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The Role of HCI in the Construction of Disability

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ABSTRACT

As a discipline concerned with the design, evaluation and implementation of interactive computing systems for human use, and with the study of major phenomena surrounding them, human-computer interaction (HCI) is involved in the phenomenon of disability. For an interaction between humans and computers to take place, there should be an interface mediating between both parties. The design of such an interface may inadvertently impose access barriers to some people. HCI literature addresses the relationship between the theory and practice of HCI and disability from different angles, some of which are diametrically opposed.

This thesis explores three modern conceptions, or models, of disability — the individualistic medical, the biopsychosocial and the social models —, investigates which model predominates in the HCI literature, and analyzes why choosing a particular model may determine and constrain the classes of problems that can be identified during a solution discovery process.

Departing from HCI's traditional discourse, which interprets the phenomenon of disability as a problem in the human body, the author, leading a team of engineers and psychologists, carried out a project in a school for children with cerebral palsy. The project was aimed to improve different areas of child development, using non-conventional user interfaces — i.e. user interfaces that use other input/output devices than the keyboard, mouse or screen.

After two years working directly within the “field of operations”, the author had the opportunity to contrast the theory underpinning HCI's methods with real practice and to expand his understandings about the relationships between HCI and disability. The research process involved an action research approach, which allowed the author and the team of experimenters to formulate new hypotheses as they learned more about the context, to review the process and, ultimately and most importantly, to readapt their actions to better serve the end beneficiaries. The experiences and learnings gathered throughout the process have been included in this thesis as a case study, for the purpose of helping HCI researchers embarking on projects relatable to the one described. Finally, the author urges the HCI community to update its discourse and to connect it with the vast literature related to modern conceptions of the phenomenon of disability.

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1 INTRODUCTION

The Association for Computing Machinery (ACM) defines human-computer interaction (HCI) as “a discipline concerned with the design, evaluation and implementation of interactive computing systems for human use and with the study of major phenomena surrounding them.” (Hewett, et al., 2009)

In spite of its apparent conciseness, the ACM’s definition is followed by a paragraph explaining that “There is currently no agreed upon definition of the range of topics which form the area of human-computer interaction.” (Hewett, et al., 2009)

This difficulty in finding a unique, concise definition has characterized the field along its history and persists until today (Grandhi, 2015). One possible explanation for this characteristic is that HCI is not a single discipline but a dialogue between many. Its scope encompasses many coexisting theories, methodologies, epistemological conceptions and subjects.

For instance, the base disciplines that have historically contributed to the field cover a wide range of research topics, including human factors (sometimes referred as human factors engineering, or ergonomics), information systems (sometimes referred as management information systems, MIS, or data processing)¹, computer science, sociology — along with anthropology — and psychology — along with cognitive science (Lazar, Feng, & Hochheiser, 2010).

As a discipline concerned with humans, HCI is necessarily connected with the phenomenon of “disability”. The reason is that, for an interaction between humans and computers to take place, there should be an interface mediating between them and the design of such interface may inadvertently impose access barriers to some people. HCI addresses this issue from different angles, some of which are diametrically opposed.

The main goal of this thesis is to explore some of the ways human-computer interaction interprets and contributes to the construction of the concept of “disability”. Beyond the multiple theories supporting different conceptions, the author carried out a 2-year HCI research project consisting in developing user interfaces for children with cerebral palsy. The project, described in this thesis, helped the author compare theory and practice and learn key insights into the role of HCI, not only in the construction of access barriers that prevent people from using technology, but also *in the construction of the phenomenon of disability itself*. In other words, it revealed how the theory and practice of HCI convey a discourse that carries within it a (particular) notion of disability.

¹ Definitions of human factors, ergonomics and information systems come from (Grudin, 2008).

Contents

This thesis is organized in three chapters.

Chapter 1 describes the discipline of human-computer interaction, summarizes its history and discusses about how it is connected with the concept of “disability”.

Chapter 2 describes a 2-year HCI research project co-directed by the author in a public school located in Uruguay that brings together children diagnosed with cerebral palsy and other motor dysfunctions. Being the school legally a *regular* school, it received, approximately one year before the project started, an amount of laptop computers of the model “XO” to distribute among the schoolchildren. These computers, popularly known as the XOs, were distributed by the government of Uruguay among all public schools in the country, as part of the One Laptop per Child (OLPC) program.

Some of the difficulties and challenges encountered during the execution of the project, lately analyzed during meaningful interdisciplinary group discussions and debriefing sessions, exceed the particularities of the project and are relatable to the kind of problems that arise when working with children, professionals, communities and institutions bound together by the phenomenon of physical disability. Researchers working on similar contexts may hopefully find in the case study described in chapter 2 a handful of insights into planning and executing their projects.

With hindsight, Chapter 3, named “The Role of HCI in the Construction of Disability”, takes these teachings to a higher level, comparing them with the currently prevailing discourses, or *models*, of disability and proposes alternative approaches to address the problem — not necessarily rooted in the use of technology. For instance, it discusses and proposes alternative ways in which the practice of HCI could be improved in such a way that could reduce exclusion and empower the people so called “disabled”.

Brief history and definition of HCI

The general consensus is that HCI as a field was formally founded in 1981, as a result of the first conference on Human Factors in Computing Systems in Gaithersburg, Maryland, United States (Lazar, Feng, & Hochheiser, 2010). This conference later turned into the annual ACM SIGCHI (Special Interest Group on Computer-Human Interaction) conference — the major international conference on human-computer interaction — popularly known as *CHI*. CHI is recognized as the most prestigious conference in the field of Human-Computer Interaction².

² For more information on the evolution of Human-Computer Interaction and its relationship with other disciplines, see (Grudin, 2008).

This agreement about the beginning of the discipline does not imply that all research done before 1981 should not be considered to be HCI work. On the quite contrary, seminal works related to the field can be traced back as far as 1945 and are taken as a fundamental part of the history of HCI (Lazar, Feng, & Hochheiser, 2010).

In 1992, the Association for Computing Machinery (ACM), through the ACM SIGCHI, published the Curricula for Human-Computer Interaction, which defines HCI as:

“A discipline concerned with the design, evaluation and implementation of interactive computing systems for human use and with the study of major phenomena surrounding them.” (Hewett, et al., 2009)

It is worth noting that the Curricula itself acknowledges that “There is currently no agreed upon the definition of the range of topics which form the area of human-computer interaction.” (Hewett, et al., 2009)

One of the reasons explaining this difficulty lies in the intrinsically interdisciplinary nature of human-computer interaction (Grandhi, 2015).

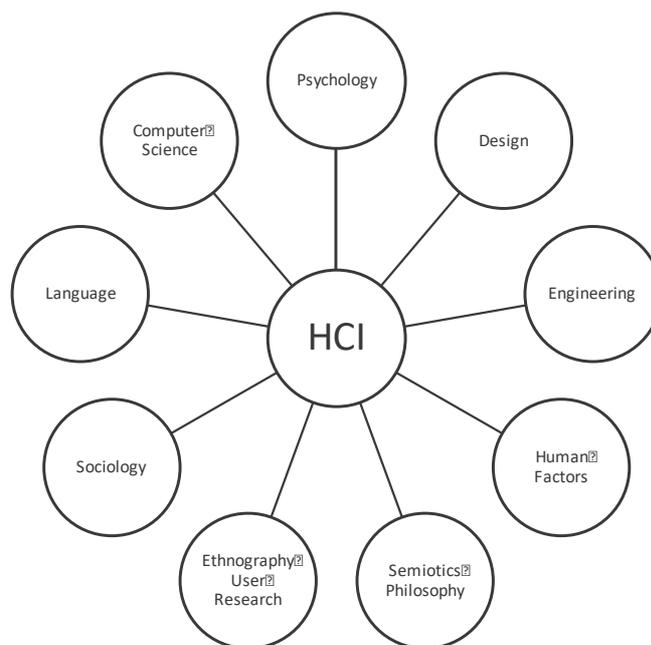


Figure 1 – The interdisciplinary nature of human-computer interaction discipline.

As research trends evolved, some disciplines converged into the field, carrying their own theory and praxis, dominating the HCI discourse at a specific point in history.

For instance, at the beginning, the dominant fields might have been human factors, engineering and psychology (Lazar, Feng, & Hochheiser, 2010). Methodologically, these fields are backed up by the experimental design model, which contributed its terms and conceptions to HCI’s discourse and practice.

Nowadays, with computing becoming ubiquitous, taking the form of smartphones, smart watches, wearables and other connected devices, new disciplines, bringing new theories and approaches, have got involved and converged into HCI. As a consequence, terms such as “information design”, “information architecture”, “interaction design” and, more recently, “user experience design”, irrupted into the human-computer interaction narrative.

A historical trace about the convergence of these new disciplines into the field could be found in (Grudin, 2008).

Interdisciplinary nature

This interdisciplinary character of HCI brings some challenges, including difficulties in evaluating, validating, reviewing and even justifying an HCI research project:

“While the HCI community might be considered by some to be an interdisciplinary community, many other conferences, professional organizations, and individuals keep the focus on their primary discipline. When interdisciplinary research gets filtered through single-discipline evaluations, there are many challenges that can occur. Some of the challenges are well-known, such as how some disciplines (e.g. computer science) focus more on conference publications and others (e.g. management information systems) focus on journal publications. Some disciplines focus on single-author publications, while others focus primarily on group-author publications. Some disciplines are very open about sharing their results, while others keep their results more confidential. Some disciplines are very self-reflective and do research studies about their discipline (trends of research, rankings, funding, collaborations), while others do not. (...) And interdisciplinary researchers can sometimes have problems convincing others at their workplace of the quality and seriousness of their work.” (Lazar, Feng, & Hochheiser, 2010).

Some scholars are emphatic about the real need of having different disciplines actively participating during the execution of an HCI research process. They argue that serious HCI research work cannot be done without the input from various research methodologies and practices at different stages of the process.

For example, Lazar, et al, discusses about how MIS, psychology, sociology, statistics and computer science can cooperate with each other, bringing their own theories and methods, for the overall benefit of achieving scientifically valid results (Lazar, Feng, & Hochheiser, 2010).

To explain their argument in a comprehensible way, they distribute the base disciplines across different phases of a typical HCI research process. For example, a typical HCI research work begins with a theoretical

framework supporting the experiment, then it formulates hypotheses, defines the research methodology, selects the subjects, executes the needed tasks to perform a quantitative or qualitative analysis and ends with a series of results and hopefully new insights into the interaction between humans and machines. Each phase is backed up by the previous one, as if they were steps of a stairway: in order to climb to the next step, one need to stand up on the previous one. Each discipline underpins and provides a solid foundation to each step — or phase of the research process. Should one step lack of stability, then the stability of the whole structure would be also compromised.

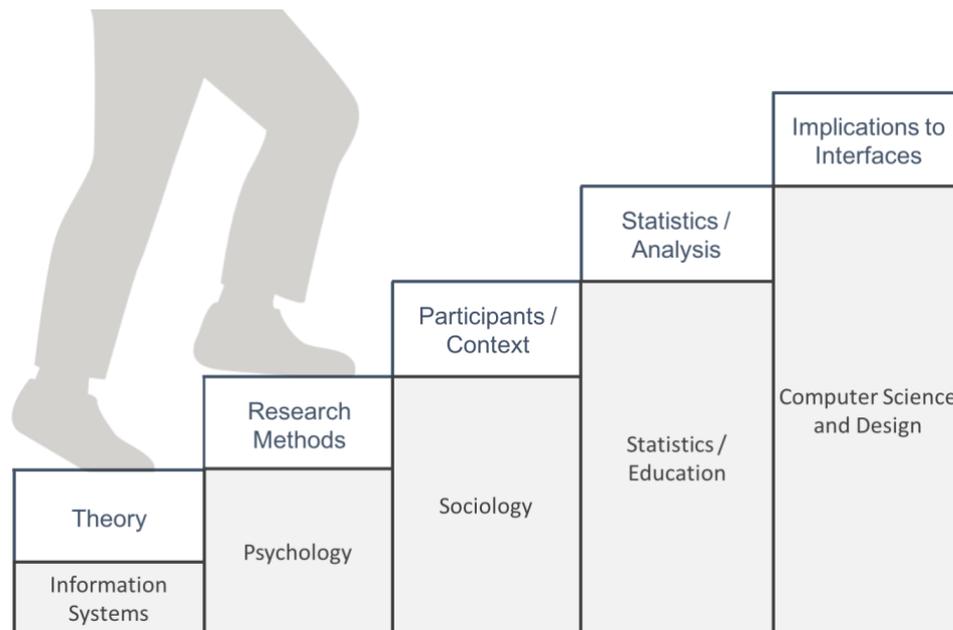


Figure 2 – Disciplines are distributed based on the particular importance they give to certain aspects of the research process. Within the context of HCI research, disciplines focused on different aspects should dialog between each other in order to excel at all stages of research. (The original scheme used the metaphor of a pipeline instead of a stair.) (Lazar, Feng, & Hochheiser, 2010) – The silhouette of the person climbing the stairs has been designed by vexels.com.

This is certainly a generalization, for disciplines may contribute not only at specific stages of the research process, but they are expected to interact with the others during the whole process. However, disciplines arguably tend to focus more intensely on particular stages of research. For example, sociology pays particular attention to the demographics of the research participants to determine if they accurately represent the population of interest. However, this procedure is not too *critical* in computer science research projects, where participants are usually selected among students. Hence, for example, bringing in sociology into the subject selection process during an HCI experiment, and not resting only on computer science’s research methods, could improve the overall validity of the results.

Thus, whatever it be the reason, constraining the theoretical foundations, procedures and good practices to only the ones provided by a single discipline, may affect the impartiality of the results. On the contrary, borrowing knowledge and methods from other disciplines can improve the overall research work (Lazar, Feng, & Hochheiser, 2010).

Multiplicity of approaches

The convergence of different disciplines across the history of HCI can be structured in three stages, or *waves* (Bødker, 2015). Each wave is characterized by its focus on a particular set of research interests and methodologies.

First wave HCI

The first wave occurred in the 1980s and was driven by cognitive science and human factors. HCI research was focused on the human being as a subject to be studied through rigid guidelines, formal methods and systematic testing (Bødker, 2015).

Hitherto, the interaction between people and computers occurred mostly on workstations situated at the workplace. The focus of HCI research work was on how to increase the efficiency in completing tasks by studying the cognitive aspects ruling people's actions when performing tasks.

A typical first-wave HCI research work circa 1980s is hardly distinguishable from any human factors research work that predates the very existence of HCI as a field of study — it is not a coincidence that the full name of the CHI conference is Human-Factors in Computing Systems.

That early resemblance between both disciplines is such that one of the most renowned academic achievements of human factors is frequently mistaken for an achievement of HCI: The Fitts' Law, devised by Paul Fitts and published in 1954, in a context that had little to do with HCI.

The Fitt's Law quantifies the difficulty in selecting a UI (user interface) component, like a button, and predicts that the time required to rapidly move to the target area is directly proportional to the distance to the target and inversely proportional to the width of the target (Fitts, 1954).

$$ID = \log_2\left(\frac{2D}{W}\right)$$

Equation 1 – Fitts' Law. The index of difficulty (ID) of selecting a target is a function of the ratio between the distance to the target (D) and the width of the target (W). ID is measured in bits.

Findings like these help mathematically explain human behavior when interacting with user interfaces. One economical implication of the Fitts' Law and other achievements of HCI, is that they give UI designers and

developers a core set of abilities and behaviors that could be extrapolated to other *typical* human beings. Hence, when designing a user interface, findings like the Fitts' Law help predict how a *typical* user will behave when performing a particular task. This helps designers disregard some baseless ideas when seeking a technological solution.

As the example suggests, a typical first-wave HCI project focuses, and its scope is limited to, individuals using a computer, without questioning the cultural, emotional or any other anthropological dimensions of human beings.

The problems arise when the base itself is founded on studies performed on *typical* human beings that attempt to extrapolate their results to *all* human beings, without any questioning. This topic is discussed below in Chapter 3.

First wave HCI's methodology is characterized by accepting the meaning of the entities surrounding the human being without ever calling them into question. For a first-wave HCI researcher a PC is a PC, the workplace is the workplace and human beings are human beings. A first-wave researcher would never ask whether the PC is being used by a single user or by many people, whether the users really need a new system or the workplace is the source of the users' problems or whether the research subjects represent humanity or not.

Methodologically, first-wave HCI is characterized by having a pragmatic approach to *meaning*, taking it for granted — and mostly ignoring it (Sengers, Boehner, & Knouf, 2009, p. 9).

Second wave HCI

The second wave emerged during the 1990s. It is characterized by research works that takes into account the environment surrounding the research subjects and not only single users interacting with single computers. In particular, it has been traditionally focused on humans interacting with machines within the workplace. The research focus is thus expanded to the time, place and circumstance in which a group of people collaborates and interacts with a set of applications.

However, for a typical second-wave approach, the context where the interaction takes place is pre-ontological. That not necessarily implies that second-wave HCI is not interested in analyzing or problematizing the context. Rather than that, it could be thought of as a hands-on, incremental, approach while a more comprehensive description of the phenomena is being formulated.

Another characteristic of the second wave approach is that it disregards people's desires, feelings or emotions, as relevant elements that are worth being dissected.

The second-wave narrative would define HCI as a discipline involving “the design, implementation and evaluation of interactive systems in the context of user’s tasks and work” (Dix, Finlay, Abowd, & Beale, p. 4). Although the context here is mentioned, in opposition to the previous wave, its methods “tend to require problems to be formalized and expressed in terms of tasks, goals and efficiency” (Sengers, Boehner, & Knouf, 2009, p. 6).

As the context become more and more relevant for researchers to help capture the increasingly complex human-computer interaction dynamics, the second wave attempted to formalize it and include it in the information flow’s equation. This endeavor was underpinned by the information-processing metaphor, which conceives the context as yet another source of information that can be formalized and transmitted to machines (Harrison, Sengers, & Tatar, 2011).

Research work by anthropologist Lucy Suchman at Xerox PARC shows a clear example of a typical second-wave HCI research project. Shuman showed that valuable information is lost when the methodology focuses only on the interaction. She found that the circumstances surrounding the interaction plays a key role in modeling the problem and thus designing successful products (Thomas, 1995).

Suchman “Observed users attempting to complete a photocopying task with the help of an expert system designed to help them identify problems and complete tasks correctly. Through analysis of videos and a framework designed to demonstrate the relevant features of the interactions between the humans and the expert system, Suchman developed a rich and detailed understanding of how differences between the human model of the copier and the expert system’s model led to communication breakdowns and tasks failures.” (Lazar, Feng, & Hochheiser, 2010, p. 222)

Situated action, distributed cognition and activity theory were important sources of theoretical reflection. A variety of methods, including participatory design workshops, prototyping and contextual inquiries, were added to the HCI research toolbox by the second wave (Bødker, 2015).

Third wave HCI

While the second wave was more focused on work settings, research works belonging to the third wave broaden the field of practice to the private sphere — e.g. homes — and larger environments.

The third wave responds to a crisis resulting from a clash between a new reality, i.e. technology becoming ubiquitous and pervading every aspect of our lives, and first- and second-wave HCI methodological and epistemological approaches. During this period, the boundaries of the workplace blur and mix with other daily activities while people use their

smartphones or other devices at home or other places, mingling work and leisure.

Third-wave researchers claim that the design of human-computer interfaces couldn't be reduced to analyzing the interaction between software and psyche. Rather, they argue that it is important to call into question the context where the interaction takes place. Instead of interpreting the context as another component that can be modeled as a mechanistic information-flow-based mathematical object, as the second wave does, the third wave's context involves other users, organizational constraints, policies, basic knowledge and traditions³ that are created, and determined, by the uses of technology (Thomas, 1995, p. 2).

Sengers, *et al*, (Sengers, Boehner, & Knouf, 2009) identifies some key characteristics of this movement.

First, meaning is seen as a construction deriving from a complex interaction between people in specific contexts and situations (Harrison & Sengers, *The Three Paradigms of HCI*, 2007). Consequently, interventions are designed for, and evaluated in, specific, local contexts.

Second, the integration between newly designed systems with existing systems and practices is emphasized. Designs are evaluated not as standalone systems but in a wider context of use, including sociocultural dimensions.

Third, human-computer interaction is not seen as a task-oriented information exchange anymore, but a discipline aimed to achieve a holistic understanding of users as thinking, feeling, sensing and relating.

Finally, third wave HCI is concerned about whether and to what extent "designers can and should control user's experiences, issues involving dimensions of politics and values" (Sengers, Boehner, & Knouf, 2009).

Social science contributed one of its research methods to third-wave HCI: ethnography, described as the practice of using some form of participation in a group to develop an understanding of the group (Lazar, Feng, & Hochheiser, 2010, p. 221).

Traditional and contemporary social science ethnographers would spend time living in traditional villages, hanging out on inner-city street corners and immersing themselves in unfamiliar settings to understand the dynamics of groups of interests (Lazar, Feng, & Hochheiser, 2010, p. 221).

HCI ethnographers would occupy an office space in a company, a school, a hospital, or any particular technological setting where participants, objects and other entities interact.

³ The author talks about "realities and a culture of understandings" rather than "basic knowledge and traditions".

Ethnography — as well as other disciplines like design and the arts — are “based on the idea that use context is, in the end, fundamentally unspecifiable and must be dealt with by other means” (Harrison, Sengers, & Tatar, 2011). These disciplines are better suited to design for “complex, difficult to formalize, lived experiences, integrating technology design with social and cultural analysis” (Sengers, Boehner, & Knouf, 2009).

Table 1 summarizes the differences between the “three waves” of HCI.

	First wave	Second wave	Third wave
Underlying paradigm	Single-user / single-computer	Rational thinking. Context is modeled as another source of information which can be formalized and transmitted to machines.	Non rational thinking. The way in which individuals come to understand the world, themselves and interaction derives crucially from their location in a physical and social world as embodied actors
Subject of study	Individual using a workstation	Social situation of interaction at workplace. Context aware, but task-focused.	People’s emotion and experience using technology across different scenarios and situations
Computerization level	One computer serves many people	Computing devices equals the number of people using them	Computing devices outnumber the people
Challenges	How to optimize the fit between humans and computers	How to optimize cooperative work	How to bring together technologies, experiences and users across

			domains (including work, but not only). How to conceptualize and study these open-ended relationships.
Context delimited to	Individual using a computer	Work settings	Beyond work settings
Human dimensions involved	Psychophysical	Cognitive	Emotions and experiences
Methodological approach	Rigid guidelines, formal methods, usability testing	Participatory design, user experience design	Exploratory approach, ethnography, cultural probes

Table 1 – Comparison between first, second and third wave HCI. The table compiles points of views shared by different authors.

The user

The common ground shared by these many interpretations of human-computer interaction is that there is an entity called *user* — typically a human, although not necessary⁴ — who interacts with a computing system.

Cooper and Bowers (Cooper & Bowers, 1995) argue that HCI justifies its very existence and derives its legitimacy as an academic and applied discipline from the presence of the user and from the kinds of problems the user has to deal with⁵.

The definition of user varies and each field of study *constructs* the user depending on their own theoretical underpinning and practical needs. For instance, a cognitive-science based approach to HCI is mechanistic, conceiving the user as a rational actor which can be modeled as an information system. On the other extreme, an HCI research rooted in social science wouldn't accept a definition of a user which doesn't take

⁴ Users do not necessarily have to be human beings. Several living and non-living creatures, including dogs, cats, plants and even dead people, have been studied by HCI-related disciplines. These works has been published in CHI and can be found in the ACM's Digital Library.

⁵ Cited in (Satchell & Dourish, 2009).

into account the context in which the individual is embedded in (Satchell & Dourish, 2009).

Some authors go beyond these points of view and challenge the very idea of “the user”. (Satchell & Dourish, 2009) compiles some of these semiological controversies:

- The user reconfigures a multifaceted human being as an adjunct to a piece of hardware or software. The authors reduce this argument to a humorous example: “asked at a party what they do, no one has ever introduced themselves as a user of Microsoft Word (even if they are).”
- The user is embedded in complicated ways within the pragmatics of design. For instance, a strategic articulation of “the user” in a design team can help legitimate particular approaches and strategies. In other words, “the user” may serve as a rhetorical device to let a person or a group gain access to resources.
- The user is a “configurable” artifact. The authors cite a paper of Steven Woolgar, a British sociologist of science and technology, who studied the case of a microcomputer manufacturing organization which designed the next model not by configuring a machine to suit a specific body of users, but rather building the machine they could attempting to configure the users to suit the machine.

(Satchell & Dourish, 2009), among other authors, argue that “the user” should be recognized as a discursive formation rather than a taken-for-granted, natural, fact. This recognition leads to the examination of in which circumstances “the user” arises, the forces that shape it and how it is used.

The next section describes the history and evolution of a particular subset of HCI theory and practice, focused on — or which construes, depending on the underpinning though — a particular kind of “users”: users with disabilities.

The history of HCI and disability

Before HCI was conceived as a discipline there was concern about the need to develop non-excluding user interfaces.

In 1963 the Association for Computing Machinery (ACM) founded the ACM Committee on Professional Activities of the Blind, aimed at addressing accessibility barriers that prevented people with loss of vision from becoming programmers.

In those days, programming involved flowcharting on paper, writing coding sheets and punching cards.

In its seminal work, the Committee estimated there were 350 visually challenged people employed in data processing activities across the United States of America (Nichols, 1969). The committee regularly published a newsletter and organized an international conference in 1969⁶.

In 1970, the committee's charters were modified to incorporate other physical disabilities, renaming itself to Special Interest Committee on Computers and the Physically Handicapped (SICCAPH). Three years later, SICCAPH was turned into a Special Interest Group (SIG) called SIGCAPH. The group published about seventy newsletters, and from 1994 to 2002 organized the biennial ACM SIGCAPH Conference on Assistive Technologies.

In 2003, SIGCAPH was renamed once more to reflect the interests of its members in a more accurate way, incorporating new research areas and applications (Hanson, 2004). The new organization was named Special Interest Group on Accessible Computing (SIGACCESS) and continues with this name until nowadays.

SIGACCESS engages researchers, professionals, academics and students working with or interested in computers and accessibility. Its goal is to facilitate sharing of information across the community through a digital library and a conference (SIGACCESS, 2009).

The conference, named International ACM SIGACCESS Conference on Computers and Accessibility (ASSETS), publishes a newsletter three times a year. The newsletter is called Accessibility and Computing Newsletter. SIGACCESS also supports a scientific journal called "TACCESS: the ACM Transactions on Accessible Computing".

In addition to ASSETS, there are several international conferences specifically related to disability and computing:

- ICCHP (International Conference on Computers Helping People with Special Needs), starting in 1986, a biennial conference in the field of Information and Communication Technology (ICT) and Assistive Technologies focused on people with disabilities and the elderly.

Pursuing the goal of allowing people to have equitable access to technology, the conference hosts submissions from scientists, policy makers and entrepreneurs serving as a forum for the "discussion of serious physical and societal issues related to the quality of life of people with special needs"⁷. ICCHP is run in

⁶ A copy of the conference's proceedings can be found in http://www.archive.org/stream/proceedingsofbli00robe/proceedingsofbli00robe_djvu.txt.

⁷ Extracted from the conference's website (ICCHP, 2012).

cooperation with the University of Linz and the Austrian Computer Society and its proceedings are published by Springer.

- UAHCI (International Conference on Universal Access in Human-Computer Interaction), starting in 2001, held together with HCI International (International Conference on Human-Computer Interaction), a biennial independent conference published by Springer. UAHCI "aims to establish an international forum for the exchange and dissemination of scientific information on theoretical, methodological and empirical research that addresses all issues related to the attainment of universal access in the development of interactive software"⁸.
- W4A (International Cross-Disciplinary Conference on Web Accessibility) started as a workshop located at the World Wide Web Conference (WWW) in 2004 and was turned into a full conference in 2007, co-located with the WWW conference and published by the ACM.

Although W4A is focused on the web and the range of barriers that prevent users from experiencing it, as the web has become the predominant delivery platform for knowledge, improving web accessibility has become one of its main goals to address.

Table 2 shows the relevance of the mentioned conferences.

Conference	Publisher	Publications	H-Index	Citations
ASSETS	ACM	562	31	4318
ICCHP	Springer	1028	13	1759
W4A	ACM	165	12	533
UAHCI	Springer	N/A ⁹	N/A	N/A

Table 2 — Relevance of the major international conferences in the field of Human-Computer Interaction and Disability (according to Microsoft Academic Search¹⁰ tool).

⁸ Extracted from the conference's website (UAHCI, 2013).

⁹ Available information only shows global metrics of HCI International.

¹⁰ <http://academic.research.microsoft.com>.

Beyond ACM's journals on HCI and disability —SIGACCESS newsletter and TACCESS—, there are other ones, like the Universal Access in the Information Society (UAIS) international journal, published by Springer.

UAIS "focuses on theoretical, methodological, and empirical research, of both a technological and non-technological nature, that addresses equitable access and active participation of potentially all citizens in the information society"¹¹. Table 3 compares the relevance of these journals.

Journal	Publisher	Publications	H-Index	Citations
UAIS	Springer	339	20	1950
ACM SIGACCESS	ACM	202	7	207
TACCESS	ACM	54	7	244

Table 3 — Relevance of the major international journals in the field of Human-Computer Interaction and Disability (according to Microsoft Academic Research).

Disability as a separate concern

It can be argued that the very existence and the prevalence of specific communities in the “field of disability”, separated from the main HCI research track, is a consequence of how the concept of “disability” is interpreted by the HCI community.

A sociological reading of this particular structure, organization and separation of concerns raises the question about why the topic “disability” has its own place in HCI theory and practice. This seemingly naïve, or even preposterous, question — an immediate answer to it would be that having disability its very own place adds relevance and visibility to the area — may address a deeper problem lurking beneath the surface of the current human society.

Having a separate branch may serve to the purpose of focusing all the efforts on a specific topic, but it could also generate further problems, like narrowing the audience down to only the HCI community interested in “disability”, and thus limiting the cross-pollination between disciplines. On a different level and from a sociological perspective, it might be argued that this separation reproduces the notion that “disability” is an objective phenomenon — in the sense that it is not subjective, not even inter-subjective — that needs to be treated, addressed, fixed, or removed.

¹¹ The description of the journal can be found in Springer's website (UAIS, 2013).

Significantly, a sociological point of view rooted in Foucault's thought would see the phenomenon of disability as an artifact constructed by modern society, rather than a body impairment. In particular, academics who "conduct their work under the rubric of disability studies" — an academic discipline that examines the meaning, nature and consequences of disability as a social construct — "have begun to problematize the foundational assumptions of many disciplines and fields of inquiry, as well as the methodologies that they employ, the criteria of evaluation to which they appeal, and the epistemological and social positioning of the researchers and theorists invested in them" (Tremain, 2015).

Such a perspective recognizes that problems related to "disability" need to be addressed through broader approaches including not only a medical-centered practice, but also sociocultural aspects involved in the construction of the concept of "disability".

Aware of this problem, many HCI disability-centered communities have adopted other theoretical frameworks which view the phenomenon of disability from a different perspective. One of them is the Universal Design approach, that will be described later.

Slow adoption of the social interpretation

HCI's "mainstream" community incorporated modern and postmodern interpretations of "disability" at a slower pace than HCI disability-specific communities.

For example, the first work presented in CHI alluding to the phenomenon of disability using the word "disability" instead of "impairment" or "handicap", was published as early as 1987. As it will be explained later, using the words "impairment" or "handicap" may indicate that the discourse is rooted in a medicalized conception of the phenomenon of disability¹².

The work summarizes the design and evaluation of a user interface aimed at reducing access barriers of an educational computer called Icon (Verburg, Field, St. Pierre, & Naumann, 1987).

Despite its incipency, the work incorporates in its discourse some key concepts that reappeared much later in critical reviews and analyses (see, for example, (Mankoff, Hayes, & Kasnitz, 2010)):

¹² While the term "impairment" is mostly accepted by disability studies and other disciplines as a pragmatic tool for expressing that one of the causes of disability may be a physical condition in the body, the term "handicap" has been tagged as offensive and universally deprecated by the WHO in 2001 (WHO, 2001).

- **Goodness of diversity:** the notion that incorporating disabled users in the design process might enrich the user experience of a broader population¹³.
- **Focus on functionality:** the principle that the ability level of a person should be specified in terms of functional capabilities, rather than in terms of disease¹⁴.
- **Design universality:** the need for general purpose, more equal and versatile, user interfaces, rather than developing adaptive devices¹⁵.

Subsequently, the number of papers using the term “disability” published in CHI increased, having a sustained growth since 2001 (see Figure 3).

¹³ From Verburg et al's work: "Physical disability is a term that describes a wide variety of conditions and ability levels. It is thus possible to encounter students who are minimally impaired and can operate a regular keyboard, as well as students who are severely impaired and can only use a computer with adaptive interfacing devices. This diversity of accessing needs calls for an equal versatility on the part of interface devices and accessing methods." (Verburg, Field, St. Pierre, & Naumann, p. 81).

¹⁴ "(...) the ability level of a student would be specified in terms of functional capabilities, rather than in terms of diagnostic categories. This principle was adopted because diagnoses are often too general to serve as a basis for specific intervention." (Verburg, Field, St. Pierre, & Naumann, p. 84).

¹⁵ "In the process of [providing access to the Icon microcomputer] (...) the potential benefit of this technology to other student groups (...) became apparent. It would not be the first time that an adaptation intended for disabled persons benefits other able-bodied persons. Whenever such synergies can be achieved integration becomes easier and more natural." (Verburg, Field, St. Pierre, & Naumann, p. 85).

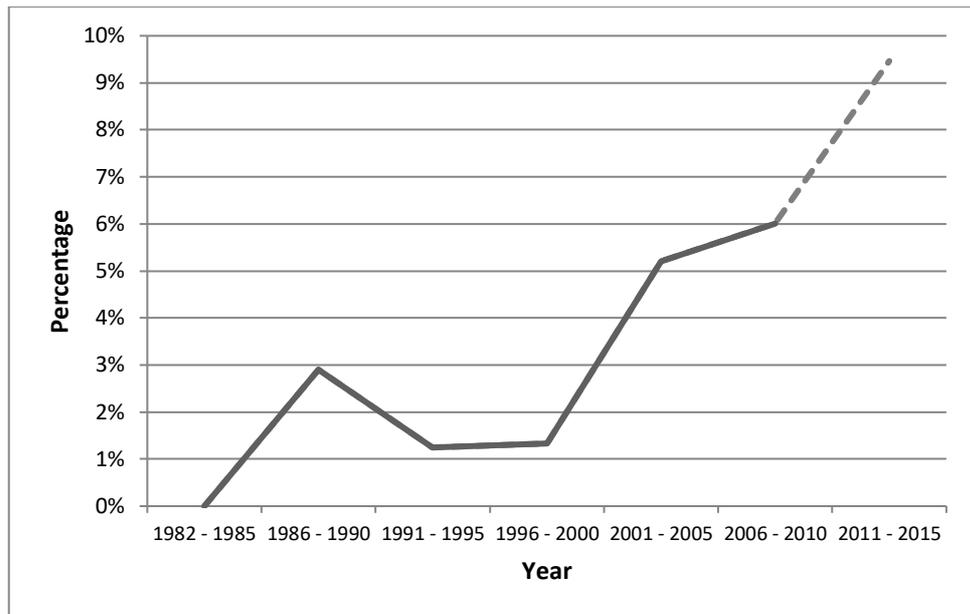


Figure 3 — Percentage of papers containing the word "disability" within CHI Proceeding Series. Period 2011 – 2015 was linearly extrapolated. Data source: The ACM Guide to Computing Literature.

Over time, this increasing interest in HCI and disability has generated a critical gaze on the way HCI researchers and practitioners have been dealing with the phenomenon of disability.

The question about the role and commitment of HCI in reducing access barriers is slowly shifting from “How to tackle the problem?” to a more critical point of view: “Are we doing it right?”.

Assistive technology versus universal design

HCI literature on “disability” covers a large variety of topics, including technological innovations, platforms to assess accessibility of certain products or services, *ad hoc* solutions to particular problems, theoretical frameworks, ethics, accessibility issues of a particular user interface (e.g. the web), assistive technology, critical review and analysis, human-rights claims and attempts to cross-pollinate with other disciplines.

The following sections compares two diametrically opposed design approaches to addressing accessibility issues: assistive technology and universal design.

Assistive technology

Assistive devices and technology can be defined as the universe of assistive, adaptive and rehabilitative devices whose primary purpose is maintaining or improving an individual’s functioning and independence to facilitate participation and to enhance overall well-being (World Health Organization). “They can also help prevent impairments and secondary

health conditions. Examples of assistive devices and technologies include wheelchairs, prostheses, hearing aids, visual aids, and specialized computer software and hardware that increase mobility, hearing, vision, or communication capacities” (World Health Organization).

Each individual experiencing disability is a unique case. The challenge for assistive technology developers is finding a trade-off between generic and custom solutions. There are cases in which assistive technology can be customized and there are cases in which *ad hoc* solutions are required.

Finding the right approach to suit an individual’s unique needs normally requires an interdisciplinary team of professionals responsible for evaluating the case, proposing and implementing (or customizing) a solution.

The definition of assistive technology is broad and it does not specify the type of technology involved nor whether it involves a computer or not. For example, a blind stick may help a person unable to see. The blind stick, according to the definition, is assistive technology.

The device may be physical or virtual. For example, an individual unable to use a physical keyboard for browsing the web may use a virtual keyboard. A virtual keyboard is a graphic representation of a physical keyboard on the screen. A moving cursor sequentially hovers key by key in order to give the user enough time to press a physical push-button when the cursor reaches the desired key. This software is, according to the definition, assistive technology.



Figure 4 – Virtual keyboard as an example of assistive technology.

With computers being ubiquitous and pervading almost every aspect of people’s lives, accessible user interfaces have become a major concern and a breeding ground for assistive technology builders.

“The general principle of ubiquitous computing is to free computers from desktop computing environment with conventional input/output method (keyboard, mouse and standalone-type screen display) and have them

widely pervaded into everyday environment” (Kim, Kim, & HyumMi, 2003).

Alternative, non-conventional user interfaces have been proposed to break down these disabling barriers. These interfaces include alternative keyboards, electronic pointing devices, joysticks, trackballs and touch screens.

HCI research focused on assistive technology has published a plethora of examples on the use of alternative interfaces that substitute the conventional graphical user interface (GUI) as an approach to tackle problems related to disability.

For example, computer-based gesture recognition can be used as a communication tool for individuals with cerebral palsy (Sears, Young, & Feng, 2008, p. 838).

In (Kortum, 2008), the authors present a comprehensive taxonomy of non-conventional user interfaces, identifying and describing ten different types: *haptic, gesture, locomotion, auditory, speech, interactive voice response, olfactory, taste, small-screen* and *multimodal* user interfaces.

For the purpose of this work, only the most relevant to the phenomenon of disability are described. Auditory, speech and interactive voice response user interfaces have been combined into one category called *voice user interfaces*.

Haptic user interfaces

Haptic user interfaces provide tactile feedback to the user. The information provided by a haptic interface can be *cutaneous* or *kinesthetic*. Cutaneous feedback stimulates skin's *mechanoreceptors* — i.e., sensory receptors that respond to mechanical stress or strain —, *thermoreceptors* — i.e., sensory receptors that respond to temperature —, or *nociceptors* — i.e., sensory receptors that lead to pain perception — through different strategies. Kinesthetic feedback interacts with the sense of *proprioception*, which allows the nervous system to interpret the relative position of the limbs in space.

The mechanisms used to produce cutaneous stimuli include the use of devices that generate static pressure or vibration — providing mechanical stimulation —, electric fields — electrical stimulation —, or thermal flows — difference in temperature. The first two strategies are mainly used to provide spatial information, whereas thermal flow is used to add qualitative information (Chouvardas, Miliou, & K., 2008), e.g. hot for crowded and cold for sparse. In assistive technology, these devices are commonly used to support Braille displays, using pins moved by actuators in order to render Braille symbols.

Kinesthetic feedback is usually provided through a robotic mechanism to receive and apply forces to the operator. The goal is to make the user feel

as if she was actually manipulating a three-dimensional object. This interaction modality was mainstreamed by the gaming industry, making flight simulators, racing games and first-person shooter games more realistic and fun. In medicine, it is used in surgical robots to assist surgery interventions (Simorov, Otte, Kopietz, & Oleynikov, 2012).

Gesture user interfaces

Gesture user interfaces use body gestures — like hand and face movements — as data input. They are inspired in nonverbal communication in humans. Gesture-based interaction covers a large variety of modalities involving different mechanisms and devices. For example, multi-touch trackpads and screens are used to react to the relative positions and movements of the user's fingertips (e.g., iGesturePad, Microsoft Surface); cameras are used along with computer-vision algorithms to track the motion of the user's hand or head, and along with face-recognition algorithms to recognize the user's facial gestures; unobtrusive body tracking technology (e.g. Microsoft Kinect motion sensor input device) allows to interact with the computer through body gestures without needing any additional tracker¹⁶.

The technology that enables gesture interfaces has become cheaper along its evolution from expensive data gloves or other intrusive equipment to accessory-free and wireless solutions (Nielsen, Moeslund, Störring, & Erik, 2008, p. 77). Technological developments like Nintendo Wii, Sony Move, and Microsoft Kinect have mainstreamed these kind of user interface.

In recent years, a myriad of research projects on gesture interfaces have published their results in HCI's major conferences. Particularly, a subset of gesture user interfaces, called *natural user interfaces* (NUI) have increasingly gained popularity in HCI research. NUIs aim at either enabling user interaction without the aid of accessories, making the interface invisible, or enabling user interaction through non-handmade (natural) objects.

Gesture interfaces have an application in the context of disability. They can potentially improve accessibility without the need of using expensive accessories. As a consequence, researchers and professionals are using them in habilitation and rehabilitation programs.

Examples of disability-related HCI works involving gesture interfaces include operating a wheelchair through head movements (Yoda, Sakaue, & Inoue, 2007); controlling the computer by a combination of mouth, lip and tongue gestures (Dalka & Czyzewski, 2009); tracking nose movements to control the mouse pointer by individuals with tetraplegia

¹⁶ Traditional motion capture techniques use physical markers (like white balls) located at specific points of the user's body. The motion is tracked by measuring the relative position and angle between the markers.

(Perini, Soria, Prati, & Cucchiara, 2006); tracking upper limb movements in games for stroke rehabilitation (Huang, Chen, Xu, & Sarrafzadeh, 2011); tracking multiple facial features (face, eye, and mouth movements) to control the mouse (Shin & Kim, 2006); and providing solutions to assist people with loss of cognitive capacity (Boussemart & Giroux, 2007).

In recent years, smartphones and tablets gave widespread access to multi-touch screens, turning them into a breeding ground for gesture-based user interface research. As opposed to one-touch screens, multi-touch devices — in general based on a technology called capacitive sensing — recognize multiple simultaneous touch points on a screen, giving the user an immediate visual feedback and a sense of direct manipulation.

Compared to conventional devices, multi-touch devices allow for a richer variety of gestures to perform certain tasks that would otherwise require keyboard shortcuts or additional steps.

Despite the potential benefits of gesture interfaces, the use of device-free interaction might be challenging for individuals lacking body structures or functions. Tsagarakis et al., cited by (Kortum, 2008, p. 83), identify several factors that might prevent users from using gesture interfaces, including problems in self-perceiving their own body, or problems involving motor and learning functions.

Locomotion interfaces

Locomotion interfaces enable users to move around in real or virtual spaces, making them feel as if they were actually moving (Whitton & Razaque, 2008, p. 107). The main characteristic of locomotion interfaces is that the whole body participates in the interaction.

In locomotion interfaces there is a constant feedback loop of information flowing from the body to the computer and all the way back. The computer senses the position, orientation and movements of the body and then feeds body's sensors through physical moves and other interactions.

In computer-simulated environments, these interfaces are known as *virtual-locomotion* interfaces. Virtual-locomotion interfaces enable users to control their *avatars* — their counterparts in the virtual world — by moving their bodies, turning posture and movement in the real world into direction and speed commands in the virtual world. Depending on the complexity of the interface, users might feel more or less immersed in the virtual world. Interfaces providing multiple-channel feedback (e.g., auditory, tactile, proprioceptive, vestibular, visual) are more likely to create a better illusion of immersion.

Locomotion interfaces, virtual or not, have been used to assist people with diverse physical conditions. For example, they have been used to

teach or assist people with vision loss to independently move in outdoor environments (Patel & Vij, 2010) and (Kulyukin, Gharpure, & Pentico, 2007).

They have been used to motivate elderly people to keep a sustained physical exercise routine over time (Ganesan & Anthony, 2012).

There are examples of locomotion interfaces supporting rehabilitation of walking through lower limb exoskeletons. A comprehensive review of lower limb exoskeletons and active orthoses¹⁷ can be found in (Dollar & Herr, 2008).

Voice user interfaces

Voice user interfaces are bidirectional, communicative connections between humans and machines (Kortum, 2008, p. 147) involving speech recognition and auditory feedback.

In the context of disability, voice user interfaces are typically used in receiving commands from, and presenting information to, people with vision loss, or individuals with motor disorders.

Over the last years, speech recognition and speech synthesis have evolved enough to allow for a relatively fluent and robust dialog between people and computers. Bandwidth growth, high-speed wireless communication and the miniaturization of high-performance computers have contributed to this evolution.

As a result, speech services have been integrated in most modern smartphones, in-vehicle navigation systems and desktop computer applications bringing new opportunities for developing assistive technology.

Voice-based GPS navigators, voice messengers, voice-activated alarms and reminders, screen narrators and applications that read text from video captured in real time are becoming widely accessible by individuals with a smartphone.

Olfactory interfaces

Olfactory interfaces refer to devices that provide users with information through smells.

Probably one of the most ordinary cases of an olfactory interface is part of the propane tank, where a chemical odorant is added to the stored propane to give it a distinct smell. The goal is to make it easy for people to immediately detect a dangerous gas leak.

¹⁷ An *orthosis* is an externally applied device that is designed and fitted to the body to correct or accommodate an existing part of the body.

Interfaces that can handle and mix different smells on demand are relatively new and rare. The reason explaining why these interfaces are not as developed as others is related to the very nature of the human olfactory system. Humans have an approximate number of 350 olfactory receptors allowing to detect approximately 0.4 million chemical compounds and distinguish thousands and tens of thousands of smells.

As a consequence, the complexity of building olfactory user interfaces lies in the difficulty of combining a small set of “primary odors” stored in capsules and try to recreate the whole spectrum of odors the human olfactory system is able to detect.

In spite of this challenge, a number of olfactory interfaces and applications have been developed in recent years, including a firefighting application that emit fire-related odors for training purposes; multimodal applications that mix audio, images and scents; simulators that allow users to explore a virtual olfactory space; arm-mounted olfactory displays; an unobtrusive “scent collar” that permits location-specific stimuli; and a “scent projector” that generates an olfactory space field through two air cannons (Kortum, 2008, pp. 276-282).

Multimodal user interfaces

Multimodal user interfaces allow users to interact with machines through different sensory and communication channels.

Typically, multimodal interfaces combine conventional visual and auditory interfaces. However, any technology can be candidate for a multimodal interface, including speech recognition, natural language understanding and gesture recognition.

Multimodal systems can be designed to allow users to choose the input modality of their choice. As a result, it has been claimed that multimodal interfaces can make computers more accessible, lowering input barriers and accommodating to a broader range of users than single-modal interfaces (Kortum, 2008, p. 392).

A review of HCI literature related to multimodal interfaces shows that they have been used in a variety of applications and scientific research. These works include building an application for cognitive rehabilitation (Cole, 2011); improving the One Laptop Per Child (OLPC) XO computer’s accessibility (Bonilla M. , Marichal, Armagno, & Lorenzo, 2010); developing applications containing animated characters that speak, make gestures and display facial expressions (Kortum, 2008, p. 399); and a system for people with vision loss that combine speech input and output with a Braille terminal and keyboard (Kortum, 2008, p. 413).

Whereas many authors claim that multimodal user interfaces are good candidates for solving accessibility problems, some others look at them with more skepticism.

Bergman and Johnson (Bergman & Johnson, 1997) suggest that providing multiple input and output channels by its own is not sufficient to resolve conflicting users' needs. The authors claim that multimodal interfaces can create as many usability issues as they attempt to solve.

The focus of assistive technology

HCI literature related to disability reflects a variety of approaches, rooted in different theoretical, methodological and ideological frameworks, to address the issue.

In general, HCI literature related to “assistive technology” assume that disability and impairment are synonyms. For instance, it is difficult to find works related to “assistive technology” not focused almost exclusively on how to augment the capacity of an “impaired body” rather than, for example, how to modify the environment to make it universally accessible.

Even though there is an inconclusive debate about what is the most suitable approach to address the phenomenon, scholars from all currents of thought agree that a pure social or environmental approach cannot solve all the problems. Neurosurgery, psychotropic medications, brain controlled prostheses, nanosurgery and other technological breakthroughs promise to “fix” most of the body dysfunctions, tipping the scale in favor of a medicalized discourse that perceives technology as the panacea for disability.

However, the focus of the debate is on the less critical cases: on the people tagged as disabled because they cannot climb stairs, the ones that are slower to learn or understand, or the ones that have difficulty using their upper limbs. Are their bodies the source of the disability, or is it the environment created by and for the “normative” people — people whose body structures and abilities are not too far away from the global standard — the one to blame for excluding them. Or is it the standard of a perfect body, ceaselessly reproduced, explicitly or implicitly, by the media, lurking behind the design of everyday objects, including technological devices and user interfaces, the one excluding and stigmatizing people.

Universal Design

The idea underpinning assistive technology is that there are two parts that need to be connected. On the one side, there are individuals with impairments and, on the other, there are environments which can't be fully accessed. The goal of assistive technology is to build a technological solution helping — assisting — the impaired body access the environment.

At the other extreme, there is an alternative design philosophy called universal design, also known as “design for all” (D4A). Universal design

emphasizes the need of finding non-specialized, non-adaptable solutions, as an approach to reduce access barriers.

As an example to compare it against assistive technology, whereas a typical assistive technology project would develop products focused on individuals with upper-limb motor difficulties, a project ruled by universal design's principles would develop universal solutions that can be used by everyone, regardless of their body functions.

The rationale behind universal design is that, while specialized design may reduce access barriers, it generates a side effect: it contributes to stigmatization of people.

The architect and industrial designer Ronald L. Mace, a victim of polio, coined the term universal design in the 1970s. In his own words, universal design is "the design of products and environments to be usable by all people, to the greatest extent possible, without the need for adaptation, specialist design" (Barnes, *Understanding Disability and the Importance of Design for All*, 2011).

Universal design has many connotations and involves multiple design areas, but it could be generalized as a design ethic aimed at delivering non-discriminative solutions. This means that any product, service, environment, or any solution aimed at providing some kind of benefit for their users should not discriminate people on the basis of their race, gender, sexual orientation, presence or absence of body functions or structures, or any other characteristic.

It is an ethic because, in the end, universal design's rules and principles govern the behaviour of real people — e.g. designers, architects, engineers and programmers — involved in the design process.

Universal design embraces a set of rules and principles that guide the solution discovery process. The Centre for Universal Design at North Carolina State University defines seven principles (Barnes, *Understanding Disability and the Importance of Design for All*, 2011):

1. Equitable use: the design is useful and marketable to people with diverse abilities.
2. Flexible in use: the design accommodates a wide range of individual preferences and abilities.
3. Simple and intuitive: the use of the design is easy to understand, regardless of the user's experience, knowledge, language skills, or current concentration level.
4. Perceptible information: the design communicates necessary information effectively to the user, regardless of their sensory abilities.
5. Tolerance for error: the design reduces hazards and adverse consequences of accidents.

6. Low Physical Effort: the design allows efficient usage with minimum effort.

7. Size and space for approach and use: appropriate space is provided to enable comfortable and effective use for anyone regardless of physical and sensory ability.

Universal Design versus Assistive Technology

The Assistive Technology Act of 1998 (amended in 2004), endorsed by the congress of the United States, relates universal design with assistive technology:

“The use of universal design principles reduces the need for many specific kinds of assistive technology devices and assistive technology services by building in accommodations for individuals with disabilities before rather than after production. The use of universal design principles also increases the likelihood that products (including services) will be compatible with existing assistive technologies. These principles are increasingly important to enhance access to information technology, telecommunications, transportation, physical structures, and consumer products” (Congress of the United States of America, 1998).

Assistive technology may be a successful tool to help solve concrete problems in a short-term. An optimistic view considers that assistive technology promotes greater independence by enabling people to perform tasks that they were formerly unable to accomplish, or had great difficulty accomplishing, by providing enhancements to or changed methods of interacting with the technology needed to accomplish such tasks.

However, a survey on assistive technology usage and abandonment performed by Sears et al. suggest that adoption rates of solutions based on assistive technology are remarkably low. According to the authors, "Many new technologies never reach the majority of the intended users due to a lack of marketing activities or cost. Even when the technologies reach the intended users, many are abandoned within a short period of time. Understanding why users adopt or abandon assistive technologies is critical for the design, implementation, and marketing of these technologies" (Sears, Young, & Feng, 2008, p. 846).

There is a chance that this issue was a consequence of the assumptions made during the solution discovery process. Each case of disability is unique, but systematically biasing the process towards building technological ramps may not be the answer to every disabled individual's needs.

Design in its many disciplines, but specially interaction design, industrial design, environmental design and architectural design, plays a fundamental role in the production of disability. Poorly designed

software and physical products, services, and environments, disable people –not only people with impairments– at various stages in their life course (Barnes, *Understanding Disability and the Importance of Design for All*, 2011).

In agreement with Welsh's *symbols of separateness* (Welsh, 1995), it can be argued that the semantics of every product or service encloses two meanings: the meaning of what the user can and cannot do within a particular context –what Norman calls *affordances*, resignifying Gibson's definition– and the interpretation of the *normal* user by the designer's point of view.

If not properly conceptualized, the built solution, through its second meaning, could become a tool of oppression.

2 CASE STUDY

Introduction

It can be difficult to grasp the complexity, depth and richness of the challenges that arise during the execution of an HCI research project involving disability, without having a firsthand practical experience of planning and executing one. This chapter is a case study describing an HCI research project that brought together HCI researchers, software engineers, cognitive psychologists and teachers, for the main purpose of addressing access barriers of the “XO laptop”. The project helped the author, and the experimenters involved in the project, not only gain experience on the field, but also allowed them to review, question and perhaps in the end reformulate what disability originally meant for them.

Overview

The XO is a shockproof, low-cost, low-power, connected laptop computer, designed by the One Laptop Per Child (OLPC) program. The laptop ships with a bundle of software tools and content aimed to foster collaborative, joyful and self-empowered learning¹⁸.

These laptops were delivered by the Uruguayan government to every child attending public schools. Among the beneficiaries of this program, there was a school for children diagnosed with motor disorders. The problem was that more than a half of the children attending this school could not use the XO, due to accessibility issues.

The school, officially named Public School No. 200 “Dr. Ricardo Caritat” (School #200), is a Uruguayan public school located in Montevideo, capital city of Uruguay.

School #200 educates children diagnosed with a broad range of motor and cognitive dysfunctions, mainly cerebral palsy (90% of students), spina bifida (8%) and other motor-related pathologies (2%).

The project, named NEXO¹⁹, was co-directed by Gustavo Armagno, the author of this thesis, and Ana Martin, a cognitive psychologist specialized

¹⁸ http://wiki.laptop.org/go/The_OLPC_Wiki

¹⁹ NEXO was sponsored by two institutions: INCO and CIBPsi. INCO (“Instituto de Computación”) is the computer science institute of the school of engineering (“Facultad de Ingeniería”) of Universidad de la República (UDELAR) — the state-funded university of Uruguay. CIBPsi (“Centro de Investigación Básica en Psicología”) is the cognitive psychology research center of the school of psychology of UDELAR.

The project got funding from SCEAM and the school of engineering. SCEAM (“Servicio Central de Extensión y Actividades en el Medio”) is a service of UDELAR responsible for sponsoring activities aimed to connect academy and society.

in cognitive disorders. NEXO lasted more than two years (2010–2012) and was divided into two stages, namely NEXO Stage One and NEXO Stage Two²⁰.

NEXO Stage One involved carrying out two pilot studies in parallel. One of them, belonging to the fields of cognitive psychology and clinical psychology, aimed to carry out a cognitive stimulation treatment using a combination of XO and an innovative interaction scheme, described below. The other one, belonging to the field of human-computer interaction, aimed to use such an interaction scheme for making the XO more accessible.

NEXO Stage Two's goals, defined after debriefing Stage One, involved finding a new interaction scheme for the XO aimed to reach out to children with severe motor disorders and low to mild levels of understanding.

Stage One took advantage of the cumulative experience proceeding from a previous work that finished a few months before NEXO started²¹. This work consisted in developing a "perceptual" user interface for improving XO's accessibility. Its mission was to provide a new way to interact with the XO, addressing accessibility issues detected in the laptop's (conventional) input/output devices: keyboard, mouse, mousepad and screen. As NEXO, it was carried out in School #200, paving the way for future operations in the field.

One of the results of NEXO's predecessor was a prototype of an innovative interaction scheme allowing users to interact with the XO through presenting printed shapes in front of the XO's camera.

This result contributed to the definition of Stage One's "engineering" goals, which involved developing a set of software educative applications (ed-apps) for the XO on top of the new interaction scheme, and evaluating the fitness of the new interaction scheme.

Stage One also had a "clinical psychological" goal, involving designing and carrying out a cognitive stimulation treatment.

The work was divided into three kinds of tasks, related with software engineering, cognitive psychology and human-computer interaction.

Tasks related with software engineering involved: turning the software part of the prototype into a software library; developing a background process that interprets input signals coming from the prototype and emulates mouse movements on the XO; developing a set of ed-apps

²⁰ Both stages were approved by UDELAR's Ethics Committee.

²¹ NEXO's predecessor was a software engineering bachelor thesis co-mentored by Gustavo Armagno and Tomas Laurenzo (Bonilla M. , Marichal, Armagno, & Laurenzo, 2010).

using Python, the default language for building apps in the XO environment.

Tasks related with human-computer interaction involved: articulating an interdisciplinary team; defining the vision and the scope of the ed-apps; assessing the level of accessibility of both the ed-apps and the new interaction scheme; carrying out an action research project.

Tasks related with cognitive psychology involved: designing and carrying out a cognitive stimulation treatment for children diagnosed with a physical dysfunction.

The first stage culminated with the construction of a new interaction device called PUI (for Perceptual User Interface) for the XO — an improved version of the original prototype — and a set of ed-apps working on top of PUI.

PUI allows to create non-conventional user interfaces using a set of printed shapes as input signals. These shapes can be printed in paper and placed in different supports. For example, they can be placed in frames made of wood or plastic, or wrapped in hard plastic shields, taking advantage of the kind of supports that are normally used at School #200 for didactical purposes.

As a preview of the sections to come, Stage One concluded with an evaluation of the general fitness of PUI as a tool to address XO's accessibility issues. In general, evaluated children who used the ed-apps showed more motivation with PUI than with conventional input (keyboard, mouse, trackpad). Notwithstanding, it was found that, in general, only those children who were already able to use conventional input, didn't find major issues with PUI. Conversely, children who had major problems using the XO through conventional input, had major problems using PUI.

One of the main teachings from Stage One was that it was necessary to involve children in the inception phase of certain ed-apps — especially the ones involving narrations, graphics and animations — for two reasons. First, intermediaries cannot accurately tell whether the children will understand the narrative, the drawings and the animations, better than the children themselves. Second, allowing the children to truly participate in the creative process is a step towards empowering them. Empowering users by giving them a stronger role in “shaping” their own tools, considering their opinions, is a good practice recommended by disciplines working with disabled children, like disability studies and occupational therapy (Kielhofner, 2005).

Stage Two's goals involved developing a new set of interaction devices and ed-apps, while promoting children's participation in the development process.

Instead of having a team focused on developing a single non-conventional interaction device — the case of PUI —, and the remaining teams focused on building a set of ed-apps on top of PUI, in the new approach each team focused on both developing a new interaction device and an ed-app using it.

The rationale behind the new goals was increasing the probabilities of encountering a solution that truly reaches the segment of people with severe motor dysfunction and low-mild levels of understanding.

The technological contribution of Stage Two was the development of three innovative interaction schemes for the XO. One of them was a shockproof version of MIT's MakeMakey built in-house, allowing users to easily assemble adaptive keyboards made of a wide variety of objects and materials, including fruits, play-doh, or any conductive material. Another scheme comprised a native QR-code reader for the XO, something that hadn't been done before. The last one was a user interface based on visual scanning (see Visual scanning interaction).

All these assertions and conclusions are discussed and refined below in this chapter.

NEXO officially ended in December 2012, after two years of an intensive combination of fieldwork and work in the lab. Both periods involved an interdisciplinary collaboration of professionals in the fields of HCI, software engineering and psychology, working together with undergraduate and graduate students of software engineering and psychology.

One of NEXO's legacies was allowing researchers from UDELAR's School of Engineering to keep working together with School #200's educators and children, exploring ways to use technology to empower children who have been diagnosed with a motor dysfunction.

This chapter describes NEXO's background, context, processes and results, for the main purpose of helping future HCI researchers addressing similar problems and contexts.

Note

The expressions *disability*, *disabled individual* and *disabled people* are widely used on this chapter.

There are opinions about whether “disability” alludes to a condition of individuals who “carry a disability” on their body, or it is a complex interaction between the human body and the environment generating barriers to participation. There is also a third current, which considers “disability” as a side effect resulting from the social construction of the notion of *normality* (see Social Model below).

Depending on the one's ideological position, the expression "disabled individual" could be interpreted as:

- An individual who lacks a body function or has an alteration in his or her body structure. This interpretation understands that individuals are *disabled by* their deficit or alteration in their bodies.
- An individual who cannot fully participate in some activity because the environment in which the activity occurs has not been designed to afford his or her abilities. In this case, the individual would be *disabled by* the environment.
- An individual who bears the label "disabled" because the western tradition, the social system, the production model and other cultural factors, have created — *constructed* — such a label. In this case, the individual would be *disabled by* society.

To add in more complexity to the matter, the definition of disability varies depending on the context in which it is being referred. For example, surveys can be more or less permissive to recognize someone's abilities, limitations, or conditions, as belonging to the definition of "disability".

In order to avoid misleading notions of "disability" — e.g. giving the notion that there is one, universally defined and accepted, definition — the author decided to quote expressions relative to "disability" in this section, as a reminder that they belong to, and are restricted to, a specific context.

Background

The mission of the One Laptop Per Child (OLPC) program is to give children in under-developing countries a laptop as a solution to bridge the digital divide, which threatens to increase the economic gap between low and high socioeconomic classes (Hourcade, Beitler, Cormenzana, & Flores, 2008).

Uruguay — population: 3,407,000 (est. 2013); GDP per capita: 16,350.73 USD (est. 2013) — deployed its own version of the OLPC program nationwide, under the name of *Plan Ceibal*²². OLPC won the first tender with its XO laptops. Other laptop providers were incorporated later.

The main goal of *Plan Ceibal* is to promote digital inclusion and reduce the digital divide, through different strategies. One of these strategies is

²² The Uruguayan national flower is the *ceibo* (known in English as *cockspur coral tree*) and "ceibal" in Spanish means "land of *ceibos*". The project's name, Ceibal, is a contrived acronym standing for Educational Connectivity of Basic Computing for Online Learning ("Conectividad Educativa de Informática Básica para el Aprendizaje en Línea").

through giving a laptop to every student attending public education centers, including primary and secondary schools²³.

By the end of 2009, the plan covered all public primary state schools.

School #200 was a special case: It is a public school that follows the national curriculum. However, it only accepts children who have been diagnosed with cerebral palsy, spina bifida, muscular dystrophy and other motor-related pathologies. It is the *only* public school in Uruguay of its kind.

In 2009, school #200 received computers from Plan Ceibal, as any other public school in Uruguay. Whereas, officially, School #200 is a “regular” school — meaning that it follows the regular educational program for public schools — it was conceived to partially or fully rehabilitate children with physical pathologies, pursuing social inclusion. The school includes preschool and primary education.

As any “regular” school, it received an amount of XOs to be distributed among its students. However, these computers are not accessible to most of School #200’s population.

For instance, schoolchildren attending the primary level received the OLPC’s XO-1 laptop computer. However, more than 50% of students don’t use them at all (Bonilla M. , Marichal, Armagno, & Lorenzo, 2010).

In 2010 the plan begun its expansion to secondary and tertiary education.

Students attending primary education received XO laptops, developed by the OLPC organization, while students attending secondary and tertiary education received both XO and Magallanes (*Magalhães*) laptops. The later were developed by the Portuguese program 'e-escolinha', an analogue to the OLPC program.

XOs are shipped with a pre-installed Linux distribution derived from Red Hat’s Fedora. They also have a pre-installed graphical user interface (GUI) named Sugar, specifically for these computers. Magallanes, on the other hand, are shipped with Microsoft Windows.

Access barriers

Both the XO and the Magallanes don’t get along with School #200’s population, due to accessibility issues. In an attempt to solve the problem, in 2009 *Plan Ceibal* delivered laptops especially adapted to be used by children with low vision. However, as two independent observations confirmed, School #200’s population diagnosed with cognitive or physical dysfunctions remained unattended.

²³ The idea of introducing information and communication technologies (ICTs) in education through providing each student with a laptop is known as the “1 to 1” model.

One of these observations²⁴, resulting from an ethnographic study carried out in the school, found that several factors prevented children from using the XO.

These factors include:

- Product design: small screen size, small keyboard.
- Faulty trackpad: XO-1's trackpad fails intermittently. For instance, mouse cursor suddenly jumps to a corner of the screen, or starts moving randomly²⁵.
- Usability flaws encountered in most used applications.
- Lack of inclusive educative apps or apps to support rehabilitation therapies.
- Lack of software accessibility helpers for children with motor difficulties.
- Limited availability of assistive technology, like switches, joysticks, or trackballs, due to budget restrictions.



Figure 5 – Accessibility issues found in XO's design.

²⁴ The study was led by the author of this thesis. See (Bonilla M. , Marichal, Armagno, & Lorenzo, 2010).

²⁵ See <http://wiki.laptop.org/go/XO-1/Touchpad/Issues>.

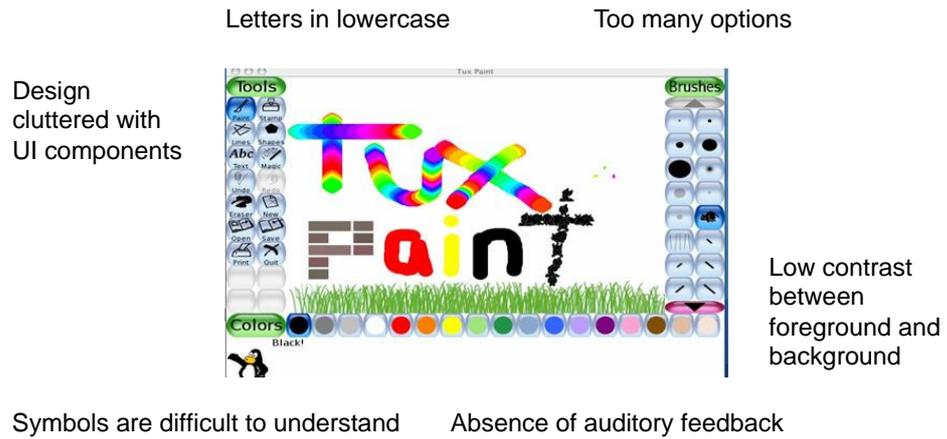


Figure 6 – Accessibility issues found in Tux Paint, one of the most used Sugar apps in the classroom.



Figure 7 – School #200’s educators adapt numeric keypads to build custom assistive input devices.

A second observation, performed months later both in School #200 and school Franklin D. Roosevelt — an institution owned by an NGO which educates children and teenagers with a population of similar characteristics as of School #200’s —, explored the adoption of the XO by the students (Moreira & Viera, 8).

That study, carried out by an independent team led by a sociologist and a psychologist, identified accessibility issues in the XO and a lack of ICT-for-inclusion appliances.

It concludes that, if there is a possibility to use *Plan Ceibal*'s XOs as a way to improve the health and well-being of vulnerable population, it is "critically important to increase the production and use of hardware and

software adaptations and to systematically review their usage and fitness." (Moreira & Viera, 8)

Both studies independently coincided in their conclusions: that (1) population diagnosed with motor dysfunctions — particularly, people with cerebral palsy and muscular dystrophy — experience accessibility issues when interacting with the XO and (2) the XO, a piece of technology that could be used for rehabilitation purposes, has not been exploited to its full potential.

These observations created a new research opportunity to explore different solutions, involving technology or not, aimed to revert this scenario.

Context of study

Every day, 90 students sharing a variety of motor dysfunctions attend the school. Approximately, 50% are boys and 50% are girls. Although most of them are children in their school age, some of them are teenagers that are not ready to be inserted in society yet. The ages range from two to twenty years old.

The school provides a set of free-of-charge shuttles for picking up students from home to school and then taking them back home. Since the students come from different and distant locations in Montevideo, the shuttles need to cover a very large area. Eight out of ten students come from low socioeconomic contexts.

School #200's personnel includes the Principal, ten educators, two physiotherapists, one ICT teacher, one psychologist, one social worker, one music therapist and nine assistants, among other employees (Bonilla M. , Marichal, Armagno, & Lorenzo, 2010).

Classrooms are divided by cognitive level instead of by age. Teachers are not allowed to spend more than two consecutive years working with the same group of children. This is, according to the school's Principal, mainly to prevent any potential degradation in the relationship between teachers and parents.

The Uruguayan academic year starts in March and ends in December. Most of the students spend three hours a day in the school, except for one special group that spends six hours.

Approximately 90% of the students have been diagnosed with cerebral palsy, 8% with spina bifida and 2% with other motor-related pathologies.

NEXO's target users were mainly schoolchildren with cerebral palsy.

Cerebral Palsy: a broad term

The definition of cerebral palsy (CP) has changed over the past century. Broadly speaking, it could be defined as an umbrella term encompassing

a group of chronic conditions affecting body movement and muscle coordination, originated by damages in the motor control centers of the developing brain²⁶. The damage can occur during pregnancy, childbirth or after birth, up to about the age of three to five.

The current notion of CP, accepted by the medical community, is given by Rosenbaum et al.:

Cerebral Palsy describes [1] a group [2] of permanent [3] disorders [4] of the development [5] of movement and posture [6], causing [7] activity limitation [8], that are attributed to [9] nonprogressive [10] disturbances [11] that occurred in the developing fetal or infant [12] brain [13]. The motor disorders of cerebral palsy are often accompanied by [14] disturbances of sensation [15], perception [16], cognition [17], communication [18], and behaviour [19], by epilepsy [20], and by secondary musculoskeletal problems [21].

(Rosenbaum, et al., 2007)

The numbers in brackets were added for the purpose of expanding each concept, as follows²⁷:

- [1] "Cerebral Palsy describes..." – the phrase indicates that CP is a descriptive diagnostic. There is a general agreement between specialists that the concept of CP *describes* an identifiable, prevalent and clinically relevant group of individuals that acquired a physical impairment at some stage of their development.
- [2] "... a group..." – the nature of CP is highly heterogeneous, considering the etiology and the kind and severity of the complementary disturbances.
- [3] "... permanent..." – the definition excludes temporary disorders. However, it recognizes that there are patterns of clinical manifestations that can vary with age.
- [4] "... disorders..." – the ordered sequence of children's development stages is altered by causes related to CP.

²⁶ The term "cerebral" refers to the *cerebrum*, one of the areas that might be affected by the injury, and "palsy", meaning paralysis, refers to one of the typical manifestations of the condition.

²⁷ This particular deconstruction of the definition of cerebral palsy was excerpted from a lecture given by pediatric neurologist Dr. Alfredo Cerisola at Teletón Rehabilitation Center in June 2012, Montevideo, Uruguay. Dr. Cerisola's version is based on Martin Bax; Murray Goldstein; Peter Rosenbaum; Alan Leviton; et al's proposed definition and classification of cerebral palsy, published in 2005 and widely accepted today (Bax, Goldstein, Rosenbaum, Leviton, & Paneth, 2005).

- [5] "... of the development..." – the notion of disturbance in early child development is crucial to the definition of CP, making it different from other phenotypically similar disturbances that can be acquired later in life, after the process of developing basic motor skills has ended.
- [6] "... movement and posture..." – CP implies difficulties an individual may have in walking, grasping, self-feeding, eye-movement coordination, speech articulation, behavior, musculoskeletal function and in social participation, with a variable severity.
- [7] "... causing..." – the activity limitation is presumed to be a consequence of the motor disorder.
- [8] "... activity limitation..." – The International Classification of Functioning, Disability and Health (ICF) manual defines activity limitations as the difficulties an individual may have in executing a task or an action (WHO, 2001, p. 10). This term ("activity limitation") extends the WHO's previous concept of disability, and recognizes and reflects the terminological and conceptual shift that has occurred at international level.
- [9] "... are attributed to..." – at the present time, a full understanding of the causal pathways and mechanisms leading to CP remain elusive.
- [10] "... nonprogressive..." – means that whatever caused the disorder, it is not active any more.
- [11] "... disturbances..." – whatever is the root problem causing CP, it must be an event that interrupts, damages or influences the expected patterns of formation, development and maturing of the brain, resulting in a permanent (but nonprogressive) disturbance of the brain.
- [12] "... developing fetal or infant..." – emphasizes the idea that disturbances occurring very early on children development impact differently on motor function than those occurring later.
- [13] "... brain..." – the event causing CP might affect the cerebrum, the cerebellum, or the brainstem. Motor disorders exclusively originated at the spinal cord are excluded from the definition.
- [14] "... are often accompanied by..." – beyond disturbances in movement and posture, other disturbances, so-called "related disturbances", might appear.
- [15] "... sensation..." – vision, audition, and other sensorial modalities might be affected, as a consequence of the primary disorder causing CP or as a by-product of activity limitations that reduce perceptive and learning experiences during early stages of human development.

- [16] "... perception..." – the ability to incorporate and interpret perceptive information might be affected.
- [17] "... cognition..." – global and specific cognitive processes might be affected.
- [18] "... communication..." – expressive or receptive communication abilities, or social interaction abilities might be affected.
- [19] "... behaviour..." – CP can lead to behavioral disorders, including psychiatric or behavioral problems such as autistic spectrum disorders, ADHD, sleep disturbances, mood disorders and anxiety disorders.
- [20] "... epilepsy..." – resulting conditions can include virtually any seizure type and many epileptic syndromes.
- [21] "... secondary musculoskeletal problems..." – shortened muscles (contractures), bone deformities and backbone problems might arise as a secondary consequence of the original brain damage.

CP is the main cause of motor disorders in infants. Nearly 1 out of 500 children are born with CP, at an increasing rate. There is evidence supporting that this growth is associated to, and possibly a consequence of, large declines in infant mortality (Vincer, et al., 2006).

Statistics show that about half of the children with CP can walk independently and approximately 30% have limited, or no walking ability. Approximately half of them will develop one or more related disorders, more frequently epilepsy, cognitive dysfunctions, and auditory and visual deficit²⁸.

There is a common consensus that treatments aimed to stimulate different areas of child development at early stages of human development lead to better chances of reducing the likelihood of developing further dysfunctions. Nonetheless, there are no standardized treatments that could be generalized to every individual with CP. In general, once the diagnosis is made and the type of CP is determined, it is necessary to address the problem using different approaches, including physical therapy, occupational therapy, recreation therapy, speech and language therapy and treatments to deal with eating and drooling problems.

Each treatment is aimed at focusing on different aspects of the condition and is carried out by interdisciplinary teams of professionals:

²⁸ Data and statistics in this section come from different sources, including (Centers for Disease Control and Prevention, 2013)

Physical therapy focuses on maintaining or improving muscle strength, stability and motor skills. It also focuses on preventing contractures, through carrying out exercises and activities.

Occupational therapy attempts to improve children's autonomy through a set of exercises that help them dress by themselves, go to school and participate in everyday activities.

Recreation therapy helps children expand their physical and cognitive skills and abilities, through encouraging their participation in social events such as art and cultural programs and sports.

Speech and language therapy tackles communication dysfunctions through a variety of strategies ranging from phoniatry to addressing swallowing disorders. For some cases, it is necessary to add alternative communication channels, like sign language or communication devices such as voice synthesizers or augmentative and alternative communication (AAC) devices.

Treatments for eating and drooling problems are meant for individuals that have little control over the muscles that move their mouth, jaw and tongue. These individuals often have difficulties to eat and drinking. They also deal with multiple risks, like inhaling food or fluid into their lungs, malnutrition, recurrent lung infections and progressive lung disease.

Such a list of treatments is far from being comprehensive, but illustrates the complexity behind addressing the kind of challenges related with CP. Other approaches include surgery, drug treatments, use of assistive technology and complementary and alternative therapies²⁹.

School #200, in coordination with other institutions, including Fundación Teletón and school Franklin D. Roosevelt, addresses the problem from different angles and through a variety of approaches, subject to budget restrictions.

Educational approaches include activities to enhance children's self-esteem, closely linked to their poor concept of self-worth, in their daily school activities, among other treatments included in the list above (Moreira & Viera, 8).

Disability in Uruguay³⁰

The World Health Organization (WHO) estimates that more than 1 billion people (nearly 15% of the world's population) are "disabled" (WHO,

²⁹ This list of treatments to tackle the core dysfunctions that arise from cerebral palsy has been compiled from different sources, including face-to-face conversations with specialists in the field. However, there is an extraordinary compilation of information about cerebral palsy in (National Institute of Neurological Disorders and Stroke, 2013).

³⁰ Source: *The situation of disabled children and teenagers in Uruguay* (Meresman, 2013).

2001). 80% live in under developing countries, like Uruguay. Most of them live in poverty and they do not have access to basic services, or rehabilitation (World Health Organization, 2011).

95 million children worldwide are “disabled” (1 out of 20) and 13 million (almost 1 out of 100) are “severely disabled”.

Up to recently, information about “disability” in Uruguay was scarce. It was not until the year 2000 when such information started to be systematically compiled in a reliable way.

The Uruguayan National Census of 2011 included the variable “disability” in the survey. The Census considers that a person is “disabled” if he or she has any permanent difficulty to see, hear, walk or climb steps, understand, or learn.

The following compilation comes from a descriptive analysis of the Census of 2011, published by UNICEF (Meresman, 2013). The definition of “disability” and all related definitions, including “disabled”, “dysfunction”, “difficulty”, and the degree, type and temporality of difficulties, should be interpreted in the context of the Census and the report of UNICEF.

According to the National Census, 15.6% of the population (517,771 people) is “disabled”³¹ in Uruguay.

Children and teenagers from zero to 17 years old represent 9.2% (47,799) of the total “disabled” population and 5.4% of children and teenagers in general.

Among “disabled” children and teenagers, 70.1% are “mildly disabled”, 24.9% are “moderately disabled” and 5% are “severely disabled”. By type of “dysfunction”:

- 4% of the children between 6 and 17 years old (23,472) have permanent difficulties to understand or learn. 36.2% of them (8,500) have “moderate to severe difficulties”.
- 2.3% of children and teenagers less than 18 years old (19,885) have “severe permanent difficulties” to see.
- 0.8% of children and teenagers less than 18 years old (6,375) have “permanent difficulties” to hear. 23.5% of them are “partially or completely deaf”.
- 0.8% of children and teenagers between 2 and 17 years old (6,274) have “permanent difficulties” to walk or climb steps.

In relation to “disability” and poverty, half of the “disabled” people in Uruguay live in low-income households. Children and teenagers living in

³¹ The novelty introduced by the Census was that the questionnaire was based on the ICF manual.

low socioeconomic contexts with less than 14 years old have 70% more chances to be “disabled” than children and teenagers with higher incomes.

In the whole country, 24% of children “with physical difficulties” between 6 and 11 years old attend regular schools, 36% attend “special” schools and 38% are totally excluded from the educational system. In teenagers between 12 and 17 years old, the number of excluded children rises to 52%.

As it was mentioned before, School #200 educates only nearly one hundred children.

In contrast with this reality, the number of Uruguayan teenagers between 12 and 17 years old, “without physical difficulties”, who have never assisted an educational institution, is negligible.

A perceptual user interface for the XO

One action point to address the lack of accessibility in the XOs arose after debriefing an HCI ethnographic study carried out in 2009 in School #200 (Bonilla M. , Marichal, Armagno, & Lorenzo, 2010): build a prototype of a “perceptual” user interface for the XO.

The idea was inspired by previous works involving the use of perceptual user interfaces in the context of disability — see, for example, (Varona, Manresa-Yee, & Perales J., 2008).

Perceptual user interfaces integrate multiple “perceptual” interaction modalities — such as computer vision, speech and sound processing, and haptic I/O — into one user interface.

One of the purposes of perceptual interfaces is to provide “a more powerful, compelling user experience than what has been available with graphical user interfaces (GUI) and the associated WIMP (windows, icons, menus, pointing, devices) implementations” (Turk & Kölsh, 2004). Interfaces like perceptual user interfaces, “that are more adaptable and flexible, and not limited to particular ways of moving a mouse or typing keys, will provide a significant benefit to” users with “physical disabilities” (Turk & Kölsh, 2004, p. 463).

The finished prototype, named PUI (for Perceptual User Interface), is a piece of software running on the XO that uses a video tracking technique to recognize square physical markers in real time³². PUI uses ARToolKit³³, an open-source tracking library for creating augmented reality

³² Soft real time would be a more accurate expression. PUI running on the XO is able to process at ~5 frames per second, which is acceptable for image recognition.

³³ <https://artoolkit.org/>

applications. The library, written in C, had never been compiled in the XO before PUI.

The prototype admits two interaction modalities. The default one is defining the recognition of a marker as an input signal. In this mode, an action is triggered when a user shows a marker to the camera. The alternative mode is defining the occlusion of a marker as an input signal. In this mode, an action is triggered when a user occludes a marker, generally arranged in a grid of markers.

PUI allows the possibility of designing custom input layouts. For instance, the markers could be printed on papers of different thickness, glued to objects, placed in frames made of different materials, or wrapped in hard plastic shields.

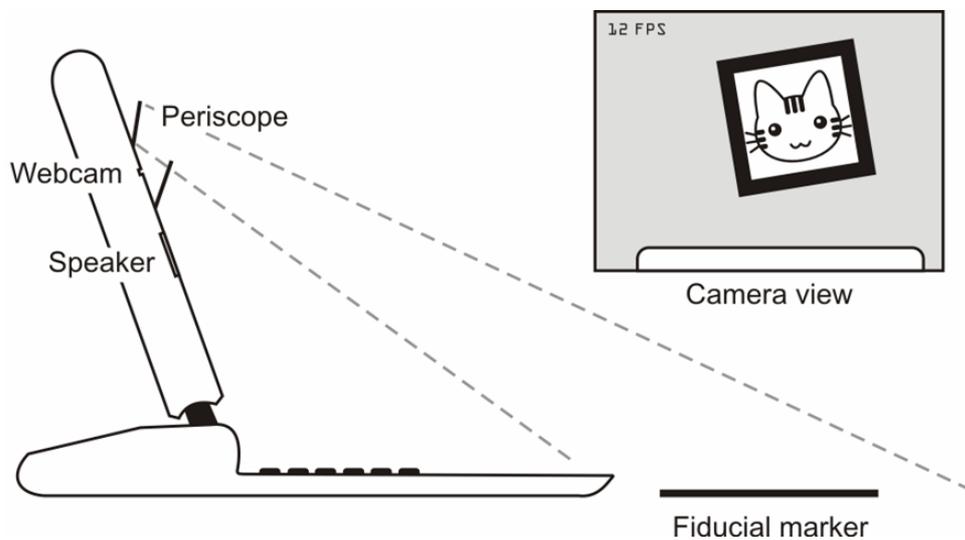


Figure 8 – Originally, PUI included a periscope made of acrylic to be mounted on the screen's case. The periscope allowed to video capture markers disposed over the table, giving the users an alternative option to showing printed markers on the vertical plane. The rationale behind building a cheap periscope was that Plan Ceibal's policy restricting root access dismissed the idea of mounting an external webcam on the XO.

The first working version of PUI was a module included in a Sugar game³⁴. The workflow was as follows³⁵:

- (1) The user opens the game.
- (2) The user positions a printed marker with a shape of an animal in front of the camera.

³⁴ PUI was later turned into a static library. Under normal circumstances, a software component like PUI, would be compiled into a shared dynamic library and linked by many user applications. However, access privileges to XO's operative system are very limited due to Plan Ceibal's security policy, preventing users from installing shared libraries.

³⁵ There is a video showing the interaction workflow in <http://youtu.be/nh7qXMtWqHU>.

- (3) The module recognizes the shape, matching it against a set of shapes, previously loaded in a setup process.
- (4) If the match is positive, then the game displays the picture matching animal on the screen and plays the sound of the animal.

PUI was based on the working hypothesis that users of the XO, and specially children diagnosed with motor dysfunctions, would benefit from such an interaction mechanism.

This working hypothesis was supported in some measure by prior facts, experiences and observations, including:

- Some HCI works suggested that perceptual user interfaces support a broader diversity of abilities than conventional interfaces (Turk & Kölsh, 2004).
- School #200's educators frequently use drawings printed in paper and then attached to different objects and materials for educational and rehabilitative purposes. The interaction scheme proposed by PUI is consistent with this practice.
- School #200 has a very tight budget to cover a large amount of expenses, including buying assistive technology, like access switches. To meet the demand, the personnel learned to assemble their own switches made of compact disks, springs, recycled wires and USB plugs. Such a task requires time, effort and skills, and the resulting product is generally not very resistant and does not last too long. PUI's alternative interaction mode consisting provides a cost-effective alternative to buying or creating electronic switches.
- Markers can contain shapes of any form and can be of different size, as long as they fit in the camera's viewport, allowing app developers and educators to devise custom input layouts.
- Input layouts can be easily replicated, compared to other input devices, like electronic switches. Once an input layout proves to be effective, it can be easily replicated many times to supply a larger population, making PUI a scalable solution.
- Broken input layouts can be easily repaired or replaced.
- The interaction scheme proposed by PUI is compatible with universal design philosophy. If the working hypothesis was true, either children dealing with accessibility issues while using the XO, or children not dealing with them, could potentially benefit from PUI.
- A new kind of educational games on top of PUI's interaction scheme could be developed for the XO.

- Other HCI research works involving the use of low-tech objects and materials, like paper, as mediators between “disabled” children and computers achieved promising results. See, for example, (Garzotto & Bordogna, 2010).

The first prototype proved that it was technically feasible to build a multimodal game for the XO, based on a perceptual interaction device, despite all the technical restrictions of the XO.

It also confirmed that there was a promising future for developing new interaction techniques for the XO, opening an opportunity to create a rich diversity of inclusive apps.

These encouraging results settled the basis for NEXO Stage One.

NEXO Stage One

NEXO comprised two stages, each one with its own objectives, strategies and procedures. Stage One lasted from March 2011 through December 2011. Stage two lasted from March 2012 through December 2012.

Goal and objectives

The goal of the first stage of NEXO was carrying out a pilot study to assess the capabilities of PUI as a mechanism to make the XO more accessible to children with mild to severe motor dysfunctions for enabling cognitive stimulation treatments based on ICT.

The objectives of the project were:

1. Turn PUI’s software component into a standalone application, able to broadcast input events to other Sugar apps running on the XO.
2. Design and develop a set of Sugar apps based on PUI.
3. Assess the validity of PUI as an interaction system aimed to enhance the accessibility of the XO.

Successful completing objectives 1 and 2 was a prerequisite to address two additional goals, related to cognitive and clinical psychology:

4. Design and execute a treatment for stimulating cognitive functions of the brain during early stages of children’s development, using PUI.
5. Assess the validity of this treatment.

Objective 4 was planned and carried out by the team of psychologists headed by NEXO’s Psychology Research Principal. It involved designing a battery of cognitive stimulation activities (CSA) using the software products resulting from objectives 1 and 2. These products were designed in pursuit of improving accessibility.

The theory and practice of objectives 4 and 5 belong to the field of clinical cognitive psychology. They were, along with the goal of improving accessibility, the driving forces guiding the product discovery phase.

As it will be concluded, this driving force may have unintentionally biased the discovery phase toward the needs of the team of psychologists, instead of focusing the design process exclusively on end users: the children and educators of School #200.

Organization of work

NEXO's work was divided in two kinds of activities: the ones related to fieldwork and the ones related to lab work. The latter encompassed software development activities, analysis of fieldwork data and socializing activities.

The students were organized in five teams each one pursuing its own goal:

Team	Composition	Goal
1	4 engineering students and 1 psychology student	Build MouseCam, a standalone Sugar app aimed to make it easy to develop apps on top of PUI's interaction scheme
2	4 engineering students and 1 psychology student	Design and develop an interactive storytelling game using PUI
3	4 engineering students and 1 psychology student	Design and develop educative apps
4	2 engineering students	Technical support
5	2 engineering students and 2 psychology students	Permanent fieldwork

Team 1 through 3 were assigned to software development projects, starting from rough product visions.

In order to define the scope of the projects, there was a product scoping phase, which involved performing onsite observations at School #200. The purpose of such phase was developing a deeper understanding of the needs of the context, defining objectives and deliverables for each product and defining the scope of each project. Engineering and psychology students were committed to work together through an *agilistic* software development process in order to build *minimum viable products*, or MVPs — in this case, a product with just enough features to validate its feasibility and applicability in the context described above (see Context of).

Team 4 was entirely composed of engineering students in charge of learning about XO's infrastructural details and giving technical support to dev teams. Infrastructural knowledge included learning about hardware constraints, understanding Sugar's API, defining the development environment, having a better understanding of Plan Ceibal's privacy policy and restrictions, and learning about how to pack and install Sugar apps.

Team 5 was responsible for establishing a "permanent" group at the school. Its work included building a relationship between the NEXO and School #200, carrying out onsite observations, helping define schedules and itineraries for product-validation activities.

Participating in fieldwork activities was mandatory to all team members at some point of the process. The main motivation behind this rule was allowing experimenters to develop a first-hand opinion about disability — and perhaps challenging their own preconceptions about the phenomenon. For example, most of the students participating in NEXO hadn't had the opportunity of socializing with a "physically disabled" children before.

Every week, one team member from teams 1–3 had to join team 5 at school #200 in order to participate in planned activities, including gathering insights about the product under construction. As a result, every week, three rotating members from teams 1–3 participated in fieldwork activities. The rule was more flexible for team 4 (support) because the team was smaller, and also because one of its members expressed "feeling very uncomfortable around disabled children".

Every two weeks, a mandatory, all-hands, meeting was organized at the lab for the purpose of socializing and re-socializing experiences about fieldwork. This meeting helped address issues like students feeling awkward or uncomfortable participating in activities at School #200.

Mentors

NEXO's permanent staff was in charge of mentoring a team of 16 software engineering students and 5 psychology students. The mentoring team was composed of NEXO's HCI Research Principal (Gustavo Armagno, Software Engineer, MSc student and HCI teacher), NEXO's Cognitive Psychology Research Principal (Ana Martin, Cognitive Psychologist, expert in cognitive treatments for people with "learning difficulties"), an Evolutionary Psychology Advisor (Ana Palas, expert in Piaget's Constructivism) and an HCI Research Advisor (Tomas Lorenzo, MSc and HCI teacher).

As part of the project, the School of Engineering and the School of Psychology approved the creation of a course on each school, for the purpose of recruiting students willing to participate in NEXO — and eventually gain some credits.

The course included the following topics:

- Introduction to Human-Computer Interaction
- User Centered Design
- Accessibility and the XO
- Non-conventional User Interfaces
- How PUI works
- How to develop educative apps on top of PUI
- Introduction to Experimental Design
- Cerebral Palsy
- Stimulation of Cognitive Functions
- WISC IV
- Guidelines to Working with Disabled Children
- Piaget’s Clinical method

Classes were in person. The management of the course’s resources (including slides, documents, guides, references and a constantly updating glossary), forum discussions, news, announcements, fieldwork schedule and work coordination, were supported by Moodle.

NEXO students attended theory classes, participated in a hands-on software development project, carried out fieldwork at school #200, wrote a final evaluation report and presented their work to the class and the mentors.

Developers

Software development projects followed an Agile software development process based on Scrum (Schwaber & Jeff, 2016).

The teams were committed to self-organize according to their own criteria for accomplishing their work. Their responsibilities included not only building the products, but also defining the products’ vision and goals and defining the scope of each project.

Each team consisted of a product owner (PO) and the development team. The PO was selected by the team among its members. She or he was responsible for understanding School #200’s needs, understanding the needs behind the product vision, acting as a point of contact between the mentors — acting as clients of the projects — and the team, following up progress and reevaluating priorities, if required by any emergent situation.

Each team named a person in charge of writing a log of the whole journey. The log was aimed to track achievements, milestones and events

occurring during fieldwork. The motivation was to keep the team alert, help detect and identify problems, as well as serve as a vehicle to share experiences with the rest of the teams.

Mentors helped the teams stay on progress and foster a continuous learning environment. The role of the mentors was closer to an XP Coach, in the XP Agile methodology, than to a Scrum Master.

Scrum defines an incremental development process divided in iterations. At the end of each iteration, the teams, guided by the iteration plan, deliver an incremented value with respect to the last iteration.

The teams synchronized twice a week at School of Engineer's MediaLab and frequently at School #200. Remote communication between teams and the mentors was supported by Moodle.

Domain experts, clients and users

The discovery and the scoping processes were driven by the goal of improving accessibility and carrying out a cognitive stimulation treatment with the schoolchildren.

It was naturally assumed that NEXO's cognitive psychologists were the authority for designing the cognitive stimulation activities. Therefore, they were considered to be the domain experts, i.e. the authorities who guided the product-design process.

A group composed of School #200's Principal, the ICT teacher and lead teachers, acted as NEXO's clients, serving as a source of requirements and practical knowledge about the context of study. They intervened in the subject-selection process — the early adopters of the products. They also helped verify and validate the product ideas and the incremental product deliveries during the process.

School #200's children, along with educators and other staff, were the end users. They participated in the product inception stage and in user testing activities.

Table 4 – Structure of stakeholders in NEXO Stage One

Group	Role
Psychologists	Domain experts
Principal, ICT teacher and lead teachers	Client
Children and staff	Users
Lead psychologists and HCI researchers	Experimenters

As it will be discussed on the Analysis section, this particular way to interpret the roles of the stakeholders, summarized in Table 4, influenced the solution-discovery process, from the scoping phase to the final products.

Assignments

In order to address NEXO’s objectives, four product ideas were initially proposed by the mentors and assigned to the teams.

During an initial, two-week inception stage, the teams narrowed down each idea, defining the product vision and the scope of each project:

Table 5 – Product vision definition in NEXO Stage One

Project name	Product vision
MouseCam	Turn PUI input signals into mouse and keyboard events, allowing to easily integrate existing Sugar apps with PUI’s interaction scheme. Such a mechanism aims to allow educators to design educative activities on top of existing apps, like TurtleArt, which could help enhance cognitive functions, such as spatial representation.

Interactive Storytelling	<p>Create an interactive storytelling game containing five scenes representing complex three-dimensional layouts and scenarios: home, a bus, the school, a friend's house and grandparent's house. Scenes are composed of a static image and a text bubble narrating the story. A recorded audio reading the text is provided to enrich the user interface. At certain points, the narrator asks the user to select one of three options displayed on the scene. Options are basically elements belonging to the scene. The story pauses until the user selects an option, using PUI. Two of the three alternatives are conceptually related, although one of them does not satisfy the narrator's request. The third one is incongruous with the rest.</p>
Tick-Tac-Toe	<p>Create a Tick-Tac-Toe game allowing two children to play remotely through the Sugar Neighborhood (a view in Sugar to connect to the internet and collaborate with other users) using PUI. Games like Tic-Tac-Toe activate cognitive processes including operative memory, attention, orientation and waiting for turns.</p>
Rock-Paper-Scissors	<p>Create a Rock-Paper-Scissors game allowing two children to play remotely through the Sugar Neighborhood using PUI. In general, children with CP cannot play games like Rock-Paper-Scissors due to upper-limb motor dysfunctions. This project aimed to provide an inclusive way to play Rock-Paper-Scissor between two children, regardless their upper-limb motor conditions.</p>

Team 1 was assigned to MouseCam, team 2 to Interactive Storytelling and team 3 to Tick-Tac-Toe and Rock-Paper-Scissors.

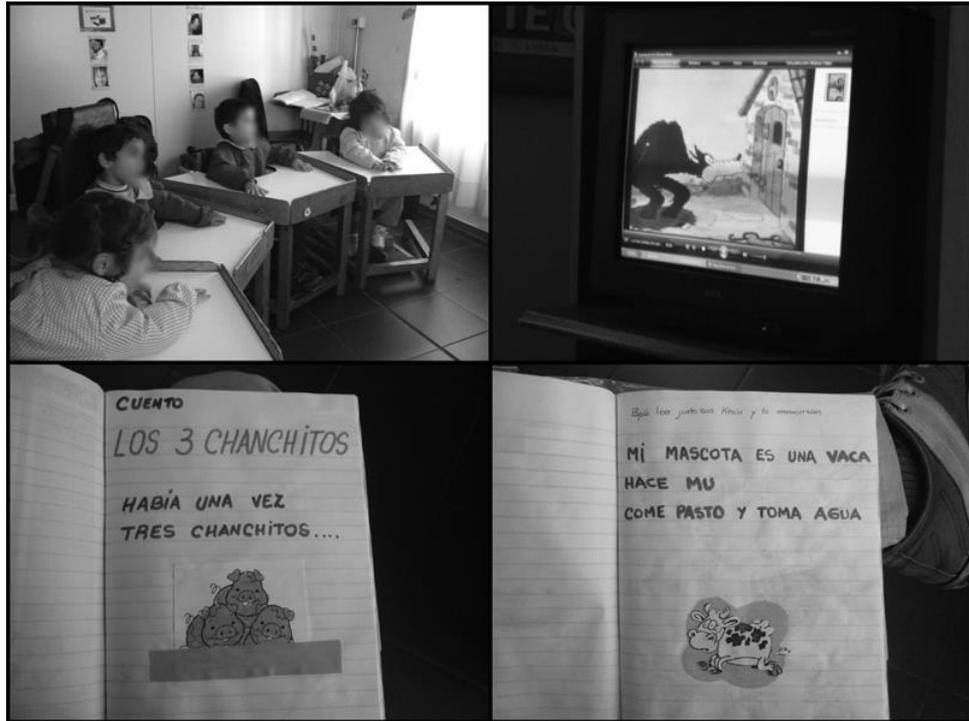


Figure 9 – Educators at school #200 uses multimedia storytelling in classroom as a didactic tool. The bottom-left picture shows a storytelling activity designed by the educators that involved watching the classic Three Little Pigs story and then asking the children to tell the story again. The page says: “Story – The 3 Little Pigs – Once upon a time, three little pigs...”. At the bottom-right corner there is a similar activity with a story about a cow. It says: “My pet is a cow and it does ‘moo’. She eats grass and drinks water.”

The product inception involved discussing each project with the domain experts, clients, users and the mentors.

Fieldwork

Action Research

Team 5 centered operations at School #200, helping carry out a long-term *action research* project.

Action research is a methodology for building knowledge about an unknown context, pursuing practical solutions to issues demanding immediate action. This knowledge is incrementally built in ongoing cycles of action and reflection, gathering intersubjective experiences from different actors, with different worldviews, working collaboratively to promote community and organizational changes (Brydon-Miller, Greenwood, & Maguire, 2003).

Action research is especially useful in contexts where there is certain degree of chaos or uncertainty (Brydon-Miller, Greenwood, & Maguire, 2003), making it extremely difficult and worthless to establish precise hypotheses beforehand.

It was proposed in 1946 by social psychologist Kurt Lewin. He proposed a “cyclical, iterative approach to research involving planning what was to be done, taking action and fact-finding about the results”. Action research “aims to solve current practical problems while expanding scientific knowledge”. It is “strongly oriented toward collaboration and change involving both researchers and subjects”. It is also a clinical method that puts researchers in a “helping role with practitioners” (Baskerville & Myers, 2004).

Action research was considered as a useful instrument for driving NEXO’s research process from a global, long-term, perspective.

Team 5’s responsibilities, in collaboration with the client, included coordinating other teams’ actions in the field, supervising and supporting interventions, gathering qualitative data from participant observations, fostering effective discussions during all-hands meetings at the lab, resolving conflicts at school and identifying opportunities for helping clients and users.

Team 5 also helped NEXO’s cognitive psychologists design and execute a pilot study to validate a cognitive stimulation treatment. This treatment consisted in a series of sessions to address a specific cognitive skill through a set of cognitive stimulation activities, or CSAs.

Subject Selection

For the treatment phase, the client and the team of cognitive psychologists selected 24 children (~1/4 of the school population), and then clinically evaluated them to identify the most vulnerable areas to be stimulated.

The experimenters encountered that the weakest areas were the ones related to mathematics, logic and abstract reasoning. The result of this evaluation defined the focus and complexity of the CSAs.

For the pilot study the subject population consisted of children with mild motor dysfunctions and slightly diminished cognitive functions.

In order to assess the effect of the treatment, researchers divided the subject population into three groups: P1T1, P1T0 and P0T0. Group P1T1 (PUI = true, treatment = true) received treatment using Sugar apps via PUI (see the example below); group P1T0 (PUI = true, treatment = false) played with a PUI-based Sugar app, but didn’t receive treatment; group P0T0 played with the XO without PUI and didn’t receive any treatment.

Cognitive Stimulation Activities (CSAs)

Each CSA involved giving directions for the children to complete a set of exercises on a selection of apps installed on the XO, including the ones developed by the teams, using PUI.

The following is a simplified description of a CSA:

Three colored sticks of about 20cm length and 1cm thick, each one holding a printed marker on one extreme, and an XO open and executing a program created with TurtleArt³⁶, are presented to the subject.

One of the markers contains an arrow pointing to the right, the other one, an arrow pointing up and the last one, an arrow pointing down. The TurtleArt program displays a turtle at the top left area of the screen over a blank screen.

One of NEXO's psychologists is designed as the moderator. The moderator, strictly following a predefined protocol, gives direction to the subject.

First, the moderator explains the concept of the turtle and how it behaves. Then, he or she shows the subject a drawing of a square. Finally, the moderator asks the subject if he or she can draw the square, using the turtle and the printed arrows. The moderator takes qualitative and quantitative notes on a predefined spreadsheet, as defined by the protocol.

User Feedback

Finally, Team 5 helped plan and execute user-feedback sessions aimed to gather functional and UX-related insights about the products under construction. For doing this, a subgroup of children were selected from the group of 24 participating in the cognitive stimulation treatment.

Results

Cognitive Evaluation

As an input for defining CSAs, and their related software products, the team of psychologists evaluated the subjects using a subset of WISC-IV³⁷ and Piagetian tests. Here is a sample of the template used by the experimenters to document the evaluation results:

³⁶ TurtleArt is a visual programming language for Sugar based on the LOGO programming language.

³⁷ Wechsler Intelligence Scale for Children (WISC-IV) is a cognitive ability assessment of verbal comprehension, perceptual reasoning, working memory, and processing speed, designed for children (<http://www.pearsonclinical.com/psychology/products/100000310/wechsler-intelligence-scale-for-children-fourth-edition-wisc-iv.html>).

Table 6 – Sample cognitive evaluation report carried out at school 200.

NEXO - School 200		Pre-intervention Evaluation Report		August 2011	
Name:	XXXXXXXXX	Age:	7 years old	Class:	2B
Brief Description of the Subject					
Difficulty to walk. Shows empathy and collaborative attitude towards adult in charge of evaluation. Doesn't show difficulties to talk or communicate. Uses both upper limbs. Understands directions.					
WISC-IV Evaluation Results					
Cubes		Concepts		Matrices	
6		7		4	
Piaget Operational Diagnosis					
Logical-Mathematical Thinking and Reasoning. Can do 5 permutations, through trial and error. In accordance with chronological age. Spatial Representation. Can achieve horizontality only on vertical position of the bottle. Loose notion of horizontality.					
Summary					
Subject presents difficulties in spatial representation and construction. Logical-mathematical thinking according to chronological age.					
Cognitive Area Demanding Treatment					
Spatial representation.					

Spatial representation and reasoning turned out to be the most compromised areas, compared to other cognitive areas. In consequence, this area was selected as a priority for the cognitive stimulation treatment.

After evaluating different Sugar apps, the experimenters decided that a combination of TurtleArt and PUI was a good choice to base the CSAs on. TurtleArt is based on the Logo programming language. Logo has been used in numerous interventions and research works related to cognitive rehabilitation and stimulation. The team took the work of Antonio Battro — an Argentinean medical doctor specialized in early cognitive development and Chief Education Officer of the OLPC program in 2008 —

as a reference in using Logo and computers for rehabilitation purposes. See, for example, (Battro, 2000).

The subjects would use a set of markers containing figures printed in paper, as instructions for the computer, to move the “turtle”.

On the other hand, defining a set of collaborative, multimodal, Sugar apps would allow children to play with other peers, traversing different abilities, to foster socialization and strengthen self-esteem.

MouseCam

When running, MouseCam allows users to control the mouse cursor directly on Sugar, using the interaction scheme proposed by PUI.

Its first version proved it was possible to enable a mechanism in Sugar for allowing other Sugar apps to use PUI, without being aware they are using it. Before MouseCam, in order to use PUI from an existing Sugar app, it was necessary to rewrite a portion of the app’s source code to import PUI’s static library and recompile it.

MouseCam V1 was pre-calibrated to recognize a predefined set of symbols for the markers. Each symbol is mapped to a mouse event, including move up, down, left, right and click. The rationale behind providing a full set of preconfigured symbols, rather than allowing the user to calibrate their own, was to simplify the setup flow. Once installed, the app is ready to be used. If the user needs to print the symbols, they are shipped in a directory inside the “activity bundle”, i.e. Sugar’s application package.

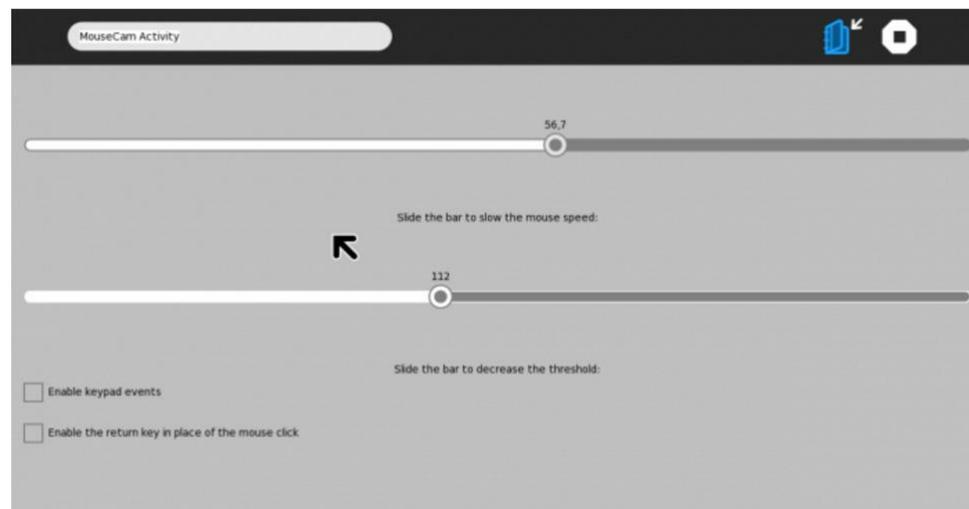


Figure 10 – MouseCam v4 control panel.

When executed, the app opens a control panel allowing the user to set up execution parameters, including the speed of the cursor and the detection threshold for adapting MouseCam to different lighting conditions.

A video of MouseCam in action can be found on NEXO's YouTube Channel (e.g., watch <https://youtu.be/rrciCWgZVSM>).

Rock-Paper-Scissors and Tic-Tac-Toe

Rock-Paper-Scissors connects two players through the XO's neighborhood. Once paired, the game asks each user to show one option — a printed symbol representing either a rock, a paper or a pair of scissors — to the video camera. Then, it waits until both users have played their symbols to display the option played by the opponent, letting the users know who won.

Rock-Paper-Scissors doesn't use MouseCam, but a custom version of PUI linked to the app and shipped in the bundle. This is because MouseCam V1 only supports symbols representing mouse events — arrows, basically.

Tic-Tac-Toe allows remote “pair to pair” and “user versus computer” play modalities. Its user interface was designed to allow users to interact through a single action: a mouse click. In order to do that, the app uses an interaction technique used in assistive technology called visual scanning. This technique is described below, in section Visual scanning interaction. In this case, the app's user interface automatically moves the cursor, sequentially highlighting the Tic-Tac-Toe's cells when the cursor hovers them, and waits for user input. To select the desired cell, the user shows the symbol representing the click action (an “X”) to the camera when the mouse cursor hovers the cell.

Interactive Storytelling

The game, named “The Adventures of Charlie”, was inspired on the “Choose Your Own Adventure” series of gamebooks, popular during the 1980s and 1990s.

The story, narrated in second person, is about Charlie, an extraterrestrial creature who landed at Guzmán's home. Guzmán is a boy aged between 6-10 years old. Charlie has the mission to learn more about humans, so he asks Guzmán for help to let him blend in with society, without being noticed as an extraterrestrial being.

Each scene is static and represents a particular scenario, e.g. Guzmán's home. It is narrated by a recorded voice, subtitled in a text contained in a bubble at the bottom of the screen. The scene ends showing three options, two of which are the correct ones. The game moves to the next scene when the user, assuming the role of Charlie, selects one of the correct options.

The plot, the options and the layout of the different graphic elements were defined by the development team aided by the team of psychologists. An external graphic designer volunteered to work on the visual design, giving it an appealing look and feel.

The game was programmed for extensibility, giving programmers the possibility to add new scenes with relative low effort. The team delivered two complete scenes, ready to be tested against end users.



Figure 11 – Interactive Storytelling game developed during NEXO Stage One. The text on the left says “Which two clothes do you think you should wear?”.

A demo of the game in action can be found in https://youtu.be/A09S_fZvFIk.

Action Research

This approach helped connect actions concerning different domains, interests and purposes. It also helped actors evaluate their acts during fieldwork, reflect on the actions performed and adjust practice, if required.

Having a semi-permanent presence at school and fostering School #200’s staff participation helped build a strong relationship between stakeholders. As a result, NEXO had consent to freely circulate at the school and perform planned activities without interference.

In the long term, it helped connect existing theories and models about “disability” with NEXO’s praxis. Furthermore, it allowed to more deeply understand the ideological underpinnings of School #200 as-an-institution and how it favors certain classes of solutions, blocking others. This analysis helped evaluate current strategies and propose new ones. Chapter 3 (The Role of HCI in the Construction of Disability) discusses the findings of this process.

Analysis

A new user interface for the XO

NEXO Stage One proved that it was possible to build a non-conventional input device for the XO, which uses computer vision for recognizing printed markers, to produce a perceptual user interface, named PUI.

It also proved that there was a workaround for bypassing Plan Caibal’s restrictions related to its security policy, allowing to create PUI-based apps without needing to pack and ship PUI’s software library within each app’s executable. This workaround consisted in converting PUI’s input

signals into mouse events, as if the user had indeed physically moved the mouse.

As a desired side effect of this solution, with some modifications to MouseCam, existing Sugar apps could use PUI's interaction scheme, without the need of updating them in any way.

To the best of the author's knowledge, it was the first time a user interface based on computer vision was built for the XO³⁸.

Did PUI reduce access barriers?

The subject selection process divided School #200's target population into in three segments: (S1) children with mild motor dysfunctions and slightly diminished cognitive functions; (S2) children with severe motor dysfunctions and severely diminished cognitive functions; (S3) children with mild to severe motor dysfunctions, but keeping reasonable levels of understanding and communication.

Children in S1 were able to use the XO with some degree of difficulty, in most of the cases using a mouse, but without the aid of any assistive device. They were also able to understand directions given by the experimenters. They showed more engaged and motivated when using PUI than the control group (T0). However, in terms of accessibility, PUI showed no extra benefit than, for example, using the mouse.

On the opposite, children in S2 were not able to access the XO, even with assistive devices, and it was difficult for them to use other computers, according to the observations. Their motor condition, combined with severe cognitive dysfunctions, prevented them from engaging in NEXO's sessions. This doesn't necessary imply that they won't be able to use PUI, or any other non-conventional user interface, in the future. It may mean that they may need more time, and more dedicated personnel, to learn to use PUI and the apps. It may also mean that PUI might not be the right approach for making the XO more accessible to this particular segment.

Segment S3 was the most suited candidate to validate the impact of PUI on accessibility. This is because children in this segment are able to understand directions during the experiment. Unfortunately, children in S3 turned out to be a rare case at school, limiting the possibilities of performing a quantitative analysis and expecting results with statistical significance.

Problems of this kind are expected on pilot studies, where the goal is to learn about a previously unknown, complex and dynamic reality.

³⁸ Perhaps a combination of factors, including XO's computing restrictions and Plan Ceibal's root restriction policy, were an up-front obstacle deterring any development effort in this direction.

NEXO Stage One allowed the experimenters to align goals and expectancies with the reality of the context. Initially, the experimenters expected to quantitatively validate the potential of PUI as a device to reduce access barriers, through a controlled experiment. However, reality turned out to be more complex than initially thought: selecting children from S3 (unable to access the XO, but able to understand how PUI works) and grouping them into treatment and control groups turned out not to be an option.

Still, an important teaching from this experience is that PUI and PUI-based apps demand a certain degree of reasoning, memory, attention and language abilities to be used properly.

Challenges of usability testing on S3

The consensus view seems to be that gathering feedback from children with motor and cognitive dysfunctions is a difficult task. The literature on HCI and disability abounds with examples of research works, addressing similar issues, target population and contexts, arriving at the same conclusion (Allsop, Gallager, Holt, Bhakta, & Wilkie, 2010).

Standardized usability testing practices based on quantitative analysis relies on a protocol, defined during the test plan, that demands a thorough execution in order to avoid procedure bias. This standard is implicitly based on the premise that the study subjects have some degree of homogeneity. For instance, it assumes that the subjects are, at least, able to understand directions given by the experimenter. It also assumes that the subjects are more or less able to communicate their experiences with the moderator.

Such a premise is not necessarily true when working with children diagnosed with motor or learning dysfunctions, because the range of abilities is highly heterogeneous, reducing the possibilities of achieving statistical significance. Additionally, some people require assistants to aid communication, introducing a new possible source of bias: relying on the subjective interpretation of the assistant.

This scenario of high variability between children's abilities was detected at School #200 during fieldwork. As a result, a case study approach, combined with direct observation, was preferred for evaluating the performance of PUI with subjects in S3.

Evaluation based on a case study approach

Three children participated in the case study evaluation: Paco, Lola and Mara³⁹. Paco and Mara were diagnosed with CP and Lola with muscular dystrophy. Paco and Mara belonged to S3; Lola, to S1.

³⁹ Names were changed to preserve anonymity.

The three of them attended ICT classes at school, but their level of engagement differed. Paco's motivation was low when working with desktop computers and had never used the XO before, due to accessibility issues, according to the educators. Mara attended the classes but never engaged. As Paco, she never used the XO. Lola showed high motivation during ICT classes and, in spite of her upper-limb difficulties, she enjoyed using her XO on daily basis.

Paco refused to participate in the activities proposed by the moderator. Researchers received advice from educators that he had behavioral disorders, not necessarily as a direct consequence of his condition. Since he responded only to his teacher and his assistant, the latter participated in the sessions in order to provide help to the moderator. In spite of this aid, Paco showed no interest in playing with the XO, or even explicitly — and sometimes aggressively — rejected any direction given by the moderator, or the assistant.

Mara was not able to understand directions given by the moderator. Since socialization for children with cerebral palsy can be a challenging issue, an assistant actively participated during the sessions providing help as an intermediary. However, Mara was not able to complete any task using PUI.

Lola engaged in the activities proposed by the moderator during the sessions. She showed motivated while playing with Rock-Paper-Scissors and Tick-Tac-Toe. However, she showed more excitement when playing with printed arrows to move the turtle, using PUI+MouseCam+TurtleArt.

Lola's level of engagement was consistent with the observations during the cognitive stimulation sessions. During these sessions, performed only by segment S1 in the pilot study, children belonging to group P1T1 (PUI on, treatment on) engaged in the activities proposed by the moderator. They showed more interest than children playing with PUI-based Rock-Paper-Scissors, Tick-Tac-Toe and Interactive Storytelling — group P1T0 (PUI on, treatment off).

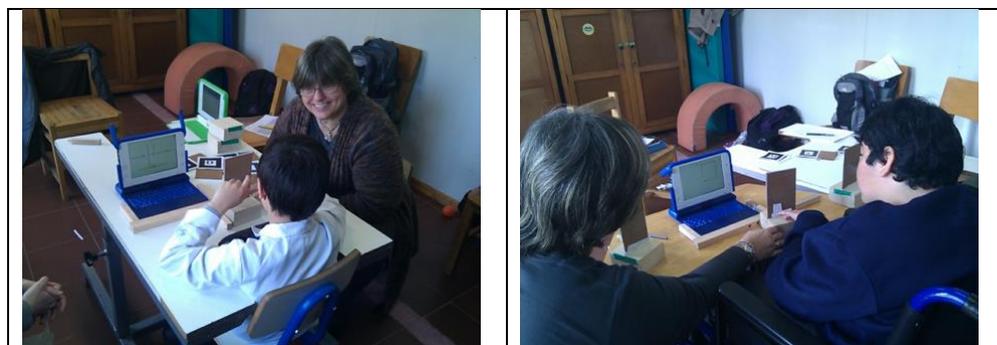


Figure 12 – NEXO Stage One explored the impact of PUI as a new contribution to cognitive stimulation treatments.

With different levels of difficulty, and trying different supports, specially made for holding the printed markers, all of the children belonging to S1 were able to interact with the XO through PUI.

In summary, only children from segment S1 engaged in activities involving the XO and PUI. In general, they showed more interest in the combination of PUI+MouseCam+TurtleArt than playing with Rock-Paper-Scissors, Tick-Tac-Toe, or Interactive StoryTelling.

Factors affecting engagement

In the case of Tick-Tac-Toe, while the subjects were in the age range to play with it (> 5 years old, according to several sources), the experimenters noticed that it was difficult for the children to learn, at the same time, the game's rules and the "language" of the user interface, i.e., the rules underpinning the interaction scheme proposed by the combination of PUI and the app. These barriers could have led to frustration and, consequently, a low engagement and some degree of reluctance to keep playing.

This result shouldn't be attributed solely, or even partially, to the children's condition. It could be interpreted that a combination of several factors may have influenced such a low engagement, including, as it was mentioned, the effort to learn the rules of the user interface, the visual and interaction design of the game, or the "playability" of the game⁴⁰. Other factors, including the environment setup for the sessions, the session plan, or even a matter of empathy between the child and the moderator, may have played their role, but in a lower degree. Otherwise, researchers shouldn't have observed motivation or excitement emotions in other sessions involving other activities.

Similar factors may have influenced the low engagement observed during sessions involving Rock-Paper-Scissors. Besides, an extra factor should be considered. Both games accepted one or two player options. However, during the sessions, and due to restrictions of different kinds, only one child participated at a time. Consequently, children always played against the computer and couldn't experience the pair-to-pair feature of the game, which could have made it more attractive to users.

Conjectures related to the game's usability and playfulness are subject to further exploration. However, the critical aspect that should be reconsidered is the user interaction language proposed by the combination of PUI and the apps.

Regarding PUI, while it was designed for simplicity, its accessibility depends to a great extent on the match between the physical support and the motor abilities of the subjects. For example, it was easy for some users to hold a stick, but impossible for others. To overcome this issue, a

⁴⁰ For a definition of "playability, see (Lennart, et al., 2009).

support made of wood was built. To add more complexity to the problem, each game defines a maximum time frame in which the user interaction should take place. For Tic-Tac-Toe, the user must stop the mouse cursor at the right moment, when the cursor reaches the desired cell position, by showing a marker containing an “X” or an “O” to the camera. If the user misses this time frame, because of his or her motor condition, then the user will need wait until the cursor reaches the desired cell again. For Tic-Tac-Toe, this time frame is configurable by regulating the speed of the cursor. If this speed is too low, then the game could become too tedious for the user.

Because of its sequential nature, the game so called “Interactive Storytelling” could be tested before the whole game was completely developed. Once the first two scenes were designed and programmed, they were presented to the children during the sessions and also to a group of educators from school #200.

The experimenters observed that it was difficult for children to follow the plot, despite the auditory output, reinforced by subtitles provided by the user interface. Most of the observed children were unable to select the correct answer from the list of options. Some of them were even unable to establish a connection between the printed shapes and the options shown on the screen.

Feedback from educators pointed at the plot of the story and the game’s visual design. Regarding flaws in the plot, they provided a very concrete and clear example:

Guzmán was the name of the protagonist and Charlie was the name of the extraterrestrial character visiting Guzmán. The development team and the domain experts choose Guzmán because they considered it was a good name for an average Uruguayan child. Likewise, they choose Charlie because they thought it was weird enough for an alien.

However, the educators pointed out that such a selection of names may have worked fifteen or twenty years ago — when the people in charge of designing the game were children — but not at the present times. They agreed that Charlie was not so unusual than Guzmán so that it might have been a better idea to swap the names for the game.

A possible cause of this expectation gap was basing early design decisions on domain experts rather than on end users. The domain experts had theoretical knowledge from cognitive science — complemented by a functional diagnostic performed to the subjects — about capacities, limitations and expected behavior of the children participating in the study. In other words, the domain experts defined a *model of the user* and developers and researchers relied on such model early in the design process. However, this model may have not been the most accurate representation of the user.

It is worth mentioning that this decision doesn't mean that end users were not considered for the design process, nor that design decisions didn't follow a user centered design process. Quite the contrary, the methodological approach was indeed user centered: each project sought feedback from users as soon as a minimum core functionality of the MVPs was ready enough to validate the product ideas. Moreover, user feedback gave developers enough input to reshape each solution and address usability and accessibility concerns.

This process may have efficiently worked in a different context. However, in a context with a high variability between users' abilities, relying on HCI design approaches that base their practice on finding an "abstract" user — or a small set of "abstract" users — representing real users, may have slowed down the learning cycle, delaying critical design decisions.

For example, in the case of Interactive Storytelling, a participatory approach involving children in the creation of the story, may have early detected, or even avoided, issues like the "Guzmán-Charlie" slip.

Conclusions

NEXO Stage One was a pilot study, aimed to assess the potential of PUI as a new interaction scheme to enable the possibility of carrying out cognitive stimulation treatments on the XO for children with CP with mild to severe motor dysfunctions.

Such a goal demanded two broad lines of work: studying the viability of PUI as a mechanism for making the XO more accessible and carrying out a small scale study to evaluate the feasibility of conducting a cognitive stimulation treatment using PUI on the XO.

Both studies were disciplinary and methodologically independent of each other, but at the same time intertwined by the same context: School #200, children with motor and cognitive difficulties, XO's accessibility issues and the same underlying interaction system — PUI.

It was a pilot study because prior to NEXO there was little or no knowledge about the context and its emerging problems. Carrying out a pilot study under such premises is recommended by HCI literature before beginning any real data collection (Lazar, Feng, & Hochheiser, 2010, p. 407).

These studies led to the following conclusions:

- Preliminary results suggest that PUI may prove beneficial to children with mild motor and cognitive disorders in cognitive stimulation treatments.
- It can't be concluded whether PUI effectively reduces access barriers or not. However, direct observation of children with mild motor and cognitive disorders using PUI suggests that it may not

be a good replacement of push buttons when used with applications requiring quick user response times.

- The action research process allowed NEXO’s team to continuously learn about its practices and to question its methods. This self-reflection ability helped identify some methodological issues that may have slowed down, or distracted, the discovery of different solutions to the problem of XO’s poor accessibility.
- Cognitive psychologists — in their role as domain experts of the cognitive stimulation treatment — replaced end users at the inception stage of each project. Allowing users to participate in product inceptions may have helped get insights into how children would use and feel about the products earlier in the development process.
- Carrying out a controlled experiment to validate the assumption that PUI improves XO’s accessibility was not possible, because the target population who would have benefited from PUI, i.e. children exceeding a minimum threshold of cognitive development who couldn’t access the XO, was hard to find at the school. This restriction of the context made researchers to change the strategy and follow a qualitative approach.
- The four development teams built a set of software solutions on top of a single interaction system in common: PUI. This organization of components created a dependency between the success of educative and rehabilitative apps and the success of MouseCam. If MouseCam had failed at simulating mouse and keyboard events on Sugar, then the scope of PUI, and the opportunity to use it with any Sugar app, would have been more limited. Early in the development process MouseCam proved technologically feasible. However, it was a single point of failure that may have compromised the overall success of the project.
- Such an organization of components also generated a dependency between the teams at fieldwork. Teams developing Rock-Paper-Scissors, Tic-Tac-Toe and Interactive StoryTelling were not able to test the value of their products with users until the first version of MouseCam was released.
- Researchers expected more cross-disciplinary cooperation between engineers and psychologists within development teams than what happened in practice. Initially, development teams were composed of four students of software engineering and one student of psychology. During the inception phase and at the beginnings of the development process this organization worked as expected. When coding peaked, and even before that, the teams had to be restructured and the psychologists were reassigned to fieldwork.

- Stage One’s methodology defined children as subjects of study rather than individuals who could participate in a solution discovery process. This approach is rooted in a *medicalized* view of the phenomenon of disability (Chapter 3 discusses about different models of disability). Empowering children to find their own solution was explored in NEXO Stage Two.

NEXO Stage Two

The assessing technology used to classify schoolchildren into three segments, mentioned in the analysis of NEXO Stage One (see Did PUI reduce access barriers?), is key to understand the rationale behind some structural and methodological changes defining NEXO Stage Two.

The boundaries of segment S1 (mild motor dysfunctions – slightly diminished cognitive functions) were easy to draw, since, during the sessions, children within this segment were able turn directions into (motor) actions on their XOs. However, there was a possibility that the limits between S2 (severe motor dysfunctions – severely diminished cognitive functions) and S3 (mild to severe motor dysfunctions – mild cognitive dysfunctions) were not well defined. The source of this suspicion is that, coincidentally, the battery of tests — WISC IV and Piagetian tests — used to evaluate and segment the population gave a low score to children with severe motor disorders.

It was also extremely difficult to come to an agreement about whether there would be a fourth segment, S4, comprising children with mild motor dysfunctions and severe cognitive dysfunctions.

Assuming that the fitness of the selected tests was correct, and that there weren’t any gross errors during the evaluation process, then the singularity of the resulting scores could be explained by, either a coincidence — a particular variety of the school population —, or an inherent problem of the procedures for assessing the cognitive development of children with cerebral palsy.

Whether the two former options cannot be disregarded, there is at least one scientific study supporting the latter. A systematic review of medical electronic databases, published in 2013 — post NEXO —, concluded that the cognitive abilities of children with CP “are likely to be underestimated because the standardized procedures of such assessments are not appropriate for the population as a whole” (Yin, Guppy, & Johnston, 2013).

The research analyzed papers published in a set of electronic databases, including PubMed and other authoritative scientific sources, containing studies that (1) measured intellectual function, (2) in children aged 4 to

18 years, (3) with CP, and (4) with psychometrics available. WISC IV was one of the tests encountered in some of the papers⁴¹.

The study suggests that there might be a procedural bias related to the tests used to measure the cognitive level of children with CP:

“(…) while there are standardized IQ assessments available that are potentially suitable for children and young people with CP, at this time individual assessments should be used and interpreted with caution. (...) Standardization of IQ assessments for children with CP is so burdened by the heterogeneity of the population that no one assessment currently presents a fair assessment of all children. As all standardized assessments have been normed for children with typical physical development, they all include items that inadvertently penalize subgroups of children with CP, as a result of their motor, communication, and/or visual impairments. This may lead to questionable, possibly invalid, results. However, if any item is modified to make it more appropriate for a certain physical impairment, the item may lose standardization, again compromising the overall assessment validity”.

Such an interpretation describes the experience observed during NEXO Stage One’s test sessions:

During a cognitive evaluation session, a child receives directions and is committed to execute a motor action. Even considering the child’s medical diagnostic, or opinions about the child’s abilities from educators and other close people, it is difficult for a moderator to make the difference between a child who can’t understand directions from a child who can’t execute an action due to a severe motor dysfunction.

The same procedural obstacle appears in the process of evaluating the accessibility of a user interface, like PUI.

In both cases, it could be hypothesized that the physical infrastructure of the tests used for selecting the candidates for the study, was an obstacle *itself* for achieving its very own purpose. In other words, there is a possibility that the technology used to assess intelligence and/or accessibility *might not be accessible enough* for children with certain level of motor dysfunction.

A potential flaw in the measuring tools, if real, could bias the subject section method and, consequently, compromise the outcome of any

⁴¹ The others were the Columbia Mental Maturity Scale, the Leiter International Performance Scale, the Peabody Picture Vocabulary Test, the Pictorial Test of Intelligence, the Raven’s Coloured Progressive Matrices, the Stanford–Binet Intelligence Scales, the Wechsler Adult Intelligence Scale, and the Wechsler Preschool and Primary Scale of Intelligence.

attempt of carrying out a controlled quantitative experiment, regardless of the context, or the number of experimental samples.

Certainly, such an assumption requires more experimental evidence before taking it as true, including thoroughly reviewing NEXO's experimental design and its execution. However, even if there were procedural errors during NEXO Stage One, the risk of being in front of a deeper problem tipped the scale in favor of finding ways to mitigate it, rather than focusing all the efforts on redoing all the experiment again. Consequently, for the second stage of NEXO, a scenario of "procedural errors during the first stage" was deferred. This decision led to two possible scenarios.

Supposing that the selection method was flawed, then there was a chance of finding an alternative method for evaluating the children, instead of using psychometric tests. If part of the target population was, in fact, "hidden" in S2, then, through the right combination of accessible technology and methods — e.g. an innovative, and inclusive, interaction scheme —, it could be possible to make the target beneficiaries grow in quantity. For instance, a new kind of user interface may allow some users in S2 to execute tasks that couldn't execute through PUI — indicating that, in fact, these users belonged to S3 instead of S2. Finding such a user interface would indicate that a selection criteria based, for example, on WISC IV, might be excluding the topmost beneficiaries of an accessible computer with the power to exercise different areas of child development — NEXO's ultimate goal. Additionally, any indication that a user interface has the potential to reach children with higher levels of understanding within segment S2, would lead to a better starting point for designing stimulation treatments and, especially, developing statistically-significant controlled experiments for validating them⁴².

Supposing that the selection method was correct and that segments S1 and S2 were well defined and predominate at school #200, then the school might not be the right context of intervention. If that were the case, then one option to improve statistical power is to reach out to more population in segment S3 via expanding the fieldwork to other contexts. Such an initiative would require more resources to increase NEXO's reach — possibly through involving decision makers and influencers in the process, to engage other institutions and organizations in the project — and coordinate a city-wide, or a national-wide, experiment. In this regard, there is an additional risk to be considered before embarking on a large-scale, quantitative experiment. There is evidence that cognitive function is positively related with physical function in children with CP (Song, 2013). A Piagetian explanation to this is that children with severe motor

⁴² If that were the case, the proposed interaction scheme could, most likely combined with other personalized evaluation techniques, potentially turn into the new assessment standard.

disorders who are not able to, up to a certain level, physically interact with the outer world at early stages of development, will sooner or later develop further intellectual dysfunctions⁴³. If that were the case, the effort for reaching out to a greater audience could be unfruitful, because the distribution of NEXO Stage One's subjects across the three segments could be a sample of a more general trend, wherein population in S3 will always remain below the threshold of statistical power.

The first scenario was selected as the preferred *working hypothesis* for NEXO Stage Two, because it was considered to be the least expensive in terms of overall effort and cost, and, most likely, the most effective one. Thus, the new instance of NEXO revolved around the goal of finding a new interaction device that could increase the probabilities of making segment S3 larger.

In pursuance of this new goal, the approach for the second stage changed some of the original plans. For instance, the ones related with designing and executing a stimulation treatment were postponed.

Instead, all the efforts focused on developing a set of prototypes of non-conventional interaction devices, and a set of games aimed to stimulate the level of engagement of the children.

The development process, and the overall methodological approach, were readapted in response to key lessons learned during Stage One, including:

- Critical design decisions revolved around feedback provided by end users, who become key participants during the product discovery phase. This change responded to the importance of getting early feedback from end users to avoid building solutions based on ill-defined user models.
- The role of the context was reconsidered. Originally thought as a mostly passive, taken-for-granted, entity, the experience showed that the context plays a crucial role as a disabling agent.
- Other factors, which were not considered at the beginning, were identified as barriers diminishing children's participation. For example, it was observed that the ability to move around and explore the surroundings was not only limited by a lack of movement in the lower limbs. On the contrary, some children in wheelchairs are *afraid of* moving across the hallways. According to the psychologists and School 200's educators and physiotherapist, this is due to an excess of anxiety, responding to

⁴³ Piaget stands that children progressively construct knowledge and understanding of the world by coordinating experiences, such as vision and hearing, with physical interactions with objects, such as grasping, sucking and stepping. This is called the sensorimotor stage of development.

different causes, including growing up with overprotective parents and experiencing discrimination.

- Beyond the impact of the body dysfunction on communication and social interaction skills, there is evidence that it is difficult for school-aged children with physical impairments to get involved in community-based activities. However, they do engage in school or home-based activities. In this regard, there is scientific evidence supporting the hypothesis that contextual factors — personal, environmental — exert a powerful influence on participation (Majnemer, Shevell, Law, & Birnbaum, 2008).
- The goal of designing a cognitive stimulation treatment limited the creative process of designing games and apps, narrowing the possibilities down to those in line with such a goal.

While the first stage of NEXO focused on the immediate accessibility problems caused by the XO, the second stage expanded the locus of action to address the classes of problems producing lack of participation. The development process and the roles of stakeholders were reformulated, shifting the attention towards end users as guiding agents of design decisions.

The second stage shared with the first stage the same vision and mission, context, staffing needs, educational goals, contents and some of the objectives. However, based on the insights discussed above, some structural and methodological changes were introduced in order to implement an open-ended, exploratory study. The following table summarizes these changes.

Table 7

NEXO Stage One	NEXO Stage Two
Context and problems described by personnel of School #200 were taken for granted.	Stage One provided a deep understanding about the context. New problems (necessities) were identified. Context is <i>pragmatically</i> taken for granted.
Aimed to augment XO's user interaction channels through PUI and a set of software applications built on top of it.	Aimed to augment XO's user interaction channels through a variety of non-conventional user interfaces, targeting diverse body functions.
Cognitive stimulation treatment "defines" software products.	Diversity of user interfaces "defines" software products.
Software products based on, and depending on, a single interaction mechanism — PUI.	Software apps depending on different interaction mechanisms.
Design decisions driven by psychologists acting as domain experts.	Design decisions driven by user testing.
Development teams composed of 4 engineering students and 1 psychology student.	Development team composed of 3 engineering students. Psychology students and mentors assisted teams during fieldwork.
Development teams were assigned to a specific project defined by the mentors.	The mentors prepared a list of product ideas and the teams had the liberty to choose and commit to one of them.
Users didn't participate in the design process.	Users participate in the design process.

Goals and objectives

The main goal of Stage Two was designing and developing a diversity of non-conventional user interfaces.

As discussed above, the rationale behind creating a diverse variety of user interfaces was to find a breach in segment S3's access barriers that PUI couldn't break.

Methodologically, Stage Two was an exploratory study aimed to find an indication that some classes of interaction mechanisms can effectively turn the XO into an accessible tool for children with mild to severe motor dysfunctions who still keep reasonable levels of understanding and communication.

Objectives

The main goal encompassed three objectives:

- Develop an interaction scheme based on tangible interaction.
- Develop an interaction scheme based on computer-vision techniques.
- Develop an interaction scheme based on a visual scanning technique.

For the second objective, five inclusive applications, described in the Results subsection below, were proposed.

Results

Tangible interaction

The device, code-named *MakeUy*, allows to turn a wide variety of physical objects into a keyboard, using the same technique as MIT's MaKey MaKey commercial product.

Both products exploit an electronic principle allowing them to detect a closed switch through a wide variety of materials, including human skin, fruits, play-doh or a pencil trace over a sheet of paper.

When the switch is closed, the device sends a signal via USB to any computer implementing the USB human interface device (UDB HID class), which includes the XO. MakeUy can detect ten different switches connected to ten digital input pins, allowing it to send ten different keypresses in parallel to the computer.

One of the differences between MakeUy and Makey-Makey is that the former is enclosed in a protective plastic box, designed to resist damage when dropped or knocked.

The main advantage of this particular tangible interaction interface is its mutability: it allows to quickly and easily build versatile user interfaces that can adapt to a wide range of motor conditions.

Computer-vision-based interaction

The motivation was to find a mechanism allowing the XO to recognize and interpret certain real-world elements when captured by the camera. Due to the XO's limitations, the scope was constrained to using QR-code tags attached to physical objects. QR-code processing requires less computing power to process symbols than other computing vision techniques.

QR-codes differ from PUI in that PUI's fiducials need to be preloaded in the XO. QR-codes, on the other hand, encode the information within the symbol, transferring the semantics of symbol identification to the symbol-generation process. Compared to PUI's fiducials, QR-codes are also less error prone, fastest to detect, don't require any lighting calibration and can *store* more information.

These competitive advantages of QR over PUI make it potentially a new opportunity for building cheaper, user-friendlier and more adaptable solutions that can be used in less demanding conditions — e.g., by reducing detection time, or relaxing restrictions concerning alignment of camera and fiducials.

The challenge involved creating a software library for enabling native QR-code reading in Sugar. There was an attempt to enable QR-code reading in Sugar before NEXO Stage Two by a third party. However, it involved sending captures of QR-codes to a web server containing all the QR-processing logic, limiting the possibilities of capturing video and making it unattractive in terms of scalability.

Visual scanning interaction

Visual scanning is an access method, intended for users with motor dysfunctions who can't use conventional input devices, to select items from a selection set on the screen.

A scanner indicator, or cursor, moves through items by sequentially highlighting item by item on the screen, allowing the user to select the highlighted item by activating a switch.

The goal was to enable this function on the XO.

Games

The process of designing and implementing the new set of interaction devices entailed finding, or creating, a set of software applications connecting the audience with the devices. This approach allowed to get design insights about the devices being developed, and also to mitigate the risk of "lack of motivation" to use the devices. In regards with the latter, the experimenters decided to find or build a set of inclusive, funny games.

A group of representative schoolchildren and educators participated in the inception phase of each game. Each project followed an iterative development process, releasing minimum viable products (MVP) at the end of each iteration. These MVP were meant to be early tested with end users. This approach was key to receive early validation from users, accelerate the learning cycle and reduce the risk of misinterpretation of the *real* needs of the users.

As a desirable goal, the games should focus on one or many psychological (Piagetian) areas of cognitive, physical, communication, social, emotional, or adaptive development.

It was part of the requirements to foster children participation, particularly during the inception phase of each product.

A description of each product follows.

*Qué Viaje!*⁴⁴

The specific objective of this project is to work on everyday habits, focusing on planning-related and visual-spatial cognitive areas, including notions of space, position and abstraction.

The app is a Sugar game using QR-code-based interaction. It is meant to be used by children with CP with low to mild cognitive and motor dysfunctions. Also, to be used by children with TBI (traumatic brain injury).

The game is about a character who travels to different places with different weather conditions and the character has to find appropriate clothes before to take for the trip. Users have to show real objects, representing clothes they would wear, to the camera. The game identifies each object by reading a QR-code attached to them, and reacts according to the user's decision.

Tortukart Memory

This project is a game focused on enhancing reasoning, memory and planning areas, through the rules of the game, and motor skills, through interacting with the computer through a variety of shapes and textures — using MakeUy as a proxy of such interaction.

The game, meant for children with mild to severe motor dysfunction, is a visual representation of a typical School #200's classroom where there are boxes hiding animals all over the place. The main character is a turtle, who has to find pairs of animals. Instead of clicking on two boxes to peek and see if the figures match, as it would be a regular memory game, the user has to move the turtle through the screen to find a way to each box.

The game has four levels of increasing difficulty.

⁴⁴ "What a trip!"

Interactive Storytelling

This project is focused on exercising spatial-temporal reasoning, narrative meaning construction and perceptual skills. It offers more than forty scenarios and three players to choose. Transitions between scenes is done when the user resolves a situation proposed on each scene. The scenes also contain multiple elements that gives visual and auditory feedback inviting the user to explore them.

The app is meant for children with low to mild motor and cognitive dysfunctions. However, it is thought to allow multiple people to be participating in the same play. In case of severe dysfunction, the activity can be driven by a pair or an adult.

XOtoXO

This project implements a messaging system based on uploading/downloading messages to/from QR-codes pasted on the environment — e.g. walls in a hallway.

The messaging system works as follow. Each QR-code contains a unique id. The user scans the QR-code using the app installed on the XO. When recognized, the app allows the user to select an image to be uploaded. While it seems like the user is uploading the image to the code, the image is being uploaded to a web server. The server allows only one image per id. When other user scans the code, the app shows the stored image to the user and allows the user to replace the image with another one.

Besides fostering the exploration of hallways during breaks, the game enables a communication channel between morning and afternoon shifts.

Attenti⁴⁵

This game exercises visual searching, short term memory and attention. The goal of the game is to find a particular object in a relatively visually complex scenario. The object is first shown to the user over a blank background before transitioning to the complex scene.

The interaction is based on visual scanning. Users can use the spacebar, mouse click, an accessibility switch, or the combination of any object and MakeUy, to stop the cursor on a cell.

The app allows to configure different parameters, including the speed of the scanning cursor, the time during the single object is shown, the time during the scenario is shown without any scanning grids, the type of scanning (random or sequential) and the cell where the character is located.

⁴⁵ “Attenti” is an Italian exclamation that means “attention!” and it is sometimes used in Uruguayan slang to come to someone’s attention.

Evaluation

The products were evaluated using quantitative and qualitative approaches. Both approaches were combined to evaluate the fitness of each product for the context being examined.

The quantitative approach followed the structure of a typical user testing protocol, where participants must complete a set of tasks proposed by a moderator.

A typical usability test quantifies different quality components affecting product usability, including learnability, efficiency, memorability, error forgiveness and satisfaction.

Learnability indicates how easy it is for users to accomplish basic tasks the first time they encounter the product. Efficiency measures how quickly users can perform tasks once they have learned the design. Memorability evaluates how easily users can reestablish proficiency when they return to use the product after a period of not using it. Error forgiveness assess how easily users can recover from errors they make. Satisfaction relates to how pleasant it is to use the design⁴⁶.

The usability test was adapted to suit School 200's context, emphasizing some quality components over others. For instance, efficiency was not considered as a relevant quality component for the case of users who require a significant extra time to complete motor-demanding tasks. Instead, other components, like learnability and satisfaction, were hierarchized, because they have a more direct impact on product accessibility. Information architecture, user interface's layout, easiness to distinguish actionable components from static components, contrast between foreground and background, were all evaluated as part of the test. Other relevant variables, like the number of times a child asked for help to perform a particular task were measured, as an indicator of product learnability.

Satisfaction was measured using Likert scales adapted to children with diminished motor or cognitive abilities. This procedure evaluated the degree of acceptance and preference of the children towards the products.

Such quantitative approach allowed to test-drive the products and analyze their fitness regarding the studied context. However, they couldn't, and were not meant to, answer whether the apps, in combination with the new interaction schemas, were adequate for users having severely diminished cognitive and motor functions.

⁴⁶ This technical definition of usability was conceived by Jakob Nielsen, who is considered one of the "fathers" of usability and user experience (UX) design — the industrial branch of human-computer interaction.

Complementarily, a qualitative approach, based on a case study evaluation, was used to assess the “degree of penetration” of the proposed solutions — i.e., the degree in which the new proposals were capable of reducing access barriers that couldn’t be addressed in NEXO Stage One.

MakeUy performed outstandingly well compared to the other interaction schemes.

The experimenters used bananas, apples, pencil-made drawings on white paper and a ball with patches made out of aluminum, as switches. An online one-button game called Flabby Physics⁴⁷ was selected for the experimental sessions.

The game consists in stretching out the “flabby balloons”, using the spacebar, and make the ball catch the star.



Figure 13 – Screen capture of Flabby Physics, a game used to test MakeUy, a tangible interaction device for the XO, built by NEXO.

Within segment S2, for most of the cases the experimenters found it difficult to conclude whether the children were understanding the game rules or not. Different layouts were tried, and a variety of objects and materials were used.

However, there was one outstanding case. There was a child belonging to segment S2, who was not able to use the XO before — according to the testimony of the school’s personnel, and in accordance with the

⁴⁷ <http://flabbyphysics.com>

observations. Against all expectations, the child was able to successfully complete the game, using MakeUy, and a banana as a switch.

At first, the child seemed to hit the switch randomly. However, after a period of trials and errors, the child started to harmonize the timing between switch presses to achieve the goal of catching the star.

Conclusions

The debrief of NEXO Stage One concluded that it was necessary to defer the idea of achieving a quantitative experimental design for validating results.

The reason was that there was a suspicion that the psychometric tests used for assessing the cognitive level of children with CP were not reliable. A study, published one year after the project ended, showed evidence that not only the ones used in NEXO, but that most of the commonly used standardized methods for assessing intelligence of children with CP might not be reliable.

If that were the case, then any experimental design based exclusively on psychometric tests for evaluating children with CP might not be trustworthy.

Considering this possibility, the strict quantitative approach was replaced by a combination of a quantitative usability study with users in segment S1, and a qualitative, personalized series of experimental sessions, based on participant observation.

The main goal was to find a user interface aimed to, hopefully, reach out to children with more severe motor disorders, as a first step toward (1) finding some evidence that psychometric tests were “hiding” potential beneficiaries and (2) accomplish NEXO’s ultimate mission — i.e. finding ways to make the XO more accessible to children with CP and other motor disorders.

The approach consisted in dividing the main goal into three objectives, aimed to expand the offer of non-conventional interaction schemes.

The first objective was building a scheme based on tangible interaction. The result was an in-house, shockproof, version of MIT’s MakeyMakey. The implemented device, named MakeUy, disrupted the conventional ways to access the XO, allowing to easily assemble adaptive keyboards of a wide variety of objects and materials. One of the key features of MakeUy is that it allows its beneficiaries to build their own custom keyboards. The dev team was able to build two versions of the kit; one of them was donated to the school at the end of the project. The intention was to donate more kits, but such a venture would have exceeded NEXO’s scope and budget.

The second objective was creating an interaction scheme based on computer vision, to make it possible for the XO to recognize arbitrary

objects presented in front of its camera. Since feature detection is too expensive for the limited computing capabilities of the XO, the approach consisted in using QR-code recognition. The result was a prototype that executes natively on the Sugar environment. Unlike other solutions available on the Sugar open-source repository, NEXO's prototype executes entirely on the host machine. Like PUI, it is packed in an open-source system library. A possible next step is to port the combination of PUI and MouseCam to the new system, and to create a language of commands encoded in QR symbols to simulate keystrokes or mouse movements.

The third objective was creating an interaction scheme based on visual scanning. The resulting prototype was a game implementing a visual scanning technique. The game had a secondary psychological goal concerning exercising visual search and attention. The discovery phase of the prototype followed a Wizard of Oz design methodology, wherein the experimenters used the XO to show static images of the game to the users, and used their pointing fingers to simulate the cursor moving through the scanning grid. This approach allowed to get early feedback from end users, validate the concept, and adjust some grid parameters, like cell size, color and stroke width.

Whereas MakeUy showed that, in at least one case, a child who was originally assigned to S2, was able to understand directions using MakeUy to access the XO, further work needs to be done in order to find conclusive evidence that MakeUy can truly reduce access barriers.

As a general conclusion after analyzing the two stages of NEXO, it is extremely difficult to put into practice a quantitative experimental design based on using psychometric tests to assess children with CP.

While NEXO Stage One was the first attempt of NEXO's research psychologists to design, and execute an experiment using a quantitative inter-group approach with children with CP, scientific literature is full of similar attempts. HCI researchers treating similar contexts should be warned about this difficult challenge.

NEXO left not only a myriad of practical experiences about dos and don'ts on how to carry out an HCI research project involving the phenomenon of disability. It also allowed the people who worked in the project to reconsider their point of views, and theorize about, such a phenomenon.

The following section is an essay that presents the author's opinion about the role of the discipline human-computer interaction in the *production* of disabled people.

3 THE ROLE OF HCI IN THE CONSTRUCTION OF DISABILITY

When the Philosophy of Man (his nature, his goals, his potentialities, his fulfillment) changes, then everything changes. Not only the philosophy of politics, of economics, of ethics and values, of interpersonal relations and of history itself change, but also the philosophy of education, the theory of how to help men becomes what they can and deeply need to become. We are now in the middle of such a change in the conception of man's capacities, potentialities and goals. A new vision is emerging of the possibilities of man and of his destiny, and its implications are many not only for our conceptions of education, but also for science, politics, literature, economics, religion, and even our conceptions of the non-human world.

Abraham H. Maslow (*Maslow, 2011*)

Introduction

The overwhelming amount of experiences left by NEXO were analyzed, discussed and reconsidered all along the lifecycle of the project. This capacity of reflection was enabled by the action research approach guiding the process at a high level. This action research process led NEXO's researchers to reconsider the phenomenon of disability, its underpinnings and its relationship with HCI.

This chapter results from such a review and it aims to answer the question of why it is *essential* for scientists and professionals involved in technology research and development, to develop a thorough understanding of the rich phenomenon of disability.

Most of the people would agree that disability is a term relating to an *impairment* of function or malfunctioning, as of an organ or structure, of the *body*. Notwithstanding, scientific and non-scientific literature show that there is no common agreement about what disability is. Far from converging into a single definition, disability turns out to be an elusive concept that can be interpreted in many ways.

For instance, a growing number of authors, human-rights activists, and international organizations — including the World Health Organization — understand that the concept of disability exceeds any medical definition, being it a discourse that is *constructed* by social conventions and practices, hardwired in the people's way of being and living, that are deeply rooted in the structure of western society.

There are several reasons as to why HCI research should take care about the complexity behind the concept of disability:

- Human-computer interaction encompasses a number of base disciplines. Each one possesses its own methodology to, at the

end of the process, draw conclusions about HCI's subject of study: the user. All methodologies have in common that they depend on selecting a reduced number of people who are representative of a broader population. If the selection mechanism does not provide "good-enough" samples — i.e. they are taken from a homogeneous population, or the small sample size is not adequate — then the experimental results could be biased. As a consequence, disregarding disabled population in a research work without fully understanding any potential consequences of such action, may compromise both scientific and practical outcomes.

- Acknowledging and understanding the complexity behind disability might help develop better ethical frameworks to guide solution development processes. In fact, any HCI research project that is not aware of the many interpretations about disability is potentially infringing, as it is exposed below, the rules of the most up-to-date ethical frameworks.
- As social actors seeking solutions for people within a particular community, researchers and developers should develop a sceptical attitude toward the first line of problems that arises at early stages of the fieldwork . Some of these early problems may be the consequence of a deeper layer of problems that might be better candidates to focus the actions on. Thus, understanding disability might help find solutions that better fit the needs of the end beneficiaries.
- It is commonly agreed — although there is lack of scientific evidence (Karel, Mao, Smith, & Carey, 2002) — that solutions resulting from a user centred design (UCD) methodology, a design methodology that gathers feedback from a group of *diverse* users, are more likely to be used and adopted by the end beneficiaries. The problem is that solutions coming from UCD processes rarely incorporate disabled people. Such a loss in diverseness narrows potential solutions down to only certain classes, reducing the probability of finding better and more scalable solutions.

Competing interpretations of the phenomenon of disability

The notion of disability has changed over the last sixty years. It has gradually moved from an individualistic medical problem to a "major socio-political issue with implications for society as a whole" (Barnes, Understanding Disability and the Importance of Design for All, 2011).

Up until recently, the term *disability*, along with *impairment* and *handicap*, were used to describe disability. The meaning of these terms created confusion and even the medical community has used them interchangeably. Therefore, it is not surprising that certain academic communities, in particular the HCI community, are still anchored to such

an outdated terminology, in spite of the not-so-recent international efforts to update the model of disability⁴⁸.

Within the context of disability, three different discourses currently prevail in the academic and professional literature and practice. Each one vindicates their own interpretation of the phenomenon, defining their own sociopolitical model of disability.

Individualistic medical model

The *individualistic medical* (IM) model is characterized by interpreting disability as a *deficit* of a physical, sensory or mental function and uses a clinical discourse to describe disability.

According to the IM model, disability is the result of a physical condition intrinsic to the individual, a *problem* in the individual's own body that may affect quality of life and cause clear disadvantages to the individual⁴⁹.

It defines and categorizes disabled people by their *impairment*, directly or indirectly referring to the individual as *the victim* of the problem.

The IM model was adopted by the World Health Organization (WHO) in 1980, in an effort to clarify the terminology, publishing the "International Classification of Impairments, Disabilities and Handicaps" (ICIDH) manual (World Health Organization, 1980).

The ICIDH approaches disability using the terms *impairment*, *handicap* and *disability*, defining them as:

- **Impairment:** a loss or *abnormality* of physical bodily structure or function, of logic-psychic origin, or physiological or anatomical origin.
- **Disability:** any limitation or function loss deriving from impairment that prevents the performance of an activity in the time-lapse considered normal for a human being.
- **Handicap:** the disadvantaged condition deriving from impairment or disability limiting a person performing a role considered normal in respect of their age, sex and social and cultural factors.

The manual defines a framework for working with disability and it focuses on the consequences of the disease.

⁴⁸ See, for example, Chapter 42 of The Human-Computer Interaction Handbook (Impairment) —a reference book in the area— which presents, in 2008, an "analysis of impairments" using an outdated language to refer to disability.

⁴⁹ The definition of the IM model has been compiled from different sources. The Wikipedia article on the topic covers most of what it is needed to understand the model and it was taken as a reference for writing this section. See http://en.wikipedia.org/wiki/Medical_model_of_disability.

Disability is, according to the manual, a process that follows the direction *impairment* → *disability* → *handicap*:

- In the first level, *impairment*, disease produces some form of pathology that may produce symptoms in the individual.
- In the second level, *disability*, individuals' performance or behaviour may be affected.
- In the third level, *handicap*, the person may suffer consequences in their daily lives.

As it can be seen, the definition uses certain terms — like *normality* and *abnormality* — that may result offensive nowadays (World Health Organization, 2011).

The IM model focuses on the individual's limitations and the ways to substitute or compensate those impairments through surgical interventions or using *assistive technology* to adapt them to society.



Figure 14 – According to the individualistic medical model, the individual's body is the cause of disability.

Bio-Psycho-Social Model

In 2001 the WHO, responding to the pressure of disability organizations to review and update the ICDH manual, proposed the *bio-psycho-social* (BPS) model of disability.

The replacing manual was called "International Classification of Functioning Disability and Health", or ICF. It was endorsed by WHO's member states in 2001 and it is aimed to shift the focus from disease to health and body functioning, acknowledging that "every human being can experience a decrement in health and thereby experience some disability" (WHO, 2001).

The ICF explicitly criticizes the prevalent IM model, encouraging its replacement. It acknowledges that the IM model does not tackle the root causes of disability and defines disability as a "complex interaction between the health condition of the individual and the contextual factors of the environment as well as personal factors" (Centers for Disease Control and Prevention, 2012).

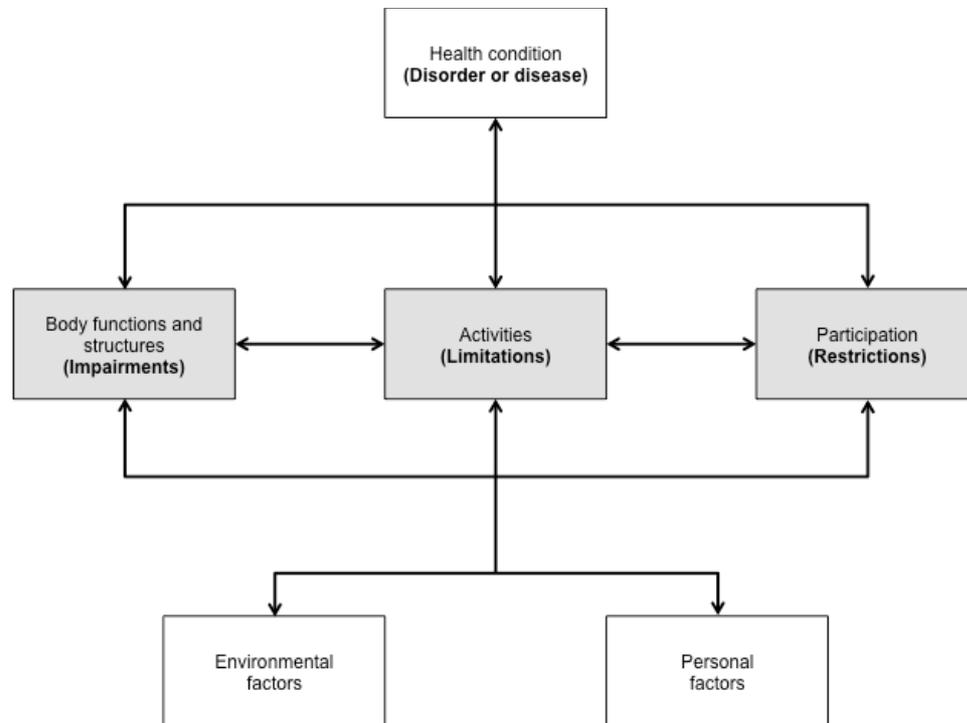


Figure 15 – Representation of the International Classification of Functioning, Disability and Health.

The manual describes functioning from three points of view: body, personal and societal. The information is organized in two parts: (1) functioning and disability and (2) contextual factors.

The *components of functioning and disability* are divided in: (a) body functions and structures; (b) activities, defined as the execution of a task or action by an individual; (c) participation, defined as the involvement of an individual in society.

Contextual factors are divided in *environmental factors* and *personal factors*.

Environmental factors describe the world in which people with different levels of functioning must live and act. These factors can be either facilitators or barriers, including: products and technology; the natural and built environment; support and relationships; attitudes; and services, systems and policies.

Personal factors are not yet conceptualized or classified by the ICF, but involve psychological constructions like motivation or self-esteem.

Under the BPS model, disability arises when the individual experiences difficulties in any or all three components of functioning, in the form of:

- *impairments*, when there are problems in body function or alteration in body structure — e.g. paralysis or blindness;
- *activity limitations*, when there are problems in executing tasks or actions — e.g. walking or eating;
- *participation restrictions*, when there are problems with involvement in any area of life — e.g. facing discrimination in employment or transportation.

Disability refers to the negative aspects of the interaction between individuals with a health condition (such as cerebral palsy, Down syndrome, depression), and personal and environmental factors (such as negative attitudes, inaccessible transportation and public buildings and limited social supports) (World Health Organization, 2011).

People labeled ‘disabled’ would be actually being disabled by the interaction between their body and the environment, experiencing a range of environment and social barriers that inhibit their active participation in the economic, political and cultural development of their communities (Barnes, Understanding Disability and the Importance of Design for All, 2011).



Figure 16 – According to the bio-psycho-social model, disability is caused by a complex interaction between the individual’s health condition and the context.

As an example scenario, a bad room acoustics in a conference room can dramatically hinder communication between a service provider and a

remote client. In that case, the environment may cause inefficiencies in the provider's work capacity that may lead both parts to a relationship break up, affecting people's work. Thereby, the BPS model would interpret that people working in this setup are actually being *disabled* by the environment.

It is possible, at least in theory, to use the ICF manual to assess the impact of the conference room's design on its users. If the results effectively show that the environment affects their abilities, then the ICF can help define policies and actions for addressing the problem — for example, hiring an acoustical consultant.

As an attempt to compare data in a consistent and internationally comparable manner, the ICF also provides a classification system that allows for identifying the kinds and levels of disability (WHO, 2001).

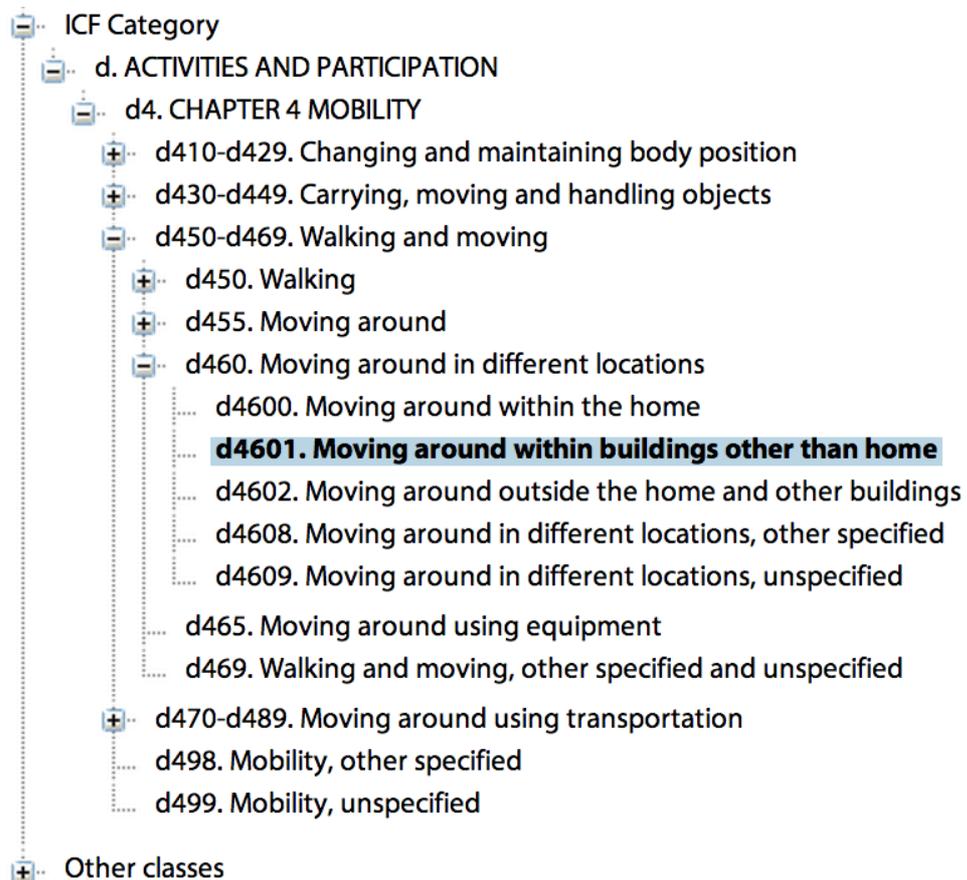


Figure 17 – An example of the ICF classification system (The National Center for Biomedical Ontology, 2012).

Social Model

The third model is the *social* model of disability. It has been proposed and promoted by international human-rights organizations, disabled activists and the Disability Studies discipline since the 1970s⁵⁰.

The social model not only criticizes the IM model, but also the BPS model, challenging them through the idea that disability is constructed by a necessity of the market for an “average human” or *l’homme moyen*⁵¹ — a constructed statistical human-being resulting from measuring different characteristics of the population — to exist. The market would need this average human to mainstream its products and services. However, as a side effect, it excludes and *disables* a large portion of the population.

According to the social model, our society measures itself against this average human, drawing the line between normality and abnormality. The closer to the average human, the more normal the people are. People far away from the average human are considered abnormal by others, and even by themselves.

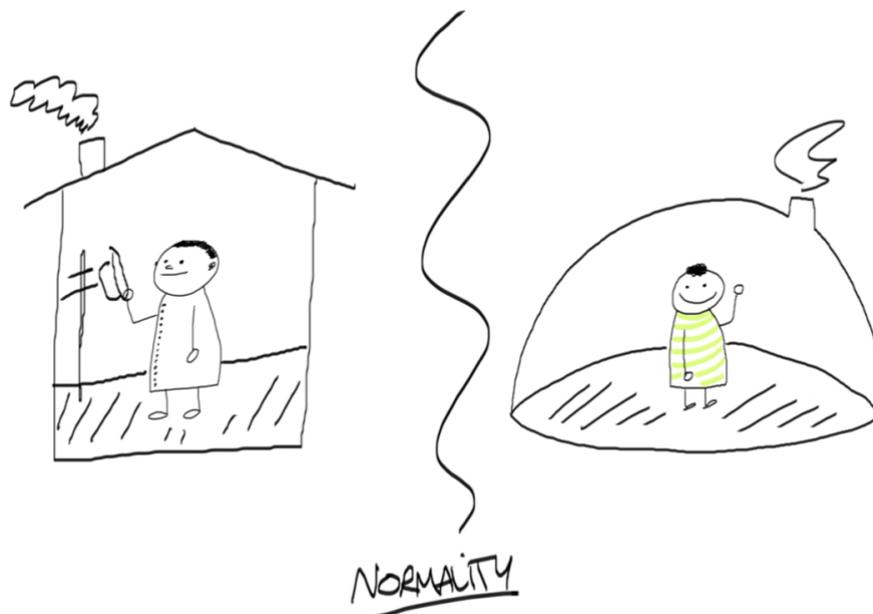


Figure 18 – According to the social model, disability is the result of drawing the line between what is normal and what is not.

According to this view, regardless of the physical, sensory, intellectual, or psychological variations that may cause functional limitations or

⁵⁰ The disabled academic Mike Oliver coined the phrase “social model of disability” in 1983.

⁵¹ The concept of the average man was described by Adolphe Quetelet in his most influential book *Sur l’homme et le développement de ses facultés, ou Essai de physique sociale*, published in 1835.

impairments on individuals, they only lead to disability when society fails to include the individual.

Their advocates affirm that society is pervaded by signs of exclusion in the form of physical structures, manufactured products, digital products, routines, social institutions, language and attitudes.

Taken to its extreme, the social model of disability implies that any attempt to change, "fix" or "cure" individuals can be an act of discrimination and prejudice.

A more moderate approach recognizes the importance of individually based interventions, including medical interventions, habilitation and rehabilitation therapies, and educational- or employment-based interventions, as long as they are aimed at shifting the "attention away from the functional limitations of individuals onto the problems caused by disabling environments, barriers and cultures" (Barnes, *Understanding Disability and the Importance of Design for All*, 2011).

The kinds of solutions proposed by the social model of disability are in general focused on empowering disabled people through different strategies, including political, social and technological interventions. The goal of each solution is to find ways to change society for including people, regardless of their individual differences.

Table 8 – Comparison of the medical, bio-psycho-social and social models of disability.

Model	Disability is	Caused by	The problem is	Solutions focused on
Medical	Impairment	Absence or loss of body functions and structures	The individual (because of his/her impairment)	“Fixing” the body
Bio-psycho-social	Complex interaction between the individual and the environment	Absence or loss of body functions and structures, barriers accessing services	Interaction between the individual and the environment	“Fixing” the body, adjusting the environment
Social	An apparatus or dispositif	Disciplinary / normalizing society, the normal / abnormal dichotomy	The notion of normality	Empowering the excluded, enhancing autonomy, analyzing the fundamentals

Although Disability Studies literature has addressed issues related to the use and development of technological solutions for tackling disability — and embracing Universal Design as the best development approach — it is not frequent to see concepts like the social model or the BPS model in technology-related literature (Mankoff, 2010).

This absence leads to questioning the current praxis of technology development and production. If technology researchers and developers — including HCI scientists and professionals — are not aware about the underlying disability model behind their products, they must be inadvertently choosing one by default. Which model are they embracing? How do they know if they are missing a whole branch of solutions, or not? What are the ethical implications of their approaches? What frameworks are they using to evaluate the effectiveness of those methodologies?

Criticism

The three models have received criticism from their advocates and detractors and there is no way to empirically prove that one is better

than the other. As Ricoeur states, validating an interpretation is not as simple as finding an empirical verification. The way to validate it is to vindicate it against competing interpretations.

Validation “is an argumentative discipline more comparable to the judicial procedures of legal interpretation. It is a logic of uncertainty and qualitative probability” (Ricoeur, *From Text to Action*, 1991, p. 159).

The following paragraphs compile the arguments against the IM, BPS and social models of disability.

Arguments against the IM model

The IM model is widely extended in the western society. Because it understands disability as a deficit in a body structure or function, the praxis rooted in the IM model is typically biased towards providing *medicalized* solutions — i.e. solutions that tend to “fix” the body.

This emphasis on the body condition enables certain classes of solutions, which typically involves providing individualistic treatments in one-size-fits-all state or private agencies.

It also limits the issue to a specific population at a specific location in time and space, ignoring the chance that any individual can potentially experience a temporary disability any time in their lives.

It may block the chance of finding more holistic approaches that conceive fixing the environment as a key part of the solution.

Finally, it reduces the phenomenon of disability to people carrying disability on their bodies, reinforcing "the view that humans are flexible and adaptable while physical and social environments are not". It also "downplays the role of legislation and policy reforms to address the various economic and social disadvantages experienced by people" labeled 'disabled' (Barnes, *Understanding Disability and the Importance of Design for All*, 2011).

It has been argued that the IM model of disability may succeed on partially solving the problem, instead of addressing a deeper problem that may involve the environment, or even the society as a whole. Its detractors affirm that alternative discourses may allow for discovering new problems and finding alternative broader and long-termed solutions.

Arguments against the BPS model

The BPS model of disability has been subject to criticism by disabled activists and organizations, including Colin Barnes, one of the main contributors to the Disability Studies discipline.

According to Barnes (Barnes, *Understanding Disability and the Importance of Design for All*, 2011), the ICF:

- reaffirms the western scientific medical approach as the basis for classifying, measuring and treating bio-psycho-sociological conditions;
- does little to facilitate researchers and policy makers to quantify the contextual (environmental and personal) factors affecting participation of individuals in society;
- reaffirms the conception of normality;
- assumes that normality is a concept that remains invariable within and across different cultures;
- does not provide a useful framework to develop policies.

Arguments against the Social model

The social model is not without its critics, ranging from advocates of the free market to academics within their own ranks.

Activists and organizations supporting the social model have been criticised for their harshness against its detractors. Anyone questioning the social model arguments “might appear particularly heartless and, especially in statist academia, possibly risk ostracism and professional difficulties” (Lester, 2002).

Since the model was developed in the turbulent 1970s in the UK, it has been suggested that it is out-dated, with no practical applications at the beginning of the twenty-first century.

From their own ranks, it has been blamed of failing at properly explaining the experience of disabled people and identifying the causes of the disadvantage.

Shakespeare, one of the founders of the Disability Studies movement, sustains a more moderated discourse than the social model’s one.

“Impairment and disability are not dichotomous”, Shakespeare says, “but describe different places on a continuum, or different aspects of a single experience.” This imprecision should be taken as an inherent part of a complex “dialectic of biological, psychological, cultural and socio-political factors, which cannot be extricated except with imprecision.” (Shakespeare & Watson, 2002)

Shakespeare begs for a substitute model that balances medical intervention with finding solutions aimed at removing social and environmental barriers.

Finally, the numbers of disability, used by social model advocates in their discourses, are also questioned and accused of being inflated for marketing and rising money purposes (Lester, 2002).

Reflections about HCI referring to disability

WHO's current interpretation of the phenomenon of disability, specified in the ICF manual sees disability as a complex phenomenon caused by different intertwining factors, including the environment, going beyond the notion of *impairment* as the only cause.

The ICF comes along with a classification system for disability. The goal is to have a consistent and internationally comparable set of root causes that hinder the participation of individuals in certain activities.

This exhaustive set of causes, the ICF states, will allow researchers from different cultures worldwide to share their results without double interpretations.

The new nomenclature discourages the use of "impairment" and "handicap" terms, that were used by the previous WHO's manual, the ICIDH, for considering them confusing and misleading.

In spite of this, a quick review of the HCI literature on disability shows that not only the WHO's model had little penetration in the HCI discourse on disability, but also that the previous discourse survives and keeps being reproduced.

The following three examples give account of this issue:

Example 1. Performing a full text search in the three major international conferences on the topic, ASSETS, ICCHP, and UAHCI52, reveals that the term "ICF" appears in⁵³:

- No results in ASSETS, out of a total of 433 published papers;
- 11 out of 718 papers in UAHCI (1.5%);
- 23 out of 916 papers in ICCHP (2.5%).

Example 2. ICCHP's papers referencing the ICF have received little attention. As an outstanding example, a paper published in 2006 by Billi et al., entitled "A Classification, Based on ICF, for Modelling Human Computer Interaction" (Billi, Burzagli, Luigi Emiliani, Gabbanini, & Graziani, 2006) was cited only once⁵⁴.

Example 3. Chapter 42 of the reference book The Human-Computer Interaction Handbook, entitled "Physical Disabilities and Computing

⁵² ASSETS is the ACM's conference on computers and accessibility, published by ACM (Association for Computing Machinery); ICCHP is the International Conference on Computers Helping People, published by Springer-Verlag; UAHCI is the International Conference on Universal Access in Human-Computer Interaction, published by Springer-Verlag.

⁵³ The search included articles ranging from 2002 to 2012.

⁵⁴ According to SpringerLink and Google Scholar search engines.

Technologies: An Analysis of Impairments" (Sears, Young, & Feng, 2008), is based on the WHO's obsolete and criticized ICDH. Despite this work provides a comprehensive description of "the more common diseases, disorders, and injuries associated with" physical impairments, providing an entry point for HCI researchers to understand the medical factors behind disability, its language is based on the *normal-abnormal* dichotomy that has been strongly criticized for being both inefficient and harmful (Oliver, 1994). In contrast with the previous example, this work has had an important impact on HCI literature, being cited in more than 70 publications, including conference papers, journal articles, and books.

This modest reference to the ICF in HCI literature related to disability raises several questions entailing practical, ethical and political implications:

- How are HCI researchers classifying disability?
- How are they communicating their results to other colleagues within the discipline and across other disciplines?
- How are they comparing different solutions, proposed by researchers in different cultures, to the same problem?
- How are they measuring the social impact of their praxis?
- Finally, the ICF warns about the failure of the IM model to understand the root causes of disability. Then, if the solution-discovery process is partially or totally missing the real problem, how can they be sure about the optimality of the solution?

An analogous search looking for relationships between HCI and the social model of disability shows that the HCI research community has paid little attention to the efforts of the Disability Studies discipline to "define the rhetoric, language, methods, and purpose of academic work related to personal and social experience of disability" (Mankoff, Hayes, & Kasnitz, 2010).

The primary diagnosis is that in general terms HCI has received little contact with the BPS and social models of disability. Furthermore, most of the most-cited papers reviewed by this thesis about HCI and disability are either explicitly based on the IM model (e.g. referring to the ICDH manual) or does not reference any model at all.

That observation suggests that HCI research on disability is taking for granted an underlying discourse, which is, in most of the cases, rooted in the IM model.

This absence of an explicit reference to a particular model of disability leads to an interesting debate about the neutrality of HCI.

Reflections about NEXO's praxis

As any other science⁵⁵, HCI is not neutral.

Behind techniques, methodologies, language and technologies lie traditions, conventions and an institutional framework that bring a particular symbolic interpretation of the context being analyzed. In other words, “we cannot work without bringing in our traditions and our symbolic interpretation of the world” (Ricoeur, *Lectures on Ideology and Utopia*, 1986).

Thus, praxis, as Ricoeur asserts, cannot be separated from ideology. Contrarily, it incorporates an ideological layer that may become distorted, but it is a component of praxis itself (Ricoeur, *Lectures on Ideology and Utopia*, 1986).

Any actor intervening in a particular context, including HCI practitioners should be aware that *that ideological layer is a foundational part of the solution* they are studying or looking for. That layer has shaped the context of application — comprising, but not limited to, buildings, stakeholders, institutions, tools, language and rules — so any solution discovery process taking for granted any particular context is potentially excluding more optimal solutions.

Revisiting School #200

NEXO, for instance, was initially conceived as an intervention in a school for children with motor impairments. Although this conception was questioned and evolved over the project, NEXO's researchers never reacted to the fact that school #200 was a one-size-fits-all institution, receiving children from locations all over Montevideo and far away from the school.

Action research allowed researchers to visualize that the very own nature of the institution was an attempt to solve a particular need at a particular historical moment. Nowadays, no disability organization would recommend building institutions of this kind. On the contrary, they foster integrating disabled people in their own communities.

This alternative point of view enabled a new look at the problem, allowing researchers to envision a new class of solutions. Rather than exclusively focusing on substituting a missing body function, or improving the environment, they were able to expand the solution space to the social dimension.

⁵⁵ It might be argued that hard sciences, like Physics or Mathematics, escape from this debate because their discourses are built on observations taken from an objective reality and not from human constructions. However, from a philosophical perspective hard sciences are based on the belief that our reality is ontologically independent from our conceptual schemes, perceptions and linguistic practices. That belief, known as *philosophical realism*, is not exempt of ideology or political implications.

For example, they realized that it was almost impossible for parents to socialize with other parents from school #200, and even to engage in activities proposed by the school. The main obstacle preventing this to happen was, according to testimonials from parents, long distances from home to school.

The solution “school #200” was, to a certain degree, the root cause of a large loss of opportunities, including: sharing experiences between families, integrating disabled and non-disabled children, generating awareness about disability in local communities and leveraging “network intelligence” effects to raise or collect money for helping families with disabled children.

Furthermore, a large portion of school #200’s budget is spent in transportation and logistics. An inclusive education paradigm as an alternative to the one-size-fits-all approach could find more creative ways to spend this budget. For example, it could be used to buy computers and assistive technology that are better suited for disabled children than XO laptops.

Once visualized, the problem admits a variety of mid-term solutions. For example, one approach could be building a social network to foster communication between parents from distant communities.

Reflections about HCI practice

Inadvertently or not, any person intervening a particular context acts as a vector, reproducing a particular worldview. Their actions have practical, ethical and political consequences.

In the case of HCI — since interactions between people and computers have turned into a massive-scale phenomenon, to the point that computers mediate between social relationships — being conscious about the scope and impact of each intervention has become a major concern.

HCI research and professional practice should not only focus on understanding the user, but also the context where the user is immersed in. Otherwise, as Phillip Agre points out in his “Conceptions of the user in computer systems design” essay, “attempts to improve things may alleviate some symptoms but they may also obscure the systemic disorder underneath” (Agre, 1995).

Having a deep understanding of the underpinnings of a particular context is particularly important when dealing with the phenomenon of disability, where physical and cultural constructions participate in the exclusion process and permit or deny the participation of people in society (Barnes, *Understanding Disability and the Importance of Design for All*, 2011).

Scientific literature underpins further, and is fed by, the practice of research. As Mike Olivier —British researcher and one of the key figures in the disability studies discipline — suggests, an appropriate discourse provides the basis to develop appropriate welfare provision and professional practice (Oliver, 1994).

HCI literature related to disability, including books, journal articles, conference papers, scientific or technical reports and dissertations, explicitly or implicitly — more often implicitly than explicitly — embraces and reproduces a particular worldview. In many cases, this worldview is aligned to the IM model.

Since, for the reasons exposed above, HCI research and professional practice can, very directly, lead to some sort of social exclusion, it becomes necessary to connect HCI literature to the vast literature related to modern conceptions of the phenomenon of disability.

4 CONCLUSIONS

The concept of disability has been interpreted in different ways along history. Even different interpretations, rooted in potentially contradicting models of reality — or worldviews — have coexisted at a certain time.

At the dawn of the 21st century, three outstanding models currently underpin the academic and industrial production and literature. Each model conveys a particular discourse, which is reproduced once and again on every research publication, community intervention, development process and manufactured product.

One of these models, the individualistic medical (IM) model of disability, defines disability as a missing function or a structural alteration in the human body — so called *impairment*. Consequently, professional practice deriving from the IM model tends to propose solutions that involve bodily interventions.

The bio-psycho-social (BPS) model defines disability as a result of a complex and problematic interaction between the abilities and health conditions of individuals and the environment. Professional practice underpinned by the BPS model tends to propose solutions that prioritize the reduction access barriers over medical interventions. It contemplates the possibility of intervening the human body only when health is compromised and any other possibility has been exhausted.

The social model defines disability as a social construction resulting from *power asymmetries* in the western society. Professional practice grounded on the social model tends to propose solutions based on empowering the excluded.

Each model has its advocates and its detractors. Though the IM model has been particularly criticized for reducing disability to a “mark” in the body that needs to be “fixed”, leaving out inclusive solutions and — according to its detractors — causing stigmatization.

As a discipline studying the interaction between humans and computing systems, human-computer interaction (HCI) is, by act or by omission, concerned with the phenomenon of disability. Every action carried out by HCI researchers and practitioners, weather it involves disabled people or not, is rooted in a particular model of disability.

A survey carried out for this thesis reveals that the BCP and social models of disability have had little penetration in HCI’s scientific literature. On the other hand, works involving assistive technology, associated with the medical model, pervades the HCI’s literature on disability. A preliminary conclusion suggests that, being aware or not, HCI as a discipline bases its practice mainly on the IM model of disability.

Whereas such an assertion deserves further study, it can be argued that some of the most-cited works on HCI and disability reproduce the IM model in their discourse. These works educate people about HCI, are the basis of further research works and underpin its practice.

The classes of problems that emerge from a particular interpretation of the field of operations — i.e. the context — are constrained by the underpinning model of disability, deliberately or inadvertently chosen by the community and the people interested in encountering solutions to them. As a result, the solution space is constrained to only those solutions targeting the classes of problems within the scope of the model — i.e., the ones that the model can describe. Therefore, the solutions that researchers and professionals can envision, build and ultimately provide, are also limited by the underpinning model of disability.

NEXO's case study, described in this thesis, provides an example of a project aimed to provide technological solutions for schoolchildren diagnosed with motor dysfunctions.

The main goal of the project was to find an interaction device which could make it possible for children attending a public school for children diagnosed with motor dysfunctions to effectively use XO laptops — a model of computers distributed by the government of Uruguay to all public schools in the country, as part of the One Laptop per Child (OLPC) program.

The solution discovery process begun with a predefined set of problems, identified by the school personnel. Problems requiring an immediate, “engineering”, attention were related to a lack of accessibility of the XO computers.

NEXO undertook an action research approach, in which a reactive, short-term, action and a sustained, self-reflexive, process coexisted. The former was aimed to solve the most urgent problems, including finding a new interaction mechanism to improve the laptops' accessibility. The later was aimed to explore, through a thorough analysis of the fieldwork experiences and structured debates, the root causes of the problems arising from the field of operations.

At the beginning, the understanding of the context and the problems was influenced mainly by the IM discourse. Based on it, one of the main goals of NEXO was, essentially, to build a generic non-conventional input device — i.e. an input device other than the keyboard, the mouse or the trackpad — that could connect a dysfunctional body function with a computer.

Regardless of the results, a successful IM-based achievement would have served only as a first step, because it would have provided schoolchildren with access to a plethora of software applications that were, as the case study shows, not suited for children with mild to severe physical disabilities. Even if these applications were accessible, they were not meant to solve one of the most challenging issues that disabled children have to deal with: an enormous difficulty to connect with other people and with the environment, to gain confidence in themselves, to feel valuable and to participate in society.

These challenges belong to the BPS interpretation of disability. However, as it is argued in this thesis, it is difficult to learn about the BPS model from studying the HCI literature. In this regard, action research allowed NEXO's HCI researchers to discover the BPS model and other approaches to disability. It allowed researchers to inspect and review NEXO's initial goals and adapt them to include more comprehensive discourses.

As a result, a new class of problems emerged, leading to a rich variety of solutions, including a mechanism to turn bananas or almost any object into a push button, a game to encourage children to move around the school's hallways and discover new places or a communication system to write virtual messages and "upload" pictures to fiducial markers hanging on the walls of the school, that could be read and overwritten by the schoolchildren of the other shift.

Finally, action research introduced NEXO's researchers to a social interpretation of the phenomenon of disability. It allowed them to call into question not only the problems, but also the context itself, providing a new meaning to what School #200 was and what it was meant for. At the end of the journey, it led to the revelation that the context itself was a preconceived solution aimed to solve a particular problem that worried a group of people in the mid-1900s, who tried to solve it using the tools they had, within the worldview of their age.

This reinterpretation of the field of operations allowed researchers to visualize new classes of problems and to think about new ideas for solving them. Some of these problems, unseen before, turned out to be even more urgent than the lack of accessibility found in the XO computers.

Beyond its material achievements, the main contribution of NEXO was to serve as a case study to allow HCI researchers to expand their vision about the phenomenon of disability.

NEXO helped its research team understand that scientists and practitioners should know that the concept of disability is a construction, that there are many interpretations of disability and that each intervention deserves a critical analysis about its own discourse.

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