Designing inclusion: a smart learning ecosystem for hearing parents of deaf children

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Abstract. Smart Learning Ecosystems are intelligent, purpose-oriented platforms supporting innovative learning. However, for these ecosystems to be true engines of innovation they should be fully accessible. This vision reflects the inclusion policies underpinning the SDGs of the Agenda 2030 that recommend the adoption of knowledge and technologies to drive a social change in the direction of inclusion and social sustainability. In this paper we present the case of a smart learning ecosystem that brings together hearing parents of deaf children and other stakeholders involved in the care and education of deaf children. After an intense user research based on digital ethnography, interviews, and a questionnaire, a prototype of a digital application supporting learning of the Italian Sign Language and communication among stakeholders was designed and tested. The prototype served the objective to raise awareness about current biases on deafness and the need to stimulate the creation of a culture of inclusion and peer-to-peer learning.

Keywords: Inclusion, deafness, digital technology, Italian Sign Language.

1 Introduction

The term "smart ecosystem" encompasses a wide range of concepts, from networking architectures to service-based software solutions. This concept has been applied to the field of education for several years to describe environments for production, reuse and adaptation of content and interactions among students and teachers. The concept has evolved also thanks to the advancements of technology which allowed the creation of open communities of learning with online facilitation and personalization of use.

Unfortunately, technological development is not always matched by full accessibility of the tools mainly due to a lack of knowledge of the needs of some minorities, be they ethnic, linguistic, or people with disabilities, who have specific needs and ways of communicating. We believe that this is one of the most important challenges of future smart learning ecosystems that have the potential to help stimulate a culture of inclusion and accessibility which, however, is not yet fully realised today.

In this paper we present a case study on learning and communication needs of

hearing parents of deaf children. These families suffer from isolation due to the difficulties in getting in contact with other families sharing the experience of the birth of a deaf child, and from a lack of knowledge about how to communicate with their child. A smart learning ecosystem able to support learning of sign language, communication and sharing within a community of practice has the potential to enable self-actualization, relatedness, and security fulfilment [1].

Before digging deeper in the case study, we provide hereafter an overview of the current status of inclusion of deaf people in a sound-oriented society with a focus on the literacy of the Italian Sign Language (LIS).

On the 19th of May 2021, the Italian parliament approved article 34-ter with which "the Italian Republic recognizes, promotes and protects the Italian Sign Language" [2]. This is an important acknowledgment which, however, requires innovative bottom-up policies and tools to generate the change of perspective necessary for a full affirmation of the LIS.

Deafness has a history of physical and social isolation, prejudice and discrimination. By examining laws, services and technologies currently used, we can have a privileged look at what values society upholds [3]. To cite a few examples, even today a deaf person communicating with LIS could wait hours or days in an emergency room, prison or courthouse due to the lack of interpreters [4]. In schools, failure to adjust noise levels causes physical and mental fatigue for students wearing prostheses or implants.

The way in which society has declined the relationship with deaf people starts from exclusion, passes through segregation, arrives at attempts of integration without a design fully attentive to human needs. In the absence of a human-centred design oriented towards social sustainability, the goals of inclusion for the future risks to remain only a good intention without practical solutions.

In order to understand problems and barriers that deaf people have to face daily in education and communication, we provide hereafter a historical look at how learning practices for deaf people have developed.

Before 1500 the deaf were totally excluded from society. Outnumbered, they lived in isolation, were uneducated, and were also thought to be foolish and dumb. In 1500, thanks to the Benedictine monks [5], the first steps were taken towards the education of the deaf through signs. The approach has a philosophical root, which dates to Plato [6], which is the foundation of smart education: it concerns the concept that the symbolic mediation, thanks to which we form concepts and combine ideas, is not bound to words. This concept is the first advancement toward a modern and inclusive society.

In this wake, the first public school for the deaf was opened in France in 1770 and in Italy in 1785 [7]. The deaf began to have an education, to communicate and acquire greater awareness of their social existence.

Different schools were formed in a unitary movement. However, the controversial path towards the establishment of a group identity, with its own language, resulted in isolation and segregation. The need for integration appeared urgent.

Basically, two different opinions began to arise in society, attributable to the still current debate between oralists and signers. The first argue that the deaf, in order to be integrated, must learn lip reading and oral communication (a difficult undertaking for a deaf person), the latter argue that the native language of the deaf is the sign

language since it flows effortlessly on the visual channel, and it is the one that allows the development of higher cognitive faculties triggered by language [5].

The need to take a unified position in this regard led to the first International Congress of educators of the deaf, held in Milan (Italy) in 1880, where the use of sign language in education was banned. Italy officially supported oralism, and the use of sign language was long considered unbecoming human dignity [8]. Sign language went clandestine while official institutes for the deaf proliferated where rehabilitation techniques were taught in relation to oralism, but to the detriment of a broader and more diversified culture.

In 1977 a new push towards integration, without a design attentive to human needs, again had negative effects on deaf people: schools for the deaf were closed and, since most of the parents of deaf children were hearing, the children were enrolled in ordinary schools. The myth of the "everyone's school" [9] oriented towards integration hides a profound inadequacy in satisfying the specific needs of deaf people, if one considers that even today there is a lack of adequate personnel and tools [10].

This brief historical excursus shows that the road to inclusion requires the design of an adequate social ecosystem based on the awareness that there are physical and cultural constraints (prejudices, discriminations, beliefs) to deal with.

This paper focuses on a particular case study regarding the difficulties and needs of hearing parents of deaf children. Considering that 95% of deaf children are born to hearing parents, this is a quite common and little studied case.

Hearing parents of deaf children are the first and most important interlocutors of the deaf infants and have the greatest impact on their wellness and happiness. Unfortunately, they are immersed in a society where the ideology of ability is in force [3]. They inhabit a liminal space as they no longer live the world of hearing only and still do not know much about deafness. On the contrary, they have a negative view of it. They see it as a lack of "normality", begin to isolate themselves and involuntarily often medicalise the relationship with their child. The child is considered a patient to be treated, deafness is a deficit to hide and get rid of as soon as possible. The news of an infant's deafness is experienced as a mourning, time is spent in hospitals, doctors, specialised centres, and speech therapy.

There is a lack of defence and construction of the child who is treated as a deaf child, with the emphasis on a deficient identity rather than on his, or her, positive identity.

The first person who distinguished the medical approach (deafness) from the cultural approach (deafhood) was Paddy Ladd, an English deaf author, activist and researcher of deaf culture. Ladd coined the term "deafhood" as a process (rather than something finite and clear) of living one's identity in a positive sense [11].

Respect for the identity of the deaf person must begin from birth, starting with knowledge of the characteristics of the child's cognitive system [12]. The development of the cognitive system needs an uptake of stimuli that flow in a simple way on the available channel, which for a deaf child is sight, and a positive social context where the child can feel safe.

An excellent example of smart education using innovative learning strategies today is the bilingual approach, supported by research in linguistics and cognitive

psychology [13], which has shown that learning LIS as a mother tongue facilitates the learning of spoken Italian and speech therapy.

Following this approach, our research focused on the design of a smart ecosystem where hearing parents of deaf children can feel safe, where they can be part of a community sharing experiences to come out of isolation, and informally learn visual means of communication with their child, including LIS.

2 User research

An intense user research was conducted between September 2021 and August 2022 using digital ethnography [14], a questionnaire and in-depth interviews [15] as primary methods of inquiry.

Digital ethnography is a virtual observation of online communities crossing each other and weaving the social network of individuals through personal reflections, debates and storytelling. Digital ethnography has taken on an increasingly central role in design, it is a very sensitive tool to grasp people's points of view and feelings, especially in human-centred design, thus assuming a key informative role.

In the following we describe the digital ethnography conducted in the initial phases of the user research, and the main outcomes achieved.

2.1 Digital ethnography

Our initial approach to the world of deafness was exploratory using a concurrent ethnography to become familiar with existing practices and beliefs.

A non-participant observation was conducted on 15 social groups on Facebook, set up around the theme of deafness and followed by a participant observation, first in covert and then in overt modality.

In the covert modality, the researchers interact with other participants in the group without revealing their role, with the aim to get spontaneous feedback. In the overt modality the researchers openly disclose their role to get more accurate feedback. The observation lasted nearly two months.

By monitoring posts published on 15 online groups, some themes recurred constantly. These included: request of information on deafness from a physiological point of view, complains of social isolation, opposition between oralists and signers, existing prejudices and discriminations, the need for family members to share problems and best practices, feelings of regret for the lack of services like subtitles or interpreters and, difficulty to access contents related to the deaf culture and LIS learning. Excerpts of posts are reported in Table 1.

Table 1. Excerpts of posts published on Facebook by theme.

Physiology	Prejudices on LIS	Communication	Isolation
"I'm abysmal deaf...not just hard of hearing".	"It is not true that LIS is necessary for all deaf children. This is massive disinformation."	"Reading your testimonies lightened our hearts, seeing so many children with beautiful smiles comforted us. Extricating yourself from bureaucracy and many checks in the hospital is not easy".	"We decided to go to an amusement park with our daughters. At the entrance they told us that deaf people cannot access any attraction without being accompanied by a hearing adult".
"Shortly after my son was born, I realised he was completely deaf. They were difficult moments. While I cried and despaired, my husband spent evenings on the Internet".	"I am a hearing and signing mother of deaf and hearing children... bilingualism was a very complex choice for us. The hearing part did not share and did not appreciate the exposure to LIS, the deaf part, or the Deaf community, did not really accept us".	"11 hours in the emergency room, nobody understood me".	"As I was about to go running to make an emergency visit. I received a message saying that I should have been accompanied by a hearing person".
"I have profound deafness, prostheses or cochlear implants are a way to hear but this doesn't change anything because deafness remains for life".		"I remember a lady who, in addition to not putting down the mask, called me stupid, or when I was laughed at because I didn't understand a customer's request. We deaf are invisible and tired".	

The first overt approach of the researchers with the members of an online group started by mentioning a really occurred episode to one of the authors of this paper related to the difficulty of communicating with a deaf woman. A post was published asking for advice on what was the best approach for a hearing person who wants to communicate with a deaf person. To create greater engagement, the post referred to the film "Tutta colpa di Freud" [16] which narrates a deaf-hearing relationship. Sharing emotions raised by the movie, understanding other people's points of view and intentions, were meant to enter in empathy with the group members. Indeed, empathising with target people is a central approach of Design Thinking [17] which promotes human-centred methods to get to know people, to observe them closely, to understand what they think, say, do and feel [18].

A second post was published concerning a heated debate underway among the group participants. It was aimed at supporting the LIS role for the cognitive development of the new-born and hoped for a wide diffusion of it. In this case - unique in all the research made of hundreds of positive posts with deaf people - aggressive responses were received. This testifies that the ancient opposition between oralists and signers is still very much alive and that, despite the scientific research has provided evidence of the advantages of the bilingual strategy - LIS as mother tongue followed by speech therapy with hearing aids [13] - the dialogue between the two strongholds are still a minefield.

2.2 Questionnaire

A questionnaire using Google Forms was built with open-ended questions requiring long answers, anonymously distributed into a Facebook group of deaf people.

It consisted of twelve items related to the topics emerged during the digital ethnography:

- what type of communication mode/language was chosen and why;
- strategies adopted by deaf people to obtain information in hospitals, stations, airports;
- technologies/strategies used in the domestic environment;
- interactions with hearing people;
- how society could be more supportive.

Even if only 7 deaf people (5 women and 2 men), aged between 40 and 71 years old responded to the survey, their answers were long, rich and informative.

They also represented a variegated sample: all of them were profoundly deaf, five of them were educated oralists and two had both oral and sign language.

An oralist person considered himself as a hearing person and did not report significant problems in interacting with hearing persons.

Older people grew up forced to speak, now feel isolated since they have difficulties in communicating with hearing persons and with deaf signers.

Complex ingroup/outgroup dynamics [19] emerged from the data collected with the questionnaire: the dichotomy between deaf and hearing people seems to be part of a wider cultural universe where some deaf people value their identity, support the existence of a deaf culture, and contrast with other deaf people who see their deafness as a disability to be overcome and aim for an idealised normality.

Answers to the questionnaire revealed that there are many facets of the deaf community stratified in a complex way. These include: CODA (Children of Deaf Adults) who are hearing children, who have learned LIS as their mother tongue; mildest deaf people who use visual and oral communication strategies in a creative way and do not like to identify themselves in any category; non-deaf who, thanks to the cochlear implant and extensive use of technologies, consider themselves hearing; older people educated in institutions for the deaf who managed to take the secondary school certificate at the age of 18. They grew up forced to speak and now have difficulties in communicating with deaf people.

All participants stated that the quality of life of the deaf person is threatened by the low accessibility of services based on auditory information and interaction modalities.

Remarkably, 80% of the respondents in the questionnaire underlined that the choice to be educated in the oral language was not autonomous but determined by the parents.

2.3 In-depth interviews

Four in-depth interviews were conducted with parents of deaf children to map their experience and identify major problems and primary needs. A semi-structured protocol with open questions was adopted. After an introduction of the interviewer and a presentation the objective of the research, the interview was conducted focusing on:
- the emotions associated with the discovery of the diagnosis;
- the prejudices encountered/experienced;
- the support received by the health care system;
- personal feelings;
- needs and expectations.

Outcomes of the interview revealed that the parents experience the diagnosis of deafness as a mourning. They had no previous knowledge on the subject but biases common to the collective imagination:

"*For us it was a blow... I didn't know anything about deafness, I have always associated deafness to seniors with a hearing aid or to sign language. I never saw a child with a hearing aid and I didn't even know what a cochlear implant is. For me, my husband and our family, it was a bang*".

It also emerged that the health care service which should support them does not adequately meet their needs and expectations. Families expect the health service to provide knowledge and psychological assistance:

"*Nobody asks the parents how they feel. Nobody understands that the parents' role is fundamental in supporting the deaf child. When you're down you cannot take care of your baby*".

Families complain of a lack of attention to emotional aspects and a subsequent mechanisation of the medical routine:

"*The doctors gave us the diagnosis of deafness of my child, and asked us to do a lot of paperwork, because there is a lot of bureaucracy to get the necessary health care... Once at home, I wondered to myself what to do*".

Apparently, people who are supposed to take care of families of deaf children seem to be excessively specialised, each one on medical and technical issues, as in an assembly line, without attention to the critical needs of parents of a deaf new-born. A psychological support for the parents is missing:

"*The doctor explained that we would be assisted by the child neuropsychiatrist in addition to the prosthetic technician, the audiologist, and so on. What is missing is psychological support for parents*".

In summary, the network of people who are supposed to support the families lacks "smartness".

On the contrary, families have found effective, bottom-up strategies to fill the gap of services and human assistance. For example, they created groups on Facebook to respond to a general need of communication and sharing with other families.

However, they find it difficult to meet other parents of deaf children in their vicinity. Some associations try to mitigate this problem.

Interviewees stated that they would expect facilitation in reaching the medical centres for the frequent checks in the first months of the child's life. The visits are often located far from home. While the father works, the mother must go to the medical care centre with the child, and almost certainly in the first months she is also breastfeeding: "*Anyway it's all a war...when I was breastfeeding, I had to go with my daughter 100 km away from home for the necessary clinical tests. Fortunately, a local association lent us a car''*.

Parents expect someone to facilitate the bureaucratic routine to take advantage of prosthesis and other support foreseen by the health care system in their situation. The prostheses (e.g., hearing aids and cochlear implants) also require technical interventions at unpredictable times and days.

In addition to a need for sociability, competence and support, interviews with family members revealed a strong prejudice towards LIS to such an extent that most of them prevented their children from learning LIS when instead their deaf children, once grown up, spontaneously asked for it:

"*one day she asked me if she could attend a course to learn LIS but I did not agree...who speaks LIS? No one, we wanted her to learn a language spoken by the whole family ... she shouldn't remain isolated*".

Hearing parents judged the LIS a ghettoising niche bearer of stigma. For them, the use of LIS betrays an attempt to mask their child's deafness and efforts to make the child appear "normal". Some of them believed that LIS is only useful for deaf children with cognitive impairment.

There is a lack of knowledge and awareness of the value of LIS, and its importance for the cognitive development of the child. At best, LIS is considered as other foreign languages that one can spontaneously decide to learn when growing up.

3. Ideation and prototyping

The user research allowed us to elicit needs and expectations of hearing parents of deaf children and to define the following requirements for a new system capable to:
-   counteract the isolation of hearing parents of deaf children by putting them in contact with other families sharing the same condition;
-   offer alternative ways to communicate with the deaf newborn including the fundamentals of LIS;
-   disseminate knowledge about deafness;
-   create a community of practice where parents can share doubts and best practices;
-   provide information to manage the bureaucratic procedures with the health care system.

In order to meet these requirements, a prototype of a mobile app was designed involving parents in co-design workshops (Fig. 1).

Different techniques were used including card sorting [20], paper prototyping [21] and digital prototyping using Figma to support interactivity [22]. The prototyping

process was iterative and incremental with several evaluation sessions conducted remotely and in presence.

Fig. 1. Card sorting (top row), paper prototyping (bottom left), remote evaluation (bottom middle), in presence evaluation (bottom right).

The information architecture [23] was defined using card sorting. This activity brought to the definition of 3 main sections of the app: 1) Health services; 3) Community; 4) Learning LIS (Fig. 2).

Fig. 2. Interactive prototype (originally in Italian, translated in English): main sections and personal profile.

The section "Health services" provides useful information to contact the health care system and manage all the bureaucratic steps to receive support and assistance. This section contains a calendar of the necessary medical examinations and medical records.

The section "Community" addresses the needs of sociability and knowledge about deafness (Fig. 3). The feature supports an existing practice observed during the digital ethnography (e.g., family members ask for advice and share best practices on Facebook). This section contains various sub-sections.

In the "Find Families" sub-section, family members, who give permission for the geolocation function, can search for parents of deaf children in a specific geographical area. Results are displayed in order of proximity to facilitate the meeting on the spot. In this way it is possible to chat with other parents, share concerns and practices, and build relationships.

In the "Find Associations" sub-function, associations of deaf people are displayed by geographical proximity to the user. These include associations/organisations supporting oralism and LIS. They are gathered in a common space so that family members can have access to the different approaches and add other associations that they know or that they form.

The "Support Other Parents" sub-function aims to stimulate peer to peer tutoring so that parents who join the community as a person in need of help can later become a person who can help other parents. The tutor status can be acquired through training (e.g., badges obtained thanks to meaningful interactions).
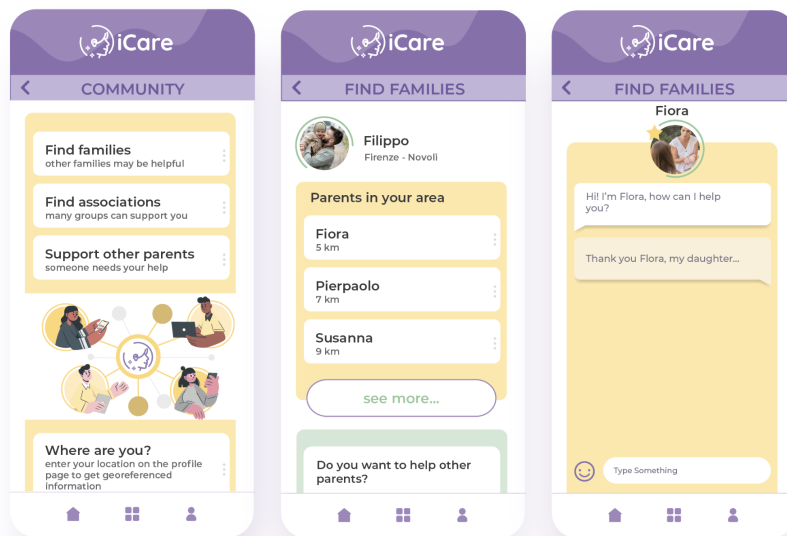

Fig. 3. Community section

The LIS section offers a basic course of LIS and provides knowledge about deafness (Fig. 4). Parents can practice sign language by getting in touch with native signers.

The "My course" sub-subsection allows enrolment in a course while the "In-Sign" subsection provides videos in LIS and a collection of basic signs that hearing parents can use with their child. It also contains exercises with simple signs to use with the new-born to build a first shared vocabulary that the child can acquire through imitation.

The "Find Babysitter" subsection allows to find referenced babysitters in the vicinity who are fluent in LIS. This service is useful also to help hearing parents in practising LIS with their child.

The "Events in LIS" subsection advertises cultural and social events in LIS like guided tours, excursions and meetings. The goal is to support experiential learning through participation in social and cultural activities.

Fig. 4. Learning LIS section

4. Testing and refinement

As said before, the interactive prototype of the digital application was developed along an incremental and iterative co-design process. Four hearing parents of deaf children, from 25 to 45 years of age, who did not participate in the previous co-design workshops were involved in evaluating the interactive prototype using cognitive walkthrough [24]. This activity was not a usability test which would have required a larger number of users. It was a formative evaluation session aimed to consolidate the current status of the prototype and test the overall concept of the App.

Participants in the test received objectives to achieve using the App. A facilitator observed the interaction with the App taking notes and filling in a feedback capture grid to collect information about what participants liked, their criticisms, questions, and opportunities for re-design. They were invited to think aloud during the test.

Overall, the prototype was well received. The participants appreciated the attention to their needs and the attempt to help them to counteract the sense of isolation.

The Community section was the most appreciated. The new way of dealing with the child's deafness compared to the current experience of isolation, changed the perception of the problem and offered a way out.

Some parents were moved as they imagined connecting with other family members, coming out of isolation and discovering that someone with similar problems lives nearby.

From a pragmatic point of view, the objectives of the scenarios were easily achieved.

While evaluating the "Support other parents" function, it emerged that a reputation rate could be integrated, asking the users to rate the quality of support received by other community members. Through this mechanism it could be possible to become a trusted support for other families.

The section "LIS" raised controversies, manifested even before exploring the section, mainly due to the prejudices of the users.

Some people disagreed precisely on the fact that there was a section dedicated to LIS, and someone said that this choice could even generate fractures and disagreements in the deaf community.

The mother of a deaf son who manages a forum on the cochlear implant with almost 15000 members, was totally against the idea of including a course of LIS in the App. However, she appreciated that the LIS section was proposed to acquire a basic level of sign language to interact with deaf new-born. She also appreciated the attempt to encourage the interaction between hearing and deaf people by participating in the cultural and social life of the deaf community. This could be a first step in overcoming the current barriers and facilitate inclusion.

5   Conclusion

This paper presented a case study of a smart ecosystem addressing the needs of hearing families of deaf children.

The user research was performed highlighting needs, expectations, cultural barriers and biases related to LIS learning.

A prototype of an App was developed to explore means to support inclusion and social sustainability, and to empower a community of deaf and hearing people in collaborating for the common good.

The Community section was designed to explore a virtual space where parents with common needs could meet, share their experience and collaborate. Even if the development of the App is at an early stage of development, the feedback received during the evaluation shows that the designed functionality stimulated a perception of trust, collaboration and mutual learning by pulling parents out of isolation and the feeling of abandonment by society.

As anticipated above, the LIS section was the most problematic and debated. However, the fact that the LIS course was proposed to establish a first interaction between the family and the deaf new-born, without precluding the subsequent choice

towards oralism resulted in a progressive change in the attitude of family members which, from hostile, became more favourable.

After the development of a demonstration prototype, the App was presented to investors and included in an incubation process to consolidate the business and financial plan and start a search for investments, crowdfunding and tenders.

The first marketing campaign was launched. It generated several leads, some people asked to join the community and requested services.

The next steps foresee the definition of the Minimum Viable Product to define and nurture the community, which is the basis of the project, and complete the implementation.

With this research we hope to have brought attention to a little-known problem that is not sufficiently supported by technological and organisational solutions. The user research has shown how important it is to assume not only the point of view of the various stakeholders involved in the design of the smart ecosystem but also to acquire a deep knowledge of the social and cultural barriers that often prevent the adoption of effective solutions.

CRediT author statement.
Alessia Pece: Conceptualization, Methodology, Formal analysis, Validation.
Patrizia Marti: Investigation, Methodology, Writing – review and editing, Visualization, Supervision.

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