



Unheard Voices: Discourse Analysis of Press Representations of People with Disabilities and Their Caregivers in Postsocialist Poland

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Abstract:

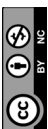
The article is devoted to the issue of disability, embedded in the Polish – post-socialist – reality. The author focused on presenting both the political situation in the country and the media discourse around disabled people and their keepers. The background of the ongoing public discussion on people with disabilities is the topic of abortion, also widely present in the Polish media.

The analysis of the press discourse (*Gazeta Wyborcza*) carried out for the purposes of this article not only provides a bitter summary of the situation of this neglected social group, but is also an opportunity to show the real life problems faced by the weakest representatives of Polish society every day life.

1. Introduction

One of the central contradictions of postsocialist democratization in Poland is the state's declining tolerance for women's reproductive rights (Mishtal, 2015), even though, according to the most recent data, 69% of the population of Poland support legalization of abortion for pregnancies up to 12 weeks (Federacja, 2018). The collapse of state socialism in Poland, however, brought a dramatic shift in state's attitudes toward abortion which, under the socialist rule, used to be legal and available to all women (Mishtal, 2015). For instance, in 1956 abortion for socioeconomic reasons was legalized for pregnancies up to 14 weeks and was offered free of charge in all public hospitals (Mishtal, 2009). Currently, as a result of the post-1989 Polish state adopting the discourse and agenda of the Catholic Church on women's reproductive rights (Mishtal, 2009), Poland has one of the most restrictive abortion laws in Europe. At the moment of writing this paper, under the current law, abortion in Poland is only permitted on the following grounds: when there is justifiable suspicion that the pregnancy constitutes a threat to the life or a serious threat to the health of the mother, that the fetus is irreversibly damaged, or that the pregnancy resulted from an illegal act (Nowicka, 1996).

Despite the restrictions listed, there are further attempts to limit the scope of what constitutes legal abortion in Poland. As for 2015, the Poland's ruling party, Law and Justice, has sought to ban all abortions and is currently making a push to outlaw abortion on the grounds of the irreversibly damaged fetus, even when it is sure to die in infancy (Santora & Berendt 2018). Supporters of the new bill, which was proposed in March 2018 by Life and Family Foundation, an organization dedicated to ending abortion, headed by Kaja Godek, herself mother of a child with Down Syndrome (Gostkiewicz, 2018), claimed that their project was only about protecting “unborn babies with disabilities” (Santora & Berendt, 2018). The opponents of the project, on the other hand, claimed that the proposed abortion ban would effectively “force” women to give birth to



terminally ill children who would later die in a “horrible suffering” several hours after being born (Kośminski, 2018). The project, opposed by Polish women’s rights organizations and their allies, ignited a national debate on abortion, which ultimately extended its focus to include not only women’s reproductive rights, but also caregiving labor required by people with disabilities. That labor is usually provided by women: there are an estimated 200,000 people in Poland who are full-time caregivers for disabled family members and many of these primary caregivers are mothers providing assistance to their disabled children (Klukowska, 2017).

Shortly after Life and Family Foundation along with some members of the Polish parliament announced their plan to ban abortion on the grounds of the irreversibly damaged fetus, a number of readers penned letters to the editor of *Gazeta Wyborcza* (*Electoral Newspaper* in English), one of the most popular newspapers published in Poland, in which they voiced their concerns regarding the proposed ban. Some of those letters were written by parents and siblings of people with disabilities, who decided to share with the wider public their experience of caring for a disabled relative in the country where the state constantly attempts to outsource and privatize the responsibility for providing care to people with disabilities by tapping into the labor of ordinary citizens, mostly women. Interestingly enough, the voice of people with disabilities themselves was almost entirely excluded from the ongoing debate. Therefore, this paper is a preliminary study of how, starting in March 2018 when the new abortion ban project was first introduced, people with disabilities became positioned as vehicles for the discussion at the intersection of women’s reproductive rights and reproductive labor. By tracing tensions and inconsistencies present in the way (presumably) non-disabled people describe caregiving labor required by people with disabilities, this study aims to broaden anthropological and linguistic insights into how an image of people with disabilities is “constructed” in Poland through language practices and how these practices influence the current discussion on abortion law and reproductive labor in Poland.

2. People with disabilities and women’s reproductive labor in postsocialist Poland – an overview

After the collapse of state socialism in Poland, much of the state’s responsibility for providing care and assistance to children, people with disabilities, and the elderly was outsourced to ordinary citizens, mostly women, by making it a component of what Melissa Caldwell (2017) calls “ethical citizenship” understood as a way of promoting care for others “not just as an essential quality of human decency but as a critical right and responsibility of being a citizen of the nation-state” (21). Previously in socialist Poland, under political circumstances Joanna Mishtal (2015) refers to as “state feminism” (27), the state provided women with generous social services in order to relieve them of the burdens of caretaking and to help them enter paid employment. As a result, to many women living under state socialism, the state assumed the role of a “virtual husband” (Mishtal, 2015), who relieved them of considerable amounts of housework. For instance, in Poland the socialist state provided many households with basic home appliances as well as opened a network of public daycare centers for children (Mishtal, 2015).

However, despite the progressive politics that helped Polish women in education and employment, the state did not tackle gender inequalities within the family. Women were still expected to take care of their children, husbands, elderly and sick relatives (Mishtal, 2015). That housework remained publicly invisible and devalued, confined to the realm of the private unlike the publicly celebrated wage labor performed by men (Gal & Kligman, 2000). Despite the scarcity of information on lives of people with disabilities during state socialism in Poland, it seems that, similarly to women’s housework, people with disabilities remained invisible as well as the people who cared for them – women. According to Polish disability rights activists, in Poland the socialist ideology which promoted the healthy, able-bodied workers pushed people with disabilities to the peripheries of social consciousness (Holtkamp, Iliaich & Pietraszek, 2008). Due to the lack of public facilities, people with disabilities were either “confined to the boundaries of their homes” or expected “to become ‘working prisoners’... trapped instead in an invalid cooperative... to take part in simple, mindless physical activities such as brush-making” (Holtkamp, Iliaich & Pietraszek, 2008).

The “communist illusion of free care” (Gal & Kligman, 2000, p.73) was eliminated in the 1990s by the post-socialist governments of Eastern European states which engaged in the “re-reforming” of their citizens. However, as noted by Gal and Kligman (2000), with the withdrawal of subsidies as a way of relieving state budgets, it was women, not abstract “individuals” and “families”, who “[took] up even more of the slack in



sick care, elder care, and child care” (p. 74). Much of this work remains undervalued, both ideologically and financially. When it comes to people with disabilities themselves, Polish disability rights activists report that the socialist legacy, with its expectations that people with disabilities remain invisible and idle, still persists. Despite the fact that social services for people with disabilities such as integrated schooling or more accessible public spaces seem to be more developed in postsocialist Poland than they were during state socialism (Gąciarz & Rudnicki, 2014), the widespread stereotyping of people with disabilities not only affects their self-perception and self-confidence but also makes their families undervalue their disabled relatives’ actual potential (Holtkamp, Iliach & Pietraszek, 2008). As a result of this conundrum of care, insufficient finances, state’s expectations toward women and stereotypes regarding disability people with disabilities and their caregivers in Poland occupy a particularly precarious position.

3. Data and methodology

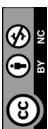
This study employs critical discourse analysis as a way of examining three letters to the editor and one editorial that appeared in the online edition of *Gazeta Wyborcza* in March 2018 in the midst of the national debate on the abortion ban project proposed by the Life and Family Foundation. Only one of those letters and editorials was penned by a person identifying himself as a person with a disability. The remaining three letters and editorials were authored either by caregivers of people with disabilities or (presumably) non-disabled people who at same point encountered a person with a disability. The researchers Paul Baker and Tony McEnery describe critical discourse analysis (CDA) as “a way of doing discourse analysis from a critical perspective, which often focuses on the theoretical concepts such as power, ideology, and domination” (2014:465). Therefore, the analysis of linguistic features of the ongoing debate on the abortion ban in case the fetus is irreversibly damaged, cannot be conducted without an analysis of wider social context, that is people’s attitudes toward people with disabilities and reproductive/caregiving labor in Poland.

In order to better map the events that led to the debate on abortion in which people with disabilities were positioned as a vehicle for discussing such issues as reproductive rights and reproductive labor, this study also employs a method of discourse analysis of archival data developed by Stanton Wortham and Angela Reyes. In their book *Discourse Analysis beyond the Speech Event* Wortham and Reyes (2015) argue that what distinguishes discourse analysis of archival data from other types of discourse analysis is that narrating events in archival studies “are more obviously cross-event phenomena, because they involve linked events of production and reception” (112). Henceforth, their model of discourse analysis of archival data consists of the following components: mapping narrated events, selecting indexicals/relevant context, configuring indexicals, and identifying positioning/action in narrating an event (Wortham and Reyes 2015). Following Wortham’s and Reyes’s argumentation, the letters to the editor and editorials selected for the purpose of this study cannot be fully understood not only without considering the historical events that have shaped attitudes toward abortion, disability, and caregiving in Poland over the past six decades, but also without examining who speaks to whom, on whose behalf, and about what in the sources analyzed in this paper. Therefore, this study is divided into two sections which look at how people with disabilities were positioned in the debate on the abortion ban from two different perspectives. The first section called “Abortion and the government that does not care” considers the problem of abortion in Poland from the perspective of insufficient support provided by the state to people with disabilities and their families. The second one titled “Self-sacrificing mothers” examines how people with disabilities provided a backdrop for discussing the sacrifices their mothers make in order to take care of them. All discourse segments in this paper were originally written in Polish – the English translations were provided by the author of this study.

4. Abortion and the government that does not care

Segment 1: Holy wombs and incubators

The baby is holy as long as it is in the womb. All the possible measures are undertaken in order to save the pregnancy and no one worries about the costs that the mother has to bear. During this time, the mother loses all her rights, she becomes an incubator. Her well-being is taken into consideration only because it may affect



the child's health... Until we provide terminally ill children and their families with dignified living conditions, no one has the right to tell a woman what she is supposed to do. The life of a terminally ill baby and its mother ends with its birth. If there will be no choice, there must be [dignified] living conditions... Firm NO! I know, because I personally experience what it means to live with a person who has been terminally ill since birth.

(Anonymous, 2018)

This excerpt appeared online in *Gazeta Wyborcza* in March 2018 in an editorial called “Mom of terminally ill Mikołaj on abortion: it is about respecting life. My life”. The piece discussed a Facebook post written by a mother of a disabled son. Since this excerpt is a direct quote from the Facebook post, the narrating event involves, on the one hand, the act of writing, with Mikołaj's mother writing, presumably, to her Facebook friends and aiming for certain effects on that audience. On the other hand, the narrating event includes many events of reading (Wortham and Reyes 2015) in which people interpret Mikołaj's mother's writing in various contexts. In the narrating event, Mikołaj's mother describes what it means to have a disabled (or terminally ill) child – she knows about the narrated events she describes through personal experience. Mikołaj's mother's narrated event describes babies who are “holy” as long as they stay in their mother's wombs, and mothers who are turned into “incubators” stripped of all their rights during pregnancy and, later, labor. By juxtaposing “holy” babies with “incubator” mothers, she paints a portrait of a society in which the life of an unborn child is considered more important than the life of its mother. She draws on her own experience to show that in Poland children with disabilities matter as long as they are unborn. Once they leave their mothers' wombs, those holy “incubators”, they disappear from the social radar. She furthermore suggests that since the state does not provide ill children and their families with “dignified living conditions”, it has no right to force women to give birth to terminally ill babies. Moreover, the use of such evaluative indexical as “dignified” implies that the current living conditions of ill children and their families are, in Mikołaj's mother's view, far from suitable. The conclusion that can be drawn from this excerpt is that the state does not really care about children with disabilities who are already born. However, this one event does not suffice to draw any conclusions about the social phenomenon occurring here.

Segment 2: On their own for 17 years

For 17 years we have been paying for everything out of pocket: caretakers, physical therapy, wheelchairs, diapers, doctors, vacations for Ola... For 17 years we have been struggling with Ola's illness on our own. Because we make our living, the state does not care about us – for the state the income level is the only criterion for assisting a family with disability [sic]... No one in a society notices Ola, no one notices us. We manage... If you dare to make a decision for all Polish women and make choices for them, then take, please, one more step and help them with children who are already born.

(Lewandowska, 2018)

This excerpt appeared in March 2018 in the online issue of *Gazeta Wyborcza* in a piece titled “I am waiting impatiently for an answer from Kaja Godek” by Monika Lewandowska, a mother of a disabled daughter – Ola. In this excerpt Lewandowska refers to a number of things and services that her family has had purchased for Ola, such as caretakers, wheelchairs, diapers, and doctors among others. She underscores that for all those things she and her family had to pay with their own money. She also uses a temporal cue, “17 years”, repeated twice in the excerpt, to signal for how long her family “has been struggling with Ola illness” on their own. She claims that since they have enough money, the state does not recognize them as in need of assistance (either financial or material). In the narrating event, Lewandowska directly addresses Kaja Godek, the founder of Life and Family Foundation who spearheaded the project on banning abortion in case the fetus is irreversibly damaged in order to protect “unborn babies with disabilities” (Santora & Berendt 2018). In her letter Lewandowska challenges Godek to start helping those children with disabilities who are already born, instead of fighting for unborn babies. In the narrated event Lewandowska gives Godek an account of how her family was left on their own with Ola's disability. She states that since they have enough money to pay for various devices and services, no one, especially the state, notices their daily struggles: “no one in society notices Ola, no one notices us”. This statement aligns with the Segment 1 in which Mikołaj's mother claimed that the state cannot force women to give birth to terminally

ill babies without providing them with proper living conditions first. Based on those two segments it appears that the state's help, if any, extended to people with disabilities and their families in Poland, is far from sufficient and therefore lawmakers and pro-life activists have no right to ban abortion on the grounds of the irreversibly damaged fetus. However, before pursuing these cross-events linkages further, let us consider one more excerpt, from a letter titled "Open letter to President Kaczyński from a person with disability #blackprotest" penned by Bartłomiej Skrzyńia Skrzyński, a disability rights activist, an academic teacher, and a wheelchair user.

Segment 3: Everyday Jesus Christ

It is not about abortion for fun, about taking away the right to live from people with disabilities – it is about the space to make choices... Not everyone is Jesus Christ, ready to give up his life for another person... In Poland, instead of providing those who are already alive with dignified life, we rummage in the law, trying to regulate through the system of bans and orders something that should not be regulated... Dear Mister Jarosław! President! As a person with a disability I appeal to you to support people with disabilities in real ways and to give up on that absurd idea of restricting the "anti-abortion law".

(Skrzyński, 2018)

This excerpt appeared in an open letter to Jarosław Kaczyński and was published online in *Gazeta Wyborcza* in March 2018. Jarosław Kaczyński is the president of the Poland's ruling party, Law and Justice, which has sought to ban all abortions ever since it came to power in 2015. The hashtag "#blackprotest" which appears in the title of the letter refers to the series of protests organized by Polish women to show their disapproval for the government's attempts to limit the scope of what constitutes legal abortion in Poland.

In the narrating event Skrzyński directly addresses Jarosław Kaczyński, the president of the Poland's ruling party and appeal to him to give up on the "absurd" idea of further restricting Polish abortion law. The use of the evaluative indexical – "absurd" clearly communicates Skrzyński's negative evaluation of the abortion ban project. In the narrated event, Skrzyński implies that the living conditions of people with disabilities should be improved. Instead of banning abortion, he suggests providing people with disabilities "who are already alive with dignified life" which echoes the statement about "dignified living conditions" made by Mikołaj's mother in Segment 1. Moreover, he claims that instead of playing with the currently existing abortion law, the state should support people with disabilities in "real ways". This evaluative indexical – "real" – used by Skrzyński in his letter, suggests that he does not believe that the efforts to ban abortion in case the fetus is irreversibly damaged are really helpful to people with disabilities.

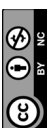
As in the other two events analyzed in this part, Skrzyński suggests that the Polish government does not really care about people with disabilities who are already born. Similarly to Mikołaj's mother, he uses such evaluative indexicals as "dignified" and "real" to indicate that the current situation of people with disabilities in Poland is far from dignified and that the proposed abortion ban is not really about improving their lives. Given the context provided in earlier events presented in this analysis, it can be concluded that the state should therefore focus on the real problems of people with disabilities and their families. The narrated events provided in the segments above describe, instead, how the state expects Polish women to give birth to children with disabilities without providing them with means to raise them in "dignified" conditions. In addition, an emerging cross-event configuration of indexicals voices the struggles that people with disabilities and their families have to face on a daily basis in Poland.

5. Self-sacrificing mothers

Segment 4: Sacrifice and devotion

With both admiration and terror I was watching his mother. A mother, who obviously sacrificed her entire life to take care of her sick son. I could feel her love, sacrifice, devotion... I did not want to wonder what I would do, if I would be able to lose myself in love toward a child just like the mother I just mentioned... I did not want to imagine her daily life devoted to taking care of such a disabled child. Did she persist with her caregiving? Or maybe she gave up and gave her son away to a nursing home or hospice?

(Świątkiewicz-Siklucka, 2018)



This excerpt appeared in March 2018 in a letter to editor titled “Heart cries quietly or several thoughts on abortion” penned by a *Gazeta Wyborcza* reader, Dorota Świątkiewicz-Siklucka. In the letter she described how several years earlier she spent some time with her own child in a hospital and how during that time she was able to observe a disabled boy and his mother, who were staying in the same room. Upon hearing about the government’s efforts to curb abortion in Poland on the basis of the irreversibly damaged fetus, she decided to share with other readers her impressions of that mother/child pair she had the chance to meet during her own child’s hospital stay. The narrating event here involves Świątkiewicz-Siklucka writing a letter to other readers of *Gazeta Wyborcza*. Świątkiewicz-Siklucka’s narrated event describes a mother who took care of her disabled son. In another part of the letter, not quoted here, the author described the son as a 7 years old boy who did not speak, who did not move, and who was not able to eat on his own. In this excerpt, when describing the mother’s caregiving efforts she uses such evaluative indexicals as “love”, “sacrifice”, “devotion”. She furthermore indicates that the mother was so devoted to her disabled son that she seemed to have given up on her own life. Therefore, in this narrated event Świątkiewicz-Siklucka paints a portrait of a devoted, self-sacrificing mother of a disabled child who, given the history of Polish women as designated nurturers and caretakers (Mishtal, 2015) meets the societal expectations toward women, who are supposed to selflessly devote their time and strength to children, elderly, sick, and disabled. However, this one event itself does not suffice to draw any conclusions about social phenomenon occurring here,

Segment 5: No time to see a dentist

I think it is about... respecting life. My life as a mother of a terminally ill child, who is locked at home prison, without a chance to go out and run errands unless somebody offers me their help. [Such errands as] going to a dentist to treat my teeth, doing groceries, buying clothes, not to mention engaging in cultural events such as going to a cinema, theatre, concert, or reading a book. I have no right to get sick myself, I have no right to vacation.

(Anonymous, 2018)

This excerpt appeared in the editorial discussed above in the Segment 1. In this segment, Mikołaj’s mother’s narrated event focuses around her life as a mother of a disabled child. Although she does not use such evaluative indexicals as “devotion”, “love” or “sacrifice” seen in the previous segment, she still manages to describe sacrifices she makes in order to take care of her son. What she says here is that she does not have time to do anything for herself, such as see a dentist or read a book. Although she uses different means to describe it, similarly to the Segment 4, she manages to imply that in Poland mothers have to give up their own lives in order to take care of their disabled children. Both pieces discuss how selfless mothers have to be in order to care for children with disabilities. Both characterize this phenomenon in terms that imply devotion, self-sacrifice, or even, in the case of Segment 5, being locked with a child in a home prison. In a way, both those segments are similar to the segments discussed in the section on “Abortion and the government that does not care” since they, too, underscore the loneliness and the lack of outside help in caring for people with disabilities in Poland.

6. Limitations and conclusion

Due to the lack of space, this study could only attempt to analyze 5 segments from 4 different sources. However, the author managed to find thirty letters to the editors, interviews and editorials in total. The open letter authored by Bartłomiej Skrzynia Skrzyński remains the only letter/editorial/interview written by a person with disability. The remaining sources do not include the opinions of people with disabilities themselves at all.

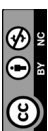
Since it is only a preliminary study, the author would like to expand her search in the future in order to include more opinions from more diverse sources. To that end, the author is planning to employ a Corpus Based Approach and use the Nexis program for her further research into representations of people with disabilities in Polish press since that tool makes it possible to quickly scan more sources at the same time. Furthermore, the author is planning on running the corpus analysis using the Word Smith 5 software in search for collocates.

This study, despite being preliminary, provides a window into how people with disabilities were employed in the Polish press in the debate on banning abortion in case the fetus is irreversibly damaged. First of all, it showed that even though both sides of the debate used people with disabilities to strengthen their arguments

(the proponents wanted to save unborn children with disabilities, while the opponents wanted to save unborn children with disabilities from suffering after being born), people with disabilities were not really given the option to speak up for themselves. Instead, except for the letter written by Bartłomiej “Skrzynia” Skrzyński, those who speak in the excerpts analyzed in this study are mothers speaking on behalf of their children with disabilities or women speaking on behalf of other women who may be affected by the proposed abortion ban. That lack of voices of people with disabilities may be the result of decades of ignoring disabled people and their needs in Poland – first under state socialism (because they were deemed as unfit to work), then, after the collapse of socialism in 1989 (since stigmas attached to disability still persist). That attitude is not unique to Poland though. In *Disability and Mobile Citizenship in Postsocialist Ukraine* Sarah D. Phillips points out that in the former Soviet Union “in many respects disabled persons... remain an ‘unknown population’” (43). Even though formally Poland never was part of the Soviet Union, it looks like disability was not “considered an appropriate subject for ideologically correct scholarship” (Phillips, 2011:43) there either. Secondly, what is really discussed in those excerpts are not really problems faced by people with disabilities in Poland, but the problems faced by families (especially women) taking care of their relatives with disabilities. All the discourse segments examined in this study underscore the fact that in Poland families with disabled children are often left on their own and they cannot expect any reasonable assistance from the state. This is a direct result of the Polish state withdrawing its support for families and individual citizens after 1989. Furthermore, the excerpts analyzed in the section on “Abortion and the state that does not care” indicate that since the state provides almost no support to families with children with disabilities, it has no right to force women to give birth to disabled children. This path of reasoning should be more closely examined during further studies on abortion and representations of people with disabilities in Polish press, since it indicates that if the state provides sufficient support, women will be more likely to give birth to children with disabilities.

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