

Women with disabilities — Human Rights Activists: Stories of Inclusivity

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How barrier-free is our society? What are the ways to inclusivity for discriminated groups? What is it like to be a woman with disability and all the while protect human rights in Ukraine?

We present “Women with disabilities — Human Rights Activists: Stories of Inclusivity” — a project made under the auspices of the WILPF and the Gender Equality and Women’s Rights Workgroup with the Civic Solidarity Platform (Ukrainian part of the sub-project “Promotion of Gender Equality in the OSCE Participating States as Contribution to Prevention of Conflicts, Strengthening of Peace and Protection of the Women’s Rights” as part of the DRA project “Strengthening the Cooperation within the OSCE Participating States: Promotion of Human Rights Protection — Strengthening the Cooperation, Sustainability and Efficiency” with financial support from the Ministry of Foreign Affairs of the Federal Republic of Germany. Activists of Kharkiv Regional Foundation “Public Alternative” interviewed twelve Ukrainian women with disabilities — human rights activists: Daryna Brykaylo, Olena Vyshnya, Valentyna Dobrydina, Daria Korzhavina, Iryna Larikova, Rayisa Kravchenko, Iryna Sarancha, Yuliia Sachuk, Uliana Pcholkina, Tetyana Furmanova, Nataliia Morotska and Iva Stishun. We asked the project participants to give answers to the same questions so as to keep the conversation going in the same direction. As expected, the answers were most diverse: our respondents shared their personal experience and each story proved to be unique.

Important note: the respondents were interviewed in August-November 2020 — the period when the whole world was hit by COVID-19 the hardest. Same as many countries worldwide, Ukraine imposed quarantine restrictions.



Auswärtiges Amt



This initiative is the Ukrainian part of the subproject “Strengthening a gender equality component in the OSCE area as a contribution to conflict prevention, sustaining peace and protecting women’s rights” of the project “Strengthening Civil Society Cooperation in the OSCE Region: Advancing Human Rights Defence – Expanding Impact, Sustainability and Acting Capacity” realizing by the Civil Solidarity Platform.

INTRODUCTION

Out of 16 standards set forth in the OSCE Guidelines on the Protection of Human Rights Defenders, there is one concerning the minority human rights defenders. Even though it is about discrimination and the people promoting defense against discrimination, it contains signs of discrimination itself. The standard specifically addresses the matters of violence and hate crime, yet it lacks focus on the risk of a person to stay excluded from the social discourse resulting from the absence of accessibility and/or equal treatment. These are the barriers facing the human rights activists who defend the human rights of the people with disabilities. Such human rights activists are often treated as of minor significance and their activity is regarded as solely focused on acquisition of social guarantees rather than defense of fundamental human rights and freedoms. Moreover, these human rights defenders are often people with disabilities themselves who have to deal with the additional barriers so as to be heard by the society, the authorities and their colleagues from the human rights community. This target group is not an object of hatred in the society but discrimination against such people manifests itself through the common perception of disability in the context of charitable and healthcare model, as well as inadvertent exclusion of the people with disabilities from social life.

It should be noted that women with disabilities are facing even more barriers while being human rights defenders and activists: in addition to discrimination by disability, they are also exposed to the gender-based stereotypes that are quite common in our society. According to the UN Guidelines “Women and Girls with Disabilities Human Rights” (Права людини жінок та дівчат з інвалідністю), disability occurs to 19.2 % of female population aged over 18, compared to

12 % for male population of the same age. Only one-third of women of the active working age are employed. 65 % of women with disabilities visit the doctor less than once a year and 76 % of them are unable to visit their gynecologist, because their offices are usually above the ground floor in a building that has no elevator. Therefore, women with disabilities who are human rights defenders and activists require special support from the society and the human rights community: to improve visibility of their performance, to enhance accessibility of the career enhancement, specifically in the sphere of human rights, protection against violence, abusive treatment and neglect of their needs in the context of their particular vulnerability.

This project is an endeavor to make the performance of human rights defenders and activists more visible in the society and the human rights community. For this purpose, we have collected stories of life and work of the women with various disabilities who defend the rights of the people with disabilities so as to demonstrate the importance of their work to the society.

Visibility of human rights work of the women with disabilities is the path toward visibility of the problems and barriers the people with disabilities have to deal with and the insight into how these barriers can be removed. It is important to involve women with disabilities in the current human rights classes and discussions, to help them overcome their physical and informational barriers, expanding the public awareness to promote a dialogue with the human rights activists defending the rights of the people with disabilities as equals.

M. Yasenovska,
President, KRF “Public Alternative”.

Defending the human rights for me — this is the path of the warrior. You are building strategy, thinking about every step, you repeal the blow, and attack at the right time to achieve the maximum result.

**Uliana
Pcholkina**



There can be no “rightly” rights or “leftly” rights. Every right of every person matters

Uliana Pcholkina, Ukrainian karate pro, social activist and a TV presenter. Finalist of Miss Wheelchair World 2017 (Warsaw, Poland) — first international beauty contest of this kind, Woman of the Third Millennium 2016, Woman of Ukraine 2019

What does defending the human rights mean to you? Just how is this whole thing about you, exactly?

My first encounter with human rights took place in childhood. My brother had a disability and I used to be always there for him, defending his rights. In the nineties and the noughties, the society had a very relative concept of what disability really is and who the people with disabilities are. Well, I would always defend my brother. Following the injury at the age of 21, I joined the category of citizens who are not particularly protected in Ukraine. When you find yourself in a situation like this, you become curious about your rights and begin studying about them. Afterwards, it's not that hard to defend the others. This is how it worked for me with human rights: evolving from my own needs to extensive defense of human rights of the others.

Can you recall your first experience defending human rights? Did you act on your own behalf or was it to the benefit of somebody else?

My brother's disability began to show when he was in the first grade. A dystrophy. It started showing on his face first. He looked kind of odd and he was moved to home schooling. It was apparent from his looks that he had a disability and I would protect him from the others even in public transport. People would regard him curiously, like, “now what is there?” Not “who” but “what”. This is how deep the roots of my human rights activities go.

What is driving you to break through the barriers?

I have no idea what can motivate one to break through the barriers... It's only natural that nothing comes without a barrier. Nothing at all. And I'm not just talking about the barriers around you. No accomplishment would come without a certain effort. That is why my goals motivate me to go on, breaking any barriers arising on my life's journey.

What kind of barriers do you encounter while defending the human rights? (Are they unique or universal?)

Apart from the institutional barriers, I think there is this one common problem when others would not understand that the rights of the others matter as much as their own. Whenever making a decision, one needs to change oneself, thereby making a stand against any stereotypes or injustice.

Can you recall any particular accomplishment in the sphere of human rights protection that you take special pride in?

Well, I can hardly recall anything in particular because I am not a defender in the classical sense of word. I mean, I am a person who always stands guard and defends, having the ability, skills and experience. So I wouldn't single anything out. Maybe there will be some accomplishments yet. (grins)

Did you or the people you protect feel any impact from the COVID-19 quarantine restrictions?

Yes. I mostly deal with the people who have spinal injuries and use wheelchairs. Our category is particularly exposed to quarantine restrictions, because a wheelchair is a means of carrying the virus: it's hard to clean, it's hard to operate. For better understanding of the

problem, you should know that our healthcare system is not fit for provision of services to the patients with disabilities. A lot of my friends have already recovered from COVID-19. A colleague of mine, the leader of our organization in Zaporizhzhia, was delivered to the hospital on the floor of the ambulance van because there was no one to lift him upright. Unable to get to the bathroom or to have a shower in the hospital, he survived in terribly inhuman conditions. There was no way out so he spent three weeks out there hopping from stool to stool, just to get to the bathroom and back to bed... It was plain awful. Being people with injuries and using wheelchairs, we understood the needs of our category like nobody else. As soon as the quarantine had set in, we realized what needs to be done and how to support our category and our leaders. We started "The Helping Wheels" — a project under the auspices of the Renaissance (*Vidrodzhennia*) Foundation where we provide psychological assistance, consulting services and guidance to the people who are changing their occupation or become students. People are filling out the question forms, we collate the information and provide it upon request. Under this project, we have provided the incontinence tools requested by the people. People are in the financial squeeze, more and more finding themselves in dire straits after losing their jobs. To find a new job is harder than before the quarantine. Strictly speaking, we took care of the others. It should be noted, not a single ombudsman, appointed by the government or the President himself, bothered to introduce any programs necessary to people with disabilities. To put it bluntly, the government has forsaken us.

What is paramount for the promotion of the inclusive communication environment in the society?

A simple question at first sight. But so many components. It is really a problem of upbringing. We should not enforce our stereotypes onto our children. They need not be specifically lectured on tolerance and inclusivity lectures. On the contrary, we need to foster intolerance toward

violation of human rights. Kids actually have no problems with the people with disabilities, unless the adults lash out "Get back!", "No!" or "Something's wrong with this man/woman!" at them. Adults indoctrinate them. We all need to change together. Change our vision of the world. Respect a human in every human being rather than focusing on our differences.

If you could compare human rights activities to any extreme sports, what would that be?

Being a karate athlete, I frequently compare my activity to this sport. Karate is a strategic fight where the parties exchange blows but the common rule is — cause no harm to the opponent. You lose points for smashing the opponent's face, using excess force, however inadvertently. There is strategy in this, a philosophy, "the path of the warrior", the path of the defender of any rights, because you cannot assault — you have to retreat or even concede a bit here, or really make an effort there, all for the sake of great accomplishments. And you need to be philosophic about what's happening around you. You need to combine strength and wisdom, otherwise you might fail.

Is there anything that you find annoying or sapping your motivation?

I am annoyed by the people who manipulate their disability status so as to attain something material, be it billions of hryvnias or simple "bring me that cup now" whenever the person is perfectly capable of fetching the cup personally. Unfortunately, manipulation and abuse of the status or the very fact of disability are not infrequent in this country. Disability is neither benefit, nor the loss. It's a social status, that's all. The government shall promote equal opportunities for every citizen. It's a complex problem, actually. Just the same, the abuse of one's disability status is annoying like nothing else.

What is the most common stereotype about yourself that you find to be profoundly inane?

A common stereotype? (*laughs*) The one that I shall give birth to a child, no matter what. I am 37 years old, “no longer a girly”, so I must have a baby. Anyway, this stereotype has nothing to do with disability.

Are there any stories that inspire you? (books, movies, music)

I can't think of a single story right off. Generally speaking, I am inspired by the stories about hardships one has to go through in life. Not just a “successful accomplishment” and “atta boy” story, but a story of a path taken by a character so that you can see how worthy the result is. Stories like that truly inspire me. Very often we only see a bright image instead of the blood and sweat one sheds on the path toward success.

What does it take to make this world a fair place?

In a nutshell, this world needs reciprocity.

What does it take to be a human rights activist? Do you consider yourself such an activist?

Well, you know, whenever I heard a “human rights activist” or a “human rights defender”, I used to picture a stereotyped image of an attorney or a lawyer who gets things done. Over the years came the understanding that I am a human rights activist as well, because I defend the rights of a certain category of people. I defend my own rights not just as a person with a disability but as a woman as well. That makes me a feminist with a disability who cares a lot about many things. I stand with the LGBTIQ community and whenever it comes to defending someone's rights, I care because I know full well what it feels like when your rights are violated. There can be no “righty” rights or “lefty” rights. Every right of every person matters. So yes, I am a human rights activist, a defender, because I care.

Interviewed by Olena Zinenko

The human rights activist must share values, know a lot, and not take failures to heart.

**Rayisa
Kravchenko**



Fighting for human rights is the mission of my lifetime

Rayisa Kravchenko, initiator of the Dzherela Charity helping the persons with intellectual disabilities, founder and executive director (up to 2019) of the All-Ukrainian Community Organization “Coalition to Protect the Rights of the Persons with Intellectual Disabilities”.

What does defending the human rights mean to you? Just how is this whole thing about you, exactly?

Fighting for human rights... you know, I could write volumes on this topic. For me it is the mission of my lifetime. Until the day when I realized that the rights of my son need to be protected, I had a profession and a job that I dropped eventually and joined a human rights organization, two of which were initiated by me.

Can you recall your first experience defending the human rights? Did you act on your own behalf or was it to the benefit of somebody else?

I was fighting for the rights of my son, his right for education, when he first went to school. He has intellectual disability (Disability Group 1) and considerable mental disorders, so he needed care. He went to a regular preschool, the so-called random inclusivity, and then went to a regular school. The kids were mean, the teachers suggested I should rather take my son to a special school, but I resisted all this pressure right until the day somebody beat him up and he walked all day with a load in his pants. And nobody bothered to give me a call, to tell what has happened and have me take him home. Only then did I take him to the school for kids like him. The commission assigned us to special school No. 17. I went there, spent 40 minutes (*grins*) waiting for the headmistress just to have a short talk and to show the assignment papers, all the while being witness to indifferent treatment out there: the boys were fighting and every single teacher or administrative officer passing by would not bat an eye until the janitor broke the fight at last. It took me these 40

minutes to observe and realize that this is not the right place for my son and, as the headmistress never turned up, I went back to the local board of psychology and education and asked for assignment to some other school. It was boarding school No. 26 where we were assigned to a great teacher. Valentyna Mykolayivna was an elderly woman whose career dated as far back as WW2. She shared precious knowledge with my son and fostered many important habits in him: neatness, proper response during the conversation and communication. It all was just great. We keep fond memories of her. A year later, we were notified that my son is admitted to his previous school. Now, the kid never set his foot in that school for a year, yet, officially, he was a student there, and no audit department found any financial improprieties. I was asked to sign a letter of resignation quietly. I said, I never signed your school entrance form in the first place. Therefore, someone else did it for me. Therefore, someone kept my records there. I had a call from the school one day but I told them, “My son officially has been your student for over a year, even though no one has seen him in the class. What if I were an alcoholic and my son were living somewhere out in the cold, hungry and beaten, and you had no idea about it?” I was so emotional back then in my desire to protect the child nobody else would care for. But let’s be rational for a moment here. He is one of a dozen students. Funds allocated to each student are modest but the economy — special education in our case — comprises of these small destinies. This case made me think long and hard about who really cares for that kid and how to protect its rights.

What is driving you to break through the barriers?

Well, you know, it’s all standard here: I am a mother and a person with disability. There must be a maternal instinct. Our All-Ukrainian community comprises of the active mothers with the strongest maternal instinct. When a child is

over thirty-six years old (like my son) and it is still vulnerable, the mother will be driven by the maternal instinct forever. My son is no more capable of protecting himself than a 5 or 6-year-old child. Physically, he is very strong and he rebels from time to time. Yet no one really notices or reacts to these fits of rebellion. No one but family. This country does not exercise any “Western” approach to matters like this, unlike, say, the U.K. where the government undertakes to protect the rights of the people who are not even aware of their rights. British system sometimes protects such people from their relatives and parents.

What kind of barriers do you encounter while defending the human rights? (Are they unique or universal?)

The way I see it, barriers are all around me: barriers in personalities of the people with disabilities, barriers in approaches of the government and the society, etc. A human being with mental disability is the creation of the God who has sent it to this Earth with a mission of some kind. This human being is as important as a president or a hetman, whatever. Personally, I find it amusing how other people can be awed by the pop stars or famous athletes. Yes, they are doing their job and get paid accordingly. Okay, fine, any caretaker who cleans the streets, properly or badly, or any waiter in a restaurant who serves food and cleans the tables, they all are doing their job, either promoting the public welfare or being in the way of it. So how come the people are unable to understand that a person with disability is one of us and we need it for what it can and is able to do? It is also known as “stigma” — these people are perceived as inferior. And it is everywhere — in politics, Constitution, etc. Take, for example, Article 70: “Citizens deemed by a court to be incompetent do not have the right to vote”. The law on people with disabilities makes provisions for inclusivity of certain target groups in the community and outlines regulations regarding their competence but it does not address the issue of how to counter segregation. This law contains elements of discrimination with regard to our target groups.

Can you recall any particular accomplishment in the sphere of human rights protection that you take special pride in?

I take special pride in the organizations I have founded, especially the *Dzherela* Charity, which caused changes to at least two hundred inhabitants of Kyiv who now live the eventful and quality lives as members of the society, enjoying positive emotions, making mothers happy. This is truly the biggest accomplishment. Formally speaking, though, we managed to establish two public institutions, as if bursting through the wall headfirst: “Social Adaptation Complex” and a communal permanent home for people with mental disabilities where each tenant has a separate room and the staff is ready to help. Well, there is the *Trampoline* as well — a rehabilitation center that provides daily services to 124 inhabitants of Kyiv on three sites.

Did you or the people you protect feel any impact from the COVID-19 quarantine restrictions?

COVID-19 epidemiological response arrangements coincided with the healthcare system reform. In my interview to a TV channel, I mentioned a psychiatric genocide that took place this year.

Robert van Voren, Chief Executive of the international foundation Human Rights in Mental Health-Federation Global Initiative on Psychiatry, who actually helped to establish our organization in 1994 and has been engaged in de-institutionalization projects in Ukraine, conducted a study back in 2017 to find out that 60,000 persons with mental and psychiatric conditions in Ukraine were held in detention facilities. This is every fourth adult diagnosed with disability of psychiatric nature. 30,000 of them have a chronic psychiatric diagnosis and are kept in clinics. Following the healthcare system reform, a lot of these people were kicked out into the streets. Daily services in all rehabilitation centers were suspended for six months due to the quarantine restrictions. Family members and next of kin were prohibited from visiting the residential care facilities. In such critical situations, one shall always keep in mind that a

person with intellectual disability does not understand what is happening to it. Such persons are unable to control their actions and cannot comply with the quarantine restrictions. A person with intellectual disability cannot wear a mask because it inhibits any communication. My son would just rip it off and toss away. Same as he would do to the money. I mean, I would give him some money and he — a 36-years-old man — may have a nice walk, buy a loaf of bread and some ice cream. But on a bad day he would tear the money to pieces or toss it under a bush and just walk away. Persons with behavioral disorders are hard to deal with. No mother can predict whether or not her child will jump out of the window or burn the house down. These people require constant and systemic assistance. And here we have it, no visits to rehabilitation center. Just like that. And there are people used to be taken care of, used to the visits, etc. Not just one or two — 30,000 tenants are unable to see their relatives for a total of six months. Sadly enough, I have information about people dying in this situation. I can go on and on about how special these people are but no one can radically and abruptly change their lives. I had it tough this year as well. They shut down the full-time residence facility for quarantine and quickly shipped my son back to me. So he spends six months with me, asking to go back to the facility and his 15 friends out there. He kept asking me, “When do they re-open the Complex and I can go back to the dormitory?” and I could not even give a clear answer. His natural reaction kicks in. He pushes me, I fall down hard, my cancer condition comes back, so I start getting ready for a surgery. Luckily, three month’s therapy worked and the surgery was called off. Whatever... now my son scares me. This is my personal story. But there are mothers out there — chronic insomniacs because their son or daughter would keep them awake all the time. Or developing cardiovascular conditions, which is pretty common with them. We are going to publish the findings of our recent study soon but I can tell now that 74 % of mothers of adults with intellectual and behavioral conditions report psychological problems. I mean, one feels troubled, and that’s one major criterion of the quality of life.

What is paramount for the promotion of the inclusive communication environment in the society?

As far as our category is concerned, we are facing three tasks. Firstly, the attitude.. One should help regular people understand that people with intellectual disabilities need to stay among regular folks, same as the blondes, excuse me for the stereotype. God has created His rules. People with intellectual disabilities come to this world and live their lives, so there shall be the rules of life for them as well. What are those rules? Procedures and regulations everywhere — in schools, stores, etc. But most strongly they manifest themselves in courts. A judge asks, “Do you understand who is being tried and for what?”, gets a positive answer and that’s it. Nobody bothers to ask the respondent what exactly he or she understands, let alone explain the consequences of each particular statement. So the person is declared incompetent. This status means civil death. The person gets deprived of all civil rights. As far as attitude is concerned, it costs little, if anything at all, because it’s in our heads. Procedures, on the other hand, entail expenditures. Implementation of procedures requires assistance, time, etc. There shall be a special format, in a simple language. If it is a printed text, it shall be easily readable. We need to have statutory and procedural guidelines, and the scientific research in the context of potential solutions to the problems of the people with disabilities. We need a resource. The resource depends on what the government wants, we know that. At the fifth anniversary of the Defectology Institute, I was asked to share my thoughts regarding the collected edition “Learning Disability Criteria”. But all kids have a capacity to learn! This is what they taught me in Europe. I just returned from London where I studied social work at the London School of Economics. I was lucky to go to the school of social work. I was mightily impressed. Back then I realized that this country is at least 50 years behind the civilized world. There is so much work to do here.

If you could compare human rights activities to any extreme sports, what would that be?

I don't know. One needs to feel the sports. As a child, I tried the artistic gymnastics but this is definitely not the kind of sports for comparison. As for the others, I wouldn't know. I don't feel them. One needs to stay calm here, like, you know, the chief of the Soviet secret police once put it: clean hands, a cool head and a burning heart. One needs to share values, know a lot, look ahead, never take negativity close to heart, and at least try to avoid burning out.

Is there anything that you find annoying or sapping your motivation?

Emotional bias. It's as if you are wasting your life by burning your emotions out on the officials who don't care for your child. Once you get started, that is. Here I am, writing a letter and worrying like hell. And I say to myself, come on, why worry, it's your life. These are your hours, your minutes, and you waste them all on someone who is not worth your time and nerves. Well, something like that. You should spend your time on yourself. Which is, I hope, is still possible in this country. I understand, I see and hear a lot from the people who know better than I that this country is being destroyed. I try to work out my strategic vision and keep working.

What is the most common stereotype about yourself that you find to be profoundly inane?

Our target group, you mean? Same thing all the time: they are inferior, they belong in a residential care facility.

Are there any stories that inspire you? (books, movies, music)

I am inspired by the nature. I like picking mushrooms. It's September, agarics are coming. I know places where I usually go mushroom hunting. I am particularly awed by Golda Meir,

her life and her fundraising strategies. Recently I came across a volume of diaries and letters by Gorki. He was an extremely talented writer, but still he did a lot of promotional work, PR, and his alias was remarkably spot-on. To come up with something like that, one needs to be talented from birth. Technologies will only take you so far, you know. It's like Kama Sutra — it's knowledge about the right to be happy in love. And love is something else entirely. It's something supernatural.

What does it take to make this world a fair place?

This world cannot be a fair place. The Bible says so. Indeed, we are social beings and creatures of nature. You know, my Latin teacher in the university kept saying that the phrase “Homo homini amicus est” (Man is a friend to a man) in the Ancient Rome really meant Homo homini lupus est (Man is a wolf to a man). In a way, it's like “cooking the books”, only in relationship. No, nothing's far or just. Here's an example: Yanukovych once signed a decree on “The Year of Social Justice in Ukraine”. I mean, it was Yanukovych who officially decreed how to build justice in Ukraine.

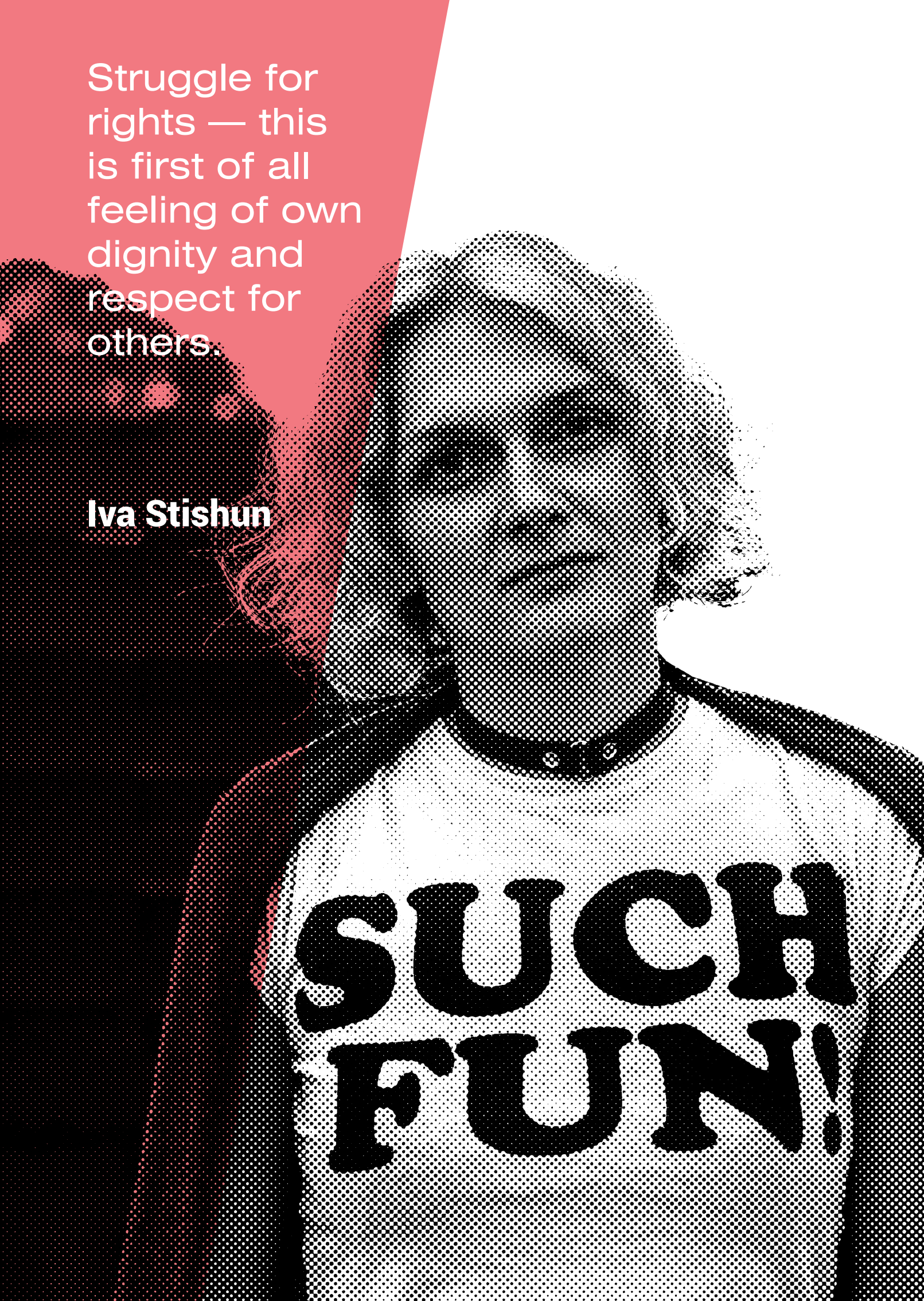
What does it take to be a human rights activist? Do you consider yourself such an activist?

Yes, I am a human rights activist. Protection of the rights of people with intellectual disabilities is my profession, so to say, day in day out. I work as a professional. I have necessary contacts. I spoke at the UN committee with my report on the rights of people with disabilities. So yes, I am a human rights activist. Suggestions? Either do not become a human rights activist, or be professional. Well, unless it concerns you personally and your own child. On second thought, if it is about you and your child, be careful with the methods you use to assert its rights.

Interviewed by Olena Zinenko

Struggle for
rights — this
is first of all
feeling of own
dignity and
respect for
others.

Iva Stishun



**SUCH
FUN!**

I'd liken my human rights activities to platform diving

Iva Stishun, *artist, activist, social arts curator*

What does defending the human rights mean to you? Just how is this whole thing about you, exactly?

It suddenly dawned on me one day that no one is going to fight for my rights. There are no “special people” who are going to do it all for you, instead of you and... without you. These are to be joint activities where each and everyone shall act in concert with the others. Fighting for one's rights means, essentially, the sense of one's own dignity and respect for the others.

Yes, it is all about me, because one day I had enough of the cinemas without subtitles and started looking for the tools and means to make movies more accessible — not just for myself but for the others as well.)

Can you recall your first experience defending the human rights? Did you act on your own behalf or was it to the benefit of somebody else?

I had to protect my right to watch the movie with subtitles, claiming it as a gift to my birthday in the cinema network which I frequented. Promo code was effective for seven days only and no subtitled movies were scheduled for that day. I had to negotiate with the operators who flat out rejected my suggestion to extend the effective period of the promo code. I made a post in social media and it worked — they suggested I should get a new promo code after the older has expired. Along the way, I made acquaintance with the network managers. One day in transit through Kyiv, I attended their accessibility forum where we had a quick meeting to negotiate the option of subtitling in general so as to attract the audience and to meet the requirements of distributors.

My heart was racing on both occasions but I felt I was doing something good. It was important to show and to explain what exactly people like you — people who lost their hearing or have poor hearing — need, and to start a normal dialogue.

What is driving you to break through the barriers?

I am motivated by discomfort and irritation. I can no longer tolerate total inaccessibility 24/7. I am personally looking for technological tools and urge the others to remember when they invite me to some events, training classes, etc., or provide services elsewhere. I need accessibility, I crave it like fresh air. This is my major motivator!

What kind of barriers do you encounter while defending the human rights? (Are they unique or universal?)

Misunderstanding is the biggest barrier. Both sides are wary and uninformed. I try to stay positive and patient, explain the same thing over and over again with a smile. A hard and tiresome mission. This fight draws all of my resources.

As far as the unique aspect is concerned, I don't look like a person who is hard of hearing. I don't wear a hearing aid and my speech is fine. People hardly ever notice or quickly forget about my hearing problems. They also find it curious about my totally unimpressive sign language skills, as I never even talked to the people who are unable to hear up until I turned 38. I actually started learning the sign language a year ago.

Universal... I guess, it's when people treat you as a sick or weak person who is unable to travel or make money unassisted, as someone who needs care, etc. People tend to feel ill at ease, somehow disquieted, instinctively fearful next to a person with disability...

Can you recall any particular accomplishment in the sphere of human rights protection that you take special pride in?

I supervise master classes in sculpting by touch we give together with a sculptor and a painter/art-therapist. And the students who attend the classes are not necessarily visually challenged! This is how I discovered the world of the people with low vision, their needs and their amazing

abilities. This is how I came to promote their involvement in joint activities as equals. This project is particularly important to me. We made it free of charge and I intend to carry on with it, because it is very important!

It also felt great, to receive the award from the UN International Fund for the exhibition dedicated to domestic violence ("The Room Where Pain Lives"), but when you see a blind boy deftly sculpting away with his fingers, you feel the joy and pride that are far more rewarding!

Did you or the people you protect feel any impact from the COVID-19 quarantine restrictions?

Yes, I did. Quarantine has sent me deep into depressive mood, isolated from my regular communications and job. It took me a while to get used to faces covered with the masks. I can no longer read the lips. Can't even tell if someone is addressing me. Online delivery couriers kept calling me despite my request to send me messages, because my hearing is poor. Once again did I feel how dependent I am on those around me, not to mention the feeling of vulnerability and weakness.

Online events and conferences were no longer an option due to the absence or poor quality of online subtitles. My sensory senses and the need to touch were all shot. It was a difficult period indeed. Keeping in touch with my significant other, my son and a friend of mine saved the day.

What is paramount for the promotion of the inclusive communication environment in the society?

The ability to overcome the fear and mistrust. People are afraid to do something "wrong" or get in the way with their "special needs". As the saying goes, for one that is missing there is no spoiling a wedding.)))

I believe, paying more attention to each other will promote better understanding and acceptance. Unfortunately, the quality of life and the abundance of day-to-day challenges and problems are driving us apart.

If you could compare human rights activities to any extreme sports, what would that be?

Platform diving.

Is there anything that you find annoying or sapping your motivation?

Yes. Fatigue from having to spend more resources to hear, to understand, to get that sense of being behind the glass with the entire world on the other side being a feature film without a sound. There are times when it feels that without hearing you can't do anything proper, misunderstanding everyone around you, acting as a retard and hampering the prompt response of the others to the situation at hand. The feeling of detachment from the things happening around you here and now, especially when the others wave you off, saying "Never mind" or "No time to explain"..

What is the most common stereotype about yourself that you find to be profoundly inane?

The one that deaf people are necessarily "deaf-mute". And that all people with poor hearing are alike, living in silence, unable to listen to the music, to dance, etc.)

Are there any stories that inspire you? (books, movies, music)

None. I used to read a lot in childhood and watched subtitled movies instead of engaging in live communication and socializing. Reality proved to be quite different and I am exploring it anew. I am inspired by the active, eventful life where you need not be a superhero constantly overcoming the obstacles and fighting against the evil, or a victim who needs care and protection. I am inspired by being myself, simply being able to breathe freely here and now.)

What does it take to make this world a fair place?

The world is a hierarchy where everyone is competing to be faster, stronger, bigger. If we stop competing and start interacting with empathy and patience, everything will change through mutual enrichment and the newly found balance. In what

I am doing, people always matter the most, not the result. This is why I called my first project “The Human Factor”. We all have vulnerabilities but together we are stronger and more capable.

What does it take to be a human rights activist? Do you consider yourself such an activist?

It came to me as a big surprise that anyone can be a human right activist, not just people with a law degree. I found this out in the school of the Educational Human Rights House Chernihiv. Human dignity is the most important, core value. I lack competence and experience for some global and specific projects, but small steps on the local level, informing the people around me is my own intuitive path toward protection of human rights. Hopefully, my activity is not wasted.

As a woman with disability, what are the challenges you have had to deal with so far? Is there anything that you find scary, insulting or discouraging?

I used to fear traveling alone. Or having to deal with bureaucracy. As a mother, I unwittingly acquired experience in protection of the child’s rights. And my own rights as a mother with disability. Maternity taught me to have no fear, forget the suffering, and to keep my head high, move on and protect my own dignity. I quit memorizing negative events and switched by focus on to the positive instead, thereby finding the strength to carry on! Aggression and pain piled up just the same, but it only motivates me — never surrender!!!

**Daria
Korzhavina**

As a human rights
activist you should
not be afraid
to say how it is,
but worth to
understand
exactly what you
are talking about.



The biggest barrier in defending the human rights is the lack of understanding the sense of a problem.

Daria Korzhavina, journalist, human rights activist, co-founder of Fight for Right NGO

What does defending the human rights mean to you? Just how is this whole thing about you, exactly?

We all are working for the common cause, or so it would seem, but what does fighting for human rights mean to me? First and foremost, it is about standing up for the rights, just to make sure no one forgets about these rights. This is what comes to mind first, because a lot of people in this country, unfortunately, have no understanding of the law, even their own rights, even the rights to the simplest things. Or they may be well aware of their rights but have no idea about how they can be exercised. That is why it is about education, and that applies even to the people you work with. And your mission is to announce to your audience, here's the right you got, and yes, you need to use it, exercise it. Again, it's about education and asserting your rights. For the people have no clue why they need it and what's the problem. Take, for example, the LGBT community, and the first question that pops to mind, what rights are you, folks, missing? You have all the rights, so what else do you need? Actually, it's the same with the people who have disabilities, who wonder what's in it for them? And you go on explaining that it's not a folly or a whim of some visually challenged person, but a totally natural right, the one recognized and legally documented worldwide.

Can you recall your first experience defending the human rights? Did you act on your own behalf or was it to the benefit of somebody else?

One is acting on one's own behalf all the time, actually. This is how it usually goes, an active person, even a visually challenged one, is working, going places, shopping in supermarkets, enjoying oneself in cafes, visiting public

institutions, etc. Assertion is always there, in the background, because you still may get yelled at from across the bus, something about your disability, your ID, escorts, things quickly escalating into a full-blown conflict. This is humiliating. There's no need to involve everyone around you into this. And so it happens that you are making a stand all the time, right from the moment when you go down into the subway and start explaining, "I am going to be late for work, do not hold me up, no, I don't want to wait for an escort, and yes, I have the right to waive an escort", and they start grabbing you instead, and down to the moment when you turn up in a polling station and start explaining that you have every right to step inside the voting booth with or without the escort, and cast your vote, because there is no other way, officially, in this country so far. In fact, my career as a human rights activist started unexpectedly. After the school, I hardly ever bothered to think about it all. I just went on with my classes in the university for quite a while, living my own life, until a friend of mine asked me in 2015 to substitute her for a dialogue in a theater. She was supposed to play her part out there. So I go down and meet there one Ihor Bondarenko, a sign language interpreter, and things evolved ever since. We were just staging our first performance, conveniently dedicated to the people with disabilities taking part in the election process. It was around the time of the real elections. So this is how I got myself involved in it all.

Cognition through cultural practice?

You got it right, actually. I am the kind of person who, whenever something's getting to me, there is an itch, a burning sensation deep inside, I am on fire, and I can't help getting in the deep of it somehow. And it suddenly dawns on me that it's not only about my own problems, it is about the people who have poor hearing and their problems, something I have never thought about before. It is absolutely

normal here, until people experience these problems firsthand. Otherwise, they wouldn't even think twice or may be totally unaware about things like these. This is how it all began for me, it only took a spark, so to say.

What is driving you to break through the barriers?

Faith. I am so optimistic, people sometimes call me an idealist. It makes them awed how strong my faith is. Then there's other people's experience. I would watch them start working and think to myself, come on, you can do it as well. Myself, I felt that things are changing, bit by bit, very slowly, not as fast as one would like, but things are changing in people's heads. And I sincerely hope that our society will heal itself, sorting out all these demons and getting rid of all the stereotypes somehow. It feels great when you talk to someone, explaining things, and you start getting feedback (truth be told, such people are few and far between), and then you notice that your companion starts listening and thinking, it gives you probably one of the greatest sensations.

What kind of barriers do you encounter while defending the human rights? (Are they unique or universal?)

Most of the barriers and the root of all problems are inside people's heads. The biggest barrier is lack of understanding. It's individual. And it tends to evolve from individual into the common. For example, you are on your way to meet some people, a regular conference at Kyiv City Council, to discuss some educational, inclusive, another really "cool" project, just like many before, and you see it's so convoluted they feel the need to reach out to the others. If it can't get through the head of an official, or public officer, Member of Parliament, city council officer, chief of department, there will be no understanding nationwide as well. This lack of understanding ultimately makes people wonder what this whole thing is all about and who really needs it. And every time you sit at such conference, you often know right away (some gut feeling that comes from experience) who is with you and who is just coasting.

Can you recall any particular accomplishment in the sphere of human rights protection that you take special pride in?

There are endless barriers to overcome. Myself, I am very proud for our organizations and the projects we have launched, such as Vicky and Julie making movies understandable. Services like these have been there for years but the girls made them more expansive. They made audio description in Ukrainian (only Russian had been available before) and this special application. It's no small feat, to pull a thing like this off in Ukraine. And you go around, explaining the importance of it all to your friends. After all, every human being has a right to come to a cinema and watch a movie personally. We take it all for granted. But many people say, "What's the big deal, anyone can give a description", and off you go again, explaining about the right for independence, self-sufficiency and all that jazz as the bottom line. This is one of the most expansive projects. And I still remember the efforts to raise funds for one miserable printer, just to print some books. These all are victories of kinds. These projects work and yield tangible results: people go to the cinema, the application is working, I know because I personally tested it. You don't need any hardware or some custom equipment. You just come to the cinema with this application installed on your phone. All it takes is to plug earphones into your telephone and launch the application. You don't have to involve anyone else, and you won't need any additional gadgets or something. Your phone does the trick. I am a bit out of step now, because there's still my job to take care of, but I know the organization is working actively. And I am willing to work along. We are handling violations of the UN Convention on the Rights of Persons with Disabilities. There are violations here in Ukraine.

Did you or the people you protect feel any impact from the COVID-19 quarantine restrictions?

Can't say anything about the quarantine. I feel sort of out of the loop here. Essentially, it had almost no impact on my life, apart from self-isolation at home. Just losing touch with the

world, that's all the impact I am feeling as an active person. Can't really say anything definitive about its effect on violation of human rights. One way or another, I have been buying products with delivery to my door. Nothing special happened during my contacts with the delivery boys. It's just going about my life in a passive way during the quarantine.

What is paramount for the promotion of the inclusive communication environment in the society?

Maybe, again, understanding of what this is all about. Inclusion in this country is just not what it's meant to be. Inclusion is an environment where everyone feels comfortable and at ease. What we actually have here is the majority of projects, even those funded by the public, are not inclusive — they all are about partial accessibility. I recall this educational hackathon with lectures for the headmasters or their deputies, school administration and teachers, who were required to write their projects the day after. The winner would get funding for his or her project. And so they would start by saying “we have an inclusive school”, “we have bathrooms revamped for the people with special needs”, “we have so many students with such and such disorders”. But, hey, stop right there! This is not inclusiveness. I am asking the simplest questions, downright ridiculous sometimes. And I say, “Imagine me coming to your school. Will I be able to find the headmaster's office all by myself? Are there Braille plates anywhere? Who is handling the children with mental disorders? Is there any special curriculum for them? Or do you keep these students just for show? I mean, yes, they are studying but does anyone really care how they are studying? A ramp for wheelchairs and a revamped bathroom are fine, but these are the elements of accessibility, not inclusiveness”. And on and on it goes. Other flaws come up. And you need to explain it all to them. Then again, there is no relevant national policy. Without any tangible support, when you need to do essentially everything by yourself, constantly proving something instead of focusing on creation, you simply waste your nerves and efforts on

providing the proof why and what needs to be done instead of making projects and drafting the appropriate laws.

If you could compare human rights activities to any extreme sports, what would that be?

Human rights and extreme sports... Do you mean hurdling, maybe? I may have been influenced by the way I found myself in this environment, because I would associate human rights protection or general interaction with all the parties involved, everyone I need to see and present my case with theater rather than the extreme sports. It makes you feel an actress of sorts, sometimes in a theater of the absurd. It's like going around, mumbling a mantra to oneself, “Now, I am calm. Oh no, here we go again” A member of parliament once told me, “I fancied myself in a theater. I wanted to study the performing arts. And here I am in the Verkhovna Rada, which is essentially the same”. This is the way I feel as well. Like an actress on the stage.

Is there anything that you find annoying or sapping your motivation?

Lots of things are demotivating. You work hard, doing your best, and it simply doesn't work out. There is a problem you are trying to tackle and it seems to be so pressing, so topical you feel physically hurt. How come no one else is hurt? It boils down to such a trifle. We know that voicing a problem is one of the very first steps toward its recognition by the society. This way you make everyone aware of the problem. You write a post in Facebook, thinking it will make such a splash, stirring the public, etc., and then you see 20 or 30 comments, 50 tops, and that's it. Hey, there are people who are simply not into kitties, right? Then it dawns on you that everyone actually loves kitties but no one likes cleaning the litter box. So you wonder from time to time, how come this damn thing doesn't work? This is totally discouraging, especially after all these talks. Or somebody does something nasty. Here's one of the most recent examples. I was not directly involved but I work with these people. They were seeing each other, talking things over, until one

day the traffic center workers hung two speakers on the same streetlight so one could not make out whether the light is red or green. And the speakers click-clack all the time. How can this happen? I have no idea. Without any common standard, everyone is doing, like, whatever: some speakers click-clack, others play someone's favorite tunes. And it kind of makes one think: some folks make it work, so it must work out some day for us as well. When I am about to start banging my head against the wall in despair, I read posts of the people who motivate me. So I see, hey, they made it again, well, it's going to work with us as well.

What is the most common stereotype about yourself that you find to be profoundly inane?

Somebody asked a colleague of mine, "Hey, how do you bring the fork to your mouth?" Or downright mean question to a guy, "How can you sleep with a woman? You don't see where to put it in!" One of the dumbest and most common stereotypes about the people with low vision is that we cannot work as well as the next guy who has good eyesight. Well, it's not about can or cannot, more like about the lower productivity. Just a few days ago I came across a comment, saying that people with low vision cannot work as well as a full-fledged person. Whatever this "full-fledged" means, I have no idea, but this is...

Are there any stories that inspire you? (books, movies, music)

Music must inspire me the most, because whenever I'm feeling down, I put some music on. ABBA is my favorite band that had an impact on my life. I ever started learning Swedish. I find Sweden most intriguing and it sort of reflected on my journalist studies — a researched their media system and it was extremely interesting. This is where I find inspiration. Sometimes I think about people and books that motivate me. And movies that inspire me. These are mostly TV shows in the afternoon when it's time to relax. Can't really recall any movies with superheroes I'd rate as motivating. Movies with audio description, like "The First 100" (the one about the first hundred heroes of the *Maidan*) and "The Distant Barking

of Dogs" (about people in the "grey zone"). These two hit my sore spot. It is just great that movies like these have audio description. One just can't help watching them. One cannot be indifferent towards one's motherland and its history that is in the making. There was this New British Film Festival with "Beast" and some short-length movies which I liked as well. I am really more into foreign movies and TV shows. The movies about the *Holodomor* and the journalist just blew me away. I did not even expect it to strike a chord like that. A topic as hard as that, the way the movie is made, wow — totally awesome.

What does it take to make this world a fair place?

There must a model for a future utopia where everyone has a chip inside one's head. The world needs equality. Not because there isn't any right now. This is not the equality I am talking about. People somehow got it in their heads that they need to climb somewhere high to survive. One would think there is a fine, beautiful life out there, so you only need to push on, always on the run, overtaking somebody else along the way, outrunning even their thoughts. Come think of it, I am not too fond of competition. I don't understand why somebody has to prove to be the best and to outdo the next guy. Everyone is good in his own way. This constant rush to the top, to the forefront, it puzzles me. Bring someone to the forefront, leave the others behind — what is fair about it? There must be a totally different behavioral model, the model where one is able to understand the life in its entirety, there must be some moral foundation or something. There is no such thing as a fair society. How can it be fair, if some are making 50 grand while the others have to eke out on 10 grand, others still have to work at night, or do two jobs, or... whatever. Just what are we talking about?

What does it take to be a human rights activist? Do you consider yourself such an activist?

Well, let's say, I'm just learning. Can't say I am some top expert. I have been working really not that long — just about five years, so that doesn't make me some mega authority or something.

Indeed, I can call myself a human rights activist. There are classes and training course we are taking. You get into the character somehow. At first, it's as if you are all for yourself. What qualities does a human rights activist need? Stamina, endless patience, self-confidence, I mean, one's voice should be like a battering ram, otherwise you won't be heard. One needs to open one's mouth, make oneself heard, saying yes, there are problems and no one will sort them out for us, yeah, people mostly love kitties but hate barking like a dog, etc. I remember trying to reason with my acquaintances, "This is your topic, why don't you make a repost, if it involves you directly?" One cannot protect all the rights at once. One needs understanding. One simply cannot protect people with disabilities as actively as, say, dolphins. And they

would come back at me, "Suppose I write this and provoke a dispute. I don't know, I am scared, I don't want, what if I will have to hang in there". This kind of attitude is hardly fitting a human rights activist. One needs to be brave enough to speak up straight, while being competent in whatever one is talking about. Have a clue about it. Also, one would need some kind of a meditation, some Zen with this mantra "I am calm, all is fine, this is totally fubar, but all is fine". This is the kind of mantra that is supposed to make you serene as Buddha. Nerves, inner turmoil... How can one separate oneself from it all, I have no idea. Maybe there is no point in stressing out, I don't know, just see no way of doing it otherwise.

Interviewed by Olena Zinenko.



Daryna Brykaylo

Human rights
activists need the
zeal and the faith.
They need to be
passionate about
what they are
doing and have
strong faith in
their own activities,
in themselves
and in the people.

Human rights activists need to have the zeal and the faith

Daryna Brykaylo, *Soul Sisters* project co-founder, civic leader in the sphere of oncology

What does defending the human rights mean to you? Just how is this whole thing about you, exactly?

The ability to talk on behalf of the person or a group of people who is or are unable to do it personally.

Can you recall your first experience defending the human rights? Did you act on your own behalf or was it to the benefit of somebody else?

I am not a human rights activist in a broad sense of this term, therefore finding an example is kind of hard. However, I do remember the moment when I told myself that I could do much more. It happened when it suddenly dawned on me that my problems are not unique — many people had them before me and many will have them after I'm gone. I believed that a small drop makes the ocean and I am able to make changes.

What is driving you to break through the barriers?

Our team and feedback from the people about what we are doing. Every time when the going gets tough, I remind myself that I am not alone and that my input matters. I assumed certain responsibility and can't just let it go.

What kind of barriers do you encounter while defending the human rights? (Are they unique or universal?)

Our team provides legal counsel to adult cancer patients. This is a complex matter to begin with, so the biggest challenge is to be on the same wavelength with every party to the process. To build a quality dialogue with multiple participants. This is where one needs to make use of one's knowledge, skills and qualities, and to keep on learning something new.

Can you recall any particular accomplishment in the sphere of human rights protection that you take special pride in?

These must be all of my accomplishments.)

Did you or the people you protect feel any impact from the COVID-19 quarantine restrictions?

Certainly. A lot of cancer patients could not get any treatment, because they needed to be admitted as in-patients but the pandemic simply prevented them from getting to the clinic in the first place. The pandemic cut the number of donors threefold. The problem with platelet concentrate got worse.

What is paramount for the promotion of the inclusive communication environment in the society?

We all are the same. We all are human. Some may have disabilities, but we are human beings first and foremost.

If you could compare human rights activities to any extreme sports, what would that be?

Maybe bungee jumping. You take a dive into the unknown, the jerk back and the adrenaline rush come next, and then you feel weightless.)

Is there anything that you find annoying or sapping your motivation?

Denigration. Most people pretty good at it. Be it someone's job, knowledge, skills or professionalism.

What is the most common stereotype about yourself that you find to be profoundly inane?

I am often told that I look fine for a cancer patient.

Are there any stories that inspire you? (books, movies, music)

I am very inspired by the stories. The stories of people who encounter problems and find the

strength to overcome them. I am working with a team of girls who inspire me tremendously. They all are my heroines.

What does it take to make this world a fair place?

The ability to speak up. Respect. And empathy. I think these three factors are the cornerstones of each personality.

What does it take to be a human rights activist? Do you consider yourself such an activist?

I don't really think I am a human rights activist. I am more like an active representative of the community. I am doing a little more for the group of people who matter to me. Human rights activists need the zeal and the faith. They need to

be passionate about what they are doing and have strong faith in their own activities, in themselves and in the people.

As a woman with disability, what are the challenges you have had to deal with so far? Is there anything that you find scary, insulting or discouraging?

Personally, I am getting all the support and acceptance from my circle of contacts. However, our community is extremely exposed to cyber bullying. Everyone who is going through the hardships of cancer treatment has to fight the bullying as well. It is as if the public is just waiting for the opportunity to voice its expert opinion about one's appearance, or how one needs to correspond to the cancer patient status, what diet one should stick to or how to spend one's money.

Yuliia Sachuk

Права людини —
Human rights mean
some kind of an
agreement between
the people, no matter
how different, that
outlines the rules
of their co-existence
for common good.
Essentially, this is
what democracy is
all about.

HUMAN RIGHTS
ARE MY PRIDE

JUSTICE

We need to be professional, responsible and strong. We need to be independent.

Yuliia Sachuk, Head of NGO “Fight for Right” (“Borotba za prava”)

What does defending the human rights mean to you? Just how is this whole thing about you, exactly?

In my mind, human rights mean, probably, what I believe in as the most harmonious way of life for all mankind. Human rights mean some kind of an agreement between the people, no matter how different, that outlines the rules of their co-existence for common good. Essentially, this is what democracy is all about. As far as my personal path is concerned, upon getting my university degree, I happened to work for a great human rights organization Amnesty International. I learned a lot more about human rights and got the appropriate experience out there. As a student of the Department of International Relations at Volyn State University (now Lesya Ukrainka Eastern European National University), I would work in various organizations that catered to people with disabilities. Perhaps, these two paths crossed, so we combine these two approaches, working in the organization and fighting for our rights. We promote and protect the rights of the people with disabilities through the human rights-based approach. Medical, social and charitable models of disability perception are most common in Ukraine today. Our mission is to make the human rights-based model effective in this country.

Can you recall your first experience defending the human rights? Did you act on your own behalf or was it to the benefit of somebody else?

Firstly, I think I first found out about the human rights in the university. The curriculum included such classes as international law, private law, public law and a class in human rights. Secondly, these were the projects of the local organization of visually challenged people. And I remember

how we fought for the right of the children, especially those with poor eyesight, to attend local schools instead of going away to boarding schools in other regions. Thirdly, we initiated the all-Ukrainian forum for the visually challenged young people. We invited young people from all over the country to Kyiv. We were aware that a lot of people are experiencing very similar problems and concluded that these problems can be dealt with in a more efficient manner on a national level. We held that forum together with other organizations that take care of people with disabilities, and in conjunction with the Ministry of Social Policy. No such events have ever been held before in Ukraine for the visually challenged youths. During the forum, it occurred to us that we should combine the efforts to protect the people with disabilities whose rights are violated. We outlined the key spheres of activity and the forum became the birth of the All-Ukrainian Non-Governmental Organization for the protection of visually challenged youths

What is driving you to break through the barriers?

I love what I'm doing. I find motivation in the people who I am working with and for — our team. I am motivated by the changes I see. I fully understand now what we need to do over the year or two, or three or ten years ahead. I am motivated by the specific results, the accomplishments. I am inspired by the sensitive issues we articulate. I mean, I see the issues that had been kept under the carpet for years are now being articulated and efforts are being made to handle them. A lot of things motivate me. To see how the society and this country and the people with disabilities benefit from my activity. I feel particularly touched when a person with disability sends me a letter saying our classes helped change his/her life. Or wherever people start speaking out loud about violation of their rights or demand proper response to such violations. This must be my biggest motivator yet.

Oh, I am also motivated by seeing how people with disabilities grow their expertise and how they change their approach. I mean, these people are fighting for their freedom and rights rather than for some privileges or additional benefits. This is a very strong motivator indeed.

What kind of barriers do you encounter while defending the human rights? (Are they unique or universal?)

I think there are universal and unique barriers when it comes to a group of people with disabilities. If we speak about human rights in general, the attitude to them in this country leaves much to be desired. The government is mostly hostile to any activities in this sphere as they often reveal extremely severe issues. As far as people with disabilities are concerned, yes, there are specific barriers. Until recently, our community has been seen as the user of privileges only. I would say the society has never perceived the community of people with disabilities in a proper manner. The government would allocate some funds to solve certain problems, but even this paltry contribution was mostly for show, through convoluted and shady procedures, seldom going beyond loud declarations. Even if you are aware of some violation, protecting one's rights will be quite a task, because legislative instruments are missing the effective and simple methods of application. That is why today, when the voice of the community is getting louder, the government is often not ready to handle it, to work in sync and be an ally in the struggle for changes we demand.

Can you recall any particular accomplishment in the sphere of human rights protection that you take special pride in?

Oh, I have a lot of examples of our involvement to be proud of. The latest, maybe... I don't know (*grins*). I'd say it's our systemic work in the sphere of political and cultural rights of the people with disability. For example, the latest version of the Electoral Code addresses inclusivity and accessibility at great length. As we know, it all came to be thanks to the contribution of quite a

number of non-governmental organizations, ours included. Our contribution came from participation in the work group handling the Central Election Commission and promoting the enforcement of the Electoral Code. The same goes for cultural rights as well. We managed to popularize the inclusivity of cinema. Specifically, we make movies more accessible to the people with poor eyesight and hearing. With the assistance from the Embassy of the Kingdom of the Netherlands, our project provides help to a number of human rights activists from various non-governmental organizations. And our sub-recipients of grants report considerable, powerful changes. Take, for example, Dmytro Zhariy, an attorney from Dnipro, who handles cases against the insurance companies for discrimination of the people with disabilities. In fact, insurance is now virtually beyond the reach of the people with disabilities. Or take, for instance, this special application one can download from 112.ua, helping the visually challenged people contact the emergency response services. Another important result is promotion of human rights approach toward assertion of the rights of the people with disabilities. As far as disabilities are concerned, this is a brand new tendency for Ukraine. We are just one of the few organizations in this country. We organize a lot of educational events. Last year, we organized the *Liderka* — first-ever project of this kind in Ukraine, the school of political involvement for girls and women with disabilities from all over this country. I take great pride in this project. It's participants proved to be remarkably strong girls and women who had never been seen or heard before. The school prompted them to join the human rights movement, to find out more about their political rights and prospects of their personal growth in this sphere. Our speakers were prominent human rights activists — Iryna Fedorovych, Oksana Potapova, Iryna Slavinska, Olena Shevchenko, Natalia Shevchuk and Olga Ayvazovska. All speakers and coaches were women with disabilities who have already reached success. And it is just great that the school made a lot of girls more aware of public activities. Some of them continued their self-training as interns in governmental authorities, committee of the

Verkhovna Rada, Central Election Commission and the office of Vice-Prime Minister for European Integration. That brought to light the long-standing problems specifically pertaining to women with disabilities, such as privacy, reproductive rights, accessibility and generally how it feels to be a woman with disability in Ukraine. We are promoting this particular intersectionality, bringing it to the focus of the public, because, as one of our participants once pointed out, “If you have a disability, you are no longer a woman, you are just a person that nobody would see as a woman”. These activists are joining a lot of initiatives and consider making a political career. One activist ran for the local office in elections held on 25 October 2020. The public tends to see “women with disability” as some kind of a very vulnerable group. Indeed, the barriers are very tough, but, through pro-active approach, we will be able to take part in decision-making process, as well as in political and social life. On the whole, this school is our great love and a big motivation for our team and for myself.

Did you or the people you protect feel any impact from the COVID-19 quarantine restrictions?

Indeed, it had a considerable impact on the performance of our organization. The scheduled offline activities went online instead. Which in itself is a quest of kinds, because this is a brand new platform for many people with disabilities. There are certain requirements to information accessibility (sign language is a factor here) as well as accessibility of our online platforms to visually challenged people. A lot of things are happening because of poor Internet connection. The quarantine further restricted the movement of people with disabilities. Our organization tries to keep working in accordance with our work schedule. Certain activities have changed but we tried our best to transform them and moved our strategically important activities online. We held online a number of training courses which actually drew a much bigger audience from all over Ukraine. Our professionals helped sort out certain problems related to the COVID-19 situation, actively helping the government

organize classes in boarding schools for children with poor eyesight or hard of hearing, or intellectual disabilities. In conjunction with the Members of Parliament and the UNICEF, we contributed our efforts to enhance the accessibility of online schools and provide guidance to the teachers as to the methods and resources they may apply to provide quality training online.

What is paramount for the promotion of the inclusive communication environment in the society?

It's too hard to tell what's most important here. If it is about the obstacles which the people with disabilities have to deal with, there may be architectural and informational problems; there are problems even with the laws, not to mention the attitude problems. No, it seems to be impossible to single out the paramount factor here. Besides, I think it would be incorrect. It's all individual, really. There's this one problem, though, that common perception is that disability needs to be something visible. For example, when we talk about disabilities, one tends to see the image of a person with low vision or hard on hearing or using a wheelchair. But very often we fail to picture persons with intellectual or psychosocial disability, and there's thoroughly inadequate governmental policy regarding protection of their rights. It's pretty hard to identify what's most important for each specific group. However, generally speaking, the government makes no adequate efforts nationwide, nobody really cares for people with disabilities as much as we would like in the context of human rights. Too often their efforts boil down to nominal, mostly declarative programs, oftentimes executed chaotically and without any thought or rhyme or reason. Very often the legislation makes no provisions for the efficient tools for implementation of a certain law aimed at protection of the rights of the people with disabilities. With all this going on, even the best ideas and international standards are doomed to fail in specific situations. In fact, most of the positive changes in human rights protection occur thanks to the perseverance and

commitment of civil society. Meanwhile, we get no adequate reaction from the human rights commissioners who are supposed to take care of the people with disabilities. And this is yet another problem. Attitude of the government toward the NGOs catering to people with disabilities might be perceived as a separate problem. This attitude strongly manifests itself in the principles of funding of such NGOs. We have been working on this problem for years already and only got the ball rolling this year. For many years, the government of this country has been allocating funds for the support of civil society on the whole but only four organizations actually received this money. And only this year did the numerous organizations and activists start the fight for enforcement of tender procedures and set the appropriate criteria. We ran up against a lot of opposition, but there are still positive changes and results.

If you could compare human rights activities to any extreme sports, what would that be?

(pause) Extreme sports... Let's see. I don't know. Without personal experience in the extreme sports, I really wouldn't know. For me, it's all hard work and, from time to time, you really get this feeling that you follow your schedule but you often need to put out random fires along the way. Here's a poorly written draft law, there's someone cut off from some service or other, and you react, using various tools. It's all very unpredictable and, quite honestly, you stress out all the time.

Is there anything that you find annoying or sapping your motivation?

Over the years, I got used to many things. Can't shake this feeling that I have been surprised enough already. In a negative sense, I mean. Sudden negative actions of the governmental officials and politicians are thoroughly demotivating. Some negative situations happen from time to time. For example, a visually challenged person was refused admittance to the swimming pool. Things like this happen all the time. Or take, for example, Members of Parliament who are anything but experts in

protection of the rights of people with disabilities suddenly get it into their heads they can lobby for the projects in this sphere. Lacking proper professional training, they are apt to set the reforms in a certain sector back for many years. I'm talking about de-institutionalization here. Then again, it's all rather puzzling. Anyway, despite the occasional disillusioning and negative emotions, strategically, what we are doing cannot be easy and definitely cannot be accomplished in a matter of a year, or two, or five... That is why we are committed to a long, hard work where we are expected to endeavor tremendous efforts to make real changes happen. According to international experience, no changes are ever easy. Anyway, motivation is much stronger.

What is the most common stereotype about yourself that you find to be profoundly inane?

Can't really tell which one is the dumbest, but such stereotypes do exist. It is commonly believed that working for the people with disabilities is some kind of a noble mission where no problems can exist, because everyone is so tolerant, therefore things are going smoothly, nicely and without a glitch, because you are helping people, etc. This is slightly off, you know, because we handle issues and problems that other people find bewildering and painful. They all require contributions from the government, funding and a lot of efforts. Officials and participants of conferences and round tables often tell us how this all is important to them, how their hearts go out to us, how they sympathize and cannot sleep at night. But when the time comes to make certain decisions, sign certain papers and allocate funds to accessibility and various programs, such as inclusive education or employment, things no longer seem so bright and sunny. That's when the real fight begins.

Are there any stories that inspire you? (books, movies, music)

Books by Umberto Eco. I keep reading and re-reading them, always finding something new to muse upon. As for music, it's mostly rock but it would be hard to single somebody out. Freddy

Mercury is my all-time hands-down number one. I love Carl Orff. Speaking about books, I am mostly reading professional literature now, whatever has to do with the rights of the people with disabilities, human rights and discrimination. Not much time left for fiction books.

What does it take to make this world a fair place?

Hmm. Hard to say. Everyone has his or her own idea of a fair world. Upholding the universal human values, consistently and all along the line, may do the trick. As regards Ukraine, this country really needs to boost its awareness of human rights. People tend to see values in various things, but not everyone sees value in human lives and rights. That's about the size of it.

What does it take to be a human rights activist? Do you consider yourself such an activist?

The truth is in the eye of the beholder. Yes, I do consider myself a human rights activist, because I'm fighting for the rights of the people with disabilities, the rights of our community and for my personal rights. And I do my best to promote the respect for human rights in Ukraine. What does it take to be a human rights activist? I don't think there is a universal, definitive answer to that. It goes without saying that we need to be professional, responsible and strong. We need to understand that once we take this path, there will be sacrifices in the reality of Ukraine, it can't be helped really. We need to be independent. That's the long and the short of it.

Interviewed by Olena Zinenko



Iryna Larikova

One thing is
for sure, my
friends who
help me, they
motivate me
as well.

One can protect human rights online and over the phone.

Iryna Larikova, activist of NGO Emmaus, postgraduate student, Chair of Media Communication, Sociology Department of the V.N. Karazin Kharkiv National University

What does defending the human rights mean to you? Just how is this whole thing about you, exactly?

It's not about me, exactly, but I am always willing to help a person in need. I lack competence in many things but since I have gone down the same path or the problem is at least familiar, I try to help. Most of the time, these are problems of social nature. I often need help myself and, thanks to my acquaintances, I normally know who to turn to. It is important to me that everyone's rights are protected. If we do not somebody else's rights, we do not break our path toward accomplishments.

Can you recall your first experience defending the human rights? Did you act on your own behalf or was it to the benefit of somebody else?

I actually try to avoid situations where I need to assert my rights. Or the rights of someone who has problems. I mostly deal with the problems of orphans and people with disabilities. It is so annoying when the city is not fit for people who use wheelchairs. Or whenever an orphan is evicted from the dorm upon the graduation (that's the problem I had to deal with). I may concede to the people who try to prove their point not because they are right but because I have no strength to make a stand and to prove those dimwits wrong. But the day after I go back and continue sorting my problems out, however with another person. It may be wrong, but sometimes I allow myself to walk all over people. It really works but one always needs to be careful and wise. Otherwise things may take a nosedive. I can't recall the time when I stood for someone else's rights but it did happen in the past. I still remember vividly this one moment when a friend

of mine and myself went on a travel and they wouldn't let us into the bus because of my friend's wheelchair. Eventually, they agreed to let us in on condition that we pay for the wheelchair as if it were another person. How's that? A wheelchair as a person!!! That's triple fare for two. A travel to another city. Not exactly cheap. I was really mad. I argued with the driver, kept the bus late for two hours, gathered quite an audience and called the police, because these people were fixing to push us off the platform. In the end, we made our trip like normal people. It was another bus but the trip cost us nothing. We only paid for our luggage. Little fish are sweet, as the saying goes. I found myself in similar situations time and again but can't really recall any particular one right away.

What is driving you to break through the barriers?

I need no motivation to help a person in need. All I need is the wish. I do not expect any rewards for or satisfaction from my deeds. Making a stand for the rights, mine or somebody else's, seems to drain all my strength away. I hate getting into arguments and telling people how they should do their work. I am not that healthy to go all over the place. Coming back home, I just sit back and analyze what has happened. Perhaps, the idea that all these efforts will be to my benefit, or the people whom I helped would have it easier, is a motivation of kinds. One thing is for sure, my friends who help me, they motivate me as well. They motivate me to carry on. Not just helping the others, but making me help myself as well.

What kind of barriers do you encounter while defending the human rights? (Are they unique or universal?)

Most of the barriers that annoy me and stand in the way are the barriers in people's heads. People simply wouldn't see a broader perspective, as if preferring to stay inside their shells. Sometimes I simply cannot get through the other people's

heads, saying the problem can be solved. They would just stand their ground and close their ears. Barriers can be avoided, if there's someone next to you who is willing to help. Speaking about physical barriers, it's about low accessibility for the people with disabilities. I always need help whenever I have to come up or down the stairs. Or cannot reach up the shelves in the stores. I am very grateful to my friends who are always there for me. And if I happen to be away from them, I never hesitate to ask people around me for help. Some people don't even need asking. They would come up to me on their own.

Can you recall any particular accomplishment in the sphere of human rights protection that you take special pride in?

There may be something but I can't recall which one.

Did you or the people you protect feel any impact from the COVID-19 quarantine restrictions?

If you are willing to help, no COVID-19 can keep you from solving the problems. Unless you get the virus yourself, that is. One can protect human rights online and over the phone. When I'm going to a service provider, I am not getting in a fight in their office just to submit some necessary papers. I am talking to people and one can surely talk over the phone. Besides, all things can be done online during the quarantine. It's all easier now. However, there may be some misunderstanding, or it can be hard to explain some things over the phone. If you raise your voice just a tiny bit or start an argument, and it frequently happens, the person on the other side refuses to talk and simply disconnects the call. The only problem here is a lot of time wasted. Once again, I do not protect anyone's rights. I can help by sharing some information or by talking to the right person.

What is paramount for the promotion of the inclusive communication environment in the society?

I don't understand the question. (

If you could compare human rights activities to any extreme sports, what would that be?

Orienteering, maybe. Not sure about how extreme that can be, though. Running, searching, taking a lot of obstacles... Do your things in time and get the good results.

Is there anything that you find annoying or sapping your motivation?

Show me a single human being alive that is not annoyed at or by something. That will make me kind of jealous. A lot of things are getting on my nerves. Misunderstanding or lack of accessibility, for example. It's maddening when people wouldn't even listen to you and you know your very future is in their hands. Wasting strength and time is annoying. Being unable to get what you are entitled for is annoying. However, all of this is making me stronger. I try to tough it out, regardless of whether or not there is something that annoys me.

What is the most common stereotype about yourself that you find to be profoundly inane?

I was raised in an orphan house where they taught me very little of use. I mean, after the boarding school I had no idea what and how to do next. I did not know how to get certificates or have my paperwork done, etc. Many people are actually aware that kids from orphan houses know nothing and can do nothing, so they choose to stay away from them. Kids from the boarding schools are good for nothing, they are thieves, go to jail all the time and their lives end badly. This is exactly how they treated me. I had to work hard to prove to myself and to the others that I know something. That I can actually do something. I am a student now, planning to get my Master's Degree and become a journalist. All those stereotypes are dumb.

Are there any stories that inspire you? (books, movies, music)

I Like "Capernaum" (2019) — a movie about a 10-year-old boy who has to work so as to bring food to his brothers and sisters. This boy named Zain lived in squalor. His parents were never

there for him. All they cared for was money and would rather keep their children hungry. The story of the boy is inspiring, because it shows that it doesn't matter how your life started. You can change things if you want, no matter how difficult it can be. You should watch this movie. It's really cool. It's actually based on a true story of real people. Not actors, I mean.

What does it take to make this world a fair place?

I can be unfair to a person who does not treat me in a fair manner. Not for the sake of paying back. Just to make this person know how it feels to be in my shoes. How it hurts. I don't know what makes other people mean but I'm sure they are not that way willingly. This world lacks simplicity and humanity. People want to look tough and important and demand to be treated as such. Ordinary people mean nothing to them. They seek glory and focus on themselves exclusively. If people learned to see and understand each other, this world might have a chance of becoming a very fair place. It's all in the heads of the people. "Do unto others as you would have them do unto you".

What does it take to be a human rights activist? Do you consider yourself such an activist?

Indeed, these are the people we need badly. Personally, I don't see myself as a human rights

activist, although sometimes I may look that way. I have to stand for my own rights and the rights of those who have it harder. I can help with some issues but I never solve the problems of the others. I believe everyone needs to gain personal experience, to be able to help the others afterwards. I am experienced and in some matters I am pretty competent as well. That is why I can help. If someone had been solving my problems in the past, I wouldn't be able to help anyone today.

As a woman with disability, what are the challenges you have had to deal with so far? Is there anything that you find scary, insulting or discouraging?

As I woman, I am not scared, insulted or discouraged by anything (so far). As a person with disability, however, I am scared for the future of this country. I am afraid that the next generation of people with disabilities will have to deal with the same problems that I am dealing with today: absence of inclusive education, poor accessibility and problems with social and healthcare services. It takes so much effort today, to just qualify for a certain disability group. As sad as it sounds, it used to be easier. Much easier. I hope there are strong human rights activists who will set about changing this country one day.



**Valentyna
Dobrydina**

I am motivated
by the positive
results of the
struggle.

When I see people succeed thanks to my support, it motivates me like nothing else.

Valentyna Dobrydina, Head of Public Organization “Chernivtsi Region Organization of the People with Disabilities “Leader””

What does defending the human rights mean to you? Just how is this whole thing about you, exactly?

Human rights watch is about dignity, justice, equal rights and compliance with Laws, Conventions and other legal documents. I have this strong sense of justice since childhood. Lies, unfair treatment of people, violation of human dignity and discrimination — I hated it all. With disability caused by the spine injury, I learned about indifference and discrimination firsthand. Back then, still in the hospital, I made a vow to make a stand for my rights and to help the others protect human rights. I became the leader of the organization of the people with disabilities, took classes and training courses in human rights and attended seminars dedicated to human rights and their protection. Ever since, for over 20 years, I have been engaged in public activities to help the people with disabilities and their families to protect their rights.

Can you recall your first experience defending the human rights? Did you act on your own behalf or was it to the benefit of somebody else?

First experience was my right to rehabilitation, the right to get a health resort package from the Department of Human Services. After the spine injury, I needed rehabilitation, the kind they could only provide at a specialized health center, but the Department of Human Resources kept rejecting my requests. I remember writing letters to the Member of Parliament, the Head of the Regional Administration and even to the President of Ukraine. That was a positive experience. I was given the package and went to the health center after all. Thereafter, my experience only expanded as I went on protecting

human rights, making a stand for myself and for the other people as well.

What is driving you to break through the barriers?

I am motivated by the positive results of the struggle. When I see people succeed thanks to my support, it motivates me like nothing else. Whenever I feel like giving up, I would recall stories of the people who went back to living normal lives, and that is one big driver for me to carry on, regardless of the barriers.

What kind of barriers do you encounter while defending the human rights? (Are they unique or universal?)

These are the lack of understanding, incompetence, and indifference of the people, the society, the officials, the authorities or the government. Disregard of the laws and other legal documents. Then there are architectural, transportation and information barriers for me to break through while riding my wheelchair.

Can you recall any particular accomplishment in the sphere of human rights protection that you take special pride in?

The biggest accomplishment for me is to make various infrastructural facilities more accessible to the people with disabilities, thereby promoting their right to access.

Did you or the people you protect feel any impact from the COVID-19 quarantine restrictions?

The right for healthcare services suffered the most during the quarantine. Members of our community (the people with disabilities) would find themselves unable to receive quality healthcare services due to the shutdown of the diagnostic center — the only facility in the entire region architecturally accessible to the people with disabilities.

What is paramount for the promotion of the inclusive communication environment in the society?

Compliance with applicable laws of Ukraine and the national building regulations, competent staff of the relevant services, promotion of thinking outside the box and shaping up positive perception of and attitude toward the people with disabilities.

If you could compare human rights activities to any extreme sports, what would that be?

Kayaking.

Is there anything that you find annoying or sapping your motivation?

Stupidity, insincerity, hypocrisy, lying.

What is the most common stereotype about yourself that you find to be profoundly inane?

The one that I am a sick person who is a sucker for pity and needs a help all the time.

Are there any stories that inspire you? (books, movies, music)

I love movies with Julia Roberts and the Ukrainian songs.

What does it take to make this world a fair place?

Kindness, honesty, love.

What does it take to be a human rights activist? Do you consider yourself such an activist?

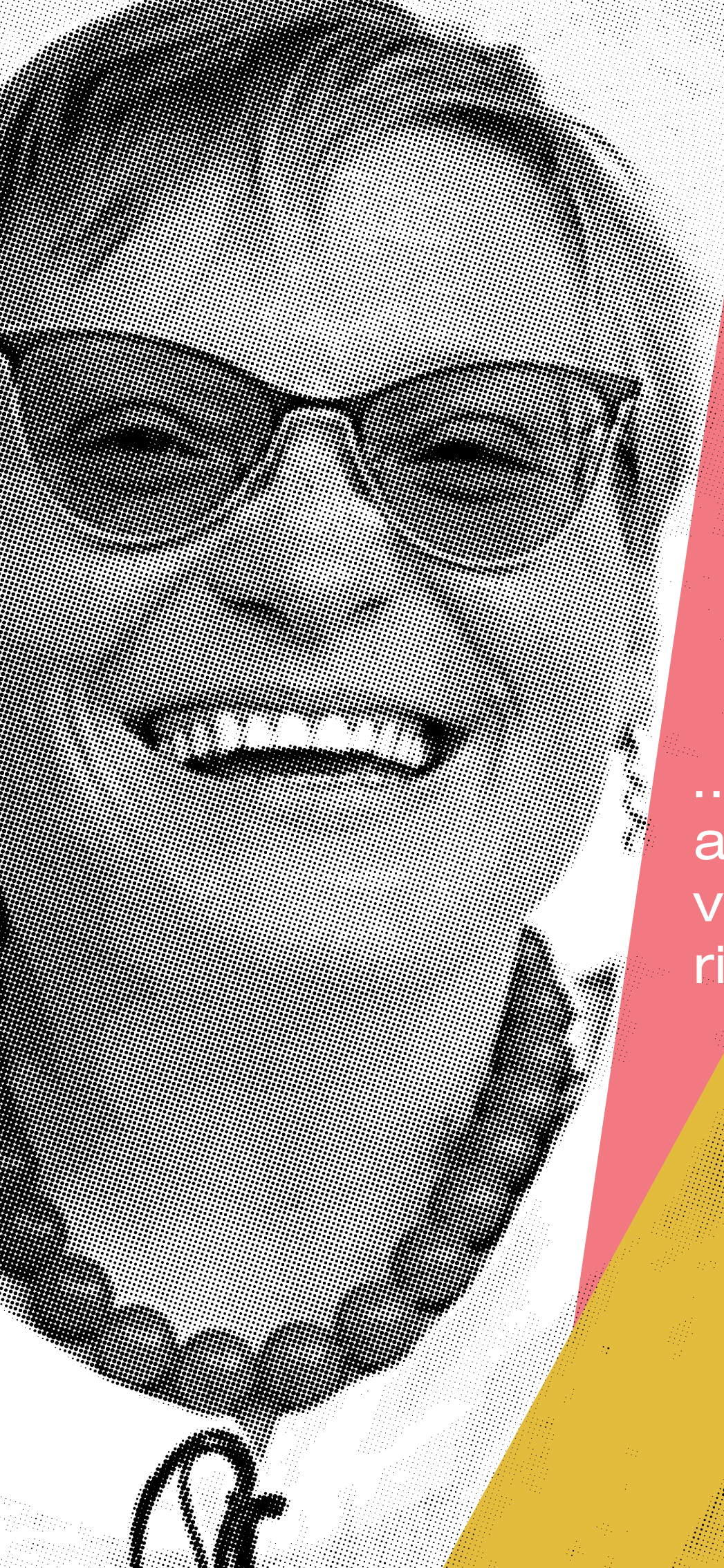
Kindness, honesty and fairness are the first things that come to mind. ☺ This kind of activity requires people of experience, professional attitude, integrity and initiative. I consider myself a human rights activist, because there are times when I'm doing this without even being aware that it's all about fighting for human rights.

As a woman with disability, what are the challenges you have had to deal with so far? Is there anything that you find scary, insulting or discouraging?

The threat of losing my life, getting no quality healthcare service because of my disability, thereby further compromising my health. Scary... Losing or hurting my family and the close ones.

Insulting... Breach of dignity.

Discouraging... People who have no understanding and will to make the world a place that is comfortable for everyone.



**Nataliia
Morotska**

... I am
allergic to
violation of
rights.



Protection of human rights is my way of life.

Nataliia Morotska, attorney, speaker of political party “Demokratychna Sokyra” (Democratic Axe) on the matters of inclusivity

What does defending the human rights mean to you? Just how is this whole thing about you, exactly?

My way of life. My *alter ego*. Because I am allergic to violation of rights. Especially cheating officials who make other people do their job. Or demand unnecessary documents and wouldn't take the necessary actions without them. Ukrainians are easy to cheat, because they are trained to be legally and politically ignorant. I am not simply helping the people. I instruct them on how they shall stand for their rights as well.

Can you recall your first experience defending the human rights? Did you act on your own behalf or was it to the benefit of somebody else?

My first experience was in 2002 or 2003 when I was a defense counsel for my significant other in a trial. It was about the collection of a debt on the basis of a receipt written under duress. We won redress for the non-pecuniary damage and had the debt restructures for three months. Indeed, I aimed higher, seeking to find the loan contract invalid on the grounds that it had been executed in a foreign currency. We filed this lawsuit the sole purpose of which was to pressure the opponent into a settlement. The opponent finally agreed on our terms.

What is driving you to break through the barriers?

Personal weakness. I want to be the proof that the people can make it as well as I did. I have quite a lot of clients without any physical disability who claim the laws in Ukraine don't work. I usually ask them why they chose to turn to me and prove them wrong.

What kind of barriers do you encounter while defending the human rights? (Are they unique or universal?)

Mostly universal. Like architectural inaccessibility of the public and municipal establishments and the officials shirking their duties.

Can you recall any particular accomplishment in the sphere of human rights protection that you take special pride in?

Oh, yes. Quite a few, actually. But that will be advertising myself as an attorney. 😊

Did you or the people you protect feel any impact from the COVID-19 quarantine restrictions?

Slightly. Only one client failed to provide documents to the investigator and turned from the victim into a witness. But this can be remedied on the stage of judicial proceedings.

What is paramount for the promotion of the inclusive communication environment in the society?

Understanding that it matters not only to the people with disability but to anyone who needs, however temporarily, help in free movement. Understanding that inclusivity means safety and comfort to anyone who wants to live a productive life.

If you could compare human rights activities to any extreme sports, what would that be?

I have never made any such comparison. To me, legal practice is more like playing the chess or the piano. You need to think several moves ahead or know which key to press for a nice tune. No! Legal practice is definitely no extreme sports.

Is there anything that you find annoying or sapping your motivation?

People unwilling to make a stand for their rights. They think the system only works if you have

money and connections. And the people unwilling to pay for quality services.

What is the most common stereotype about yourself that you find to be profoundly inane?

The one that I am helpless. This is really ludicrous, because my opponents tend to underestimate me this way.

Are there any stories that inspire you? (books, movies, music)

Stories of purposeful people. People who fight their way through, defeating the system or thinking outside the box. Movies like “G.I. Jane”, “Beethoven” and “Andrea Bocelli”.

What does it take to make this world a fair place?

Justice.

What does it take to be a human rights activist? Do you consider yourself such an activist?

Knowledge, principles and the sense of purpose. I am a human rights activist through and through.

As a woman with disability, what are the challenges you have had to deal with so far? Is there anything that you find scary, insulting or discouraging?

Two men in a small room were pressuring me. I arrived for the negotiations alone so there was no one to protect me. One guy was extremely teed off. I thought he was going to hit me. But I stood my ground. And prevailed.

I am not discussing my fears in the public, because there may be someone willing to use them against me.



Olena Vyshnya

I am not touched by some mad impulse and an act of momentary bravery as much as by some routine events and accomplishments when one needs to overcome oneself.

Protecting human rights means improving the life of society. Which means the life of each of us.

Olena Vyshnya, Head of NGO “Dia-Zen”
(organization protecting the rights of diabetic patients and their families).

What does defending the human rights mean to you? Just how is this whole thing about you, exactly?

Improved quality of life of the society, which means the life of each of us. I think everyone of us feels the need to create. I want to believe it. Protection of human rights and freedoms, protection of human dignity — it's all so fundamental, natural and harmonious, it makes me want to ask people, just how is this whole thing NOT about you? How?

Can you recall your first experience defending the human rights? Did you act on your own behalf or was it to the benefit of somebody else?

Interesting question. I seem to recall now this self-organized protest in the kindergarten. To this day do I remember my mood back then: “This is going to be tough, but it needs to be done”. For all I know, I am still saying this to myself when I make decisions. I am not getting any high from human rights work. It gives me no drive. This may sound trite, but — who else is there, if not ourselves?

What is driving you to break through the barriers?

Hope that this whole world, this society can be fixed, and a human being is able to change the reality. I am still a child deep inside, a dreamer full of hopes and believing in miracles. I am this kind of a person who makes a wish to the chime of the New Year's bells — “World peace”. A child somehow saved from formality, numerous stereotypes and social pressing. But this little girl is strong and free — she is my powerful driver. And there's my internal “rain drops” strategy. Public activity is like rain drops that pull into puddles and grow into the torrents no one can

control. Drops as breaking points in public opinion. I have no idea, though, where and when it all will reach the point of no return and the change becomes inevitable. But I do know that even a tiny drop is capable of bringing changes to the reality.

What kind of barriers do you encounter while defending the human rights? (Are they unique or universal?)

Flawed laws and officials shirking their duties. It's not just shirking but rather total distortion... Barriers are made of fears, passivity, “see no evil” mentality and indifference. This, unfortunately, can be found in many people that make up this society.

Can you recall any particular accomplishment in the sphere of human rights protection that you take special pride in?

Hard to say, really. I can't seem to recall any particular case or story. There are times when my work seems to be mundane and routine. However, seeing people's reaction makes me aware that I am actually doing something good, important and something that makes a difference.

Did you or the people you protect feel any impact from the COVID-19 quarantine restrictions?

People with diabetes are in the high risk zone. Absence or rationing of insulin, the need to search for vital medicine in various drugstores, standing in the lines for prescriptions in the clinic and the lines for the medicines — it all means greater exposure for these people.

What is paramount for the promotion of the inclusive communication environment in the society?

Inclusive thinking. Which takes an extensive strategic advocacy and awareness-building.

If you could compare human rights activities to any extreme sports, what would that be?

Running. I know, there is nothing extreme about it, unless it is a marathon with no finish in sight. An endless marathon. Passing the baton is the best personal finish you might hope for, if only there is someone to pick it up...

Is there anything that you find annoying or sapping your motivation?

Indifference and ignorance.

\What is the most common stereotype about yourself that you find to be profoundly inane?

As far as my work is concerned, people often ask me "Why do you even care?" — the question I simply refuse to understand. The question that is constantly tormenting me is why nobody seems to care?

Are there any stories that inspire you? (books, movies, music)

Well, there are books and there are movies. But lately, I have been mostly inspired by the people around us. Stories of strong will and commitment. Like stories of women who raise children with disabilities and still find the time and strength to help people who are terminally ill. They inspire and motivate to live and enjoy the life here and now.

I am not touched by some mad impulse and an act of momentary bravery as much as by some routine events and accomplishments when one needs to overcome oneself. They don't get as much flak or seem so glamorous... but they do inspire me.

What does it take to make this world a fair place?

Fairness is such a subjective category. Without going in too deep, this world needs... Empathy. Freedoms. Along with personal and collective Responsibility.

What does it take to be a human rights activist? Do you consider yourself such an activist?

Yes, I am a human rights activist. In real life, these are strong and brave women. Altruists. I wish they would take better care of themselves to avoid burning out.

As a woman with disability, what are the challenges you have had to deal with so far? Is there anything that you find scary, insulting or discouraging?

Sexism. Our society is shot through with it. Ignorant officials. Talking to them almost always means exposure to some kind of a psychological abuse.

No respect for human dignity and no concept of "service" in healthcare system.



Tetyana
Furmanova

Go for personal
contact, there's
nothing to be
afraid of! And
everything will
be OK!

Events where people with and without disabilities mingle are of ultimate importance.

Tetyana Furmanova

What does defending the human rights mean to you? Just how is this whole thing about you, exactly?

For me it's my own story of life, right from the birth... Ever since childhood, I have been showing that I am no different from the others, with just one arm missing. I am able to live my life like anybody else, without any special patronage. Maybe being slightly different made me want to learn to ride the bike, to swim, to climb the trees or to be the first one to take a dip in a cold river, "opening the season"... In junior school, I was the best student in the local DIY club.))) Scout's honor!

What kind of barriers do you encounter while defending the human rights? (Are they unique or universal?)

The barriers I had to take... I don't even keep them in my memory, although they were many indeed.) One day before I became a first-grader, some lady from the school dropped by, saw my missing arm, glanced at my Mom somehow sorrowfully and said, "Poor girl... Well, hopefully she will be able make at least C's". Back then, in 1987, most people were thinking like that. Oh, by the way, my parents we also sure I would live with them all the time, for what else is out there for me, etc) But I proved to be a good student and after school went to Kharkiv all by myself, to enter the university. Yes, I left my home at the age of 16. And yes, there was this "sympathizer" in the maternity wing who whispered to my Mom, "You can give that kid up. You are still young, you can have a healthy one!" Oh how my Mom wept and whined... Now she recalls that day with a comment, "Could I ever be dumber!"

Can you recall any particular accomplishment in the sphere of human rights protection that you take special pride in?

As far as the human rights protection is concerned, I take the biggest pride in the life stories of my acquaintances, old and recent, who have disabilities. Here are some of them.

Natalie — a grownup girl who can type on the keyboard with her nose. She's got a severe case of the ICP. I convinced her mother (a very distrustful person) to let me take Natalie along with a dozen more persons using wheelchairs to a zoo. That was the girl's dream come true! And I was happy to help her have it. We've been keeping in touch ever since, sending postcards, etc.

Ruslan — a young man with heavily deformed lower extremities. I just met him in the street and took his phone number. He did not believe I could give him a call and suggest something. But it happened! I got him involved in an event dedicated to children with disabilities. He sang to a big audience. It also was his dream, for he loved singing. One day he even walked up five floors to visit me!) Personal communication like this gives strength and inspires, I think. People grow more confident in themselves. They develop a sense of self-respect and the world around them no longer seems to be that hostile. I personally got a lot of other people involved in the event where Ruslan sang. A lot of them made friends back then, and it brings me joy. We are social after all, so we naturally seek some recognition from the society. I have a lot of stories from a military hospital where I used to work as a volunteer. Some other time, maybe..

What is paramount for the promotion of the inclusive communication environment in the society?

Events where people with and without disabilities mingle are of ultimate importance for the promotion of the inclusive communication environment. It inspires everyone! And I'm not talking about some concert with dancing and singing (whoever feels inclined to do it) and the public applauds only because the performers are

using wheelchairs or missing an extremity... No, they laud them for the honest, hard labor, no matter which, disability notwithstanding. I want to dispel the myths about misery through disability... One day some people kind of “complimented” me, “Hey, you don’t look like handicapped at all. So pretty, always in good spirits, fashionably dressed...” Hmmm... These stereotypes go back to the times of “...hopefully she will be able make at least C’s”. Oh, here’s another story for you. My father-in-law has Parkinson disease. Some folks came to visit him. Saw him sitting in a wheelchair, talking is hard for him, so they think he is soft upstairs as well... I think we never ever persuaded them that they were wrong. It all comes from ignorance and reluctance on both sides of the board (someone is too focused on the victim attitude, the others have no idea how to behave). Go for personal contact, there’s nothing to be afraid of! And everything will be OK!

If you could compare human rights activities to any extreme sports, what would that be?

Human rights protection and the extreme sports... I’d say it’s like skydiving. Scared like hell before jumping. Then it’s total bliss! But if you are still scared and fail to chill, you may break your legs or spine. Therefore, you can either get a kick out of your life or harm yourself... It’s all in your head!

As a woman with disability, what are the challenges you have had to deal with so far? Is there anything that you find scary, insulting or discouraging?

I don’t fancy myself a human rights activist. No. not at all. But, to be honest, it does feel nice when you know that you serve as an example for other! And they often tell me that I am.)



**Iryna
Sarancha**

For me,
protecting
human
rights
means
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human life.

**I cannot be indifferent.
I share my experience —
positive and negative alike**

Iryna Sarancha, Chairman of the Board of the NGO Vinnytsia City Organization for Social Development of Certain Categories of Vulnerable Youths “Parostok”, Associate Professor of the Department of Psychology and Social Work at Vinnytsia Mykhailo Kotsiubynskyi State Pedagogical University, PhD in Pedagogy

What does defending the human rights mean to you? Just how is this whole thing about you, exactly?

For me, protecting human rights means protecting human life. This activity is important as it gives you and everyone else an opportunity to live a quality life.

Can you recall your first experience defending the human rights? Did you act on your own behalf or was it to the benefit of somebody else?

This must be the experience of making a stand for my right to education. I was 18 years old and intended to enter the Pedagogical University in Vinnytsia. Writing is a real struggle for me, so we found out about the option where they set up a commission for an individual spelling test. I needed the approval from the Department of Education at the Vinnytsia Regional State Administration. A very young girl with a disability, I would go there to assert my rights.

What is driving you to break through the barriers?

Quite honestly, life is made up barriers — you take one, another comes up. I think one needs to come to terms with the fact that one will have to take barrier after barrier all the time. So you need to be in a state where there can be no sitting back. Where one needs to be in a combative mood all the time — to be able to fight for oneself and for the people who, say, matter to you. I think this is what's driving me as a human rights activist.

What keeps this combative mood going?

You know, as I take barrier after barrier, I see people like myself or who have it even worse than I. I cannot be indifferent. I share my experience — positive and negative alike.

What kind of barriers do you encounter while defending the human rights? (Are they unique or universal?)

Unfortunately, this whole country is a barrier in many aspects. Physical barriers, information barriers or, say, psychological barriers. Take, for example, the right for education. I have seen a lot of cases when things were bright and shiny on paper but in real life it was quite the opposite. Physical barrier... I live in Vinnytsia. They say, it's a barrier-free city. I must beg to differ. There are endless barriers to take 1.

Can you recall any particular accomplishment in the sphere of human rights protection that you take special pride in?

Quite a lot of them, actually. There is a couple of spectacular cases, though, that burned into memory for life as the examples of spectacularly stereotyped attitude toward people with disabilities. I will tell you about a few that still hurt me the most. We had this boy with an advanced case of ICP. When the time has come for his to get a passport, his parents took him with all necessary documents to a residents registration office in Vinnytsia. So this boy comes to the office and they ask him point blank, “Why do you need the passport at all? What good will it do to you?” This was the first nasty event that stuck in memory. Another case was when I worked as a deputy director of the State Center for Rehabilitation of Children with Disabilities. And in all of my 17 years of career out there I remember this girl with an extremely nasty case of ICP whom we helped to prepare for the entrance exams to Vinnytsia State

Pedagogical University. She wanted to be a mathematician. Severe disability, extreme case of speech disorder. But the kid had a dream. And we followed her dream. We prepared her well. But I happened to be sent to Montreal, Canada, to take part in the human rights school right around the time when the girl was scheduled to take her entrance exams. I was confident she would make it. We had completed all bureaucratic procedures together. Her parents and herself were experienced on the matters like that already. So I return to this country, see this girl and she says "I failed". I say, "What? Why?" She got a "B" on her math exam but when the time came for the spelling test, they took her to the general group and she got a "D". I barge into the warden's office, "What's going on here? Please where is the logic? I don't understand you. You all are teachers here, so what's the problem?" The warden looks me in the eye and says, "Since you seem to care so much, go to Kyiv and sort this mess out yourself". No problem. I jump in the car and go to Kyiv, straight to the Ministry of Education, get an appointment with Deputy Minister, explain him what has happened. He picks up his phone and tells the warden, "I don't care about the paperwork or how you formalize it but this girl has to be admitted". On my way back, I saw the entire family waiting for me at the entry point to Vinnytsia, a ceremonial loaf of bread in hands, to indicate in their own way that things will be fine. But the girl changed her mind. She was broken. She said, "I will never be able to set my foot inside that institution". Then there is a case that speaks volumes. I know this woman with muscular dystrophy. And they wanted to have her operated on without her approval. To cut the tube. Doctors decided she won't need it anymore. We raised a huge scandal and the girl was left alone. In fact, there are scores of such stories. Here's another case. You'd be amazed to know how many people with disability live in Ukraine, with certain education and experience, and totally abandoned. I have a degree in Pedagogy. I am a psychologist and a special needs expert. One day I took part in an "open" tender to fill the position of the director of the *Promin* Rehabilitation Center. I was supposed to

draft and present my concept of further development of the center. So I went to Kyiv, presented my program, earned a round of applause and somebody told me in the lobby afterwards, "You did great but we don't need you as a candidate to this position".

Did you or the people you protect feel any impact from the COVID-19 quarantine restrictions?

Oh yes, we do. We have a day care group for the people with severe mental development disorder. I think the quarantine restrictions hit them the hardest, because these kids are unable to use any gadgets. With this quarantine going on, they are totally cut off from the society. In fact, we are only able to provide social services to them only thanks to the support from the City Council. But this category of people feels the impact the hardest.

What is paramount for the promotion of the inclusive communication environment in the society?

Understanding what inclusive communication means. And personal involvement. To promote inclusivity is easier than to explain its importance? We are currently working on a very interesting initiative. Don't know how it all will play out, though. Well, there's this NGO called "Influence Group". We work on the joint project with them, developing recommendations to political parties in the context of inclusivity. Anyway, I seriously wonder if any party ever opens the file at all.

If you could compare human rights activities to any extreme sports, what would that be?

Not really sure. First thing that comes to mind is rock climbing. Why? Because the higher you get, the fear gets stronger yet. You don't really know how much longer you can carry on. I used to watch the climbers. And I understand this constant stress, including emotional overload, and you never know when you are going to slip, when you are going to say, "Enough is enough, don't want to know or see anyone!"

Is there anything that you find annoying or sapping your motivation?

Fatigue, maybe. Fatigue and constant stress. It is so hard to be on guard all the time.

What is the most common stereotype about yourself that you find to be profoundly inane?

“She is omnipotent”. Few people really understand the need to be weak, to be different, but you have to keep on fighting and to appear strong. There are times when you no longer want any of it. You want things to be quiet, easily available and normal, but it never really works that way.

Are there any stories that inspire you? (books, movies, music)

Quite a lot, you know. The life story of Mother Teresa must be the most inspiring one. I am a believer. A reporter observing Mother Teresa once admired her dedication to help other people and exclaimed, “I wouldn’t do what you do for a million dollars!”, to which Mother Teresa replied, “I wouldn’t either”. She was inspired by the love of Christ. This driver deep inside of me is worth more than many things

I wouldn’t dare to explain. First I thought I wanted to be someone else, to earn recognition. Then came the time when I realized the utter senselessness of these motives. It all gives you nothing but you keep working, getting some kind of a high from what you are doing. Finding this drive seems to be the most important thing in life.

Still I dare to ask about the music. What kind of music gives you the drive you need?

Classical. I just love the sound of organ.

What does it take to make this world a fair place?

A fair world... Probably, people respecting one another.

What does it take to be a human rights activist? Do you consider yourself such an activist?

There shall be no room for indifference. To me, the concept of personal involvement is the main feature of the entire human rights movement. And yes, I am a human rights activist.

Interviewed by Olena Zinenko.

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