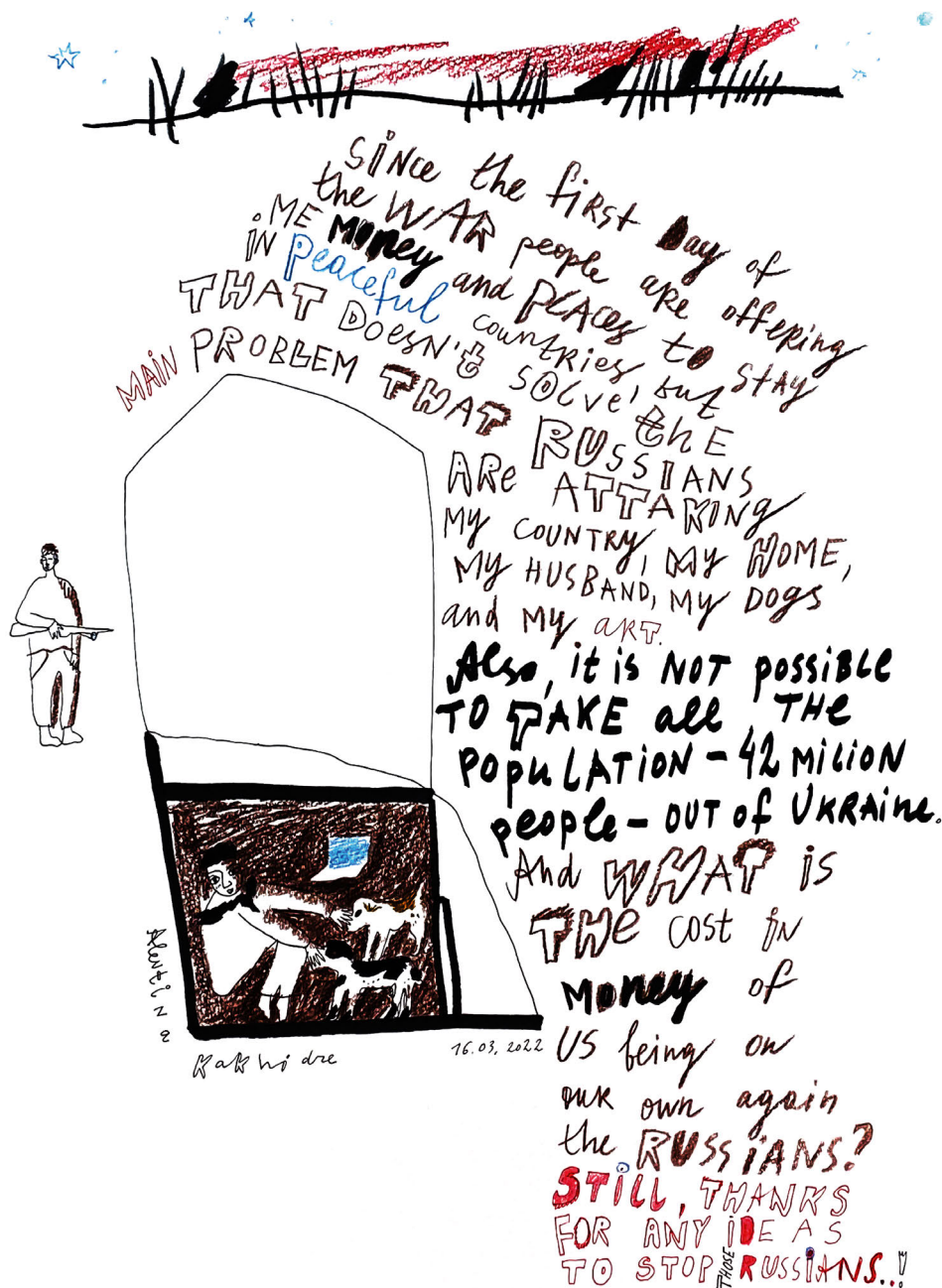




Fight for Right

Hanna Zaremba-Kosovych and Viktoriia Kharchenko
on the Experiences of People with Disabilities during
the Full-Scale Invasion

The conversation was recorded online on June 23, 2023

■ **Viktoriia Kharchenko (V. Kh.):** I work as an advocacy manager at Fight for Right, an NGO focused on supporting people with disabilities. Until February 24, 2022, I lived in Kyiv and worked exclusively in the public sector, where I was involved in various projects and in defending the rights of vulnerable groups.

■ **Hanna Zaremba-Kosovych (H. Z-K.):** I am the Head of the Community Strengthening Department at Fight for Right and also a researcher, sociologist, and anthropologist. Together with Viktoriia, in the spring of 2022, we began documenting the experiences of people with disabilities following Russia's full-scale invasion of Ukraine. I took charge of conducting interviews, while Viktoriia coordinated the process and managed recruitment. I wrote the report that summarized our work, and Viktoriia handled the editing.

■ **Natalia Otrishchenko (N. O.):** Thinking back to the spring of 2022—though it's not an easy time to revisit—can you recall what motivated you to launch this research initiative?

■ **H. Z-K.:** After February 24, 2022, Viktoriia and I became actively involved in efforts to save people with disabilities, doing as much as we could. I helped evacuate people from Lviv to the Ukrainian-Polish border. During that time, I started keeping a volunteer diary and realized the importance of recording the experiences of people with disabilities—not just those who were evacuated, but also those who remained in various regions of Ukraine. However, I quickly understood that I wasn't ready to conduct interviews at that moment, and

people weren't always prepared to share their stories. Even if they were willing, there was the question of whether they fully grasped the implications of speaking on the record. Personal family circumstances also played a role—by March, I felt too emotionally drained to dedicate myself to interviews.

Then, a more formal and bureaucratic opportunity presented itself. In one of our projects we needed to adjust some activities, and that shift gave us a window to start recording interviews. We realized we could incorporate this work into the project's framework.

We also had a network of human rights defenders for people with disabilities, built through warm and active collaboration even before February 24, in preparation for a possible full-scale invasion. After the escalation, we stayed in touch, checking on how they were and where they were. These were the first people we approached, asking, "Would you be willing to let us record interviews?" With these trusted connections, we felt comfortable sharing our thoughts about starting this work and received their support to proceed.

■ V. Kh.: My experience is a bit different. While Hanna was physically volunteering, I was abroad as of February 28, 2022, when we left. From that day, I started working on our hotline. We had opened a psychological support line before the war, but it soon turned into a hotline for evacuation calls. I took charge of medical evacuations, and my work at that time was entirely focused on talking to people—I didn't have the time to reflect or think about anything else.

By April 30, I finished my work on the hotline, and around that time, a donor we had worked with before the full-scale invasion approached us with an offer to use their funds for some of our initiatives. Then Hanna suggested documenting the experiences of people with disabilities, and I thought it was a brilliant idea. By then, I had already moved to the Balkans, and to better understand the context, I read extensively about the Balkan wars. But I couldn't find much about the experiences of people with disabilities in those texts. I didn't want their stories to be overlooked in the context of the Russo-Ukrainian war. Our goal became to document these stories—not in a legal sense, but from a social perspective. Now, I regularly hear from the people we've worked with, asking if there will be some summary of their experiences—whether in the form of a text or a presentation. It's important for people to see their experiences reflected so that they can read about themselves. We are currently finalizing the bureaucratic approvals for the report and hope to publish it soon.

■ H. Z-K.: I'd add that Viktoriia and I started exploring theoretical developments and advanced research related to disability and war together. We examined a lot of veteran experiences, from the First and Second World Wars, to the Vietnam War, the Iraq War, and the Russo-Ukrainian war, which was still called the ATO [Anti-Terrorist Operation] at that time. When it comes to people who already had a disability in the pre-war period, however, as opposed to getting it during the conflict, there's very little research on that.

We—or future generations—will need to write the history of the Russo-Ukrainian war, and it must be written as a cohesive narrative, not in fragmented pieces. When we do begin to write that history, we have to reflect the everyday lives of people from various social groups. Of course, there are shared experiences, but there are also unique challenges faced by people with disabilities, things that people without disabilities, or people with other types of disabilities, do not encounter. For example, someone in a wheelchair faces different challenges than someone who is deaf. It was important for us to highlight these differences.

I graduated from the Faculty of History, so I see this as an opportunity to create sources for future historians. But for our colleagues who are human rights defenders, there's also an immediate, urgent need. It was vital for us to understand these experiences in order to adjust our emergency response systems and advocate more effectively for the rights of people with disabilities during wartime. Recording these experiences provided the foundation for several other studies. For example, we examined the specifics of evacuating people with disabilities during the full-scale invasion.

It's important to note that for most of the narrators, sharing their experiences was incredibly significant. Some of them expressed it very clearly: "We realize how much the voices of people with disabilities go unheard—not just during the full-scale invasion, but generally, when it comes to other areas of society. We want our experiences to be preserved and hope that they will be considered when formulating policies."

■ N. O.: I'm really struck by your thoughtful and careful approach in deciding when to begin this work, as well as the fact that you've made such an effort to involve the community in these conversations and in exploring this field. Your goal to conduct research for change is so vital, especially in times of war, when we are all incredibly vulnerable. It's crucial to be sensitive to our own feelings and limits—knowing where we can or cannot go—and to be attuned to the feelings

and wishes of others. Could you tell me more about your team and who you've collaborated with on this initiative?

■ H. Z-K.: We had a psychologist who worked on the hotline, but she was also available to support our team and, if needed, counsel our participants themselves. Additionally, we had a very sensitive communications manager working with us. We spent a lot of time considering how to publicly announce that we were starting such a project and how to present the experiences we were documenting—how much of it should be made public or kept private. We had several discussions around these issues. Our team also included people who transcribed the interviews, some of whom are members of the disabled community. It's very important for us to involve them in any project as much as possible.

■ N. O.: Could you share how you planned this project, how you envisioned it for yourselves, and any key decisions you made throughout the process?

■ H. Z-K.: When the idea of recording came up, we discussed using the format of oral history interviews. We prepared several sets of questions that we wanted to address. We began by asking the person to tell us about themselves, then asked them to recall February 24, 2022, and from that point, they built their narrative. We also asked whether they felt the effects of their disability differently after the full-scale invasion, so they could highlight that aspect. We were interested in hearing from both women and men with disabilities, as well as those with visible and invisible disabilities. We tried to conclude the interview with more positive questions, asking about their vision of victory—where they see themselves when it happens. At the end, we would dream together about how it should be, and I found that dreaming to be a helpful part of the process.

The challenge for us was that we realized this project would be public, and part of our narrators' stories would also become public. We didn't know exactly how to handle this, so we had many discussions with our communications manager. We made sure to inform our narrators that, in addition to recording the interviews, we intended to use their testimonies in the media in a slightly modified form, and we asked for their consent. We were very transparent about this and kept records via informed consent documents. Some of the people we interviewed were from the public sector, so they understood how the information they provided could be used and trusted us as representatives of Fight for Right. There were no concerns or objections in these cases. However, I understand that there may have been people

who don't work with the media as often, and they might have been hesitant to be recorded.

■ V. Kh.: To find storytellers, we relied on the human rights network of Fight for Right, which includes people with various disabilities, from different regions, and with diverse experiences. These are our colleagues with whom we already work. Another group consisted of people we had helped evacuate. When we invited them to share their stories, we tried to approach it as gently as possible. Some of them had already participated in interviews before the full-scale invasion, while others had no prior experience or were hesitant about being interviewed. In reality, each experience was very different.

■ H. Z-K.: I took it upon myself to find people with intellectual disabilities, as I work directly with this group. I reached out to good friends of mine and asked if they would be willing to participate in interviews. There were some refusals, and I'm not sure if it was because they didn't want to talk about the war, or if it was related to the specifics of their disability. In the end, most of our narrators came from this close network, so to speak.

I also noticed that when we began recording in May of last year—the first conversation was held on May 11, 2022—people were more motivated to give interviews. There were fewer refusals at that point. However, by late summer and early fall, it became more difficult to find people willing to talk. I believe this was due to people's psychoemotional state. In the spring, we were all living through a very new experience, and I think there was a strong desire to share it, to talk about it. But as time passed and we began to adapt to the new realities, there was less of a need to define the experience, and perhaps it became more difficult to reflect on it. People no longer wanted to return to the past, and a new layer of reflection had emerged.

■ N. O.: If we keep in mind the goal of archiving these interviews to ensure that the experiences of people with disabilities aren't lost among the numerous war stories surrounding us, what policies do you have in place to preserve this data? How do you plan to organize access to these materials—who will have access, and when? How do you envision the future of these interviews as part of an archive? I'd love to hear your thoughts on this.

■ H. Z-K.: This is actually a very complex issue. Right now, we are storing notes, transcripts, and photos on a secure Google Drive provided by our organization. Regarding making them public, I understand how crucial it is to do so. There's a larger goal of writing the history of the Russo-Ukrainian war in a holistic way, and this project

will contribute to that overall mosaic, so it should eventually be made public.

We've signed informed consent forms with the people we've interviewed, stating that the materials will be archived. However, I believe that when it comes time to present everything we've recorded as a cohesive whole, we will need to discuss it with our narrators again and get their permission to make their stories public. This raises new legal and ethical questions for us—how to approach it in the right way. We may not receive permission from everyone, and we're uncertain what the security situation will be at that point. We don't know how people will feel about their stories once some time has passed. For those who have suffered from war crimes, people talk about their experiences in very different ways. The timing of their experience matters—whether it happened two weeks ago, two months ago, or six months ago. Many people want to forget their traumatic experiences and may not want to share them at all. So, creating an open archive will be a big challenge. I believe that part of the history may never be made public. However, the overall goal is to eventually make at least some of these materials accessible to the public.

■ **N. O.:** Because we are living through this event, it's hard for us to step back and view it as a whole. We also can't know yet what its long-term consequences will be for us personally or for the communities we belong to. So it's difficult, but also crucial, to talk about potential solutions and explore ways forward. We're discussing whether we need a single archive that can house various projects. If our goal is to write a coherent history, then this approach makes sense. However, there are legal and ethical concerns around obtaining consent from interviewees to share their stories. Many agreed to be interviewed for a specific initiative, trusting the individuals or organizations involved. These issues definitely need to be addressed.

You've listened to many stories, analyzed and reflected on them, all while navigating your personal circumstances. How did you take care of yourselves during this process?

■ **H. Z-K.:** At the time, I don't think I paid much attention to self-care. I was deeply immersed in my work, constantly focused on doing something for the people around me who were also experiencing the war. I didn't take breaks because I kept asking myself questions like, "How can I rest when there's a war? Is it relatively safe in Lviv, and do I even have the right to rest?" This mindset eventually caught up with me by the end of summer 2022, when things became overwhelming. I had to pause the interviews for a while because I no longer had the

emotional capacity to record or reflect on them. Now I'm trying to take steps to stay resilient—getting enough sleep, going for walks, and doing things I enjoy. But I'll admit, I'm not always successful.

■ V. Kh.: I think it's crucial to be honest with yourself and acknowledge when you're having a day where you simply can't function—you can't work, you can't be a support to others, and you're just not okay. The sooner you accept this, the better. Instead of pushing yourself further with guilt or overwork, focus on stepping back and taking care of yourself: get proper sleep, eat well (ideally something healthy), do something you enjoy, and allow yourself small, comforting pleasures.

■ N. O.: If you had the chance to advise someone who might be planning to conduct interviews during the full-scale war, what would you say to them?

■ H. Z-K.: I would suggest reflecting on the same questions you asked us, Natalia, and asking them of yourself. Why are you conducting these interviews? How do you plan to use them? What is the purpose behind these recordings? Then, ask yourself even more: Do you currently have the resources to carry out these interviews? What questions will you ask, and which ones will you avoid? Why do you think certain questions are necessary while others are not? Who is the person you will be listening to, and do you have the emotional capacity to truly hear their story right now? Lastly, consider what resources you might need to sustain yourself during and after the interviews.

I truly enjoy recording interviews, doing fieldwork, and immersing myself in research—it's something I'm passionate about. But now, over a year since we conducted these interviews, I sometimes wonder: How did I manage to do it? Where did I find the strength? Did I deplete myself in the process? We must be acutely aware that interviews involving traumatic experiences can deeply affect not just those we speak to, but us as interviewers as well. These stories, combined with our own experiences of living through these times, leave an imprint on our mental and emotional state. It's essential to be attentive—to yourself, to the people you interview, and to those in your immediate life, like friends and family. These experiences inevitably shape your interactions and communication with others.

■ V. Kh.: When you're in the midst of a significant event and working constantly, it's difficult to step back and gain perspective on your own state. It's vital to either remind yourself—or have someone remind you—that what you're doing is meaningful.