Ambitions. Rights. Belonging.

People with intellectual disabilities and their families in Ukraine

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Introduction

Of the 2.7 million people with disabilities in Ukraine, **260 000 are people with intellectual and psycho-social disabilities[1].** Their situation is not, and never has been, an easy one.

People with intellectual disabilities face severe discrimination, restriction of autonomy and institutionalisation. This was the case even before Russia launched its full-scale invasion against Ukraine on February 24, 2022. Since then, the lives of people with intellectual disabilities and their families have become even more difficult.

The barriers people with intellectual disabilities face across Europe – limited legal capacity, stigmatisation, limited access to education, employment, healthcare, and housing – reach new heights in times of war.

In Ukraine, the Russian war has led to destruction of infrastructure, forced displacement, inadequate shelter and disrupted healthcare access – all of which disproportionately affect people with intellectual disabilities.

The loss of community networks that once supported them leave them and their families in states of isolation and insecurity.

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[1] The Concept for the Development of Mental Health Care in Ukraine until 2030, approved by the Cabinet of Ministers of Ukraine on 27 December 2017, No. 1018-r Концепція розвитку охорони психічного здоров'я в Україні на період до 2030 року, схвалена розпорядженням Кабінету Міністрів України відвід 27 грудня 2017 р. № 1018-р https://zakon.rada.gov.ua/laws/show/1018-2017-%D1%80#Text

Already widely overlooked before the war, people with intellectual disabilities – especially those living in institutions and / or with complex support needs – and their families are more segregated than ever.

When it comes to available and accurate information about the reality of people with intellectual disabilities, there is a big gap. This gap is widened in times of war.[2]

Inclusion Europe has been contributing to closing the data gap though its flagship report, the Inclusion indicators. 7 crucial indicators show the inclusion of people with intellectual disabilities and their families in Europe. Scores are calculated per indicator, with 10 being the best, and 1 the worst possible score. The average score is used to compare the European countries' overall results.

The 7 Inclusion indicators are:

1. Right to decide and right to vote.
2. Right to live independently and to be included in the community.
3. Housing and support.
4. Education.
5. Employment.
6. Healthcare.
7. Representation.

In Inclusion indicators 2024 report, **Ukraine had the lowest overall score with 3.5 out of 10** points,[3] reflecting the hardships its people with intellectual disabilities and their families face.

[2] Disability & Society, Volume 39, 2024, Issue 11: The experiences of people with intellectual disabilities living in Ukraine during the first months of the Russian invasion. A lack of fulfillment of basic necessities and support and uncertainty towards reforms. https://www.tandfonline.com/doi/full/10.1080/09687599.2023.2229502#abstract

[3] Inclusion indicators 2024, Inclusion.eu/indicators. Belgium also scored 3.5 out of 10.

The report you are reading now serves as another tool to better understand the lives of people with intellectual disabilities and their families in Ukraine.

Inclusion Europe worked closely with our member, the VGO Coalition, for this report.

The VGO Coalition created a focus group, of which 11 people with intellectual disabilities, or in some cases their family members, shared their experiences and views to inform this report. They offer new and much needed understanding of the reality of the war's impact on Ukrainians with intellectual disabilities.

The participants were between 12 and 45 years old. Their living situations and the ways the war has impacted them vary a lot. Their stories are at the core of this report.

Unfortunately, we were unable to gain similar stories and experiences from people in institutions.

Personal Stories

The stories are shared with the approval of the persons and their legal representatives.

People agreed to publishing their stories as they want everyone to know about their life during the Russian war on Ukraine.

It is important to remember these stories are of people who have the support of their families and can attend day-centres or similar support activities. There are many thousands who don't have similar support, or who are in institutions, and we cannot hear their stories as we were unable to reach them.

Artem Khanikov

I am 12 years old and I live with my parents in Vinnytsia, Ukraine. We had to move from Kherson due to the war, looking for safety in a new city. The move changed a lot of my life, including a new school, new friends, and having to find new hobbies. Despite some challenges at the beginning, I am doing well.

I have partial legal capacity because I am younger than 18 years old. Although I can express his opinions and preferences, important decisions are made by my parents. For example, while I can say what I would like to buy, it is ultimately up to my mother to decide. My parents also help me to understand and make decisions.

I enjoy living in Vinnytsia with my parents and sister, Ksyusha. The decision to move was made by my parents. I participate in the community by playing sports like karate, doing athletics at the stadium, and swimming. I also enjoy going to the cinema and theatre. In my neighbourhood, I have friends such as Hlib, Vanya, Nastya, and Niya, who I know from school.

I live togeter with my parents and sister. My ideal home would include a garden, a dog, a cat, a trampoline, a pool, and a swing. I help with chores at home and get support from

my father and sister with this. Shopping is done by my parents. Sometimes my parents explain to me on how they spend money. They also support me with understanding official papers, and with my hobbies.

I go to a school where I study subjects like mathematics, Ukrainian language, physical education, and art. I also have piano lessons at a music school. My mother chose the school, making sure I would get the support I need. I take the bus to school. I enjoy spending time with my classmates, who are fun and supportive. I also like school, mostly during activities like lunch and physical education. While most of the schoolwork is doable, I find the Ukrainian language class more difficult. I get help of a second teacher and sometimes I get different learning materials.

I do not work right now, I am still in school. I get disability benefits through my mother, which helps support the family.

I have access to a general practitioner, whose office is a few bus stops away. My mother usually calls to make appointments and goes with me to the doctor. The doctor discusses issues directly with my mother and performs necessary examinations. I also visit a dentist once a year for routine check-ups. I am overall happy with the healthcare I get, but I miss the massages I used to receive in Kherson and the sports equipment I had there, such as a climbing wall and training gear.

I am a member of a self-advocacy group. In Kherson, the group met weekly at the "Sunny World" centre, where we engaged in activities like crafts, training, and sharing meals. The group has met with officials, including the mayor and police, to discuss our needs and share our experiences. I feel that while people usually listen, they don’t always help.

Anton Onyshchuk

I am 16 years old and currently live with me parents in the city of Kirovohrad. I originally come from Kherson but was forced to leave my home due to war and move to a safer area. This move to a new city not only meant finding a new home but also starting at a new school, making new friends, and discovering new hobbies.

Although I am still underage and therefore cannot participate in elections. It is important for me to have the ability to make decisions about my life, including choosing my friends and activities. My parents support me with major decisions.

In Kirovohrad, I have joined activities such as visiting the local gym for workouts and participating in cultural events in the city and nearby Kremenchuk. Despite initial challenges after moving, I have made friends and found new hobbies.

I live with my parents in a rented flat. My parents help me with household chores and managing finances. I strive to be as independent as possible, for example, by going shopping for clothes and groceries with my parents, and I do not need support when going out to meet my friends.

I attend a school for children with vision impairments close to my home and I enjoy the school mainly because of my friends. I find some subjects, especially mathematics and physics, difficult. I sometimes see a psychologist, who helps me improve my communication skills.

I have access to healthcare services. My general practitioner's office is within walking distance from my home, and my mother schedules appointments for me. Before the war I regularly visited a neurologist, but this specialist is not available in the city I live in now. The doctor speaks in easy-to-understand language and my parents support me with all and any healthcare decisions. I do not have a regular dentist and only visits one infrequently.

I am active in a self-advocacy group that meets weekly. Along with other members, I share experiences and discusses how we can support each other. II also participated in

the Hear our Voices! self-advocacy conference in Tallinn in 2023, where I met other young people and shared my experiences. For me, self-advocacy is the best way to promote the rights of people with intellectual disabilities, because only we can know what we really need.

Ivan Melnyk

I am 17 years old from Kyiv, Ukraine. Born and raised in the capital, I faced a difficult change when I had to leave Kyiv for the first time due to the war. Leaving my home was hard for me. I loved my room, because it was filled with books. I am sensitive to loud sounds, like alarms and crowds. I study on an individual basis because I find it hard to focus in a regular classroom, and I get top grades. I currently have no friends, but I dream of working as a scientist and having friendly colleagues who share my interests. I have autism and severe bronchial asthma, spending much of my time at home or in the hospital.

I have limited legal capacity, and my mother, who is also my legal guardian, supports me in making decisions. I do not make decisions about where or with whom I live; I live with my mother and grandmother in my grandmother's flat. My mother takes care of all finances. My mother supports me in making decisions by explaining which options there are. I have never voted, because I am underage.

I like where I live, because I have my own room filled with books that I love. I enjoy walks with my mother around a nearby lake. I also like to visit museums in Kyiv, when I feel well enough. I feel safe when I am with my mother, as we have similar interests. I do not go out alone, and most of my activities take place at home. I have no friends, but I hope to find some in the future.

My household is run entirely by my mother and grandmother. I need assistance with all aspects of home care, including cooking. Shopping for essentials and clothes is also handled by my mother.

I am enrolled in a high school, Lyceum, with a focus on biology and chemistry. First, I struggled with attending school because of bullying and then I changed to individual lessons, which work better for me. I enjoy learning without the distraction of classmates and has done well in school since the change. However, I need constant support, such as help finding my classroom and keeping track of my things.

At seventeen, I am still in school and has not worked yet. I receive disability benefits, managed by my mother, to support our household. I would like to work later but it might be difficult because of my health.

I have significant healthcare needs due to my severe asthma and autism. While I have a general practitioner, most of my medical issues require specialists such as psychiatrists and pulmonologists. They are often located far across Kyiv. This makes accessing care difficult, as public transport is not possible during asthma episodes, and my family does not own a car. The local children's hospital where I was registered, "Ohmatdyt," was heavily damaged in a missile strike, which made our search for care even more difficult. I depend on my mother for all medical guidance, including medication management, as I often forget to take or incorrectly handle my medicines.

I am an active members of a self-advocacy group that meets twice a month. The group focuses on educating our members about our rights and how to defend them. I have experience advocating for myself, such as when I successfully secured documentation from the military commission that showed that I cannot enter service. I also requested individual learning arrangements at school due to my asthma. I have found that people are more likely to listen and respond when I defend my own rights.

Vladyslav Panov

I am 18 and live in Brody, a small town in Ukraine's Lviv region, with my mother, younger sister, stepfather, and baby brother. I feel very connected to my hometown and the people there, who know me well. I love collecting bells, joining activities, and watching YouTube videos, especially about trains and bells. The war has deeply affected me, mainly because of the fear caused by air raid alarms.

I have full legal capacity and my mother supports me. While I can pick items in stores, I have trouble understanding prices, and my mother often helps me decide. I do not have close friends, but I get along well with others in the daycare program. I have not voted because I was not 18 yet during the last elections.

I live with my family in a small apartment with a shared yard where I feel safe and welcomed. While I can explore the neighbourhood and visit shops with my mother or sister, I do not go out on my own. I enjoy city events and trips, but loud music and large crowds can overwhelm me, so I often head home early. I like planned outings, such as historical tours and visits to local attractions, which my mother usually plans.

I live in a two-room apartment with my family. Even though there is not much space I have space for my bell collection and a cabinet where I keep snacks. I need help with household chores like cleaning, washing dishes, and cooking, which my mother supports me with. I use pictures on my phone to show the food I want, but my mother takes care of most shopping. I enjoy some independence when picking out personal items, such as perfumes. My mother fully manages all finances and official documents.

I went to a general school with an inclusive program. At first, I was in a regular class, but I struggled and switched to individual instruction after a month. This setup allowed me to study through the 9th grade and finish basic education. Although I was officially part of a class, I didn’t make any friends. My mother and a social worker helped me throughout school, providing constant support with both academic and practical tasks.

I do not have a job, but I take part in occupational therapy at a social workshop. There, I learn basic skills like making simple dishes such as salads and cookies. I enjoy rolling out dough, but I do not like decorating the cookies. This unpaid program helps me build skills with the support of social workers. I also receive disability support.

My general practitioner is located 30 minutes away, and the family car makes visits possible. However, I find medical appointments difficult because I feel anxious about being touched by strangers. My mother takes care of all communication with doctors and makes decisions about my treatment. Since childhood, I have not had a dentist who could meet my needs. I also need help understanding medical information and decisions, which my mother supports me with.

I was previously active in a self-advocacy group where members discussed various topics, including household chores and leisure activities. Although the group hasn't met in several months, I am interested in rejoining if it starts again.

Liya Oliynyk

I am a 26-year-old self-advocate from Kharkiv, Ukraine. I don't like hiding in basements during air raids and I feel sorry for the people who suffer because of the war. Despite the war, I have kept in touch with my friends and kept doin activities I loves, like drawing and dancing.

I have full legal capacity and can make my own decisions; my mother supports me by explaining things clearly and using simple language. I have voted in elections, attending voting sessions with my mother, who helped explain the candidates and voting procedures.

My living situation has been affected by the war. I live with my mother and I depend on her for both companionship and safety, especially during air raids. Before the war, I enjoyed outdoor activities, like helping to clean her neighbourhood and playing basketball. However, because of the ongoing missile attacks, I now stay indoors most of the time. When explosions scare me, I find comfort by holding my mother's hand and reciting prayers I learned to calm myself.

My mother and I had to move after a missile strike hit our home, relocating to a safer apartment within Kharkiv. At first, we spent a month living in shelters, but now we adjusted to frequent air raid warnings and often take cover in our apartment. I help my mother with household chores, enjoy cleaning and preparing food like salads. I rely on my mother’s support with grocery shopping and handling documents and finances.

I attended a special school, which my mother chose. The school was about seven stops away by public transport. I enjoyed the friendly atmosphere and the bonds I have with classmates, many of whom I still keep in touch with. While I found it challenging to keep up with the curriculum, I loved the school environment and took part in activities like music and embroidery. My teachers and some classmates offered support whenever I needed it.

Before the war, I worked as an assistant cook, a job my mother helped me find through a social project supporting people with disabilities. I worked one or two days a week, earning 50 hryvnias per hour, which didn’t affect my disability pension. The restaurant was far from home, but I eventually became able to travel there on my own. Although I didn’t have close friends at work, I appreciated the experience.

I have access to a family doctor, although it’s become more difficult due to the war since my doctor’s office is now far from where I live. For dental care, I am lucky to have my mother, who is a dentist. This family support makes medical care less stressful for me, as I completely trust her mother. While I am generally happy with my healthcare, my mother plays a key role in explaining medical instructions in simple terms so I can understand and follow them.

I am an active member of a self-advocacy group that meets both online and in person, whenever air raid warnings aren't active. Our group meets on Thursdays and Saturdays when there are no air alarms. The group focuses on discussing topics like rights, employment, and education opportunities. We work together to decide on the topics for each meeting and provide mutual support. Due to the war, official interactions with government officials are limited, but my mother and I have reached out to social services for information about retraining courses.

Dmytro Khnykin

Dmytro is 30 years old, and lives in a one-room apartment in Kyiv, Ukraine, which he inherited with his sister, Kateryna, after their mother passed away. He enjoys activities like watching cartoons, listening to music, drawing, and sculpting with plasticine. Dmytro values spending time with friends and enjoys walking around the city. However, he has faced significant challenges due to his epilepsy and the ongoing war.

Dmytro has full legal capacity but depends heavily on his sister for making decisions. He cannot independently choose where to live or with whom. While he can choose his friends, decisions like shopping and other daily choices are managed by his sister, as he cannot navigate these tasks alone. Dmytro has not participated in elections, as he has shown no interest in voting.

Dmytro lives with his sister in a one-room apartment in Kyiv. He likes it there. His sister supports him on walks and shopping trips. Due to financial limitations and the war, Dmytro is unable to attend cultural events and has lost touch with many friends from the charity organization "Dzherela" because of his frequent epileptic seizures.

Dmytro requires ongoing support at home. His sister helps with tasks such as cleaning, cooking, and personal hygiene, as he cannot manage these independently. Although he can dress himself, he needs support with purchasing clothes, food, and other essentials. His sister is responsible for all financial and household tasks.

Dmytro attended a special boarding school in Kyiv but faced severe bullying from both classmates and teachers, which led to him switching to individual lessons. This traumatic experience has left emotional scars that he still recalls as an adult. Despite these struggles, Dmytro completed his basic education.

Dmytro has never worked in a paid job. He relies on a disability pension for financial support, which is managed by his sister. The fear of losing his pension prevents him from considering employment, and his medical conditions require a lot of support.

Dmytro has a family doctor near his home and visits a dentist once every one to two years. However, his access to medical care is limited, as he does not receive the necessary medications for his epilepsy and cannot undergo certain procedures like MRIs or dental X-rays. His sister accompanies him to all medical appointments, explaining his symptoms and helping him understand the doctor's advice.

Dmytro is a member of the charity organization "Dzherela" and participates in online advocacy group meetings with his sister's support when his health allows. The group has worked with Kyiv city officials to advocate for improved accessibility in the city. Although Dmytro occasionally faces negative attitudes from others, he remains optimistic and believes that the group's advocacy efforts are starting to make a difference.

Vasyl Myriavchyk

I am 32 years old and a self-advocate living in Uzhhorod, with my mother and our pet dog, Rozi. I have a wide range of interests, including working at a puppet theatre, learning to be a barista at an inclusive café workshop, and creating beaded artwork that I sell. I am also actively involved in the Uzhhorod City Executive Committee's youth council, where I represent individuals with intellectual disabilities.

I have full legal capacity, which means I can make my own decisions. While I consult with my mother on some matters, such as where to live and with whom, I take charge when choosing my friends and making purchases. I vote in elections, and I discuss candidates with my mother so I can make informed choices.

I live in a two-room apartment with my mother and enjoy the area. I am active in the community, walking my dog, visiting shops, and attending cultural events like cafés and theatres. I dream of one day living in Canada. My friends, whom I met at a rehabilitation centre, share similar experiences and backgrounds.

I live with my mother, who supports me with tasks such as paying bills and managing expenses. While I can handle some responsibilities independently, like shopping, I prefer support with more complicated tasks. My ideal home would be on a farm with a horse, I love animals.

I attended school in Uzhhorod, where I followed an individual learning plan. The school was about 6-7 km from my home. I needed help with academic tasks, and a social worker supported me during my school years. Although learning was challenging, I enjoyed school, especially when studying topics that interested me.

I have worked at the Uzhhorod Puppet Theatre "Bavka" for over nine years, where I am responsible for maintaining the premises. I found this job through the employment centre. I also trained for six months to become an assistant cook at an inclusive café, where I learned to make coffee. I receive a salary for my work at the theatre and gets a disability pension. Although I initially needed support commuting to work, I eventually became confident enough to travel independently.

I am happy with my healthcare. I have a general practitioner just five minutes from my home and visits my dentist every six months. I need medical advice to be explained in simple terms and relies on my mother to support with decisions and interpreting medical information. This support makes sure I can manage my health well.

I am involved in a self-advocacy group that meets weekly. The group focuses on discussing rights and responsibilities and sometimes holds meetings online. While I feel that people listen to me, I sometimes think their understanding is limited. Through my active participation, I aim to raise awareness of the rights of people with intellectual disabilities and improve how we are understood.

Volodymyr Mashina

I am 35 years old and a self-advocate living in Obukhiv, a small city in the Kyiv region of Ukraine. I live with my parents in a two-room apartment. I enjoy decorating items using the decoupage technique, participating in Playback theatre, and exploring different cities through online travel. I am an active member of a self-advocacy group and attend psychological support sessions.

I have full legal capacity and make decisions with input from my parents. I want to get married but feel discouraged because I don't have a stable income or a place to live on my own. While I shop for groceries on my own, I am supported by my mother over the phone. My friends are mainly from my self-advocacy group and the “Dzherela” rehabilitation centre. I vote independently, making decisions based on my own judgment and the information on the ballot.

I live with my parents and our cat, Maika, in our family apartment. I like my current home but dream of living independently in Kyiv. In my community, I enjoy visiting shops, the local market, the post office, and church. I also like to cycle around the city and sometimes attend cultural events at the community centre. I met most of my friends through the rehabilitation centre and “Dzherela.”

I live with my parents, who manage the household and support me with finances, grocery shopping, and general maintenance. While I help with planning outings and some chores, I depend on my parents for tasks like managing paperwork, making financial decisions, and buying materials for my hobbies. My goal is to live independently one day in Kyiv.

I attended school in Obukhiv, where I was first placed in regular classes but later transitioned to home-based learning. My school experience was difficult, particularly in social interactions and keeping up with assignments. My mother provided the support I needed to continue my education.

I have tried working in a bakery and an office, but these jobs were difficult because of my disability and the support I need. I do not currently work but receive a disability pension. Some of my former colleagues also had disabilities. Sometimes I got support from social workers during my short-term jobs.

I have access to a family doctor located 2.5 km from my home. My parents support me with scheduling appointments and understanding medical information. I also have a dentist he visits when necessary. Barriers to healthcare include long waiting times and expensive medications. The destruction of a factory that produced affordable glasses during the war has made it harder for me to get the glasses I need.

I am a member of a self-advocacy group that meets 1-2 times a week to discuss the rights and responsibilities of people with intellectual disabilities. My group has engaged with public figures like Marina Poroshenko to raise awareness about issues affecting our community. I believe that being part of this group strengthens our advocacy efforts, and I remain hopeful for positive societal changes.

Vitaliy Zegelev

Vitaliy is 38 years old and lives in Kyiv, Ukraine, with his mother in a two-room apartment. He has his own room and needs full-time care because of his severe disabilities and epilepsy. Vitaliy doesn't speak, but he feels comforted by his favourite item — a bicycle handlebar he has loved since he was three years old.

Vitaliy cannot make decisions on his own. His mother, who is his legal guardian, makes all the important choices for him, like where he lives and what he buys. Vitaliy has never voted or participated in elections.

Vitaliy cannot live on his own because of his health. His epilepsy and fear of loud noises keep him from going outside, especially since the war started. He hasn't left their apartment in three years and depends on his mother for everything he needs.

Vitaliy's mother takes care of everything for him. She helps him with daily tasks like eating, bathing, and getting dressed. She also handles grocery shopping, paying bills, and managing documents. As she gets older, she worries about what will happen to Vitaliy when she can no longer care for him.

Vitaliy went to a special school called "Nadiya," where teachers came to his home to help him learn. He didn't attend regular classes but sometimes had visits from classmates. He found learning difficult, but he enjoyed activities and making friends through the charity organisation "Dzherela."

Vitaliy has never had a job because of his disabilities and his health. He receives a disability pension, which his mother manages for him. Doctors have said that "working would not be safe for him".

Getting healthcare for Vitaliy is hard. He doesn't have a family doctor, and doctors won't visit him at home. Since he cannot leave the apartment, he misses out on the care he needs. He has not had dental procedures under general anaesthesia since he was a child. His mother struggles to get the right medicines and is unhappy with the medical services available.

Before the war, Vitaliy attended meetings from "Dzherela." Now, he takes part in online self-advocacy meetings when the electricity and internet are working. These meetings have helped his mother learn how to advocate for his needs, like calling the city hotline to report problems with heating. She has learned new ways to speak up for him and get help.

Oksana Shtefanyuk

I am 39 years old and live with my mother in a two-room apartment in Novyi Rozdil, Ukraine. I enjoy my home, which is on the ground floor, and I take care of it independently. I am actively involved in the activities of the NGO Centre for leisure for people with disabilities 'tavor', where I volunteer, help others, and create handmade items to sell.

I make my own decisions and have full legal capacity. While I consult my sister for financial advice, I decide on friendships, purchases, and my future. I plan to get married. I participate in elections by reading the information on ballots and boards to choose candidates myself.

I enjoy being active in my community. I often shop, take walks with friends, and attend cultural activities, like masterclasses and visits to the local centre and cafés. Although some neighbours have moved abroad, I stay connected with my friends at the *"Tavor"* Centre.

I am self-sufficient and manage my daily life independently, including cleaning, cooking, and shopping. I also organise my finances on my own. While I don't need help at home, I value the support and social activities provided by the *"Tavor"* Centre.

I attended school, just three minutes from my home. I studied alongside classmates with and without disabilities and enjoyed school, despite some difficulties with communication. My class teacher was supportive, and I look back fondly on my school days.

I do not currently work but receive a disability pension. I am open to working in the future and I am not worried about losing my pension if I do. For now, I focus on volunteering and my activities with the *"Tavor"* Centre.

I have a general practitioner located 15 minutes from my home. I schedule my own appointments and follow through with treatments and tests when needed. I also visit a

dentist once a year and consult a gynaecologist when referred by my doctor. I am satisfied with my healthcare and do not need additional medical support.

I am an active member of a self-advocacy group that meets every two weeks. I have even represented the group internationally, including at the Europe in Action conference in Glasgow, Scotland, in 2024. My ideas and contributions are valued by group members and the coalition director. I am passionate about advocating for people with disabilities and promoting inclusive solutions in my community and beyond.

Vyacheslav Deynychenko

Vyacheslav is 45 years old and lives in Sumy, Ukraine, with his mother, who is his caregiver and legal guardian. He has been bedridden since he suffered a stroke at 18. He is blind and unable to leave the house. Vyacheslav depends entirely on his mother for all his daily needs. He has his own room at home, which he enjoys, but he remains isolated from the outside world.

Vyacheslav's mother supports him to make decisions, as he has limited legal capacity. Although he cannot independently manage finances or decide where to live, he has participated in elections with her support. His mother explains the candidates to him. Vyacheslav does not have social interactions or friendships due to his health and isolation.

Vyacheslav lives in his family home, and his mother decided he should stay with her so she could meet his medical needs. He is unable to leave the house due to his condition and the ongoing war, which has made his life even more isolated. He does not have visitors or opportunities to interact with his community, making his life very lonely.

Vyacheslav's mother manages everything in their household. She provides round-the-clock care, assisting him with eating, dressing, and hygiene. She also handles shopping, cooking, financial matters, and medical appointments. With no outside help, she often feels overwhelmed by the responsibility.

Vyacheslav attended school in Sumy until third grade, when health complications made it difficult to continue. After surgery for vascular issues, he switched to home-based education, where teachers came to his house. Before his health worsened, he enjoyed school, especially the social aspects.

Vyacheslav has never been able to work due to his medical history. After his stroke at 18, he was left unable to pursue any kind of job. He receives a disability pension, which his mother manages.

Vyacheslav has significant healthcare needs. A family doctor provides consultations over the phone or occasionally visits their home. However, specialised care, such as dental treatment or physiotherapy, has been unavailable, especially during the war. Vyacheslav's mother feels that his medical needs are not fully met and finds it difficult to access proper support.

Vyacheslav sometimes joins online self-advocacy meetings with his mother's help. While he mostly listens to others during these sessions, they offer him a connection to the outside world. Living in a war zone just 60 kilometres from the Russian border has added to their challenges, but these meetings provide both Vyacheslav and his mother with a sense of community and support.

Situation of people living in institutions

In Ukraine, people with intellectual disabilities are the group most represented in long-term "care" institutions.[9] The VGO Coalition reported that in 2024 **the number of people with intellectual disabilities in institutions were:**

- 20,000 in larger institutions,
- 100 in smaller institutions,
- 1,000 in psychiatric hospitals.[4]

Ukraine's system of institutionalisation has not changed much in the last 20 years, employing more than 60,000 staff across almost 700 facilities nationwide.[5]

While Ukraine has a deinstitutionalisation plan, or at least the government has declared intentions to close institutions, no administrative steps have been taken. There is no financial support planned for deinstitutionalisation, and appropriate laws and regulations have not been made.[6]

People with intellectual disabilities are in danger of being institutionalised when they do not have family members to support and care for them. Many already enter the system as children. Once entered, it is very hard to get out.

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[4] Inclusion Europe: Inclusion indicators 2024, Ukraine, p. 128-129, https://str.inclusion.eu/17d0cedb3ec6748196eed9f05.pdf.

[5] Inclusion Europe, Call to Action: Building a rights-based child protection system in Ukraine free from institutions, p. 2, 2020. https://www.inclusion-europe.eu/wp-content/uploads/2020/12/EU-Ukraine-Call-to-Action_final.pdf.

[6] Inclusion Europe: Inclusion indicators 2024, Ukraine, p. 128-129.

The war has made things much harder for residents of institutions. As cities have been destroyed and residents have fled Russian aggression, people in institutions have been left behind or transferred to institutions in safer areas of the country. As a result, people living in institutions are experiencing abandonment, overcrowding, and even more neglect than before.

There is very little information on people with intellectual disabilities in institutions. The UN Briefing note that was published February 1, 2022, shortly before the war began, provides the deepest and most current insights to date.[7]

[7] UN Briefing note on the human rights situation of persons with intellectual and psychosocial disabilities in Ukraine.

1. Right to decide and right to vote

Before the war

For people with intellectual disabilities the right to decide and vote in Ukraine is and has been limited for a long time. This is because their **legal capacity can be fully removed.**[8]

Taking away legal capacity is a human rights violation and denies those affected the right to self-determination. In Ukraine, **over 40,000 people with intellectual disabilities are not allowed to make decisions over their own lives,** including who to vote for or if they want to stand for elections.[9] Even over 10 years after Ukraine ratified the United Nations Convention on the Rights of Persons with Disabilities (UN CRPD) no measures have been taken to implement its article 12 on equal recognition before the law.[10]

Once legal capacity is removed, it is very hard to gain it back. In 2022, the UN found that the success rate of restoring legal capacity was as low as 22 percent.[11]

This affects both people with intellectual disabilities living with their families, and those forced to live in institutions. But while many people with intellectual disabilities rely on their family members, mainly their mothers, for support in decision-making, this is not an option for those without families.

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[8] Inclusion Indicators 2024, Ukraine, p. 128-129.

[9] UN Briefing note on the human rights situation of persons with intellectual and psychosocial disabilities in Ukraine.

[10] UN Briefing note on the human rights situation of persons with intellectual and psychosocial disabilities in Ukraine.

[11] UN Briefing note on the human rights situation of persons with intellectual and psychosocial disabilities in Ukraine.

For most people living in institutions, the state (frequently represented by the institutions itself) becomes their legal guardian. People in institutions rarely get practical or legal support when it comes to making their own decisions, let alone in taking part in elections.

There is a general absence of supported decision-making mechanisms in Ukraine. This is very problematic, because it reinforces the notion that the removal of legal agency and guardianship is the only way that relatives are allowed to provide legal support to persons with intellectual disabilities, especially those with severe disabilities and / or complex support needs.[12]

But, even if a person with an intellectual disability is allowed to vote, voting is too often not accessible. Inaccessible official websites, and a lack of important information in easy-to-read and understand language don't give people with intellectual disabilities much choice when it comes to choosing a support person for informed decision-making. The only real option is to consult family members. Only two of the participants with full legal capacity cast their vote completely independently, only based on ballot information and personal judgment.

During the war

Ukrainian law prohibits holding elections under martial law: Neither the parliamentary elections scheduled for October 2023, nor the presidential elections due March 2024 were held. The Ukrainian government states that "even if it did allow [elections], dozens

[12] UN Briefing note on the human rights situation of persons with intellectual and psychosocial disabilities in Ukraine, P.6.

of unsolvable practical and security issues would render it literally impossible to ensure a fair electoral process in the circumstances of a total war."[13]

Young people like Vladyslav Panov, who turned 18 during the war, are stuck in a situation they didn't choose nor influence and are waiting to make their voice heard. It is imperative that after the war, voting is accessible to all. The results of future elections will determine the situation of people with intellectual disabilities on a national, regional and local scale.

Ukraine scored 2.7 out of 10 on right to decide and right to vote.

[13] Official website of the government of Ukraine: https://war.ukraine.ua/articles/not-sacrificing-democracy-why-ukraine-cannot-hold-elections-under-the-martial-law/.

2. Right to live independently and to be included in the community

Before the war

Before the war the options to live independently were already quite limited for people with intellectual disabilities and strongly depended on their families.

Insufficient benefits, a lack of accessible and affordable housing, and very limited employment opportunities all contributed to the financial limitations people with intellectual disabilities face.

Nonetheless, taking part in community life was a lot easier, and more common, as infrastructure was intact, and schools, community centres and self-advocacy organisations could offer meetings on a more regular basis.

But even before the war people with intellectual disabilities in Ukraine faced very high risks of institutionalisation. In Ukraine, people with intellectual disabilities who lose family members or whose families can no longer care for them are forcibly placed into institutions. Once institutionalised, most are trapped for life, with only few making it out and reintegrating into the community.[14] Many are placed into institutions as children already.[15]

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[14] UN Briefing note on the human rights situation of persons with intellectual and psychosocial disabilities in Ukraine.

[15] Ukraine has one of the highest child institutionalisation rates worldwide, with rate of 1,5%. In 2020 an estimated 100,000 children and young people resided in various institutions.
Inclusion Europe, Call to Action: Building a rights-based child protection system in Ukraine free from institutions, 2020.

Large institutions are often located in remote areas, far away from local communities.[16] This isolates residents, denying them the opportunity to see or live with their loved ones and infringes on their right to partake in community life.

During the war

The war has noticeably and negatively influenced the right to live independently and to be included in the community for many people with intellectual disabilities. While some have adapted and found ways to participate in community life, many face increased isolation, loss of routine, and limited opportunities to actively engage with others. Relocation of one's home, the severity and frequency of shelling and air raids, and physical and mental health needs all play a role when determining this indicator.

The war has forced many Ukrainians to relocate to a safer place, to leave behind their home and their community, forcing them to start anew. This can be challenging for people with intellectual disabilities and their families, who have spent years building strong support networks in their communities.

Some adapt well and quickly become active in their new communities, after relocating due to the war. Like Artem Khanikov and Anton Onyshchuk, who quickly integrated into their new communities and formed new friendships by participating in sports and attending cultural events. For others, like Oksana Shtefanyuk, not much has changed. Every-day activities such as visiting shops, dog-walking, and social gatherings are still

[16] UN Briefing note on the human rights situation of persons with intellectual and psychosocial disabilities in Ukraine.

possible, and they have been able to remain active members of their communities, despite the war.

But not all have maintained or regained a comparable sense of ‘normalcy’ during the past two and a half years. For many the change of the overall atmosphere and the constant danger have led to less and less community participation and independence. This includes Liya Oliynyk, who moved back in with her mother due to the war and reported needing her mother’s support now more than before. Because of ongoing missile attacks she barely goes outside anymore. Similarly, Vladyslav Panov does not leave the house alone anymore, due to fear caused by air raid alarms.

In some cases, the fear of war related noises and dangers leads to even extremer forms of isolation. For example, Vitaliy Zegelev developed such a fear of loud noises, that he has not gone outdoors for three years, and relies on his mother for daily needs.

> *“The Russians are shelling us every day. My ideal place to live is where there is no war.”*
> *Liya Oliynyk*

People whose health has declined and those with complex support needs also face increased isolation and loneliness.

Ivan Melnyk, who has severe asthma and autism, spends most of his time at home in Kyiv. He has no friends and engages only in limited activities like going on walks with his mother. Similarly, Dmytro Khnykin’s participation in community life has decreased due to his frequent epileptic seizures. Once active in the "Dzherela" charity organization, Mr.

Khnykin has lost touch with many friends. Vyacheslav Deynychenko from Sumy, a city only 60km from the Russian border, is confined to his home because of his medical needs. He lives alone with his mother, who is his sole caregiver. His mother often feels overwhelmed and alone, as Mr. Deynychenko never receives visitors and has been “forgotten by all”.

Ukraine scored 4.5 out of 10 on right to live independently and to be included.

3. Housing and support

Before the war

Many lived with their parents until they were unable to provide daily support. Many people with intellectual disabilities and families also did not have access to good disability support.

Family members served as disability support providers instead of being just a family.

During the war

The war in Ukraine has caused a general housing crisis. Community centres providing vital support for people with intellectual disabilities have been destroyed due to the war. Thousands of homes have been destroyed, killing many and causing internal displacement or homelessness of surviving residents.

In the Kyiv region, 4,835 private houses and 161 high-rise buildings were destroyed, leaving 11,319 families in need of housing.[17]

Cities in Eastern Ukraine are especially affected by the loss of housing and support. Before the war over 400,000 people lived in Mariupol. Russia's occupation has left tens

[17] Milan Šveřepa for FEANTSA: The impact of the Russian invasion of Ukraine: What the homeless sector can learn from the disability sector. https://www.feantsa.org/public/user/Resources/magazine/2022/Summer/FEANTSA_magazine_a9_s22.pdf.

of thousands dead[18] and hundreds of thousands without housing.[19] A rise in rents and a lack of affordable and accessible housing add to the growing number of internally displaced persons and those experiencing homelessness.

There are many reasons why the dangers of the housing crisis disproportionately affect people with intellectual disabilities and their families:

1. **Inaccessible shelters and temporary housing**

Air-raid shelters and temporary housing often fail to meet the needs of people with intellectual disabilities.[20] Generally, shelters are simple set-ups, such as basements or corridors of big buildings. Already unlikely to fully protect civilians from the dangers of a full-scale war, the risk of exposure is much higher for people with intellectual disabilities, especially those with complex support needs.

Firstly, the loud and frequent sounding of the air-raid siren can cause considerable stress for people with intellectual disabilities. The sounds can be frightening and make it difficult to understand what is going on. The stress caused can make it impossible for people with intellectual disabilities to react quickly and find shelter on their own. For Vitaliy Zegelev, the air-raid sirens have caused such intense fear, that he has not left his

[18] Human Rights Watch estimated that it is likely that many more died in Mariupol in the first year of the war than their estimated number of 10,284. https://www.hrw.org/feature/russia-ukraine-war-mariupol/counting-the-dead.

[19] Milan Šveřepa for FEANTSA: The impact of the Russian invasion of Ukraine: What the homeless sector can learn from the disability sector.

[20] European Disability Forum (EDF): Rights of persons with disabilities during the war in Ukraine - Summary of monitoring report. https://www.edf-feph.org/publications/rights-of-persons-with-disabilities-during-the-war-in-ukraine-summary-of-monitoring-report/.

home for nearly 3 years. This means that even while the sirens are warning civilians to seek shelter and evacuate, Mr. Zegelev is confined to his apartment and at a bigger risk of danger.

Secondly, as minimum accessibility requirements are not considered in the design of shelters and temporary housing,[21] families are forced to decide between staying behind in unsafe zones or adapting to inadequate shelter/housing. Both expose people with intellectual disabilities and their families to extreme stress, and can cause intense fear, panic, and long-lasting trauma. The effect of inadequate shelter on people with intellectual disabilities can be seen with Liya Oliynyk. After a missile hit Ms. Oliynyk's home, she and her mother spent a month living in shelters, before relocating to a safer apartment within Kharkiv. While Ms. Oliynyk reported having adapted to the frequent alarms, she also cited greater dependency on her mother, as the war has made her fearful of leaving the house alone.

In some cases, people with intellectual disabilities and their families don't have a choice at all. Many shelters/temporary housings are completely inaccessible to wheelchair users and people with complex support needs or health conditions. For Vyacheslav Deynychenko, who is bedridden, and taken care of by his mother alone, the only way to

[21] In Ukraine, there is a regulation gap when it comes to inclusive and accessible temporary housing. There are no legally defined requirements to meet minimum standards of inclusivity and accessibility for people with (intellectual) disabilities. Thus, there is a lack of state control for the construction and use of such buildings. EDF: Rights of persons with disabilities during the war in Ukraine - Summary of monitoring report.

safety would be if his mother carried him.[22] People with autism also face greater danger as they cannot stay in overcrowded places due to their sensory needs.

The inaccessibility of temporary housing and a lack of clear information on how to reach safety show that people with intellectual disabilities are not considered in the drafting and implementation of evacuation plans. Instead, the responsibility for their safety and wellbeing is left completely to family members (mostly mothers, or sisters) that are often their only support persons or caretakers.

2. Challenges of relocating and the importance of support

As Russia continues to destroy homes, many people have had to relocate to safer areas of Ukraine, leaving their homes and communal support systems behind. This can be incredibly hard for people with intellectual disabilities and their families, who have spent years building close relationships and support networks within their communities. The lack of available and affordable housing, the dangers of moving in a war zone, and other logistical challenges make relocating in Ukraine very difficult.

Having to relocate made it clear to Vladyslav Panov and his family how much he valued the community of his hometown, where he is well known and where he knows his way around.

[22] Disability & Society, Volume 39, 2024, Issue 11: The experiences of people with intellectual disabilities living in Ukraine during the first months of the Russian invasion. A lack of fulfillment of basic necessities and support and uncertainty towards reforms.

“Only after I was forced to live away from home for a while in 2022 did I realize how much I love my city.”
- Vladyslav Panov

Artem Khanikov and Anton Onyshchuk moved from Kherson to safer parts of Ukraine with their parents. Ms. Oliynyk moved homes within Kherson with her mother.

“At the beginning of the war, a rocket hit our house, so my mother and I moved to another apartment, where we now live.
Our house in the village was under Russian occupation. My mother and I decided to move to a safer place in Kharkiv. When we were told that Russian tanks and Russian soldiers had entered, we moved with my mother to another district of the city of Kharkiv. I was scared, I didn't understand what was happening. I wanted to hide with my mother in a safe place.”

- Liya Oliynyk

Most people with intellectual disabilities that live with their families receive support solely from family members. This includes the self-advocates participating in our focus group.

3. Support and care work of (female) family members

As many cannot access safety without support, the pressure on family members providing support and care to their loved one with an intellectual disability has grown a lot because of the war. As men have gone to the frontlines, caregiving responsibilities

are solely on women. Female family members, especially mothers, are left to carry the brunt of household tasks, financial responsibilities, and the support needs of their loved ones with intellectual disabilities.[23] These responsibilities weigh especially heavy on the mothers and sisters of those with complex support needs. Caring for a family member alone in times of war can cause significant psychological and physical distress. Research by Tilburg University showed that especially mothers of people with intellectual disabilities were prone to experience frequent panic attacks, sleeping problems and other stress-related complaints due to war.[24] The mothers of Mr. Zegelev and Mr. Deyneychenko both reported feeling overwhelmed and worried what would happen to their children once they could no longer take care of them. The decrease in reliable community support and accessible social services add to their isolation and the dangers their loved ones face.

4. Increased risk of homelessness

The war has significantly increased homelessness across Ukraine, and people with intellectual disabilities are particularly vulnerable.[25]

For people with intellectual disabilities, the loss of a caregiver often means losing access to housing. People with small support systems such as Mr. Melnyk, Mr. Zegelev, or Mr. Deynychenko have a high risk of becoming homeless, in case their mothers are no longer able to provide care and support.

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[23] As reported by the UN, women make up 95 per cent of family members serving as guardians for in Ukraine. UN Briefing note on the human rights situation of persons with intellectual and psychosocial disabilities in Ukraine, p.8.

[24] Disability & Society, Volume 39, 2024, Issue 11: The experiences of people with intellectual disabilities living in Ukraine during the first months of the Russian invasion. A lack of fulfillment of basic necessities and support and uncertainty towards reforms.

[25] Depaul International, Homelessness in Ukraine: https://int.depaulcharity.org/wp-content/uploads/sites/12/2024/09/Homelessness-in-Ukraine-Report-EN.pdf.

For Mr. Khnykin, who lives with his sister in an apartment they inherited from their mother, the risk of homelessness is not quite as imminent. But as he relies on her for support with every-day tasks is not clear what would happen without her.

People with intellectual disabilities without families usually either face homelessness or institutionalisation without family members there to support them.

5. Life in institutions

Even though large institutions are cut off from communities and the living conditions are horrible they remain almost the only option for accommodation and social care outside of families.[26] This is mainly due to the lack of community-based services, which has increased during the war, as community centres have been destroyed or have been repurposed to be used as shelter.[27]

Another major obstacle preventing people with intellectual disabilities to live independently is the lack of accessible and affordable housing. [28]

Inside institutions people with intellectual disabilities experience a multitude of human rights violations.[29] The war has made things worse. Residents rarely receive

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[26] Inclusion Europe: Raisa Kravchenko from VGO Coalition in a speech at the Europe in action to end segregation conference, September 22, 2022, 'Do not use Ukraine recovery money for institutions, but for support of independent living', https://www.inclusion-europe.eu/ukraine-recovery-money-deinstitutionalisation/.

[27] Inclusion Europe: In her speech, Raisa Kravchenko highlighted the lack of funding for representative organisations and the negative effect it has on people with intellectual disabilities: "This is why the services of the NGOs are so important. They make it possible to prevent people from going into institutions." Raisa Kravchenko from VGO Coalition in a speech at the Europe in action to end segregation conference, September 22, 2022: 'Do not use Ukraine recovery money for institutions, but for support of independent living'.

[28] UN Briefing note on the human rights situation of persons with intellectual and psychosocial disabilities in Ukraine.

[29] The UN reported of torture, ill-treatment, involuntary medication, forced labor, deprivation of personal liberty, denial of private life, of family life, and of sexual and reproductive health taking place in Ukrainian long-term care institutions. UN Briefing note on the human rights situation of persons with intellectual and psychosocial disabilities in Ukraine.

individualised care due to a lack of qualified and motivated staff. The dangers of the war, low salaries and difficult working conditions reduce number of staff even further.[30]

In areas under threat or occupation by Russia, institutions have either become isolated or been evacuated. As people working in institutions have fled to safer parts of Ukraine, some residents have been left behind.[31]

Some institutions that were evacuated were merged with institutions in safer areas, leading to overcrowding and even worse living conditions than before.[32] While fewer people work in institutions,[33] more are forced to live there as family members have died (and continue to) because of the war.[34]

Ukraine scored 3.5 out of 10 on housing and support.

[30] UN Briefing note on the human rights situation of persons with intellectual and psychosocial disabilities in Ukraine.

[31] Inclusion Europe: 'Weeks of Horror, and we cannot possibly leave', https://www.inclusion-europe.eu/weeks-of-horror-and-we-cannot-possibly-leave/ ; Disability & Society, Volume 39, 2024, Issue 11: The experiences of people with intellectual disabilities living in Ukraine during the first months of the Russian invasion. A lack of fulfillment of basic necessities and support and uncertainty towards reforms.

[32] Disability & Society, Volume 39, 2024, Issue 11: The experiences of people with intellectual disabilities living in Ukraine during the first months of the Russian invasion. A lack of fulfillment of basic necessities and support and uncertainty towards reforms.

[33] The UN identified inflexible legislative staffing regulations as another reason for low numbers of institution employees. Despite institutions being merged and the growing number and needs of residents, Ukraine's legislature has not caught up. UN Briefing note on the human rights situation of persons with intellectual and psychosocial disabilities in Ukraine.

[34] Raisa Kravchenko from VGO Coalition in a speech at the Europe in action to end segregation conference, September 22, 2022: 'Do not use Ukraine recovery money for institutions, but for support of independent living'.

4. Education

Before the war

Education opportunities for people with intellectual disabilities in Ukraine have always been limited.

People with intellectual disabilities attended mainstream or special schools or received individualised education outside of regular classes. While some students successfully completed basic education and were socially included in ordinary schools this is not the norm. Because of bullying, a lack of preparation in schools to accommodate them, and pressure on parents to withdraw their children from school, inclusion in mainstream education was often unsuccessful.

Adequate support for people with intellectual disabilities was (and is) very rare in mainstream education. This is why, in some cases, students welcome individualised education themselves, as it sometimes can be their only option to receive any (proper) education at all. Special schools sometimes offer an environment free from bullying and stigma. Generally, the overall education system struggles to create an inclusive environment due to a lack of resources and awareness.

Poor access to inclusive education applies to all fields of education, starting at pre-school. The lack of basic, vocational and higher education for people with intellectual

disabilities is a major factor hindering their independence.[35] Denying education also means denying inclusion and participation in all other aspects of life.

For people with intellectual disabilities, not getting good quality education and access to community-based services as a child, highly increases the risk of being institutionalised as an adult.[36]

During the war

The war has further complicated access to education for people with intellectual disabilities.

Particularly, families with children under 5 years face significant barriers, with less than half of them able to return to kindergarten or early educational activities.[37]

With only 25% of schools in Ukraine operating full-time and in-person,[38] the majority of students rely on online learning, which is frequently disrupted by power outages and damaged infrastructure. Some schools have leveraged digital learning methods introduced during the Covid pandemic to maintain education continuity. Students with

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[35] UN Briefing note on the human rights situation of persons with intellectual and psychosocial disabilities in Ukraine.

[36] UN Briefing note on the human rights situation of persons with intellectual and psychosocial disabilities in Ukraine, p.19.

[37] UNICEF: War has hampered education for 5.3 million children in Ukraine, January 2023, https://www.unicef.org/ukraine/en/press-releases/war-has-hampered-education#:~:text=Only%20approximately%2025%20per%20cent,kindergarten%20and%20join%20educational%20activities.

[38] UNICEF: War has hampered education for 5,3 million children in Ukraine, January 2023.

intellectual disabilities now have more access to education because limits on individualised education have been removed. However, many still face challenges because online learning depends on electricity and the internet, and schools lack inclusive policies and trained teachers.

For people living in institutions chances to receive good quality education was already bad before the war. Children with intellectual disabilities living in institutions in general don't have access to inclusive basic education and only have access to special education within their institution. Those with complex support needs are usually neglected or excluded from education completely.[39] As the war has led to severe overcrowding and worsened work conditions it is safe to assume education in institutions has not gotten better.

Ukraine scored 5 out of 10 on education.

[39] UN Briefing note on the human rights situation of persons with intellectual and psychosocial disabilities in Ukraine, p.19.

5. Employment

Before the war

Employment opportunities for people with intellectual disabilities in Ukraine have always been very limited.

The Social Ministry of Ukraine reported that only 17% of people with disabilities were employed in 2021.[40] The percentage of employed people with intellectual disabilities is generally smaller than the overall number of people with disabilities in employment.

The stigmatisation people with intellectual disabilities face is reflected in their lack of opportunity on the open labour market.[41] While people with intellectual disabilities do not risk losing their disability benefits when they earn their own salary, jobs are not very accessible and almost impossible to find. Especially those with complex support needs or health issues have very slim chances of finding a job that would accommodate them.

Some self-advocates reported working in 'protected employment' before the war, such as working in a café and a kitchen, but they were not paid equal wages.

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[40] League of the Strong: https://ls.org.ua/en/statements/statement-on-reforming-employment-for-people-with-disabilities/.

[41] Due to stigmatisation, it is virtually impossible for people with intellectual disabilities to find formal employment. UN Briefing note on the human rights situation of persons with intellectual and psychosocial disabilities in Ukraine, p.20.

Labor legislation does not address the needs of people with intellectual disabilities at all and does not consider support services at the workplace.[42]

During the war

For the small number of people with intellectual disabilities employed on the open labour market, and those in 'protected employment' the war has complicated transport, support and other aspects of employment.

Self-advocates previously working in 'protected employment' reported losing their jobs due to the war. Others don't see themselves working at all because of health reasons and the lack of individualised support employers are able to offer.

For people in institutions the chances of finding employment during the war are non-existent. The UN voiced concerns about forced labour even before the war broke out, as residents of institutions were observed working as caretakers for other residents without their full and free consent.[43] As the numbers of residents have risen while the numbers of staff have fallen, it is likely that these practices have increased during the past years.

Ukraine scored 3 out of 10 on employment.

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[42] UN Briefing note on the human rights situation of persons with intellectual and psychosocial disabilities in Ukraine, p.20.

[43] UN Briefing note on the human rights situation of persons with intellectual and psychosocial disabilities in Ukraine, p. 20.

6. Healthcare

Before the war

Healthcare for people with intellectual disabilities in Ukraine was difficult to access even before the war. A lack of trained professionals and unnecessarily complicated logistics forced many people with intellectual disabilities to rely on family members for scheduling appointments, understanding medical advice, and getting to healthcare facilities. In rural areas or smaller cities access to specialists like neurologists or dentists was often already limited. The VGO Coalition reported that even after ratifying the UN CRPD in 2010 national authorities of Ukraine neither developed nor approved procedures to mainstream easy-to-read and understand information.[44] The lack of comprehensive healthcare has left little room for people with intellectual disabilities to visit their doctor or manage their medication independently.

After the Psychiatric care reform, held in Ukraine in 2020, access to healthcare further deteriorated, as many outpatient mental health facilities were cut. This made it harder for many to be received by their psychiatrist. As social protection, such as disability benefits and access to social services, often still depends on medical solutions, healthcare logistics became even more difficult for many people with intellectual disabilities and their families.

In most cases, family members take on the role of caregivers because there are no realistic alternatives (except institutionalisation). Caring for a loved one because you

[44] Submission on situation in Ukraine, reference CRPD /27th session from All Ukrainian VGO coalition for people with intellectual disabilities on the rights of Ukrainians with intellectual disabilities, September 2022, https://www.inclusion-europe.eu/includenews-september-2022/.

have no choice, takes a toll on family members and disrupts a healthy family dynamic. This especially applies to family members of people with complex support needs such as the mothers of Vitaliy Zegelev and Vyacheslav Deynychenko, as well as Dmytro Khnykin's sister.

Sexual and reproductive health and rights of people with intellectual disabilities are not respected in Ukraine. Even though forced sterilisation is illegal, it is still performed.[45] This is a grave human rights violation.

For those living in institutions access to health services within the community has been very limited, even before the war. Especially in rural areas, where there are not enough medical and social workers. Certain health care specialists remain completely unavailable to residents of institutions. The main reason is the high turnover of medical staff in facilities due to their remote locations. This applies to institutions across Ukraine, as most are located in rural areas and segregated from the community.

People with intellectual disabilities, especially women, in institutions experience limitations as well as violations when it comes to their sexual and reproductive health and rights. In 2022 the UN reported that residents of institutions were:

- denied their right to decide freely on the number and spacing of their children,
- were given no access to age-appropriate and easy-to-read and understand sex education,

[45] Inclusion Europe: Inclusion indicators 2024, Ukraine, p. 128-129.

- and were frequently denied access to sexual and reproductive health care.[46]

The UN report also found that women in institutions were given hormonal contraception against their will. Some had only given consent after they were threatened to be forcibly transferred away from their partners.[47]

Besides the low quality of health care access and services, those living in institutions are denied their right to bodily autonomy. Ukrainian legislation allows for involuntary admission and treatment to psychiatric institutions.[48] This makes involuntary medication of people with intellectual disabilities extremely likely and goes against articles 14, 15, and 17 of the UN CRPD.

During the war

The war has made accessing healthcare even harder for people with intellectual disabilities and their families. Bombed hospitals, damaged infrastructure, and the displacement of healthcare professionals have created severe barriers. As of August 2024, the WHO recorded 1940 attacks on health care in Ukraine since start of full-scale

[46] UN Briefing note on the human rights situation of persons with intellectual and psychosocial disabilities in Ukraine, p. 18.

[47] UN Briefing note on the human rights situation of persons with intellectual and psychosocial disabilities in Ukraine, p. 18.

[48] UN Briefing note on the human rights situation of persons with intellectual and psychosocial disabilities in Ukraine, p. 16.

war.[49] In December 2024, the Ministry of Health of Ukraine reported that Russia had damaged 1 938 medical facilities in 715 healthcare institutions.[50] Russia also destroyed 297 facilities in 114 medical institutions completely.[51] Across Ukraine hospitals in the oblasts of Kharkiv, Donetsk, Mykolaiv, Kyiv, Chernihiv, Dnipro, Kherson, and Zaporizhzhia are affected the most.[52] However, it is currently impossible to know the extent of damage to medical facilities in the temporarily occupied territories. Additionally, the war has caused many to leave their homes in search of safety, including doctors and nurses.

People with intellectual disabilities are directly affected by Russia's aggression and destruction. For example, Volodomyr Mashina could not get the glasses he needed, because the factory that produced affordable glasses was destroyed during the war. The local children's hospital, where Ivan Melnyk was registered was heavily damaged in a missile strike, which has made his search for care even more difficult.
Targeted attacks on energy infrastructure have reduced Ukraine's power-generating capacity, affecting the country's healthcare facilities.[53] As infrastructure has been destroyed, prices for fuel and medicine have risen. Almost all households face problems

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[49] WHO: https://www.who.int/europe/news-room/19-08-2024-grim-milestone-on-world-humanitarian-day--who-records-1940-attacks-on-health-care-in-ukraine-since-start-of-full-scale-war
For further information go to the WHO's Surveillance system for attacks on healthcare (SSA): WHO: Surveillance system for attacks on health care:
https://extranet.who.int/ssa/LeftMenu/Index.aspx.

[50] Ministry of Health of Ukraine: Destruction of Ukrainian health in numbers, December 2024, https://moz.gov.ua/en/destruction-of-ukrainian-hospitals-in-numbers-during-the-full-scale-war-russia-damaged-1938-and-destroyed-another-297-ukrainian-medical-facilities.

[51] Ministry of Health of Ukraine: Destruction of Ukrainian health in numbers, December 2024.

[52] Ministry of Health of Ukraine: Destruction of Ukrainian health in numbers, December 2024.

[53] UN OCHA: Ukraine Humanitarian needs and response plan, January 2025:
https://reliefweb.int/report/ukraine/ukraine-humanitarian-needs-and-response-plan-2025-january-2025-enuk?_gl=1*soa2yw*_ga*NTc0NzI5MTUxLjE3Mzc0NjU4MDc.*_ga_E60ZNX2F68*MTczNzU3OTE0Mi40LjAuMTczNzU3OTE0Mi42MC4wLjA.

when needing medicine, primarily due to the rise in prices, but also due to limited availability. This includes Dmytro Khnykin, who, because of the war, does not receive the necessary medications for his epilepsy. Vitaliy Zegelev's mother also struggles to get the right medication for her son.

The dangers of the war have also led to a lack of available transportation. This makes it practically impossible for most people with intellectual disabilities to go to the doctor by themselves. Even with accompanying family members, travelling across the city or to the next town requires time, money, and the availability of the doctor. Ivan Melnyk has significant healthcare due to his severe asthma. His medical issues require specialists such as psychiatrists and pulmonologists, which are often located far across the city. As public transport is not possible for him during an asthma episode, and his family does not own a car, accessing care becomes incredibly difficult. For people living in rural areas this problem is even greater, with no doctors around and the next pharmacy sometimes being as far as over 100 km away.[54] In some cases doctors provide consultations over the phone, however power outages and internet disruptions make telehealth services unreliable.

People with complex support needs who cannot leave their homes, such as Vyacheslav Deynychenko, have to rely on the care of their family members and occasional home visits from the doctor, if they have one. Specialised care such as dental treatment or physiotherapy has become completely unavailable to many due to the war.

Main barriers to accessing healthcare during the war are:

- Cost of treatment,
- Cost of medicine,

[54] UN OCHA: https://www.unocha.org/publications/report/ukraine/essential-health-care-older-people-affected-war-ukraine

- Limited availability of medication,
- Limited availability of transportation,
- Danger of transportation and lack of time.[55]

The war has also taken and continues to take a toll on the mental health of people with intellectual disabilities and their families. Families now face an even greater burden in ensuring their loved ones receive healthcare in a much more difficult situation than before Russia invaded Ukraine.[56]

While some families have found temporary solutions through telehealth or local doctors, the healthcare system is failing to meet the needs of many people with intellectual disabilities. The war has made accessing basic healthcare a daily struggle, leaving families to fill the gaps in an already strained system.

For people in institutions the war has led to further deterioration of the health care they receive. As doctors and medical staff continue to flee to safer areas and institutions have been merged, the lack of staff has gotten even worse while the amount of individual needs in one place have increased.

Ukraine scored 4.6 out of 10 on healthcare.

[55] WHO, Newsroom: Accessing health care in Ukraine after 8 months of war: "The main reasons for not getting medicine included the increased price of medicine (84%) and the unavailability of medicines at the pharmacy (46%)." https://www.who.int/europe/news-room/24-10-2022-accessing-health-care-in-ukraine-after-8-months-of-war--the-health-system-remains-resilient--but-key-health-services-and-medicine-are-increasingly-unaffordable.

[56] Inclusion Europe: 100 days: Ukrainians with intellectual disabilities and their families surviving the war, June 2022, https://www.inclusion-europe.eu/100-days-people-intellectual-disabilities-ukraine/.

7. Representation

Before the war

There are over 2.7 million people with disabilities in Ukraine, of which some 260 000 are people with intellectual disabilities.[57] The greatest representative organisation of people with intellectual disabilities in Ukraine is the VGO Coalition. The coalition consists of 118 local organisations and represents some 14 000 families of people with intellectual disabilities. Even before the war, the VGO Coalition did not receive sufficient government funding for their advocacy work. While some local governments promote social inclusion, they are the exception.[58]

Before the war, the coalition's members were active organisations that provided a reliable and regular platform for people with intellectual disabilities to exchange experiences and ideas. In many, the self-advocates were supported to be exactly that: advocates for their rights and those of other people with intellectual disabilities. Vasyl Myriavchyk, for example, actively participated in a weekly self-advocacy group and worked with the Uzhhorod City Executive Committee's youth council to raise awareness about inclusion. Similarly, Liya Oliynyk contributed to discussions on employment and education opportunities within her group. For some, like Oksana Shtefanyuk and Anton Onyshchuk, these groups served as a steppingstone to becoming their community's representative in the international disability movement.

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[57] Inclusion Europe, *"Weeks of horror and we cannot possibly leave",* https://www.inclusion-europe.eu/weeks-of-horror-and-we-cannot-possibly-leave/.

[58] Milan Šveřepa, for FEANTSA: The impact of the Russian invasion of Ukraine: What the homeless sector can learn from the disability sector.

Despite the shared efforts, progress in Ukrainian legislation and society remained slow, and advocacy too often depended on individual families' persistence. These groups and their meetings provided a safe space and a valued community for many, nonetheless.

During the war

The war has made the work of organisations representing people with intellectual disabilities and their families incredibly difficult.[59] The dangers of the war and the lack of funding make community activities very hard to organise. In many cases, the groups have lost their meeting spots as they have been repurposed to provide shelter for internally displaced persons. In some, the Russian aggression has left community buildings and usual meeting spots completely destroyed and unusable.

Despite the mountain of difficulties these local organisations face, they have prevailed, for the most part thanks only to their own determination. All but one self-advocate reported ongoing activities in their representative groups. Most are having meetings online due to the war.

It is incredible what the women of the VGO Coalition and their local branches have done, all while providing 24/7 support for their own family members with disabilities. They have shared their stories with CNN, the New York Times, and Time Magazine – spreading awareness of the reality and needs of people with intellectual disabilities on a

[59] Inclusion Europe: 100 days: Ukrainians with intellectual disabilities and their families surviving the war, June 2022.

global scale. They have raised money and distributed it to individual families in need. And they have attended webinar after webinar about their situation and needs while sitting in a basement with bad internet connection, rockets hitting neighbouring houses.[60]

While local and international organisations from the disability movement have rallied to create awareness, raise and distribute money, and better the situation of people with intellectual disabilities and their families, big actors have fallen behind on their promises.[61] Governments and relief organisations have not supported the representative organisations of people with intellectual disabilities and have failed to direct aid to them specifically.[62] Leaving it up to chance whom the aid actually reaches puts people with intellectual disabilities and their families at a great disadvantage, as they face more barriers than most in these difficult times of war.

People with intellectual disabilities living in institutions belong to a large but mostly invisible group of people in Ukraine. The exact amount of people with intellectual disabilities being forced to live in these places remains unknown. As legal capacity is removed, and most residents have no families to fight for their rights and visibility most people and their stories remain unseen and unheard. Russia's war on Ukraine and the humanitarian crisis it has caused means even less attention for those who already had it very bad in times of peace.

Ukraine scored 4 out of 10 on representation.

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[60] Milan Šveřepa, for FEANTSA: The impact of the Russian invasion of Ukraine: What the homeless sector can learn from the disability sector.

[61] Inclusion Europe: 100 days: Ukrainians with intellectual disabilities and their families surviving the war, June 2022.

[62] Inclusion Europe: Report on funding for people with intellectual disabilities in Ukraine, December 2024, https://str.inclusion.eu/8e3d483bde63779991d09961f.pdf.

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