The TalkingBox.

Revealing Strengths of Adults with Severe Cognitive Disabilities

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ABSTRACT

In this paper, we present a case study of the iterative design of TalkingBox, a communication device designed with a person with a severe cognitive disability and his support network. TalkingBox combines graphic symbols with tangible technology to foster the use of symbolic communication by leveraging the person's strength and interest in memory matching games. In the course of designing, trialing and iterating the TalkingBox, we discovered that the design supported not only the development of symbolic communication, but also revealed new interests and strengths of our participant. TalkingBox highlighted opportunities for interactions with peers, revealed new skills in visual discrimination, and evidenced interests. These could, in turn, support staff and family to adapt their support. More importantly, TalkingBox had become a living portfolio presenting our participant with severe disability through the lens of their strengths. We discuss opportunities for research through co-design to open new avenues for future communication technologies.

CCS CONCEPTS

• **Human-centered computing** → Accessibility; Accessibility technologies.

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KEYWORDS

Adults with severe cognitive disabilities, Augmentative Alternative Communication, Tangible Interfaces

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1 INTRODUCTION

Respectfully designing with people with severe cognitive disabilities is challenging. Even with the best intentions to design a technology that is personalized, meaningful and based on the strengths of a person with disabilities [3, 5], we may risk to impose substantial learning demands during the process of designing and using technologies. If the disabilities are profound, designers and researchers can easily slip into a deficit-oriented attempt to compensate for the lack of certain abilities. Ultimately, a large number of assistive technologies is abandoned [21].

One of the hallmarks of designing successful technologies with and for people with disabilities is a strong focus on individual strengths and interests. Recent work has shown a great deal of promise and effectiveness over this approach [5]. However, revealing strengths and interest might not be a simple task in the context of people with severe disabilities who are non-speaking [3, 10], and proxies (e.g. support workers) are often not aware of peoples' strengths, especially long after adults with severe disabilities have abandoned technology to support communication [9].

In this paper we present a case study where personalised tangible technologies evolve to further reveal personality and strengths of individuals with severe disability to both designers and people in

their support networks. We follow the story of Chris and the TalkingBox, which has overtime become a new positive lens with people around them are seeing Chris. We also discuss how this can offer an alternative framing for augmented alternative communication.

2 RESEARCH GAP

There is a dearth of research on how to co-design with people with moderate to severe cognitive disabilities. As these participants are mostly non-verbal there is a strong tendency to consider communication technologies that will propel different interaction strategies and investigate the challenges and competences of end users with severe disabilities. However, the research and design for this group is still lagging [14].

Notable exceptions include work by Hornof et al. [3] Rajapakse et al. [17, 18], Robinson et al. [20]. These studies have shown that designing for the person with severe disabilities is like designing for a "universe of one" [2], strengthening an approach that fully engages with people with cognitive disabilities ensuring an opportunity to express their thoughts and feelings [17], and offers new ways to document and reflect on the co-design process [20].

However, these studies have been conducted mainly in the of the homes of people with severe disabilities, together with their families. Hence, there is limited knowledge on how to design with people with severe cognitive disabilities outside the controlled and familiar environment of the home.

In this case study, we aim to provide design insights that look at the co-design process inside the community centre and with paid support staff. Beyond the desire to expand on people‘s agency and control over their environment, it is important to extend this work to encompass opportunities to engage with peers and promote peoples‘ strengths and interest to others. Additionally, as reported by a number of researchers [21], the uptake of assistive technologies is often poor and accessible to only a few adults with severe disabilities. Most of these bespoke solutions will be introduced as artefacts that need to be learned which puts the strengths and competences of potential end users at the fringe of technology use and design [12, 14].

3 CASE STUDY CONTEXT AND METHOD

3.1 Case study setting

This case study builds on 2 years of fieldwork in a Learning & Lifestyle centre (community day centre). The centre offers daily assistance in educational and recreational activities for 30-35 adults with cognitive disabilities in the age range of 19-55. The majority of individuals with severe disabilities at the centre are minimally or non-verbal. The staff members (support workers) at the centre are of diverse educational background and their role is primarily to attend to safety and daily support for adults with severe disabilities.

The fieldwork was conducted by the lead researcher, who is a former social worker and had previously been trained in special education and cognitive science. The fieldwork included ongoing engagement through participant observation and interviews with four people with severe disability and their family and support workers over the last 2 years. Throughout this time, the lead author participated in a variety of centre activities (dance, bus outings, celebratory gatherings etc.) and designed various low and mid-tech interventions with people with disability, staff, and family members to support communication.

3.2 Participants

This study focuses on one participant with severe disability, Chris (pseudonym), and his personal attendant (one-on-one support worker), Mitch (pseudonym). Chris is in his late teens and he shows signs of understanding basic verbal communication: he engages in finger-flicking and occasionally shows closeness to Mitch by raising his both hands in the air and greeting him whilst simultaneously vocalising pleasure and satisfaction. To communicate with Mitch, Chris engages in gross physical actions that rely on background expectancies [8] – going to the kitchen and waiting for Mitch (which Mitch interprets as "I need my poppers") or going to his locker to bring his backpack ("I want to go home"). Chris also uses gross body movement to interrupt undesirable interaction (e.g. pushing away to indicate that he does not want to communicate right now). Chris needs one-on-one support most of the time as he cannot talk or use intelligible manual signs.

In the past, Chris used to play with toys, iPad and use Picture Exchange Communication System (PECS) boards. His mother indicated that the PECS board was used to mainly express his requests. However, two years after an unexpected illness (and long hospital recovery), Chris has lost his ability to navigate PECS board or show any desire to engage with toys or iPads. Chris‘s parents have not tried any symbolic communication since then, but Chris has shown signs of using 2D and 3D tangible representations (e.g. using picture tiles). Six months prior to our study engagement, Chris transitioned to the day centre, sharing the space with 30 other peers. In the centre, Chris is mainly passive, interacts with his closest communication partner (Mitch) and rarely interacts with other peers in the environment. Mitch expressed a desire to involve Chris in participatory and meaningful activities: *"He likes jumping, and throwing the ball, and we do that. He likes driving in the car, and we do that. I follow him wherever he wants to go and whatever he desires to do. But I'd like to engage him more".*

3.3 Focus on Chris‘s strengths

Identifying which of Chris's strengths would constitute an appropriate starting point for a design was the result of attentive engagement with him and his family by the researcher. This type of work [7, 17] is a necessary step to fully and respectfully involve participants with severe cognitive disability and their support network as co-designers. We summarise the outcomes of this process which served to inform our first iteration.

During an interview with Chris‘s mother, she revealed that Chris "has a great memory" and "it's freaky sometimes of how good he can be. He can recognize and remember where we left our car at the shopping mall amongst hundreds of other cars". In addition, Mitch has mentioned his appreciation for street signs and an affinity towards rectangular and squared shapes. Earlier, in high school, Chris was able to play a memory matching game that he has since not been able to demonstrate again. We saw this as a design opportunity to step in and offer an engaging activity at the centre. We introduced an original memory cardboard game – Pelmanism

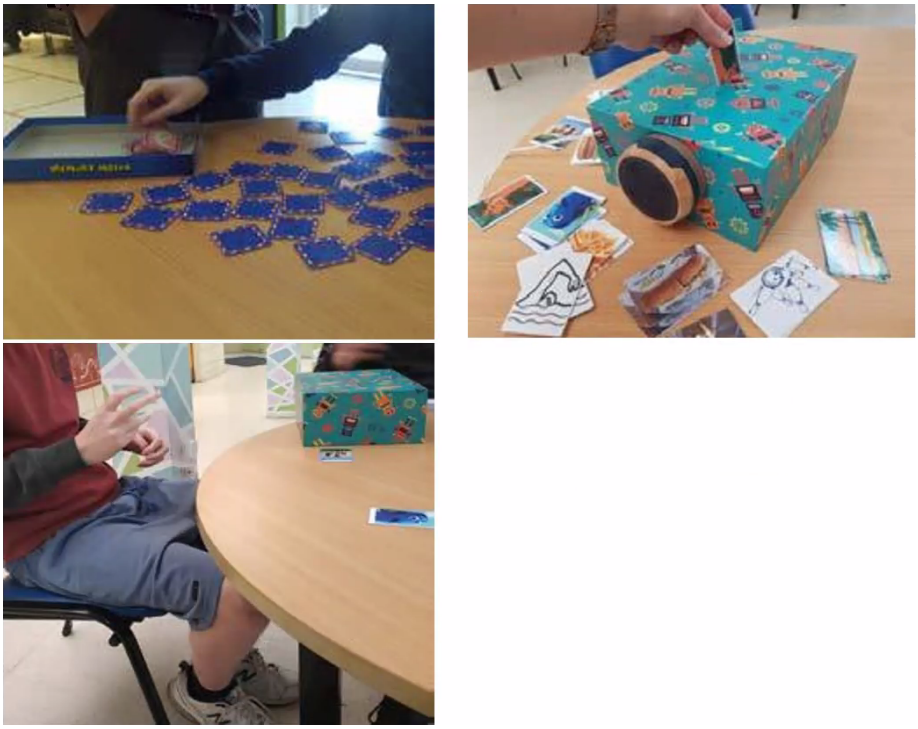

Figure 1: (top-left) Pelmanism, Chris playing the memory matching game (unless a box/lid is on the table Chris will not play the game; (top-right) - TalkingBox prototype has a slot on the top to enter cards that represent items of personal interest (e.g. bowling). When two matching cards are entered, a sound (e.g. spoken word bowling) is played; (bottom-left) - Chris waiting his turn to put the next pair of cards inside the box (eye contact on the box waiting for the sound to be activated)

(figure 1, top-left). This game is a standardized memory matching game that can be bought off-shelf. The memory matching game and later the TalkingBox were implemented with no scoring scheme imposed; the game scenario was set such that Chris could make as many mistakes as he wanted. With this in mind, we also aimed to avoid competition between players that can lead to undesirable consequences for highly anxious individuals.

3.4 The memory matching game

To start with, with the help of Mitch, we demonstrated the rules of the cardboard tile game, in an embodied manner, using a hand over hand technique. We started with an 8-tile game within the category of mundane and familiar objects (house, bed, car etc.). In the midst of Chris's attempts to play the game, we noticed signs of agitation whilst holding the two matching tiles which seemed as if Chris wanted to do something with the tiles (put them off or place them somewhere). Reflecting in situ, we moved the lid of the cardboard game close to Chris to enable him to discard the tiles. He immediately started to lay the matching tiles inside the box continuing to the next pair of tiles. Mitch later explained this lid as a *"game changer"*, showing the importance of having a concrete and embodied goal for Chris (Figure 1top-left). Inspired by Chris's visible strengths and ability to engage with the content of interest, we decided to move forward and augment Chris's memory matching skills. Chris's parents suggested to further explore these opportunities. His mother was particularly interested in Chris's progress, pointing out *"Let us see, if he continues to make such progress, we were thinking of engaging him in speech therapy sessions"*. For us, this was a unique opportunity to showcase how design can help parents and Chris strive to achieve new goals.

Although everyone was keen to engage and follow up on Chris's progress, it was not entirely clear what else could be done. The TalkingBox prototype was inspired by our desire to instantiate a new path to explore Chris's skills and strengths. Together with Mitch, we envisioned a box that could expand memory matching skills by assigning sounds to the existing cards. As graphic symbol communication is the crux of communication technologies, in which his mother expressed great interest, we were inclined to explore the cause-effect of graphic symbol communication aligned with prior strong interests in the memory game.

3.5 TalkingBox prototype and concept design

The TalkingBox was designed by augmenting an off-the-shelf gift box with a Raspberry Pi 3 microcomputer, RFID reader and a speaker. A slit was cut in the top of the box, and a larger hole was made on one side to house the speaker. The RFID reader was positioned inside the box close to the top slit. The TalkingBox is accompanied by 25 pairs of RFID cards that have the dimensions of a standard credit card. Each card has a picture or symbol on it. When a matching pair of cards is inserted consecutively into

the box, a Python program running on the Pi registers that a pair has been scanned and plays the pair's associated sound (Figure 1 - top-right).

The pictorial sets were inspired by the Visual Scene Displays (VSDs) [13] concept, amplifying language learning through meaningful and motivating vocabulary. Real photographs were also used, providing visual contextual support at the one-word level. The visual-audio pairing thus provided access to spoken vocabulary describing events that Chris had already experienced, reinforcing his receptive language skills. The task of developing prior comprehension skills is an important contribution and "partner in augmented language acquisition and use" [19].

The TalkingBox presented a unique opportunity to merge Chris' strong interest in the memory game and his support network's desire to expand his vocabulary acquisition. We thus aimed to explore prospects to develop and fine-tune Chris's comprehension skills, with some uncertainty as to the extent of Chris' receptive language skills and strengths that we could target.

3.6 TalkingBox – trial study

We conducted a pilot case study following a research through design approach [15] for the talking box itself, and iterated with short cycles of observation /reflection/redesign for the cards and their use.

The first iteration of the TalkingBox was introduced to Mitch, demonstrating its main concept – the sound will play when two tiles are matched and placed in the box. Mitch then led the deployment of the prototype and its variations throughout a seven-week field study. Mitch and Chris were given the opportunity to choose the way in which they wanted to engage with the box.

We conducted observations and took notes *in-situ*. Photographs and short videos were also captured. Brief interviews with Mitch and other support workers were conducted to discuss their experience and challenges in using the TalkingBox. Based on the feedback and observations we made changes to the box design, the cards and associated photographs and sounds, and the ways in which we used them with various participants. The following section describes both our observations of how the TalkingBox was used and our design iterations.

4 FINDINGS

4.1 Initial iteration – Personalized memory game

The first set of cards represented objects of interest and real photographs taken by Mitch (his bed, subway sandwich, chips, beach, lunch time etc.). The voice associated with the cards was Mitch's. This was done because Chris was often reluctant to engage in new educational activities, and hence we wanted to reduce any potential risk of anxiety due to unknown content.

The first iteration was the usual memory game scenario, with Mitch deciding to place the TalkingBox on the table where Chris was usually seated. Mitch briefly demonstrated the interaction with the TalkingBox. He has focused the on the novel interaction of placing the matched tiles in the slot at the top of the box. This caused a certain level of agitation as Chris has never seen the box before. The first round of the game was followed by a hand-over-hand technique navigating Chris's movement towards the top of the box. The new rule was quickly adopted. From day one the box became part of Chris' daily routine. Chris continued to play the game for 10 to 15 minutes each day.

Initially, Chris did not seem to react to the sound effects activated by placing the cards in the box. Often, he would insert more cards before the pronunciation of the word for the prior matching pair was even finished. At the end of week two, he started to wait for the words to finish before selecting the next pair (Figure 1- bottom-left). Mitch commented *"I am still not sure, but it seems that he cares about the sounds now"*.

4.2 TalkingBox Expansion – Unanticipated interactions

As soon as the TalkingBox became part of Chris's routine, the device caught the attention of other adults with cognitive disabilities in the centre. Some adults approached the table standing or sitting near Chris and looking over his shoulder. In some situations, where Chris was taking too long to find the matching pairs, one of his peers reached out to find the match (Figure 2- left). One minimally verbal participant sitting near Chris mimicked spoken words (*"beach", "skyzone", "chips"*) (Figure 2- right). Mitch offered his assistance to the other curious adults and demonstrated the game for them.

4.3 TalkingBox as a visual probe

Over the following weeks, TalkingBox became a probe for Chris' support network to explore and learn about Chris' strengths and interests. In the day centre Chris would stare at certain signs or objects that were mostly rectangular shapes. His preference for street signs was known to us, however Mitch and his parents did not know to what extent he is able to discriminate colours, shapes or sizes or even levels of detail in the picture, an important skill for graphic symbol communication, especially when translating to universal symbol matching. Chris could discern and match real photographs and familiar objects, yet Mitch was interested in exploring Chris' visual abilities further. In the second iteration we added few extra matching tiles with embedded symbols to represent street signs. To make things a bit more complicated we decided to explore if similar signs can be discriminated and if certain levels of detail can be spotted in the picture tile (Figure 3). In the first week of using newly established cards Chris was not able to match the street sign cards accordingly. If the cards were not properly matched the box would not generate sounds. In the second week Chris was focusing more on the cards to learn to visually discriminate. By the end of week three he was able to correspondingly match all the sign cards that he was not able to do in the first week. It seemed that the weekly practice and the familiarization with the new cards led to successful adoption and appropriate card match up.

4.4 TalkingBox as a social probe

TalkingBox also served as a probe to explore opportunities for interaction between Chris and his peers. At the start of this study, Chris rarely engaged in interaction with other peers. Being a non-speaking individual, initiating interaction with other peers can be challenging. Often, such attempts are carefully scaffolded by

Figure 2: A peer noticed that Chris has a problem finding a matching tile. He reaches out to flip the card and show it to Chris (right) - A peer is sitting next to Chris repeating the activated words

Figure 3: A close up of different RFID cards. Every card is different in this set. Turn left and turn right cards can be easily confused. Similarly, the two tiles with variety of different street signs are hard to discriminate without deep concentration and focus.

Figure 4: transparent box a bridge to a social experience. Chris is placing the cards in the box and Ryan is picking them up and putting in the TalkingBox

support workers at the centre who supervise and provide assistance between the two individuals with severe cognitive disabilities.

Hence, to explore Chris‘s willingness to interact with other peers at the centre, we suggested to use the memory game in concert with one more peer. Unlike Chris, who enjoyed playing the game, Ryan did not express any interest in the game itself, although he was fond of the sounds coming out from the box. Ryan is a person with severe autism and cognitive disability. He also rarely engages with other peers. To meet Ryan's interests we assigned tile cards with his favourite music themes from Disney movies. 10 extra cards were made and added to the existing set. In the first iteration, Chris and Ryan were sitting at the table. Mitch tried to demonstrate how Chris could match the cards and then give them to Ryan to put in the box. However, Chris did not want to give cards to Ryan. To bridge the interaction between Ryan and Chris we put a transparent plastic box into which Chris could put the cards before they were placed in the TalkingBox. To Chris it was more important to meet his idiosyncratic need to put things in the box rather than giving them to Ryan. The transparent box aimed to liaise between Chris‘s and Ryan‘s communicative intent. As a result of placing the transparent box in the middle (Figure 4). Chris would lay the tiles in it, and Ryan would take them from the box, placing them instantly in the slot on the memory game box. Mitch remarked "*he has never seen these two guys playing together*" in such a way.

4.5 TalkingBox as a living portfolio

Finally, TalkingBox became a living portfolio, through which Chris was able to be seen for his strengths by the community, potentially opening new avenues for new technologies. Although the TalkingBox has brought a great deal of enjoyment to certain individuals, it went unnoticed by some support workers and peers in the environment in the first few weeks. Not everyone was present when Chris was using the TalkingBox. For the majority of the other support workers, Chris was an enigma, an anxious and introverted person who at times was hard to engage with. At the beginning of our work, Chris was perceived by many through his easy to spot disoriented gait, a person uneasy with the close presence of others who sits in the corner focused on twitching his fingers. Other support workers would rarely interact and play with Chris, being unable to discern his interests.

The TalkingBox has changed that. Chris' visible enjoyment in using the box and Mitch's assistance throughout the course of the study, together with our efforts, has shifted the perception of people

Figure 5: A manager approaching the table to express his admiration for Chris‘s progress at the same time suggesting to expand our efforts

at the centre. Many were approaching and saying “I didn’t know this, this is cool”. The frontline manager has even organized a staff meeting as a showcase of Chris‘s progress “I think we can do the same with other customers”. In the middle of prototyping phase one of the senior managers was visiting the centre. Upon seeing how Chris uses the box, he suggested to present our design in other day centres run by the same Disability Provider (Figure 5).

Mitch would often send short video excerpts to his parents presenting Chris‘s progress. His parents have found the TalkingBox to be a turning point in their decision to seek further professional and clinical support “*We are considering speech therapy. It seems that he is in a good place now*”.

In week seven, upon deciding to seek clinical support, one speech and one occupational therapist visited the day centre. As part of their assessment Mitch has been invited to have a short meeting. We were present at the main office when Mitch suggested to demonstrate Chris‘s abilities and the TalkingBox project. He invited Chris to come to the office, sit at the big desk and play the game. The speech therapist found this to be interesting, saying that we should leverage on prior progress and set the milestones organizing their intervention around the TalkingBox. They recommended to consider replacing memory card tiles and slowly introducing universal symbols. Rather than just using the real photograph of Chris‘s bed they wanted to print out a card symbol that can represent any bed.

5 DISCUSSION

This case study has shown how TalkingBox, a simple technology to assist communication between a person with severe cognitive disabilities and his peers and support network, has provided opportunities to explore and reveal strengths and interests. This in turn has created opportunities for design, to further personalize the technology and to expand its use to other people with cognitive disabilities. Furthermore, as a probe, TalkingBox provided opportunities to explore strengths as well as interactions with peers. In the end, we have seen how TalkingBox has become a living portfolio that revealed Chris‘s strengths to others.

For other researchers in the area of assistive technology, this case study offers a nuanced description of how we can leverage interest to slowly introduce potential and future learning goals, even in cases when certain individuals have very specific interests [5]. We did not include details on how to create the conditions for identifying strengths that can help start the design after design process [16], or build a relationship with participants conducive to their inclusion as co-designers. Instead, we refer these researchers to the concept of respectful design [17], as an overarching principle, and to frameworks such as co-design beyond words [6]. Working with non-verbal participants can be challenging and this paper provides a brief case study of how we can establish understanding of end-user/s, the context in which they live or spend time and what is the role of certain stakeholders without a need to exclude or decenter the user themselves. We also provide a co-design approach that can balance the interest, interaction, and personalization of the suggested medium fidelity prototype.

In terms of generalization, the focus on strength is not exactly new [5] and is likely to be effective in terms of engagement with many other participants. As tangible technologies augment the modalities of interaction, and particularly support embodiment [2], they are also likely to be an effective approach to continue to explore transition to symbolic communication, and beyond. It was interesting and surprising that the principle of a memory game was attractive to other participants, however we must be cognizant that this interest may have been compounded by other factors such as novelty, interest in engaging with our participant, and interest in interacting with the researcher. However, in the case study we offer a model to generalize the use of the device without generalizing its audience or intent. Although, the TalkingBox was created for Chris it also created opportunities for interaction that can be shared and adopted for others (e.g. Ryan).

Confounding factors have also likely contributed to the engagement of Chris. Novelty and interaction with our researcher could have added to the already entangled qualities of personalization and tangible appeal of the box. As a result, long-term engagement will rely on members of Chris’s support network to continuously renew novelty and interaction. In turn, a continuous renewal of the symbols within TalkingBox will continue to challenge and reveal Chris’s strengths and interest, keeping it alive as a living portfolio.

We think that it is important to move away from the solution-centric perspective often prevalent in work with people with severe disabilities, and instead focus on how we can publicly promote users’ strengths and their agency. Also, we want to highlight that the TalkingBox, as a visual and social probe, is different from the notion of cultural probes used as inspirations for design [11], but more aligned to Soro et al [1] “cross-cultural dialogical probes”, which engage designers and participants together in shared experience of the probe in order to elaborate understanding about its context of use and possibilities. Further, with the TalkingBox we intended to “probe” people‘s collective rather than only their individual understanding and experience. Finally, employing our medium fidelity prototype we present a shift from the TalkingBox as a probe and investigative tool towards a living portfolio, which overall represents a shift in agency, where the same artefact becomes a means for the person with disability to showcase their often undermined strengths and abilities.

For researchers studying communication technologies or Augmentative Alternative Communication (AAC), this case study highlights the value of tangible interactive designs that offer multimodal interaction [13]. It points to resisting the temptation to use or develop sophisticated communication devices that can impose substantial learning demands, and suggests that interaction design instead aim to prioritize peoples‘ specific interests and contextual needs. We found it beneficial to step away from the well tried and well established low-tech approaches that often find limited success in long term use, and also from high-tech screen-based solutions, which come with the accompanying complexity of having to operate a computational device, and instead focus on tangible mid-tech alternatives, as these afford both social use and multimodal interaction. With our study we did not directly target Chris‘s communication competence. The TalkingBox was not developed as a communication device that enables information transmission. Rather, we worked to develop the prototype and the conditions that could potentially open space for a meaningful conversation, mutual learning and practice and adoption of new words and symbols (either photographs or symbols). Coincidentally, Chris even used one RFID assigned card (chips) not only to play the game but to express his intent that he wants this food item for lunch. This subtle request was carefully interpreted by his support worker– "*He stopped for a moment. He was looking at the card and started making this sound that he does when he wants something. Then, I asked him if he wants chips for lunch" (Mitch).*

6 FUTURE WORK

In future, we plan to consider the benefits of extending the TalkingBox prototype, first to enable greater customizability and ease of adding sounds to RFID cards via an app. This will enable control for Chris and Mitch to personalize and extend the repository of images themselves. Second, enabling the TalkingBox to interact with other devices (iPad, Android Tablet) so that, for example, by placing his cards of interest inside the box in sequence to denote a schedule of desired activities for the day, this can then be easily transferred to Mitch‘s phone and subsequently be used outside the community centre for communication (e.g. while shopping for groceries to alleviate Chris‘s anxiety and enhance the choice making activity). Also, this can possibly gradually lead to a bridge for Chris to interact with other digitally based devices.

While our case study to a certain extent enables appropriation beyond the initial game set up, our design insights were still limited to the use of the working prototype, however, we believe that there should be a tendency to orient ourselves, as design researchers, to create good conditions for social innovation [4]. In the community centre, in which this study was conducted, only one support worker was effectively involved in this work. Due to a high turnover in staff (Mitch will likely leave the centre soon), and due to the complexity of the daily life in the centre, it is worth considering the overall social practice and dynamics in the centre. This can significantly improve and create conditions to sustain the community response to the implementation of bespoke technologies.

7 CONCLUSION

Our case study illustrates how tangible interfaces centred on the interests and strengths of people with cognitive disability can serve as a probe to explore and reveal further strengths, and effectively become a proxy for others in the community to perceive these relevant strengths. The tangibility and simplicity of our design has proven not only engaging for Chris, but also for the others in the centre, opening up avenues to explore its value for social interaction, inclusiveness and participation. In our current and future work, we seek to continue to work with Chris and his supporting team. As Chris is now being involved in speech therapy, we see an opportunity to extend our previous design efforts and investigate an interests and strengths-based approach to complement his communication goals.

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