Towards Communication and Information Access for Deaf People

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ABSTRACT

In tightly circumscribed communication situations an interactive system resident on a mobile device can assist Deaf people with their communication and information needs. The Deaf users considered here use South African Sign Language and information is conveyed by a collection of pre-recorded video clips and images. The system was developed according to our method of community-based co-design. We present several stages of the development as a series of case studies and highlight our experience. The first stage involved ethnographically inspired methods such as cultural probes. In the next stage we co-designed a medical consultation system that was ultimately dropped for technical reasons. A smaller system was developed for pharmaceutical dispensing and successfully implemented and tested. It now awaits deployment in an actual pharmacy. We also developed a preliminary authoring tool to tackle the problem of content generation for interactive computer literacy training. We are also working on another medical health information tool. We intend that a generic authoring tool be able to generate mobile applications for all of these scenarios. These mobile applications bridge communication gaps for Deaf people via accessible and affordable assistive technology.

CATEGORIES AND SUBJECT DESCRIPTORS

• Human-centered computing~Empirical studies in interaction design • Human-centered computing~Ubiquitous and mobile computing design and evaluation methods • Human-centered computing~Accessibility design and evaluation methods • *Human-centered computing~Systems and tools for interaction design* • *Human-centered computing~Accessibility systems and tools* • *Social and professional topics~People with disabilities* • Social and professional topics~Cultural characteristics • Applied computing~Computer-assisted instruction

KEYWORDS

Assistive Technology; Authoring Tools; Co-design; Health Care; Information and Communications Technology for Development; International Computer Drivers Licence; Mobile Computing; Pharmacy.

1. INTRODUCTION

The aim of our work is to provide Deaf users with a practical way of communicating in their own language, South African Sign Language (SASL). This is a vital part of the Deaf identity combines cultural pride, disability and lack of economic strength. A large number of Deaf people use SASL; it is estimated that there are at least 500 000, while the Deaf Federation of South Africa (DeafSA) put the number of SASL users at over 1.5 million [1]; making it one of the bigger language groups in the country.

Following international convention we write Deaf with a capital D to denote a cultural, linguistic group who uses, in this case, SASL as their preferred language. This is as opposed to deaf with a small d which refers to a medical condition, i.e., loss of hearing. In the latter case the emphasis is only on the impairment. This is a self-identification by the Deaf community and moves the discussion beyond disability to one of digital exclusion of a disadvantaged community. Note that SASL is a unique language unrelated to any spoken language [2].

After two decades of democracy and transformation telecommunication access is still clearly unequal with Deaf people in South Africa even more disadvantaged than their hearing counterparts. Since 1994 there has been an increasing empowerment of Deaf people. SASL is accepted as a distinct language in its own right; although not an official language, it is directly mentioned in the constitution and it is recognized in the South African Schools Act [2].

The recent debacle with the interpreter at Nelson Mandela's memorial service on 11th December 2013, led to an apology by the Minister of Arts and Culture Paul Mashatile [3]. This again emphasized the marginal position of Deaf people and challenges they face in communication even at the most important social events.

1.1 Right of Communication

The notion of Universal Access is well established in the telecommunications field and has been extended in a number of ways in the Information Society. Our work returns to basic ideas of Universal Access for Communication. As noted by Msimang [4] the experience of South Africa is *not* one of Universal Access but the absence of it, and attempts to redress the historic deprivation. He also points out that "In terms of the Telecommunications Act, the Minister may define the categories of 'needy' persons to whom assistance, in the form of subsidies, should be given". While the Deaf are included, there seems to have been little progress since the original discussion paper of 1998 [5].

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1.2 South African National Development Plan

More recently in 2011, the National Development Plan (NDP) [6] declared general aims toward bridging the Digital Divide within South Africa. These included: ensuring "access to low-cost, high-speed international bandwidth with open-access policies", extending broadband penetration to 100% by 2020, and "expanding ICT access in all rural areas" [6]. The NDP specifically mentions efforts to integrate "issues of disability into all facets of society, and ensure equitable service provision for persons with disabilities" [6]. However, the reality for the South African Deaf community is that smart phones are still very expensive, there are no government subsidies for their use and call charges are very high, access to the Internet is limited, national relay services do not exist and even if they did, the bandwidth required for sign language transmission in video is out of reach of most Deaf people.

2. COMPUTER-BASED SUPPORT FOR SIGNED COMMUNICATION

There are several uses to which computers can be put to assist Deaf people. One distinction is between enabling Deaf people to communicate with hearing people *versus* enabling Deaf people to communicate with each other. Another distinction is whether the input by the Deaf user is signing or text.

Text, as a medium, can potentially be used for Deaf people to communicate amongst themselves and with hearing people. This functionality is available on SMS ("text") messages on cell phones but these lack the instantaneous liveness indicator (to show someone is typing) found on alternative applications such as WhatsApp (www.whatsapp.com). Liveness indicators help to create a sense of being co-present with the person being contacted. Deaf users are however inhibited by text communication, particularly with hearing people, because many Deaf people have low levels of written language literacy (which of necessity takes place in a language other than their first language, namely SASL).

A service offered in some developed countries is that of a Video Relay Service (VRS), e.g., in the USA this is regulated by the Federal Communications Commission [7,8]. With VRS a caller using sign language can communicate with a live VRS interpreter by using a video connection. The VRS interpreter signs the telephone conversation with the sign language user and voices to a hearing person who uses a standard telephone.

Another variant on using computers is to try to mimic VRS. This involves recognizing signing automatically and then encoding the recognized language for translation to voice.

Such encoding can also be used for highly compressed transmission of the encoded signs. Such signs would then be recreated at the other end by a signing "avatar".

This whole effort depends on solving very complex problems in Artificial Intelligence. A leader in this research is Matt Huenerfauth at CUNY: see "American Sign Language Animation" (eniac.cs.qc.cuny.edu/matt/research html). There was also the European 5th Framework project ViSiCAST (Virtual human Signing: Capture, Animation, Storage & Transmission, 2000–2002) and its follow-up eSign (2002–2004) which ended without seeming to make much impact (www.visicast.cmp.uea.ac.uk). A great deal of information is carried in facial expressions during singing and this has yet to be included in animations [9]. We are not expecting breakthroughs in this area soon.

2.1 Context

We work closely with a grassroots NGO called DCCT (Deaf Community of Cape Town — http://www.dcct.org.za/) which is staffed almost entirely by Deaf people and serves the needs of the larger Deaf community in the Western Cape. It was founded by members of the community in response to a dearth of services and support from mainstream and official sources. Most Deaf adults are semi-literate, at best, due to disadvantageous educational practices at schools for deaf learners. Many are unemployed, but those who are employed are often underemployed in menial jobs. This adversely affects the socio-economic level of the community as a whole. The Deaf Community is underdeveloped in terms of ICT (Information and Communications Technology) access and participation. In general we believe that ICT can be an enabling technology that supports development and empowerment. Thus this group might benefit from ICT interventions.

2.2 Research Methodology

Our approach has been one of Action Research, mostly viewed as a paradigm rather than a specific methodology [10,11,12,13]. The aim has thus been to achieve a dual aim of action intervention and research learning (unlike McKay and Marshall [10] we do not see that this requires a separate research and action cycle; our pragmatist epistemology avoids the separation of action and thinking [14]). Given our background in experimental computer science this has always involved building computing artefacts, intervening with communities and then reflecting on the experience of using such a system.

The standard engineering aim in such situations is to build systems that are "fit for purpose". This implicitly depends on users who are able to state their needs clearly in terms that can be understood by technologists. It has become apparent that uncovering the specific purpose for which a new artefact is needed is problematic. Methods that deal with "customers" are not adequate to encompass the context within which we practice ICT for Development (ICT4D). This is because such approaches assume customers are similarly educated and from the same culture and can express their needs in a language that Computer Science practitioners understand [15].

We now realize such notions of the aims of design have to be challenged. Designers have to work with users as co-designers and together identify the problem that needs to be addressed, the means of tackling the issues and then together decide on measures of success. The systems are designed and evaluated using Community-Based Co-Design (CBCD) methods [16].

2.2.1 Community-Based

"Community-Based" conveys the fact that we deal with groups of people rather than individuals (in the developed world computers are geared to individual requirements). We need to remain sensitive to major cultural differences and develop ways of entering into design conversations with people who do not have technical skills but who are knowledgeable on their own needs. We realize too that there is no "one" community with whom we work. In every design situation there are many communities: the elders, the youth, women, migrants, people with disabilities, and so on. Each of these has to be given a voice in design. In order for that to happen we must recognize groups of stakeholders, identify gatekeepers and consider how all the diverse needs might be investigated.

2.2.2 Co-Design

"Co-design" derives from the application of the action research paradigm in a design setting: both the computer experts and the community members are designers on an equal footing and work cooperatively. There is an ambiguity in the use of the term "co-design" in the literature. For some co-design is something done in the early stages of eliciting user requirements and

Figure 1: Reporting a Crime Scenario: *"I tried to explain what happened, but there was no one around who knew sign language. I learned how to speak at school, but every time I meet people like this, they act like I'm retarded or something".*

signifies using techniques such as cultural probes, generative sessions, technology probes and so forth. From our point of view this is better called "early stage co-design" [17,18] (also see Marti and Bannon [19] for a critical discussion of different ways of managing user-involvement). We employ all of those techniques where appropriate but co-design goes further when combined with action research and continues to all stages of artefact development and evaluation. This is part of a trend in empowering people and moving away from a rhetoric of "compassion" [20]: from ICT for D to D with ICT.

Once stakeholders have been identified a common language (or metaphor as it is sometimes called in computing) has to be developed. With sophisticated users this language can be based on crude mock-ups of a computer interface ("paper prototypes") since such people can readily imagine how this might work in an ICT artefact. Where a common understanding of technology does not exist, co-designers have to be given insight into the possibilities offered by the technology by means of approximations implemented using technology.

A key feature of co-design is for technical experts to keep their own design decisions in abeyance. It is a serious mistake to commit (psychologically) to a design solution before the co-designers have found their voice.

3. COMMUNICATION ACCESS FOR DEAF PEOPLE IN CIRCUMSCRIBED SITUATIONS

We have spent many years working on various aspects of supporting communication access for Deaf people. For this part of the project we look at issues that arise when Deaf people want to access services provided by the larger hearing culture within which DCCT is situated. Detailed contextual enquiry and the use of generative methods produced a number of possible scenarios, including reporting a crime at a police station (Figure 1), consulting a doctor at a hospital, and dealing with the department of Home Affairs. A generic authoring tool would be ideal to create tools that are able to handle multiple scenarios (Section 3.3).

The scenario jointly selected by the Deaf community and researchers for initial detailed design and prototyping was medical consultation. The trial itself was very successful in proving the usefulness of the approach (Section 4.1). The drawback uncovered was that a medical consultation was too broad and open-ended and would need much more content as well as a VRS. We wanted to do real field trials and so we decided to switch to a more constrained scenario, namely dispensing medication at a hospital pharmacy (Section 4.2).

In parallel we explored computer supported computer literacy training, which also gave us the opportunity to build our first version of an authoring tool (Section 4.3).

3.1 SignSupport

We have created a number of prototype systems via the CBCD method. These systems all share a common basic architecture we have called SignSupport (Figure 2).

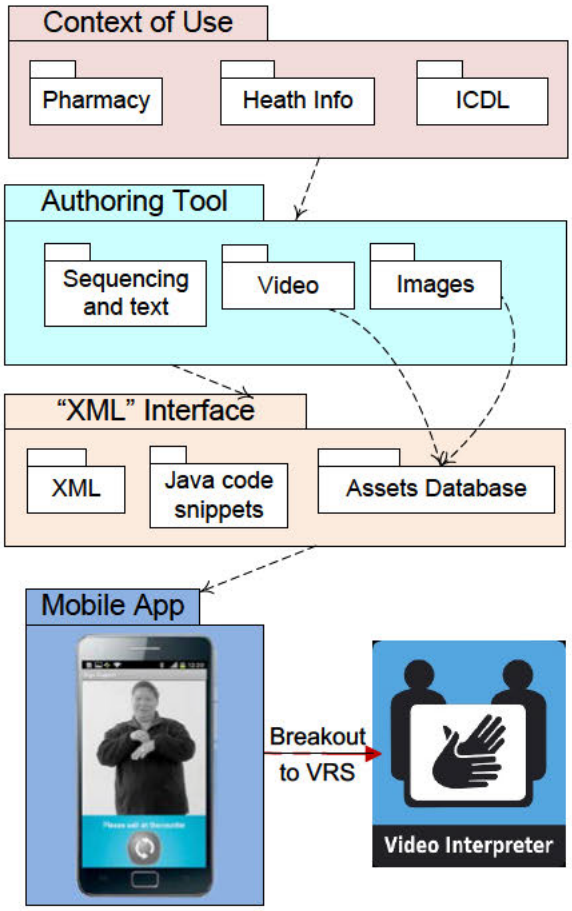

Figure 2: SignSupport Conceptual Design Architecture. *The top layer shows the various, strictly constrained, «Contexts of Use» of the system (ICDL is computer literacy training). The «Authoring Tool» enables a domain expert to put together a sequence of events and displayable assets for each use so as to enable communication. The authoring tool generates the scripts and assets that act as the clearly defined «XML Interface» to the «Mobile App» which runs the actual context specific application on the Deaf user's device. If the communication needs go beyond the limited design context the system makes provision for optional breakout to a Video Relay Service.*

SignSupport targets the communication needs of Deaf people in circumscribed contexts where they want to access services in a community that mostly cannot sign. Such situations would

include critical situations such as visits to a medical doctor or getting prescription medication from a hospital pharmacy, or learning contexts such as accessing health information or learning how to use a computer.

We have already piloted various aspects of the system and executed detailed designs of others. The current phase of our ongoing research project with the Deaf community, namely communication in circumscribed contexts, started with requests from the community. One was an interest in gaining computer literacy and the other was for support in civic engagement (for example, doctors at hospitals, police, etc.).

The key to the widespread use of SignSupport will be the ability to create content. This is an intensive process that requires input from domain specialists in the context of application. For each scenario the most common possible interactions within the frame of communication have to be mapped out.

3.2 Generic Use of SignSupport based Systems

The general use of SignSupport is for those situations where the communication needs can be constrained by the context such that sequences of pre-recorded signing video clips suffice to inform the Deaf user. The hearing user needs some training in the use of the communication system.

All communication takes place by means of the mediation provided by a mobile phone in possession of the Deaf user. This phone contains all the material needed to facilitate communication and is typically passed back and forth between the Deaf user and the hearing service provider.

The Deaf user can provide input by responding to questions built into the system. The prompts are provided by images and video clips. The Deaf user's responses are recorded and are displayed as text for the hearing service provider, who is given the phone and then records information in response to text questions. These saved responses result in the display of images and video sequences when the Deaf user gets the phone back.

Naturally such a system is only a partial solution and cannot cater for unusually complex situations. In such a case we plan to breakout to a video relay system. Currently this faces technical and affordability hurdles. The video relay service will have to receive state funding, a political problem. Secondly the phones will have to have high quality front facing cameras and high communications bandwidth that prioritizes video.

3.3 Authoring Tool

Once a new scenario is identified for implementation, a domain expert will be included to help formulate the conversation/ dialogue required. The authoring tool provides:

1. an interface for the dialogue to be mapped out and to populate the dialogue with videos and images;
2. an asset manager (database) to hold all this information;
3. an output generator that produces the information for the application in a given scenario;
4. an interface to help both domain and SASL experts verify the content and ordering of the SignSupport scenario.

The output from the authoring tool is a well-defined schema for the dialogue together with links to sign language videos and pictures. A mobile application processes the schema in order to present the user interface to the end users.

4. RESULTS

We have created initial versions of all these components. The first fully worked out scenario was a hardcoded Android app for a hospital pharmacy dispensing scenario. An initial version of the authoring tool has been developed for the computer literacy training scenario (ICDL).

4.1 Initial Design Pilot: Doctor's Consultation

Our initial design was the scenario of visiting a medical doctor. We performed a detailed design of the doctor's consultation including full scale mock-ups and user testing (Figure 3). Some Deaf users were confused about the idea of entering information about themselves onto a cellphone displayed on the computer screen in order to inform a fictitious doctor about their feigned complaints. As the task they were asked to do carried on they became surer of the setup.

Figure 3: Testing the Medical Consultation Scenario: *Composite image of video camera recording and computer screen capturing.*

To quote one user:

> *"At first I didn't understand the process and how it worked, what it's meant for. […] But after a while I felt more comfortable."*

All participants explained that they thought the SignSupport concept could be very useful in daily life, especially to explain invisible things, such as 'headache', 'a blocked nose' or 'a few days'. They mentioned the police station and banks as other places where they would like to use it. When asked about whether they would trust the system to correctly explain their answers to the hearing doctor, they said they had no doubt about it. Another user said:

> *"With this system you press a button and he knows if you have a headache. I think hearing people may want to use this system as well… get the right medication."*

The trials conclusively showed the usefulness of the approach and Deaf participants expressed a desire to use the application on a mobile phone. A mobile prototype was built on Symbian to allow a Deaf person using SASL to tell a hearing doctor how s/he is feeling and provided a way for the doctor to respond [21]. The prototype embedded SASL videos inside XHTML pages using Adobe Flash. The prototype asked medical questions using SASL videos, organized to identify a medical problem. The answers to the questions were then displayed in English on the phone and shown to the doctor. It was envisaged that a content authoring tool could be used to populate the prototype in a context free manner allowing for plug and play scenarios such as a doctor's consultation, Department of Home Affairs or police station.

Results indicated that most of the Deaf people found the system user friendly, with acceptable levels of sign language clarity and security of private information. They reported that they would consider using the system in real life. However, it became clear that the two-way communication between doctor and patient had too many open-ended possibilities that our

system could not support with pre-recorded videos. Together with our Deaf co-designers, we re-focussed the work toward a more limited domain scenario, e.g. pharmacy dispensing.

4.2 Pharmacy Dispensing

The re-focus resulted in the design of a communication tool for a simpler dialogue tree in the pharmacy context [22]. An industrial design engineer combined Vision in Product Design [23] and traditional human-centred techniques to design a feasible communication tool for a Deaf person to use at the pharmacy. Interviews, storyboards, and role play were the main techniques used to unfold the users' needs and wishes. The investigation revealed that Deaf patients clearly need to understand their medication requirements prescribed by the doctor and dispensed by the pharmacist. This is a challenge as many Deaf people are functionally illiterate [24]. SignSupport was re-designed to serve as a portable SASL interpreter of a limited communication scenario where a Deaf patient communicates with a pharmacist independently. This included medical instruction, warnings, recommendations and usage information. The evaluation of SignSupport design by both Deaf people and pharmacists, in assisting communication was promising and the recommendation was to implement the design for clinical trials.

A multi-disciplinary collaboration resulted in the iterative development of a mobile communication tool to support a Deaf person in understanding usage directions for medication dispensed at a pharmacy [25]. This collaboration improved usability and correctness of the user interface [26]. The tool translates medicine instruction given in English text to South African Sign Language videos, which are relayed to a Deaf user on a mobile phone. Communication between pharmacists and Deaf patients were studied to extract relevant exchanges between the two users. We incorporated the common elements of these dialogues to represent content in a verifiable manner to ensure that the mobile tool relays the correct information to the Deaf user. Instructions are made available for a Deaf patient in sign language videos.

Figure 4: Mock-up of a Hospital Pharmacy used for testing the Pharmacy SignSupport. *Staffed by pharmacy students and with Deaf users from DCCT.*

A pharmacy setup was created (See Figure 4) to conduct trials of the tool with groups of end users, in order to collect usability data with recorded participant observation, questionnaires and focus group discussions. Subsequently, pre-recorded sign language videos, stored on a phone's memory card, were tested for correctness. The results of the user trials indicated that SignSupport is accessible, intelligible and affordable to Deaf users. Pharmacists reported the efficacy with which SignSupport enabled them to fulfil their professional obligations, i.e. making sure that their patients understood their medicine instruction.

The implications of this work highlighted several other issues. Firstly, an affordable and accessible video relay service (VRS) would need to be established locally to handle the need for true two-way communication where a Deaf person requires clarification from the pharmacist, and vice versa. Secondly, limitations in mock trials include the satisficing of answers, i.e. responding according to what you believe someone wants to hear. Lastly, participants were neither ill nor dispensing actual medication, i.e. the urgent need for clear communication was absent. Both of the latter issues can only be addressed by taking the application to an actual clinical pharmacy setting. The mock trial showed that the technology is ready for this move. The responsibility for the clinical trial lies with a research pharmacist in collaboration with the rest of the multi-disciplinary team.

4.3 Authoring Computer Literacy

International Computer Driving Licence (ICDL) training has been an ongoing activity at DCCT that was originally requested by the community. The ICDL (www.icdl.org.za) is an internationally recognized computer skills certification programme run by the ECDL foundation (www.ecdl.com). We are collaborating with *Computer 4 Kids*, a Southern Africa educational ICT company run by educators (www.computers4kids.co.za). The company offers an E-Learner package to assist learners of all ages and educators with obtaining ICDL qualification. Since there are a number of different lessons in a course this was an ideal environment to start exploring the creation of an authoring tool. They have given us access to their product and have agreed that we can look into ways of converting some of the support material into a form more suitable for Deaf learners.

Computer literacy for Deaf learners is better facilitated by sign language mediation. At present this is provided by a teacher but this has several drawbacks:

1. It is very demanding on the teacher.
2. Students cannot learn at their own pace.
3. It is expensive.
4. Learning can only occur in class.

A pilot version of the ICDL authoring tool has been completed and tested in the lab (Figure 5). Field trials will begin shortly.

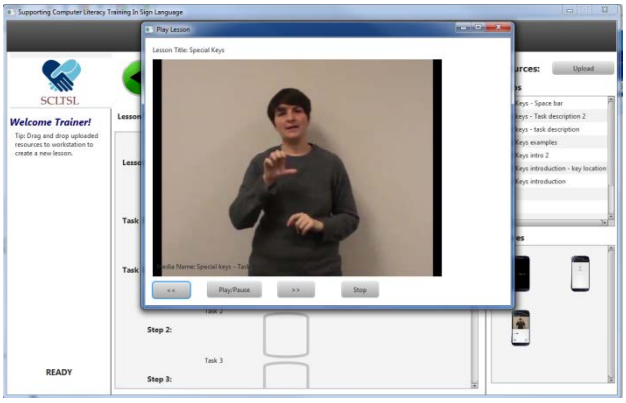

Figure 5: Pilot version of the ICDL Authoring tool. *The pop-up shows a video clip being previewed before inclusion. The list of assets that can be included are on the right, while the centre panel shows the structure of the lesson being prepared.*

4.4 Health information

In the South African healthcare context, many Deaf people cannot acquire accurate information from reliable sources to maintain their health or to participate in choices of treatment for

themselves. Due to barriers to communication and information, many Deaf people acquire healthcare knowledge from Deaf friends who may not have access to the correct information either. This inaccurate information leaves the Deaf person with misunderstandings and misconceptions and can have a long-term impact on the Deaf person's health.

The aim is to develop SignSupport further to assist Deaf people to access accurate healthcare information. Therefore, appropriateness and usability of the health knowledge sources, tools and services will be evaluated together by Deaf people and health knowledge providers. This extension is complimentary to the other SignSupport healthcare interventions.

5. DISCUSSION

While much progress has been made providing independent communication for Deaf people in limited domains, there are several significant challenges that remain to be addressed in order to provide accessible, affordable and sustainable ICT solutions to communication barriers. We understand that the smart phones currently required to run the resulting communication aids are expensive and to make them affordable we maintain a pool of phones at a community centre for loan to members. We do however expect the cost of phones that can run this system to reduce over time. We have also intentionally focussed on such limited communication domains because we can pre-define a constrained dialogue and pre-record all of the needed sign language videos on the phone without the need to go to the Internet. This significantly reduces the cost of use.

Accessibility of the system is particularly important when dealing with a community that is semi-literate and possesses limited ICT skills. Targeted training in SASL must be part of the delivery of the system. All the initial design work included making sure that Deaf users found the system easy to use. To address SignSupport's limited pre-recorded two-way communication, we expect to add a video relay system and will endeavour to produce one that consumes a minimum of bandwidth to minimize usage costs.

The authoring tool is designed to ease of production, and cost, of new content for existing and future scenarios. To ensure the sustainability of the system, Deaf people are empowered to identify a scenario, populate a scenario with signed content using the authoring tool, and automatically generate a mobile app to run that content.

Currently, the project is supported by research funding. Just as the Deaf community assumed payment of their Internet service, our main challenge is to devise a sustainable business model that can be managed by the Deaf Community itself.

6. CONCLUSION

Deaf people are entitled to accessible, affordable and sustainable appropriate ICT systems. SignSupport is firmly on the way towards achieving such a solution. We have implemented SignSupport for both medical and pharmacy interactions, and the pharmacy scenario is ready to be trialled at an actual pharmacy. We are building a computer literacy training application to assist us in delivering the International Computer Driver's License course for Deaf learners. We have built a prototype of an authoring tool to generate the content for a mobile training aid. The next step is to develop the authoring tool into a generalised system to handle multiple scenarios.

7. ACKNOWLEDGEMENTS

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