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Assistive technology provision: towards an international framework for assuring availability and accessibility of affordable high-quality assistive technology

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ABSTRACT

Purpose: This is a position paper describing the elements of an international framework for assistive technology provision that could guide the development of policies, systems and service delivery procedures across the world. It describes general requirements, quality criteria and possible approaches that may help to enhance the accessibility of affordable and high quality assistive technology solutions.

Materials and methods: The paper is based on the experience of the authors, an analysis of the existing literature and the inputs from many colleagues in the field of assistive technology provision. It includes the results of discussions of an earlier version of the paper during an international conference on the topic in August 2017.

Results and conclusion: The paper ends with the recommendation to develop an international standard for assistive technology provision. Such a standard can have a major impact on the accessibility of AT for people with disabilities. The paper outlines some the key elements to be included in a standard.

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► IMPLICATIONS FOR REHABILITATION

- Assistive technology is a key element in rehabilitation, but many people have no access to affordable AT solutions. The recommendations in the paper aim to inform policies, systems and service delivery procedures on how to improve access to AT across the world.

Introduction

Assistive technology (AT) is an umbrella term for products and related services used by persons with disability to enable and enhance their inclusion in all domains of participation. AT can be used by people of all ages and with all types of impairment (locomotor, visual, hearing, speech or cognition) and all sorts of limitations in activities, and for short or long periods of time. The combination of products and strategies to meet an individual's needs is called an "AT solution", and is developed via processes of assessment, trial and adaptation [1,2]. Some AT solutions are simple and require low-tech devices, others are very expensive and complex. This variety of user groups and the wide range of assistive products and related services make the provision of AT a complex issue. This complexity is further increased by the fact that the impact of a particular AT solution depends largely on the aspirations and individual characteristics of the user. There is not one AT solution that fits all; what works for one user might not work at all for another.

When this complexity is placed in the context of the worldwide increase in the number of persons with disability [3], and thus, the number of people who might benefit from AT in their daily lives, it is obvious that there is a worldwide challenge to develop policies, provision systems and procedures that assure the availability and accessibility of affordable high-quality AT for those



who need it. The details of this challenge are different for each country, but the question is global: how can we assure that as many people as possible have access to assistive products and services that optimally support them to participate in society?

This paper outlines the elements of an international framework for AT provision that could guide the development of policies, systems and service delivery procedures across the world. It does not prescribe how AT provision should be organized, but describes general requirements, quality criteria and possible approaches.

The paper is based on an analysis of existing literature in this field and a consultation of experts from different countries and parts of the world. A draft version of the paper was discussed at the GREAT conference in Geneva (Global Research, Innovation and Education in Assistive Technology) that took place in August 2017 as part of the World Health Organisation's GATE initiative. Inputs from that discussion were included in this final version.

Assistive technology as a human right

Public AT provision systems have been in place in many countries for many years, as part of their national or regional healthcare and welfare systems. With the publication of the United Nations Convention on the Rights of Persons with Disabilities (CRPD) [4] an

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international legal obligation for countries was created. This convention, among many other things, commits the ratifying states to enforce appropriate measures to facilitate access to AT solutions for those who need them to improve independence in daily life and to participate in society on an equal basis with others. The CRPD has encouraged the development of AT provision systems, policies and procedures and granted AT the status of a human right. The CRPD sets standards for ratifying countries to meet while addressing inclusion of persons with disabilities. It is built on principles including “respect for inherent dignity, individual autonomy including the freedom to make one’s own choices” (article 3(a)). Ratifying states are obliged to “ensure and promote the full realization of all human rights and fundamental freedoms for all people with disabilities” (article 4(1)), including promoting the availability, knowledge and use of AT (article 4(1)(g) and article 26(3)).

More than 170 countries have ratified the CRPD, indicating a commitment to give effect to the rights it embodies and be bound by its guidelines. Ratifying states are obliged to harmonize their relevant national laws and policies with the CRPD. This would mean designing laws and policies in such a way that they ensure access to support services including AT for all persons with disabilities requiring it. This includes older people and people with a chronic disease. It is a human right that persons with disabilities have access to assistive technology that is affordable and matched to their needs, in line with the United Nations Universal Declaration of Human Rights (UDHR) [5]. In particular, the right for persons with disabilities to access the freedoms identified in the UDHR, such as the right to not be subjected to degrading treatment, the right to work, and the right to access education, may be protected through the provision of AT.

Access to affordable Assistive Technology is a human right, with a foundation in the United Nations Convention on the Rights of People with Disabilities.

Elements of assistive technology provision

The term “Assistive Technology provision” entails everything that is needed to assure that a person with disability who might benefit from AT actually obtains it and obtains the most appropriate AT solution for that individual. A key element is the service delivery process, that is the process through which an individual goes to obtain an AT solution that meets his or her needs. For optimal AT provision, however, many other elements are also essential. These elements include: good quality AT products have to be available at affordable prices; people – end users and professionals involved – have to know that certain solutions exist; there have to be professional services providing advice and support; there have to be policies and procedures to decide about eligibility for certain solutions and funding mechanisms; there has to be training on use; there have to be follow-up services; and there has to be an infrastructure for maintenance and repairs; etc. All these elements can be organized or arranged in different ways, but they have to be in place for AT provision to be effective.

The following six paragraphs set out basic requirements and possible approaches for these elements. The first five elements can be considered pre-conditions, the sixth is the service delivery process, which is the key process from a user perspective.

Availability of affordable high quality assistive products and services

Availability of affordable high-quality assistive products is a serious problem for many people with disabilities. The market for

assistive products is characterized by relatively small companies, mostly with a national or regional scope. Exceptions are in the fields of wheelchairs, prosthetics and orthotics, but even here the numbers of products sold are insufficient to reach economy of scale to reduce production costs and lower prices. As a result most assistive products are expensive, sometimes extremely expensive. The consequence of this is that, even in high-income countries, many assistive products are only available to those who can afford to buy them privately, rather than through a public provision system. For low- and middle-income countries these assistive products are simply out of reach. Although everyday ubiquitous technologies like smartphones and tablet computers are becoming more easily available and affordable, and these technologies increasingly offer assistive solutions, the majority of the existing products are not within reach for the majority of the people with disabilities.

An additional problem is that the AT market is not an open market, in the sense that end users generally have very little choice. Decisions are made by intermediary bodies like insurance companies or municipalities, or by donor-driven organizations and projects, but very rarely the user directly. This creates a market in which there are clear needs but users without direct purchasing power. Additionally, procurement of AT products is often outsourced to third parties. While bulk procurement of assistive products by governments, insurance companies or other agencies can reduce time, effort and costs, it increases the distance between end users’ needs and outcomes and purchasing decisions.

According to a global study quoted in In a WHO and USAID (United States Agency for International Development) Joint paper [6] 53% of the countries surveyed in 2005 had not initiated programs relating to AT provision. In these countries, AT provision occurred via non-governmental organizations (NGOs), with limited reach and a narrow scope of assistive products (e.g., wheelchairs or prosthetics). In a way this fragments the market and masks part of the needs in society. States should take responsibility for developing national policies on AT provision, including policies on manufacturing and trade of assistive products.

With the publication of the Priority Assistive Products List (APL), the WHO has set a minimum standard for assistive products that should be available in all countries [7]. Companies should be strongly encouraged to produce and sell high-quality assistive products on this list at the lowest possible prices without compromising on quality standards. For some assistive products, this will require research into new production techniques and supply chain efficiencies, including local production to shorten the delivery chain and save costs for transport etc. Such research should be supported. In countries without production capabilities arrangements for easy trading and import tax waivers should be considered.

The availability and affordability of assistive products can be strongly stimulated by challenging companies to produce and sell high quality products from the WHO Priority Assistive Products List (APL) at affordable prices, and by stimulating research into new production techniques, including local production of proven technologies.

States should develop national policies on AT provision, including a policy on manufacturing and trade of assistive products. Establishing an international authority that can support states in this area and can exert pressure on states should be considered.

An important development is that mainstream technologies, with the smartphone and the tablet computer as most obvious examples, offer features that allow them to function as assistive products. This has opened a whole new market of apps and other digital products developed for specific populations of people with

disability. Examples include navigation support apps for persons who are visually impaired, speech operated environmental control systems that run on a smartphone and augmentative and alternative communication (AAC) apps. These applications have the potential to become available to large user groups at very low prices, although buying mainstream technologies is often not within reach of people with disability.

The use of mainstream technologies as a generic platform for specific assistive products and services should be strongly encouraged.

A specific area that deserves attention is that of self-provision. Very often people develop assistive products themselves with very simple and cheap means. Such products can be very effective. It would be worthwhile to disseminate information about such cheap solutions and to develop guidelines/tips for making them. This might contribute to a more accessible provision system.

Information systems

To be able to benefit from any AT solution people must know of its existence. This implies that information systems are key to any AT provision system. Such information should be available to end users as well as professionals involved. Effective awareness raising is challenging, and information provision should be considered as an on-going dialog rather than a one-off transaction. The number of assistive products and related services is large (many thousands) and growing exponentially as a result of developments in technology. The challenge is not only to provide information about the existence of particular assistive products, but also about their quality, usability, effectiveness and availability. And preferably such information is neutral/independent (not influenced by commercial or other interests) and supported by research evidence that is based on user experiences.

In Europe, there has been a long-term investment in providing information about assistive products. This has led to the European Assistive Technology Information Network (EASTIN) search engine, which connects websites from a number of European countries and makes the information publically available to end users and professionals. In the United States of America a similar database exists: AbleData, and also Australia has such a database: National Equipment Database. It is a major challenge to keep this information updated. Many of the underlying national websites are under continuous threat of being closed. In most countries such information systems are not available. And in some countries, especially in rural area, the concept of information through a website is still non-existent. Here, information dissemination needs to be done through community based channels in print or verbally. States should take the responsibility for such information systems and ensure their availability and quality.

It is essential that countries assure that neutral/independent evidence based information about AT and related services is available for end users and professionals. The WHO priority assistive products list (APL) provides a good starting point for developing such national information systems and the structure of the EASTIN website provides a useful framework to build upon.

Professional services, advice and support

Information about assistive products is necessary but insufficient to ensure adequate AT provision. Developing an individual AT solution (which is the device plus related support and services, such as training for the user to safely and effectively operate a given product) requires high level professional knowledge and skills. Not only knowledge of the available assistive products and

how to use them, but also knowledge and skills to assess the needs and ambitions of the individual, and about the way AT interacts with other support or treatment a person may need. There is no specific discipline trained for this task, except for the field of prosthetics and orthotics. AT is not frequently enough a major topic in the training of healthcare professionals, and different healthcare professionals have different scope and depth across assistive products. Occupational therapists probably have the best basic training to play a role in AT provision and service delivery, but in many countries, this discipline does not exist or only in very low numbers. Only some countries offer postgraduate courses in AT provision, resulting in a serious lack of expertise and skills available in most countries. Developing training programs for professionals to work in this field is fundamental to improving AT provision and service delivery worldwide. Professional organizations like AAATE, RESNA and ARATA can play an important role in developing such programs.

It is very important to increase the quantity of AT advisors. The traditional way of training them in formalized education systems will take many years. Therefore, others approaches to training should be applied, for example building on the “train the trainer” principle in which existing AT advisors are trained to train colleagues around them about the principles of AT. Such pyramid like structure of training may improve awareness and access to AT and service delivery worldwide, especially in low- and middle-income countries.

It is essential that training programmes for professionals to work in the field of AT are developed and become available worldwide. In connection to this, the development of an accreditation system for AT experts might be considered. Professionals involved may be healthcare professionals but also social and community workers and, in settings where these are not available, non professional people, for example supported by online tools and information.

If there are professionals with sufficient knowledge and skills, it is essential that they are able to offer independent advice and support. In most countries, such independent advice does not exist. The available professionals are directly linked to and work on behalf of the commissioning body and sometimes to the manufacturer of certain assistive products. Ideally people would have access to independent centres of expertise, where they are assessed and receive professional advice.

Each country should assure the availability of independent centres of expertise where people can get high quality advice and support in the process of obtaining AT. In Italy a good example of a network of such centres exists. This could serve as a model.

All professionals involved in AT service delivery, including clinicians and technicians, should have clearly described roles and responsibilities and their competencies should be embedded in international standards of education and training that define core competencies.

Eligibility and funding mechanisms

Many people with disability who would benefit from AT do not have the means to pay for it themselves. This is particularly true in low- and middle-income countries, but also in high-income countries for expensive and complex products. In most cases, there will be a need for some kind of financial support. According to the earlier mentioned WHO&USAID Joint Paper [6] in 2005, about one-third of the countries surveyed had not allocated financial resources for developing and providing assistive products or associated services. In those countries where there is an allocated budget, the financing policies may vary from covering full cost of

AT to partial costs of a limited list of assistive products. In some countries, there is the possibility of having a personal budget or a voucher system, that give users choice within a specified price and/or assistive product range.

A key policy issue in relation to funding mechanisms is deciding who is eligible for obtaining AT and determining the range and extent of funding. This is a very complicated issue. In contrast to the intentions of the CRPD most countries rely on medical definitions and diagnostic criteria to determine eligibility [8]. Developing eligibility models that start from a functional perspective and the individual ambitions and context of a person to participate in society is a major challenge to improve AT provision worldwide. The ICF framework [9] offers a starting point that can be used to operationalize (parts of) these models, and some interesting instruments have been developed that could play a role in this (e.g. WHODAS 2.0 [10] and the Impact-s tool [11]), but a generic decision model does not exist yet. Such a model would help to distribute available resources in a fair and equitable way to those who need them most, irrespective of the funding mechanism chosen.

There is a need for generic models to support decision-making on eligibility of AT devices and services that start from a functional perspective and the ambitions of the individual to participate in society, instead of medical criteria. The development of such models should be stimulated.

Infrastructure for maintenance and repair

Appropriate infrastructures to support the use of AT for persons with disabilities are required to ensure that products and services continue to meet the needs of the user. In education, for example, a voice-output device is of no use to a student with a communication impairment if it is broken or if the batteries have run out. This is an all too common scenario for AT users. A structure incorporating a schedule for maintenance and a mechanism for repair of devices is needed to ensure optimal performance for the user. The use can often play an important role in maintenance and repair. This should be part of the advice and training on delivery of an AT device.

At service delivery systems and models

The service delivery process is informed by the national legislation, existing policies and the elements described in the five previous paragraphs. In a study analysing AT provision and service delivery in 16 European countries in 1994, seven essential steps in AT service delivery were identified. Although organized in very different ways, these steps could be found in all participating countries. In 2013, the AAATE published a position paper in which these same steps were mentioned as still relevant and adequate [1]. These seven steps are: (1) initiative – first contact; (2) assessment – evaluation of needs; (3) typology of the AT solution – choosing the appropriate type of AT; (4) selection – selecting the specific device; (5) authorization for financing – obtaining funding; (6) delivery – getting the device to the user; (7) management and follow up – continued support [12]. There is recognition that all seven steps are important to achieve the functional outcome desired for AT use, but they are not consistently used in practice [1,3,13,14].

For the development of service delivery processes the seven steps identified by the AAATE can serve as a structuring framework.

The aim of AT provision is generally to maintain an individual's functioning and independence and to facilitate participation,

giving less emphasis to remediation of impairments [15–17]. Cook and Polgar [15] give 5 principles that should guide AT provision:

1. The process is person centered and not product of service centred;
2. The outcome is enablement of participation in desired activities;
3. An evidence-informed process is used;
4. AT provision is conducted in an ethical manner;
5. AT services are provided in a sustainable manner.

Although these principles do not give direct clues for service delivery practice, they are important quality criteria for service delivery policies and processes.

The aforementioned position paper of the AAATE sets out six general quality criteria for AT service delivery. These criteria were developed from a European study, but are also applicable to other countries and settings. They are:

Accessibility. A service delivery system is accessible when no one is excluded from the services or in any other way discriminated against. It is essential that the system is driven by user needs and that funds are available to remove financial barriers. People should know that there is a service delivery system, that assistive products exist, and where to go to access the system. It should be easy to obtain appropriate AT solutions without unnecessary delay. Elements of accessibility are the scope of the system (who is eligible), its simplicity, the availability of information to the public, financial barriers and costs for the user, duration of the process and the complexity of procedures.

Competence. Professionals involved must have the knowledge and skills needed to properly meet the user needs. Competence is about the availability of knowledge, skills and experience necessary to serve the client. Elements are the educational level of professionals, the possibilities for further education, the use of protocols and standards, the availability of information and the possibility to learn from feedback.

Coordination. A service delivery system needs to be coordinated on three levels: within the primary process “around” an individual client (with often different professionals being involved), during the various steps in the process for an individual client, and in relation with other policies and processes regarding AT or other forms of support for the individual.

Efficiency. A service delivery system is efficient when it is able to achieve the best AT solution for the highest number of users, using the available resources in the shortest time and at the lowest cost. Elements of efficiency are complexity of procedures and regulations, duration of the process, control of the system over the process, mechanisms able to control the costs and effectiveness, and delegation of decision-making power to the appropriate level of competence.

Flexibility. A service delivery system is flexible when it is able to respond to different needs of users, when it is able to adopt new technologies in an easy way and when researchers and developers get support for their work, coordinate their work, cooperate and communicate with users, designers, producers and utilize new technology to meet needs.

User influence. Users should be involved in all aspects of a service delivery system and in their own service delivery process. Lack of user involvement exposes the risk of wrong or ineffective intervention, abandonment of assistive products provided and waste of resources. User influence indicators include the presence and strength of user organizations, the availability of legal protection of the user's rights, the involvement of users at a policy level, user empowerment during the individual assessment, communication with the user in the service delivery process and the influence of the user on decisions in the process.

The six quality criteria for AT service delivery and the principles described by Cook & Polgar may serve as building blocks for a quality assurance framework for AT service delivery.

Effects, costs and economic impact of AT and related services

It is widely acknowledged that AT can have a dramatic positive impact on people's lives. This can be illustrated through a simple thought-experiment in which one imagines the consequences if all people who wear spectacles or hearing aids would have to hand them in. In the scientific literature, however, not much is known about the impact and cost-effectiveness of AT. Although there are some studies [18,19], this has been a neglected field for many years. This is partly due to the fact that AT is not acknowledged as a major separate issue in most healthcare and welfare systems, but is also due to the complexity of evaluating the impact of AT. AT is almost always provided alongside other interventions like treatment, education or other forms of support, making it difficult to extract the specific added value of AT. More importantly, the effects of AT are individual and depend largely on the ambitions, capabilities and personal context of the user. This complexity creates a challenge for research into the effects and costs of AT. Such research is, however, extremely important to support the development of evidence-guided AT provision systems. The emphasis should be on evaluating existing AT.

Research into the (societal) impact and costs of AT is essential for the development of evidence-guided AT provision systems and service delivery processes. Such research should be strongly stimulated through specific funding calls and as part of existing research funding streams.

Towards an international standard for AT provision

It is time to develop an AT provision standard. Without a standard method or tool to connect services and outcomes, there is a lack of comparable data for AT, leading to problems in assessing the impacts of current policies and developing new ones. Development of an internationally relevant, evidence-based infrastructure for AT services is critical to advancing all aspects of the global priority research agenda regarding AT. By delineating the key elements of AT services and how they interact, a process standard for AT provision would define a standard of practice with benchmarks to assess quality of services, provide the basis for educational curriculum and certification, and enable the collection of data to assess the impact of AT for policy decision making. Establishment of core quality performance indicators for AT provision will support efficient and effective services by optimizing decision-making. How services are provided will be governed by national legislation, specific regulations and cultural expectations.

There are established processes for developing and appraising international standards and several authors from different countries have published proposals to guide the scope and content [20,21]. Such a standard should be based on interdisciplinary conceptual and process models and adopt a common "language". An AT process standard should assure the user remains central to all activities, enable interdisciplinary interaction, recognize the value of considering pre-interventions which may mitigate the AT services needed, be applicable to any type or level of disability, and address the factors which influence user satisfaction with or abandonment of AT. A standardized framework for AT service provision would allow for the insertion of existing and evolving performance standards at both the individual and organizational level.

It would function as a platform to develop and support further strategies and resources to improve AT provision worldwide.

The development of an international AT standard could be achieved in collaboration with the WHO and a recognized standards regulatory body, in partnership with international AT networks and associations like AAATE, RESNA, ARATA and RESJA.

To further drive and support the development of good AT provision policies, provision systems and service delivery procedures, an international AT provision standard should be developed.

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