Design after Design to bridge between People with Cognitive or Sensory Impairments and their Proxies

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Abstract
A carer or teacher often plays the role of proxy or spokesperson for a person with an intellectual disability or form of cognitive or sensory impairment. However, simple functioning interactive design prototypes enable people with cognitive or sensory impairments to try out the prototypes and participate in a process of *design in use* or *design after design*. In this paper we examine two cases of design after design. One case involves adults with cognitive or sensory impairments, the other, children identified with language delays and special needs on the Autism spectrum.

Proxies were consulted iteratively during the invention of prototypes, which were then trialled. For the person with cognitive or intellectual impairments, the prototypes enabled concrete expression of likes, dislikes, capabilities, emotional wants and needs and forms of expression that hitherto had not been fostered. Carers and designers were surprised at the ways in which the technology was used and how it fostered new forms of social interaction and expression. We conclude that design after design is an effective approach for engaging people with intellectual disabilities, giving them greater capacity for expression and power in design and offering the potential to expand and deepen their social relationships.

Keywords
Intellectual Disabilities, Autism Spectrum Disorder, Technology Probes, Reflective Agile Iterative Design, Social Networks, Proxy, Design in Use, Design after Design.

Introduction
How can we best undertake collaborative design (Co-design) with people with intellectual and cognitive disabilities? Co-design is both an ethical and pragmatic approach that commits designers to engage with people who will use or be affected by their designs from the outset, in order to prioritise their agency and quality of experience. Co-design relies on partnership in which participants bring essential knowledge of their own context and culture while designers bring technical and design facilitation skills. This creates opportunities for mutual learning and development. When participants have a different cognitive, sensory experience of the world, it is particularly important to engage them fully in the design process, as designers have little experience to see the world from their perspective. This raises the question then of how best to involve them.

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"Does he take sugar?" was the title of a UK Radio 4 series that presented topics on disability until the late 1990s. The title referred to the tendency of people, when identifying someone that seems different, to ask the carer instead of the person themselves about their needs and wants, (Rogers and Marsden, 2013). The assumption is made first that someone else will speak for them and presumably that it is easier to ask the person who might not apparantly have disabilities.

Rogers and Marsden (2013) identify the problem that there is a tendency for researchers to engage in this overlooking of people with disabilities, treating them in a third person sense, by developing technological solutions for "them" based on our understanding of what they need. Researchers also tend to engage in compensatory design, designing to compensate for a deficit, by providing for a lack of something, (sight, memory, access to the internet, the ability to look after oneself etc). While these technologies may well have value, the emphasis is on trying to rectify the person with difference, rather than educating and designing for society to accept mind–body–emotional differences. (Holt et al, 2012) CoDesign has the opportunity to put people with cognitive and intellectual disabilities in the driving seat, so that we can much better understand their needs and aspirations and also how mainstream society might better include and engage them. Even those who cannot answer the "Do You Take Sugar" question might be able to answer if addressed in a different way.

With these concerns in mind, we consider the role of the proxy or carer in subject of designing with people with cognitive and intellectual disabilities. People with cognitive and intellectual disabilities are often supported by close networks of family, carers, support workers, healthcare workers and friends. One recognized way to design with people with cognitive and intellectual disabilities is to involve people in their close networks as proxies, who are used to living with them and can speak about them. But, this approach does come with drawbacks. How do we ensure that the person with intellectual disabilities is being accurately represented and that we are tapping into their own perspective as well as those of their carer network?

We first examine literature on designing with proxies, and *design in use* or *design after design*. We then describe two case studies one involving young adults and one involving children. Each case designed a prototype with proxies and then engaged people with intellectual and cognitive impairments in use and *design after design* (Ehn, 2008).

Prior Literature - Design with Informants and Design with Intellectual Disability

Scaife et al (1997) wrestled with how to include children in a participatory design process for designing new interactive learning environments for teaching ecology. They observed that children may not be able to act as full participants, because while they could give input about what they liked and struggled with, they could not design to teach concepts that they had not yet grasped themselves. Yet it was problematic to only consider them as testers, because in a conventional users-as-testers approach, the onus is entirely on the designers to take on board and translate the users reactions. Designers in this situation may be reluctant to fully reconsider their designs, such that the actual contribution made by users to the redesign of a system/interface is "too little, too late".

Scaife et al (1997) devised an Informant design framework for involving various participants in the design process that aims to maximize their input at different stages of design. It recognized that different informants (teachers, psychologists, children, software designers) had effective contributions to make at different stages of the design process.

Francis, Balbo and Firth (2009) provided three guidelines to work with people with autism and Asperger syndrome. That is, 1) a designer needs to engage with parents or carers as proxies to elicit requirements 2) the method needs to empower parents and carers as mediators to negotiate with autism, and 3) a designer acts as a consultant to enhance the eliciting process rather than hinder the situation. Their focus was thus almost exclusively on effective elicitation from the proxy, which although not the whole story, is nonetheless important.

Holone and Herstad (2013) investigated how to create musicking experiences for children with severe disabilities, typically having a combination of cognitive, sensoric and motoric disabilities. They found patience and extra time is needed. Such children are often in the role of recipient and when placed in the unfamiliar role of decision maker it is important to take things slowly because a lot of time is needed to adjust power relations. They observe that the need for helpers to facilitate communication has potential drawbacks. Because helpers act as two-way filters between the child and the environment, they have a great deal of knowledge and developed their own ways of working with a child and views on what will work and how to work. These views are helpful but can possibly be restrictive.

Iversen and Brodersen (2008) argued that in order to elicit requirements from the perspective of children, it is important to gather user requirements in the geographical and social context of the children in an open-ended study. The lack of an artificially created context will tend to lead to more natural adult-child communication that is part of the social practice, whatever it may be.

Abdullah and Brereton (2012) explored a child-led approach for engaging with children with ASD and intellectual disabilities, drawing upon therapy based methods of Hanen (Pepper and Weitzman, 2004) and Greenspan (Greenspan et al 1998). They emphasized the importance of ensuring engagement at the level of each interactional turn by giving the child the chance to lead, following his or her natural interest in an ordinary setting. This means joining in and playing on the same level as the child, looking into their eyes and waiting for the child to take their turn, with the child using whatever competences they have. Although the child may not be able to conduct a meta level or reflective narrative to discuss an activity that they have undertaken (children with intellectual disabilities and communication impairments are invariably in this position), the child, by their actions in the moment fully contributes to the interaction and expresses choices. It is these actions themselves in the context that guide therapeutic or design interventions. It is the child doing what they do in that situation. Technology prototypes can be used to build on this approach, as explored this paper.

Hourcade proposed four principles to consider when designing technologies for populations with special needs (Alper, Hourcade and Gilutz, 2012): deep engagement, interdisciplinarity, individuality, and practicality. Deep engagement necessitates involving the important people who spend much time with them, their parents, siblings, teachers, special education staff, and therapists. Interdisciplinarity is needed in order to draw upon wider sets of expertise from communication, occupational therapy, developmental psychology, special education, and learning sciences etc. Interactive technologies for children with special needs need to address individual needs and avoid one-size-fits-all approaches. Finally, practical systems are needed that benefit this population rather than focusing upon generating lab results and papers.

In particular we expand upon this need for practicality. Given practical working designs, people with intellectual and cognitive disabilities can engage with them and give feedback. Approaches that use technology probes (Hutchinson et al 2002), rapid technology probes (Güldenpfennig and Fitzpatrick, 2013)), and reflective agile iterative design approaches (RAID) that iteratively evolve working technologies in use (Heyer and Brereton, 2010) are important, because they prioritise actual use and design after design (Ehn, 2008) by the community of need and their networks, which is one of the best ways to ensure engagement and to understand how designs will be adopted into these networks.

Suchman (2002) has argued that rather focusing on the designer/user opposition we should see design as an "entry into the networks of relations that make technical systems possible". Suchman and Jordan (1997) and Ehn(2008) have articulated how design continues in use as people figure out ways of using and adapting technologies to their own purposes. Ehn refers to this as design-after-design. In this paper we pay explicit attention to the process of design-after-design that occurs after introducing simple interactive prototypes to people with cognitive and sensory impairments and children with developmental delays in speech and ASD.

Alper etal (2012) et al also emphasize the importance of fun, to which we return after describing the lessons from our two case studies.

Two case studies are described. The first involves design with a Disability Service Organisation (DSO) to support young adults with intellectual disabilities. The second involved design with school teachers at the special unit of a State School to support children with severe language delays, identified as having Autism Spectrum Disorder.

Both cases involve design after design with the DSO adult service users and the children. Two cases are provided because each enriches the view from the other. The lessons are largely reinforcing but the cases have differences due to the differing contexts, the different design approaches and the differing abilities of the children and the adults. The first case involved a longer iterative consultation in the design but a shorter examination of use, whereas the second case involved a less intense iterative consultation in design, but a six month use trial that allowed longer observation of design after design.

Case Study 1: Developing Services for Adults with Intellectual Disabilities

Overview
The first case describes a project that has engaged university Information Technology (IT) students with an organization that provides services for teenagers and adults with intellectual disabilities. The University has an established collaboration agreement with the service organization in order to provide community service opportunities for students. The service organization in turn welcomes the opportunity to engage students in co-design projects with clients with intellectual disabilities, their *service users*. The project described here ran across two 13 week semesters and involved 2 teams of students. The students designed a computer/mobile application that can support users with disabilities to express the goals that they want to achieve.

Role of the Proxies
The main contact point for students and academic staff and the initiator of the project was a manager of the disability services section of the organization. The manager had a very good understanding of how the families and service users behave during the meeting process for defining their goals, and had a good understanding of the capabilities of the service users. He provided helpful design advice about ease of use, clear and limited numbers of steps in any interaction, and use of colourful content and icons and large buttons.

The manager suggested that service users generally engage a lot more these days with IT devices (mainly tablets), and was keen to have IT students to work on this design project.

The manager organized several on site visits to the organization, which has facilities for teaching life skills and communal activities. This provided the students with an opportunity to regularly meet service users, parents, support workers and lifeskills teachers from education support services. Through these visits and discussions, design intervention ideas emerged. The process of need identification took place, not through workshops with particular activities, but rather through visiting the community centre regularly, observing activities and undertaking discussions with proxies such as the manager, lifeskills teachers and parents as well as with service users. Discussions were often in context, with lifeskills teachers and service users demonstrating what they do, the difficulties they encountered and showing what they enjoyed. Students would observe, ask questions and together design ideas would evolve that were discussed, students receiving feedback on ideas and proposals in context. This context also provided opportunities for testing ongoing prototypes.

Design Intervention
The design intervention aimed to address the need to help service users with intellectual disabilities to express their own goals. When people with intellectual disabilities (service users) and their families come to the support organisation, they have an initial meeting with support workers where in addition to administrative and lifestyle issues, they set a small number of goals. Such a goal might be being able to practice gardening, finding the

courage to order a coffee and sit at a table at a café, or being able to independently take the bus. These goals are reviewed regularly and can provide a sense of achievement when they are met. They also provide the support workers a framework to individualise educational programs for each service user. Presently these goals are mostly discussed with the families of the people with intellectual disabilities, however people with intellectual disabilities themselves too often lack involvement and a strong say in this very important process. Yet, unless someone defines a goal for themselves it can result in reduced motivation to achieve the goal, so there is a strong desire on the part of the service organization to improve this process.

First student team:
The first project involved a team developing a web-based application that would allow the users to express their goals using images pre-defined by the organization and organized in categories.

During prototype testing students collected useful feedback from people with intellectual disabilities using the prototypes; the need for simplicity of the interface; the need for safeguarding against unintentional actions (such as deleting content or leaving the application by accident); the preference for photographs over cartoon images because the users could relate to them better, the preference for pictures of the actual garden of their premises, for example, as opposed to any other garden.

Teachers in the lifestyle skills program at the Organisation also provided a lot of feedback in terms of usability but mostly on functionality, requesting a stronger emphasis on the goal definition phase rather than the goal tracking phase that had been implemented and was still too complex for wider adoption. The manager also reported an increased use of mobile devices. Thus the intial design was identified to be somewhat off the mark through this iterative engagement with the proxies identifying more goal definition and mobile devices as key.

Joining together a need for a simpler interface, an extended choice in the pictures available, and a better way to relate to the pictures, the idea of creating a mobile application where users could create a picture of themselves achieving their goals emerged.

Second student team:

The second student team developed a mobile application to allow a service user with an intellectual disability to "place themselves in the picture", and share the image with their supervisor. The process begins with the user selecting a background image, which is either stored locally on the device, or found on Flickr through the application interface. Once the background image is displayed on the screen, the user is able to press the camera icon to take a photo of themselves, which is then superimposed on the selected background image. The user then has the choice to save the image, email it to their supervisor or share it through media dependent upon the applications within the device.

Figure 1. The aim of the Endeavour Mobile application is to provide an interactive person-centred tool for clients and supporters of the Endeavour Foundation. The application user will be "placing themselves in the picture", so that they can visualise a desired future state, plan towards it, and express themselves in ways previously unavailable.

Design after Design

Although there was a lot of feedback to refine the first student team's prototype, it did not reach a point where it could be used. The second teams prototype of the revised concept reached a design maturity that really allowed the service users to play with it and engage in a process of design after design. When they tried the prototype, the service users took ownership of it and provided new directions for the design. We observed that technology is not a challenge for all individuals with special needs and many are adept at manipulating the interface, being unafraid to explore and try, sometimes in marked contrast to their (often older) support workers who were more reticent.

Within 30-40 minutes the service users could use the application independently and some started to teach their friends how to use it. Throughout this process we observed the user interaction with other users and with the application in order to identify the pros and cons of the design. We also asked the users for feedback, including input into the icon based search functionality planned for the next iteration for categorising common words and images.

A key finding of the prototype testing session was that the users' excitement and motivation for using the application was different than the motivations of the proxies. Once they had the concrete prototype in their hands that they could use, the users immediately emailed their images to parents and friends rather than their supervisors, and several service users independently thought to use the application numerous times

superimposing themselves with their friends and emailing between one another and parents. The student designers and proxies had not imagined that more than one person would be placed in any one picture, or that service users would share their goal images with anyone other than their supervisor.

The student developers themselves were impressed with the success of the application, and were immediately considering additional functionality beyond the scope of the project due to the positive experience which itself created vision of further potential. The capabilities of the people with intellectual disabilities, revealed through their concrete actions with the application, also inspired the student designers and the proxies in the service organization.

Summary of Case Study 1

This case study showed that while the proxies are good at expressing initial requirements, setting realistic limits of what can be achieved, and imagining some possibilities, a design grows in many and sometimes unexpected ways once in use. Service users through concrete actions can participate well in using prototypes, using them creatively and in unimagined ways, and not using them if they are off the mark. This process of design after design was an effective way for service users to participate and express themselves and their design wants and needs.

In design after design, the service users indicated the desire for a social communication platform and a fun game, more than envisaged in the mere initial goal setting framework. Additionally, the proxies (the manager but also the teachers) had not expected such a rapid adoption of the application, and the mutual support by the service users to learn to use it. It is however important to highlight that the proxy played an essential role in initiating the project, as the users would not have been able to express the need for it themselves.

Case Study 2: Supporting Communication between Home and School for Children with Autism Spectrum Disorder (ASD) and Language Delays

Overview
The second case describes some key findings from the design and trial of the MyCalendar iPad application. The application was co-designed by a research team, school teachers and one parent/researcher. It supports children with ASD and language delays to communicate across the settings of home and school through photos and videos taken by themselves, their parents/carers or teachers.

Role of the Proxies
The proxies in this case are teachers from the special education unit at a primary school and one researcher/parent of a child with ASD and language delays. We refer to them as the proxy team. It is often the case that researchers in the area of intellectual disability have a family member with an intellectual disability and this is the case for one member of this research team. The researcher's child had left the school by the time the MyCalendar app was completed and was not part of the school trial.

The proxy team and the research team undertook a contextual interview and discussion in a special education unit classroom of the primary school. The teachers stated that there are many applications and interventions that aim to teach kids with ASD specific skills, but few that explore how to support their communication across settings using everyday technologies. They observed that the children with ASD and language delays all loved photos and videos and were usually capable of taking photos and videos on an iPad. Based upon these discussions, the idea of an audio-visual calendar app to support communication between home and school arose (Figures 2 and 3). The design concept formed quite quickly due to extensive experience of teachers in taking and using photos in class and iPad use, the parent researchers experience of iPad use, and the felt need to improve home-school communication. These key elements drove the design.

The research team returned to the school twice to discuss the interaction design of the concept, showing printouts of each screen that was envisaged and discussing and refining it with the teacher proxies. Once the design was deployed in a six month trial, one researcher visited the school each week to back up the iPad minis and resolve any problems. Each parent was interviewed separately about use during the trial. In addition, two evening meetings were held with the parents and teachers to discuss how the app was being used. The research team did not have any active discussion with the children themselves.

Design intervention

The purpose of the photo calendar is to support communication between child, teacher and parent and to track a child's development over time. The calendar was envisaged as a place for both teacher and parent to leave notes about the child. Photos would help the child and parent communicate and reflect over time.
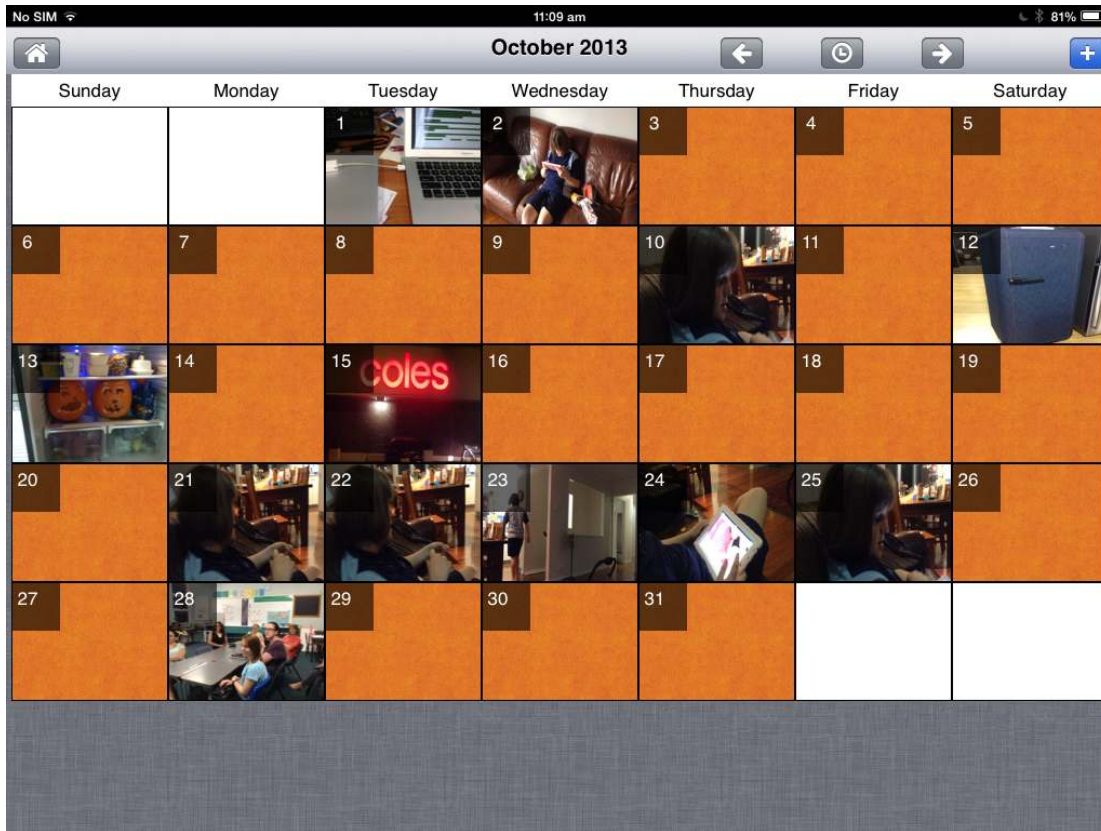
Figure 2 The MyCalendar app designed for the iPad or IPad mini

The app had four interrelated goals:
1. to support children with limited verbal skills to communicate what happened at school with the parent and what happened at home with the teacher.
2. to help parents/carers and teachers to understand how the child participates in the other environment.
3. to take a child centred approach by focusing on the child's interests, because this would encourage the child's communication,
4. To keep a record of the child's development over time and support discussion between parent and teacher of the skills to focus on in each child's Individualised Education Plan.

A minimal viable photo and video calendar application was prototyped for the iPad as seen in Figures 2 and 3. The app allowed users (the child, their teacher and parents/carers) to take photos and videos and put them into the relevant day of a calendar. Notes could be added to the photo and videos entries and they could be tagged with relevant skills that the children were developing as part of their Individualized Education Plan.

Ten families participated in a 6 month trial of the calendar app that had run for twenty-two weeks at the time of writing. Children were selected by the Special Education teachers to participate if they had ASD and language delays and were in Years Prep to

Year 2 of the Australian primary school system, aged between 5 and 7 years old. Each participating child was given an iPad mini.
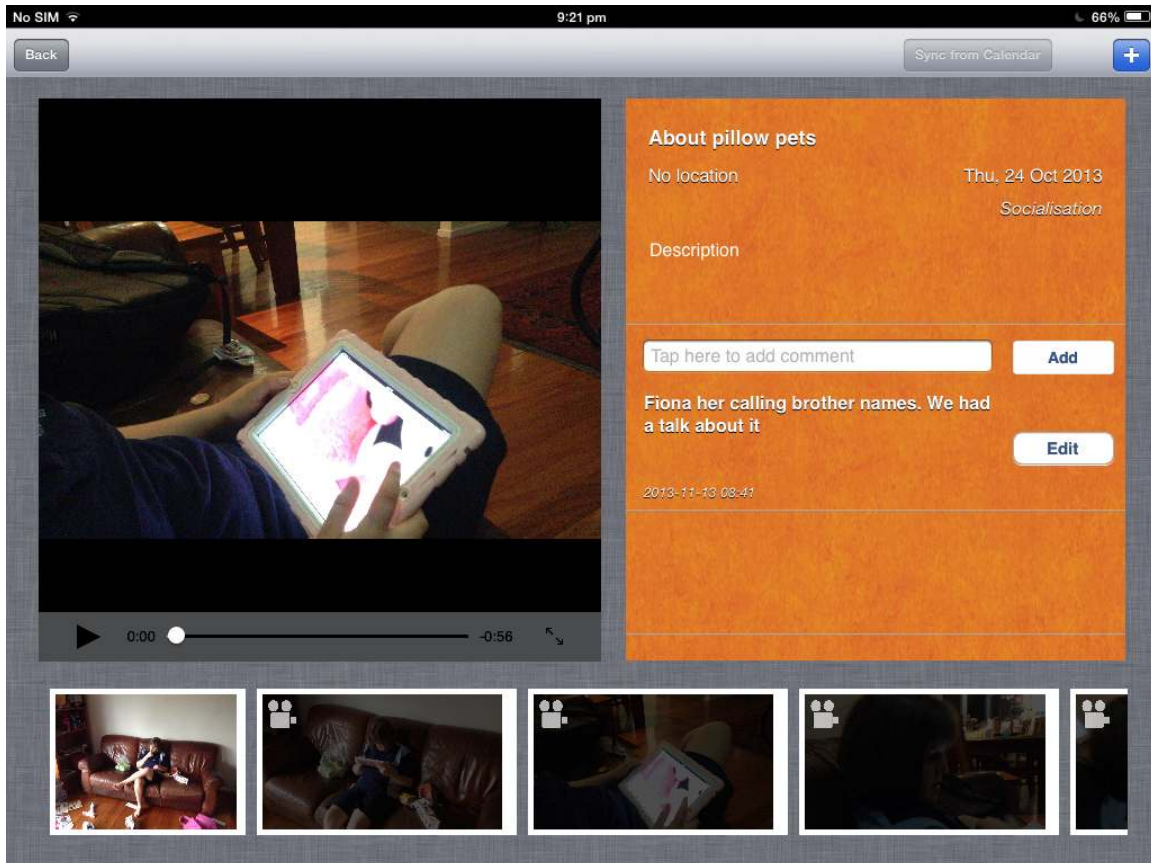

Figure 3 A day view in the MyCalendar app, showing photos and videos for that day

Design after Design
In total, 4 teachers and 10 families with 11 children participated, one family having twins both with ASD and language delays. The duration of the study so far has been over two terms, including the six week summer holiday. The participants have taken 1434 photos and 220 videos in total over Term 4, 2013 and Term 1, 2014, which on average amounts to seven photos and one video per week per family. Almost all families want to continue with the trial and the teachers wish to extend the trial to other students.

Several aspects of use emerged in design after design that we did not anticipate. Almost all of these uses related to mobilizing of different networks of relations than had been previously imagined.

The initial discussion with teachers and parent envisaged the iPad calendar app as a way principally to support the parent–child–teacher relationship. However, once the teachers saw the app, they saw it as a way to intervene in the class dynamics and incorporated the

calendar into daily class activities. The MyCalendar became used for show and tell, either by projecting each child's photos on the large classroom screen to support language and sharing (Figures 4 and 5), or by having the child sit in the presenter seat of the circle and show their iPad to the others.

Figure 4 MyCalendar pictures from home are shown on the classroom screen so that a child can share with classmates during daily show and tell.

The effect of this sharing then led to a second kind of interaction, children talking in simple language to other children and to their parents about content they had seen in the MyCalendar. At a focus group to discuss the MyCalendar App one teacher reported that "friendships have blossomed because the children have seen who's got different toys at home and each child's special interests have come out. Luke now wants to go to Hailey's house to see her My Little Ponies. So that's making the kids interact as well" Luke's Mum chimed in "He's been saying to Hailey's Mum, I want to come and see your ponies. He's been saying to me I want to go to Hailey's house to see her ponies." (Figure 6)

	Conversation between teacher and Adam:
	Teacher: What's happening here Adam? Adam: Buying shoes Teacher: Do you feel very happy and proud of buying shoes? Adam: Yes
	Conversation between teacher and David: Teacher: What is happening here? David: Lily. Teacher: Who's that? David: Lily and Charlie. Teacher: Who else? David: Roberto. Teacher: Where are you? David: Swing Teacher: Are you happy with your friend? David: Yes

Figure 5 Conversations between teacher and children with language delays that are supported through the photos and videos
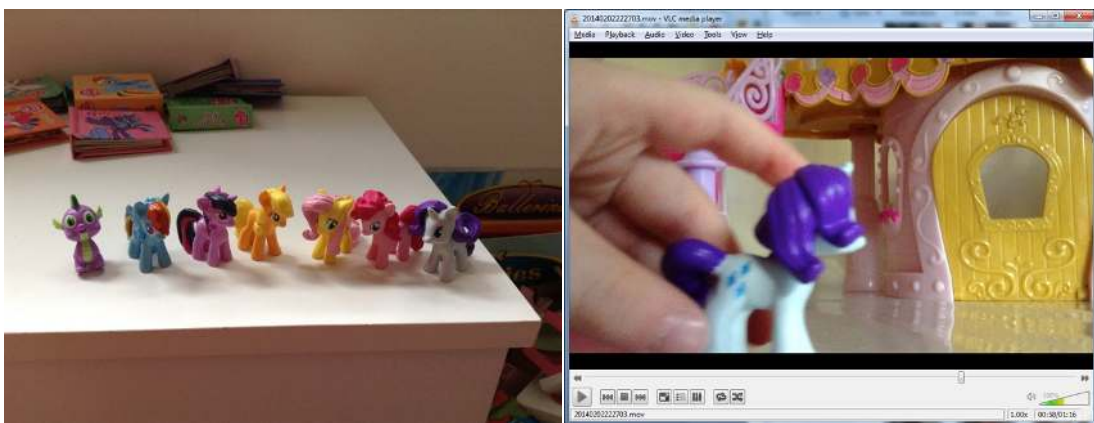

Figure 6 The photo and video calendar has enabled children to communicate their special interests to friends leading to requests for playdates. One child recorded a video and photos of her "My little ponies" in action.

A third kind of interaction revealed was the way in which parents used the calendar app photos to prepare their children for a future activity and reduce their anxiety approaching the activity. Two parents in the iPad study had photograph entries of their children having haircuts, each on two occasions. In each case the parent reported that they had used the photo of their child having the first cut as a preparation for the second haircut to refamiliarise them with the experience, and to reduce their anxiety about going, making them calmer and better behaved.

A fourth and related interaction was the way that parents showed and shared videos of their own children with other parents where they felt that their children were modeling good behavior that might be helpful to another parent. One parent reported her child being very anxious about swimming, leading to much screaming. When the child did swim, the mother took a video and uploaded it to MyCalendar. The child repeatedly plays this video of himself swimming successfully. The mother then shared the video with another parent whose child also had anxiety about swimming, so that she could model a classmate's behavior.

A parent of the twins with ASD and language delays, reported that one of her sons had very little language and was much less verbal than the other and that as a consequence he received less attention. The mother developed a daily routine after dinner of talking through what they had done at school and home with the photos/videos on the each of their iPads. Her less verbal son became very excited each evening at the opportunity to have the focus on him and his day. It made her realize how important this interaction was for him, because it gave him a chance to express himself in ways that he had not been able to before.

The iPad app also brought teacher and parent disagreements into focus. Parents often seek academic goals of reading and writing for their primary school age children, whereas teachers often aim to focus upon supporting the children to socialize, sit still, maintain attention and interact successfully within social situations and within a school environment.

Design after design saw parents, children and teachers appropriate the iPad application into new forms of use. Only one child was active in taking their own videos and photos. At their stage of development this was largely done by parents and teachers. However, photos were largely taken of activities that children enjoyed, with emphasis by the school on positive interaction. Children engaged with photos and activities they enjoyed and expressed desires for communication and play around these photos. Design revisions identified have been to facilitate audio note taking as well as written notes, to make it easier to comment on activities. Children can now indicate smiling faces on media that they like. In addition design revisions to promote sharing between children and extending the concept to making stories with images have emerged.
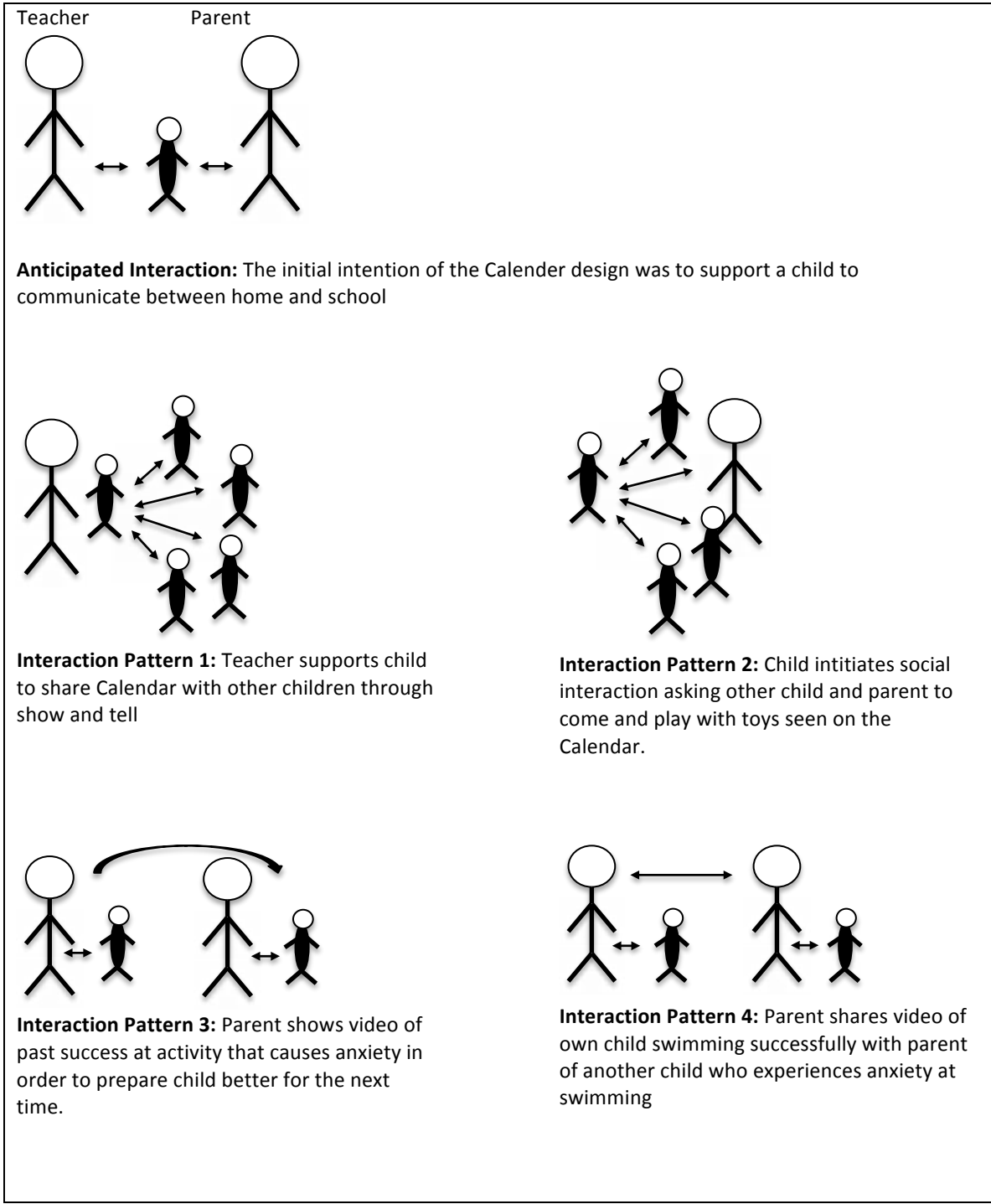
Teacher   Parent

Anticipated Interaction: The initial intention of the Calender design was to support a child to communicate between home and school

Interaction Pattern 1: Teacher supports child to share Calendar with other children through show and tell

Interaction Pattern 2: Child intitiates social interaction asking other child and parent to come and play with toys seen on the Calendar.

Interaction Pattern 3: Parent shows video of past success at activity that causes anxiety in order to prepare child better for the next time.

Interaction Pattern 4: Parent shares video of own child swimming successfully with parent of another child who experiences anxiety at swimming

Figure 7: Several different kinds of social relationships were engaged in with the technology in addition to those originally envisaged by the designers and proxies.

Summary of Case Study 2
The key findings in relation to proxy involvement are that once the MyCalendar app was put into use, it was used in a very different ways and to support many different kinds of social relations than had initially been envisaged by the proxies, as illustrated in Figure 7. The proxies had the germ of a good idea, but the idea was enriched and expanded in many ways once the simple prototype entered use.

The app also gave children a voice. It is difficult to engage prep to year 2 children with ASD and language delays in design. But, by seeing which videos and photos they look at and choose for show and tell, the children are able to direct interaction to their preferred topics. Through their engagement children expressed the desire for playdates, the desire to be able to communicate at dinner, favourite videos and so on.

Discussion
The two case study projects both revealed that once simple prototypes are put into the hands of children and adults with cognitive and sensory impairments, design after design begins. With a simple and concrete prototype, people with cognitive and sensory impariments, who may be less able to express abstract concepts, are able to show, share and interact. This gives designers important feedback about their intentions and capabilities, expressed through their interactions with technologies in their network of social relations. Invariably, the people they choose to interact with are their friends. Children used the Calendar app as a way to engage with other children. Parents used it as a way to engage with other parents. Teachers shifted their classroom practices to use the Calendar app to support sharing among children. Adults and teens with intellectual disabilities used the "Put yourself in the picture" app to make shared pictures with their friends and to email them to their friends and parents.

Carers, parents, teachers, service organization workers and therapists are all an important part of the network of social relations for people with cognitive and sensory impairments. They facilitate and advise on design in many ways. However, they typically and understandably express their own objectives, often in the context of their role as a carer or service provider. These objectives are different (although related) to those expressed by the people with cognitive and sensory impairments themselves through their interactions with technology.

When using proxies and informants to inform design, Scaife et als (1997) framework still has validity. However we would build on it and adapt it in five ways.

1.Today it is easy enough to design interactive and working prototypes. It is important to engage people with cognitive and sensory impairments with concrete prototypes as early as possible, so that they can give feedback through their interest, opinions and actions.

2. Feedback is not only about content and individual interaction with the device, it is increasingly about aspects of social engagement and social relations, particularly for people with cognitive and intellectual disabilities.

3. Proxies provide a useful and important perspective, often through the lens of their support role. However, the person with cognitive and sensory impairments may express a different view when the technology and social situation allows them to express it concretely. Working prototypes allowed many forms of appropriation, expression and new kinds of social interaction by the people with cognitive and sensory impairments. Working prototypes have become a key part of design approaches that view engagement, reciprocity and design in use as foundations for research over and above approaches that emphasize prior observation and ethnographic research (Brereton et al 2014).

4. The proxy is not only an informant. They are part of the social network that needs to be designed for and with. Design has potential to allow them to shift their perspective of people with cognitive and intellectual impairments and delays, what these people are capable of and how they will relate to them in the future, because new designs provide new avenues for expression. The appropriation of designs after design was critical because it showed capabilities and imaginations of the people with cognitive and sensory impairments in IT use that often surprised their carers. In both cases the visual interface and other affordances of the design allowed this expression to take place. In the MyCalendar App, children often returned to their favourite pictures and they could show their interests through the pictures, allowing them to direct the conversation. The new powers of expression enabled in the children in turn changed the actions of the proxy. This emergs in design after design.

5. Social inclusion with peers, friendship and fun are very important to people with intellectual and cognitive impairments, and these aspects tend to be overlooked by proxies. Through design after design, we realized the importance of the designs enabling sharing with peers. Our next prototypes will allow an even greater capability for users with cognitive and sensory impairments to be able to share in fun ways with their peers.

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