DISABILITY RIGHTS
international
UKRAINE

voices: women, children and disabilities

reflection-project

Kyiv — 2024

“VOICES: women, children and disabilities” — this is the reflection-project created from first-person accounts, presented through a series of exhibitions, and dedicated to women’s experiences.

The first project in the series we implemented in 2012. Social art-project “VOICES: unspoken stories about food, body and emotions” shed light on the experiences of 12 women who have had different eating disorders. The first stage encompassed real life stories, photo exhibition and sound installation. During the second project in the series in 2014 called “VOICES: women and disability” 12 women talked about the influence of disability on their education, self-expression, employment and daily life. These are stories about double discrimination — discrimination based on gender and disability.

In the current project we interviewed 12 women from various parts of Ukraine who have experience of motherhood and disability — either their own disability or of their children. We asked them how their lives changed after the children were born, how their typical day looks like, we asked them about their dreams, what supports them in their life and what they need. We also talked about barriers they face and about acceptance of disability. During the interview we wanted to focus on the experiences of the women, although all women talked about their children first.

We used the transcriptions of the interviews and made a montage of the text without rewriting the story to preserve the authentic voice of each woman. Voices are presented as a mosaic of quotes. In the illustrations, we used a negative collage technique to express the following motifs:

- every woman can find herself in the shoes of the heroins;
- under peer pressure, women risk reducing their identity to the role of a “caregiver”
- the experience of women who have disabilities themselves and/or are raising a child with a disability is still invisible to both society and the state.

This united fabric of experience shows the invisible daily struggle that women have for the right to their own time, their own space, their own voice. How they reclaim themselves. It also highlights the fact that disability is not inherent to a person, but arises on the verge of their contact with the environment.

When a woman becomes a mother her life is divided into “before” and “after”. A woman is never alone again but may feel very lonely. Being a mother means experiencing the whole range of feelings, very often such feelings are not acceptable to talk about.

In addition to the biological and psychological dimensions, there is also a social one. With a new role comes new expectations. Women are still expected to devote most of their time to the upbringing and caring for the children. Children should be a priority, self-realization can wait, and involving other (especially non-family) people is a shame and possible only for very good reasons. These are stories that are still resonating today.

If a child with a disability is born into a family, all these expectations multiply. Women are mostly responsible for caring for children in the family, and in the case of a child with a disability, women bear all the responsibility. It may seem strange, but this also applies to mothers who have a disability themselves. People say those women gave birth, so they have to rely on their own strength.

There is still a stereotype in society: “sick” children are born mostly in dysfunctional families, especially to such mothers. Doctors with “good intentions” convince that a “sick” child should be left in a specialized institution and a “healthy” child should be born again. The medical model sees disability as a disease and cultivates a sense of guilt in women, which pushes them to seek endless rehabilitation and ways to bring their child back to “normal”. This creates a constant feeling of being a “bad mom”.

Families of children with disabilities are often left alone to face most of the new challenges, and very often remain in an information vacuum. Forced isolation results not only from the architectural inaccessibility of public space, but also from stigma and fear of otherness. Psychosocial disorders and intellectual disabilities cause a desire to withdraw. Most often, social assistance is only in the form of a small pension. The system of social services and support at the community level is not working well. Of course, except when women create it themselves.

Only a transition to a legal model of disability that puts people and their rights at the center is the only way to ensure a truly democratic society. Wellcoming and safe for everyone.

Olha

I enjoy having coffee with my husband in the morning, it is a kind of a process of communication about yesterday and about plans for today. I then raise Nikita from bed, we do all the morning hygiene together, I feed him, he stays at home, and I leave for work. I work half of the day, and then I rush home. I am the hands and legs of my son. He needs continuous support in all social and day-to-day routines.

When I was a student, I used to volunteer for the French humanitarian mission who came to the children's institution. For the first time, I saw children who had severe developmental disabilities. It was a hard experience for me. I have had it carved in my heart for the rest of my life; I recall how a mother was visiting her institutionalised daughter with cerebral palsy. It was many-many years ago but I talk about this now and I have tears in my eyes.

> **I don't want to be a super mum. I wish to be a mum, a regular mum, with my weaknesses. I want to enjoy being a mum, I don't want to carry motherhood as a medal on my neck, medal that drags you to the ground.**

The age difference between my children is six years; Marusya was a baby in a baby carrier backpack, Nikita was in a stroller. I hate it when people say "I wish you patience" or "you are such "a super mum". I don't want to be a super mum. I wish to be a mum, a regular mum, with my weaknesses. I want to enjoy being a mum, I don't want to carry motherhood as a medal on my neck, medal that drags you to the ground.

When I was getting my education, we all dreamt of being interpreters. But life took its own turn when Nikita was born. After maternity leave, I didn't go back to the university, I was offered a job as a speech therapist. Yesterday I received greetings on the Day of Social Workers, and it made me feel sad. I don't feel like it's my professional holiday to celebrate. I was as if dragged into this work because of circumstances. I want to be a psychologist.

I felt inferior because I had a child with a disability. I couldn't have the life like my friends, neighbours, and most people. Very often my husband and I recall how Nikita was growing up: he didn't grow with other children in the playground. I had a wish to leave, to walk separately, not to listen to irrelevant questions, not to see other children developing, and not to focus on what he couldn't do. It was a period of self-isolation from society.

Marusya is younger and for some time she lived with the knowledge that everything happening in our family is normal. But it was this way until the first year at school. When she started her school, she was scared that other children would not play with her, and would not sit with her at one desk. I saw her frightened eyes when me and Nikita came to take her from school, we talked about it at home, we cried all together.

During Marusya's teenage years I saw she was afraid again. She would criticize me a lot that I was always with Nikita, that I spend most of the time with Nikita, she complained that she lacked my attention. There was a lot of aggression against Nikita because he was the one who took me from her. It was a very challenging time. But now they are very friendly. I can feel it and I appreciate it.

Uzhhorod

Nikita can go for a walk by himself. It became possible because of the electric wheelchair. The process was hard. He wanted it a lot, he asked "let me have a ride myself", I felt scared. We have thought-through routes, if you do not follow those, the wheelchair will get stuck. The greatest barrier for me now is physical accessibility. One may have super wheelchairs and devices, but it is irrelevant if you have no chance to freely move around and have access.

Today I know that there is a reason to enjoy life and to have a happy family. I keep asking myself if my life would turn differently — how would it look? The first years of struggle before acceptance can't be avoided, but they lead to what is now. Don't be afraid, be happy and enjoy your children — they're worth it.

> **In the circle of mothers who have children with disabilities I feel recharged. It is when I talk openly, and feel understood.**

Now I have a big dream — I would love to build a house of supportive living. It is both, care for my son and care for myself, because I understand once I grow older, I won't be able to support him physically. It is also to care for my daughter. I don't want her to take over my responsibilities. I want Nikita to live his own life, and I want Marusya to be his good friend and to visit him, or the other way around.

"a super mum"

Victoriia

The first two years were the most challenging. I can't recall the first year, I didn't exist as a person back then, only my child and the diagnosis existed, and doctors. Even my husband didn't exist. We almost got divorced, and had a family crisis — it was caused by the fact that when you have a child with a disability you face it alone. When doctors came to examine the child, their hands shook, they were afraid to touch the child and I then realized that everything was bad. For over a year my brain refused to accept the fact that my child has a disability.

As mum I was alone with all the doctors, medical examinations, decisions to be made. It had its consequences: chronic exhaustion, depression, suicidal thoughts. When I joined the group therapy for the first time, there were mothers of children with disabilities, I got rid of the feeling that I am alone in this world with such a huge grief.

They offered me at the maternity hospital to abandon my child. Head of the Department at the maternity hospital met me at the entrance to the ward and said "I have something important to tell you. Are you aware that there are specialized institutions where you can leave your child? Your child is a vegetable, it is going to be disabled for its whole life." It was 2017, in Kyiv. "I recommend you write a rejection letter and give birth to a healthy child." They told me: you will feel burnt out, give up and will give Sofia away. I have always been afraid to burn out.

When you immerse yourself into the problems of disability of your child, you eventually become "a social outcast" and once you find activities that engage you socially — they become a resource. I chose confectionery, I have baked for over three years now, but initially it was more like therapy. Eventually I started to receive orders, it was vital for self-fulfillment and contentment, it dragged me out of social oblivion. I worked for over eight years as a manager of foreign economic activity. I loved the job and I planned to go back to the office. I planned that I would give birth and take a one-year-old child to the kindergarten. I planned with my husband to launch a business. All those plans got ruined.

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At first, they predicted she would die before she was one year old, then — three years old, then — five. Now the prediction is ten years old. As long as my child is alive, I'll take care of her. The older she gets, the more difficult it becomes. When Sofia weighed six kg in a sling wrapped around me— it was easier, when she was three years old in a small Yoyo stroller which I could take on the public transport, on taxi, I could easily fold it, and now she's in a specialised large wheelchair that weighs 25 kg.

I must figure out how to live in a country that doesn't want to see such children, families, and doesn't provide any support. Inclusion in Ukraine was announced over nine years ago, but only on paper. Children with complex disabilities and high support needs are left out too. There are no programs of rehabilitation, there are no programs of socialization in the kindergartens, there are no specialists who could care for such children, and parents are left alone.

Kyiv

They didn't give my child a birth certificate. I went to their office and they kept repeating "Your child is about to die. We refuse to write you a birth certificate."

I came up with a hashtag #live_your_life three years ago, when I started my own therapy. When my husband has a chance, he stays with the daughter. I spend with her 95% of my time: at the events, meetings with friends, on the trips, during the walks, in the theatre, at the museums. It is part of her social life.

When I lived in Poznyaky district of Kyiv, it took over four years for the mothers in my neighbourhood to get used to Sofia. There were mothers from other neighbourhoods, they very often took their children away from my child, cleaned their hands with napkins because "epilepsy can be transmitted by contact."

#live_your_life

Sofia and I became the face of the advocacy campaign to legalise medical cannabis. It was my life-saving straw, and I can with my voice actively participate in the process of change in Ukraine. I started sharing my experience of using cannabis and how it helped to stop seizures. It does not treat, but it is a way that helps to ease the child's seizure.

It is worth reading more about human rights, to know once's rights, it helps to avoid a lot of trashy situations in life. It turns out when the doctor was shouting at me during the labour and made my husband leave the ward, I could have called the police and change the doctor. Maybe then everything would have been different.

Olena

Ternopil

Two children. Volodya is the older child. He is nine and has a complex disability with high support needs which makes him dependent on his environment. Any daily routine — eating, change of diapers, everything must be done for him. Anya is a younger child. Both are in their second year in the school, but Volodya is home schooled.

My average day starts early in the morning. Around six. I get up, wash and rush into the kitchen to prepare something to eat. My schedule is very rigid. It is a school time of the year, and my routine is built around it. On average, teachers come over around ten in the morning or in the second half of the day, when Volodya is awake. I always monitor when he is taking his midday nap through the camera installed in our bedroom. I am constantly occupied with some work, no time to slow down, breathe out or even to eat. At times, I eat while standing. Eating is usually a very hectic process.

In the past nine years of my life, I did not have even a single day when I would have been alone. I am always alert, always concerned that something might happen, or I might need to do something. I lack lightness. I am in a continuous mother-mode. I am in charge of everything at home. I am a round the clock manager, with no weekends, no sick leave, as nothing is a reason to stop performing my duties. I want to learn to switch my attention to something else. I want to get rid of this feeling as if I am always monitoring everything.

When Volodya was born, in the first years of his life it was very difficult. Especially in those moments when I could see that most children at his age already walked and he could hardly hold his head. It was a life-altering moment, when I realised that life is never going to be the same. They told me his diagnoses at the hospital, very bluntly. I still remember that day. A lot of unfamiliar people in the hall, the doctor entered saying “What do you expect — your child is disabled.” That was it.

I was searching for a lifesaver in order to hold on to it, to understand — it could not have been the end of life, when you could just sit and enjoy your life. I started looking for mothers who had similar experiences.

In 2018 I launched a movement “Life without borders”. It was a very cool informal project that changed my life. I started a national flashmobe “Like everyone else” — I declared and showed that there are children with difficult forms of disability. My goal was not only to show that a child with disabilities can be born in any family. I also wanted to highlight that these are children primarily.

My level of communication improved. I became more open and confident, because I realised that there is a connection between the world around me and my child. If I lacked confidence, stopped trying to achieve a better life for my child — such as rehabilitation, classes — my child would never receive it. I have to be stronger, strong enough for two people.

Recently I was interviewed for the position of a psychologist. I wonder if men are ever asked “Do you have children?” I said that I had two. I told them that Volodya is a child with a disability. They said “We’ll call you back.”

be strong enough for two people

Even when you have two children and one child with complex disabilities and high support needs you can still grow, achieve goals and develop. It is vital to set goals. Volodya encouraged me to such self-development — I received a second degree in psychology.

“It is expected that you have to dedicate your time to children. If you spend too much time working — you are a bad mother.” It is an example of making a woman feel guilty in every aspect of her life. At times you hear this from your husband, at times from his parents, at times even from my own mum. For them, you are mainly a carer.

I find my support in my inner strength. Also, my husband supports me by spending time with the child.

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There is no such value in providing support in the family “I know that you want to work, develop your professional skills as a psychologist — let me help you, take time to study.” Or I may help you and hire a nanny. Or I will spend some time with the child. Or I will pay for your studies. Or I will simply ask — how are you?

I lack new bright moments. If I have a chance to work more and earn money, it will give me a chance to travel. Volodya is most of the time at home, and I have to be there too. If there was a daycare or school for him during my work time, it would make my life easier.

What does it mean for me to be stuck? It is to stop. As if you sink into a swamp. You stop existing. It does not matter if your child has a disability or not — you can always have your own space, some time for the soul. Never stop. Let this cliché “mother of a child with a disability” never stop you. Never listen to anyone but yourself. Follow your dream. You have only one life.

Liliya

Maksym has spinal muscular atrophy – it is rare for people to live long with such a condition.

I don't remember what life was like before Maksym was born. When I was pregnant, I had some dreams, hopes. When I heard the diagnosis of Maksym — it turned my life upside down. There was no time to get over it, to catch up with everything that happened, my brain froze and I didn't understand what to do next, and how to live my life. What does it mean he's going to die? When is he going to die? Maksym has spinal muscular atrophy — it is rare for people to live long with such a condition. I said to myself "He is my child. No matter how long he lives, I will be there for him." I didn't plan to let him live in specialized institutions.

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For two years I was adapting to the new life. I realised that the world is cruel, and everything is different from what you expect. It turns out, you're already grown up. Year after year things were getting better.

At first my mum helped me and later I had to look for a nanny. I have a nanny at least once or twice a week to have some time for myself. I call it my weekend. When you spend time around the clock with your child — you have emotional burnout. And I had to rescue myself otherwise I would not be able to give my child anything. No matter how much you love your child. If you ignore your depression — nothing good is going to come out of it. I reached out for help because I felt that I could not cope.

I live with Maksym alone, our nanny comes once a week. At times, the nanny may get sick. When it gets warm outside, I can go out but when it's winter time — I can't do anything. I spend most of the time then crossing out days in the calendar and counting days until the nanny is available again. She`s been with us for over five years. I taught her how to take care of Maksym — if I change anything, she knows about it. I spent most of my money on a nurse and nanny because having them means I can have some rest. I choose myself and my emotional well-being. I can try to cut expenses on something else.

Lviv

I choose myself

When I go for a walk with Maksym people look at me as if we are aliens, they don't allow their children near us, they look scared. I started working on a book in the form of a diary.

I wrote about my fears, my pain, as a confession. It is one thing to write a book and it is a very different approach when you write it honestly, so that the person reading it would think — I have very similar pain, I also feel bad at times, I give up. I wanted for the parents when they read it to understand that they are not alone, that at times it gets very hard. At times it is so hard that you think "when this child is going to die so that I get free." It does not mean that you will do something with the child, of course, not! It only means that you're a human being and you're weak. It is ok.

I would love to have more time for myself. Also, I would like to be less anxious. Parents who have children with disabilities are usually very anxious, at times extremely so. When people say "I walked 20 000 steps today", I think to myself — I would love to walk so much too, if I had a chance to leave home. At times I can't even take the garbage out because I have Maksym who needs constant attention.

Families who have children with disabilities face more challenges during the war. As children get older, their needs grow too. We spend a lot of money on equipment — different types of tubes, syringes.

I wanted to become a psychotherapist. My parents told me that the profession had no future and it is not a job for a woman. I still regret that I didn't do it. When I have free time, I read books, and take courses. I used to work as a designer. Now I work as an assistant for a blogger, and I study to become a psychologist.

I am who I am. I don't try to prove anything to anyone. Those who have not been in my shoes have absolutely no right to tell me what to do. Children with disabilities are born not only in poor families. When we are young, we think that nothing can happen to us. "It happened to Lilya. It will not happen to me. It can't happen to me." I always fight against the word disability. First, you must look at the person and then their disability.

Diagnoses is not a sentence; it is not the end. Yes, it is hard. It is going to be even more challenging if you're at the beginning of your road. But you will cope. It is important to accept this surreal reality. I didn't fight the diagnosis of Maksym. I loved him. Every day, every minute, every hour, every year. I loved him. I accepted him the way he is. I don't try to change him. Such an approach requires a lot of strength, love and motivation. Everything revolves around such acceptance. One day he is going to die. I don't know if I will feel depressed, happy, or I'll be free from everything.

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Alyona

Mykolayiv oblast

I temporarily live in Mykolayiv oblast. My mum lives here too. I can even sometime to go out with friends and have coffee — my mum backs me up with the child. Before, I spent half of my life in Kharkiv, I studied there. I have a degree in medicine and pharmacology.

I spend most of my time taking care of my child. When he was a little boy, I had a nanny. It was a bright light of the day — when I did not have to be 24/7 with my child. Then it was very difficult, nannies did not stay long with us. I thought back then that they lacked motivation.

When he started his school, we did not know about his diagnosis back then. In the public kindergarten the principle said "I will do everything in my power to make your child leave this place." I always received calls with complaints to take the child home earlier. I had to leave the job again.

We were told indirectly, with hints, always referred somewhere "Why don't you talk to psychologist, psychiatrist." I felt guilty, I felt as if I am a bad mother and do not take good care of my child.

When I take him to bed, this is the moment when I have time for myself. I go to bed late, I try to use the time when he is asleep. My day is divided into "before" and "after". I used to cook. Then I felt sorry for myself. I thought that if I keep cooking at night — I will feel completely burnt out. I came up with a different plan — I stopped feeling bad as a mum because I ate at the restaurants with my child.

When we lived at first [after the full-scale invasion of Russia in Ukraine] in Uzhhorod, we thought "Well, tomorrow we'll go back home." After a while I decided to look for better conditions. But in order to have those better conditions, at least a two-bedroom apartment, father of Arseniy said, "I am sorry, it is too expensive for me." He supports us financially. In everything he can. I do not have any income.

There is a habitual thinking in society that when you try to deal with your psychological well-being this means "you have nothing better to do". I know from experience that when you have depression, anxiety disorder – it may be a temporary disability. From my experience I know that it limits you in so many ways.

My mum always supports me. But she has little understanding why the child behaves the way he does and keeps telling me "You have to spend more time on his upbringing. He keeps swearing — you have to explain to him that it is bad." On the one hand, she helps, on the other — she puts pressure on me.

After the child was born my life changed a lot. I suffered from postnatal depression. When I had depression before the child was born, I could take medicine. Breastfeeding is a very challenging process. I was prescribed medicine that was compatible with breastfeeding — but there was a lot of pressure from my husband, my mum and my husband's parents. I was accused of harming Arseniy's health.

don't want to be a victim

Back then my husband supported me with nannies, but I could feel his criticism, maybe, it was the social pressure he experienced. With time, I started to take things easier, I declared that I have depression and that I have the right to have it.

I realised that I do not care what others think about it. What do I spend my money on? On psychologists. Then I felt better. And after I changed my mindset, the people around me started to change too. I thought at that moment — why I kept silent for so long. I could have felt better long ago.

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First diagnosis was attention deficit hyperactivity disorder, oppositional defiant disorder (the type that is characterised by swearing), bipolar disorder, autism and asperger's syndrome. When this list was getting longer, it was very challenging, I felt sorry for myself. Four years ago, I kept asking God "Why? What for?" I had a lot of thoughts in my head, I couldn't put those thoughts together. I wanted to get married for the second time. But I realised — who would want to marry me? I felt ashamed. Final self-acceptance happened when Arseniy got into the hospital in the summer. He was hospitalised for psychosis.

When his father took Arseniy in summer, I started a new job. I thought to myself "great, now I can build my career." I want financial independence from the man who long ago stopped being my husband. Three months later he brought Arseniy back and said "No, I can't combine my job with childcare. I will keep supporting you."

I dream that people with any form of disability will be fully integrated into society, and would not feel different or worthless. Any person is valuable as they are. I wish for children like my Arseniy to be able to fulfil their potential, work and develop their strong qualities.

My dream for myself is to be useful for society. I want to be a tool in God's hands. I have a challenging path behind me but I don't want to be a victim. I want to be useful. I want to take this potential, all my experience, my pain and transform it into something amazing. Something that may help others.

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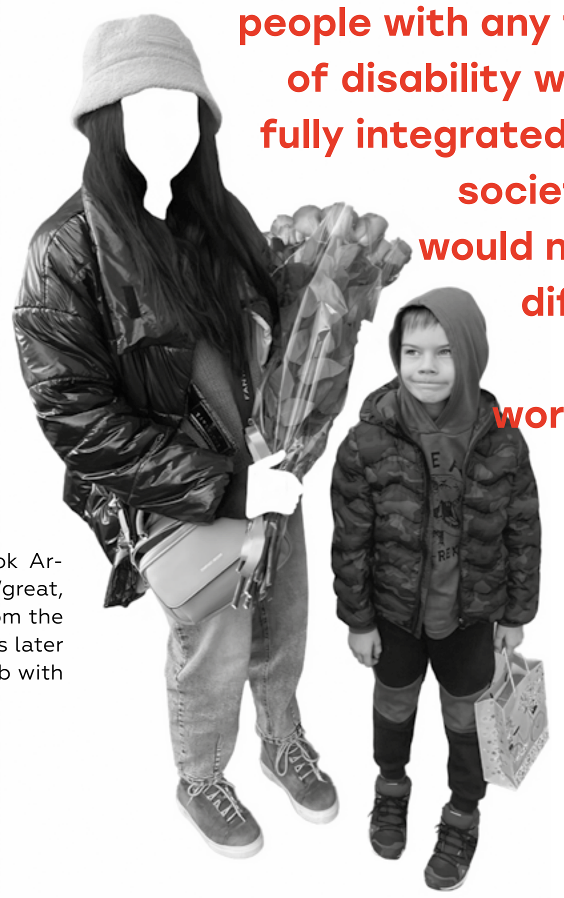


Vira

never give up

When I was a child, I kept crying — Why did it happen? Why me? And my mum kept repeating — God didn't give you hands but He gave you intellect and wisdom. As time was passing by, my feet substituted my arms. I gradually realised that nothing is going to change, I have to learn to live as it is. I am very stubborn. With years I realised that neither tears, nor anything else is going to help me. Life goes on and I must value every moment, especially now.

Since I was three, I have started taking spoon with my feet, I watched what everyone else did — and I followed their actions. I have one leg longer and the other is shorter, I have to use prosthesis. Eventually, I started walking and eating by myself, I picked up toys with my feet. I watched my mum and sister embroidering. And I took needle and thread when I was six and started embroidering.

I did not attend the kindergarten, I was homeschooled, teachers would come home. When I came to school for the first time, the principal explained — we have a very special Vira, who does everything - even though there was no need to explain. I grew up here in the village, I was born here, all my friends are here. I always was a leader among other children, organising everything.

I started doing make up when I was twelve. I enjoyed taking care of myself and I still love doing it. I watched videos online, I practiced a lot on my girlfriends. I did my eyebrows, and then I took care of my friend's eyebrows. It was then when I started to make some income.

When I graduated from school I was offered to go to study at Kremenets but I refused. I still need someone to support me with daily routine. I never travelled anywhere. I don't have a degree. I used to work online a bit. I attended make-up courses and watched professionals at work. Not everyone has the talent to do the job. I am self-taught.

It was scarier to get married than to give birth to children. When I was pregnant with my first child, I visited all possible geneticists. It felt funny because I knew that everything is going to be fine. When I had my second child I submitted official letter refusing to do any medical genetical exams. My mum only helped me to wash children, and I woke up myself to change them at night. My sister had two girls and I took care of them.

Then another sister had a baby-girl. I had had a lot of experience before I had my own child. My husband helped me too. My baby-boy was born two years later after the older girl. I gave birth alone, without husband. I am not afraid and do not hide that I am raising my children alone. At times it is very difficult financially and psychologically, but you can't run away from it — it is life. State should be helping us but, unfortunately, we receive no help.

There are a lot of people like me. We have to share stories with the world, so that other people like me would not live in isolation, would believe in themselves. There is nothing shameful in showing oneself. I received a lot of judgement, even from my husband's family. I was dating my husband for five years. God makes the final decision, we are not together anymore. I can't say that I lack attention from men. I meet other men and I tell them — this is who I am. If the person is bad — I reduce communication and avoid him.

Our day starts early in the morning — coffee, wake up children, prepare them for school. When children leave for school, I clean the house, start laundry. When children come back from school, we do homework together. We play games in the evening, we talk. I have a lot of flowers at home, I keep the flowers I love, and they also require care and time. There is not much to do in the village. There are no after school activities. I dream that my children and I would live in the city.

There are a lot of people like me. We have to share stories with the world, so that other people like me would not live in isolation, would believe in themselves. There is nothing shameful in showing oneself. I received a lot of judgement, even from my husband's family.

My strength is in the very fact that I have to do something every day. First of all, I prove myself that I can do this. I know that there are no situations that cannot be resolved. I am a fighter; I don't like whining. I can stand for myself and my children. I became stronger with time. Now I never stay silent — I know my rights. Vira before and now — these are two different people. Present-day Vira has been through a lot in life. I had a lot of failures, and a lot of disappointments.

My advice: love yourself, love your children, no matter how imperfect those children are. There are very different situations, God gives only those tests which we can handle. Never give up, keep going, love, be loved, take care of your family and everything will be fine.

> **I was invited for a show, and I hadn't thought that I would make it. I broke a record [Ukrainian nomination “The fastest make up with the feet”] and dedicated it to my children. As their mother, even though I have no arms, I am still valuable in this life, and I will not leave my children alone.**

Zaliztsi

Oksana

I raise two children. The older son Bohdan is 12 years old, the younger one Nazar — 9. Bohdan has a severe genetic disorder — Larsen's syndrome.

Every day is the same for me. No matter what the circumstances are — I do everything, all the time, regularly, routinely. I get up early. At times I do not sleep at all — there are night shifts with Bohdan, when day changes into night, and then night into morning again. After that I go out with the younger son to play, we do shopping, laundry, cleaning — and I work all day until evening. And then I can do my job until midnight — one o'clock at night. My husband and his mum help me with the younger son. And I focus on Bohdan.

When Bohdan was five, he got into an intensive care unit. I thought that I was a bad mum and didn't give him enough attention. It was a moment when I thought less about myself and more about my child. It was hard to get out of such thinking, a lot was happening. There was enteral nutrition, we switched to a breathing apparatus, connected to electric sanitation, pulse oximeters, cough suppressants — machines were beeping all the time.

I didn't spend much time caring for myself. At all. I was dedicated to children around the clock, their upbringing, care, supporting my husband, house, making sure it is clean, maintained and there was food. It took me a while to stop being super-mum and remember that I was a woman, who had her dreams, wishes. I worked a lot with a psychologist, talked through my problems, my fears. I shared my perception of my child and all the way to the topic of how to live further when I wanted to commit suicide. She taught me how to love myself, focus on myself, my health, my hobbies. I think they [my family] understand me otherwise I would have no time for myself. I want to see life around me; I don't want to be closed within four walls.

I would love to work as normal people. I would love to wake up in the morning, feed my child and leave for work. I would love to do my job and create beauty. I would love to change the environment.

I graduated from two universities. One of my degrees is in graphic design. I am a very creative person. I get energy from talking to other people. I have a small-scale awareness raising work: I have Instagram, chat for mothers, where we discuss various topics starting from adaptive clothing, nuances related to taking care of gastrostomy, tracheostomy, special nutrition. When I see that one of the mothers is in despair — I support her. It is a beautiful moment when someone says "Girl, it's ok, keep going."

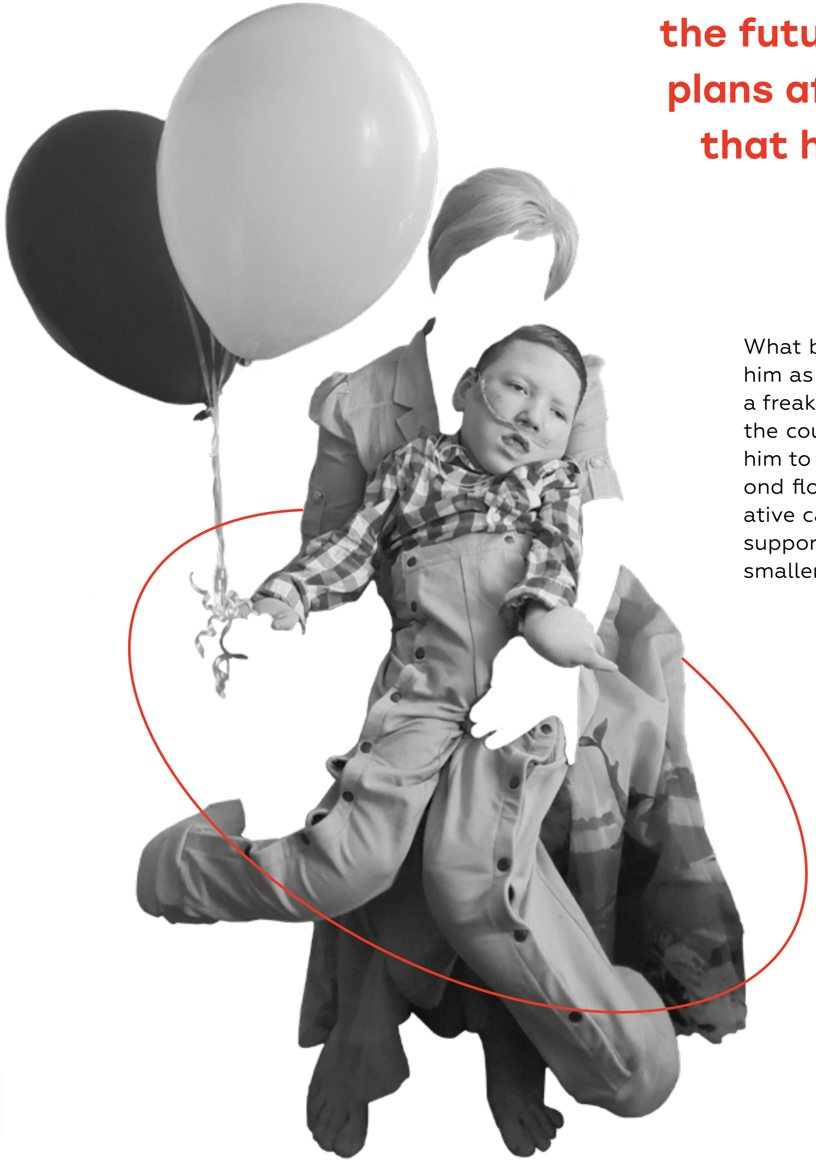
I would love to work as normal people. I would love to wake up in the morning, feed my child and leave for work. I would love to do my job and create beauty. I would love to change the environment. I have not been officially employed for a long time. I have been scared that I won't be able to return to social life. I was afraid that I would be irrelevant. I felt that I fell out of life. People see me like this "Who is she? Well, she cares for a twelve-year-old, living in the previous century."

The first year after the birth was very challenging. It was hard to accept that I have a child with such a severe condition. It was hard to accept that my life had changed so drastically, I had to be with the child all the time, a child that could neither talk nor show anything, and I never knew what to expect. I didn't leave my home, I was depressed. At the time there was almost no social media, resources, or chats. Each mum was isolated.

Kherson

Girl, it's ok, keep going

I live now in a war zone, and I can't plan for what is going to happen in an hour, forget about plans for the future. All my dreams are related to plans after the death of my son. I know that he is going to die sooner or later, he has a severe condition. I take it as a given.

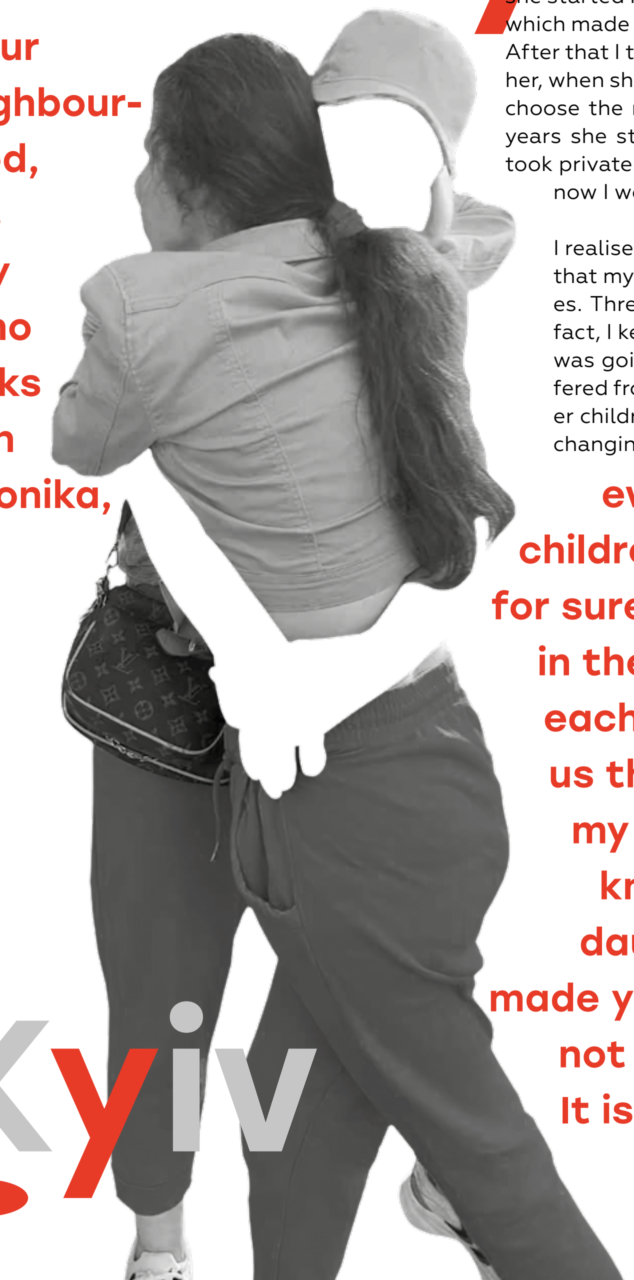


What barriers do I have? My child depends on machines. I perceive him as a healthy human being, but for the rest of the society he is a freak, monster, with tubes… All his body is distorted. The roads in the country, lack of ramps, equipped elevators — I can't even take him to the hospital because there is no way to take him to the second floor. Doctors come home only in case of emergency or palliative care services. In Kherson we have no such services. I have no support at all. There are a lot of challenges — some larger and some smaller. They all add up and hang in the air.

The conditions are very hard right now, even though there is tons of humanitarian aid, we don't get anything. No one gives us anything, or sends us anything, they don't fulfil their responsibilities, don't check on us. They might not even know if my child is still alive or not. They pay me social benefits. That's it.

You should not dedicate all your life to the child. It is not going to change the situation. It is important to love your child. Also, it is important to accept the context as normal and stable for your family, learn to live with it. It is important to have some time for yourself and not to be afraid to ask for help and talk to a psychologist or a consultant on any issue you have.

Natalya



My name is Natalya. I am forty-seven. My daughter is sixteen. I take care of her and do not work. My child was born healthy, and then she started having seizures. She took medicine to help with seizures which made her feel even worse. Until four years she was bedridden. After that I threw away all the medication and started taking care of her, when she was six — she started to walk. I had only one task — to choose the right medication. We found very light pills and in two years she stopped taking those. She started to walk. At first, we took private sessions of ABA. I learnt the necessary skills there and now I work with the child myself.

There was a moment when I realised that my child had a disability, but doctors kept saying that my child was fine, and that it was me who made up diseases. Three months later she was getting worse. As a matter of fact, I kept telling doctors that after the vaccination something was going wrong with my child. I told doctors — look, she suffered from seizures. Doctors told me she had cramps. I saw other children her age and I knew these were not cramps. She was changing. I had to prove it each time we went to see a doctor.

In our neighbourhood, it is only I who walks with Veronika, even though I know there are more children like her in the area. I know this for sure because I talk to other mothers in the specialised chats, and we know each other. They say "Oh, people give us those looks." I say "Wait a minute, my daughter is 16, all neighbourhood knows her, we go everywhere. Your daughter is six. My Veronika already made you a social path in the area." It is not always the problem with society. It is also a problem with the parents.

Kyiv

Back then I trusted doctors, they drugged her and it made her a vegetable — "Wait a minute, she was fine and now because of the medication she looks into one point and those pills cause even more seizures." They answered "what do you expect — you have a child like this. Either she is going to be bedridden or she is going to have seizures, or she'll have a fever 37° C — and it may happen that you will not be able to take her to the hospital because of the internal bleeding. Medication to prevent seizures is your only option!" For four years I gave my child the pills.

> **I wish we could go out and go somewhere together. The stable condition of my child. Everything else – no problem.**

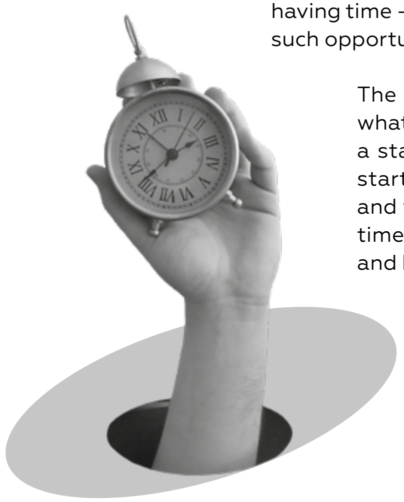
My job was to sell glasses that were made by an ophthalmologic clinic. At first, I had shopping stands, when I was 19-20, then I had small shops. And then I started working in the clinic. Doctor prescribed glasses, and I used to make them. I was active all my life, self-sufficient, with a large social network. I worked with professors; I had such an honour. But once I got pregnant — I stopped working.

we bear the responsibility

I would not like to change anything about my life. I lived — I had a job, I grew personally , I met my husband there, I was dating him. When we had our family, we knew that we can't live one without another. My husband was 35, and I was — 32. I think it helped that we were aware, grown-ups. There are three of us now: he, I and our child. And we bear the responsibility.

We are afraid for her behaviour, for her condition. She grows, and now, after all the bombings, her condition is getting worse. When she was small, I could embrace her tightly. Last year she responded better to the sirens. This year — she may wake up in the middle of the night, scream, run somewhere. And now when she has her periods — she gets very anxious a week before.

The only thing I wish I could change is having time — time I can decide what to do with. I have no such opportunity. I could plan before, but now — I can't.



The thoughts of the future scares me. I realise what it is going to be like. I wish Veronika had a stable condition. I have no dreams for her to start talking. I wish she had normal behaviour, and we could walk in the street. This year she at times does not want to go anywhere, she resists, and her body is changing. She stands and starts bending, pinching and beating herself. I wish we could go out and go somewhere together. The stable condition of my child. Everything else — no problem.

My husband and I are together for many years. We live according to different times and different standards. We had many things in our life. The only thing that keeps us going is our daughter. We could get emotional and get divorced, and each of us would have a different family. We both were advised to get divorced. When I was with my daughter in the playground, people used to say that my husband would leave me. He was told that his life would be hard with the child. There was a moment in life when I felt jealous of my husband because of Veronika. He has his own difficult moments too. We are not a perfect family. We know one thing — we have Veronika and we want to make her life good.

Halyna

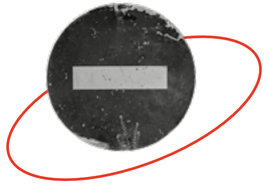
Chortkiv

I work as a manipulation nurse in the infectious diseases department of a hospital. I have two children. The elder daughter — she's twenty-six, she's a grown up, she works. The younger son — he's eighteen. He's autistic. He's still at school and only in the ninth grade because he started later than other children.

He was born as an average child. He was developing well until he was two. And then there was a regression. He lost speech, stopped making eye contact, he didn't react to his name. The word "autistic" I heard only once before, in some American movie. I was so ignorant about the topic that I started looking for some other causes, did medical check-ups. The word `psychiatrist` was scary to pronounce. He was diagnosed with the delayed psycho-speech development and later we were offered to go to Kyiv for further testing. I decided not to go anywhere because I thought that my child was doing fine. When he was five years old, I took him to the professor in Kyiv for further testing and he was diagnosed with autism.

At first, we were forced to leave the kindergarten "You see, your child does not respond, does not follow the instructions, acts hysterical." That was when we started working with him: he learnt to sit, follow, use gross motor skills, fine motor skills. His IQ was 28 points. Now he has just moderate intellectual disability.

Then my life changed. I had various stages of realization, re-consideration, rejection, then acceptance. I lost a lot of time. I had to do something, and I didn't know what to do. We started going to Kyiv every half a year to participate in the program. It is only now that I know that it was based on applied behavior analysis.



The change for me was in feeling different. I started looking closer and realized that other children develop differently and I withdrew to the circle of my family. I was ashamed, I was walking with the child and avoided letting him play with his peers. I was wondering how I should behave so that others didn't stare at me. It was challenging to meet new people — it was hard for me to explain each time why he was the way he was.

I have support. There are other mothers, a lot of girl friends who came into my life thanks to Mykola. I have four close friends: we meet once a month and have coffee together. These are very uplifting meetings, peer-to-peer, type of meetings that give you source of energy. My husband is at home and takes care of our son. They both get along really well together. My tasks are to prepare clothes in the morning and to cook for them.

There is nothing in memories with my son that I miss. I only miss my older daughter. They have a large age gap. I spent more time with my son when all the health problems emerged. When she was a teenager (I only now realise it) she didn't receive enough attention.

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my own perspective

I had one more dream but at the moment it is on hold. We had a very long fight to keep the centre. I wanted to be a director there, but I realised that local authorities would not allow it. At first, they offered me to lead it but later they refused.

I study psychology now. I want to work with young kids with autism. I wish I continued my education after I graduated from medical college. Back then psychological degrees were rare, but I could have enrolled at medical university and studied speech therapy there. When I was pregnant with the second child — I started my education at the medical college and took evening classes, bachelor's degree in nursing. Last year I started my master's degree. My thesis focuses on pre-school and school-age children with autistic spectrum.

The village where my mum lives is my place of power. Here I have my garden, flowers, cats — I adore them. When I return from work and they approach me from everywhere, or sit near the gate and wait for me. We also have two dogs, I also love them. I have a lot of flowers. I take care of them, talk to them. I must bring six buckets of water to take care of them. Soil heals me. I am a peasant in my soul.

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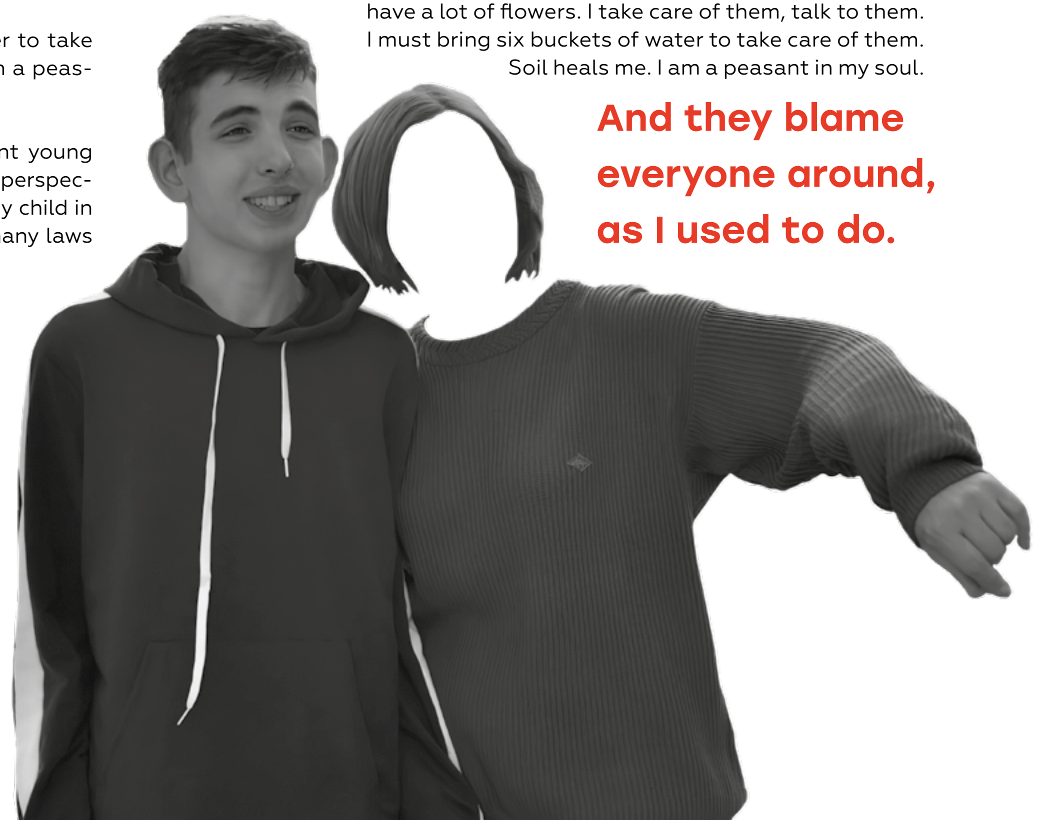
I was a very calm, confident young woman. Now I have my own perspective, vision. I stand up for my child in any area, I have learnt so many laws in so many areas — education, social care, even military code. I am a pain in the neck. Even more so recently, when we started standing up for our centre — some people are afraid of me, some can't stand me. There are also those who respect me.

There are a lot of parents who deny the problem. While parents are too withdrawn, the problem does not go away, and the child grows. You don't have to hide your child. Parents pretend that nothing happens.

And they blame everyone around, as I used to do.



Olha Husyatyn

My life started to change when I was 25. Gradually. Myopathy — the loss of muscle functions within 22 years. Every single day. I must get used to the fact that every day there is something new I can't do.

No one was ready for this. There was a change in the way I walked, I noticed it. When I was pregnant and even when my daughter was one year old, I did not suspect anything. I thought that all the changes that happen with my body are caused by pregnancy. My husband was abroad, he had a job there. I had no time to care for myself, there was no opportunity to take time and do a proper medical examination.

I have a degree in medicine, and I knew exactly what to anticipate when diagnosed. My first goal was to stay alive until my child was eighteen, and then I would see how things go. My child is 22 now and has her own family. My disease is progressing. For the past years it took away my legs and arms, and almost stole my whole body.

If my workplace was in an accessible place, if it was a specially equipped office on the first floor or at least there was a lift, I could still be working.

After I stopped taking care of the child, I could walk to my work with my own feet. It continued for a year or two but then I had to have someone give me a lift to work. A year later, my husband would carry me to the third floor of the workplace. I continued to work for another seven years in the hospital. If my workplace was in an accessible place, if it was a specially equipped office on the first floor or at least there was a lift, I could still be working.

Head of the social security department has no idea what it is like to be a person with a severe disability. I can't comb my hair, change my clothes, go to the restroom, get up from bed, go to bed, or change seats; I can't cook food or even to warm up or take the prepared food. The only thing I still can do — is to eat. I can't turn at night. I must be turned from side to side. I believe it is important to voice such things, not to be ashamed of it. It is important to voice it not to receive pity but to bring understanding of how to support families such as mine. It is not always about money but also about physical and psychological support. Unfortunately, it is not provided either.

With time I could walk less, socialise less, eventually all my friends and acquaintances disappeared. From 2012 until 2018 I became invisible in the village, hardly appearing in the streets. When I left the house in the electric wheelchair for the first time, it was obvious that people try to avoid the conversation.

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Every human being needs another human being

My main hobby is embroidery, it is my life, it saves me. I started to study more about embroidery in 2014. I had a goal to create my own collection — to embroider shirts with patterns from various regions of Ukraine. I learnt a lot of techniques but some are physically challenging for my hands.

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They haven't assembled the lift. I have been analysing the behaviour of the local government for the past few years — I feel like they come up with various reasons not to follow the norms. It is not only about the accessibility of my accommodation, but also accessibility in the village. All public buildings are not accessible — pension fund, department of social security of the population, also village council. A ramp is installed only at the stadium, at the hospital, outpatient clinic and drug store.

I often hear from people that I am an inspiration for them. They tell me that I'm hard to break and they admire my strength. For me it's the opposite – it feels like a burden. No one understands what price I must pay.

The most vital factor is architectural accessibility. It is even easier to get over psychological-mental inaccessibility than architectural. What I do within my accommodation, at times posting online — it is not much. Much better effect is when you can do your own exhibition, when you can visit a museum, cinema. Face to face communication is vital, not via phone. Every human being needs another human being.

Last week the head of the legal department told me that ramps in our apartment building is a reasonable accommodation. When I asked him to show me how to use it, he answered "I'm not you. I don't need it." Such response only proves that he doesn't treat me as a human being. I believe that civil servants should be ashamed to ignore the needs of those who are least protected. How about protecting the right of a person to be a human being?

Olena

Kryvyi Rih

I am the head of the NGO "InTerns" for children with disabilities in Kryvyi Rih. Organization has worked for four years now. It has been over four years since the daily routine of our family has changed too. Morning is pretty similar to any other family: help us God to live through the day. Breakfast first, then — classes. We study at home; I develop the schedule for my son. I want him to get used to the thinking that he can't just watch cartoons all day long. When my husband is back at home, I start my job.

Half a year ago we launched a social space where we work with children, teenagers and grown-ups with disabilities. I am grateful to my husband for his support. But for him, I would not be able neither to do the tasks, nor work on projects or have time for myself. He understands me as a woman who wants to grow, and I am grateful to him for this.

When we have classes for children, I always take Makar with me. I want him to socialise so that other children could engage. The key aspect of our centre is that we have children with and without disability. We have a pre-school group of children 4-8 years of age. Makar is 10, he is also in that group. Other mums very often say "Don't look at him, it is a sick boy or a girl." In our space we unite children. They communicate and begin to understand — yes, we are all different. Some people can walk, others can't. Some people can talk, others can't. Some people scream but we still understand them.

When Makar was born, I had a large support group: my husband and my parents. First diagnoses, first words, first doctor said, "Leave your child behind and give birth to another one." But my parents and my husband, despite these words, approached me and supported me, they didn't let me get depressed. They have always been there for me. They would let me have some minutes, hours, nights to stay alone. They would let me spend some time with my girlfriends.

Every year I communicate with more mothers who love their children and do not see any disability. They live a regular life. They have adapted. Rehabilitations were every month. Makar couldn't eat properly, he was always tired, there was no result. Then I took a step back: a child is a child — he needs his childhood and games. My husband supported me on the idea. He is my stronghold. In everything.

I lack understanding in society. It is a hard topic for us all. We have all the necessary laws, but we as parents of the best children in the world, must fight for services we need. I wish employment services, social services would have fewer people who stab you in the back and prevent you from getting the necessary social assistance. We show society that such children existed, they are out there, and they will be.

I feel great inner energy and driving force that keeps me moving when I see that children within our organization get results. Many parents get isolated and keep their children away in apartments. Over time children grow up to become teenagers. I don't understand it. Everyone has to communicate. Children who attended our culinary, psychological, art-therapy courses — they smile, they are in the circle of friends. I aim to share with parents who gave up that a smile of a child is already a result. Children may not become professional artists, but if they make even one stroke — it is already the result, because he/she can smile and spend time with peers.

I aim to share with parents who gave up that a smile of a child is already a result. Children may not become professional artists, but if they make even one stroke – it is already the result, because he/she can smile and spend time with peers.

Every child, whatever their diagnosis, deserves a family love. We have no right to give up and leave them in children's institutions. We have only one right — to be parents who love their children despite their diagnosis. Diagnosis is on paper. In life — it is love, warmth and tasty food for a child. Child is not guilty of anything. Absolutely. It is not going to be easy, but it is your child, and she/he is the best.

There is a belief that there were no children with disabilities before. They were not talked about, they were hidden. When such children were born, it was believed that their mother was a drug addict or alcoholic. If the child is sick, it is the mother's fault and the father`s.

a child needs his childhood

If there is a daycare where you can leave the child and go to work, then a lot of problems disappear. A lot of mothers have psychological barriers when they start to work because they do not want to talk about their children. This means they lack acceptance.

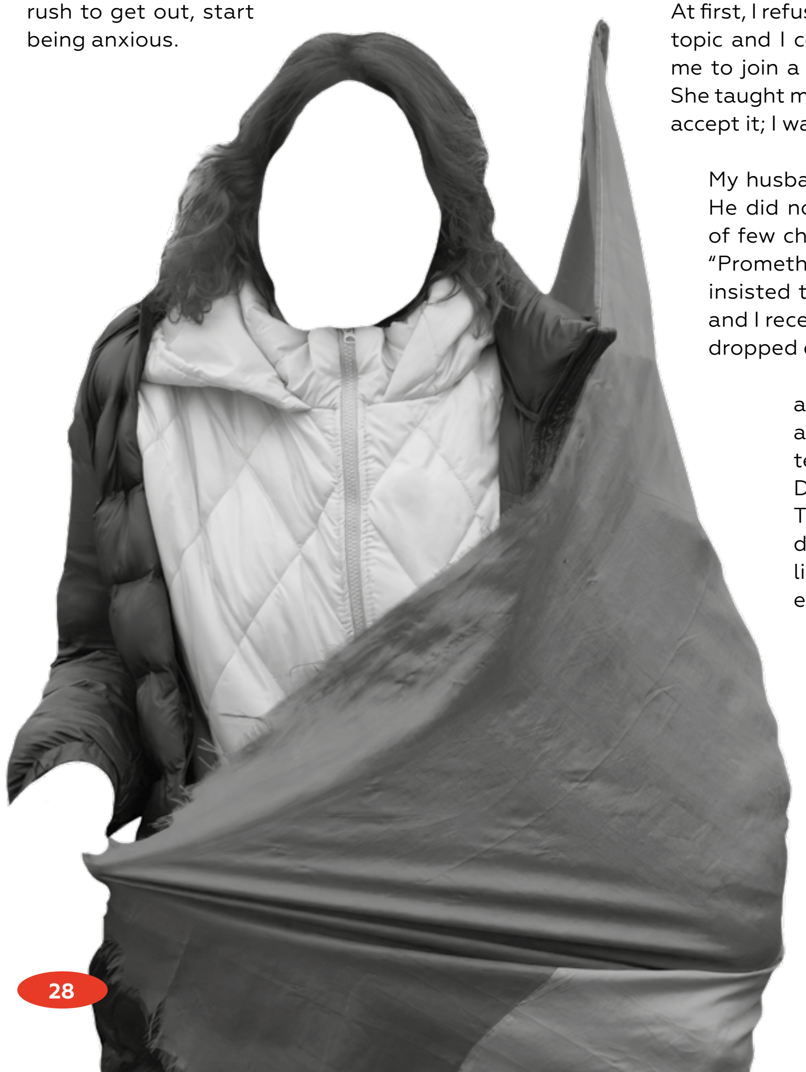
When I pass by Makar's classmates (he studies at a regular secondary school) they say "Hi, Makar! He's our classmate." Their words inspire me. When our friends, very different people greet us and shake hands with Makar — I feel proud. I'm proud for my child, for people, to see their change, and, of course, for myself. I would love to say to the future mums: try to focus not only on disability but also — personality.

Nataliya

I have two children: Vladyslav is sixteen years old, Oleksandr — twelve. When the second child was born, when he was about one year old, I could see that something was wrong. I consulted with a pediatrician but the response was typical for Ukraine. "Wait until your child is three years old and then everything will be fine, your child will start talking." When he was two years old — I could hardly control him. He did not listen to what I said, did not respond. He did not take "no" for an answer. When we were in a public transport he would be calm for one-two stops and then would rush to get out, start being anxious.

I was completely lost, I looked for help, I did not know what to do and what steps to take next. I wished to have a normal family: take my child to the kindergarten, go for work and then come back in the evening to pick him up, spend an evening with my child. I had a very bad experience with the public kindergarten.

A child psychiatrist had him tested and diagnosed with child autism. At first, I refused to believe. I started reading literature on the topic and I could see some similarities. Psychiatrist invited me to join a group of parents who attended ABA-therapy. She taught me privately how to care for him. I did not want to accept it; I was very critical of the situation.



My husband had a complete rejection. He did not support me. He did not want to hear anything at all. My son was the first of few children diagnosed at this age. He attended the centre "Prometheus" and a public kindergarten (because my husband insisted that we should try both). My son kept biting, beating, and I received a lot of complaints. Eventually, I got tired, and he dropped out.

The director of the centre worked a lot with me. She told me "Don't rush, treat him as a normal child. You come to the kindergarten, leave him there, come back in the evening. Don't insist on anything, let the situation go." Those words comforted me. It was something different, unlike the ABA-therapy, where I felt like I must teach him and be responsible for everything. "No, you are the mother, you have to love him and care for him, as for the development — let the situation go." I did exactly that.

No one expects the birth of a child like this. I had to learn to accept those problems. Once you accept the situation, you realise that it is nothing else but a different approach to the development of a child.

Once, I was dragging him back home from the bus stop. It was wintertime. He was heavier and I could not carry him anymore. I put him down, he laid on the snow screaming. I was desperate that I could not carry him, and exhausted I sat next to him. A woman was passing by and commented "what kind of a mother are you?" I swallowed her words silently.

learn to accept

When he was six-year-old the director of the centre suggested that we enrol him into a regular school. The local IRC (Inclusive Resource Centre) insisted that he should attend an inclusive classroom where most children are children without disability. Inclusive education in Ukraine was just emerging. I remember the first parents meeting before the school year — all parents gathered and were announced that there will be children with disabilities in the class. No surnames or diagnoses were mentioned. Some parents were totally against such an approach. I did not pay attention because everyone has the right to their own opinion. If they do not like it — they can leave.

Sashko [my son] started visiting the centre in 2013, and I started working there in 2016. The centre was offered a space in another part of the city and I was responsible for organizing the bus commuting for children. Also, there were philanthropists who offered a grant but there was no one to manage it and I was offered to lead the project. At first, my husband was against the job and said that I should stay at home and take care of children, cook. He has never thought that what I do is a real job. Especially when he compared his salary and mine, it was a miserable payment. I recall when I worked as a hairdresser — he also believed that it was not a real job. I had to fight his attitude for quite a while. He is ten years older than I am. Now I think he got used to it. There was a period in life when we took night shifts at the centre. Centre is like family for me. I don't think the word "work" fits in here. It is a part of life.

I love my job and my family. Despite all the challenges, my family is still together. A lot of families fall apart. We get up in the morning, we go to work, children go to school. Sasha attends the centre. We get back home, and I feel like we are a regular family. We can go for a walk, have dinner together, watch a movie.

I have a lot of plans and goals, but they all are related to my family, my children, and my work. I have never thought about the question – what is it that I want for myself?

Zaporizhzhia

our team of authors

We are Disability Rights International Ukraine (DRI Ukraine). DRI Ukraine is a non-governmental organisation and a local partner of the international human rights organization Disability Rights International (USA). DRI Ukraine was established by women with disabilities, women who have children with disabilities, formerly institutionalised women and social work professionals.

The key goal of the organisation is protection of human rights of people with disability in Ukraine, in particular the right to full integration into the community (according to Article 19 of the UN Convention on the Rights of Persons with Disabilities): every child with a disability must be brought up in a family, every adult with a disability has the right to independent dignified living in the community and control over their life.

The steps we take to fulfil the goal mentioned above:

Advocacy. We advocate the importance of developing community-based services from birth to infinity for children and adults with disabilities. We promote an approach that focuses on people and their needs, rather than institutions and beds.

Monitoring. With our reports, we demonstrate that institutions are not safe and necessary. Segregated services and education for children and adults with disabilities almost always equal violence.

Support. We support families who of people with disabilities, especially focusing on women raising children with disabilities. We research the needs and experiences of such families and communicate those needs to the main stakeholders in both the government and the donor community. We empower women with disabilities and women raising children with disabilities.

Focus. We focus on the development of self-advocacy for people with disabilities and strengthening the leadership potential of family members of people with disabilities.

Catalogue “VOICES: women, children and disabilities”

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