Norway

Atlas Alliance

HAIY National Assembly of People with Disabilities of Ukraine | All-Ukrainian Public Association

The Norwegian Federation of Organisations of Persons with Disabilities

ANALYTICAL REPORT

Realization of Reproductive Rights by Women with Disabilities in Ukraine: Pathway, Barriers, and Ways for Improvement

Based on the findings from a study conducted in seven territorial communities in Ukraine

Short version

This report was prepared as part of the Woman's Health Project implement1ed by the National Assembly of People with Disabilities of Ukraine (NAPD) in partnership with the Norwegian Federation of Persons with Disabilities (FFO).

The full version of the report is available in the Publications section of the NAPD website: https://naiu.org.ua/vydannya

Summary

This report presents an overview of the current situation with ensuring and practical implementation of reproductive rights of women with disabilities in Ukraine in wartime.

The methodology of the study made it possible to incorporate lived experiences of women with different impairments and the practical view of the medical community. The Conclusions section offers clear recommendations to support implementation of cross-cutting changes at the legal and operational levels.

The study was based on a hybrid methodology and covered seven territorial communities in Ukraine.

It included an online survey that was completed by 373 women with different impairments and 107 healthcare professionals. Further, focus group discussions were held with 20 women with disabilities, and 8 medical doctors shared their experience during in-depth interviews. Quantitative data from the survey were complemented with qualitative evidence and a review of national legislation, clinical guidelines and specifications for healthcare service packages of the National Health Service of Ukraine (NHSU) as compared with the international commitments of Ukraine and best standards.

In Ukraine, at the level of national legislation, the protection of reproductive rights of women is guaranteed by a range of international treaties, the Constitution and sectoral laws that guarantee the right to healthcare, free reproductive choice and protection from discrimination.

However, a key conclusion from the study indicates that for women with disabilities these rights guaranteed by law ‘do not work in practice’, i.e. the gap between legislation and its practical implementation is the main reason why women are unable to exercise their rights.

The study findings highlight the key issues.

Only a third of surveyed women see a gynecologist regularly, while some of them have never seen this professional. Just a small number of women take screening tests, e.g. PAP-test, breast exam, mammography. Women using wheelchairs undergo screenings times less often as compared to the average value due to physical inaccessibility of medical rooms and medical equipment.

Nearly every third participant encountered barriers in communication and interaction with healthcare practitioners.

Nine out of ten women rely on the public healthcare system, yet it is publicly funded healthcare facilities that lack universally designed medical equipment and physically accessible rooms.

Less than a half of the healthcare facilities have universally designed gynecological chairs and only a few have diagnostic equipment suitable for women with physical disabilities.

Nearly a half of the surveyed healthcare professionals never took any training on providing care to women with disabilities, although they need it.

At healthcare facilities located in the pilot communities, a round-the-clock sign language translation service is practically absent.

Of greatest concern is that these are not individual shortcomings of the system, but rather inter-linked problems.

It is particularly important to note the problem with 'invisibility' of the needs of women with disabilities. What is not measured is hard to improve. Without sufficient information about the numbers of women who require adapted healthcare services, the barriers they face, and the outcomes of provided care, it is extremely problematic to plan staff, organizational and financial resources.

Key indicators determined by the study.

Indicator	Value
Regular visits to gynecologist	nearly 35%
Regular PAP-test among women using wheelchairs	nearly 18%
Regular breast exam among women using wheelchairs	nearly 7%
Respondents who encountered dismissive attitudes	nearly 29%
Respondents relying on public healthcare	nearly 90%
Healthcare facilities with universally designed gynecological chair	Less than 50%
Healthcare facilities with a mammograph suitable to examine women with physical impairments	Very few

Based on the study findings, it may be concluded that each single barrier listed above is neither critical, nor non-removable. The majority of the necessary steps fall within the domains of management, standardization, control, and understanding of disability and challenges faced by women with disabilities.

Successful local cases from individual communities, e.g. social taxi service, electronic booking of appointments with gynecologist, universally designed medical equipment, mobile medical teams serving remote and frontline communities, prove that changes are both realistic and achievable.

For this purpose, Ukraine has the full range of international commitments and sufficient legal framework; only specific national mechanisms are missing to enable their implementation.

Based on the analysis of the study findings, the report offers a system of targeted recommendations categorized by the levels of responsibility.

At the national level, the recommendations include alignment of the legal norms regarding legal capacity and supported decision-making, prohibition of forced interventions, ensuring inclusivity of clinical protocols and more active uptake of international guidelines, introduction of a uniform measurable accessibility standard and addressing statistical invisibility through the use of disaggregated data.

Important warning! Women with disabilities should not become a separate 'patient group' to be served by a different type of healthcare. This report does not advocate building a parallel healthcare system, but rather suggests that the existing one should be made more flexible, inclusive and patient-oriented for all.

At the level of the Ministry of Health and the National Health Service of Ukraine, it is recommended to identify the requirements for universally designed equipment with specific criteria; stipulate accessibility as a condition for a granting a healthcare services contract, eliminate inconsistencies in inclusivity requirements in health service packages; revise the pay scales and reception hours; and consistently strengthen tele-health.

At the community level, the recommendations comprise improving the transport logistics (getting to the healthcare facility); introducing the operation of mobile medical teams, particularly in frontline areas, ensuring physical and informational accessibility of healthcare facilities; providing social follow-up after during the postnatal period; and strengthening interdepartmental coordination of services.

At the level of healthcare facility, it is recommended to remove physical barriers at sanitary and hygienic premises, doctor's offices, and patient rooms; ensure training for medical staff; improve the quality of service delivery (electronic appointments, sign language translation service, etc.); conduct preventative measures with girls and women with different disabilities and with their legal representatives; use plain language and easy-read language for communication; and collect disaggregated data.

The overarching idea of the report is that women with disabilities do not require any special treatment or conditions – what they need is ***access on the same basis with others*** *to high-quality healthcare services in order to exercise their reproductive rights.*

The implementation of recommendations outlined in this report would make it possible to transform the declared rights into real opportunity for each woman with disability to receive guaranteed services to protect own health, realize her right to motherhood and achieve self-actualization in a respectful environment, regardless of her disability type, place of residence or any social factors.

Recommendations to the Analytical Report

The national level recommendations are addressed to the Verkhovna Rada (Parliament) of Ukraine, Cabinet of Ministers of Ukraine and central executive authorities. They are intended to overcome the fundamental causes of the gaps between law and practice, both in legislation and strategic regulations. These recommendations are essential, because a failure to implement them would deprive all other measures of sustainable legal foundation.

It is recommended to align the Ukrainian legislation on legal capacity with the UN Convention on the Rights of Persons with Disabilities and the Istanbul Convention. The state should replace the system of deprivation of legal capacity with a supported decision-making model. This will prohibit guardians or other persons to decide on matters related to contraception, sterilization or termination of pregnancy instead of the woman herself. The law should explicitly guarantee that any reproductive intervention may be possible only with free and informed consent of the patient, whether with disability or not.

New laws on reproductive health (specifically on assisted reproductive technologies) should clearly guarantee access to services, non-discrimination and the right for women with disabilities to make decisions. To this end, organizations of people with disabilities and disability experts should continuously follow up and monitor these draft laws at each state of their parliamentary deliberations.

It is important to ensure inclusive nature of clinical protocols and standards of medical care. Despite being up-to-date from a clinical point of view, they still do not include any instructions on providing care to patients with disabilities. Additionally, more active use should be made of international protocols (based on the effective Decree No. 751 of the Ministry of Health as amended by Decree No. 1422), which already stipulate such rules – these should be formally approved, translated and communicated to doctors.

It is essential to establish a uniform legally enacted and measurable standard for accessibility of healthcare services. This standard should apply at all levels – from the National Strategy for creating barrier-free environment to licensing conditions and contracts awarded by NHSU. It should set clear and verifiable requirements to physical environment, medical equipment, ways of communication and information formats; stipulate inclusivity as a mandatory requirement for obtaining a medical license; and provide for legal accountability for failure to observe these conditions.

The collection of statistical data on women with disabilities should be required by law. It is recommended to introduce mandatory data disaggregation based on disability in the e-health system and health statistics. Data should be collected on actual needs and capabilities of the individual, specifically through the short list of the Washington Group questions. Collected

statistics should be used to inform accurate planning, allocation of funding and monitoring of healthcare services. Observance of international requirements should be ensured.

Importantly, the majority of the proposed recommendations are fully consistent with the international commitments already undertaken by Ukraine. Therefore, their implementation is not a mere recommendation, but a duty of the state under existing international treaties. These national level recommendations must necessarily be implemented in an on-going dialogue with organizations of people with disabilities – from the stage when decisions are developed to evaluation of their effectiveness, pursuant to the fundamental principle 'nothing for us without us'.

1. Recommendations to the Ministry of Health and the National Health Service of Ukraine

It is essential to move away from the ill-informed division of equipment into "regular" and "special" categories. *Instead, clear and measurable criteria should be legislated to implement universally designed medical equipment.*

Accessibility should be stipulated as a mandatory and controllable condition of the contract for the delivery of medical services within woman's health packages. During the process of contracting healthcare facilities, the observance of the national building regulations should be checked not "just at the entrance", but also inside the building (medical rooms, bathrooms, corridors).

Additionally, translation into the Ukrainian sign language and provision of information in alternative formats should be mandatorily required.

It is necessary to remove inconsistencies in inclusivity requirements between specifications and extend harmonized requirements to accessible equipment, communication, information, accommodated beds and tele-health to all relevant medical service packages (outpatient care, screening, specialized services, assisted reproductive technologies), rather than just to individual ones.

It is important to develop and implement standards for safe high-tech diagnostics for women with disabilities. This will need to be regulated on the normative level, e.g. maximum duration of the test/examination, number of staff involved, monitoring procedure, the involvement of a multi-disciplinary team, and ensuring the patient's right to support.

Alongside this, it is important to unify the terminology used in specifications by replacing vague terms with exhaustive and measurable inclusivity criteria.

It is recommended to revise pay rates and standard appointment times taking into account the needs of patients with disabilities, i.e. the standard time for seeing such patients should be increased and such increase should be supported with respective pay rate.

It is necessary to evaluate the impact of financial indicators (specifically, with regard to the network of maternity centres) on access to services for vulnerable groups before such

financial indicators are introduced or changed in order to avoid unintentional worsening of access for women with disabilities in small communities.

It is recommended to develop and approve national guidelines, changes to protocols and standards on care provision to women with disabilities (separately for patients with physical, neurological, sensory and intellectual disabilities).

These recommendations identify the Ministry of Health and the National Health Service of Ukraine as the key agents of practical changes who are in the position to ensure inclusive nature of healthcare services across the country.

It is advisable to implement these sectoral recommendations in stages, starting from those that offer a maximum effect at the lowest cost and do not require lengthy preparation. This will help demonstrate quick outcomes, gain support and lay the foundation for more complex reforms.

2. Recommendations for local government bodies and communities

It is necessary to introduce or develop a specialized transportation 'door-to-door' service (social taxi) for women with disabilities who need to travel to healthcare facilities. The study shows that the transport barrier is one of the most acute problems and its removal will have the fastest positive impact on the largest number of women.

It is recommended to implement mobile formats for service delivery, i.e. mobile medical teams with portable equipment that bring the service closer directly to a woman, specifically in rural areas, frontline and remote settlements. This is particularly important in the situation when the network of healthcare facilities is reduced and the services are concentrated in large centers.

It is essential to ensure indoor accessibility of municipal healthcare facilities. Taking into account that many primary and secondary care facilities are owned by municipalities, local government bodies are responsible for their accessibility and may allocate respective funds through their local budgets and investment programmes.

It is advised to improve the care pathways at the local level, i.e. raise awareness among women about their right to make an appointment with a gynecologist directly (art. 35-2 of the Foundations of legislation on healthcare; Decree No. 586 of the Ministry of Health; procurement terms and conditions of the National Health Service of Ukraine); remove artificial barriers at the medical records office; organize a flexible schedule for patients who have to travel longer distances; and prioritize women with reduced mobility in appointment booking.

Access to information should be ensured, e.g. by disseminating easy-to-understand materials in accessible formats about reproductive health services that are provided free-of-charge and where to seek medical care.

It is essential to consider the needs of women with disabilities during the planning of recovery and repairs of healthcare facilities, i.e. the requirements for universal design and accessible

equipment should be incorporated already at the design stage.

The measures recommended for implementation at the local level offer the quickest effect and the majority of them can be put in practice within the existing powers and budgets of communities provided that the political will is in place.

The experiences of communities participating in the study demonstrates that where the local government takes the initiative, the access to services for women with disabilities markedly improves. Dissemination of best practices among communities, specifically through exchange of experience and methodological support, is a practical and cost-effective way to improve accessibility across the country. These recommendations should be integrated into strategic documents of the communities, i.e. their local programmes, budgets, investment plans and recovery strategies. Furthermore, women with disabilities and organizations of people with disabilities should be directly included to the planning of local health and social programmes in line with the principle 'nothing for us without us'.

Local government bodies should consider access to reproductive services as an integral part of the overall strategy for building an inclusive community, and not as a separate policy.

3. Recommendations for healthcare facilities

It is necessary to remove indoor barriers within the facility. Many of such measures do not require significant funds and may be implemented as part of routine fitting-out of the premises.

It is recommended to make postnatal and gynecological patient rooms accessible, which will improve comfort and quality of service delivery for women with disabilities.

It is essential to guarantee confidentiality and privacy for patients, which will ensure the realization of their legal right to medical secrecy. The study shows that this right is often breached due to a number of organizational issues.

Medical examination should be conducted safely and with respect for a woman. This means mandatory procurement of universally designed and adapted medical equipment, which will enable women to undergo procedures without traumatization, discomfort or belittlement of their dignity.

It is recommended to implement tools for accessible communication, i.e. arrange translation from/to the Ukrainian sign language, specifically via remote video-translation services; prepare printed and digital materials in accessible formats (in Braille, enlarged font, plain language and in easy-read format); and extend the duration of visits for patients who need more time for communication or examination.

It is important to foster inclusive corporate culture, mutual respect and prevention of discrimination among medical staff.

Awareness-raising activities should reach all groups of healthcare workers, including doctors, junior and medium-level medical staff, and staff of the medical records office.

It is advised to identify a designated person at each healthcare facility to coordinate the relevant measures and liaise, as required, with organizations of persons with disabilities.

The recommendations for healthcare facilities refer to the level where systemic requirements are translated into real and tangible experience for a woman. Although being dependent on decisions made at higher levels, a healthcare facility still has a significant freedom for independent action and its leadership plays the key role by nurturing culture and setting standards for the staff to follow.

4. Training for healthcare workers and overcoming of biases

It is recommended to incorporate inclusive competencies into pre-service training curricula in medicine to ensure that new generations of doctors, midwives and medical nurses can acquire the relevant knowledge at the start of their professional carrier.

Within the continuous professional development system regular practical trainings should be introduced covering management of pregnancy and delivery in women with disabilities, communication with patients with different disabilities, etc. It is key to ensure a systemic, rather than one-time, nature of such training and support it with funding from the central public budget or from the National Health Service of Ukraine. The study demonstrates that occasional training courses do not offer a viable solution, as they fail to reach the majority of staff and are not continued.

It is important to involve organizations of persons with disabilities and women with disabilities themselves to conduct training pursuant to the principle 'nothing for us without us'.

Awareness-raining work is needed designed to overcome societal biases regarding sexuality and motherhood among women with disabilities. Educational activities targeting both the medical community and wider public are a long-term, yet necessary measure to change stereotypes.

Girls and women with disabilities should be provided access to sex education and awareness-raising in accessible formats, specifically suitable for persons with intellectual disabilities and those in institutional settings.

It is recommended to develop and disseminate methodological materials for healthcare workers, i.e. practical guides on providing care for patients with different disabilities.

Despite its gradual effect, such educational track is fundamentally important, as it helps develop human capital and shape the culture – two factors that ensure truly meaningful outcomes of systemic and infrastructural changes.

5. Monitoring, data collection and next steps

The final set of recommendations is intended to ensure sustainability and accountability of changes. It includes. data collection, monitoring and further research. Without these tools even the best solutions are at risk of remaining sporadic and non-measurable, and progress not evidence-based.

It is necessary to introduce systemic collection of data disaggregated by disability in the area of reproductive health, i.e. by integrating the relevant requirements into the e-health system and medical reporting templates based on a functional approach.

It is recommended to implement regular monitoring of accessibility of healthcare facilities and the quality of services for women with disabilities by involving independent actors, specifically organizations of persons with disabilities. The results should be made public and used to inform policy adjustments.

It is necessary to set measurable targets (indicators) for accessibility of reproductive health services for women with disabilities.

Further research is needed, specifically to reach the most isolated groups ('the most vulnerable among vulnerable') that may have been overlooked by this study in view of its online format. This will help gain a clearer understanding of the situation, monitor the dynamics and evaluate the impact of measures implemented.

It is important to ensure the participation of women with disabilities in decisions that affect them at all levels from planning of community-based services to of national policy development.

NATIONAL ASSEMBLY OF PEOPLE WITH DISABILITIES OF UKRAINE

Reitarska str., 8/5A, office 110, Kyiv, 01054

Telephone: +380 44 279 6182

E-mail: office-naiu@ukr.net

Website: www.naiu.org.ua/en