012 and the implementation of the European Union's standards guidelines into the national policy. The medical-charity model had dominated the way disability had been perceived

both by the Polish society and the Polish social policy system. The state support was mainly based on the granting of small cash benefits, with restrictive requirements for these two groups, which are still in force today. For instance, the requirement that one of the carers of a child with a disability has to resign from work (without any additional opportunities), then she/he may receive a small benefit. The amounts of these benefits were not sufficient to cover the required hours of rehabilitation, medical devices, etc. Moreover, the forced resignation from employment has caused social, professional, and public exclusion. It has resulted in the discrimination and stigmatization of carers (see Niedbalski 2020; Sałkowska 2020). Therefore, poor financial situation, discrimination, and the lack of adequate support were, among other things, the primary needs and challenges of families with disabilities.

The protests began with a group of parents of children with disabilities from an association called “I have a future”, which evolved into a social movement of disabled children’s parents – RON (Pol. *Rodzice Osób Niepełnosprawnych*; the Polish abbreviation for “Parents of Disabled Persons”). The association, based in Toruń, has tried to draw the government’s attention to the needs of families with disabilities and inadequate state support since 2009. As the conversations with the government’s representatives were unsuccessful, parents took several local protests (Matuszak 2011) and some in Warsaw in front of the Polish Sejm (Rędziaś 2012), as well as in front of the Chancellery of the Prime Minister.

On March 19th, 2014, the RON movement organized a protest in front of the Prime Minister Chancellery. Then, at the invitation of the Solidarity Poland party¹ to a press conference, the protesters entered the Sejm building. During the conference, they announced the occupation of the Sejm. The RON’s demands were, among others: to increase the amounts of the allowance and the nursing benefit for carers of people with disabilities; professional care for a disabled child; receiving a minimum wage for care work; more accessible personal assistance for people with disabilities, which would enable the carer to return to the labor market; the elimination of the criteria for family benefits or the provision of necessary nursing measures by the state.

On March 27th, 2014, a new group has appeared and joined the protest of the RON – a movement of carers of adults with disabilities, who protested in front of the Sejm. Their demands were slightly different, although the main demands included an increase in the benefits for carers and a change in the caregiver support system. A representative of the movement of carers of adults with disabilities took part in the scientific research described below.

The protesters suspended their action in April 2014. There were four effects of the protest. The first one was to increase the amount of the nursing benefit for parents of children and people whose disability occurred before the age of 18 or 25 (in the case of people continuing education). However, the carers of adults with disabilities (protesters in front of the Sejm) did not receive this type of support. Secondly, the “Disability Round Table” initiative was announced. It was supposed to enable the

1 The Solidarity Poland party – a Polish political party created by former activists of the Law and Justice party (Pol. Prawo i Sprawiedliwość). Characteristics: national conservatism and Euroscepticism.

cooperation and discussion between the government and parents, experts, and activists in order to build adequate support for people with disabilities. This initiative ended in 2015 with the change of government and, therefore, its effects are unknown. The third consequence was a split within the RON movement. Some parents left the movement, because they had different views on systemic support for their children. They joined the "Disability – One Front" movement. The fourth effect was making the public aware of the needs of families with a disability and an ineffective support system.

The second occupation of the Sejm by the RON movement took place on April 18th, 2018. The occupation lasted 40 days. The pattern was similar. During a press conference in the government building – this time at the invitation of the Modern party² – the leader of the RON, Iwona Hartwich, announced the start of the Sejm occupation. The reason was the failure to fulfill the promises of the Civic Platform³ government and the Law and Justice⁴ government as well as the poor financial situation of families with disabilities. The postulates included, among others: equating the amount of the social pension with the lowest ZUS pension for total incapacity for work; the gradual increase of this amount to the minimum subsistence amount calculated for a household with a person with a disability; introducing a rehabilitation allowance for people with disabilities; free hygiene products, especially for bedridden people; abolishing incapacitation and replacing it with a medical guardian in the person of a parent or another close person; free use of rehabilitation for children with disabilities.

The government banned protesters and other outsiders from entering and leaving the building during the protest. The protesters had windows closed and slept on mattresses by artificial light. They had no access to elevators and bathrooms with showers.

From the outside, the occupation of the Sejm was supported by various allies, including the Women's Agreement on March 8th, the Warsaw Women's Strike, and Citizens of Solidarity in Akcja OSA (Kubisa and Rakowska 2018). They organized daily pickets, several street protests in Warsaw and in other Polish cities, or collections of necessities for the protesters.

As a result of the protest, the amount of the social pension was increased to the amount of the minimum pension for total inability to work; increasing the amount of the care allowance of 153 PLN for persons with disabilities; the establishment of the Solidarity Support Fund for Persons with Disabilities in 2019; during the protest, the government introduced the Accessibility Plus program (the result of several years of work with the community of people with disabilities). The then family minister Elżbieta Rafalska announced the introduction of a social responsibility package – a reform of the disability certification system (Ministerstwo Rodziny, Pracy i Polityki Społecznej 2018). However,

2 The Modern party (Pol. Nowoczesna) – a Polish political party of a centrist and liberal character.

3 The Civic Platform (Pol. Platforma Obywatelska) – Polish political party related to: Christian democracy, social liberalism, liberal conservatism, pro-Europeanism.

4 The Law and Justice (Pol. Prawo i Sprawiedliwość) – a Polish political party. Characteristics: national conservatism, right-wing populism, Euroscepticism.

despite numerous assurances from the government about completing work on the new adjudication system, the changes were not introduced.

The protest in the Sejm in 2014 focused on the demands of advanced carers of children with disabilities. The occupation of the Sejm in 2018 turned out to be different – the aim was to implement the rights of people with disabilities to state support. One thing is certain, namely that the RON movement is a new actor on the scene. Its members do not need the representation of young people's with disability interests by non-governmental organizations that had previously represented the interests of people with disabilities.

Selected literature on protests – an overview

The literature overview proves that various researchers have analyzed the 2014 and 2018 protests. Woynarowska (2019) inquires about discourses describing both events. She emphasizes the politicians' discourse where adult persons with disabilities are perceived as eternal children who need to be cared for. In this discourse, persons with disability have no right to speak for themselves. They have no agency. They are bodies that need medical treatment and care. The politicians' perspective is a manifestation of a medical model of disability. Concern expressed by politicians is paternalistic and has a moral aspect. In their opinion, it is immoral to take "a child with a disability" to the Sejm and stay there for 40 days, additionally without medical treatment and proper care.

The protesters' corporality played a considerable role in the entire protest. Disabled bodies were disturbing and challenging for some politicians. A comment made by one of the politicians, who said that there is a "stench" in the corridors of the Sejm, clearly underlines the "non-parliamentary" nature of the events taking place. It contrasts the seriousness and dignity of the parliament with the triviality of the protest, the sacrum of high politics with the profane of the humdrum camp (cf. Lipko-Konieczna 2018). "The right use of bodies and objects in the protest serves to increase the visibility of the movement and raise the profile of issues it is addressing within the public-media space" (Ślosarski 2018: 22). Since protesters stay for many days in one place, the dynamics of the protest are emphasized with the changing props, according to the principle that "apart from the number of protesters, timing and location of the protest, such elements as leaflets, badges, and banners, etc. are also important" (Ślosarski 2018: 27). Placards informed about the number of days that the protest lasted. They also served to show quotations from politicians and other decision-makers. Protesters presented their demands and informed about their situation on banners. All these objects – placards and banners – are the material equivalents of social interactions reflecting the position of the protesters vis-à-vis the dominant narrative that deteriorates their social status. In response to the protesters' actions, Sejm guards separated them from the rest of the parliamentary space by hanging the curtains. Moreover, they kept opening and closing the sanitary facilities, switching the lights on and off, and changing rules related to the delivery of meals. According to Ślosarski (2018: 29), "The issues related to the materiality of the protest can be summarised as two parallel processes: the embodiment of protest

objects and the objectification of bodies in public space.” In this particular case, the disabled bodies’ objectification seems crucial. There is a clash of two opposing narratives: the exhibitionist shocking with a disability *versus* the protesters giving ‘an object lesson’ so that the general public can learn the tragic nature of the disability. However, whichever of these narratives we endorse, there is no doubt that the protesters’ corporality, especially those with disabilities, has been reduced to the role of a ‘bargaining chip’ in reading the movement symbolism.

The protest is also analyzed as a part of a political game between the government and the opposition. Dobrzycki (2019) compared how two Polish weeklies (“Newsweek” and “Sieci”) presented the protest in 2019. The language used in both cases was simple but highly emotional, highly tabloidized. It referred to aggression, combat, and military.

According to Dobrzycki, if we treated the texts and all mentions about the protests in both magazines as a whole story, we would get two opposite “black and white” worlds. Moreover, it turned out that the protest and the protesters are only theoretically at the center of that story. Both weeklies used the protest for a political game between the opposition and the government. “Newsweek” fought against the government, while “Sieci” defended the PiS party and treated the protesters (parents and people with disabilities) as enemies who collaborated with the opposition.

Using the example of the protest, “Newsweek” shows its readers a world in which “PiS is ready to slander those groups that dared to protest against their actions in various public spheres with the worst slander” (Dobrzycki 2019: 49). The protesters are presented as a vulnerable group exposed to attacks by aggressive representatives of the authorities (e.g. guards, MPs). The protesters cannot defend themselves; they are gradually locked in the building until none of them can leave the Sejm (and if they do, they will not come back). No one can enter the building, not even people who would like to help the protesters (e.g. Janina Ochojska or Wanda Traczyk-Stawska). The government “isolates itself from the nation, and also separates its citizens and does not allow for social control” (Dobrzycki 2019: 56). The protesters cannot receive help, although the opposition members try to help them. The support of the female deputies from the opposition has presented the protest as something close to people. The reader could see the “ordinary” life of the protesters, feel a bond with them, and cheer them on in their fight with the authorities. “The society is receiving a kind of signal that it should now pay more attention to the operation of the government, because it may want to take action against the weakest group” (Dobrzycki 2019: 56).

On the other hand, the periodical “Sieci” presents the protest as an efficiently organized political action aimed at blackmailing the rulers and the government to agree to all the protesters’ claims. The final effect of the protest is to overthrow the government. This is due to cooperation with the opposition. The protesters were also encouraged not to vote for PiS in the next elections. Such actions are supposed to suggest the politicization of the protest. From the beginning of the Sejm occupation, the protesters were portrayed as enemies of the government, allied with the opposition that wanted new rules.

According to the literature overview, the protest has become the subject of sociological, cultural, and media reflection. Press releases and discourses about the protest and protesters were analyzed and discussed. The protest and its material objects were also a subject of interpretation. We intend to present a subjective perspective of the protests' participants and active supporters.

A methodological sketch

We aim at understanding the goals, motivations, and meanings of the protest for protesters and their supporters. Therefore, we employed a qualitative approach. Purposive sampling was applied. The sample chosen for this study was designed to reflect the heterogeneity of persons involved in the protest in any possible way. There were two main categories of the respondents. The first one included persons who participated in the protest held inside the Sejm building (mainly carers of people with disabilities). The second included the protest's supporters, i.e. persons who were not physically involved in the protest inside the Sejm building. These are persons who actively participated in the protests organized in front of the building and who organized help for the protesters from the Sejm. Among the protest's participants and supporters, there were persons both with and without disabilities. Eight individual in-depth interviews were carried out. A small sample results from both difficulties met in the research process and the limited research group availability. The most spectacular protest was held in 2018, and interviews were conducted in 2019. Although some crucial *gatekeepers* agreed to support us in contacting potential respondents, they were not eager to participate in a research project. This may result from the "research exploitation" of the particular group, namely carers of persons with disability, which is one of the most important ethical challenges in inquiring vulnerable social groups (see: Liamputtong 2007; Sałkowska 2018). In this specific case, difficulties in reaching the respondents may have also been the consequence of high media coverage of the protest and the tiredness that it caused among its participants. Recruiting protest supporters was easier than persons who actively took part in the event.

High ethical standards required in disability studies were applied at every stage of the research process (Niedbalski 2016; Całek 2020). Recruitment and sampling issues were already discussed. Respondents had been asked for informed consent before the interview started. Interviews were carried out in the most suitable place and time for the interviewees. Each interview was recorded, anonymized, and transcribed.

Data analysis was carried out with the Atlas.ti support. A combination of theoretical and open-coding approaches was applied during the data analysis. Preliminary theoretical codes that result from key research questions and literature review were completed by codes that emerged during multiple transcripts readings (Gibbs 2018). This combined approach enabled the comprehensive overview of the collected data.

The study had two dimensions. The first one involved the micro-level. Here, the aim was to learn about individual goals, motivations, attitudes toward protests, and their meaning in an individual's life, i.e. the subjective perception of protests. At the next level of collective actions, the aim was to reconstruct the place of protests among other activities carried out by formal and informal groups and organizations of people with disabilities, or acting on their behalf.

The results of the study

Goals of the protests

There are three types of goals identified by the interviewees. These three types are interconnected, but it is worth identifying them separately.

The first goal can be described as political and civic. The protests were organized so that decision-makers could finally notice people with disabilities, listen to them, and the aim was for the political parties to include the needs of this group in their agendas. One of the interviewees, a man with a disability who participated in the supporting protests in front of the Sejm, says:

[...] politicians do not notice us at all. We are not noticed at all. [...] I have never heard that we do something for the disabled, because they are important for us. We are not important. I would like politicians to really feel that we are the electorate, that we have our own needs, that we simply are there, because at the moment, we do not feel that we are there... You know, we are entirely treated as a third category. Perhaps even the tenth. [...] You know, in fact, as disabled, we have fewer rights than animals [P3].

The mother of a person with a disability says that the protests were a cry of 'We are there' [P9]. This is a desperate demand for being noticed and taken into account – also as voters – by political parties. The protesters have been crying out: 'take us seriously as people on whom your [politicians'] future may also depend'. People with disabilities are also voters. Therefore, it is essential to recognize their needs and create a program that at least partly responds to them. Thus, the protest had a civic dimension: it aimed to present people with disabilities as citizens demanding their rights and representing their interests, just as other socio-professional groups have done. The political and civic goal also acquires a dimension related to dignity: people with disabilities want to be recognized as citizens and taken seriously as voters. One of the female participants also stresses that the protest was organized in order...

[...] for them to comply with the convention on the right of European disabled people. And that is not the case. What is the point of it being signed when it is not there? [P6].

Interestingly, the claims and demands relating to the implementation of the provisions of the UN Convention on the Rights of Persons with Disabilities (CRPD)⁵ did not emerge until the protests in 2018. In 2014, protesters were unlikely to refer to this document (cf. Kubicki, Bakalarczyk and Mac-kiewicz-Ziccardi 2019). This change suggests better technical and substantive preparation for the protest and a growing awareness of the rights of people with disabilities.

Another goal can be characterized as economic. It is linked to higher living costs due to the disability, which are borne by people with disabilities and their families. Also, the dignity aspect stands out in this context: one of the protests' demands involved a financial allowance increase. A woman with a disability says:

Well, the aim was to fund the needs of people with disabilities... which, of course, is very necessary, because we all know how it works [...] because we ourselves have also sometimes wondered about the costs of disability, that these costs are simply higher than normal, so these needs are higher, and the state, too, should participate in financial support for these people. [...] needs for living, indispensable needs, because these are people who need constant care... and we know that these carers take care of them and give up their jobs, so the state support here is necessary to the highest possible extent [P1].

Another interviewee, the mother of an adult with a disability, adds:

[...] 2014 was a year for carers and parents, we received 418 zlotys and then 420 zlotys, and for eight years I had it, I received it. So, we fought for a decent pay. Because we could not go to work and we had 420 zlotys. Even if a child were to be healthy enough in his disability to be able to go, for example, for four hours, we are not allowed, even to this day, to earn a single zloty. We had to do something to raise the standard of living of the family [P6].

The economic goal also has an educational, informational, and awareness-raising aspect, not only aimed at politicians, but also at other people who have no experience with disability. The protest is intended to show how the life of a person with a disability and his/her family can look like. And, in particular, that of a female carer (women are more likely to play caregiving roles in the family). The protests in the Sejm undoubtedly had this dimension: private, intimate activities such as nursing and hygiene care took place in the public space. One of the things raised by the interviewees was the issue of nappies which were delivered to those protesters who needed them. Activities from the private sphere were moved into the public or even the political sphere, clearly showing that 'the personal is political' (cf. Lipko-Konieczna 2018). A protester, the mother of an adult with a disability, adds that one of the aims was to show that adults with disabilities exist and they are "fully-abled citizens", and the government should "ensure a decent life for these people" [P6].

5 Poland ratified the UN Convention on the Rights of Persons with Disabilities in 2012.

One of the interviewees, a man with a disability, points out that there is a certain danger in showing the situation of people with disabilities. He sees it as a threat to the social perception of people with disabilities. He notes that the protests were organized in order to “[...] show the problem of this particular community” [P2]. He notes, however, that the community of persons with disabilities has been homogenized. He stresses that not every person with a disability has the exact needs. According to him, the protest should not be about the disability as such, but about the requirements that result from the disability. He is critical of the protests and the way they have been organized, precisely because people with disabilities were treated as a homogeneous group. He believes that the support should be based on the needs of the individual and their carer. The interviewee raises an extremely important terminological point. A single term, “disability”, is supposed to describe many physiological and psychological states and various needs. Almost every disability faces different barriers, difficulties, and needs. Only when those various needs are met, can we enable the realization of rights.

Undoubtedly, the goal related to dignity is overriding, because dignity, by its nature, is related to the financial situation of the person concerned and their ability to exercise and enforce their rights.

Another aspect is highlighted by those supporting the 2018 protest. These people were not physically present in the Sejm. They protested in front of the building. The interviewee, a non-disabled person, says that the purpose of the solidarity protest was to highlight diversity:

It was more about extending the demands in the sense that, whenever we were able, we would include, or rather the voices of these various other groups could resonate [...] in my opinion, it was very important to supplement the narrative coming from the Sejm, so that various groups present under the Sejm could somehow supplement that narrative [P5].

This diversity reflects the criticism of one of the interviewees who stressed that all people with disabilities and their relatives were treated as a homogeneous group during the Sejm protest. Meanwhile, during the protests held under the Sejm, attempts were made to highlight internal diversity. This protest tried to show that the phrase “Parents of Persons with Disabilities” (RON), oversimplified and often parroted by the media, conceals different people with different problems and needs. As part of the “open microphone” letters from people with various disabilities were read out, retired mothers who were carers were represented, as well as carers of adults with disabilities.

The main and overriding goal was to regain dignity – in the political and civic context as well as in the financial context. Dignity means, among other things, being treated seriously and exercising rights.

Motivations

The goals are linked to the motivation of those who participated and supported the protests. Why did these people actively participate in or support the protests? For some people, especially those with disabilities, “it [was] so obvious” [P1]. The protest concerned people with disabilities and their situation, and, therefore, directly affected this interviewee:

[...] I myself am disabled, a person with a disability, so I believe that I should not stand indifferent when my community protests and I understand their demands, so I have to join in. I should join in, even though perhaps the demands do not concern me, but I, so to say, support them, because I understand their hardship, yes? Their needs, their difficulties [P1];

[...] this protest related to disability is of direct concern to me because I am disabled, so, naturally, I had to get more involved in it [P3].

The interviewees underlined that even if the particular demands made by the protesters did not concern them directly, the protest itself did. They signaled that they understood these demands and the needs of people with disabilities. They characterized their attitude in this respect as ‘professional solidarity’, i.e. solidarity with other people in a similar situation. Participation in the protest was, therefore, not so much a fight for one’s own interests as a fight for the interests of a specific group, specific people, and an expression of support for them:

[...] if they do harm to a disabled person, it is as if they did harm to me, too. So it feels like, you know. It is like professional solidarity [P3];

[...] the disabled are the weakest group. Of course when the weakest are harmed, then naturally you feel that you have to get involved, and besides, I am also disabled, and... well, what comes out of it is simply social solidarity [P3].

The mother of an adult man with a disability also underlines the inevitability of her support for the Sejm protest:

There was no other way but to go to these protests, because they [protesters] were simply laying down on that floor for us and there was no way we would not go and they would not feel supported. It was impossible for us to sit at home in front of the TV and watch the protest [P9].

The voices of carers in particular express disappointment with the Polish social policy and the neglecting of the needs of people with disabilities and their families. The sentiment expressed as ‘having fewer rights than animals’ is also expressed in the feeling of being a second-class citizen, excluded from programs such as the Family 500+ subsidy for childcaring:

The current government divides society, does not treat people equally, even with the disabled. Everyone got 500 zlotys just like that, with no conditions, without any problems. Mrs Rafalska⁶ was even boasting that you can get the money via the Internet with a single click, that you can apply for 500+, and she is boasting about how many thousands of these applications were submitted by parents within just a few hours, whereas we must apply for this and appear in front of even more medical boards. This is simply humiliating for us. Dividing up society by saying that healthy children are better than sick children, what is the purpose of it. I don't know, maybe in our country, disabled people are loathed. No government, as I said, has spoiled us, the disabled, but the way that the Law and Justice humiliated us, no government has ever humiliated us [P9].

For people who had no private experiences with a disability, the motivation to participate in the solidarity protest under the Sejm was that the protest fit their activist lifestyle. One interviewee [P5] considers participation in these protests a "civic duty" or the need to express solidarity with the protesters who need support. The motivation to participate was a result of disappointment with the (lack of) actions undertaken by the political parties:

I feel that solid political support was missing [...]. In this sense, I really didn't want the people with disabilities who came there every day not to have such organisational support, that the Warsaw Women's Strike, which organised all this, that the girls wouldn't be alone there, I just wanted more people to be there, so I had to be there too [P5].

Apart from a sense of civic duty or a solidarity expression with the protesters, the interviewee pointed out the universal character of the experience of disability as such. She notes that in the future, probably most of us will be dependent on the support of other people or institutions for various reasons, such as advanced age. Hence, the protest was carried out on behalf of and in the interest of future generations.

Activist support and commitment did not just mean coming to the Sejm to protest regularly. It meant genuine work for the organizational support of the entire protest, including assistance for people with disabilities, contacts with the media and ensuring that the diversity of the protesters is reflected by them, as well as organizing parcels with products necessary for protesters in the Sejm.

Likewise, another interviewee, a non-disabled person who supported the 2018 protest and was involved in the 2014 protest, expresses a sense of duty. The duty, in this case, is not strictly civic but, rather, stems from a sense of responsibility and belonging to a certain community:

[...] I have such an internal imperative that, since I have been involved in this for a long time, I can also place it in a broader context and compare it with events I have studied and experienced directly. I see this as some sort of a duty on my part that I should not completely stand

6 Elżbieta Rafalska was the Minister of Family, Labor, and Social Policy.

aside. I also suspect that I would also be, in fact, when the last protest in May [2019] took place, I was also marching there, even though we do not always get on well with the organisers of that protest [P7].

The motivation to participate in the protests involved, above all, a sense of duty and solidarity with the protesters. It also results from the lifestyle and beliefs of the interviewees. The protests of 2014 and 2018 were not the only protests or demonstrations in which the interviewees took part. Some of them actively supported protests related to other issues, such as the so-called Black Protest.

The protest's importance and benefits at the collective level

In this part, we locate the protest among other collective actions undertaken by persons with disabilities and their carers.

The protests were extraordinary events compared to other activities carried out by the community of people with disabilities. For some time, people with disabilities and their carers became protagonists of news bulletins, and their situation turned into the subject of a public debate. As an interviewee comments:

[...] protests are the clearest, most spectacular, most visible. There are various foundations, often we do not know even about their existence, and patients and the disabled do not know about them either. Although they may be doing a great job and could help a lot, it is difficult, it is difficult to find out about them. The [protest] was rather a kind of a leap; things would move, move by themselves somewhere and somehow, without much publicity. And [the protest] struck such, such a clear chord, so I think that it is like... stronger, more powerful... but also these people, because... it had to be a... the situation must have been so difficult that the persons were determined to start such a protest, because it gives no pleasure to stay out of home... you know, in such dramatic conditions... [...] difficult, for so many days. Well, that does require a lot of determination [P1].

Another interviewee [P7] stresses that protests were part of a longer process. According to him, they are the culminating events of activities in favor of people with disabilities. Despite being the most spectacular, they are just another event. Between these publicized events there were many minor protests. [P7]. The introductory part of this paper has covered these "minor protests."

The protest can thus be seen as a kind of spurt, a one-off action that attracts the attention of both the public and politicians, and shows that the governments and decision-makers should not ignore the demands of the community of people with disabilities. On the other hand, protests can be aggressive and expose people with disabilities to offensive and humiliating comments in the public space and on social media:

[...] in the 21st century you do most of the job in the office, not on the street. Especially since, at the moment, my child's dignity is at stake. When I go out on the streets and everyone is pointing the finger at her, I simply do not want that. I was in parliament once, and although nobody says about it, and they behaved very well towards my daughter, but things were quite different in 2018, when we were simply different because, because by no means, right? But, but the comments, whether on Twitter or on some websites, Facebook groups... Well, they were shocking at that time, so it is high time to put an end to such protests, and to learn how to negotiate in the office [P4].

The interviewees' comments suggest that the protests have triggered internal divisions within the community, e.g. "[the 2014 protest] divided a lot the community, people moved away" [P8]. Protests have emphasized the differences in the particular needs and problems, how the demands are formulated and pursued (protest on the streets versus negotiations), and between the movement's leaders.

Legislative framework was another factor that has divided the movement from the inside:

In December 2012, the law changed and the movement split into two groups, i.e., carers of children and carers of adults, by way of simplification [P7].

This division was most salient during the 2014 protest, when carers of children with disabilities protested in the Sejm building, whereas a parallel protest of carers of adults with disabilities took place outside the Sejm. This division was perpetuated by the legal differentiation between the carers of children and adults with disabilities, which ultimately broke down the unity within the community, thus limiting the possibility of exerting significant pressure on the government to improve the situation of the entire community of carers (Kubicki 2017).

Differentiation of attitudes toward the support system has also divided the movement leading to an internal conflict. Parents supporting the demands for an attendance allowance increase and the professionalization of care coalesced around the "I have a future" association, which led to the establishment of the movement of Parents of Persons with Disabilities (RON), which, in turn, organized the protest in 2018. The second group of parents, who left RON in 2014, began to work around the "Disability – Single Front" association, which distanced itself from the activities of the RON movement (Bakalarczyk 2016). This group aims to provide care to children by introducing systemic changes, not necessarily related to increasing the benefits for carers or the professionalization of care. From the point of view of these parents, it is necessary to engage in alternative methods of dialog with the governing party to provide proper, comprehensive care for children in specialist centers⁷ or through the support of a personal assistant of a person with a disability so that carers can take up employment.

7 They are referring to facilities where a parent can leave their child during working hours.

The scene of formal and informal initiatives has changed. An interviewee supporting the 2018 protest (a protest supporter) places it among activist movements rather than actions directed at a particular social group. She notes that this protest has put the disability issue on the activists' agenda:

[The protest] has brought this subject into the realm of demonstrations and causes that people take up [...] in such street activism. [...] [D]emonstrations [...] make the topics salient in a way for them to be a source of conflict and social activity. I mean, for example, a conflict between society and the state. And this problem was in this manner posed very clearly. It has emerged from this specialist bubble of people who are dealing with or are interested in various issues related precisely to the UN Convention, the subject of incapacitating people or whatever. [...] And now it has suddenly entered the sphere of social problems [P5].

Thus, owing to the protest, the problems of people with disabilities ceased to be niche and became noticeable, and perhaps more understandable to the public. The protest has also put these issues on other social movements' agendas. Therefore, the protests undoubtedly contributed to defining disability as a social problem (cf. Becker 1966).

As a protest's consequence, disability and the situation of people with disabilities has emerged as a topic for a public debate. This fact was acknowledged even by those interviewees who oppose these actions: "[...] a nationwide debate has begun on needs, the support for people with disabilities" [P4].

The dissemination of issues related to disability can be seen by looking at the way the journalists referred to the "protest of the disabled" [P1]. According to this interviewee, the protest achieved one of its goals: the recognition of people with disabilities as a voters' block whose support should be sought after:

[...] every political party now before the elections, pushes this topic, everyone talks about the disabled and everyone wants to give them something [P1].⁸

On the other hand, the mainstreaming of disability in the media may negatively affect the public perception of the community. Especially since 2014, carers and parents of people with disabilities may be seen as "parasites": "It seems to me that the society is a little bit upset: why should they pay for the disabled" [P8].

This interviewee stresses that there is constant talk about the needs of parents and carers, and that the opinions of people with disabilities themselves are not taken into account: "[...] everyone forgets about people with disabilities and their voice is not heard" [P8].

8 This conclusion seems somewhat exaggerated, because, as suggested by the analysis of electoral manifestos of candidates in the 2020 presidential elections, only Szymon Hołownia has presented an extensive plan directly aimed at the community of people with disabilities (see Greniuk and Przybyszewski 2020).

In addition, as for tangible benefits of the protest, the interviewees refer to the increase in benefits for carers of people with disabilities. As a result of the 2018 protest, an allowance of 500 PLN was introduced for people with disabilities, which boosted the dignity of those protesting.

It is true that the protest, especially in the initial phase, was accompanied by the mobilization of politicians from the Law and Justice (PiS) party and the opposition. They presented various legislative proposals for people with disabilities in a relatively short time. After the first meeting of the protesters with the President, who announced the preparation of a draft law implementing the protesters' demands, the opposition parties came forward with their legislative proposals: the Civic Platform (PO) presented a draft bill on assistance to dependent persons; the Modern (Pol. Nowoczesna) party drafted a bill on social pension. It suggests that the RON protest "mobilized" politicians to seek solutions in the area of disability. The question remains as to what extent this involvement was actually based on the genuine needs and problems experienced by the community of persons with disabilities. To what extent was it just another element in the political game between the parties reported by the media? The submission of draft bills (by the government and the opposition), which were drafted within a few days/weeks during the 2014 and 2018 protests, can, in a way, be subsumed under the category of an incomplete pattern of understanding the protest as a public problem: "spectacular event – media outcry – political intervention." In order to complete the sequence of events presented by Andrzej Zybała, there would have to occur the final stage of using expert analysis that would thoroughly consider the effects of the proposed solution and its alternatives (Bakalarczyk 2015). Eventually, as mentioned by an interviewee [P6], opposition politicians signed a pact on the implementation of the four demands of the peoples with disabilities which stipulates that should they take over the reins of power, the politicians commit themselves to: introducing a monthly rehabilitation allowance of 500 PLN for adult people with disabilities who are unable to live independently; reform the system of disability assessment; implement the judgment of the Constitutional Court on attendance allowance; and guarantee genuine and broadest access to public facilities for people with disabilities (Greniuk and Przybyszewski 2018).

The benefits mentioned by the interviewees have the systemic dimension (specific solutions for people with disabilities and their carers) and the collective dimension (the emergence of the issue of disability in public debate). The systemic aspect, in particular, shows up as concrete benefits for specific people, so it can also be considered within the individual context (the improvement of living conditions).

The protest's importance and its consequences at the individual level

As mentioned before, the protests have brought tangible benefits to people with disabilities and their families. In addition to these benefits, there are unquantifiable consequences at the individual level.

The interviewees emphasize the social consequences of the protests. In the first place, they could get to know other people in a similar situation, as was explained by the mother of a man with a disability

who actively supported the 2018 protests: “We have nice new friends after the protest”. They keep in touch with each other, support each other, exchange experiences [P9]:

[...] we are in touch all the time; we are together all the time, well, we are quite close, so we discuss all our daily concerns with each other there [P6].

Another protest participant stresses that he got to know the backstage of the parliamentary process and people in various public functions, which definitely impresses him [P4]. The experience of participating in the protest pushed him to do further activity: “[...] it gave me such, such a drive that I cannot imagine life without this... without this struggle” [P4].

The mother of a man with a disability notes that the act of participation in the protest under the Sejm building in 2018 emphasized and affirmed her son’s disability:

[...] we usually did not even realise that we were disabled. Our life looked normal. I just put him on a wheelchair, take him to the shop and we go together to the supermarket, we go to the cinema, we go to the concert, the Łazienki park. We were living a normal life then, only the protest made us realise that we really are disabled and in practice, we are alone and made us realise our situation and how they treat us [P9].

As she says, she was ‘brutally made aware’ of her son’s disability and the disdainful treatment of people with disabilities. After the protest, she feels even more unjustly treated and humiliated. She is all the more worried about her son’s future, which is a common concern among parents of people with disabilities (cf., e.g., Niedbalski 2020). The participation in the solidarity protest has confirmed her identity as a mother of a person with a disability.

The protesters, particularly those who occupied the Sejm building, became recognizable, which changed the way they are perceived both by the local community and, more broadly, by the media (including the social media). By their participation in the protest, some interviewees were made aware of their belonging to a broad group and allowed them to seek support from other people in a similar situation. By realizing that they belong to a discriminated and stigmatized group, they reaffirmed the situation in which the members of this group find themselves, i.e. the situation of the person with a disability or their carers.

Concluding remarks

In this paper, we aimed to understand better the protest’s background and its meaning to its participants and supporters. We briefly presented the events and actions that led to the culmination of 2018 and the Sejm building occupation. We reconstructed the aims, motivations, and protest’s consequences at both individual and collective levels. The main issue that arises from the interviews is

“dignity” – the person with a disability’s dignity and a parent’s or carer’s dignity. The critical point is that protest reached out further and gained the attention of different social movements and activists in other social areas. It left the disability enclave, and maybe for a while disability became the issue discussed widely in the media.

Interestingly, some problems appear when we answer the question, “Whose protest was it?” Protests were presented as “protests of parents of persons with disabilities.” “#RON” had become the protests’ symbol and a sign that stands for protest’s support, for example on social media. What is more, even in the academic literature, a parent and a child or adult with a disability are all often presented and perceived as inseparable. The social movement and mobilization behind the Sejm occupation were inspired by parents, not by persons with disabilities, and it was not the persons with disabilities protest, but their parents’, despite media widely describing the event as a “protest of persons with disabilities”. As one interviewee has said, the voice of persons with disabilities is not heard. Although some interviewees have stated that their main demand was to be heard and noticed, the vast majority of the public debate around the protest was dominated by political games and medical and charity discourse that concentrated on “poor disabled persons” who need help instead of the discriminated group whose rights need to be exercised.

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Cytowanie

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Protesty rodziców osób z niepełnosprawnościami w Polsce. Wyniki badań jakościowych wśród uczestników i sojuszników

Abstrakt: Artykuł dotyczy protestu organizowanego przez rodziców, opiekunów, osoby z niepełnosprawnościami i ich sympatyków w gmachu Sejmu RP w 2018 roku. Trwał on 42 dni i był wspierany regularnie przez „mniejsze” protesty organizowane przed budynkiem Sejmu oraz sporadycznie w kilku miastach Polski. Był to drugi ogólnopolski protest ruchu rodziców osób niepełnosprawnych (RON) w polskim parlamencie – pierwszy odbył się w 2014 roku (artykuł również odnosi się do tego wydarzenia).

Opracowanie ma na celu przedstawienie i omówienie zjawiska protestu w 2018 roku na dwóch płaszczyznach. Na poziomie mikro zrekonstruowano znaczenie protestu dla jego uczestników i sympatyków. Przedstawiono indywidualne motywacje, postawy wobec protestu, subiektywne postrzeganie całej akcji oraz jej miejsca w życiu uczestników i sympatyków. Na drugim poziomie (zbiorowym) protest ułożono wśród innych działań prowadzonych przez formalne i nieformalne grupy oraz organizacje osób niepełnosprawnych lub działające w ich imieniu. Zidentyfikowano także zyski i straty protestu, zwłaszcza z subiektywnej perspektywy uczestników. Zastosowano podejście jakościowe, które obejmowało przeprowadzenie indywidualnych pogłębionych wywiadów z uczestnikami i sympatykami protestu. Uczestnicy badania zostali wybrani według celowego schematu doboru próby. Ogólny przegląd wyników pokazuje, że chociaż nie ma znaczących różnic w opiniach opiekunów na temat konieczności protestu, to różne są opinie na temat jego przebiegu. Protest pokazał, że środowisko opiekunów osób z niepełnosprawnościami jest heterogeniczne. Krótki przegląd literatury nie wyjaśnia, czy był to protest rodziców, czy osób niepełnosprawnych. To zamieszanie pokazuje, że mimo protestów nadal istnieje tendencja do postrzegania rodziców (opiekunów) i osoby z niepełnosprawnością jako nierozłącznej całości.

Słowa kluczowe: protest, ruch społeczny, niepełnosprawność, rodzice osób z niepełnosprawnością, opiekunowie osób z niepełnosprawnością