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Augmentative and Alternative Communication and digital participation

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Communication is a basic need for all people to fully participate in life. Persons with disabilities may face particular challenges in developing their communication skills and using them appropriately in different situations. Augmentative and Alternative Communication (AAC) tools and methods can assist individuals in this process. Increasing digitization has changed the way everyone communicates, and this offers opportunities for persons using AAC. This paper briefly outlines what has been achieved in terms of digitalization in AAC. The need for full, adapted access to technology is highlighted and research desiderata are identified.

KEYWORDS

Augmentative and Alternative Communication, digitization, new technologies, participation, barrier, special needs

Introduction

Today's societies are characterized by a high degree of digitization in many areas of life. Accordingly, participation in digitization is commonplace and a natural part of life for many people. The following reflections on participation will focus on the issue of social participation in digital environments (Bernasconi and Terfloth, 2019).

Persons with disabilities are at particular risk of exclusion in digital contexts, as they are particularly affected by the 'digital divide' on the first level: they are statistically less likely to have access to digital devices and the internet, their daily activities in digital environments are correspondingly lower, and surveys show that they feel less included in digital society (Scholz et al., 2017; Johansson et al., 2021; Mason et al., 2021). The extent of the digital divide appears to vary by disability. The group reporting the greatest difficulties in using digital applications and the internet includes people with communication, speech and language disorders (Johansson et al., 2021).

Impairments in speech, language and communication affect a basic human need that is essential for development, empowerment and social participation, as well as psychological wellbeing. Accordingly, the International Classification of Functioning, Disability and Health (ICF) highlights the importance of communication as a core area of activity and participation. It relates to the roles of individuals as receivers and senders of messages, as well as the use of communication devices and techniques (ICF: d3). Participation limitations are threatened when individuals are impaired in their spoken and/or written language skills.

The focus of the further explanation is on social participation with all aspects of social inclusion in everyday environments. Communication and interaction are of great importance in this area, as social participation includes aspects of one's own communicative initiative as well as the role of a person as an addressee of communication. Digital spaces and digitally mediated communication are an essential part of everyday life and therefore

the barriers to access for people with disabilities must be considered and reduced. The legal basis for this is the United Nations Convention on the Rights of Persons with Disabilities (CRPD): Article 9 of the CRPD emphasizes the potential of information and communication technologies for the empowerment and participation of persons with disabilities in all aspects of life.

The group of people with limited communication skillsvery heterogeneous in their resources and needs-can benefit from Augmentative and Alternative Communication (AAC). The target population for AAC includes all individuals whose currently available resources of natural modes of expression are inadequate for satisfactory communication. This condition may be temporary, prolonged, or expected to be permanent. This group includes neurological disorders such as stroke (Dietz et al., 2020), amyotrophic lateral sclerosis (ALS) (Peters, 2022), people with congenital or acquired physical-motor disorders such as infantile cerebral palsy (ICP) (Hidecker, 2022), people with intellectual impairments such as Down syndrome (Shahid et al., 2022), Rett syndrome (Unholz-Bowden et al., 2023), and people with temporary communication impairments such as those resulting from accidents, surgery, or shock (Cummings, 2023). The use of AAC may be considered, for example, as an aid to language acquisition or as a means of expression for individuals who do not communicate through spoken language. AAC encompasses a wide range of methods and interventions that facilitate successful communication. A mix of methods and procedures is usually used to ensure appropriate expression in a variety of life situations. These may include endogenous methods such as gestures, sounds and facial expressions. In addition, non-endogenous methods are used, such as pictures, symbols, or talking buttons and speech computers (Spreer and Wahl, 2020)

In order to provide a form of AAC that is appropriate to the individual's communicative needs and abilities, it is necessary to look closely at the individual. The Participation Model (Beukelman and Mirenda, 2005) analyses needs and interventions by comparing wants and needs with current opportunities. Patterns of participation vary from person to person, so precise interventions are needed. AAC aims to achieve participation equivalent to that of non-disabled peers. Assessing the person's activities in different areas (work, school, leisure) and comparing them with non-disabled peers helps to set realistic goals. Assessment of current participation and communication skills is essential. The model assumes equal social participation for people with communication impairments. Identifying and reducing barriers to opportunity and access are critical to the successful implementation of AAC. Barriers to access are similar to deficits in contextual factors in the ICF.

The starting point for the following considerations are the issues identified by McNaughton and Bryen (2007) as priorities for research and development in the field of AAC. The focus is on technologies to enable remote communication and connectivity, as well as adapted applications and tools. New developments in recent years, such as those arising from social media, will be addressed.

Digitization in Augmentative and Alternative Communication

Resources available in AAC can be classified according to their technical complexity: "No-tech AAC" are endogenous resources, such as gestures, vocalizations, muscle tone etc., "low-tech AAC" are simple communication aids such as picture boards, etc., "mid-tech AAC" include simple electronic devices such as buttons to display messages. Of particular interest for digital participation considerations are "high-tech AAC" devices, which are dynamic devices that contain page sets of letters, words, phrases, pictures, and/or symbols that the person navigates between to compose messages (Elsahar et al., 2019). As communication tools, high-tech systems can often be used for other functions and usually have interfaces with digital applications e.g., environmental control for windows, doors or E-mail program and consumer electronics (Chen et al., 2021).

High-tech systems have become particularly important since the introduction of tablet computers because they are readily available, inexpensive, and usually easy to use or adapt. The rapid development of these digital technologies has brought great advances in mobility and independence for people who use AAC.

Smartphones and tablet computers are widely used around the world, both to expand communication options and to enable interaction at different levels, such as in social networks. People with disabilities benefit equally from these extensive opportunities, as these technologies allow these groups to interact and access information in the same way as people without disabilities (Isaksson and Björquist, 2021). In their study, Bryen et al. (2017) showed that exactly the same standard applications on devices are used by people with disabilities as by people without disabilities. For example, sharing photos and videos, browsing the web, and sending text messages are just as common. However, a large proportion of the people surveyed in the study say that there is an urgent need to adapt and modify the usability of devices to meet their needs. At the time of the study, however, such adaptations were not standard. In recent years, hardware manufacturers have taken a number of steps to improve usability and accessibility. Features such as reading aloud, voice control, and customization options such as colors, font sizes, fonts, etc. are now standard on devices. They allow for extensive customization of device interfaces and functionality. Persons with disabilities in particular benefit from these customization options (Gandhewar and Mohan, 2022).

In particular, AAC users can benefit from the very generous adaptability of devices and gain broad access to the use of devices, but AAC users sometimes require highly specialized applications and input capabilities that are often not covered by the current adaptability of devices. In recent years, more work has been done to create accessibility guidelines for technology, which aim to design technological solutions so that they can be beneficially used by people with communication disabilities (Saturno et al., 2015). For example, Samuelsson and Ekström (2019) showed that technological aids can be used beneficially by people with dementia by enabling them to talk about important aspects of their lives. In particular, they showed that people with dementia were more likely to take the initiative to communicate using technology, i.e. to create communication opportunities in a self-determined way.

McNaughton and Light (2013) have already shown that the use of new digital devices, especially the iPad, a tablet computer manufactured by Apple Inc., is particularly high among people with disabilities. These devices are potentially less stigmatizing than traditional classic voice recorders and voice computers because they fit in any pocket and (may) lead to greater social acceptance due to their shape, size, and usage options. The introduction of the iPad as a mass market device in 2011 has led to major changes in the AAC community as these devices open up a wide range of possibilities for AAC use. There are a number of requirements that need to be met in order for this to happen. Among other things, it is desirable that manufacturers provide as many options as possible, e.g., for entering commands, text, letters, words, etc., so that individualization can be easily achieved (McNaughton and Light, 2013; Buchholz et al., 2020). In addition, there is a focus on the usability of applications. The design of applications applied to devices is sometimes very creative and thus violates recommendations for the design of online applications, such as the current Web Accessibility Guidelines (https://www.w3.org/ WAI/standards-guidelines/wcag/), and is therefore very often not optimally implemented in terms of design, adaptability and control (Du et al., 2022). It is essential that manufacturers work closely with research and development, but also with users, to best understand the needs of the people who will later use the devices (McNaughton and Light, 2013). For a recent review of accessible application design see Zaina et al. (2022).

On the other hand, there is an urgent need for trained individuals who understand the possibilities of using technology in the context of AAC. For example, according to a study by Mackenzie et al. (2016) that examined the provision of digital technologies to patients with ALS, the timing of provision is critical. Patients, who also use the devices primarily for applications such as writing messages, online shopping, searching for information, video telephony, etc., need to be introduced to the possibilities of using the devices beyond traditional input methods such as mouse and keyboard in a timely manner. This requires extensive knowledge on the part of caregivers about the use of alternative input methods, such as eye control. Sebold and Renner (2019) focused their study on the usability of technologies and concluded that different input devices play an important role in the care process of people with physical impairments on the hardware level, but on the software side, features such as word and text prediction positively influence the communication possibilities.

Augmentative and Alternative Communication in Digitization

Digitization has led to profound social changes in recent years. The use of media has become a matter of course in many areas, and it is impossible to imagine life without it. The development of technologies, the collection and storage of data, and the increasing automation of processes have led to lasting changes in people's working and living environments. The age of digitization is characterized by cultural and social realities and ways of life that go hand in hand with digitization, make it possible, and have become the norm for people (Stalder, 2016). This in turn requires that people have the opportunity to use digital technologies. Here,

however, especially for people with disabilities, technical barriers mostly arise with regard to the accessibility and usability of digital technologies. As indicated in the previous section, there is an urgent need to open up opportunities for people to use technologies to enable (social) participation. Light and McNaughton (2014) state that the removal of barriers on the one hand and environmental support on the other hand play a very important role in the acquisition of communicative competence for people who use AAC in order to, among other things, increase confidence in one's own abilities so that the necessary communicative competence can be built up at the linguistic, operational, social and strategic levels. Everyone has complex communication needs. Individuals who require and use AAC to communicate exhibit a further increase in complexity. Light (1989) defines a complex dynamic interpersonal construct for this group of individuals that emphasizes functionality and appropriateness of communication and postulates sufficient knowledge, judgment, and appropriate skills as its foundation. In the age of digitization, this construct must also be considered in relation to communication in digital space.

New technologies, such as tablet computers, are opening up new spaces for face-to-face communication by using them as voice computers or talkers. However, people with disabilities are also using them to communicate at a distance. For example, Hynan et al. (2014) show that the use of online social media is a way for people to participate in social life in a self-determined way and to enrich social relationships at different levels through self-expression in the networks. However, according to the authors, support, especially at the technical level, from educational institutions, families and friends is essential in order to be able to use these new forms of communication.

People with disabilities are particularly dependent on support when using digital media (Ramsten et al., 2020). These support needs are particularly relevant for people with intellectual disabilities, learning disabilities, and motor impairments. When appropriate support is provided, the use of digital technologies is possible in a variety of settings, which can have a positive impact on an individual's participation (Darcy et al., 2016). Digitization enables participation and improves quality of life. Caron and Light (2015) interviewed people with ALS in an online focus group about their use of social media. Participants emphasized that social media can strengthen links with communication partners and (other) support networks. Particularly for ALS patients, whose ability to communicate changes significantly over the course of the disease, access to different forms of communication is an essential component of continued independent participation in social life. Digital social networks can be a key component that should not be underestimated. These effects can also be demonstrated for people with motor disorders such as ICP (Caron and Light, 2016).

Very often, however, there are barriers within the technologies that make them difficult for these groups to use, and these need to be addressed first. Once these barriers are overcome, digital technologies are widely used. Hemsley et al. (2015) examined the use of the social network Twitter by people with communication impairments and found that the networks were primarily used to converse with others at the micro (direct communication with individual other users) or meso level (communication with the group of followers), less often to participate in discussions of larger and unknown groups via hashtags (macro level). Users' own social presentation was clearly in the background. A recent study analyzing posts on the social media platform Instagram highlighted its relevance for young adults in terms of identity representation (Tollan, 2022), which seems to be particularly important with regard to the normalization of disability in everyday life. Thus, social media can also play an important role in self-advocacy.

Discussion

The studies briefly reviewed here show that digitization is profoundly expanding the possibilities for interaction between people, and that people with disabilities also want to and do use communication in the context of digitization. The expansion of communication and interaction opportunities through the use of digital technologies is an essential component for the full participation of persons with disabilities in society and is, in principle, already enshrined in law from a human rights perspective. In addition to the use of AAC technologies as communication aids in face-to-face interactions, the potential for their use in digitally mediated communication, such as social networking, is enormous. People who use AAC can benefit from the asynchronous nature of digital communication, which often does not require an immediate response.

A prerequisite for participation in digitization on the part of the person who uses AAC is not only appropriate technical equipment, but also a supportive network of professionals, family members, and peers. All stakeholders need extensive knowledge, which in turn can be improved through training opportunities. Encouraging individual case studies (e.g., Grigis and Lazzari, 2013; King et al., 2020) indicate that the use of high-tech AAC can be learned by different user groups. Professionals should be made aware that communication needs exist beyond the personal, close environment and face-to-face interaction, and appropriate resources need to be provided.

However, the removal of communication barriers should not only be considered at the personal level, but the demand for accessibility of digital offerings (also) for people who use AAC is quite general. Existing laws and guidelines on accessibility provide a basis, but the needs of users with communication impairments are not sufficiently or consistently taken into account. Features that increase the accessibility of digital content [e.g., text-tospeech (TTS), speech-to-text (STT), and the use of objectively understandable communication symbols (CS)] are still too rarely provided, while the rapid development of artificial intelligence suggests great progress in this regard (Elsahar et al., 2019; Sennott et al., 2019). The idea of universal design, which focuses on proactively creating accessibility for all potential user groups, needs to be much more widely adopted as a relevant mandate for stakeholders, policy makers, and society at large. In particular, people with special needs should be involved in the development process. Support networks for people who use AAC also require sustained professionalization and development (Grans and Wahl, 2013; Jacobsson, 2022). Extensive needs have been identified, particularly with regard to the use of modern technology and its implementation in the lives of people who use AAC. Social networks will play a special role in the context of AAC in the future. Waller (2019) states that there is a need to lower the requirements for technology. Both people with cognitive impairments and people with communication disorders need to be empowered to use these technologies, especially social networks (Grace et al., 2019; Waller, 2019). For this to happen, users must be consistently involved in the (further) development with regard to individual physical and linguistic needs (Pampoulou, 2019). This requires further intensive research (Bosse et al., 2020).

Research is also needed to critically examine existing practices of AAC provision in light of the participation model (Beukelman and Mirenda, 2005). In addition to research on needs, attitudes, and barriers, there is a need for presentations of best practices, such as individual case studies. In addition, collaborative projects involving AAC users, researchers, developers, and professionals are needed to jointly explore the potential of digital technologies for AAC and to empower AAC for digitization.

In addition to in-depth research on the perspectives of users, there seems to be a lack of evaluated approaches and studies that address the needs for training and education of professionals and other supporters in the field of AAC care and digitization. Opportunities for inter- and transdisciplinary collaboration may be offered by the discipline of media pedagogy.

Author contributions

All authors listed have made a substantial, direct, and intellectual contribution to the work and approved it for publication.

Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

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