The Brazilian and United States experiences on the empowerment of people with disabilities through technologies

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ABSTRACT

Technologies have long enabled individuals to overcome natural restriction and human limitations. This paper highlights some of Brazil's and United States' policies on the subject. Additionally, brings examples of assistive technology and ambient assisted living available in U.S.A market to support people with intellectual disabilities.

Keywords: Assistive technology. Ambient assisted living. Smart homes. Universal designing. Cognitive disabilities.

Experiências de Brasil e Estados Unidos sobre o empoderamento de pessoas com deficiência através de tecnologias

RESUMO

As tecnologias sempre permitiram aos indivíduos superar restrições naturais e limitações humanas. Este artigo destaca algumas das políticas do Brasil e dos Estados Unidos nesse campo. Além disso, traz exemplos de tecnologia assistiva e ambient assisted living disponíveis no mercado americano para apoiar pessoas com deficiência intelectual.

***Palavras-chave**: Tecnologia assistiva. Ambiente assistido. Casas inteligentes. Design universal. Dificuldades cognitivas.*

Experiencias de Brasil y Estados Unidos sobre el empoderamiento de personas con discapacidad a través de tecnologías

RESUMEN

Las tecnologías siempre permitieron a los individuos superar restricciones naturales y limitaciones humanas. Este artículo destaca algunas de las políticas de Brasil y Estados Unidos en este campo. Además, trae ejemplos de tecnología asistida y ambient assisted living disponibles en el mercado estadounidense para apoyar a las personas con discapacidad intelectual.

***Palabras clave**: Tecnología asistiva. Ambiente asistido. Casas inteligentes. Diseño universal. Dificultades cognitivas.*

INTRODUCTION

According to the 2015 Disability Status Report from Cornell University, 5 percent of North Americans, roughly 16 million, are people identified with a mental disability (ERICKSON, 2016). In Brazil, 1.4 percent of the population, around 3 million, are people with a mental disability[1] (IBGE, 2010). The number of people with disabilities drives politicians, researchers, and advocacy groups to identify effective means to promote optimal functionality for people with disability in the community in the both countries. Additionally, the governments of both countries us similar strategies to support people with disability.

The primary aim of this article is a retrospective comparison of government processes in both Brazil and the United States in regards to federal sponsored empowerment of people with disabilities and promote innovation within the field of Assistive Technology (AT) for people with disabilities. The second goal is to provide an overview of the products and services to people with intellectual disabilities (Assistive Technology) and the modification in an environment to support autonomy (Ambient Assisted Living and Smart Homes) in United States. (1). The methodology adopted was a literature review in Portuguese and English.

The definition of disability used throughout this paper is the one proposed by International Classification of Function Disability and Health that conceptualizes a person's level of functioning as a dynamic interaction between health conditions and environmental factors. These environmental factors range from physical factors (such as climate, terrain or building design) to social factors (advocates, institutions, and laws). Interaction with environmental factors is an essential aspect of the scientific understanding of 'functioning and disability' (ICF, 2001).

[1]5.1% Cognitive Disability (asked of persons ages 5 or older if because of a physical, mental, or emotional condition, does this person have serious difficulty concentrating, remembering, or making decisions?) and 5.6% Independent Living Disability (asked of persons ages 15 or older if because of a physical, mental, or emotional condition, does this person have difficulty doing errands alone such as visiting a doctor's office or shopping?)

THE STRATEGIES TO PROMOTE INCLUSION THROUGHOUT ASSISTIVE TECHNOLOGIES (AT)

Brazil started the process of deinstitutionalization know by "Reforma Psiquiátrica" in the early 70s and culminated in 2001 with the Federal Law 10.216 to start the closure of all public institutions (manicômio). It is typical of the psychiatric reform dynamics for the emergence, at different times and in different regions, of innovative experiences and new technologies to meet the challenge of care and social inclusion (BRASIL, 2005). The new services are offered by the "Centros de Atenção Psicossocial" (CAPS). The CAPS are locally coordinated and manage the mental health programs sponsored by the Brazilian universal health service (SUS). The program contains clinical services and assistant living program that promote inclusion of people with disabilities known as the "Serviço Residencial Terapêutico (SRT)" and "Centros de convivência". Otherwise, the assistive technology in Brazil, since 2004, has the Secretaria Especial dos Direitos Humanos da Presidência da República, with Committees and regulations to promote the production of AT and the assessment of the products and services.

The National Program for Assistive Technology (Programa Nacional de Tecnologia Assistiva), through which R$ 60 million in credit lines was made available in the form of non-reimbursable funds during the period 2012-2014 to fund projects submitted by a consortia of universities and other Science and Technology Institutions, as well as companies engaged in the assistive technology (AT) field, and R$ 90 million in subsidized credit, at an interest of 4% per year between 2012 and 2014, for innovation projects undertaken by firms in the AT sector. The goal was to compensate for the lack of information on AT products for industry professionals, persons with disabilities, the elderly, and their families (UN, 2011).

The United States health system, Medicare and Medicaid, was introduced in the 60s. At that time, the products and services available to persons with

disabilities were originally limited to mobility-oriented, low-technology objects such as crutches, wheelchairs, and artificial limbs. In the late 1960s, people with disabilities began to express their needs in the context of civil rights, arguing that they had an equal right to access all domains of functionality.

This led to the creation of the National Institute on Disability and Rehabilitative Research (NIDRR) in 1973 and the implementation of the Supplemental Security Income program in 1974. These programs allowed state governments to accelerate deinstitutionalization and enhanced the mission to support research in technologies and increase the scientific information available in usable format to enhance the opportunities for individuals with disabilities.

From the early 1980s until about 1985, individuals developed and operated assisted living models and US government started to sponsor research and development in the emerging technologies before they became commonly known as Functional Electrical Stimulation (FES) and Universal Design (UD). The years from 1986 to 1993 were characterized by the growing awareness and interest from consumer groups and public policy leaders and continued the development and small-scale replication by care providers (LANE, 2015).

After over forty years of Unites States attention and investment, the expectation was to see a tremendous expansion of AT products and services while having total deinstitutionalization to promote independent living through technologies

however, the prevalence of a cognitive disability and independent living disability was still as low as 10.7 percent of Americans considered non-institutionalized (RALEY,2015).

Brazil and United States adopted similar strategies to close institutions (manicômio), and both governments invested in the academic sector to enhance the production of AT. Further, the National Center for Excellence in Assistive Technology (Centro Nacional de Referência em Tecnologia Assistiva) launched a virtual catalogue of more than nineteen thousand assistive technology products available in Brazil, according to ASSITIVA. According to ABLEDATA, there are an estimated twenty-six thousand assistive technologies available at the U.S. market. Both countries AT products range from no-tech to high-tech.

As in Brazil, the majority of people with disabilities in U.S. who need AT to compensate for their functional limitations are either unemployed or underemployed. This majority is dependent on reimbursement for AT purchases through a third-party source (e.g., government agency, insurance company). U.S. Medicaid and Sistema Unico de Saude (SUS) provides reimbursement to AT devices that are deemed medically necessary, called Durable Medical Equipment (DME). This limitation in turn limits industry incentives for producing and supporting non-DME category AT products and services to support people with intellectual disabilities in both countries (MUSUMECI, 2017)

ASSISTIVE TECHNOLOGY PRODUCTS EMPOWERING PEOPLE WITH INTELLECTUAL DISABILITY (AT)

Assistive technologies are any item, piece of equipment, or product system, whether acquired commercially off the shelf, modified, or customize, that is used to increase, maintain, or improve functional capabilities, communicate, and visualize activities that improves quality of life of people with disability (IDEA, 2004). These technologies assist individuals to accomplish work and/or overall process. It is useful to support cognitive function across all individuals rather than for a particular group. For example, similar cognitive challenges may occur across different user groups, or a given technology may support multiple cognitive functions (SAYKO, 2015).

Assistive technologies can be divided into two main categories: low tech and high tech. The low tech items are usually inexpensive, simple to make, and easy to obtain. Examples of low tech devices are a *specialized page turner* or a *program modification*

that increases time or access to classroom notes. In the classroom and elsewhere, these assistive devices allow learners with disabilities to participate in educational activities. The *automatic door opener* improves accessibility to public places for people in a wheelchair, *Big Mack switches* can make it possible for people with limited motor skills to play with toys and games.

High tech equipment is usually more expensive and often requires training the person using it as well as others who are supporting the AT user. However, with the increased use of technology in everyday life, these devices are often allowing the user to easily blend in because they are universal in design like *monitoring cameras, digital recorders,* and *cause and effect software program* technologies that provides autonomy and safety for people with disabilities to perform tasks as cooking, dressing, and grooming in ambient living or smart homes.

High tech products are designed to empower and support autonomy. Designing new AT through the framework of universal design means the production of new technology must have usability which focuses on the widest range of functional capabilities (including people with various deficits) and should be available all over the word.

Other examples of high tech products are: the *No Screen Timeout*[2] which is helpful for people who find it difficult to decide what to answer, or have difficulty entering the answer quickly; the *slow talk control*[3] which is a feature that allows individuals to slow the speed of speech in real time when checking voice messages; *Tell Me What You Want to Do*"[4] function on Microsoft that helps people quickly get to features or actions they want; *Microsoft natural speech screen readers*[5], that makes Websites more accessible with easy speech, reading and reduce barriers between the content and audiences by translation tools text to speech components.

Also, the challenge of linking a person with disability to the AT to support a given set of tasks can be the most complex of the challenges. According to a recent systematic review in the United States, 13.5% to 65% of AT suffered "abandonment" or non-use largely due to inadequate customization to individuals and their life contexts. (THOMAS, 2010). These few examples of AT products and services available United States market that are able to support intellectual and motor impaired people in their daily activities and empower to living autonomously in their community if adequately customized.

AMBIENT ASSISTED LIVING AND SMART HOMES EMPOWERING PEOPLE WITH INTELLECTUAL DISABILITY

Ambient Assisted Living (AAL) aims at applying technology to enable people with specific needs to prolong their living in their preferred environments. In other words, it aims to construct and provid safe and adapted environments for people with specific needs to empower them to live more independently (MATOS, 2015). Smart home systems can support assisted ambient living systems. The research concerning smart technologies that supported independent living in buildings found that 43% of the intelligent-assistive technologies are located in the kitchen (medication, glasses/cup, stove, kettle, fridge and coffee pot), 22% bedroom, and 20% bathroom, the entrance/hall/corridor, while the lounge is clearly not equipped enough (12%) (LABONNATE, 2017).

Both Smart Home and Ambient Assisted Living systems are using sensory data collectors to recognize a single activity whereas others can contribute to several activities. Figure 1 is a summary of the steps of the ALL system.

[2]Samsung phones now offer "No Screen Timeout," which keeps a phone screen open when the phone displays an alert or a question that requires an answer.

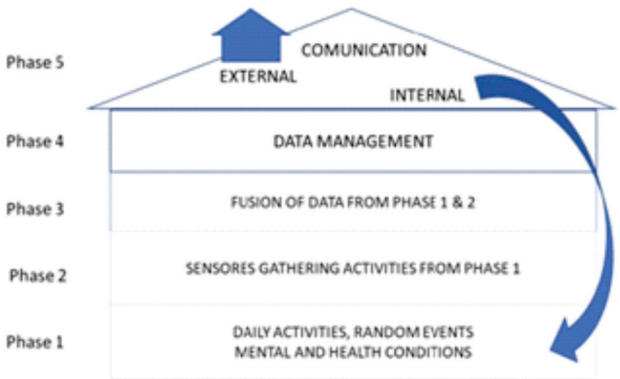
[3]Panasonic offer a "slow talk control" Panasonic, Amplified Cordless Phone with Digital Answering Machine –1 Handset –KX-TGM450S, *http://shop.panasonic.com/home-and-office/cordless-corded-telephones/amplified-telephones/KXTGM450S.html*

[4]Microsoft's Outlook 2016 offers a "Tell Me What You Want to Do", Do Things Quickly with Tell Me, *https://support.office.com/en-us/article/Do-things-quickly-with-Tell-Me-f20d2198-17b8-4b09-a3e5007a337f1e4e*

[5]*https://www.texthelp.com/en-us*/products/browsealoud.aspx

In figure 1, for example, the action of boiling water executed by the resident with a disability (phase 1). The action of turn the stove can trigger the motion sensor and the camera in front of the oven (phase 2). The data from motion sensor and camera are merged by the ALL system and produce a fused data report (phase 3). The fused information report is used to manage the resident's safety while performing that activity. If boiling the water is a scheduled daily activity, the resident is safe and stays on task in front of the stove, no external communication (phase 5) is need. If boiling the water is an event not scheduled but the resident is safe and stays on task in front of the stove, an internal communication would inquire if the resident's health condition, and based upon the health condition the AAL management system would require external communication, like calling a health care provider (phase 5). Finally, another situation that would require internal communication is if the resident is not safe or does not stay on task and leaves the kitchen on phase 1.

Figure 1 – Illustration of ambient assisted living system.



Source: DaLee C.K. (2017).

The AAL systems are developed for personalized (daily activities), adaptive (random events), and anticipatory requirements (call the health care provider), necessitating high-speed internet connection and quality-of-service to achieve interoperability, usability, security, and accuracy (MEMON, 2014). The lack of accesses of high-speed internet connection can create a "digital division" for people accesses the AAL system benefits. Due to the recent technological advancements, healthcare professionals have faced the challenges of over confidence in the information provided by the house. Concerns exists such as sensors failing or providing unprecise information, the resident needing to call 911, or skipping a consultation because the house did not detect any health issue. Also, these technologies have moral and ethical implications by violating autonomy, spatial privacy, overreliance on technology, and potential concerns of data collection and dissemination (MASTROGIOVANNI, 2011) (FORKAN, 2017).

Finally, personalized configurations which implies that the medical sensors, network, system, and applications are configured and installed in correspondence to the requirements and preferences of the residence and caregivers. The personalization can be made by automatic identification of the user, and that reduces the complexity and increase the accessibility. Translating the needs into designs that will appropriately situate and customize technologies for diverse home environment and care situations is the main factor of usability and empowerment of individuals with disability (HWANG, 2012).

CONCLUSION

In both countries, the recent efforts in empowering people with cognitive disabilities was the result of greater awareness among people with cognitive disabilities, caregivers, industry, and stakeholders about the need of inclusion by technologies. Brazil and the United States have similar strategies to address deinstitutionalization, and both countries are using the system of exploratory-grant system to sponsor AT development for persons with disabilities.

The United States has been leading some initiatives over the past few years; however, there was no evidence that Brazil is following the same pathway because Brazil has different productivity on AT, specially the communication devices, and AT used at schools. Also, the literature review was not clear if the delay on the use of the AAL system is a Brazilian strategy of expecting full maturity of the AAL system or a lack of government sponsorship.

The population with disabilities is a heterogeneous group with a wide variety of skills, interests, abilities, and impairments. Consequently, according to the literature review, the diversity enhanced the reliance on universal design to develop AT and AAL systems. The framework of universal design in the elaboration of computer software and hardware is to avoid costly and burdensome retrofits. It is expected that the principle of universal design is widely applied to reduce the digital division by offering personalized products and low rates of technology abandonment.

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