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Strengthening the national ecosystem for the provision and use of assistive technology / augmentative and alternative communication for children with disabilities in UKRAINE

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Cover image: @ UNICEF Ukraine/year/author

Margaryta with her mother Albina at the Children's Rehabilitation Center Dzherelo in Lviv, Ukraine

Norad

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List of Abbreviations

AAATE	Association for the Advancement of Assistive Technology in Europe
AAC	Augmentative and Alternative Communication
AT	Assistive Technology
ATA-C	Assistive Technology Capacity Assessment Tool
ATC	Amalgamated territorial communities
CMU	Cabinet of Ministers of Ukraine
CRC	Convention on the Rights of the Children
CRPD	Convention on the Rights of Persons with Disabilities
EASTIN	European Assistive Technology Information Network
ECI	Early Childhood Intervention
IRC	Inclusive Resource Centre
ISAAC	International Society for Augmentative and Alternative Communication
MAC	Medical Advisory Commission
MES	Ministry of Education and Science of Ukraine
MH	Ministry of Health
MSEC	Medical and Social Examination Commission
MSP	Ministry of Social Policy
NGO	Non-Governmental Organisation
NHSU	National Health Service of Ukraine
PMG	Program of Medical Guarantees
PMPC	Psychological, medical and pedagogical consultation
r-ATA	rapid Assistive Technology Assessment tool
SEN	Special Educational Needs
WHO	World Health Organisation

ГОСТ

1. Introduction

1.1. The report

This report is the result of a country assessment regarding the country's capacity to respond to the needs of children with disabilities regarding Assistive Technology (AT) and Augmentative and Alternative Communication (AAC). The assessment was conducted in the period May-October 2022 by the author with the support of colleagues in Ukraine. The main objective was to complement the WHO surveys (r-ATA and ATA-C) and to provide an additional assessment of challenges and needs of children with disabilities for AT and AAC for learning and participation as well as system gaps specific to children with disabilities.

The report intends to add additional insights, primarily informed by information gathered from stakeholders involved in AT and AAC provision at grass root level. The object of our analysis are thus children with disabilities in Ukraine and their care and education providing ecosystems.

Different resources have been used to assess the state of the art of AT and AAC access and use in Ukraine, the most important ones being official reports, scientific articles, and, as mentioned, semi structured interviews and unstructured interviews with colleagues that know the national situation well. In case of affirmations based on desk research, the sources are mentioned. In case information is taken from websites, the link to the original source is included in a footnote. Quotations or statements of single informants are reported in italic and quotation marks if they are transcribed literally. In case they are summarised, they are referenced or accompanied by the names of the opinion holders between square brackets.

There are a number of limitations to this report that need to be acknowledged:

- The limited timeframe and available resources (24 days) did not allow to equally investigate all aspects of AT provision. Especially the section regarding the availability of products on the Ukrainian market and barriers to access that market should require a more in-depth analysis.
- Ukraine is a big country with a large population, which makes it difficult to pretend that this study provides a complete picture of the complexity at stake when discussing the situation of children with disabilities in Ukraine and their access to AT and AAC.
- Due to the war in Ukraine it has not been possible to visit the country to observe practices, or to gather information directly from a large number of relevant stakeholders, including government officials. Further some experts were difficult to reach for an interview due to the war conditions.
- The framework used (see below) does not take into account disruptive changes or humanitarian crises, the reason why the assessment primarily refers to pre- and post-war scenarios.

1.2. The AT and AAC Capacity Framework for Children

The report is structured according to the Assistive Technology and Alternative and Augmentative Capacity Framework for Children which was written on purpose by the author and David Banes for UNICEF. UNICEF identified the need to have a framework that addresses the needs of children with disabilities throughout their lives and across settings such as home, school and community. It is widely recognised by the international scientific community that the greatest impact on the lives of persons with disabilities is obtained when intervention takes place as early as possible.

The framework, accompanied by a tool to assess AT and AAC capacity, provides the opportunity to support low and middle-income countries to set up assistive technology systems and services that are accessible to children and capable of responding to identified needs in their specific contexts.

The World Health Organisation (WHO) defines **Assistive Technology** (AT) as an umbrella term covering the systems and services related to the delivery of assistive products and services. The definition highlights that AT is not just about products, but also about services and systems. This is extremely important as having access to appropriate AT is not a straightforward and simple process. Professional services and providers are needed that can support the user in defining the right personal AT solution that can be effectively used in an enabling environment.

Similarly, the definition of assistive technology based on United States' Federal Technology Related Assistance to Individuals with Disabilities Act of 1988 (Tech Act), is extremely broad. It includes *"any item, piece of equipment, or product system whether acquired commercially off the shelf, modified, or customised, that is used to increase, maintain, or improve functional capabilities of individuals with disabilities."* The definition focuses on any kind of product that used by persons with disabilities can have an important impact on their autonomy and independence. The definition expands the range of educational applications by focusing on technologies "*used to increase, maintain, or improve the functional capabilities of persons with disabilities"* - Improving such capabilities is an obvious aim for those supporting the development of the child in formal, informal, or non-formal education.

The International Society for **Augmentative and Alternative Communication** (ISAAC) defines Augmentative and Alternative Communication on its website as *"a set of tools and strategies that an individual uses to solve every day communicative challenges. Communication can take many forms such as: speech, a shared glance, text, gestures, facial expressions, touch, sign language, symbols, pictures, speech-generating devices, etc."* It further highlights that everyone uses multiple forms of communication, based upon the context and our communication partner. It concludes by saying that *"the form is less important than the successful understanding of the message".*[1] When we consider technologies supporting AAC, high-tech devices could include computers, tablets, phones, electronic equipment, and software or apps. These need not be expensive. Low-tech devices are manually operated and might consist of simple communication books or cards. Even in these cases, increasingly, a high-tech option is used to create low-tech resources for a child.

The design of a specific framework to address the needs of children with disabilities drew heavily upon the work of the **WHO GATE initiative** that has identified 5 areas of intervention relevant to foster access to AT.

The 5P's identified are:

- People
- Policy
- Products
- Provision
- Personnel

However, in the framework attention was paid to the variations in each of the aspects of the ecosystem when applied to children. Full definitions and explanations of each are available in the Framework for AT and AAC Capacity for Children.

The framework recognizes the need to address the specifics of AT and AAC capacity but finds that implementation of AT and AAC technologies is most likely to succeed in a classroom and educational setting that is founded upon inclusive principles and draws upon a framework for universal design for learning. As a result, the findings of the research are placed within a broader context of inclusive education practice in Ukraine.

[1] https://isaac-online.org/english/what-is-aac/

The framework is completed with **a data collection tool** that allows for systematic data gathering useful for the assessment of AT capacity and the identification of gaps. For each P questions are formulated that, once answered, provide information on the state of the art in the country under examination.

1.3. Core concepts underlying the framework

1.3.1 Access to AT is a human right

The most important policy driver that fosters the provision of AT and AAC to persons with disabilities is the UN Convention on the Rights of Persons with Disabilities (CRPD)- adopted in 2006.[2] Article 4 lists among the obligations of the signing state parties to:

"(g) To undertake or promote research and development of, and to promote the availability and use of new technologies, including information and communications technologies, mobility aids, devices and assistive technologies, suitable for persons with disabilities, giving priority to technologies at an affordable cost;

(h) To provide accessible information to persons with disabilities about mobility aids, devices and assistive technologies, including new technologies, as well as other forms of assistance, support services and facilities."

Article 7 of the Convention is on children with disabilities, and comma 3 reads:

"States Parties shall ensure that children with disabilities have the right to express their views freely on all matters affecting them, their views being given due weight in accordance with their age and maturity, on an equal basis with other children, and to be provided with disability and age-appropriate assistance to realise that right."

The Convention on the Rights of the Child (CRC) – adopted in 1989 – spells out the rights that all children have, including children with disabilities.[3] Some of these rights are particularly relevant to assistive technology such as the rights to the protection and care necessary for well-being and health, including rehabilitation. But also to develop to the fullest; to education; to freedom of expression; and to participate fully in family, cultural and social life. In Article 23, the CRC specifically recognizes the right of children with disabilities to special care and assistance, which should be provided free of charge whenever possible.

1.3.2 Quality service delivery systems

The AAATE/EASTIN position paper on AT service delivery systems defines criteria for the quality of AT service delivery processes. The quality of the service delivery process is vital for the success of the intervention. The six criteria are accessibility, competence, coordination, efficiency, flexibility, and user influence (Andrich et al., 2013). The paper also moves away from a device or product focussed approach to a more holistic view of responding to needs seeing AT products as part of a wider **Assistive Solution**. In this model, it is **a combination of assistive technologies with personal assistance and environmental adaptations** that leads to greater access and inclusion. This is helpful to consider as it helps to focus on the need to **integrate actions at multiple levels** and for elements of provision to be mutually supportive. This has relevance to our consideration of provision for children as we should be conscious of the relationship between AT capacity and the wider **environment**, including the status of Universal Design for Learning, the extent to which the built environment is accessible and underlying **attitudes** that facilitate or hinder the promotion of inclusive education. For this reason a **multidisciplinary approach and interdisciplinary**

[2] https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html
[3] https://www.ohchr.org/en/instruments-mechanisms/instruments/convention-rights-child

collaboration is recommended for assessment and support services providing independent advice (Hoogerwerf et al., 2002).

In establishing a common framework for evaluating AT capacity for children and in education, these features are useful to incorporate either as part of data collection or in undertaking analysis of that data and establishing strategies and actions for capacity building.

1.4. AT Capacity Objectives

The Framework lists a coherent set of objectives for any AT delivering ecosystem responding to the needs of children with disabilities. The objectives can also be seen as high level areas of desired performance of the system, with indicators that can be used to assess the current state of the art. Having these high level objectives referring to different aspects of access to AT makes it possible to define **global and interconnected strategies** to move from A to B, from where we are and where we would like to be.

These high level objectives are:

- The disabilities and educational needs of children are identified as early as possible, and provide the basis for allocation of support, including assistive and communication technologies, to achieve their full potential. (People)
- Policies are in place that guarantee that children with disabilities have access to appropriate assistive and communications technology to develop their full potential and for their inclusion and participation. (Policy)
- A range of AT and AAC products are available that address the needs of children with a disability and are distributed across the country in a timely and cost-effective manner. (Products)
- AT and AAC Provision systems offer effective supply and support of the technologies required by children with disabilities and are flexible, efficient, competent, and outcome-oriented. (Provision)
- Professionals in Education, Health and Social Care have the skills, knowledge, attitudes and understanding to provide guidance and support needed to implement AT and AAC solutions fully into practice. (Personnel)
- AT and AAC intervention is timely and adapts to the changing needs of the child. (Pace)
- AT and AAC is provided taking into account the wider life experience of children with disabilities in different settings and circumstances. (Place)
- AT and AAC provision and support is provided by an ecosystem in which adults in different roles work together for the best interest of the child. (Partnerships)

Pace, Place and Partnerships are three additional but transversal dimensions that take into account **the impact of time, location and supportive resources** as factors to be considered when analysing AT delivery systems and their effectiveness, and are particularly relevant for children as they grow and develop. What is timely intervention in one case might be too late or too early in another, what is available in one place, might not be in another and human resources that are helpful in one situation might be useless or even a barrier in another.

2. Findings

2.1. AT in Ukraine as recently assessed by a WHO report

Over the last decade important reforms were introduced by the Ukrainian government for the benefit of children with disabilities, in particular in the area of access to inclusive education and deinstitutionalisation. These processes are still ongoing, although the Russian invasion of the country has obviously altered the priorities of the government and devastated the lives of most Ukranians, leading to many uncertainties regarding the country's destination. Although a section in this report is dedicated to the situation of children during the war, and the impact of the war on social and education policies will have to be assessed in the future, the focus of the report is on the pre-war situation and possible post war scenarios.

An extensive assessment of the situation of AT in Ukraine was recently performed by the WHO and published in 2022, just before the Russian invasion (WHO, 2022). The highly informative report contains different sections reflecting the 5 P model as elaborated by the WHO. The 5 P's stand for People, Policy, Products, Provision, Personnel and represent dimensions impacting on full access to AT and in which barriers and opportunities can be identified. These sections in the report are based on desk research and consultations with policymakers and other experts. In a second part of the report data about access to AT using the rATA methodology are provided.

The key findings of the report are the following:

"The system in Ukraine has distinct strengths and advantages: the Ministry of Social Policy has a strong commitment to developing the assistive technology sector, persons with disabilities are entitled to a wide range of assistive products free of charge, there are many certified assistive technology providers, and persons with disabilities are free to choose where to get their assistive products. The assistive technology sector is developing and progressing in the right direction.

Nevertheless, challenges remain, and many opportunities exist to strengthen the sector and improve its effectiveness and efficiency in all areas, including the following.

- *Policy – only persons registered as disabled are eligible for a Government-funded assistive product, and the different ministries involved in the provision of assistive technology have developed parallel systems.*
- *Products – many products on the market are low-quality. Outside the domains of mobility and self-care, there are limited options and low availability of assistive products.*
- *Provision – assistive products are often provided without complete services. Rehabilitation services and facilities are separated from service delivery.*
- *Personnel – there are few assistive technology professionals trained to international standards."*

(WHO, 2022)

Unfortunately, the WHO report is not very specific when it comes to analysing the situation of children with disabilities and their access to AT and AAC which is the focus of this report.

2.2. The 5 P's: People, Policy, Products, Provision, Personnel

Improving access to AT and AAC for children with disabilities as a policy objective touches upon many wider areas of policy, such as the situation of disabled people in general, the situation of children in general, the situation of wider social and educational policies, as well as the state's organisation and budget. For the scope of this report wider policies have only been assessed and described when particularly relevant for the understanding of the issues under investigation in this report. Such wider background information most of the time is summarised by the author, with reference to more detailed descriptions and reports where details can be found.

The experience of children with disabilities is mainly determined by the opportunities provided by their families and by the educational system. Nevertheless, also health and social or community services play an important role, reason why where possible these have been included in the analysis as well.

As mentioned in Section 1, for the description of the State of the Art the Framework has been used that was developed by David Banes and the author. That framework is based on the 5 P's model developed by the World Health Organisation under the GATE initiative. The 5 P's stand for People, Policy, Products, Provision and Personnel, considered the 5 most relevant dimensions for the analysis of opportunities and barriers for AT access and for the development of AT interventions.

2.2.1. People

Under the section People the framework seeks to investigate the situation of the population that are potential users of the assistive technology products and services and AAC systems. Addressing their needs places them at the heart of any ecosystem. The type of information collected regards statistics, the definition, classification and certification of disability, the living conditions of children with disabilities, the available services and culturally determined perceptions of disability.

Findings

Ukraine is the second largest country in Europe in landmass and has a total population of 43.7 million. Like many European countries, Ukraine has an ageing population. Almost 14% of the population are aged 0–14 years, while 12% are aged 15–24 years; 57% of the population are aged 25–64 years, while 15% are aged 65 years or over.

According to the State Statistics Service, 2,703,006 persons with disabilities are registered in Ukraine as of January 2020, 163,886 of whom are children. Currently, of the 78,380 children with SEN and disabilities enrolled in the institutions of secondary education, nearly 37,000 (47%) still attend segregated special schools, often located far from the family's home (State Statistical Service, 2020).

According to UNICEF they remain *"one of the most marginalized and isolated groups in Ukraine and face many barriers on a daily basis in access to opportunities, namely education. Other problems include stigma and discrimination, lack of child-centered and individualised learning methodologies, inflexible curricula, lack of assistive devices, inaccessible teaching materials, physical inaccessibility of schools, etc. The lack of these components means that families prefer specialized boarding schools and other institutions. About half of the children in Ukrainian institutions have a disability or developmental delay."*[4]

[4] Source: https://www.unicef.org/ukraine/en/press-releases/disability-day-2021#:~:text=According%20to%20the%20State%20Statistics,access%20to%20opportunities%2C%20namely%20education. (retrieved, 29.10.2022).

Although there is some data available regarding people with disabilities, much information is missing. For example, the national census data collection does not collect information on disability.

An important source of data is the Ministry of Social Policy (MSP) that administers the Centralized Data Bank on Disability, an automated system for determining the needs of persons with disabilities, children with disabilities, and other certain categories of population, that according to the legislation are entitled to technical and other means of rehabilitation, rehabilitation services, health resort treatment, etc. within rehabilitation means and rehabilitation services. The database determines entitlement for access to rehabilitation services and is based on the certification of disability. For access to AT by the MSP there are six groups identified: Musculoskeletal and neurological disorders, Intellectual and mental disabilities, hearing impairments, visual impairments, disabilities of internal organs and disabilities caused by cancer (WHO, 2022).

Because the available data are based on certified disabilities, but do not provide information on the barriers that people with disabilities in Ukraine face, the National Action Plan for the Implementation of the Convention on the Rights of Persons with Disabilities (CRPD) until 2025 (Cabinet of Ministers of Ukraine, 2021), has listed some new objectives:

"-the gathering of data by the State Statistics Service of information about persons with disabilities in the field of education, health care, justice, employment and the inclusion of those data in the annual statistical bulletin "Social Protection of the Population of Ukraine" as well as in its annual publication on the official website of the State Statistics Service;
-the conduction of a survey by the Ministry of Social Policy, on the barriers people with disabilities face in society;
-the commitment to more systematically collect disability related data in the field of health care, education, social protection and social services, justice, urban planning activities."

To obtain statistical data on the number of young children with developmental disabilities, by Order of the Cabinet of Ministers of Ukraine of 22.05.2019 N 350, in 10 pilot regions (oblasts), namely: Vinnytska, Dnipropetrovska, Donetska, Zakarpatska, Zaporizhska, Kirovogradska, Lvivska, Odeska and Kharkivska, a pilot project has started that uses a model of online screening (screening test in form of a questionnaire, easy to fill out online) in order to collect data and to analyse the needs of the population in receiving the service of early intervention, but until now no information about the results have been found.

Regarding the certification of a disability, the process is different for adults and children who are seen by different commissions, the so-called Medical Advisory Commissions (MAC) who also advises regarding AT, mostly for mobility. The Commission does not advise on rehabilitation pathways which is done by rehabilitation facilities or educational pathways which is done by Inclusive Resource Centres (IRCs). According to the resolution of Cabinet of Ministers "Changes in organisation of education of children with SEN" #765 dated July 21, 2021, the main tasks of IRCs are: to provide comprehensive assessment, provide supervision of children with Special Educational Needs (SEN), provide educational institutions with recommendations on individual development program, consulting parents of children with SEN regarding the specifics of child's development. IRC specialists do not provide recommendations regarding a type of school. Parents can consider IRC recommendations on child's development when choosing the educational institution.

Martynchuk et al. looked into issues related to the conceptualisation and definition of children with special educational needs and inclusive education. Before the 2017 Law on Education the focus was on disability and developmental disorders to classify and direct children, while the 2017 law interprets the term 'person with special education needs' as the 'person who needs additional permanent or temporary support in the educational process to provide his/her right to education'.

According to Martynchuk et al. *"this step seems to provide new opportunities to move from the identification of a diagnosis to focusing on children as active individuals who have something to contribute to society".* They nevertheless conclude that *"when looking at the conceptualisation of students with SEN, the analysis of Ukrainian documents shows that the definitions used are diverse, and it is not possible to find a coherent conceptualisation of the term 'students with SEN' at the national level. However, the findings demonstrate a slight shift in the documents' definitions regarding the use of the concept 'persons with SEN', which can possibly indicate a move towards the realisation of inclusion."* (Martynchuk et al., 2021)

Parents in Ukraine can decide whether to raise the child in the family or to entrust it to a specialised institute or special schools with boarding facilities. It was the opinion of all informants that increasingly children remain with their parents and that nowadays only rarely children are institutionalised. However, **there is a high number of institutions (internats) subordinated to the MSP, where children with disabilities live. Formal education is not provided to these children, although many of them can be considered as children with SEN.**

When a child with a disability is born parents will typically see doctors and rehabilitation specialists. Most informants agreed on the fact that in most cases parents will receive recommendations from doctors and some information on available services, but that there are very few public and only some private services that intervene beyond the strictly medical sphere [Raspopova, Ishchenko, Usatenko]. Some public services are free of charge but might have waiting lists, the reason why many parents prefer to refer to private services. An additional challenge is that a significant number of parents, like in many other countries, are hesitating to accept the disabling condition of the child, which leads to delays in seeking support outside medical rehabilitation, or, in the worst case, to the request for institutionalisation [Bloemkolk, Usatenko, Kukuruza]. Little psychological or educational support is provided by the public sector. After an initial period of disorientation, many parents eventually might find their ways to NGO's that provide support services or parent peer counselling.

Early Childhood Intervention (ECI) services are increasingly available for families across the country, but they still need to be further developed [Kukuruza, Bloemkolk]. ECI has governmental recognition and a working group of experts is working on further service development. ECI is addressed by the MSP, supported by a working group of experts.

Severely disabled children will receive education at home. They will follow a programme that is determined by a (mostly special) school, but the teachers will go to their homes [Ishchenko].

Conclusions

Ukrainian society is moving towards a more person-centred inclusive approach in addressing the challenges related to disability, although negative attitudes and stigma are still widely present in society. Parent associations and NGOs, together with the government, are drivers of change. The level of institutionalisation of children with disabilities remains high, although increasingly families decide to raise their children in the family, notwithstanding the general lack of orientation, guidance and support services.

2.2.2. Policy

Under the section Policy the framework seeks to investigate general and specific relevant legislation and policy in education, assistive technology, AAC and other relevant domains, as well as funding made available to support the implementation.

Findings

General

Ensuring the equality and free development of the personality of citizens with disabilities, meeting their natural, political, social and other needs is determined by:

-the Constitution of Ukraine (June 28, 1996);
-the UN Convention on the Rights of Persons with Disabilities (ratified by Ukraine on December 16, 2009),
-the European social charter (ratified by Ukraine on September 14, 2006).

Further by the following Laws of Ukraine:

-"On the Basics of Social Protection of Persons with Disabilities in Ukraine" (March 21, 1991);
-"On the Rehabilitation of Persons with Disabilities in Ukraine" (October 6, 2005);
-"On the Principles of Prevention and Counteraction of Discrimination in Ukraine" (September 6, 2012);
-"On Education" (September 5, 2017);
-"On rehabilitation in health care" (December 3, 2020)
and other current laws and by-laws, in particular the National Strategy for the Creation of a Barrier-Free Space in Ukraine for the Period Until 2030 year (approved by the order of the Cabinet of Ministers of Ukraine dated April 14, 2021).

An Action Plan is in place to implement the recommendations of the UN Committee on the Rights of Persons with Disabilities after reading the first report of Ukraine on the implementation of the UN Convention on the Rights of Persons with Disabilities until 2025. Fostering accessibility is among the key recommendations that require action (Cabinet of Ministers of Ukraine, 2021).

Health and social care

The MSP is the central executive body that ensures the formation of State policy in the field of protection of the rights of persons with disabilities. The MSP's role in rehabilitation includes, but is not limited to: assistive technology (procurement, product, policy and provision), rehabilitation centres for persons with disabilities (including children); and early identification/early intervention for children needing rehabilitation or social services. The existing system of "Medical and Social Examination" enacts the determination of the official status of a "person with invalidity" through the Medical and Social Examination Commissions (MSEC). It is followed by the provision of social support (e.g. pension and other types of social payments), assistive devices and aids, and different "types of rehabilitation" (from the list of 8 types: medical, medico-social, social, psychological-pedagogical, physical, professional, labour, rehabilitation by physical culture and sports).

In a recent report Golyk and colleagues describe the advancement of rehabilitation in Ukraine. They also looked into the situation of persons with disabilities and wrote that *"When referring to a MSEC a person has a number of medical records after the medical service provision. These records traditionally contain almost no information on functioning/disability according to the ICF. MSECs assess functioning of the person using the old framework of the International Classification of Impairments, Disabilities and Handicaps (ICIDH) and classifies them into 1 of 3 "groups of invalidity". The bio-psycho-social approach is not used for the assessment at all. Therefore, personal functioning needs are not effectively addressed."* (Golyk et al, 2021).

Since 2017, Ukraine has been conducting the healthcare reform "money follows the patient", and, in 2018, the National Health Service of Ukraine (NHSU) was created. Since 1 April 2020 the implementation of the Program of Medical Guarantees (PMG) has led to the reform of secondary and tertiary healthcare levels. The PMG includes 3 packages of programmes for medical rehabilitation, including for children from 0 to 3 years old, and for persons with neurological and musculoskeletal conditions. The National Health System dashboard also states that 211 healthcare facilities (207 municipal, 4 private) were contracted for neurorehabilitation, 222 (218 municipal, 4 private) for rehabilitation in musculoskeletal conditions, and 63 (all municipal) for rehabilitation in the developmental age. Rehabilitation packages included minimum requirements for such services, listed necessary staff, the basic set of equipment, and a statement of necessity for a multidisciplinary rehabilitation team, goal-setting principles, and use of the ICF. (Golyk et al, 2021).

Official steps toward changes in basic rehabilitation legislation have been enacted. On 3 December 2020 the Ukrainian parliament adopted the Law of Ukraine "About rehabilitation in healthcare". After implementation of its provisions via a set of regulatory documents Ukraine will be able to:

- provide rehabilitation services at all healthcare levels during all rehabilitation phases;
- implement multidisciplinary rehabilitation under the leadership of PRM physicians at healthcare facilities;
- start a system-wide ICF implementation upon completing WHO approval of ICF translation into Ukrainian;
- use the unified official document for rehabilitation in healthcare "Individual rehabilitation plan", based on the ICF model and including all components of the rehabilitation cycle;
- use licensing for "Medical practice with the possibility of providing rehabilitation in healthcare", based on a bio-psycho-social platform, in contrast to the existing traditional and "Medical practice" only based on the bio-medical platform. (Golyk et. al., 2021)

Education

Horishna and colleagues (2020) describe the trends in inclusive education in Ukraine. They describe how the introduction of an inclusive approach to the mainstream school began in the 90s of the last century, after the ratification of the Declaration on the Rights of the Child by the Supreme Court of Ukraine in 1991, but efforts to progress on the way of inclusive education were incidental and not systematic. An important step for the legal regulation of inclusive education was the adoption of the Procedure for organizing inclusive education in general education institutions in 2011[5] and the law "On Education" in 2017[6]. (Horishna et al., 2020)

In Ukraine, a multi-track model is applied in Education. Opportunities to get an education for children with disabilities are provided by special and inclusive classes in primary and secondary schools, special schools, and individual forms of education, delivered at home. Based on data from the Ministry of Education and Science (MES) Horishna reports that the number of children with disabilities in special classes in regular education rose between 2016 and 2019, while the number of children in special educational institutes decreased. (Horishna et al., 2020)

According to the decision of the Cabinet of Ministers of Ukraine[7] since the 1st of September 2017, the recruitment of students with mental retardation in the first grades of special schools has been discontinued and educational opportunities for these children should be created in special and inclusive classes in mainstream schools. As a policy objective the document also stipulates that by 2022, all students in special schools will go to regular schools, thus gaining equal access to

[5] Resolution of the Cabinet of Ministers of Ukraine of August 15, 2011 No. 872 On Approving the Procedure for Organizing Inclusive Education in General Educational Institutions.
[6] Law of Ukraine on education No. 2145–VIII of September 5, 2017.
[7] Pro vnesennia zmin do postanovy Kabinetu Ministriv Ukrainy vid 23 kvitnia 2003 r. No 585 (2016)

education, which will contribute to their successful development and socialization. It is unclear to what extent this objective has been reached.

Also according to Martynchuk and colleagues (2021) Ukraine strives to give the opportunity to all students to attend ordinary schools. Nonetheless, the educational culture is somehow slowly moving towards inclusion, and a great number of students with SEN are still placed in special schools, educational rehabilitation centres and full-time segregated classes while getting individual (home-based) forms of education. According to this group of researchers, inclusion policies have been in place since 2001 in Ukraine, and currently, the country is pursuing large-scale education reforms aimed at achieving the 'New Ukrainian School', which will embody a more inclusive ideology and acceptance of diversity. Although, according to the researchers, there is a high consciousness regarding the acceptance of inclusive values, paradoxically, the country still does not provide sufficient implementation of inclusive practices. Studies have shown that this gap is linked to insufficient conceptualisation of inclusion and inclusive education, which has complicated attempts to reach a consensus regarding the implementation of inclusive practices. According to the authors the conceptualisation of inclusion, inclusive education and students with SEN is vague, confusing and contradictory with little evolution in legislative documents over the last decades. Further, effective mechanisms for implementing inclusive education were not developed. The main reasons behind these tensions stem from the fact that Ukraine's specific history, political and cultural positions lie in its legacy dating back to the Soviet Era, which was characterised by deeply rooted systems of diagnosis, categorisation and correction. (Martynchuk et. al, 2021)

Inclusive Resource Centres

The Law "On Education" and its Action plan introduced some important reforms, among which the reform of the psychological, medical and pedagogical consultation (PMPC) teams in inclusive resource centres (IRC). *"Until September 2018, the needs of all students with SEN were assessed by the PMPC teams. Specialists examined students at different stages of their lives and issued a conclusion and recommendations regarding the programme and forms for education. Starting in September 2018, the PMPC was reorganised into the IRC's. The main tasks of the IRC are to provide a complex psychological—pedagogical assessment of students' needs and to give them systematic professional support within an inclusive educational environment (CMU, 2017). Based on the assessment, the IRC and the parents decide which programme and forms of education are appropriate for a student."* (Martynchuk et. al, 2021)

Inclusive Resource Centres are being established at the community level. They provide a comprehensive psychological and pedagogical assessment of child development, psychological and pedagogical support to the learning process, psychological and pedagogical, correctional and developmental services to children with SEN aged 2 to 18 years. At the beginning of 2019, there were more than 500 such institutions in the country. (Horishna, 2020)

An important factor to consider is the level of decentralisation which is in place since 2014. The basic level of local government bodies is represented by the amalgamated territorial communities (ATC), which are responsible for creating conditions for providing quality educational services and improving the quality of education of children living and studying in a certain geographical area. In 2018 there were 725 of such ATC's. They are responsible for the creation of educational districts and educational institutions, including classes and groups with inclusive education, ensuring the rights and opportunities of persons with SEN for their education, taking into account their individual needs, capabilities, and interests (provision the means for training, development of an inclusive environment, implementation of universal design and reasonable adaptation); organizing the provision of educational, psychological, and correctional services (creation of inclusive resource centers, their staffing). (Horishna, 2020)

Early Intervention

The development of Early Intervention is expected to receive a significant boost from the approval of the Action Plan for the implementation of the "Concept of creation and development of the early intervention system for the period up to 2026" by the Cabinet of Ministers of Ukraine of September 15, 2021 No 1117-r. The Action Plan was developed following a concept note of the Cabinet of Ministers of May 26th, 2021. The Concept note is entitled "Concept of creation and development of system of early intervention" and it states that *"Implementation of the early intervention system at the national and local levels requires the development of a single integrated concept of early intervention system, which combines medical, psychological, social and educational components, aimed at early detection and prevention of developmental disorders in children, improving their development, improving quality of life, support and support for families with children under the age of four who have developmental disabilities or who are at risk of such disorders."*

The resulting action plan, approved three months later, foresees the development of early intervention centres across the country with well trained and equipped staff, able to provide support and to guide interventions. The following commitments are extracted from the Action Plan:

"Ensuring the establishment of centers (services, offices) of early intervention on the basis of the existing network of institutions, taking into account the needs and financial capabilities of the relevant administrative-territorial unit. (Event 23 and end-goal)".

Event number 14 reads: *"Introduction at the local level of programs aimed at raising awareness of families with children with developmental disabilities or at risk of such violations, on the functioning of the network of institutions, organizations, enterprises that provide early intervention, in order to reduce institutionalization of young children and disability of children."*

Event number 18 reads: *"Development of training programs for specialists in child care and its optimal development, in particular on the organization of the developmental environment, the use of special tools for child development and providing the necessary communication."*

A National Council for Early Childhood Intervention exists, under the leadership of the vice-prime minister. The MSP coordinates while the Ministry of Health (MH) and MES collaborate. NGO's and expert centres are represented in the council as well.

Currently work is going on in the drafting of a new law and supporting documents for the regulation and financing of ECI interventions in the whole country [Kukuruza].

AAC

Quite recently, on September 9, 2022, the MES has published "Methodological recommendations for the use of alternative and augmentative communication methods in educational institutions."[8] The document was prepared by a working group of academics, experts from the Ministry and experts from NGO's united in the AAC Community. The guidelines address different aspects of AAC implementation: it defines AAC, it reports on international research -*"The use of AAC tools does not prevent the development of verbal communication, but on the contrary, it stimulates one's own verbalizations*-, it discusses issues related to the assessment of needs-" *The assessment of the child's needs in the ADC is carried out by specialists in education, medicine or the social sphere who have undergone appropriate training"*- and implementation pathways based on a variety of cases. The document was widely distributed by the Ministry according to their official channels (e.g. the heads of the regional departments of education and science administrations).

[8] https://mon.gov.ua/storage/app/media/inkluzyvne-navchannya/2022/09/14/List-4.2373-22-09.09.2022-Pro.metod.rekom.14.09.2022.pdf

When it comes to the role of educational institutions the document recommends that the needs assessment should involve specialists that can come from different professional backgrounds but that should be able to assess different aspects. All information about AAC tools, the method of their introduction, the teaching and education with the support of AAC, etc. must be recorded in the child's personal record by the relevant specialist (speech therapist, psychologist or special needs teacher. *"Pedagogical workers must take the recommendations of the support team specialists into account, who can determine the type of AAC and provide recommendations regarding its introduction, further communication of the child, etc. All teachers of an educational institution should contribute to the communicative and speech development of a child that does not have developed oral speech. Also, they should use the AAC tools in their work in the form in which they were assigned by the specialist of the team of psychological and pedagogical support (speech therapist, psychologist, correctional teacher). All members of the team of psychological and pedagogical support must work on the development of communicative and speech development of a child who needs AAC in the same direction and move gradually and together."* Being so new it is not possible to assess the impact of these recommendations, but it is definitely a great step in the right direction.

A group of experts that has formed an AAC Community Round Table has recently published a resolution with the aim to support the development of a national AAC system. The resolution lists the challenges for developing such a national AAC system and calls for actions. The challenges identified relate to the lack of information and awareness, the lack of service delivery systems and actors, the lack of strategies to provide the tools, the lack of training and competences. The resolution proposes to study the best international and national practices for the introduction of a system of AAC at the national level involving higher educational institutions, public organizations, experts. Further to implement a study into the needs for AAC, involving the MH, the MES and the MSP as well as commissioners of the President of Ukraine. Further to determine a public list of service providers that can implement AAC. Finally the resolution calls upon the listed Ministries to consider providing potential users of AAC with the technical means.[9]

Conclusions

In all areas of public policy that are relevant for children with disabilities there are significant steps made over the last years, in particular in inclusive education and early intervention. New structures and intervention models are developed or under development. Nevertheless the situation on the field remains behind. Action plans should focus on creating a culture of inclusion, providing temporarily workable strategies and tools for those that need to implement inclusive policies. Obviously the Government and its Ministries have a major role to play. Fortunately there is concertation with the third sector in place, which is a resource for driving change, as there are significant experiences and organisations with competence already working in the field. Although there seems to be an organic system-thinking approach in place, a unique piece of legislation ordering and organising child and family focussed services from a holistic and long term perspective that includes access to AT and AAC, is missing.

2.2.3. Products

Under the section Products the framework seeks to investigate the availability of AT and AAC products in the country, including an analysis of sales channels, after sales services and the approach to products.

[9] https://aac.org.ua/ukrainian-aac-system/

Findings

Due to time constraints it has not been possible to fully explore this section of the framework. The information provided is based on what is reported by the informants and some data collected randomly.

Overall the impression is that the market for digital AT and AAC is not very much developed, mainly due to the lack of demand (which is not the same as a lack of potential need), also due to the lack of systematic procurement of AAC products by the government. Like in other countries, low demand makes it difficult for international digital AT and AAC software and hardware producers to penetrate markets with low demand in addition to language requirements.

The localisation of products and services as well as the setting up of sales networks and after sales support are expensive investments that require significant sales perspectives before companies will decide to undertake them.

Major international companies are therefore not present in the country and do not provide local support services.

Some companies are active on the market of products for inclusive education, such as Vema Kids, specialised in inclusive furniture.

Accessible books are produced by DyvoGra that has a significant catalogue and also produces symbol sets.

For non-digital assistive products the situation is slightly different. There are AT providing companies, many of them with local production, that appear on the list of accredited vendors of the MSP, but they deliver the assistive products as identified by the ministerial list (mainly solutions for mobility and daily living).

As the WHO 2022 AT assessment report writes: *"All assistive products provided by the Ministry of Social Policy and their price margins are listed in Ministry Order No. 1208 of 2019. The list is modelled on ISO:9999 and products are organized in a hierarchy: classes, subclasses, product variations/divisions. Under product variations, manufacturer's models are also listed. A wide variety of mobility and self-care products are available, but only five products for people with sensory or cognitive impairments, namely: voice recorders, mechanical or electronic watches, mobile phones and white canes. [..] Users reported having difficulties finding certain products, such as wheelchairs with postural support for older children, active wheelchairs for children and prosthetic components for children. The only multifunctional wheelchairs on the catalogue are postural support strollers for young children – there are no wheelchairs with postural support for older children. Many wheelchair models come in only one or two sizes, or come only in sizes too large for the average person, making it more difficult for persons with smaller body frames to find well-fitting products."*

As a result of the analysis, the report recommends to: "*Expand provision of high-quality assistive products for all functional domains: develop an Assistive Products List to include all domains of assistive products, including products for vision, hearing communication and cognition.*" (WHO Regional Office for Europe, 2021)

The MES also has a list of assistive products considered *"special means of correction of psychophysical development"* of persons with special educational needs in educational institutions. The list is from 2018, it holds a large amount of assistive products ranging to hard and software for pc's and for different types of disabilities, multimedia equipment, toys and solutions for gaming, assistive products for positioning and workstation creation, learning aids, etc.. The list is currently under revision.

Conclusions

The market for digital AT and AAC products and tools for learning and communication is not very well developed, largely due to the lack of demand, which, as highlighted, is not an indicator for a lack of need. Barriers include awareness about their existence, the competences to choose and use them effectively, the absence of applications in Ukrainian language. However, there are initiatives in the country that could boost the demand, although the choice of appropriate technologies for the individual learner should not be left entirely in the hands of commercial players.

2.2.4. Provision

Under the section Provision the framework seeks to investigate the existing models of provision of AT. It specifically looks into aspects of provision such as the responsibilities, the needs determination, decision making and funding, as well as outcomes measurement.

Findings

Access to Assistive products is well described in the WHO report *A situation assessment of assistive technology in Ukraine* (2022). The main player is the MSP who provides Assistive Products based on a list and following the certification of a disability by a MSEC, who also provides indications regarding the types of assistive products. The MSP provides eligible users with a list of accredited suppliers that can deliver the products. The user is free to choose a supplier. The process is practically similar in case of children, with the difference that the Commission is a Medical Advisory Commission. Other access channels to Assistive Products are through the MH and the MES, each with a different procedure. For a list of what is supplied by which Ministry see the table reproduced below:

Disability group	Ministry and provider	Categories of assistive product provided
1. Musculoskeletal and neurological disorders	Ministry of Social Policy: social protection bodies, prosthetics and orthotics service centres Ministry of Health: health-care facilities Ministry of Education and Science: educational institutions of all types Ministry of Youth and Sports: bodies for youth and sports	Prostheses, orthoses, orthopaedic shoes, walking aids, self-care products, wheelchairs Absorbent incontinence products, hand-held urinals Adapted furniture, computer programs for learning Special sports equipment
2. Intellectual and mental disabilities	Ministry of Social Policy: social protection bodies, prosthetics and orthotics service centres Ministry of Youth and Sports: bodies for youth and sports	Mobile phones (with SOS button) Special sports equipment
3. Hearing impairments	Ministry of Social Policy: social protection bodies, prosthetics and orthotics service centres Ministry of Health: health-care facilities Ministry of Education and Science: educational institutions of all types Ministry of Youth and Sports: bodies for youth and sports	Mobile phones Hearing aids Computer programs for learning, special textbooks Special sports equipment

Disability group	Ministry and provider	Categories of assistive product provided
4. Visual impairments	Ministry of Social Policy: social protection bodies, prosthetics and orthotics service centres Ministry of Health: health-care facilities Ministry of Education and Science: educational institutions of all types Bodies for youth and sports	White canes, audio players, voice recorders, talking/touching watches, electronic and portable magnifiers Spectacles, thermometers/ glucometers with speech output Special purpose furniture, computer programs for learning, special textbooks Special sports equipment
5. Disabilities of internal organs	Ministry of Social Policy: social protection bodies, prosthetics and orthotics service centres Ministry of Health: health-care facilities	Prostheses, orthoses, orthopaedic shoes, walking aids, self-care products, wheelchairs Absorbent incontinence products, hand-held urinals
6. Disabilities caused by cancer	Ministry of Social Policy: social protection bodies, prosthetics and orthotics service centres Ministry of Health: health-care facilities	Prostheses, orthoses, orthopaedic shoes, walking aids, self-care products, wheelchairs Absorbent incontinence products, hand-held urinals

Source: WHO, 2022 (table 1 on page 5 and 6)

The report highlights a number of core problems related to the way provision is currently organised and which can be summarised as: fragmentation in procedures, products and provision:

-Complexity and fragmentation of procedures, which make it difficult for the citizen to find his/her way and cover all needs.

"For example, a child with cerebral palsy who needs a wheelchair, continence products and communication software for studying will have to register with three different ministries and follow a separate procedure to obtain each product."

-Each Ministry has its own lists of assistive products that can be provided, which is a challenge as most products do not belong to a single area of life.

"For example, people have access to important devices such as digital magnifiers, keyboard and mouse emulation software and communication software only through educational facilities; however, these products are also needed in other areas of life, such as employment and recreation."

-The channels through which assistive products are provided differs from Ministry to Ministry. People have to attend different appointments at different locations to obtain the products they need. This also results in duplication of services and an inefficient use of resources. (WHO, 2022)

In addition, the classifications used to list assistive products are not homogeneous across the different Ministries, for example the ISO classification is used by the MSP, but not by the MES.

Ministry of Education and Science procedure: children with special educational needs have access to assistive technology delivered by the MES in the context of inclusive education. The student undergoes an assessment at one of the 635 Inclusive Resource Centres where an individual

education plan will be developed that will specify the assistive product the student needs. It is then the responsibility of the school or educational facility to purchase the required devices. After procurement, the assistive product becomes property of the school and the child has access to the device only when attending school. The Inclusive Resource Centres are staffed with psychologists, logopeds, rehabilitation experts, nurses (the one in Lviv) and other special education teachers who will support the implementation of the inclusive education programme, including support with fitting and using assistive technology. (WHO, 2022).

According to one of the informants of this report, the legislation is ahead of the real situation. "*There is a lack of clear procedures. The school, for example, can only order equipment for the full class, not individual assistive products for the learner with disabilities. Only equipment for the entire class. Parents have to procure the specific AT for their child. The school will recommend, and parents need to find a way to buy it. The Ministry of Social Policy will therefore need to revise the list to include more assistive products and AAC for children in various areas of need.*"

Conclusions

AT provision in Ukraine at the moment is fragmented and not person-centred, or "life-project"-centred. The main players are the MSP and the MES that provide assistive products and solutions for inclusive learning. This fragmentation risks to lead to inefficiencies and inadequate public expenditure if needs are not assessed professionally and according to international good practice. A provision system should be put in place that values the role multidisciplinary teams composed of professionals with a technical, education and health related background that can advise the different actors in the care, education and support ecosystem about the role that technology can play for the development of the child and for its future.

2.2.5. Personnel

Under the section Personnel the framework seeks to investigate the human resources available to support AT deployment, the different actors and their roles and professional preparation and training needs.

Findings

The WHO report "Situation assessment of rehabilitation in Ukraine" published in 2021 provides an overview of the existence of professional roles in Ukraine in the field of rehabilitation. It concludes that:

"There is a lack of comprehensive, consolidated and up-to-date information on numbers and locations of the rehabilitation workforce working in Ukraine."

Three rehabilitation workforce professions are formally recognized (physical and rehabilitation medicine specialist, physical therapist, occupational therapist) and these professions have received authorization to work in health facilities. Since 2019, master's programmes in physical and occupational therapy have been recognized, although no standard curriculum existed at that time. On September 5, 2022, the Ministry of Education and Science in Ukraine passed legislation creating a standard of education at the master's level for the education of physical and occupational therapists. Graduates are called physical therapists and ergotherapists (occupational therapists). A State qualifying examination is in place for graduates of these master's programmes. December 7, 2021 the first state qualifying exam was conducted.

When it comes to speech and language therapists the situation is described as such:

"The profession of speech and language therapist does not exist in Ukraine, but logoped (special educator) does exist. Logopeds may practise within the education system (focusing on children to

develop their speech and articulation) and some of them work in health care institutions. Within the education system, there are 1355 logoped offices in kindergartens and primary schools – in each office there is at least one logoped. In addition, there are 635 inclusive resource centres; it is estimated that over 50% employ logopeds. Within the master's programme for special education, most focus on development of speech and articulation for children. The programme does not include a wide range of communication disorders; courses on swallowing dysfunction are completely absent.

Other than a few speech and language therapists who have received training outside Ukraine, there is no speech and language therapist with the capacity to work in a clinical setting; this work is covered by logopeds with training for special education and development of speech and articulation. Logopedy does not exist in health care and no formal training programme for logopeds exists outside special education. There is no consistent understanding of the profession of speech and language therapist or why it is needed for children and adults. Currently, the Ministry of Health is working on the introduction of the profession of speech and language therapist and a new educational specialty, cognitive and communicative therapy." (WHO, 2021)

Analysis by Horishna and colleagues on existing research into teacher education for inclusion and the attitude of different population groups to inclusion in education shows that teachers are not ready to work in inclusive classes due to the lack of appropriate training in the presence of a less than positive attitude to inclusive education, a lack of understanding of its essence and role, both for children with SEN and for the whole society. (Horishna, 2020)

According to Skrypnyk et al. (2020), research shows that teachers of children with special needs do not collaborate sufficiently around the goals of a child with special needs while they use different procedures, methods and means for supporting the child and do not find the correct balance between education and rehabilitation services. Also the absence of monitoring is mentioned as an issue. Building capacity in team working is recommended by this study as well as the co-design of a Case Development Plan. Conditions for success are, according to the study, the presence of a team coordinator and the direct involvement of parents as equal participants in the child's educational process, which should be implemented in a variety of ways: *"in discussing the educational plan, the content and scope of interventions, decision-makings, synchronous development of SMART-goals at home, the initiation of a communication diary, monitoring."* The study further demonstrates that better cooperation can contribute to improving the learning and development of students with SEN as well as the climate in the classroom. (Skrypnyk et al. 2020)

Budnyk et all (2022) report on the difficulties that rural schools have to implement inclusive education. A major issue is the lack of qualified teachers and school assistants, due to the fact that there are better career opportunities in the cities. Rural schools experience a shortage of teacher's assistants, a pedagogical profession that was introduced in Ukraine in 2012. Often a mother of a child with a disability assumes the role of the child's assistant. According to the researchers the quality of inclusive education is largely determined by psychological aspects, namely attitudes towards students with SEN by teachers and peers, reason why they consider this area *"to be one of the priorities in forming a new philosophy of inclusion, celebrating diversity and co-creation in inclusive learning environment of rural schools."* (Budnyk et. all, 2022)

In the area of ECI over the last years an increasing number of regional and local teams were established. Their composition is typically multidisciplinary, involving professionals with a background in psychology, physiotherapy, speech and language therapy or logopaedy, medicine (doctors, defectologists) and social work. Many training programmes have been set up to develop competences in ECI. The expected new law on ECI should also provide indications about the professionals involved and their responsibilities and competences.

Regarding the competences of teachers the recently launched recommendations for the use of AAC in education recommends that *"Every pedagogical worker who is faced with the education or upbringing of a child who needs SEN has the right to receive qualified assistance from the support team and the opportunity to undergo special training if necessary. Monitoring of acquired and established knowledge, abilities and skills should be carried out once every three months in preschool education institutions and once per semester in general secondary education institutions. The results of monitoring must be recorded in the individual record of a child with SEN."*

Conclusions

At this stage there is not a clear picture of who should support the AT or AAC adoption of children with disabilities. Most relevant professionals have not received specific training on this and as a consequence are not professionally prepared to conduct AT needs assessments or to implement AT adoption pathways. Learning opportunities in AT and AAC are not delivered systemically yet.

3. Impact of the war

The Russian invasion of Ukraine has a huge impact on the situation of children with disabilities and on the work that was ongoing to support them. Many children live abroad in host countries. Unfortunately, many children with more complex needs living in institutes are at risk of being left behind as a report of Disability Rights International of May 2022 denounces. The report goes beyond the situation created by the war and reveals the terrible situation of children with disabilities in orphanages or institutes. The report also includes recommendations for the government. (Disability Rights International, 2022)

Anna Kukuruza of the Early Childhood Intervention Centre in Kharkiv describes in an interview I had with her how the war has impacted on the way of working and on the way ECI teams are organised. Many services moved online, which was facilitated by the experience that was developed during the COVID period. The work of regional or local ECI teams was interrupted because many colleagues went abroad or to other parts of the country and it was no longer possible to meet physically. Also many professionals due to their displacement had to look for other jobs to gain a living. But ongoing support to the families was needed as daily routines and activities of daily living have changed. Teams of experts now are formed based on their expertise, more than on their physical vicinity. According to Anna this might lead to better knowledge exchange and new forms of services also after the war.

Also, Valentyna Ishchenko of the "See with the Heart" Association has similar experiences. The Association she belongs to moved many activities online, supporting children and families in the diaspora with online classes, psychological support and counselling to parents. The connection with existing services in the country is only slowly to develop. Partially because many families aim at returning to Ukraine as soon as possible.

In a recent presentation at the 4th International Conference on Augmentative and Alternative communication[10] (11-13 November 2022) Oksana Kryvonogova of the Odessa Regional Methodic Center of Early Intervention and Hanna Usatenko from DyvoGra spoke about the impact of the war on the development of AAC. Notwithstanding the dramatic impact of the war they highlighted the evidence gathered on the importance of AAC for reaching, connecting and including people in humanitarian crises (e.g. emergency situations, evacuations, life in shelters, adapting to daily routine in war time or welcoming countries, adaptation to new environments, challenges in situations of language variety, new vocabulary etc.).

Within Ukraine itself, the barriers to school attendance related to the war are many.

As of October 2022, as per information from the Ministry of Education and Science, over 330 schools were fully destroyed and 2,400 more were damaged.[11] Further, the number of pupils or students that attend their institutions on a daily basis is determined by the capacity of the shelters. Using missiles and kamikaze drones, Russia has intensified attacks on Ukrainian energy infrastructure, causing regular blackouts across the country. This situation caused additional challenges for schools to organize the educational process which is interrupted by frequent air alarms, power outages and problems with heating.

It is not difficult to imagine the difficulties that families with children with disabilities meet in these specific circumstances. Luckily many have found a safe place in neighbouring countries, and are supported in their primary needs, but the impact of the disruption brought by the war on the development of the children is not clear. Also the access to AT and AAC resources in the countries that have welcomed the refugee families is not clear yet and it would be important to map those needs and to identify solutions soon.

[10] https://en.aac2022.assistfoundation.eu/
[11] https://saveschools.in.ua/en/

4. Discussion

The most important concept for understanding and fostering access to AT, and why this is so important, is that we are discussing a human right. There are several policy frameworks stooled on international conventions that affirm that access to AT is a human rights issue. Also there are many publications, policy papers and initiatives that highlight the need for a paradigm shift from the medical model of AT provision to the social or human rights based model. For most countries this is not an easy process as many opinions regarding disability are informed by stereotypes and prejudice. Changing processes and organisational models in society that are based on these values is a long process, also because some of them are based on well-meant care or caritative approaches (alleviate suffering) more than on emancipatory approaches.

Changing systems might require the allocation of resources which might not all, or immediately, be available. How to use the available resources is a relevant dilemma for policymakers, as the needs are many. More than the amount of resources, relevant in this context is their efficient spending, going in the right direction and ensuring progressive realization of rights of children with disabilities. This means having the right medium- and long-term vision, continuous commitment and the ability to plan and implement a step by step approach.

What this report argues is that a lot of progress can be made with low cost policies and solutions, although some money will have to be made available to boost access to AT for all children. In this context it is important to remember that investing in the autonomy of children with disabilities in the long term leads to important benefits in terms of more independence and a reduced needs of care, more inclusive and sustainable societies.

It is important to understand that fostering access to AT is like planting seeds that need fertile ground and that can only grow when the national, local, family and individual culture are open to the idea that it is worth investing in children with disabilities and in their independence and participation. This is not obvious as in many countries, as argued before, the transition from a medical model to approach disability to a social or rights-based model is far from being computed, including in the countries that consider themselves ahead of others in this regard.

There are many other barriers that need to be addressed in order to be successful in boosting appropriate AT and AAC use- please note the choice for the word "use" and not "provision" - and that require investigation, analysis, intervention. Examples are the lack of competencies and skills, the lack of assessment strategies and service delivery models, the lack of funding, the lack of infrastructure or inappropriate infrastructure, etc.

It is finally important that AT and AAC are not seen as a separate isolated field of intervention, but transversally part of any intervention to support the development of children with disabilities and their autonomy. AT, by its enabling role, affects all policy areas such as Early Childhood Intervention, Inclusive education, Vocational training, Social integration, Welfare, Sports, etc. Building AT and AAC capacity is for that reason relevant for different professionals in different sectors, of course each with an appropriate level of competencies needed to support the Ukrainian children in reaching their specific full potential in all areas of activity and participation. It is not necessary that all professionals become AT experts. Appropriate levels of competencies range between awareness of key concepts, sufficient to "do no harm", to being able to overview together with colleagues all factors that need to be taken into account to make appropriate selections on tools and strategies and how to use and evaluate them.

At policy level, in Ukraine, there is an increasing support for inclusive quality education for children with disabilities, recognising the importance of inclusion in mainstream settings and person centred approaches. Legislation and action plans have been developed on early childhood intervention, on inclusive education and more recently guidelines on AAC have been published. The inclusive education model has thus made progress, but is not completed yet due to many barriers comprehensively listed by Horishna et al.:

"Difficulties in implementation of inclusive approach in education are associated with the lack of a common understanding of inclusive education, the imperfection of the regulatory framework, the institutional weakness of the newly established amalgamated territorial communities which are responsible for the introduction of inclusive approach at the local level, the uncoordinated efforts of state and local governments, poor material and technical resources of educational institutions, lack of qualified teachers prepared to work with children in conditions of inclusive education." (Horishna et al., 2020)

In other words, the situation on the ground is remaining behind and many schools are not prepared to support learners with disabilities in an appropriate way. Special classes in mainstream public schools are the result, while for a significant part of the children special education in schools or institutes remain the norm.

The Inclusive Resource Centres are definitely an already existing opportunity to boost inclusive education and the fact that they work with multi-professional teams definitely put them in the right position for picking up a leadership role and drive the change. However, these teams need training and resources in order to be able to advise parents and school staff appropriately and to monitor inclusive pathways in schools. A more in-depth analysis of their training needs and service standards would be advisable. When it comes to AT and AAC they should have good knowledge on available technology-based solutions and strategies for their use, in order to be able to transfer this knowledge and the related skills to teaching professionals.

Further the classroom conditions should be assessed, as well as the available staff in schools and their preparation, in order to make inclusive education increasingly a reality. The presence of AT and AAC users in classrooms might require different space management, appositely prepared work stations, the need for wifi connections, beside more pedagogical challenges such as the attentive management of the relations and dynamics within the group, etc.

An important challenge is to put an AT service delivery system in place that is able to bridge the gap between the needs of the child and the available solutions, including the strategies of use. This requires a multidisciplinary or transdisciplinary assessment during which all factors that impact on the technology adoption should be taken into account, including the health and social condition of the child, his or her stage of development and expected development, needs, ambitions and talents, contextual and environmental resources, next steps, etc. Once that picture is clear, available solutions have to be identified. Locally produced or already adapted and low cost solutions should be privileged, as long as quality standards are met and the matching between the child, the context and the technology is optimal. Investing in services that can guarantee the most effective expenditure in AT provision does not only lead to cost savings, but also to reduce the risk of AT abandonment with related frustrations and a negative impact on self-perception.

The availability of a list of AT's and educational support for the inclusive classroom is an important resource for the country. The list should be regularly updated and schools that don't feel confident in choosing solutions should be supported by experts. In updating the list, experts of the Ministry of Education should take a leadership role and provide the information with relevant examples of use, tutorials and web based training sessions. In updating the list, which could also be updated dynamically, the community of experts and teachers should be consulted, for example by feedback forms or user forums.

Procurement from the side of the MES of specially designed assistive products could be based on small numbers, while for mainstream devices or more commonly used AT's larger amounts could be procured and held on stock.

Once updated the list of AT's that can be procured by the MES and delivered to schools, equipment should ideally be given in property to the students. In case AT cannot become property of the child, a kind of semi-permanent loan system could be considered where AT has to be returned to the school only if it is no longer used or appropriate for the student. It should incentivised that a child, if possible, takes its personal equipment with him or her when going home or in other life environments, and especially in the transition from one school to another.

Inclusive Resource Centres, especially those serving bigger territories or larger shifts of the population, could consider the development of a small demo centre with different and the most common AT and AAC solutions and a loan library for assistive technology supporting education. The presence in the team of an AT expert would be a prerequisite. The ongoing process of decentralisation of powers in education is a favourable condition to implement such centres. However, having such competence at IRC level is probably not enough to support the more complex cases. To address the needs of more severely disabled children and support their teachers, regional public AT centres should be developed, one stop "shops", where independent professional advice can be obtained and with budget availability to come to personalised solutions, including their procurement, customisation and some training in their use. Such centres should respond to service quality criteria and expenditure for equipment should be duly justified.

The network of ECI teams is an important resource for developing better AT and AAC services. Their role is fundamental in impacting on the way families perceive their children with disabilities and on the development of their autonomy, for example in the area of communication.

There seems to be a lot to do in terms of changing attitudes. Undoubtedly over the last 20 years a lot has been achieved in moving from a traditional "defectology" model leading to segregation and discrimination, to a more social and rights based model aiming at inclusion [Kukuruza]. But traditional ways of looking at disability are very hard to die and if these new views, much more respective of the individual and his or her rights, only slowly make their way, in society more should be done to speed up that process. New initiatives to highlight the impact of technology to the activity and participation of children with disabilities could be developed, using different communication means and formats. Especially the use of alternative communication as a valid communication channel should be highlighted and media organisations can play an important role.

Some observations have to be made about the role of NGO's and parents associations. Their role as advocates and early adopters has to be recognised, as well as the resulting competences in their possession. No government should ignore that amount of expertise. The role of the public authorities should be to support this expertise to further develop it into professional and sustainable services, funded also with public money. Accreditation systems of services could be put in place if not yet available, although there should be space for funding innovative initiatives of NGO's as well.

5. Recommendations

The following recommendations are relevant for the entire system of stakeholders in the country, including the Government, UNICEF, NGO's.

5.1 People

- The rights of children with disabilities to develop their full potential should be the guiding principle in the development, implementation and evaluation of policies and actions. Acknowledge the role of assistive technology as an enabling factor.
- Carefully analyse the impact of the war on families with children with disabilities and make sure that also their specific AT and AAC needs are catered for.
- Establish a national program of targeted support and guidance on the usage of AT for children in all stages of their development. Highlight the benefits for the users, their families and for the community.
- Include awareness raising through multiple channels including traditional and social media. Identify ambassadors and success stories to narrate the life changing impact of AT and AAC.
- Give high priority to the empowerment of parents, the real gatekeepers. Try to connect them to existing support services as early as possible. Offer early intervention programmes and support that include awareness on communication challenges and assistive solutions for all areas of development.
- Establish clear and consistent language and terminology to describe the needs of the children that is utilised across ministries and considered suitable by those with a disability.
- Implement usage of the ICF to underpin the evaluation process and identification of needs, especially when applied to AT/AAC.
- Establish a process to coordinate cases across sectors, settings and life stages. Especially where the child is transitioning from one context to another and through different life stages. Pretend that different professionals talk to each other and work together for the best interest of the child, if needed breaking through silo's.
- Involve associations of parents, persons with disabilities and other civil society organisations in the development of policy, pathways, services and wider solutions. Develop partnerships with them. Foster an approach that strengthens their initiatives and help them to critically evaluate their own achievements.

5.2 Policy

- Reiterate the public commitment of the government of Ukraine to implement the rights of all persons with disabilities as described in the UNCRPD.
- Establish a clear national AT policy that defines a coordinated approach to inclusion of AT/AAC on an "as needs basis" in all stages of a child's development, in all areas of participation and addressing all aspects of the delivery chain.

- Mainstream AT/AAC and its principles (e.g. enabling, participation and empowerment) in all policies relevant for educational and social inclusion of children and families with disabilities.
- Build a unique AT provision system for the rapid provision of high quality assistive products based on clear person-centred assessment strategies with recommendations and keep its delivery under the control of the Ministry of Social Policies and its local articulations.
- Guarantee within an AT delivery system professional and independent support for the assessment of more complex needs and the recommendations of personalised solutions taking into account the long-term perspective and development of the individual's needs and ambitions, as well as environmental factors and contextual resources.
- Investigate, within a framework of personalised approaches, the potential benefits of a model of procurement and storage of high-use, or high-demand assistive solutions, without neglecting provisions for less frequently required solutions.
- Co-produce together with all stakeholders a quality assurance framework for access to AT/AAC able to guarantee quality procedures and quality outcomes.
- Further support the development of Early Childhood Intervention in the country with an eye for assistive technology and alternative communication from a child developmental perspective.
- Increase the speed of implementation of the recommendations of the "Action Plan of measures to implement the recommendations set out in the concluding observations of the UN Committee on the Rights of Persons with Disabilities to the first report of Ukraine on the implementation of the UN Convention on the Rights of Persons with Disabilities until 2020", in particular recommendation 20. "Ensure accessibility of the school environment and educational institutions, materials and educational programs for children with disabilities".
- Empower the role of Inclusive Resource Centres through training, the development of quality standards and clear guidance of inclusive education strategies and tools. Connect them in a national network with shared resources and peer review mechanisms.
- Invest in capacity building actions identifying clear expectations and anticipated outcomes with allocated responsibilities, sufficient funding, expert resources and mechanisms to measure quality and progression.
- Establish and implement policy to introduce a process of escalation in the identification and provision of AT to facilitate low cost rapid first intervention.
- Ensure that AT and AAC policy supports and encourages the use of free and low-cost solutions including options integrated into consumer or educational technology and open-source enhancements.

5.3 Products

- Seek innovative approaches including grants and awards to support the development of new AT/AAC in Ukraine, including localising existing solutions and co-designing innovative solutions involving end users and professional users.
- Accompany the rising demand for AT/AAC solutions with creating favourable conditions for AT developing and selling companies to invest in Ukraine (e.g. tax exemptions, etc.).

- Incentivise national vendors to increase product range with associated local technical support and warranties.
- Clarify the role of national and international vendors and reduce any restrictions on importation and exportation.
- Build competence in the use of AT products across stakeholders.
- Make full use of open licences to maximise the impact of new technologies produced in Ukraine.

5.4 Provision

- Introduce incentives to increase the availability of assistive technology services from NGO's and build upon existing strengths of civil society organisations.
- Review the process of evaluation to fully integrate AT needs and recommendations into disability assessments and include in those assessments views of experts looking at the "whole life" experience of the child.
- Update and expand the National Lists of assistive technologies of all Ministries to increase the diversity of products to facilitate full range of options. Consider merging the provision systems into one delivered with the support of local assessment teams.
- Establish a process for addressing specific requests for forms of assistive technology that are not included in the National AT list for provision and that are equally important.
- Establish a transparent process for registering new products on the approved national lists of AT, with clear criteria for inclusion and frequent updates.
- To foster quicker adoption of solutions, provide indications to schools for model tablet/PC/phone with the most commonly used software solutions in line with current trends in AT (a kind of starters kit), without excluding other options.
- Encourage the growth of independent (non for profit) AT services across the delivery chain to expand community-based services and independent advice.
- Create a national system of AT centres according to a hub and spoke model.

5.5 Personnel

- Support the development of a national AT association for professionals and their institutes with links to other international organisations such as AAATE, GAATO and ISAAC.
- Include awareness and knowledge about AT and AAC in the training of professionals and the certification of their competences.
- Design and implement a program of professional development in Universal Design for Learning for all teachers in Ukraine and make this compulsory.
- Establish and recognise the profession of Speech and Language therapist, with appropriate initial education programmes and certification of competences.

- Develop and conduct a more in-depth analysis of the training needs and service standards of IRC.
- Develop teacher and therapist competencies in AT use within teaching and learning, as well as in other AT application areas.
- Insist on the inclusion of compulsory modules on AT and AAC in initial education courses of teachers and other professionals.
- Adapt AT/AAC modules for use in in-service training and continuing professional development.
- Identify and utilise open training units that permit translation including creative commons and Open Educational Resources.
- Seek and curate sources of support and information in both Ukrainian and other appropriate languages.
- Expand the role of regional specialist teams to build capacity in AT/AAC within schools.
- Establish a clear expectation that teachers will adopt a model of anticipation of needs in their planning of teaching and learning.
- Monitor and update all capacity building for impact and recognise best practices in Ukraine through publicly recognised awards for schools and individual teachers.
- Encourage and incentivize those teachers highlighted as offering best practice to act as mentors with a model of peer support.

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Web resources:
https://www.tobiidynavox.com/pages/ukraine-refugee-communication-resources

Annex 1. Relevant organisations

(source: their respective websites)

AAC in Ukraine

AAC in Ukraine is an association of professionals and users; experts in assistive technologies for communication. The aim of the community is to align with the best international practices for speech support. The team was formed in 2019 as a non-profit institution to advocate for people with speech impairments, to provide free access to education and information using alternative and augmentative communication (AAC). Several NGOs and private members belong to the community, which is coordinated by and closely related to the DyvoGra social enterprise.

In 2020 a project of social partnership with international business and state educational institutions was awarded with a Partnership for Sustainability Award in Ukraine. The name of the project was "Alternative and augmentative communication. Opportunities for therapy and social integration for people with autism spectrum disorder and speech impairments". As a result educational products with AAC and an online course for communicative partners were created. This free video course about AAC recorded within the initiative was viewed 20 000 times during just the 1st month.

In 2021 an app Digital Inclusion was created by DyvoGra with the support of Huawei Ukraine and using expertise of the Ministery of Education and Science of Ukraine as a sustainable result of this partnership. The communication tool is free for users and can be downloaded at dimobi.org.ua.

We use Ukrainian localized symbols created by DyvoGra Social Enterprise. We explore best AAC practices in Ukraine, share with colleagues and invite professionals from other countries to make lectures about AAC and assistance in communication for Ukrainian community. Since 2022 we`ve been providing courses in AAC online for users, relatives and professionals.

Contact: Hanna Usatenko, managing partner. partnership@aac.org.ua.

Association of Parents of Children with Autism

The charitable foundation "Association of Parents of Children with Autism" has existed since 2013, organized by parents. The mission of the Foundation is to help parents.

We believe that only strong and educated parents can become support for their children. From the first day, we have been engaged in informing society, organizing events that will unite parents. There are meetings with officials in the area of health protection, education, social protection with the goal of advocating autism problems in Ukraine.

Preparation and participation in holding parliamentary hearings in the Verkhovna Rada, work in the working groups of the Ministry of Health (MOH) and the Expert Council on Autism of the Ministry of Education and Science of Ukraine (MES). Cooperation with the Ministry of Education on providing access to education for children with autism through the organization of inclusive education. Cooperation with the Ministry of Social Policy to enable families to receive assistance and social services at their place of residence. Support for family services to avoid segregation of children. Organizing and holding events dedicated to the International Autism Awareness Month every year with the participation of representatives of the Ministry of Education and the Ministry of Health. Organization of events to inform about autism and epilepsy in cooperation with neurologists and psychiatrists, activities related to the organization of the system of assistance to children with autism, children with disabilities and special educational needs. Communication

with the media (interviews with newspapers, magazines, radio, participation in shows, programs). Organization of educational events, lectures, participation in conferences as speakers. Advising parents on the procedure for registering a disability, organizing an educational route, medical care, organizing education.

Providing recommendations to educational institutions. Support parents in conflict situations. Cooperation with public organizations and community assistance centers throughout Ukraine.

Link to Facebook page./

Currently, the organization is a partner of the international initiative "Autism Unity", whose mission is to help displaced Ukrainian families in Ukraine and Europe. https://autismunity.org/about-us

Child with Future. International non-governmental organization.

The goals of the children with autism support foundation "Child with future", which started its work in 2011, are:

- Providing comprehensive support and assistance to families with autistic children and protection of their rights.
- Raising public awareness and education about autism.
- Establishing sustainable and effective communication between all parties interested autism.
- Introduction and adaptation of the best international practices and experiences related on autism in Ukraine.
- Ukraine's entry into the TOP 10 autism-friendly countries.

The Foundation is well connected to the various Ministries. Since July, 2012 it is an active member of the Public Council under the Ministry of Health of Ukraine.During the years 2013-2014 it was a member of multi-disciplinary working groups on the development of medical and health care technology for the standardization of documents relating to "Autism".It is a part of the expert-advisory council on autism at the Ministry of Education and Science of Ukraine, a part of the working group on pre-school education of children with special needs at the Ministry of Education and Science of Ukraine.

Sources:

https://cwf.com.ua/en/ &

https://www.edf-feph.org/blog/interview-with-child-with-future-on-the-situation-of-children-with-autism-in-ukraine/

DyvoGra Social Enterprise

DyvoGra is a social enterprise, a team of 6 professionals in philology, publishing and special education. It provides solutions for speech and communication development: books, cards, games, posters and online solutions with pictograms that help children and adults with speech impairments of autism to speak and communicate.

Starting from 2015 DyvoGra team promotes assistive technologies in Ukraine and creates products for speech and communication development with own set of pictograms. Part of the profit

is aimed to create free posters with pictograms to raise a culture of assistive technologies in communities, families and educational institutions.

It declares its mission as to help people with speech impairments remove barriers in communication, to gain autonomy and stay connected with others. The products help to build communication "bridges" using alternative means: pictograms, gestures, digital solutions.

In 2016 DyvoGra made the first book in Ukrainian adapted with pictograms by translating the Snow White fairy tail made originally by Uovonero in Italian. In 2018-2020 the company produced books, cards and games with pictograms printed and online, as well as videos to promote assistive technologies in Ukraine. As a result of its social responsibility policy some materials in Ukrainian are free for download.

DyvoGra products make reading and education inclusive, accessible for people with speech impairments using alternative and augmentative communication.

In 2021 DyvoGra pictograms were included in a free app for communication "Digital Inclusion" In 2020 the team was awarded as a finalist of a Partnership for Sustainability awards. Research results about pictograms and signs usage are presented on national conferences and abroad, showing local expertise on an international level.

Contact: Hanna Usatenko, DyvoGra founder. hanna.usatenko@dyvogra.com

Dzherelo Children's Rehabilitation Centre

The Dzherelo Children's Rehabilitation Centre, a charitable organization in Lviv, Ukraine, was founded in 1993 by parents of the Nadiya Association together with volunteers from Canada. In 2008, the Lviv City government established the Lviv Municipal Rehabilitation Centre at Dzherelo. Over the last 22 years Dzherelo has provided services to over 5,000 children and youth with special needs. The Centre has become a model for the establishment of similar institutions in other cities of Ukraine. The facility was built and equipped according to European accessibility standards thanks to the generosity of international donors.

The Dzherelo Children's Rehabilitation Centre provides a comprehensive program of educational and rehabilitation services to children and youth with cerebral palsy, Down syndrome, autism spectrum disorder, attention deficit hyperactivity disorder, and other developmental disabilities.

Created as an alternative to the state-run institutions, or "internats", and operating as a charitable non-profit facility, the Centre is a pioneer and model in its field not only in the city of Lviv, but in all of Ukraine.

Dzherelo is helping to build an inclusive society that welcomes people with special needs, respects their dignity and rights, appreciates their unique gifts, and provides them with opportunities to realize their full potential.

Source : https://www.uuarc.org/our-programs/aid-to-orphans-orphanages/dzherelo-children-s-rehabilitation-centre/

PERSPECTIVA 21.3

PERSPECTIVA 21.3 is a charity organisation which represents the interests of people with intellectual disability. It provides conditions for a full and dignified life for people with Down Syndrome, autism and other intellectual disabilities. Perspectiva 21.3 reaches its mission by

providing support to people with intellectual disabilities to have meaningful day activities. For this purpose, it provides services of social and vocational training, with safe employment opportunities and teaching life skills for supported living.The work is supported by partners and donor organisations, local businesses, churches, and municipal authorities

Address: Brovary, Popovicha st, 8. 07403 Kyiv.

Source: https://perspectiva21-3.org/en/

See with the Heart Association (NGO)

The Association based in Kiev helps children with disabilities since 2014. Since the war started the Association has moved its services online to remain in contact with the families that moved to other parts of the country or to other countries in Europe. It organises special online classes for children over 12 and young adults with complex developmental disabilities. It further provides online support to families including psychological support. Also teachers are supported with professional expertise in order to improve their teaching to children with disabilities.



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