# **Analytical Report**

# Access to Rehabilitation Services for Adults and Children with Disabilities

Summary

This analytical report on access to rehabilitation services for adults and children with disabilities was prepared as part of the project implemented by the National Assembly of Persons with Disabilities of Ukraine with support of the European Disability Forum and CBM.

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The authors are grateful to study participants for their answers to the survey form that will inform suggestions on possible solutions to identified issues and further advocacy work.

## **Background**

The National Assembly of Persons with Disabilities of Ukraine (NAPD) carried out a survey of adults with disabilities, legal representatives of children with disabilities (under 18 years old) and adults with disabilities considered incapable (lacking legal capacity) to explore their experiences related to receiving rehabilitation services, provision with medical devices and/or assistive rehabilitation devices (ARDs) in Ukraine.

The purpose of the study was to examine the opportunities to exercise the rights guaranteed by law to adults with disabilities and children with disabilities to receive rehabilitation services, be provided with medical devices and/or assistive rehabilitation devices, and to review the related practices and urgent issues.

Under the law, adults with disabilities and children with disabilities are entitled to receive free-of-charge rehabilitation services as set out in the Law of Ukraine on rehabilitation of persons with disabilities.<sup>1</sup>

Further, adults with disabilities and children with disabilities are covered by the Law of Ukraine on rehabilitation in healthcare, which grants all Ukrainian citizens the right to rehabilitative help in the healthcare sector.

Rehabilitation interventions are provided at state-owned, municipal and private rehabilitation facilities (centres), and rehabilitative help in the healthcare sector is provided at rehabilitation facilities, units and divisions of healthcare facilities irrespective of their ownership by rehabilitation professionals and multi-disciplinary teams.

Adults and children with disabilities are also entitled to receive free medical devices and other products and/or assistive rehabilitation devices through healthcare authorities; as well as assistive rehabilitation devices, i.e. technical and other rehabilitation devices, through territorial offices of the Social Protection Fund for Persons with Disabilities.<sup>2</sup>

The study involved 685 respondents of which 44% were parents of children with disabilities, 42% had a disability themselves, and 14% represented adults lacking legal capacity. Among the respondents 46.3% were people with mobility problems; 26.0% – people with mental disorders; 25.7% – people with central and peripheral nervous system disorders; and 25.3% – people with intellectual disabilities. The remaining group had hearing and visual disabilities, disorders of internal organs, cancer diseases.

The largest share of respondents (53%) were from 18 to 64 years old; a third of the survey forms related to children from 7 to 18 years old; 10% of the forms were

<sup>&</sup>lt;sup>1</sup> № 2961-IV dated October 6, 2005: https://zakon.rada.gov.ua/laws/show/2961-15.

<sup>&</sup>lt;sup>2</sup> № 321 dated April 5 2012: https://zakon.rada.gov.ua/laws/show/321-2012-%D0%BF#Text

completed by parents of children under 6; whereas only 3% of the forms were received from people over 65.

# **Analysis of study findings**

One of the first survey items asked respondents how they learn about the delivery of rehabilitation services and provision of assistive rehabilitation devices and medical devices. The analysis of answers indicates four most common sources of information:

- 1. social networks, i.e. Facebook, Telegram, etc. (48.6% of respondents);
- 2. acquaintances (45.0%);
- 3. internet (news, announcements, interviews, etc.) (39.6%);
- 4. non-governmental organizations (35.9%).

The respondents also receive information from media, official web pages of central and local executive authorities and local government bodies, from family physicians. Additionally, a small group of respondents themselves read legislative documents, obtain information from medical and social evaluation boards, from social workers, family members, and rehabilitation facilities. The analysis also suggests that, sadly, individual participants don't have any information and believe that it is not publicized.

The authors hope that the participation in this study offered these respondents a base of knowledge about their rights in the area of rehabilitation.

The main criteria for selecting a rehabilitation facility are:

- availability of qualified staff;
- comprehensive nature of rehabilitation services provided;
- proximity to one's place of residence.

The recommendations of the family physician, officers of public welfare authority and other competent individuals appeared to be less influential and ranged from 13% to 26%.

Maximum proximity of the rehabilitation facility to one's place was important for 46% of respondents.

However, only a third of the participants reported that rehabilitation facilities which they needed were available in their territorial community / at their area of residence.

A half of the respondents (50%) did not have such community-based facilities.

Sadly, 19% of participants had absolutely no knowledge whether any rehabilitation facility that could meet their needs / the needs of their ward/child with disability existed in their territorial community/area of residence at the time of the study.

Only 32% of respondents received rehabilitation in line with the time frames specified by the Individual Rehabilitation Programme / Individual Rehabilitation Plan (IRP).

The study findings suggest that the general trend of receiving and providing rehabilitation services is low

# Rehabilitation services provided at healthcare rehabilitation facilities

According to the website of the National Health Service of Ukraine<sup>3</sup>, as of June 1, 2023, contracts were signed with approximately 3500 medical service providers. Of them only 12% provide rehabilitative help to children and adults (419 providers with signed contracts):

- 259 providers working in in-patient settings (61.8% of the total number of providers of rehabilitative help);
- 409 providers in out-patient settings (97.6% of the total number of providers offering rehabilitative help).

The study showed that 29% of respondents received services at rehabilitation facilities operating in the healthcare sector, whereas the remaining 71% did not receive such services.

The types of rehabilitation services received are detailed in the diagram below. It demonstrates that physical and rehabilitative medicine has the largest share of over 50% and physical therapy services are a little over 22%. The other types of services are less numerous.

<sup>&</sup>lt;sup>3</sup> https://edata.e-health.gov.ua/e-data/dashboard/pmg-contracts



Note: Question "What types of rehabilitation services did you/your ward/your child receive at rehabilitation facilities? The types of rehabilitation services from top to bottom with respective numbers of recipients and shares: prosthetics and orthotics -7 (3.6%); psychological counseling -23 (11.7%); speech and language therapy -19 (9.7%); occupational therapy -4 (2.0%); physical therapy -44 (22.4%); and physical and rehabilitative medicine -99 (50.5%).

Of the total number of participants who received rehabilitation services at healthcare rehabilitation facilities, 67% had an Individual Rehabilitation Plan (IRP) developed by a multidisciplinary rehabilitation team / rehabilitation professional; for 14% IRP was not drafted; and 19% could not answer this question.

Some of the key factors that determined the availability (or failure to develop) the IRP included:

- the lack of knowledge about the need for an IRP (nobody offered it, nobody provided relevant information);
- no multidisciplinary rehabilitation team at the healthcare facility where the services are provided;
- the lack / frequent changes of specific rehabilitation professionals;
- the lack of professionals specializing in the condition/disease of the person to assess his or her needs.

The evidence from the survey forms suggest that in 66% of cases the person's opinion was taken into account in the process of developing and drafting the IRP as required by law. The rest of respondents were equally split into the group whose opinion was not considered and the group who were unable to give a definitive answer to this question.

Among the key reasons for failure to consider their opinions in the course of developing the IRP people with disabilities, legal representatives of incapable adults with disabilities, and parents of children with disabilities reported the following:

- professionals refer to the lack of specific requirements in legislation;
- shortage of professionals, while there are many those needing rehabilitation services;
- personal characteristics of professionals (omission to act, irresponsibility, not thinking it necessary to listen to the client's opinion, etc.).

In the majority of cases rehabilitation services for adults and children with disabilities at healthcare rehabilitation facilities were funded from the national budget (70%); out-of-pocket (16%) and from charity donations, by sponsors and from other sources.

According to survey findings, only 14% of those needing rehabilitation were provided with transportation to travel to the selected healthcare rehabilitation facility.



Note: Question "Did the healthcare rehabilitation facilty provide transportation to you / your ward / your chlid?". Answers from top to bottom: "We booking social taxi" -6 respondents (3.1%); "The rehabilitation facility was located within walking distance" -19 (9.7%); "We ordered a taxi" -24 (12.2); "We used public transport" -55 (28.1%); "We used own transport" -65 (33.2%); and "We were provided with transportation service" -27 (13.8%).

The survey findings clearly show that rehabilitation facilities in the healthcare sector fail to adhere to the legislative requirement to provide transportation as part of rehabilitation services. Likewise, social taxi services do not fully meet the transportation needs of adults and children with disabilities. Approximately 74% of those in need of transportation have to make their own arrangements to get to the healthcare rehabilitation facility.

The study also looked at architectural and information accessibility of rehabilitation facilities operating in the healthcare sector.

### Accessibility of healthcare rehabilitation facility

Aspect of accessibility	Available	Missing	Respondent could not answer the question as he/she did not need any special accommodations or equipment
Ramp	40.8 %	12.8 %	46.4 %
Lift	5.6 %	7.7 %	86.7 %
Accessible restroom	37.2 %	12.2 %	50.6 %
Accessible elevator	24.5 %	14.8 %	60.7 %
Accessible medical equipment	16.3 %	17.3 %	66.4 %
Contrasting markings	3.6 %	1.5 %	94.9 %
Information in Braille	4.6 %	2.6 %	92.8 %
Sign language	5.6 %	5.6 %	88.8 %

Among additional accessibility features that were needed and available during the delivery of rehabilitation services respondents noted provision with ARDs and rooms to provide services located on the ground floor.

Under the law, while staying at healthcare rehabilitation facility adults and children with disabilities are entitled to receive assistive rehabilitation devices. However, the study demonstrated that 38% of respondents who received rehabilitation services at healthcare rehabilitation facilities were not offered ARDs that they needed.

Respondents believed that the failure to provide ARDs could be explained by the following key factors:

- the lack of funding;
- the lack of required assistive devices at the rehabilitation facility;
- the lack of awareness of the staff about the right to be provided with ARDs directly at the rehabilitation facility.

For 33% of respondents who were provided with assistive rehabilitation devices while at the healthcare rehabilitation facility, the needs focused on three groups of products:

- wheelchairs 28%;
- orthotics services 23%;
- canes, crutches and walkers -12%.

On the whole, 56% of respondents who received these services and devices were satisfied with their quality, 9% were not, and another 35% had complaints regarding them.

The analysis of findings suggests that respondents identify a number of barriers to the access to rehabilitative help in the healthcare sector:

- the lack (mutual substitutions) of professionals who provide rehabilitation services for different disability groups;
- inadequate training of professionals;
- use of group sessions instead of individualized approach to deliver rehabilitation services;
- low funding for rehabilitation services (while the services are expensive, budgetary allocations do not cover even the necessary minimum range (people have to co-pay));
- inadequate quality of ARDs (e.g. hard orthotic devices);
- lack of necessary equipment to provide rehabilitation services (lifts, verticalizers);
- impact of the overall situation in the country on the rehabilitation process (during the air-raid alarm the interventions are not provided/ are rescheduled; healthcare rehabilitation facilities were destroyed);
- lack of accommodation and catering services for children with disabilities and escort persons;
- the system has changed only "on paper", but not in practice;
- poor transportation services provided by rehabilitation facilities, lack of infrastructure (roads, transport vehicles).

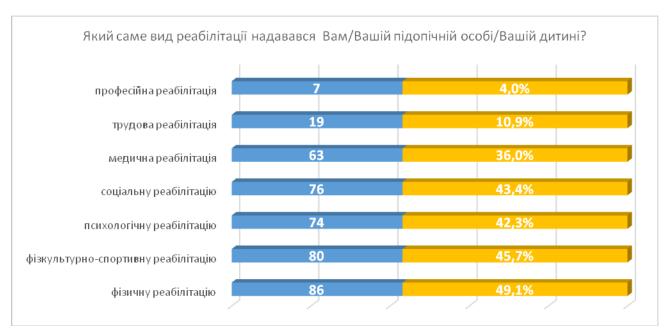
# Rehabilitation services provided at welfare rehabilitation facilities

According to the data of the National Health Service of Ukraine for the given period, as at January 1, 2023, 118 rehabilitation facilities were operational in the national welfare sector and provided comprehensive rehabilitation services.

The situation with the delivery of rehabilitation services at rehabilitation facilities in the welfare sector is similar to that in the healthcare sector.

According to the study findings, among respondents with disabilities, legal representatives of incapable adults with disabilities, and parents of children with disabilities only 26% exercised their right to receive rehabilitation services at welfare rehabilitation facilities, 57% were not aware of this right, and 17% did not need these services.

The types of rehabilitation services provided are listed in the diagram below.



Note: Question "What type of rehabilitation services was provided to you / your ward / your child?". Answers from top to bottom: "professional rehabilitation" was provided to 7 persons (4.0%); labour rehabilitation - 19 (10.9%); medical rehabilitation - 63 (36.0%); social rehabilitation - 76 (43.4%); psychological rehabilitation - 74 (42.3%); physical culture and sports rehabilitation - 80 (45.7%); physical rehabilitation - 86 (49.1%).

The law stipulates that before providing rehabilitation services rehabilitation committees at welfare rehabilitation facilities are to develop Individual Rehabilitation Plans for adults and children with disabilities. According to the study findings,

- 66% of respondents confirmed that an IRP was developed for them;
- 11% reported that it was not drafted;
- 23% could not answer this question.

Among the key reasons for the *failure to develop an IRP* respondents mentioned the following:

- the lack of awareness among rehabilitation recipients of the need for an IRP, while the staff of the rehabilitation facility did not offer to develop it;
- the lack of professionals specializing in specific disorders (autism, visual and hearing disabilities);
- the practice of prescribing specific rehabilitation services depending on the availability of relevant professionals.

In the process of designing the IRP professionals from the rehabilitation committees at welfare rehabilitation facilities took into account the opinion of the person with disability, legal representative of incapable adult with disability and parents of children with disability. This was true in 72% of cases when an IRP was developed, which is 8% higher compared to the same indicator for rehabilitation facilities operating in the healthcare sector.

The respondent's opinion was not considered in 8% of cases, which is also 9% lower compared to the healthcare sector. The share of respondents who could not answer this question was relatively similar for rehabilitation facilities in the welfare and healthcare sectors -20% and 19% respectively.

Among the reasons to explain why their opinion was not considered in the process of drafting the IRP, respondents noted the following:

- the lack of an individualized approach to the delivery of rehabilitation services or "one size fits all" mentality;
- the lack of awareness among service recipients that professionals must develop an IRP in collaboration with them.

The rehabilitation services provided at welfare rehabilitation facilities were funded from:

- public budget nearly by 80%;
- out-of-pocket -10%.

The funding for rehabilitation services provided to the rest of the respondents came from charitable donations, sponsors and other sources. Therefore, the share of free-of-charge rehabilitation services at welfare rehabilitation facilities is larger compared to that in healthcare settings.

Pursuant to the study findings, only 17% of people in need of rehabilitation were provided with transportation to travel to the location of the selected welfare rehabilitation facility.



Note: Question "Were you / your ward / your child provided with transport services to travel to the selected welfare rehabilitation facility?". Answers from top to bottom: "We booked social taxi" – 3 persons (1.7%); "The

rehabilitation facility was located within walking distance" -21 (12.0%); "We used a taxi" -16 (9.1%); "We used public transport" -49 (28.0%); "We traveled by own trasport" -56 (32.0%); "The trasport service was provided" -30 (17.1%).

Based on the analysis of completed survey forms it may be concluded that the legal norm requiring welfare rehabilitation facilities to provide transportation services is not complied with nearly to the same degree as in the healthcare sector. Approximately 70% of adults with disabilities, legal representative of incapable adults with disabilities, and parents of children with disabilities have to find their own solutions and arrange transportation to the welfare rehabilitation facility themselves.

The survey also included a question concerning the availability and/or lack of accessibility features to meet the needs of adults and children with disabilities who require special accommodations or equipment at welfare rehabilitation facilities.

Aspect of accessibility	Available	Missing	Respondent could not answer the question as he/she did not need any special accommodations or equipment
Ramp	42.9 %	10.3 %	46.80%
Lift	6.3 %	8.0 %	85.70%
Accessible restroom	41.1 %	11.4 %	47.50%
Accessible elevator	25.1 %	10.3 %	64.60%
Accessible medical equipment	13.7 %	10.9 %	75.40%
Contrast markings	4.6 %	4.0 %	91.40%
Information in Braille	4.6 %	4.0 %	91.40%
Sign language	4.6 %	2.3 %	93.10%

On the whole, the share of those who were satisfied with rehabilitation services received at welfare settings is significantly higher compared to healthcare settings – at 88%, whereas 12% did not find them satisfactory.

The overwhelming majority of factors that hampered high-quality delivery of rehabilitation services at welfare rehabilitation facilities *fully reflect* the barriers highlighted by respondents in their answers about access to rehabilitative help at healthcare settings, such as:

- shortage of professionals;
- inadequate number of services for high-quality rehabilitation;
- lack of individualized approach to the delivery of rehabilitation services;
- inadequate resources to provide rehabilitation services for different disability groups, specifically for persons with visual disabilities;

- lack of accommodation and catering services for a child and escort person during a rehabilitation course at an in-patient setting;
- outdated forms and methods of rehabilitation and obsolete equipment at rehabilitation facilities.

# 3.3. Rehabilitation services provided at private rehabilitation facilities

The survey findings indicate that 24% of the total number of respondents received rehabilitation services at private rehabilitation facilities, 22% did not need for them; and the remaining 54% were not aware of this right.

The rehabilitation services received by respondents at private rehabilitation facilities are listed in the table below.

Type of rehabilitation	% of recipients of the total number of respondents
Professional rehabilitation	2.5%
Prothetics – orthotics	3.7%
Labour rehabilitation	6.8%
Medical rehabilitatoin	17.9%
Occupational rehabilitation	20.4%
Social rehabilitation	24.7%
Physical rehabilitation	27.2%
Psychological rehabilitation	30.9%
Physical culture and sports rehabilitation	30.9%
Psychological counseling	32.7%
Physical therapy	40.7%
Speech and language therapy	41.4%
Physical and rehabilitative medicine	49.4%

In 70% of cases private rehabilitation facilities developed IRPs before providing rehabilitation services to adults and children with disabilities. For the rest of respondents no IRP was developed or the respondent was not informed of its development since he/she could not give a definitive answer to this question.

The main reasons for the failure to draft an IRP as reported by respondents were:

- the lack of awareness of the respondent about the need to develop the IRP;
- professionals at the facility did not offer to develop the IRP;
- refusal to develop the IRP;
- an oral agreement on the range of rehabilitation services to be provided.

The survey results show that 62% of those receiving rehabilitation services at private rehabilitation facilities pay for the required services out-of-pocket, and only for 19% these expenses were covered from public funds. This is in contrast to rehabilitation at

healthcare and welfare rehabilitation facilities, where the services are mostly funded from the public budget. For the rest of the respondents in this category the rehabilitation services were covered by charitable foundations, sponsors and other sources.

Only 10% of respondents reported that the selected private rehabilitation facility provided transportation service to travel to its location, which is lower compared to the relevant indicators for state-owned and municipal rehabilitation facilities. Transportation services to travel to the private rehabilitation facilities were arranged as follows:

- 10% of respondents were provided with transportation service;
- 49.4% traveled to the facility by own transport;
- 18.5% used public transport;
- 9.9% ordered a taxi;
- 7.4% within walking distance;
- 1.2% booked social taxi.

The completed survey forms were reviewed for accessibility at private rehabilitation facilities to meet the needs of adults and children with disabilities who require special accommodations or equipment.

### Accessibility of private rehabilitation facilities

Aspect of accessibility	Available	Missing	Respondent could not answer the question as he/she did not need any special accommodations or equipment
Ramp	39.5%	12.3%	48.20%
Lift	9.3%	10.5%	80.20%
Accessible restroom	37.0%	12.3%	50.70%
Accessible elevator	23.5%	16.0%	60.50%
Accessible medical equipment	13.6%	13.6%	72.80%
Contrast marking	5.6%	3.7%	90.70%
Information in Braille	4.9%	1.9%	93.20%
Sign language	7.4%	6.2%	86.40%

The satisfaction with rehabilitation services provided by private rehabilitation facilities compared to state-owned and municipal settings was at the highest level at 93%.

Among the key barriers that impeded access to rehabilitation services and ARDs at private rehabilitation facilities respondents noted challenges similar to those typical for healthcare and welfare settings. However, added to these were:

- high cost of rehabilitation services;
- insensitive attitudes of professionals towards rehabilitation clients;

- specialists are not prepared to change their work practices to respond to individual differences of the child;
- rehabilitation services were effective only at the start of the rehabilitation.

# Provision with medical devices and other products

The survey findings indicate that of the total number of respondents nearly 52% of adults and children with disabilities need to be provided with medical devices and other products. The rest of respondents were equally divided into those who did not need medical devices and those who were totally unaware of this right.

Still, as can be seen from the diagram below, only 49% received such help, including 17% in in-patient settings and 32% in out-patient settings.



Note: Question "Did you receive medical products?". Answer options from left to right: "Yes", "No", "Did not need them". Colour codes: blue – in-patient settings; light blue – out-patient settings.

# Analysis of the needs for medical devices and other products at in-patient and outpatient settings

The analysis of completed survey forms suggests that respondents needed all types of medical devices and other products indicated in the table below. Among the listed items, the most needs related to diapers (44%), bed mats (31%), medical devices with speech output such as blood sugar monitors, thermometers and blood pressure monitors (21%), eye glasses (18%), hearing aids (16%), single-use gloves (17%), and incontinence liners (11%).

Medical products and other devices	Received at in-patient settings over the past 2 years	Received at out-patient settings over the past 2 years
Artificial prosthetic cardiac valve		_
Bifurcated system		_
Tube system	6.7%	-
Conduit		-
Electric cardiac pacemaker		-
Coronary angiography system		-
Coronary stenting system without drug- delivery coating	6.7%	-
Coronary artery bypass surgery system		_
System for mechanical heart valve		_
implantation, single-chamber electric cardiac		
pacemaker (SSI) with bipolar electrode, dual-		
chamber electric cardiac pacemaker (DDDR)		
Cardioverter defibrillator		-
Orbital implant		-
Prosthetic jaw	13.3%	-
Dental prosthesis	40.0%	-
Cochlear implant	20.0% 13.3%	-
Voice prosthesis Prosthetic ear	13.3%	-
Valvular liquor shunt implant	6.7%	-
Joint prosthetic implants, including joint	6.7%	
prosthetic implants with extension for cancer patients	0.770	
Hearing aid	-	10.6%
Speech processor	-	2.8%
Prosthetic eye	-	0.7%
Epiprosthesis	-	
Portable medical suction device	-	
Oxygen concentrator (oxygen generation system)	-	
Pulse oximeter, portable, fingertip (pediatric, adult)	-	0.7%
Eye glasses (frames and lenses for vision correction (pediatric, adult)	-	2.8%
Urine bag	-	9.2%
External condom catheter	-	2.8%
Incontinence liners	-	2.8%
Ostomy bag		1.4%
Urostomy bag		1117
Tracheostomy tube (pediatric, adult)	_	
Gastronasal tube		
Catheter	_	6.4%
Lubricant, water-soluble (for alternate	<del>-</del>	0.4%
catheterization)	-	0.770
Sealing paste	-	
Absorbent powder	<u> </u>	0.7%
Items for antiseptic treatment in the course of providing care (hand and wound disinfection,		5.0%

cleaning skin around stoma)		
Bed mats (absorbent)	-	18.4%
Diapers (pediatric, adult)	-	69.5%
Holding straps/bands to fix urine bag to the leg/bed	_	0.7%
Single-use examination gloves (sterile/non-sterile), for	-	5.7%
Medical devices with voice output: blood sugar meters, thermometers and blood pressure meters	-	4.3%

Among the key reasons for not being able to receive medical devices and other products at in-patient and out-patient settings respondents noted the following:

- the lack of funding or lack of required devices and products;
- poor quality of devices and lack of individualized approach (e.g. baby diapers were offered to children with disabilities);
- the needed medical devices and products were offered in smaller quantities than stipulated by legislation;
- a long waiting list to receive medical devices and other products at in-patient settings;
- the lack of information, including lack of access to information for persons with hearing disabilities;
- the family practitioner or treating physician at in-patient setting does not work to ensure that the patient receives medical devices and other products (as before, they draw up a list of the required devices and products which patients are to buy out-of-pocket);
- medical devices and other products are not provided due to the reorganization of the Ukrainian Social Insurance Fund that used to administer this type of help;
- the lack of information about or lack of a procedure to receive the needed medical devices and/or products (e.g. eye glasses, other devices for blind people);
- medical devices and/or products are not provided due to military hostilities and constant shelling;
- "we do not receive [them] because we still have to register after we relocated to the new place and became internally displaced";
- there is no out-patient clinic or it is not accessible because the elevator is now working.

Respondents were asked about their satisfaction with the quality of received medical devices and other products. They were divided in their opinions in two equal groups.

Specifically, they mentioned a number of weaknesses in the provision of medical devices and other rehabilitation products:

- the devices were of poor quality or were missing;
- the list of medical devices and other products was limited;
- the available sizes and types did not meet individual needs;
- total corruption in healthcare.

#### Provision with assistive rehabilitation devices

The provision with assistive devices is funded from the public budget allocated on a yearly basis to the Ministry of Social Policy of Ukraine. The 2023 National Budget includes 2.8 bln. UAH for these purposes. Ukraine has 106 enterprises that produce, supply and provide assistive rehabilitation devices and offer repair and technical maintenance services.

Based on the study findings, nearly 58% of adults and children with disabilities need assistive rehabilitation devices, and 46% received ARDs over the past two years.



Note: Diagram "Persons who need and are provided with assistive rehabilitation devices". Answer options from left to right: "Yes", "No" and "Did not need ARDs". Colour codes: blue – those needing ARDs; brown – received ARDs.

The analysis of completed survey forms indicates that there is a need for all types of ARDs detailed below. Among the listed ARDs the highest demand is for orthopedic footwear (59.1%), wheelchairs (39.6%), special furniture items, such as orthopedic beds, mattresses, desks, table desks, bedside tables, etc. (36.6%), special communication, navigation and information sharing devices (32.3%), assistive hygiene items, such as bathtub/shower seats or stools, toilet chairs, etc. (30.6%), orthotic devices for the spine, upper and lower limbs (14.9%).

#### Provision with assistive rehabilitation devices

Type of device/product	% of respondents who were provided with ARDs over the past 2 years
Prosthetic devices for upper and/or lower limbs	
Orthotic devices for the spine, upper and lower limbs	2.8%
Orthopedic footwear	45.9%
Brest prosthesis	
Wheelchair	28.0%
Walkers, canes, crutches	3.2%
Assistive hygiene items (bathtub/shower seats or stools, toilet chairs, etc.)	6.0%
Special furniture items (orthopedic beds, mattresses, desks, table desks, bedside tables, etc.)	5.5%
Special communication, navigation and information sharing devices	8.7%

Respondents offered the following key reasons for not being able to receive the needed ARDs:

- the lack of funding or a waiting list to received ARDs;
- the available range of ARDs did not include the required designs to meet the need of an individual adult or child with disability;
- a limited choice of available technical devices:
- the lack of information about the opportunity to receive ARDs that are covered from the public budget;
- excessive bureaucracy (the need to obtain a lot of different documents to apply);
- low awareness on the local level about the actual situation with ARD provision ("they say that due to the war now there is no such thing as free-of-charge provision");
- the Social Insurance Fund that used to provide ARDs for people with labourrelated disabilities is currently undergoing reorganization;
- in the majority of cases the lack of the services to enable individualized selection of ARDs;
- inadequate knowledge of the staff to provide expert advice at public welfare authorities;
- the lack of opportunities to receive ARDs due to military hostilities (respondents were or are now in the occupied territory).

Almost 61% of the total number of respondents receiving ARDs were satisfied with their quality.

The rest of the study participants explained their dissatisfaction with received ARDs mainly by the following reasons:

- poor quality of ARDs, e.g. the cane broke quickly, the brake handle on the walker was hard to press down, the shoes tore too quickly;
- ARDs were produced without taking measurements and without consideration of functional capabilities of adults and children with disabilities;
- the need for significant extra payments for additional adjustments that are necessary to fully use the ARD.

# Conclusions and recommendations on providing rehabilitation services, medical devices and/or ARDs to adults and children with disabilities in Ukraine

The study findings suggest that the situation with rehabilitation services at rehabilitation facilities operating in the welfare sector is almost similar to that in the healthcare sector.

Of the total number of respondents, i.e. adults with disabilities, legal representatives of incapable adults with disabilities and parents of children with disabilities, 29% received services at healthcare rehabilitation facilities, and 26% at welfare rehabilitation settings.

The share of respondents who were satisfied with rehabilitation services received at welfare facilities is 88%, which is significantly higher compared to the healthcare sector.

The highest levels of satisfaction at 93% were noted for rehabilitation services provided at private rehabilitation facilities as compared to state-owned and municipal settings.

The analysis demonstrated that people with disabilities are faced with significant and numerous barriers to access to rehabilitation services, necessary medical devices and ARDs. The obstacles to the provision of rehabilitation services for people with disabilities exist at the level of providers, individual and organizational, and at the level of the state. They may also be attributed to the demand for such services and their use by people with disabilities and their families. Often, challenges encountered by people with disabilities as they try to access rehabilitation services are not caused by their specific disability, but rather reflect much broader problems, i.e. limited knowledge of legislation both among providers of rehabilitation services, medical devices and assistive devices and those needing them. Some of the main barriers to access to rehabilitation services are described below.

#### INSTITUTIONAL BARRIERS

- Practically no a unified approach to the system of rehabilitation for persons with disabilities; inadequate inter-departmental and inter-sectoral communication. No comprehensive review of the quality evaluation system for rehabilitation services and of the monitoring and control systems.
- Numerous (widespread) instances of violation of rehabilitation rights, while the
  relevant guarantees are declared in the regulatory documents. This mostly refers
  to provision with assistive and other devices in the course of rehabilitation at
  facilities operating within the healthcare sector and to the provision with medical

devices at out-patient settings. The study demonstrated that over 38% of respondents who received rehabilitation services at healthcare rehabilitation facilities were not offered to be provided with ARDs despite the fact that they needed them.

- Poor levels of competence and professionalism of specialists at public authorities, staff of rehabilitation facilities and healthcare workers who are responsible to ensure the rights and guarantees for adults and children with disabilities regarding the provision with rehabilitation services, medical devices and/or ARDs.
- Insufficient number or a complete lack of community-based rehabilitation facilities where an adult or child with disability can receive comprehensive rehabilitation services, particularly in rural areas.
- A shortage of trained multi-disciplinary teams at healthcare facilities to work with persons with different types of impairments. The shortage of professionals to provide the needed rehabilitation services and ARDs leads to a situation when rehabilitation services are not provided in full or are of low quality. Respondents highlighted that physical and rehabilitative medicine services made up the largest share (50%) of the needed services, with physical therapy being a little over 22%. The other types of rehabilitation services provided at healthcare settings were few.

#### PHYSICAL BARRIERS

- The available rehabilitation facilities are not accessible enough for people with disabilities. They do not have ramps or lifts at the entrance to the building, there are no accessible elevators and restrooms; these settings are not fitted out with necessary medical and rehabilitation equipment, which is user-friendly for people with disabilities; they don't have clear signage for people visual, intellectual and mental disabilities.
- The rehabilitation services are often physically/territorially inaccessible for people with disabilities. Only one third of the respondents had the needed rehabilitation facilities in their community / area of residence, and, consequently, in the overwhelming majority of cases the rehabilitation facility is located far from the home of the person who requires its services or in an area without accessible transportation.
- The lack of transport accessibility. Rehabilitation facilities in the welfare and healthcare sectors almost fail to comply with the legal requirement to provide transportation services. Nearly 70% of adults with disabilities, legal representatives of incapable adults with disabilities and parents of children with

disabilities have to make their own arrangements to travel to the rehabilitation facility. This situation is further exacerbated by the war-related damage and destruction of transport infrastructure.

#### **COMMUNICATION BARRIERS**

• Low awareness among adults with disabilities, legal representatives of incapable adults with disabilities and parents of children with disabilities about the rights and guarantees stipulated by law.

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• Failure to collect feedback from recipients of rehabilitation services, ARDs, medical devices, which does not contribute to the improvement of quality and comprehensiveness of rehabilitation services, medical devices and assistive devices.

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- Rehabilitation professionals do not always consider the opinion of the person with disability who needs rehabilitation services or the opinion of parents of a child with disability in the course of developing the Individual Rehabilitation Plan. The analysis demonstrated that rehabilitation facilities operating in the welfare sector failed to take into account the respondent's opinion in 8% of cases when developing the IRP, while in the healthcare sector this indicator was even higher by 9%.
- For people with hearing disabilities the major obstacle to accessing rehabilitation services was related to limited access to services of sign language translators.
- A practical lack of information in accessible formats about the provision of rehabilitation services.

#### FINANCIAL BARRIERS

- Insufficient funding for rehabilitation services, medical devices and/or assistive rehabilitation devices in Ukraine. In some communities there are no funds for these expense areas. As a consequence, rehabilitation services for adults and children with disabilities at welfare rehabilitation facilities in the majority of cases were funded from the national budget (80%), while in the healthcare sector the share of central budget funding was somewhat smaller at 70%. Meanwhile, in the private rehabilitation facilities 62% of recipients of rehabilitation services pay for them out-of-pocket and only for 19% these expenses are covered from public funds.
- Poor quality and inadequate range of medical devices and assistive rehabilitation devices, as the result of underfunding for these areas.

To ensure the right of adults and children with disabilities to access rehabilitation services, provide them with medical devices and/or ARDs in Ukraine and to improve the level of such guarantees it is necessary to:

- provide services in evidence-based manner taking into account specific needs of users and to design these services with a focus on specific outcomes;
- integrate rehabilitation services into the processes of planning, reforming and funding the welfare and healthcare sectors;
- build-in rehabilitation parameters into data collection processes from different sources, including healthcare and welfare organizations, demographic statistics;
- inform public on an ongoing basis about the legal rights to be provided with rehabilitation services, medical devices and/or assistive rehabilitation devices using accessible formats and modern technology;
- improve the level of training and knowledge of community workers, family practitioners and treating physicians in the area of rehabilitation;
- create or support (where available) community-based facilities that provide comprehensive (social, psychological, sports and physical) rehabilitation to meet the needs of the community (or, possibly, several communities) and facilities on the regional level where more professional help can be provided;
- develop transportation services for community members with reduced mobility;
- improve systems for planning, pre-service education and professional training and regulation of professional practice in rehabilitation taking into account competence-based approaches;
- deliver training based on international standards for professionals on providing rehabilitative help for all people with disabilities irrespective of their functional impairments;
- ensure acceptability, accessibility and quality of services;
- increase funding for services, medical devices and assistive devices, while making them affordable;
- consider introducing a compensation scheme for medical devices purchased outof-pocket rather than provide them in out-patient settings, or a reimbursement scheme;
- monitor and control the delivery of rehabilitation services, provision of assistive devices, medical devices and other products and ensure quality control;

• include the issue of rehabilitation in welfare and healthcare sectors into recovery plans/strategies for Ukraine.