

DO WE REALLY
HAVE ANY
REPRESENTATIVE
OF PEOPLE WITH
DISABILITIES IN
THE ROOM? AND
IF NOT,
WHY NOT?
THOSE ARE
THE QUESTIONS
THAT NEED TO BE
ASKED.

Katarzyna Bierzanowska
(Pełnoprawna)

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by Alexandra Ivanciu and Jolanta Nowaczyk

Hello Katarzyna, let's start with a short introduction. Could you tell us a few words about yourself?

I'm Katarzyna Bierzanowska. I work as a translator and as a human rights activist, focused mostly on the grounds of people with disabilities and on feminism which is more inclusive, with regard to combining the two. I run an initiative called Pełnoprawna in Poland, and I cooperate with different NGOs and with different representatives, from both the public and private sectors, to support them by introducing accessibility or becoming more intersectional, inclusive so to say. So I also do some educational work about human rights for different people, from kindergarten to elderly people about human rights.

You mentioned Pełnoprawna. Maybe you could explain this name to non-Polish speakers?

Pełnosprawny, which is very close to pełnoprawny, means "fully-abled" body. If you delete the "s" and you say "pełnoprawny", you have "fully-fleshed", with legal empowerment, being more like the subject, not the object, and then when you say "pełnoprawna", it's a female version of the word. If you say "niepełnosprawny", it means simply "disabled". So the word is a combination of four aspects: gender, rights, ability, and disability. That's what is included in the name.

That sounds really amazing, this language play, how many things one can do with it. You are the co-author of a report about access to abortion for people with disabilities. But it's only in Polish so maybe you could tell us about this report, what are the most important points, what are the most important conclusions, recommendations?

Maybe I will start with the fact that first, with a group of researchers, some years ago, we prepared the first report which was about gynecological accessibility for people with disabilities. Since the results were quite striking, after some time, and of course after the events in Poland when the restrictions on abortion rights became even bigger, we decided to prepare the report also on abortion, and its accessibility for people with disabilities.

What we wanted to achieve was to give as much space as possible for women or people with disabilities themselves. Because when the entire discussion in Poland started with the protest, then the discussion in the media and social media, the voices of women with disabilities, were actually omitted. And I was trying through Pełnoprawna to give them a platform to speak for themselves. These were women with different disabilities, like visual disability or physical disabilities, and hearing disabilities, but on another hand, also women with children with disabilities or people working in political areas, journalists, and activists working in this area, to speak for the community. The voice was heard, it was a successful platform, but still, it was just one drop in the ocean, so it was not enough. On another hand there were a lot of threads and, I would say, arguments concerning disability itself, in political and social debates on abortion law in Poland. That is why we found it so important to really give a voice to women with disabilities.

I am saying "women", because while we address people with disabilities in general, however, we know that female empowerment in the area of people with disabilities is still a missing lesson, this is why we find it important to indicate that

gender matters when it comes to the disability.

There were three of us, two researchers and me, as an activist, but I also participated in some parts of the research itself. We needed to give some interpretation, methodology and so on... even if people don't understand the content itself, you can see that quotations of the women who decided to participate in the project take up most of the space. We are still trying and we think we will be able to translate that, together with Women Enabled, but not sure yet.

However, there were basically two groups of women we were talking to. There were women with disabilities with experience of abortion, and also women with disabilities and their reflection on what abortion would be if one day they might need it, and what is their opinion on accessibility and right to abortion in Poland, also access to protest and social discourse. And the third part I would say, consisted of individual interviews with women with intellectual disabilities, most of them living in institutions, which is a totally different voice in this debate. We took that to present first of all their opinions, which were not known in society at all, to make people more aware that people with disabilities have the opinion on abortion.

Also when we talked about abortion due to some fetus disease or whatever, people with disabilities are one of the most crucial groups that should have been given the voice to. That was our aim. And then of course to present our conclusions, what is necessary, what is missing, what is needed, and the recommendations. The final group was the discussion with legal experts, medical staff, and abortion

activists, so people who support abortion rights but are outside of the system in Poland, mostly collectives and informal groups that work in Poland and abroad, even if abroad, supporting people from Poland.

This is very impressive work!

You mentioned that people with disabilities are not taken into consideration when it comes to discussing the possibility of a child being born with a disability... I was reading a short article about how pro-choice activists can use a certain language that is against people with disabilities... I mean there is some contradiction there and I wonder how... I can imagine you tackled this topic also, so how can we do it better? What would be the strategies you propose?

I guess I know what you mean... So I think the main problem is... I mean there are a lot of problems in this area. You can either be a feminist, or you can be a person with a disability and belong to the so-called "community" or the environment of people with disabilities fighting for their rights. And very rarely those two communities and those two worlds are ready to meet up. That's the main difficulty, because the feminist movement is not ready or very inclusive and very aware of the actual needs and actual voices of people with disabilities, especially women, and on another hand, the movement of people with disabilities is not necessarily feminist. Poland is also not LGBT-friendly and so on and so forth. So we have two worlds that are in contradiction to themselves. You need to create a new cloud, for combining those two identities. I would say it's easier to implement accessibility into the feminist world because I would say the rules are more open, and what I hear from the

feminist movement is that “Ok, we haven’t been doing that, I agree, but we agree we need to do that”. While the community of people with disabilities says: “We know there are some feminists out there, but we don’t feel they need to be part of our movement. We don’t feel like women should be a special group in our movement, which is quite difficult. Especially in Poland, there is a huge division in the community, and in the movement when it comes to people with disabilities, when it comes to different kinds of rights. They don’t see the relation between the mechanisms of discrimination and those analogies are missing. There is the United Nations Convention on the rights of people with disabilities, which is in Poland considered the most important document giving us the direction to follow when it comes to the rights of people with disabilities. There is an article about the right to life, which I would say is translated into Polish in a tricky way. When we were ratifying the convention, we were discussing the translation itself, however when there was a discussion in Geneva at the United Nations, there were representatives from one of the most radical and catholic oriented organization, Ordo Iuris, and they were there, which was quite striking to us because they actually have nothing to do with people with disabilities rights. But they went up to Geneva, to tell that there is a huge violation of the convention for people with disabilities concerning this right, because we have no ground, even if reproductive rights are anyway poor in Poland, we as people with disabilities have no ground to decide when the abortion is possible, which means for example when the fetus has a disability then it’s violating the right to life. Some of the representatives

of the Polish movement of people with disabilities follow this reasoning, so they feel it’s more important not to discriminate, so to say, in commas, “discriminate” people before they were born, because they might have disabilities. However, fortunately, the UN said very directly that the convention concerns only people who were born. They cut the discussion totally. The convention is quite general so there is a lot of room for interpretation, and after some time fortunately the UN started to issue interpretation of particular articles. Also, they did that about the article about the right to life so... we should say, the discussion has ended. But in Poland it is not. That’s the problem.

It’s hard to discuss that because... first of all we don’t assume, when we talk about abortion and disabilities, in any way, disability, disease, or anything that we consider that is outside of the norm, then we have voices of people who have no experience of his being outside of physical or mental or intellectual norm, or their parents or their representatives. So first of all we don’t have any direct voices and second of all, we don’t assume that the legal regulations on abortion consider anyhow women with disabilities. All the protests have never mentioned the situation when women with disabilities can be pregnant and don’t want to be pregnant. This is a game-changer because then we can see how badly the regulations work, how discriminated against women are. There is so much ableist content in this entire discussion... Even when we support the right to abortion and we want to give examples, there is this trap that we start to devalue people with disabilities. This is a huge trap. Also what was tricky was... when we try

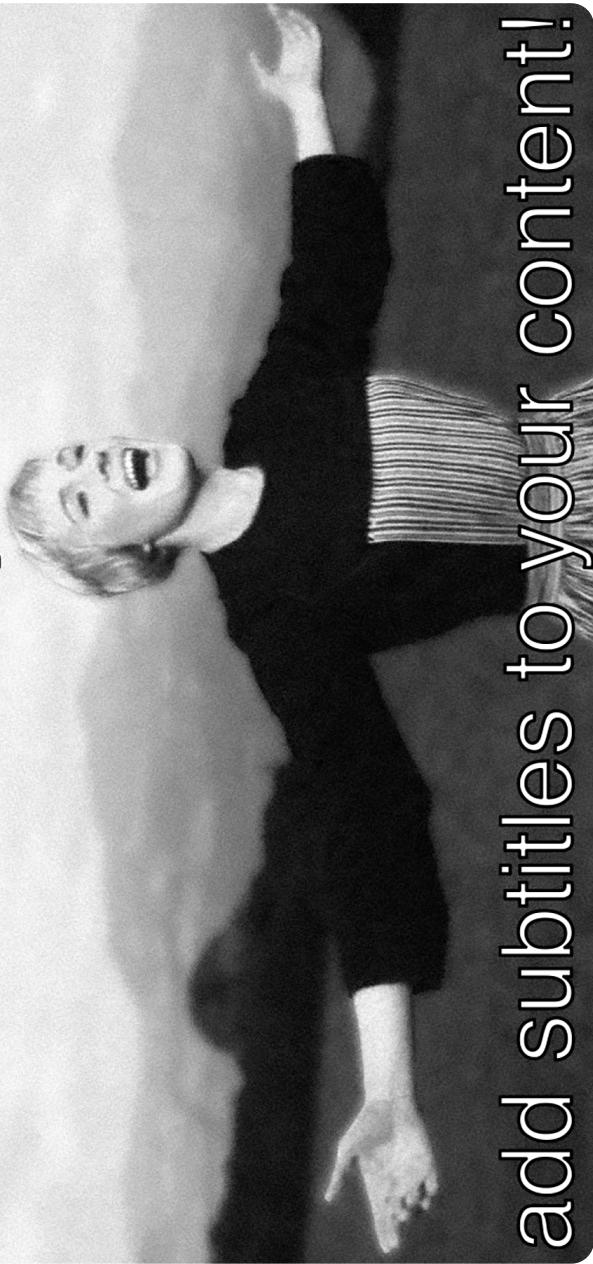
to go step by step backwards, then we realize when the problem starts. Women with disabilities were never considered to be potential mothers, because they are not considered to have sexual life, because they are not considered to be grown-ups who can make decisions for themselves. So we see that infantilization is a ground for what we have further on. There are two scenarios: when they want to be pregnant and set up a family, then they are not very encouraged to make this decision by a gynecologist. They hear that is maybe not a good idea, maybe they should consider it twice, and so on. When the woman with disabilities comes to a medical representative and says: I am pregnant, then she can hear: Maybe we can do something about that. This appeared in our previous report. So then the legal regulations are no longer... something that we need to abide by. And the final issue is with women with intellectual disability. Especially the ones living in institutions where a lot of human rights are violated, when they are pregnant... First of all, they are given contraception without their knowledge, second, there are still cases of illegal sterilization. Third, once a woman becomes pregnant, children are very often taken away from them, without them even knowing them, even without letting them see the baby and make their own decision. So women are confused, they are in a very difficult mental state because legally they are deprived of fundamental rights. These are voices that will never be heard, I don't know if never, but for sure not in my lifetime. What we only talk about and hear is the discussion about children with Down Syndrome, which is crucial! But when everything boils down to that, then the discussion is like... futile, I would say.

Thank you for this very complex answer! Since our research focuses on care networks, maybe you can share some recommendations for activists coming from your report. Of course, they are doing their best, but still, probably there is a lot of space to improve on accessibility.

Yes... There is a lot to do. When we discussed with different collectives, it was not very surprising for us but it was interesting to see that there is so much to do. Because first when we started to talk about it - if you pose a simple question, is your activity or support accessible to women with disability? Some of the activists say: yes, we can help people with disabilities. But they don't understand that it is not about your mental readiness to help people with disabilities, but if you have the infrastructure and if you communicate that, what are your tools, the actual very materialized, tangible tools to support women with disabilities. And then it becomes like a black hole because they had no idea where to start to find answers and how to analyze... because accessibility was never a filter. I'm not saying that to blame them because I am aware of where that comes from but what I want to say is that even with people who are aware of the complexity of the subject of reproduction rights or abortion, people who are human rights sensitive, what's important to realize, that even such activists who are open to react to that and respond to that, they didn't have access to the knowledge or to the tools to even start thinking that they are missing something.

Our work started from my cooperation with Abortion Dream Team, during the protests when I invited Natalia for the discussion at

add subtitles to your content!



add subtitles to your content!

Pełnoprawna and I asked her about cases of women with disabilities in their collective. She got a bit confused, and she said: “Ok, I know what you mean... we need to start our journey together from now on”. They started with very small steps, and then they started to see that they have actual recipients. So they see what is missing, what can be done right now, and what can be done in a long-term strategy. They still have a lot to do but we are in touch and I'm a pain in their neck. When it comes to very specific examples...

First of all, collectives run very often on the basis of social media. So the question is, is your social media anyhow accessible? And I know that when I ask this question activists say but what does it require, what does it take, to say that our social media is accessible? If you publish some videos, do you provide at least for some of them, translation into sign language? Do you provide subtitles, especially the one advanced that means they cover the SDH standard, subtitles for the deaf and hard of hearing? When you publish some graphic and visual content, do you provide alternative text for people with visual disability? Do you have a visual representation in your graphic of women with disabilities? Is it always the normative body? Is it always a normative person? Because that was one of the major voices of our respondents in our report: they said they never considered themselves to be the recipients of let's say Abortion Dream Team's content. Because it was never addressed directly. And that is the case of many people with disabilities, when we see the hotel offer or some university offer, we never assume this is something we can reach for. Because most probably have

barriers. So unless you have some particular top on the website when you talk about accessibility, or you have some contact when we can ask about that, we never assume that the accessibility is there. So that's why communication matters so much. Many of those collectives have been working not for one year... but five years, sometimes ten years now. So we ask them: Is anyone with disabilities part of your team? And if not, try to figure out why. Because it's not just like you know... "if somebody would be open, we would invite such a person". This is not necessarily like that. You need to have tools for equal treatment and sometimes they might not be enough. You address queer people, because very often in such collectives they are queer people, but not I would say non-white, or who don't have able-bodies. These are questions that need to be asked. Of course, they might remain open, but it's important to have a discussion within the team.

Also accessibility of the website. There is this WCAG standard, which is a web accessibility guideline that needs to be fulfilled in order to make a website accessible. And also different communication paths. Very often there was only an email address or a phone number. If you are a person who is deaf, then a phone number might be not the best solution. What are your procedures then? Because you need to have a sign language interpretation that covers somebody's visual aspect, I mean a face or facial or recognition somehow. So how can you provide protection, I mean anonymity, in the sense of security of such people?

There were cases when collectives were reached by someone who said "My daughter needs an abortion and she cannot

contact you directly" because she had different kinds of disabilities, sometimes intellectual, sometimes it was visual. For the activists that was enough, to assume that we are talking to the mother. But then... why? Is it really necessary? What are our steps to decide, in that case, it's ok but in another case, we really need to talk to the person. We need to remember that people with disabilities are very very often economically and socially dependent. And the decision of abortion is made for them, not on behalf of them.

Also finally the entire procedure support. I realize that collectives might be able to cover all of the accessibility issues if it comes to the abortion itself and possibly this is not even their job. But did we have a discussion? Because I would say no. So how far can their support reach? In our report, we indicated in quite a detailed way what the obstacles are, once we want to have an abortion both by pills and once we want to go to the clinic. There are also problems with accessible transport, accessible accommodation, accessible toilets, assistance dogs, with accessible housing in case of pharmacological abortion, who can support you with that? When you have a visual disability, how can you judge what's going on? You cannot see the pads or your bleeding. Sometimes someone physically needs to give you the pill if you can't do that yourself. Is it still ok? What about assistance, are they protected? If somebody is your personal assistant on a daily basis, is this really a person you want to be your support person in case of abortion? Economical issues, and so on and so forth... So quite a lot of procedures to which I would say we maybe still don't have ready answers but we need to ask, and what we miss right

now very much is a discussion within the abortion supporters community, to try to find answers, try to ask people and to look for solutions.

If it comes to media representation... If those activists are asked to be visible or heard, just imagine instead of you, a woman with a disability or an activist with a disability who works in the area, because those voices are still very much missing. I think that's a good start.

Also when we provide different content and events, I mean, some conferences, some online debates, do we really have any representative of people with disabilities in the room? And if not, why not? So those are the questions that need to be asked. If we have an online event, do we describe accessibility? Very often we do not, so how are women with disabilities going to know that this is something that we consider them? So it's more or less that. Of course, we can keep talking and talking, because there is a lot of work to be done, however, I would say those are the most crucial examples I see at this time.

Are there other initiatives that cover the topic of reproductive rights for people with disabilities in Central-Eastern Europe or in general that you know of?

I know there was one initiative in Australia and there was also a publication, but I would need to search for it.

Then there is an organization called Women Enabled¹, and they wrote a statement while the protests were going on in Poland so they supported the issue, they were aware of the problem. This is again the community of women with disabilities.

¹ <https://womenenabled.org/publications/>



Cross-sectional but within the community of women with disabilities, not cross-sectional when it comes to subjects or areas of activism. This is mostly it, as far as I know. But I wasn't doing global research, maybe there is something I haven't discovered yet.

Yes, it would be great if you could send us this publication. Is there anything missing in our conversation, or something that you would like to add?

Maybe one thing... when I was talking about recommendations... I have it in my mind but I am still looking for ways to convince people that this is real. If we take women with disabilities in the discussion about abortion as real players then we have a huge leverage. We don't treat them as a group of interest although this is really something that might influence a lot if we are persistent in that. We still have two cases in which abortion is technically allowed. However, we all know that it still doesn't work even in those two cases. If we still have this women's health ground, it is a huge part of the women with disabilities. Any pregnancy for a woman with a disability is a potential threat actually to her health. That's why it's important we can, I'm gonna say that word, use women with disabilities in the discussion to simply verify what are the holes and missing points in the system right now. Even if we are not talking about a particular case, if we have women with disabilities who fear for their life when they are pregnant, and even when they want to keep a pregnancy, what can the system give them? And this is not socially controversial, which gives us huge leverage. People can say, socially, ok, women with disabilities can

keep their pregnancy and there are many cases like that, and when they hear that very often she is convinced not to, then we have this paradox. On the other hand, if she is supposed to keep the pregnancy, is the medical system ready for her to become a mother and to take care of her as a patient with a disability? No! So if she needs an abortion, what are the accessible abortion procedures? That might be then, as a consequence, used also for either women without disabilities or for people who are not pregnant but experience disability.

So I think there is a huge potential in this cooperation, and I think we still don't see that. Although I feel this very strongly, it's very hard to explain that to the communities. I feel there is this huge potential to invite women with disabilities to the discussion and to really really hear those voices!

Very often women said in our report that what they would need to deal with is... being pregnant and abortion is the top of the iceberg, but behind that... for instance, we had one deaf woman who said that "Ok, if I would be pregnant and I would need to terminate my pregnancy, there are a lot of problems connected with that." But one of the major points for her would be the first decision. Because in her abortion decision, she would need to think - not only about her partner, or about being a mother or not, about all the procedures, but also about the community of deaf people. Because there is no way that the community will not know about that, and the community is very narrow. So for her, it was a decision: either I want to be in the community of deaf people which is practically her world, or do I want to make a decision which is mine

and to terminate the pregnancy? This is a totally different dilemma than in the case of women who don't experience different kinds of disabilities. For instance, some women had the question: how do I know that I am pregnant? For women with intellectual disabilities or visual disabilities? Are pregnancy tests accessible? This is how far back we need to go in order to start thinking about accessible reproduction rights, it starts so much earlier than abortion clinics or calling Women Help Women, it's way, way before.

Alicja Tysi c came to my mind, she was a famous person who accused the state of Poland in front of the European Parliament. She was partially visually impaired, she refused to get an abortion even though it was quite clear that the pregnancy was dangerous to her health.

What is interesting in this situation is that the doctor, D bski, one of the most popular doctors, who denied her right to abortion for inadequate reasons of course... There is a D bski clinic in Warsaw which is one of the very, very, very few gynecologist clinics which are accessible to women with disabilities.

Oh my God!

Yeah, and many women with disabilities are patients at this clinic, of course, different doctors work there but still you know the name and you know where you are going... If it comes to Alicja Tysi c, it is a very important case! However, if you think of it, very often what's missing is that no activist or no media is talking about her as a woman with a disability. Her identity as a person with a disability is put as 3rd or 4th... They

say that she was visually impaired or had some visual difficulties and so on, but it's like a medical diagnosis, not an identity. We were making some effort to see whether she herself addressed her identity, and she was actually not talking about her identity, and there is nothing wrong about that, but it's interesting that for her it was the fight for abortion, like for women's rights, from her position, when she had vision issues, but it wasn't her fight as a person with disability. It's very emblematic... and symptomatic as well.

I never thought about her this way.

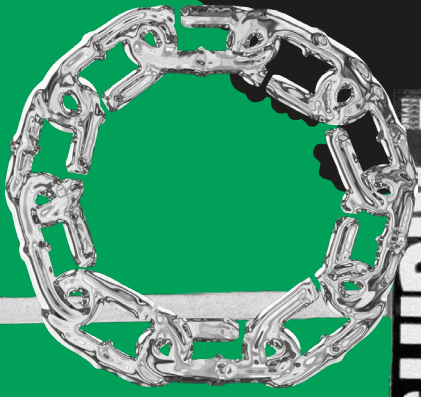
Yes, this identity disappears very often. You must know about many cases from different countries which were a huge breakthrough in the fight for abortion law. In many cases when we are talking about fetal deficiency - this is all about disability but if you take a closer look into the media content and even narratives of relatives, the parents, the partners - the disability identity is almost never mentioned. It's not that fight. That's why we need to put it there every time we can to make it more visible and more heard.

Thank you so much for this interview! I think it's an amazing contribution to our project. There are so many points we have to discuss concerning our project also...

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