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Challenges and Opportunities in Using Augmentative and Alternative Communication (AAC) Technologies

Design Considerations for Adults with Severe Disabilities

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ABSTRACT

There is a growing body of research that demonstrates the value of augmentative and alternative communication (AAC) technologies for children and adults with complex communication needs. Despite these advancements, we have found that adults with severe intellectual disabilities and their families still face many challenges when learning about and using traditional AAC technologies. The majority of adult individuals with severe disabilities in our study have prior experiences with using various AAC devices, yet a high rate of abandonment is noted. Under such circumstances and in order to support more effective design and increased use of AAC, it is important to look beyond the interaction with dedicated AAC devices, and gain a better understanding of AAC use, practices and care support. In a six-month study that comprised participating in speech therapy sessions and working together with families, support workers and adults with severe disabilities, we lay out the foundations for a design framework that needs to consider a) current AAC cultural status b) modelling of AAC use c) creation of AAC user-friendly environments and d) personalization of AAC dedicated devices and the potential for AAC tangible (mid-tech) alternatives. We conclude with implications for design.

CCS CONCEPTS

- Human-centered computing~Empirical studies in HCI
- Social and professional topics~Assistive technologies

KEYWORDS

Augmentative Alternative Technologies (AAC); Adults with Severe Disabilities; Tangible Technologies

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1 INTRODUCTION

Children and adults with disabilities who have complex communication needs are an intended user group for Augmentative Alternative Communication (AAC) technologies. AAC broadly refers to methods that supplement or replace speech or writing. Common AAC technologies include low-tech methods like Picture Exchange Communication System (PECS) as well as high-tech solutions, like the app Proloquo2Go (figure 1-right) that allows people to communicate by selecting images on their tablet computer, which in turn generates a speech output. Such AAC options are often found to be effective as they enable children and adults to communicate their needs and desires [17,14]. Innovations in the AAC field have also provided an opportunity for people with disabilities to participate in different social activities, thus affecting their overall quality of life [17].

Despite the potential benefits of AAC technologies, there appears to be a high rate of AAC non-use and abandonment, particularly amongst people with severe disabilities [33,18]. Challenges for adults with severe disabilities are seen on the level of AAC uptake that utilizes traditional AAC technologies such as grid matrix interactive displays in contrived environments and with decontextualized AAC symbols [17]. Furthermore, current assistive technology (AT) market opportunities are diminished as the manufacturers “face significant challenges with the development, funding, and support of assistive technologies for those with the most severe disabilities” [18]. Investigating current AAC technology solutions and designing novel AAC tools for and with adults with severe disabilities is complex and demands an in-depth study to understand the current use and the status of existing AAC technologies. Thus, there is a need for a combined effort (of researchers, designers, AAC researchers and clinicians) to work on developing better designs and more successful strategies for AAC [44].

The present study aims to address these challenges by examining current practices of AAC use and how they relate to opportunities for design with adult AAC end-users and their families. We present the outcomes of a six-month qualitative study exploring AAC use from the outset of engagement between speech therapists (ST), adults with severe disabilities, their families, and support workers. We explore the main issues with which the adults with severe disabilities and their proxies are confronted when using AAC technologies. In this paper, we present our results according to four central and emerging themes a) AAC cultural status b) AAC modelling strategies c) importance of AAC user-friendly environments and d) personalization of AAC devices. Based on our findings, we propose three design considerations 1) formation of AAC publics 2) designing systems targeting capacity enhancement and 3) turning to the design of tangible or mid-tech AAC solutions and personalization of AAC devices. With this work, we intend to contribute a better understanding of the current status and use of AAC technologies, and new design avenues for future design research with adults with severe disabilities.

2 RELATED WORK

Augmentative and Alternative Communication (AAC) is a specialist area of research that brings together different researchers such as speech therapists, behavioural clinicians and rehabilitation experts [32, p.205]. In practice, AAC devices are mainly delivered with assistance from speech therapists. The learning cycle of using AAC technologies never stops, however, it is expected that families and their children will essentially take over and independently grow their use of AAC technologies.

Unlike unaided AAC approaches (manual signs, gestures), aided AAC use includes various materials or equipment (communication boards, photographs or iPad apps - figure 1) [7]. Recent technology innovations have allowed for the AAC field to build on this progress by developing a number of AAC devices that are user-friendly, stimulus provoking and have greater functionality [17]. High-tech AAC options such as the one in figure 1 (Proloquo2Go®- right) are widely accepted and based on traditional grid matrix displays. On the other hand, recent attempts to improve these interactive displays and provide support for beginner communicators has led to a rise of apps that are now based on Visual-Scene Displays (Snap Scene®). Visual Scene Displays (VSD) are interactive displays that offer real-world scenes capturing meaningful events from peoples' lives in the form of a photograph [29] or videos [35]. Other solutions embrace mid-tech AAC devices that leave space for users to interact, having embedded sounds and reduced complexity of operational demands (e.g. GoTalk 9+®). Low-tech AAC approaches are the most rudimentary forms of AAC encapsulating the traditional tangible methods (e.g. communication boards, Picture Exchange Communication System – PECS etc.). The whole range of AAC devices offers opportunities for people with complex communication needs to develop linguistic, operational, strategic and social competences [32, p.11].

At present, the AAC research field is faced with many barriers. Successful adoption and use of low-, mid- and high-tech AAC

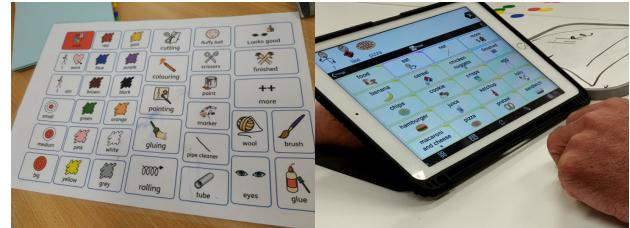


Figure 1. Example of low-tech Communication Board (left) and high-tech Proloquo2Go application by © Assistive Ware

systems pose many challenges for different users. Research demonstrates that for some individuals, representing an action with graphic symbols might present a barrier to effective communication [30]. Programming AAC vocabulary is a core activity of many systems, yet parents and their children face many challenges in getting the right words or synchronizing vocabulary with certain meaningful events [21]. It might also be time consuming and difficult for parents and children to constantly engage in reprogramming the devices. Programming some of these devices might be hard and complex [22], which potentially leaves children and adults feeling ineffectual and worn-out. AAC intervention research is in need of more robust and rigorous studies that will contribute to building a large repository of evidence-based strategies [25]. Many of the strategies are still focused on contexts away from potential daily use, leading people with disabilities and their families to struggle with using AAC devices [16]. The AAC field is thus in need of Human-Computer Interaction (HCI) research to understand and articulate the needs of people with complex communication needs, and to find a good fit between the technology and people [15]. Light & McNaughton [16] remind us that we need to look for ways to extend existing AAC research and services and "embrace a more holistic view in order to maximize outcomes for individuals with complex communication needs". If we can enable these designs to respond to peoples' particular needs, we can facilitate more effective communication [37].

To address the high rate of abandonment, a number of AAC researchers are now looking more closely at aspects of its wider use in different contexts [17]. One possible avenue for research might examine the diversity of users, such as in the case of people with severe disabilities. Design research conducted with adults with severe disabilities might bring the change that can benefit a wider public of users, making AAC technologies more user-friendly, effective and less operationally and cognitively demanding [13].

Design and AAC

In his book *Design Meets Disability*, Pullin [9] identifies some pressing design issues and proposes a shift to an interdisciplinary approach that addresses less prevailing design topics such as fashion, simplicity, agency, expression, and how people with disabilities feel about and experience different designs. Following these footsteps, some researchers have responded by

incorporating AAC solutions that offer strategies and additional features for AAC interactive displays by integrating how the users



Figure 2. Pragmatic Dynamic Organization Display (PODD) - (left) and broken iPad case (right)

(for example, people with Amyotrophic Lateral Sclerosis) can alter expressivity in their synthetic voice [1]. Other researchers are searching for solutions to make AAC devices “context aware”. In a study by Kane et al. [39] the AAC system developed adapts to its users by recognizing their current location and conversational partners and in turn responds by making vocabulary alterations aligned with these contexts. Similarly, McKillop [6] deploys a context aware keyboard that adapts to user’s current location, providing corresponding phrases to its user.

Recent work by Ibrahim et al. [38] points to a need to understand children’s communication needs and AAC design. They look at the specifics of AAC communication in a context where children with severe speech impairments communicate daily needs to their peers or teachers. The team stresses a need to replace the sender-receiver model, and instead, look at a situated model of communication. Their view adopts a new framework, shifting emphasis beyond the sole focus on AAC displays and a child’s capability to use these devices. They draw our attention to other concerns, for example, how technology can assist children to better express their needs through alternative communication modes (e.g. gestures, pointing).

Despite these advancements, there have still only been rare attempts to search for more evidence of why people abandon AAC use. It is particularly important to examine these reasons in the context of supporting adults with severe disabilities. Adults with severe disabilities may in some cases “end up in their final school year without effective communication strategies or access to conventional communication modes” [45] which can in turn lessen opportunities to offer already existing and new AAC technologies. It is rare to find studies about people with disabilities and their AAC use that takes the research beyond the narrow focus on interactions with an AAC device. Thus, looking at the contextual use, family and support workers’ knowledge, and attitudes and other environmental factors that can impede or support AAC use is highly relevant in progressing design for adults with disabilities.

3 STUDY CONTEXT

The present study was conducted in the midst of policy changes at a national level. The National Disability Insurance Scheme (NDIS), which has been rolled out throughout Australia, offers a new funding policy to support people with disabilities in the age range from 18-65. The NDIS has been the most significant social wellbeing reform since the introduction of Medicare [31]. This has changed the status of families of people with disabilities by shifting the scheme from block- to individualized-funding [42].

The NDIS newly established act is based on the foundational premise that people with disabilities and their families have the right to make their own decisions beyond the influence of service agencies in shaping their opinion [2]. Under this new arrangement, families of people with severe disabilities can seek professional assistance that spans different clinical support (physiotherapist, occupational therapist and speech therapist). The frequency and type of professional support is decided together with the families, adults with disabilities, and specifically assigned local support coordinators.

The day centre in which this study was conducted has between 30-35 clients who visit the centre in the period from 9am-2pm Monday to Friday. Predominantly, their clients are younger individuals with disabilities in the age range of 19-35. A minority of clients (10-15%) are adults with severe disabilities. Out of the total number of clients, almost a third of the clients are non- or minimally-verbal.

The present study is based on a 6-month field work focusing on care and speech therapy practices. We joined our efforts with a day centre for adults with intellectual disabilities, run by a large Disability Service Organization (DSO). The day centre is a community-based centre that offers learning and life skills development, community participation, health improvement activities, and technology supported activities. On a weekly basis there are approximately 15 support workers (including volunteers) and a site manager (frontline manager), responsible for the delivery of person-centred support and learning opportunities. The professional background of support workers is diverse – experience in disability work fluctuates (from 6 months to 10 years) and few support workers have vocational qualifications in human services (e.g. social work). Their roles differ in accordance to their skills and experience. This service delivery function is supported by enabling functions of the organisation, including Service Design, with a focus on learning, technology, work and community engagement. A certain number of support workers facilitate group workshop activities (AUSLAN workshop, photography class, bus outing, art and crafts, road safety etc.), whereas others are focused on more individual work as personal attendants (popularly known as one-on-one workers), providing persons’ with severe intellectual disabilities assistance with daily basic needs and public access. The centre tries to meet the needs of all their clients, sometimes being left to handle complex cases without additional professional assistance from speech, occupational, and behavioural therapists.

This paper is based on field work with four individuals with severe disabilities who were in the process of acquiring professional and clinical support when we began our field work. In section 5.1 we present results from the interviews and field observations with four families of adults with severe disabilities. Later, only two cases are chosen as only these families decided to seek professional assistance (speech therapy support).

Participants

Our work was initially focused on four families of people with severe disabilities (Mary, Alex, Jack & Jeff), recruited via an opportunistic sample strategy and with the assistance of the day centre’s site manager [28, p.245]. However, only two out of the

four families decided to receive professional speech therapy support. Thus, throughout the paper the focus is mainly on these two families. Two adults with disabilities, Alex and Mary (pseudonyms) are 29 year-old and 38 year-old clients. The two adults have challenging behaviours (pica eating disorders and occasional inappropriate confrontational behaviours). They receive similar levels of support with regards to basic needs of toileting, eating and dressing. Mary is minimally verbal using about 10-15 intelligible words daily and sometimes repeating words she has just heard (echolalia). Mary uses pointing strategies to reach for preferred objects or activities. She becomes anxious and agitated by certain sounds and loud environments. In turn, she can react by grabbing people nearby. Her gait is aided and she needs support during longer walks. Her balance and coordination are sometimes disrupted by her attention to different objects in the environment which can lead to sudden falls. Alex is non-verbal with no intelligible oral speech. He can use 5 to 6 signs with both hands to request food or other items in the environment. He also heavily relies on pointing strategies and a few recognizable utterances to express satisfaction and dissatisfaction. On a day to day basis Alex's and Mary's communication is mainly directed towards adult's interlocutors (their support workers and family members). We have rarely witnessed these two adults interacting with other peers in the environment.

4 METHOD & ANALYSIS

To gain an understanding of the daily challenges and opportunities, we conducted observations in the day centre and at family homes. Interviews were an additional method of inquiry and they were conducted prior to the speech therapy sessions with four families of adults with severe disabilities. We conducted different types of interviews adapted to different circumstances. In the day centre these were mainly observations, recording short videos and conducting contextual interviews [40] of no more than 30 minutes duration. Support workers are busy during the day and therefore most interviews with them were undertaken during transportation (public outings) or occasionally during their breaks. Informal talks were also part of our data collection method and they were noted usually by writing down short statements or reminders in-situ (on the phone or in the notebook). Interviews with families were conducted both at homes and in the day centre. Usually this would be done with only one family member present and in one case with multiple family members present. The interview touched upon their daily challenges, and amongst other topics, their communication challenges. As part of their NDIS plan, both families had 10 hours allocated to speech therapy sessions per year. They had been implemented fortnightly over a five month duration, with each session lasting for one hour. We were present during all of the one-hour sessions, and when we had the opportunity, we would stay 30 minutes longer to conduct post-reflective interviews with the speech therapists. After a few sessions, we would invite parents to reflect on the progress, and involve support workers in post-reflective interview sessions as well.

Our analysis followed a qualitative thematic analysis approach [46,47]. It was based on inductive and iterative coding, beginning with our observation and initial interviews. After every interview or informal conversation, we would go back to the field and discuss certain inconsistencies exploring new and emerging themes. Data analysis and the results of our interviews guided our further data collection and created new themes for exploration. As we were new to AAC technologies, we had analysed our data together with the literature, ensuring that we were sensitive to the context of the study [19]. As the literature in HCI and design studies lacks studies on this specific topic, we mainly informed our research by engaging with literature from other communities (e.g. Augmentative and Alternative Communication Journal). We collaboratively discussed our results amongst team members making sure that all team members are up to date on current developments.

5 FINDINGS

In this section, we present the emerging themes as the result of the six-month field engagement: the cultural status of AAC technologies, modelling AAC use, scaffolding AAC-friendly environments, and personalization.

5.1 Cultural Support for AAC Use

Inspired by the typology of Bourdieu's formulation of capital [34] we draw attention to the cultural resources of families and support workers to support successful AAC uptake. We also reflect a current AAC status within the system of social relations.

Prior to the outset of speech therapy sessions, interviewed parents had already been familiar with the AAC devices. Upon our first visits, every family had catalogued a number of low and high-tech solutions over the course of their children's school education. The AAC devices were kept at locations that were not accessible or exposed, exhibiting signs of long-term abandonment. The low-tech versions of AAC such as Picture Exchange Communication System (PECS) or Pragmatic Organization Dynamic Display (PODD), and in one family the high-tech option Proloquo2Go (P2Go), were presented to us as *archival artefacts* inciting stories of previous uptake failures and dislikes by their children (figure 2).

"He used to use PECS, he used to be very good at it...He had health issues...we think that he lost some functions. We tried PECS, PODD and P2G0." (Mother 1- M1)

"He was made by them (high school teachers) to use it. He didn't like it and I don't know why. I think he sees this as a burden of communication" (M2)

"He (Jack) was good at using P2Go. At school he would use it but at home he was not interested in using it. He is not interested in talking. But we can't use P2Go...He can't use iPads anymore. There were five and he's broken them."(Father 1 - F1) **fig 2.** (right)

Malcom's (support worker) opinion towards Jack's likeability of the P2Go app was contested by a support worker who described the use of the app as means to reach more desired content. The

alluring elements of other apps on the iPad were *interfering* with the consistency of the P2Go app use, resulting in successive distractions to its uptake.

"For him I think that iPad was not his speech device, it was just his way to get access to YouTube on the iPad. When asked to use it he would usually exit out and look for YouTube. If he was asked to stay on the screen he would excessively look for the music icon and that was all" (Support worker 1 – SW1).

For one parent, the communication development and AAC technologies were *reminiscent* of his own previous history of communication challenges. As a result, he was wary of the technologies and of having a large network of potential communication partners, while at the same time acknowledging that in the long run this was going to be necessary.

"Pretty much I am the only one who understands her. I've been around for 38 years and she doesn't even need to say a thing. I read between the lines; But you are not always going to be there. I had that sort of focus on just me and Mary as one unit. I think all parents of people with disabilities...it's a safety thing for you. You know what they are talking about so it doesn't matter what anyone else does but I learned that it's not right. She is going to struggle if I am not here. She needs to able to communicate to a lots of other people, best she can. (F2)

For the other three families the AAC was reminiscent of the accumulated negative experiences where previous professional support was referred to as problematic and at times inadequate.

"We went to see this very, very, very famous speech pathologist. Long time ago when it was 90 dollars, but I didn't mind...She tried many times....and after a while she didn't want to work with him" (M2)

"This might sound like an arrogant thing to say, but after all these years with the speech pathologists I think I can do it better than anyone else" (M1)

The AAC development and proliferation of the existing market devices was for many an unknown factor. Both families and staff had been unfamiliar with the current advancements, which left many to wonder what more can be done. It was also unclear to what extent communicative progress can be made, which in the words of three parents and two support workers was a stumbling block to AAC use.

"You don't know what to expect at this point. For 30 years it didn't happen, who can guarantee me that now. If you look at his personality and disability... I do not expect much. I would like to think it's possible" (M2)

"I think many believed he can't make it. I was also suspicious. There was this thing when you are older... if you can still learn" (SW2).

For two families, confidence in using the AAC device was predicated on prior history and confidence in technology use. One mother was anxious by the pressuring demands of the general iPad use, seeking assistance to program the device. The other

family was also dependent on previous technology experience. They were exposed to new devices and new software explicating some concerns on how to handle it. The other two families were more inclined towards the current technological trends, but not informed about the AAC existing market offers.

Often, AAC technologies are presented as a "magic wand exit strategy" targeting complex communication needs by "giving voice to the voiceless". They are advertised as such [27, p.2] and related research with families of children with disabilities demonstrates a certain disposition towards the expectations of parents hoping to leverage on the human communicative potential. Although this might be the case with younger children and families who are getting more exposed to AAC market opportunities and thus have higher hopes and expectations, we found that in cases of adults with severe disabilities many families were more subdued in their expectations. Perhaps, it is difficult to say how realistic or unrealistic these expectations were, however, in some cases it seemed that parents were not sharing the excitement of the potential AAC progress as much as our team who believed that it might be beneficial.

"I would like to think that will come. I'm happy to go with it and let the speech therapist to decide it. At the moment I'm the only one who understands her. But basically, I just want to have a bit more communication, whether it's a signal like signs and speech. Put it this way. I don't see as a deterrent...Saying that I'd like her to touch that and say "I want...", if that is possible. It may not be" (F2)

As much as the intrinsic factors shaped the social and material status of the AAC technologies, such as interest of adults in AAC devices or their family values and attitude towards AAC, extrinsic factors were equally important. When asked about the other limiting factors to AAC use, one support worker singled out *system-led expectations* and how the bar needs to be raised within the system of supports. For the support worker and his decade long experience of working with adults with severe disabilities, we summarize his opinion as follows:

"It's in general, how the system works and where the money has been put. It's the government as well. They are putting a lot of money into younger guys. They want them in the workforce. I am not very sure about how this thing works but it's all probably about how you can access the capacity building and funding, working with people like Brianna or John (pseudonyms). When you build that capacity, they can go out and work in the community, which is good. But to access that funding the companies (service agencies) are more inclined towards younger ones, more functional people." (SW2)

When it comes to the academic status and the contribution of research, speech therapists (SP) have stated that there is a paucity of relevant studies with adults with severe disabilities, and consequently the lack of guidelines. One ST made a remark saying that her previous job experience of working with children was less challenging than the work with the adults.

"I don't have that many success stories. It's really sad. I've been working with adults since last year. It's more challenging than with the kids. Children are learning... their expectation is that the children are learning all the time. It is expected that the child needs to learn a word "on"... They've got more opportunities. The reason I say I don't have that very many success stories is that I have a client who is fifty. It's disheartening. I get to a point... I talk to my supervisor and she is like, let's talk about your success stories". (Speech therapist 2 – ST2)

Families are the most important source of daily assistance for adults with disabilities [43] and this fact alone can already put a substantial burden of care on parents. As the family members are getting older their children are also getting older, and consequently there is an increase of assistance needed for their children. Adding any new learning activity that demands daily attention might be overwhelming. Building social capital through expansion that includes other family members, friends and families in similar situation can become a valuable resource. When we discussed this topic in the context of AAC adoption, family opinions and attitudes varied. One family had been protective of their privacy saying that "We are very private. Not that many people come to our place". On the other hand, one other family had shown interest but expressed a lack of time to engage.

R: Do you know some other families who are using AAC devices?

M2: No, I don't know anyone. I'm not aware. I don't really go to any family meetings.

R: Would you go to those meetings?

M2: If I had a little bit more time I'd go. It is useful to have a relationship because you learn more, there is a benefit in it. But you have to have time for it."

Overall we found that families and therapists struggled to support AAC use for adults with severe disabilities. Therapists found the rate of progress challenging, and families became used to their own ways of communicating and to some extent withdrew socially.

5.2 Modelling AAC Technology Use

The larger part of successful AAC use is based on the support of families and support workers in modelling AAC use. However, in practice this support is not always successful. We pinpoint the barriers of implementing AAC instructional strategies.

For the larger part of the speech therapy sessions, the interactive modelling technique used was Aided Language Modelling (ALM), an intervention premised on the theoretical and evidence-based practice that uses AAC modelling strategies as a firm footing for AAC adoption and use [36]. AAC modelling spans different intervention strategies implemented in accord with the preferential evidence- or practice-based model approach by STs. In the two case studies both speech therapists used Aided

Language Stimulation (ALS) [23] encompassing different variations of the same strategy. ALS entails two main aspects: a) modelling AAC device use as the adult speaks and b) engaging in the context of naturalistic communication interaction [36]. For example, during the interaction, Mary's speech therapist would



Figure 3. (left) - P2Go (© Assistive Ware) and painting activity (right) - bucket with inciting stimuli

Say "let's paint the dog" and then point to the symbol of the "dog" on the communication board and then say "dog", or if the device was used, such as P2Go, they would tap on the relevant icon on the interactive display and wait for the corresponding word to be pronounced. In Mary's case, the speech therapist used an instructional strategy pointing with her index finger or hand over hand technique to guide the process of detecting the icon on the screen (figure 3-left.). After several repetitions and demonstrations, the speech therapist would model the AAC use in a combination with a time-delay [11], an instructional strategy that was used to draw attention on Mary, with an expectant look waiting for Mary to pick up on the therapist's cue changing her role from respondent to initiator by pressing the desired icon by herself [41]. However, in both cases (Mary & Alex), the modelling intervention had taken place in a *contrived contextual arrangement* where there was no opportunity or enough time to try out the devices in naturally occurring situations (e.g. during lunch times, during art or craft activities, at bowling, in the gym, dressing up etc.). Rather, speech therapists adapted this approach of modelling the device use within the therapy session expecting to transfer the knowledge and instructional strategies to a broader audience of communication partners (parents, support workers), who could further model the AAC use outside the context of speech therapy sessions. What we see in figure 3 (right) is one such example in which the ST used an adult-led strategy initiating the interaction by displaying a bucket full of potentially desired items that could be used in combination with the AAC device after the adult had chosen the desired item (balloons, puppy, etc.). That way the ST was trying to make *decontextualized* intervention contextually applicable and context-relevant to a certain extent. Altogether, this differed from the desired naturalistic approach in which the instruction takes place during the natural activities (leisure time, snack time).

Implementing such AAC modelling strategies demands a joint effort of all relevant parties, such as parents, friends, peer communication partners, support workers, speech therapists [26] and if available, AT specialists or makers. We found that in practice we rarely see all these parties gathered around to ensure the rightful appropriation of the dedicated device. It seems that, often, one or two persons will bear the responsibility of undertaking the needed AAC modelling work.

"You go to a doctor and you say this the problem and the doctor fixes you. The hardest thing is teaching them. The research shows that everyone in her environment needs to be using it... My thing with leaving the paintable things was that when I come on Monday I go

"where are the paintable things"... There are all still blank, what's been happening. Sometimes, I'll go "here is the AAC, the craft activity, now you do it." I'm watching. You've seen me doing it, now I will watch you. You have to put the onus on them. Some clients, no matter how many times I turn up, they won't do it" (ST2)

"I am hoping that through a repetition with the speechy of doing all this stuff it will become her second nature. I'd like to think that the girls (e.g. support workers) can bring it to her routine daily if that is possible; I'd like to think that the device can stay here through the week (in the centre). Then, I can take it home at weekends and work with it" (F2)

In our two case studies, the location of sessions was different, with different proxies present in the sessions. In one case, the mother was not present at the sessions in the day centre whereas in the other case study, the father and one support worker were always present during the speech therapy session. Both adults were exposed to a high turnover of staff on a weekly basis. For speech therapists, this was a logistic concern preventing them from responding appropriately. Thus, for the larger part of the sessions the post-reflective phase and transfer of information was reliant on the 'word of mouth', hoping that the support worker present at the sessions will share the information with other colleagues. As a consequence, the information transfer would usually lack the rich contextual explanations and fine-grained details of the therapist interventions.

"It was good. We were painting the animal and pointing to different pictures of the animal and saying it. You point to the picture and you say the name and like that in cycles". (SW3)

Developing an ability to match pictures to objects or objects to pictures emerges over time [20]. Although, we might see positive outcomes in one specific context, it does not guarantee a full symbolic use in some other contexts [20]. Thus, using the device has to be expanded to other situations, with constant repetitions over a period of months and an abundance of 'trial and error'.

"It's a lot of trial and error. And you have to practice. It's like going to physio. You have to practice all the time, over and over again." (ST2)

However, putting it into practice was challenging.

"At the end of the day it's us who are putting it (AAC) in the practice. We need to be more proactive. It's probably us, the staff. And it would be much easier if there is more regularity in staff. To be honest. We all need to sit down, we who work with Alex and I suggested that to the ST but it never happened. But it's also not happening at home, but I'm not blaming anyone, their life is already hard as it is [short break]. It is in his bag and sometimes I just forget that it is there. It needs to get part of our routine. I usually use it early in the morning to exchange the information about the daily schedule." (SW2)

The use of the Snap+Core First ® app was prevented by support workers for fear of losing the device.

"We don't bring it with us because I am just afraid that we will lose it. He will not carry it with himself, we have to do that for him and sometimes we have a lot to do and we just chose not to bring it along" (SW4)

When support workers present at the sessions were asked to repeat the same modelling procedure it seemed that they usually struggled to deliver these procedural goals. In our post-reflective interviews with support workers it seemed that they struggled to replicate the modelling procedure as demonstrated by STs. Despite the good will to deliver this task, support workers were saying that Mary just does not want to do it. "She was not interested". Other problems stemmed from the fact that one worker who was present at the therapy session did not have enough time to show other support workers how it can be done.

Further, it was indicated that the sharing of information that directly impacts Alex could not be adequately sourced by the organisation – that is, very little, if no time is made available for support workers to reflect, review and share current and practical supports for the client. Further comments suggested concern regarding who and on what authority was able to advise colleagues in the same role/position of what needed to occur in order to support the client. It was a suggested solution in engaging a person with more authority that can help them to foster the AAC use.

"It has to be a team effort. When it comes from me no one is gonna take me seriously. If it comes from the authority it's more concrete and it becomes a rule... It becomes part of your job description" (SW2)

The interaction in the centre or at home embodied predominately linguistic aspects of formal language exchange. Families or support workers used verbal communication as the basic vehicle to treat different requests by adults with disabilities talking their way through most of the interaction with adults. For example, Alex had his own self-coined sign dictionary (e.g. sign for chips or train ride) to which rarely anyone responded in a symmetrical manner, by using the same signs when posing questions to Alex. There were also plenty of opportunities for families or support workers to engage in AAC use whilst assisting Alex or Mary to, for example, dress up. However, the dominant position of verbal language use was constantly competing with AAC use. When asking support workers why this might be the case, they said that it was just "easier for both of us, I understand what she wanted and he understands what I wanted".

Overall, we observed that although STs modelled AAC use, there was insufficient means to transfer the AAC modelling and use strategies to the many other support workers and families. As a result, AAC devices were not used with sufficient frequency and intensity to make a difference, and their use did not transfer across contexts.

5.3 Scaffolding AAC user-friendly environments

Learning to use AAC devices is tied to the immediate environment of use. We therefore look at the specifics of how the immediate environment supports AAC uptake. The focus of AAC intervention typically sheds light on the specific needs of the individual, and the functional misalignments of AAC with the surrounding environment, which as a result puts emphasis on individual change of the person with disabilities in using the AAC device. Even when speech therapists are aware of the shortcomings of AAC, their position within the system of supports sometimes does not allow for changes beyond the individual level or narrow circle of support. Clinicians lack time to provide and include others in the system of supports. Thus, the system of AAC support focusses on individual intervention and is a subject to naturally and coincidentally emerging environmental changes.

“Don’t get us wrong but there are some things we can’t change. We are more focused on individual clients as opposed to the whole service, and the organizational outcomes. Our hands are really tied” (ST1)

In a context in which we have a higher prevalence of younger people with an increased level of adaptive skills, the focus on adults with severe disabilities naturally falls short of a needed environmental focus. Introducing new AAC technologies demands more effort on the part of staff in the day centre to open up space for communication opportunities and to have the AAC system constantly within the reach of the adults with disabilities. Furthermore, the environment needs to recognize the symbolic way of communication as valuable for these individuals.

“When you are at the start of your intervention you want to make people feel like they are not the only one in the environment who are using this way of communication. It has to be valued and recognized” (ST1)

“Everyone that works with these clients are verbal communicators. But the clients that they are working with are not communicating verbally. It’s almost like you need a support worker to be nonverbal and proficient in AAC, and it’s very, very hard to find that. (ST2)

Supporting aided AAC device use for beginner communicators requires environments that will maximize access to objects, their AAC dedicated devices, toys, chances to communicate with peers and to promote other means of communication and expression. Although, professionals and other proxies (family, support workers) are often focused on single pieces of AAC technology, to be able to make progress, research evidence tells us that a multimodal process that integrates a variety of means and tools of communication is needed [15]. In our two case studies we observed a dominance of one communication modality. In Mary’s case, support workers were mainly focusing on print screen P2Go communication boards, often out of reach during daily activities. They were kept in the main office where sometimes it was hard to track them down. In Alex’s case, his iPad (Snap+Core First ®) was kept in his locker and only occasionally used during morning routines. A supplementary low-tech option (communication

board) was only used by his mother, where she, as opposed to support workers was only using this modality saying that “it is just easier and more efficient for me to use the boards instead of the app”. In the day centre, only support workers who were working with these two adults had been familiar with the current technologies, leaving others with little information on the current advancement. The majority of other staff members had been introduced for the first time to AAC technologies and their potential benefits. Looking for more tangible clues in the day centre and at family homes, we found no exposure to symbolic communication or tangible visual linguistic cues. The same way as typically developing children or younger adults are exposed to linguistic and spoken language throughout the day, we expected to see more visual and tangible complements. When we asked staff and family members why this might be the case, they responded by saying that “it would be much easier if you suggest something to me. Then we can see if that will work here”.

The above points to barriers that prevent staff and families from making changes in the environment; a) there is a lack of training for support staff (“I didn’t realize how much effort needs just to get someone to use picture exchange system”) b) the creative capacity and communication knowledge of professionals to scaffold and create space for AAC user-friendly environments needs fostering (“I think we need to think of more examples similar to for example visual schedules”) and c) teamwork is needed among staff to deliver AAC relevant goals (“We need to put more effort to understand what certain individuals in our centre can do (*frontline manager*)”).

5.4 Personalization of AAC devices

Rather than looking only at how high-tech or low-tech AACs are used on daily basis, we exemplify the possibility of having alternative, personalized ways of communicating. To ensure a good fit between AAC dedicated devices and adults’ personal preferences, the AAC assessment process is crucial. A key step within this involves the selection of an appropriate AAC device. In our two case studies, this process had already started during the first two therapy sessions through feature matching, to determine what device might be appropriate for certain skills or lack thereof. In both cases, the family was present at the meetings where it was discussed what communication tools and AAC devices might be appropriate. Although, this fit must be based on the preferences and linguistic and operational competences of adults with disabilities, in practice, the selection of the device stems from the complex interplay between knowledge, attitudes, price and preferences of different stakeholders. When presented with the two devices (P2Go and Snap + Core First) Alex’s mother saw a P2Go as a good fit “I like the font here much better than on the other one. And the layout is better”. At the first trial of P2Go app, Alex was introduced to the device by showing him a few symbols on the screen and prompting him to place his requests for biscuits that were already on the table in front of him. Alex managed to use the device requesting the biscuits. In the following session, ST trialled the app in the day centre under similar conditions. Just before lunch time, Alex was asked to request his favourite food demonstrating an operational and linguistic

competence of using the device. Having had these two trial sessions with P2Go, in the third session the ST suggested to Alex's mother that it was a good time to decide what app to purchase. While P2Go had shown good outcomes, the mother decided to go with Snap + Core First as she was drawn to its additional features that she thought might be a good fit for Alex's future device use. The option of having a visual timer, visual schedule, means to statistically follow the frequency of symbol use (e.g. number of times Alex pressed the food symbol), and the lower price of the device were the determining factors of choosing Snap +Core First over P2Go. Alex's mother's decision also reflected the ST's preferences. As the backup option, the ST suggested creating a small symbol communication board using a printed version of the screen for cases when the device was not accessible to Alex.

"It's good. I personally like SnapCore more than P2Go. Yes, it's cheaper, Alex seems to like it...It's also good because when I'm in the office I can see the results of how many times they have used the device and what was the most desirable item". (ST1)

During the ST sessions, the question of how the two adults might feel about the technology was rarely asked. For example, there was no time or conscious effort to discuss sensory preferences of the two adults. As both software packages (P2Go and Snap+Core) offer a voice bank repository spanning different sound-pattern packages, the decision to proceed with the male English adult voice or female English adult voice was not a subject of in-depth discussion. The decision was largely made between the ST and the family members. There was little space to scrutinize this decision through close interaction together with the end-users, Alex and Mary. Despite the fact that operational demands of AAC displays are important, we believe that "look-like-feels-like" prototyping of AAC [9, p. 141] use is equally important. For example, being able to determine the tactile preferences (e.g. is the individual tactile-seeking or tactile-avoiding) is salient as the future use of iPads or any other suggested device can be abandoned if it does not meet these criteria. For example, in both cases the ST had mentioned a few viable options to meet the needs of carrying the device during the day activities (inside or outside the centre). The discussion revolved around the robustness of the iPad case and its capacity to amplify the volume on the device. However, the aesthetic pleasure or its sensory (tactile) enticement slipped out of focus placing this issue at the fringes of AAC device use discussion.

Although the devices (apps and communication boards) had only been used occasionally and short term (no longer than 15 minutes a day), there was an overarching goal and focus on using these dedicated AAC options more frequently. Yet, if we look at the prevalence of other communication modalities during the day, embodied communication was far more present. Alex and Mary would choose to use signs, gestures, and different postures to communicate certain intents. Juxtaposed with their sensory preferences and their eagerness to engage with other tools in the environment (e.g. Alex's likeability towards bottles and chopsticks; or Mary's preference towards magazines and pillows) other modalities could have been instrumentalized to serve the

purpose of reaching final communicative goals. However, lack of time and the focus on existing and standard instruments and AAC devices has put these other modalities and potential tools in the background.

Another barrier to making AAC devices "more fitting" has arisen from the lack of experience and exposure to how the devices (Snap + Core First or P2Go) can be used in different situations. Support workers and families have not had enough experience to articulate these issues. As primary supporters for AAC use, a certain level of responsibility was expected of them to program the device (adding vocabulary, changing the screen layout etc.) [22]. When asking parents and support workers how the functionality of the apps could be improved, all came to similar conclusions "it's hard at this stage. It will take more time, probably months before I can tell you something. In accord, both STs had an issue with finding a good way to express the potential with the current AAC devices and software packages. "When you asked me what is the difference between LAMP or P2Go it was hard for me to tell you. I am still learning. Some other STs can tell you probably more".

In summary, AAC can be potentially personalised by attending to users' sensory and other preferences, and by making time to understand their use in a variety of situations.

6 DISCUSSION

The findings above demonstrate that adult's use of AAC technologies is complex and tied to a set of different factors that directly or indirectly influence their AAC use. Delivering AAC devices and short instructions to families, carers and adults with severe disabilities alone does not guarantee positive outcomes [15]. Rather, the whole process is perplexed with inconveniences and constant barriers that have to be addressed daily. Beginner communicators, like Alex and Mary are learning a new language to express their needs and wants, and learning a new language takes time and continuous effort. Turning to one or two AAC devices substantially limits adults with disabilities as there are other more prevalent modes of communication or ways of expression. The approach has to be flexible, generating a larger number of potential devices that can support one individual in ways that fit the immediate environment [12]. Prescribing and further using AAC technologies must take a more holistic approach that fits adults' daily lives and needs [16].

6.1 Formation of AAC Publics

Recently, there was a surge in interest around the concept of publics and what role design can play [24,8,5]. Design of publics means, for example, juxtaposing AAC operational demands and objective technological advancements (matters of fact [5]) together with experiential and subjective use of AAC devices (matters of concern [5]), could lead to the formation of publics in which AAC objects, their material, and societal status can become an object of debate. As such, AAC devices could "function as expressions of matters of concern, encapsulating aspects of an issue to make them accessible to a broader public" [5]. Building on our study results, we see publics design as an approach to process

and articulate present AAC issues for adults with severe disabilities by giving them a form that makes them accessible, noticed, and recognized by the wider public. Challenging the current lack of knowledge on AAC technology, the present study participants and other potential AAC users and their proxies can benefit from raising awareness of the AAC potential impact on the communication development. We can work together with participants to engage in prototyping scenarios articulating beneficial aspects of low-, mid- and high-tech AAC solutions for people with severe disabilities. Designing social media tools can also help to spread useful AAC information sharing successful AAC uptake stories of people with severe disabilities, connecting different families and organizing a hub where speech therapists can share their clinical successful or less successful stories. Following controversies such as the trust in the current system of supports, and attitudes toward the real benefits for AAC uptake can bring different stakeholders together to discuss these matters. We can draw upon positive examples such as in the study of [24], where similar matters of concern are raised leveraging on, for example, a Facebook community that enables different groups of people to become part of a narrative that emphasizes the positive image of dyslexia in the wider community.

6.2 Building Capacity of Families and Support workers

Providing appropriate instructions in modelling AAC use is important. “Receiving technology is only half of the battle”, and the other part includes training and expertise that needs to be developed in day to day use [4]. Scaffolding effective support for AAC use requires educational activities directed at close instructional partners [3]. Finding ways to teach parents and support workers strategies of time delay, effective use of the AAC dedicated device, inclusion of the device in naturally occurring interaction, and programming the device, are just a few issues that might arise during the instructional phase. To meet these needs we need to consider designing systems that can appropriately respond to these issues. During our field work we had video recorded a few therapy sessions. Nearing the end of the speech therapy cycle, a new support worker was included as part of Mary’s support team. Wanting to engage Mary in the painting activity and knowing that the AAC therapist was previously working on using communication boards, she expressed the desire to use the boards along with the painting activity. Being present in the centre at the moment when she approached one other support worker to ask how to use “these boards”, we offered to provide our video recordings as a possible guidance. Ten minutes before the painting activity started we lent her our phone to watch the video. This particular moment was noted by the designer as a potential inspirational design strategy. Drawing upon similar examples of designing systems that can promote video learning and learner reflection might be an avenue to take. It creates a space in which we can design video modelling or in-prompt video systems [10] that can contribute to more efficient and effective strategies of transferring knowledge from speech therapy sessions to other instructional partners such as parents or support workers.

6.3 Turn to Mid-tech or Tangible Technologies

Traditionally, AAC technologies have been focused on the deficits of people with complex communication needs paying little attention to their strengths and competences [16]. In many cases, this has led to a focus on the technology alone, proliferating different AAC devices and expecting that people with disabilities and their families will adapt to use it. As such, for a long time many intervention strategies were persistently focused on providing instructions on how to operate these technologies [15] overlooking the real needs, skills and preferences of adults with disabilities. Current advancements in the field of design have recognized these shortcomings, hoping to change this skewed focus and suggest better strategies. The strategy of personalizing dedicated AAC device use is one such example suggesting context aware high-tech AAC alternatives by adapting the current vocabulary list to individual’s current location and conversational partners [39]. However, to be able to fully embrace communication progress and strengths of adults with severe disabilities, design could take part of helping families and speech therapists to develop mid-tech or tangible AAC alternatives that can put in place other modalities of communicative expression. The embodied nature of communication, which is often disregarded, can in turn be a focus of design work. As designers, we should look for ways to engage with adults with severe disabilities by appropriating their objects of interest. In our study we have been inspired by many examples from naturally occurring interactions that can be a useful strategy to design tangible AAC tools. Adults with disabilities have shown us what they like, in many cases, daily objects of interest (bottles, different games- memory matching, pillows and spinners) and we see no reason why design cannot leverage these objects of interest and turn them into viable AAC communication tools.

7 CONCLUSION

The reported study synthesises six-months of field work at a day centre and in family homes of adults with severe disabilities. Our aim was to explore use and non-use of AAC technology in order to understand design considerations for creating more effective AAC technologies that are used. Qualitative research and thematic analysis revealed the major barriers to AAC use. We contribute three design considerations that arise from our findings a) design for the formation of AAC publics, b) design systems that can enhance family and support workers’ AAC modelling capacity and c) consider tangible and mid-tech approaches to support the embodied nature of communication.

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