

A Right to the Frivolous? Renegotiating a Wellbeing Agenda for AT Research

“Happiness is not all that matters, but first of all, it does matter (and that is important), and second, it can often provide useful evidence on whether or not we are achieving our objectives in general” (Sen 2008 :27) .

Assistive products (APs) are broadly defined as *“any product (including devices, equipment, instruments, and software), either specially designed and produced or generally available, whose primary purpose is to maintain or improve an individual’s functioning and independence and thereby promote their wellbeing”* (Khasnabis et al 2015). Although the concept of wellbeing is extremely slippery and researchers have yet to agree on a single definition for it, as individuals we instinctively develop mental models about what does, and does not, promote our happiness and wellbeing. Considerations about values, wellbeing and happiness are extremely personal and are shaped by a variety of factors ranging from our age and socio-cultural background to our life experiences (Schwartz & Bardi 2001).

However, when it comes to assistive technology (AT) research, our focus seems to be primarily geared towards values and activities in the domains of education, employment, transport or health, often framed according to an outcome driven perspective that is heavily influenced by what is seen as useful (often what is measurable), vs what is frivolous (less tangible social or emotional aspects).

This disparity parallels the priorities of the disability rights movement and disability studies research that have helped to shape the research agenda around disability and AT. Often influenced by labour movement politics, or feminism, there appears to have been more concern with public and practical aspects of social life as opposed to the more private and sensitive ones (Shakespeare, 2014). The focus on the public utilitarian function of AT becomes even more evident when we consider AT research carried out in the Global South. In this context the success of an intervention is usually assessed using measures of outcome and impact which can be somehow linked to economic improvement (Alkire, 2016).

In this editorial, we are not suggesting that enabling people with disabilities to gain a good education, obtain a fulfilling job or be able to vote are not important goals for the APs we develop and research. But are those the only worthwhile goals? Should we not also enquire whether existing and future APs could help people with disabilities to develop meaningful friendships, enjoy fulfilling sex lives with their partners of choice, cook sociable dinners, or engage in their favourite hobbies? Although sporadic publications focus on the role of APs in the context of personal relationships, sexuality, or fun and play for people with disabilities do exist, these are rare, and often framed around utilitarian goals. For example, research around AT and play is largely focused on children and often examined in connection to learning outcomes. Similarly, sex and sexuality are often explored solely in connection to dysfunction, abuse or sexual health (Shakespeare and Richardson 2018).

These unbalanced narratives show how the AT research agenda is dictated by a set of universal priorities that are largely focused on global measurable goals that do not necessarily match the everyday values of people with disabilities. We invite researchers and practitioners to consider ways to find a better balance between public

and private aspects of life, and between utilitarian and emotional values. Both approaches have a significant impact on the lives of people with disabilities.

Ultimately, as AT researchers we need to actively engage with people with disabilities to uncover their priorities, understand what different people with disabilities most value in life, and identify how current and future APs might help to make a positive impact on wellbeing. Aspects of life such as friendship, socialisation, sexuality, love and play might indeed be more frivolous than practical ones such as education, health, employment and civil rights, but they are inherent to our shared humanity and fundamental to our happiness.

References

Alkire, S. (2016). The capability approach and well-being measurement for public policy.

Khasnabis, C., Mirza, Z., & MacLachlan, M. (2015). Opening the GATE to inclusion for people with disabilities. *The Lancet*.

Schwartz, S. H., & Bardi, A. (2001). Value hierarchies across cultures: Taking a similarities perspective. *Journal of cross-cultural Psychology*, 32(3), 268-290.

Sen, A. K. 2008. "The Economics of Happiness and Capability." L. Bruni, F. Comim, and M. Pugno, eds., *Capabilities and Happiness*, 16–27. New York: Oxford University Press.

Shakespeare, T. (2014) *Disability Rights and Wrongs Revisited* (Routledge, London)

Shakespeare T, Richardson S. (2018) The sexual politics of disability, twenty years on, *Scandinavian Journal of Disability Research*, 20(1), pp.82–91: <http://doi.org/10.16993/sjdr.25>