Chapter 5

Information Challenges of the Deaf in their Health and Social Care Needs

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ABSTRACT

The members of the deaf communities have been excluded for many years from society and their own culture. Deaf culture is a term applied to the social movement that holds deafness to be a difference in human experience (which includes the right to use Sign Language) rather than a disability. The deaf suffer, daily, through life-threatening situations that go unattended, mostly due to lack of awareness, proper practices, and policies, among others. The Deaf are in dire need of acknowledgment of their plight, in particular by Health and Social Care practitioners, politicians, and researchers. This chapter calls attention to this minority and its needs, including social, political, citizenship, strategies, and polices dimensions. It presents a Human-Computer Interaction architecture with which to inform the design of Information and Communication Technologies to aid Health and Social Care professionals in their work with the deaf.

INTRODUCTION

The changes brought about by the ICT – Information and Communication Technologies made information, communication, and knowledge paramount to full exercise of citizenship. These transformations did not happen evenly, and si-

multaneously: many groups, communities, and countries have benefited, leaving, on the other extreme, entire societies in dire exclusion (Castells, 2003). Although some countries may be witnessing an increase of expenditure in Health and Social Care (HSC), that increase is neither adequate nor universal. Some countries (e.g. Bra-

zil) and some groups, specifically the members of the Deaf community, are underserved, at the cost of life-threatening situations, mostly due to the lack of awareness and proper practices and wrong policies.

HSC practices presuppose knowledge of reality. The information society demands from the individuals a behavior based on access and use of information. Excluded from the information society, the society adds to the Deaf's grievance the lack of awareness for their needs in all sectors. In the often disregarded and misinterpreted assistance actions to citizens of Deaf communities, there is a lack of understanding about their real difficulties: mainly, the need to address their Sign Language (SL). Natural Language and its acquisition has long been the subject of researches, which have proven its crucial role in intellectual development, social integration and full citizenship exercise (Chomsky, 1988; Vygotsky, 1962) the lack thereof brings all sorts of unwanted consequences, and deems assistance impractical.

The Deaf have been excluded from society for a long time, mostly by prejudices, and, worst, by current (wrong) "medical" approach (i.e. one that tries to bring the Deaf to the "hearing" normality). The plight of the Deaf lingers, making it hard for the members of the Deaf community to receive proper care, and, thus, be able to pursue inclusion and full citizenship. Research (Skliar, 1999) shows all sorts of prejudice, abuse and life-threatening situations, whose demand for HSC are not met, mostly due to "ignorance" (i.e. not knowing the reality and not seeing the reality) of the hard conditions the Deaf face within their own families in particular, and society in general; a daily drama the members of the Deaf community must endure: isolation, abuse, intellectual deprivation, disrespectful treatment among others, in regards to their specific needs: a profound reflection upon this state of affairs is much need; one that promotes a shift in attitude. From HSC standpoint, the consequences of the lack of this new proposed focus are two-fold: the absence of proper services when needed, and the lack of public policies that do not reflect reality.

This chapter aims at raising awareness to the needs of the Deaf (e.g. challenges, needs, exclusion), by presenting results of information behavior research as evidence of the lack of necessary and adequate approach to the Deaf's plight (e.g. lack of policies, research, tools among others). The Human-Computer Interaction (HCI) architecture is presented, with some specific technological frameworks, in order to inform the development of tools and Intellectual Artifacts. Those artifacts should be developed to aid the professionals involved to better assist the Deaf in their HSC needs. Intellectual Artifact is a product created by an intellectual activity, based on the interpretation of a problem, and the conception of the solution, presented in a linguistic and computational code (De Souza, 2005).

HEALTH AND SOCIAL CARE FOR THE DEAF

The Deaf are members of the society with specific characteristics, such as culture, identity, and means of communication, among others, who must be respected in their needs. In such cases, HSC must aggregate other dimensions when it comes to awareness, public policies, tools, etc., and must break down the barriers of appearances, so that effective knowledge about the elements that constitutes the reality with which practioners and researchers must act upon the social issue can emerge. Therefore, capacitation must occur, in order for planning and action with propriety, so that HSC may become a transforming agent for this minority, whose need for full-fledged citizenship cannot be deprived of such services and policies.

Sign Language and Citizenship

Natural Language and its acquisition has long been the subject of researches, which have proven its crucial role in intellectual development, social integration and full citizenship exercise (Chomsky, 1988; Vygotsky, 1962). As for the Deaf, they were

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