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A model to enhance interaction for people with severe intellectual disability in healthcare, education and interpreting

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Abstract

ICT tools are powerful instruments of communication which provide equality to those suffering from severe intellectual disability. We are presenting a model of comprehensive multimodal communication in order to enhance their chances to interact with others and improve professionals' understanding of intellectual disability.

Most of the existing literature on different disabilities focuses its attention on people who have some capacities to perform certain skills to a certain degree. Light and McNaughton (2014) claim that significant support is required to integrate people with severe or profound intellectual disabilities (SID) into their own communities.

Our model allows effective learning and proactive interaction for both the disabled and for the professionals. Moreover, it offers resources and a wide range of knowledge about the syndromes and the right strategies to be used.

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1. Background

While ICT tools have been around in the field of healthcare and disability environments for a long time, most of the efforts have not had the desired effect of achieving a standardize use among all agents involved in the communication or assistance tasks with the ill or the disabled. EC+ is a research project conceived with the purpose of filling this gap.

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The great potential of ICT tools will help disabled people to optimize communication and thus increase equality. Anderson et al (2009: 92) state that technologies must be user-friendly and socially accepted. They also affirm that to standardize the use of ICT tools, teachers and caregivers must have a positive attitude towards them, as well as a willingness to learn how to use them, which is not always the case. As Grgurict et al (2015:132) pose, there is no trust in technologies among many users and besides, those users generally suffer from more than one impairment at the same time. That is especially true of people affected by rare syndromes, and, hence, severe intellectual disabilities. Grgurict et al (2015:133) support the advantages of using multimodal interfaces that can address many of the target group requirements. Therefore, we intend to design user-friendly resources in our research.

Further commitment on the part of professionals is necessary since the number of disabled people is on the increase. As Quintanilla (2014) states, the situation of this population even in Europe needs urgent attention:

There are more than 80 million people with disabilities in Europe and with the ageing of the population; this number is likely to increase in the years ahead. Numerous international legal instruments and programmers of action have been developed. However, the international standards are not reflected in the actual situation of people with disabilities †(p. 1)

According to research literature, the situation is similar in a global context. According to the American Association on Intellectual and Developmental Disabilities (AAIDD), intellectual disability implies significant limitations in intellectual functioning and adaptive behaviour, as expressed in conceptual, social and practical skills. SID subjects are among the most vulnerable groups. As recent research underlines it is crucial to promote equality for people with severe intellectual disabilities in healthcare and all paths of life (Crotty & Doody, 2015) and authors such as Agran et al, (2013) also puts forward that technologies can promote equality by enhancing communication.

However, most of the research on disability focuses on people who have some capacities to perform certain skills to a certain degree. Thus, Light and McNaughton (2014) underline the importance to focus on the needs of the severely intellectually impaired:

There is really a need to offer resources for all subjects who have communication needs, but especially there is a lack of them for those severely intellectually impaired. [...] to ensure ease of access for all individuals who require AAC, and, (d) to maximize AAC solutions to support a wide variety of communication functions ‡(p. 107).

This claim is also found in the UN Convention on the Rights People with Disabilities§, which emphasizes the need of support for disabled people to exercise their legal capacity.

Until the 80s, the use of the AAC for this group of people was not even considered. Currently, there are still a number of obstacles to be overcome, including the barriers to carry out communicative exchanges. Opportunities for communication for this population can be found in inclusive settings (schools, homes and society), but it is assumed that the instruction of these subjects, using AAC, is only appropriate in very structured contexts, thus limiting any use outside of them. This makes it much more difficult to carry out communicative exchanges (Beukelman & Mirenda, 2013: 210).

While there is a strong commitment towards improving communication skills among people with severe intellectual disability during childhood (Brun et al, 2015), further communication strategies dwindle in adolescence and adulthood since, according to healthcare staff, therapists and teachers, those patients have reached the maximum of their potential when it comes to communication skills. This may well be the case in patients with severe syndromes that hinder oral communication (Camprubí-Sánchez et al, 2006: 2). However, in many cases, some skills in receptive and non-verbal communication are superior to verbal (Artigas et al, 2005: 7). This will require strategies and a standardized model to reduce stress and guarantee quality in intervention and care for all subjects with profound or severe intellectual disabilities. After all, a good many of those patients experience panic or stressful situations due to frustration, since

† <http://www.refworld.org/pdfid/55b255374.pdf> [Retrieved: 15-5-2016]

‡ <http://assembly.coe.int/nw/xml/XRef/Xref-XML2HTML-en.asp?fileid=21339&lang=en> [Retrieved: 15-5-2016]

§ <http://www.un.org/disabilities/convention/conventionfull.shtml> [Retrieved: 14-5-2016]

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