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Technical Perspective : "The User as a Key Ingredient in AAC Design" <https://dl.acm.org/doi/10.1145/3629475>

Communication is the essence of being human. We interact with one another using body language, gesture and speech. The way in which we dress and adorn ourselves enables us to share our personality and mood with others. But it is our ability to use complex language that enables us to communicate our thoughts, ideas, emotions and personality in depth.

Augmentative and Alternative Communication (AAC) describes methods and strategies used to augment unintelligible natural speech or to provide alternative solutions for individuals with little or no functional speech due to physical and/or intellectual disabilities. AAC ranges from unaided methods in the form of gesture or sign language, through to symbol and word boards. The advent of text-to-speech technology in the 1980's revolutionised the field. Today, speech generation apps can be downloaded onto a range of mobile devices, including smart phone technology and offer a variety of accents and age ranges. Individuals who lose their voices can even 'bank' their voices for future use!

Despite these advances, the reality is that augmented communication remains prohibitively slow due to the physical and cognitive skills needed to enter text using a keyboard or scanning interface. A rate of around 67 words per minute (wpm) has been suggested as the target goal for improved mobile text entry. In comparison, typical text entry rates for disabled typists using AAC average at around 8 to 10 wpm. This discrepancy is increased when considering comparative speech rates of 125 to 185 wpm. Don't be fooled by augmented communication that gives the impression of speedy communication – such interactions are usually prepared speeches that have taken significant time and effort to construct. Imagine trying to get your voice heard in an interactive conversation when it has run on for 10 minutes before you manage to construct your message...

There is no single solution to solving the problem of communication rate. Research into word/phrase prediction and keyboard/interface design can only improve the rate to some extent. The physical environment, social context and personal characteristics must also be considered when matching and designing technology to meet the needs of any user. One of the factors underlying the low adoption / high abandonment rate of AAC technology is the limited involvement of end users throughout the development cycle. Instead, proxy users in the form of clinicians and parents take the role of end users. In the few projects where people who use AAC are involved, this involvement is mainly restricted to the role of informants who comment on the final product and not as co-designers.

Similarly, there are very few published studies that report the active participation of users of AAC throughout the user-centred design project. Ethical, practical and attitudinal excuses are often used to exclude people with complex disabilities from the design process. Studies often report use by secondary users in the mistaken belief that they can simulate the physical, sensory and cognitive characteristics of a disabled user. This is further complicated by the heterogeneous nature of having a disability – we are each wonderfully unique!

Research tells us that any technology will fail unless end users are actively involved in the research and development of technology. This is especially true when designing technology for users with disabilities.

The following paper describes the design of a physical object to support communication and focuses on the active involvement of Mark Steidl, an expert user of AAC, as a member of the design team.

In this paper, the end user's role in the design process provides a unique window into how Mark's expertise as an AAC user has been harnessed. The HCI researchers engineered a design environment in which Mark was enabled and supported to 'voice' his experience of using the technology prototypes. Mark and his family's experiences were valued by the HCI researchers. For example, his request that the object have a smile resulted in a literature review and collaborative interface design activities despite Mark's inability to sketch.

Not only is Mark an active member of the design team, he is also an author of the paper. The term "participatory research" is often used interchangeably with user involvement in design. Instead, participatory research strives to place the research participants at the centre and forefront of the research design, i.e., involved in the directing and planning of the research from inception to conclusion.

There are examples of research projects with people who use AAC on advisory groups. Others succeed in attracting funding to employ end-users on project teams in their role as expert users of AAC. The ultimate challenge is to move towards a more participatory research model in which users of AAC are researchers driving innovation and setting the research agenda.

This paper demonstrates that we can and should regard people who use AAC as experts, valuing their insights and skills. It exemplifies how this can be achieved and underpins the disability activist mantra: "Nothing about us without us"!

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