Communication-aid design for adults with complex communication needs

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Many individuals in our society have Complex Communication Needs (CCN). This means that they lack the necessary verbal skills for their daily communication requirements. Augmentative and Alternative Communication (AAC) aids exist to help these individuals to communicate, but, despite many studies describing these aids as beneficial (Beukelman & Mirenda, 2005, p. 6), the design and adult use of these aids can be problematic (McNaughton & Beukelman, 2010). This paper outlines a study of existing AAC, the original intention of which was to re-design individual communication aids so as to better suit adults. However, analysis of the study data showed that the research needed to change direction. Reasons for this, as well as some preliminary data analyses of studies involving people with CCN, are presented.

Keywords: communication, disability, design, CCN, AAC.

1. Introduction

Much of the literature about the use of AAC focuses on children’s use of these aids to help develop and augment their communication and other skills early in their lives (Howlin, Susan et al., 2004). Research into adult use of AAC suggests that, once those individuals leave secondary school, they face a challenging time of advocacy to receive funding and source professional support for the ongoing use and development of suitable AAC aids (Iacono, Johnson et al., 2008, p. 443).

As intellectual conditions and abilities vary widely among individuals with a CCN, it is important to fit the correct type of AAC to each individual. By contrast, school staff and parents can liaise with speech pathologists and other experts to facilitate communication and AAC assessments for younger people (Iacono, West et al., 2009). Adults may not have a support network to provide this, (ISAAC, 2014), and because individual needs vary so widely, it can be difficult to identify the best AAC intervention type for a particular individual.

Careful analysis of many of the communication aids used by adults suggested that there are problems within the AAC systems. Many of the picture-based AAC sets, for example, use juvenile-styled illustrations, originally designed for children’s use, and the vocabulary of many of these sets may lack the sophistication needed to support effective adult communication (Bryen, 2008).

With this in mind, data were gathered on the current types and use of adult communication aids at a disability day centre in an outer suburb of Melbourne, Australia. The objective was to redesign a subset of picture-based AAC aids for specific adults with Autism, who frequented that day centre. In initial talks with the centre management concerning the scope of the research partnership, it was agreed that a group of six clients with Autism would participate in the study. As evidence suggests, individuals with Autism can be strong visual learners (Grandin, 2006; Hodgdon, 1995), and the researcher’s professional background is in graphic design, so it was decided to focus on this form of AAC. The centre management believed that the clients in this select group would benefit most from this form of intervention. An underlying assumption was that AAC would be used across the centre, in various forms and with different degrees of effectiveness.

Whilst a number of picture cards were stored at the centre, after completion of the AAC documentation phase, it became evident that no individual and very little shared AAC was actually used by staff or clients. Therefore, instead of this research merely aiming to redesign a small number of individual clients’ communication aids, the scope of the research was broadened to identify patterns of specific communication challenges that staff and clients across the centre faced. One reason for this change was an attempt to gain insight into the apparent omission to use AAC aids at the centre. Another reason was the possibility that a design solution could be developed that could benefit people with CCN more widely than the small group of clients initially selected. The research also broadened to consider individuals with a wider range of conditions beyond Autism, as well as involving staff and parents.
2. Complex Communication Needs (CCN)

In the year 2000, there were an estimated 1 in 500 people in Australia, with Complex Communication Needs (CCN) (Perry, Reilly et al., 2004). Individuals with CCN are unable to meet their daily communication needs by relying exclusively on speech. There are many reasons for an individual’s lack of speech, from temporary loss or aphasia, because of surgery or trauma, to permanent loss, due to acquired or congenital conditions such as Autism, Cerebral Palsy, an Intellectual Disability, or a combination of co-morbidities.

Research into this area is important for several reasons. The implications of a lack of functional speech are wide-ranging and include health and financial issues for the individual and society. The majority of research efforts into conditions affecting speech involve children rather than adults, who have often left support networks. By contrast, children with a disability, receive help at both primary and secondary school levels (Iacono, Johnson et al., 2008).

2.1 CCN and Augmentative and Alternative Communication

Augmentative and Alternative Communication (AAC) systems include a range of procedures and devices to help individuals who lack spoken word skills, enabling them to potentially communicate. AAC can be Unaided or Aided, with users generally employing a mixture of the two during their daily communication. Unaided AAC requires no equipment external to the user's body: it includes procedures such as manual signing, pantomimes and gestures. Aided AAC incorporates the use of devices external to the individual users and involves the use of communication books, speech-generating computers or communication devices (Robitaille, 2010, p. 123). Aided AAC can contain sets of printed or digital letters, words, photographs, drawings or symbols, which can be used to augment or replace speech. Individuals may point to a drawn picture representing an object, for example, to request that object (Mirenda & Iacono, 2009, p. 96).

The use of AAC can be multi-modal, so individuals may rely on many different types of such communication-support every day to deal with different situations. The “Best Practice” literature indicates that AAC should be grounded in evidence-based practice and assigned according to what is best suited to each person.

Although picture-based AAC can be used to take advantage of an individual's visual thinking, some forms of this type of AAC are slow to use. One factor contributing to this is that many pictures are necessary to compose a visual sentence, and this can slow an augmented conversation from 150 words/minute to less than 15 (Beukelman & Mirenda, 2005, p. 67). As well as the juvenile-styled illustrations in many picture sets, concrete concepts like nouns are typically much easier to represent as static images than abstract concepts, like verbs, that can be much more challenging to depict (Ralf W Schlosser & Shane, 2010).

3. Project organisation and phases

The day centre has approximately 20 full-time staff and over 70 clients, who come to the centre to take part in many daily vocational and life-skill activities. Many staff and clients were involved with the research in various ways as detailed in the next section.

The different research methods outlined below were used at the day centre over a period of 3 weeks. Data collection began with the photographic, archival documentation of AAC in the centre. When this was complete, discussion with staff revealed that AAC was hardly used at all on-site, which led the researcher to revise the methods originally intended. Consequently, the research methods used included focus groups with staff, observation of staff and client interactions, and phone interviews with some clients’ parents. The scope of the research now changed to identify the types of challenges staff and clients faced when attempting to communicate with each other.

3.1 Method

3.1.1 Documentation

Documentation of the AAC in the day centre included visual inspection and photographic capture of information display material, such as posters and signage, picture cards used to depict objects and activities,
and schedules informing clients and staff of daily activities. Photographs were taken of approximately 280 picture cards, (depicting objects like clothes or food and actions like ‘get dressed’ or ‘wash hands’) as well as of 48 small posters and signage. The posters and signage included pictorial signs for toilets (ISO, 2015), safety signs for fire extinguisher and fire blanket, and small picture signs of food, cutlery or cleaning utensils used to denote relevant storage areas. Only the small picture signage specifically used AAC graphic images, and these were inconsistently presented with a mixture of different graphic styles and print quality. The rest were generic information displays. Copies of three different daily visual schedules were collected. These schedules typically contained a charted display of what was happening in each day, as written notes and accompanying pictures. On one day, for example, a group session of craft activity was noted: it displayed the written word ‘craft’, a ball of string and the names of staff and clients expected to be present. No other forms of AAC were found, including speech generating or other AAC devices (Hodgdon, 1995).

The centre manager assigned a staff member to allow the researcher access to all rooms in the centre, to show the researcher relevant storage areas in three rooms, and to ensure the documentation process could be conducted away from clients as they rotated through various activities in different rooms throughout the day. The staff member was on duty, so they needed to balance time with the researcher and their regular duties.

To fully document AAC in the centre, it was also necessary to photograph any individual communication aids the clients had, such as communication books. These typically contain photographs or pictures relevant to clients’ lives, with images of relatives, their needs, with favourite objects, food, activities, and information about their condition. When asked about the location of any of these books, the staff member mentioned that, if any clients brought them from home, staff did not seem to use them during daily activities at the centre.

Documentation of the AAC aids in the centre took five hours, during one weekday, with the assigned staff member giving approximately 30 minutes of their time for research support. Because of the staff’s busy schedule at the centre, planning for the documentation took many weeks of email communication before a suitable time for staff and the researcher could be agreed upon.

The empirical part of the research is summarised in three sections below.

3.1.2 Focus groups

A total of 15 centre staff members were recruited by the centre management in consultation with the researcher for participation in two focus groups (Bloor, Frankland et al., 2001), run at the centre on two afternoons. Twelve participants took part in the first group (ten female, two male), and three in the second group (two female, one male). All participants volunteered their time, and the centre provided snacks and drinks. Informed-consent forms, together with information sheets, were prepared to facilitate and guide the focus group discussions. The information sheets outlined the objectives of the overall research project, introduced researchers and the university involved, and provided participants with information about the procedure (including a request to audio record the session) plus ethics. Information sheets also contained the following prompt to facilitate discussion:

“It would be most helpful if you could give some thought to the kinds of difficulties you have experienced understanding clients when they attempt to communicate something to you. I would also like you to talk about the kinds of difficulties you believe your clients have experienced when you have attempted to communicate something to them”.

Audio recordings were transcribed ad verbatim and analysed using affinity diagramming to categorise and arrange the data into category-hierarchies (Beyer & Holtzblatt, 1998, p. 24). This process was repeated by analysing emerging themes common to both focus groups. Selections of quotes from focus-group discussions were then arranged within each of the themes to provide contextual and illustrative examples for each.

The predominant themes emerging in both focus groups fell into four main categories: communication from staff member to client, from client to staff member, between clients and between staff members.

During staff to client communication, staff found it challenging to communicate personal hygiene issues with clients, as these required a very delicate balance between maintaining respect for the client and highlighting a health issue. As individuals with intellectual conditions sometimes struggle with self esteem (Barnhill, 2001), the delivery and phrasing of sensitive topics such as these are of concern to disability workers and their clients, as the following quotes illustrate:
"Personal hygiene, and still trying to maintain that respect. You can't turn around and say, 'Dude, you really stink.' You can't do that so it's really difficult."

This delicate approach extended to trying to pre-empt a toilet visit as well:

"Personal care. Some of them can't say, 'I need to go to the toilet.' It's prompting too. For them to go."

Staff to client communication about issues that limited or controlled behaviour and actions were also raised. This included discussions about the appropriate way in which clients were expected to behave, staff responsibilities and safety issues:

"For some of us, it's difficult to communicate that the clients have responsibilities here. They really have to abide by some of the regulations of the place. Take a cup out and wash it. They don’t understand why in the morning they have to come to home group. We sit them down and say (it's for) safety reasons. Fire drill. And they still don’t understand. For them it's more a social thing, to come in the mornings to a room. For them it's social."

"How to explain what our role as staff members is. Where the limitations are. What they think they are. 'I'm not your housekeeping tea lady.' A good example of that is: we caught up with that client before and he said, 'I'm having problems with my relationship. Can you fix it?'

"How to communicate to a client not to hit strangers or the public. How not to approach. Not to touch."

Client communication to staff was discussed, and a number of topics were identified in both focus groups. The difficulties of a client communicating about hygiene was another challenge:

"Personal stuff. A client took me to one side the other day and said, 'Can I please have a spare pair of underwear?' Everything was confidential, but I could tell that it was really personal and she really understood. I think she showed a bit of trust. You've got to deal with that delicately."

Client communication about their well-being and current emotional state to staff was described as challenging to gauge. Here are some illustrative comments:

"Expressing that emotion or they personally don't understand that emotion. Trying to get them to understand that emotion, or identifying it. For instance, the emotion of rejection. He doesn't understand really that you're trying to help him without rejection. How to go through it, knowing that his acting out has originated in his sense of rejection."

"Are they lonely? Are they happy?"

"When he gets upset. He just shuts down. He doesn't talk. He just sits there. So he's getting to that part where he doesn't express what he's feeling. He has something blocking him, from telling us what he feels and what he thinks. Unless you prompt him."

"Their feelings. Their emotions. Their well-being. It often gets to a physical point until we notice."

Clear communication between clients was important for matters of safety and for maintaining a professional working relationship with all individuals at the centre. The focus groups raised some challenges there too:

"There’s one of the clients here that likes to help a lot. He drags around other clients and they get really annoyed and angry. So if you tell him no, thank you for you help and you can do something else he still doesn't listen and still drags them around."

Communication between staff was discussed. Of particular interest here was the importance of the sharing of information:

"Staff to staff communication. If they've picked up something and they do something a certain way with one client but hasn't let another staff member know."

"This is one of the barriers. (Clients) have information that only comes out in situations and discussions. So I might harbour information about someone for 20 years and not say anything because I haven't been prompted to say anything about that."

"He has epilepsy. No one knew and it's not in his file. That should be on the front page."

The data from these focus groups pointed to discussions about safety and boundaries in each of the four categories. Documentation revealed that there were just two standard, safety posters in the centre. This is therefore one example of a category worth exploring further with respect to designing refinements to publicly-shown AAC in the centre. If static images do not give enough information about the nature of a particular danger or annoyance, it might be worthwhile to explore animation as an alternative means of display (Ralf W. Schlosser, Shane et al., 2011). As the posters / displays would be used publicly and for more than one client, technologies that are expensive to use for just one client could still be considered here. The use of low-tech or no-tech animation could be trialled in this case as well, such as a lenticular poster.
(Tolliver-Nigro, 2010), a paper-based system where two or more images exist on paper and are revealed separately as the viewer moves through different positions in front of the image/s.

Discussions about hygiene and determining the current, personal state of clients were often highlighted across communication categories, so exploring discrete methods of AAC that could be used to communicate a client's well-being or situation would be beneficial also, as it could save embarrassment for clients and staff alike. Experimentation with the design of images or animation for small screens would be a viable method to explore.

The successful sharing of information between staff members, about clients' conditions and recent history was of concern to focus group participants. A digital, shared repository of client information, appropriately safeguarded and networked to parents, disability support services, staff and clients would be an ideal AAC solution to this challenge.

Clearly, the focus groups yielded valuable information for further exploration and possibilities for the design and development of alternative AAC. However, as the data represented only staff perceptions and opinions, it was worthwhile also to capture clients' viewpoints. Staff and client interactions were therefore observed next.

3.1.3 Observations

Nineteen observation sessions were run over five days, each session lasting a maximum of 30 minutes. Sessions were conducted in two main ways, with thirteen of these conducted during client group activities within the day centre, and six during client group activities away from the centre. One-hour breaks between sessions with the same staff member were observed within the centre, and 30 minutes outside of the centre, to give participants an opportunity to interact without the researcher being present. Group client sessions would typically consist of two staff members and between five and eight clients of varying abilities and conditions. Observations would target the communication exchanges involving one staff member at a time, and observing all their exchanges with all of the clients present in any given group at the time.

A range of different activities was observed in both sets of observation. Observations at the centre included group craft and other activities and during staff / client lunch breaks. Observations away from the centre included a ten-pin bowling activity session, and a lunch break at a shopping-centre food court. The objective of these sessions was to learn more about patterns in the staff-client verbal and non-verbal communication exchanges. An observation protocol had been prepared a priori targeting various aspects of communication. The purpose of that was to identify the types and quantity of staff-client/client-staff communications, such as comments, noting who would initiate questions and provide answers, and so forth. Accordingly, each complete communication exchange (such as one question and one corresponding answer) was noted as one type of incident in the various categories. Additionally, the number of incidents in other communication categories is outlined below:

An instruction was defined as a descriptive verbal or non-verbal communication requesting an action of another individual. A demonstration was defined as a verbal communication describing a sequence of actions, or as a touch used as a communication. A compliment was defined as an exchange praising an individual. A reprimand was described as a communication attempting to control or alter an individual's actions. A staff information exchange was defined as one closed communication-loop that included one question and one answer or a comment and a response exchange. Non-verbal responses included communication by key-word signing, (a refined version of manual sign language traditionally used by deaf people) (Beukelman & Mirenda, 2005, p. 50) other gestures, smiles, nods and noises.

Of the 999 total communication incidents observed, data analysis showed that more than 70% (n=731) were staff-initiated and less than 30% (n=268) client-initiated. The majority of the staff-initiated incidents were verbal questions to clients (23% of total incidents n=233), followed by staff-to-staff information exchanges (14% of total incidents n=137), and then instructions given verbally to clients (11% of total incidents n=111).

Of client-initiated communications, questions answered verbally by clients comprised 11% (n=113) of the total number of communication incidents, followed by the non-verbal answers / reactions by clients to staff of 8% of total incidents (n=77). Clients who verbally asked staff questions comprised 7% (n=69) of the total number of communication incidents.

Given that the majority of communication exchanges were staff-initiated and that there was very little communication initiated by non-verbal clients, the use of AAC to provide these clients with a means of
communication could therefore be beneficial, as it would give non-verbal communicators a means of expression. Verbal clients able to use verbal language could still benefit from augmentative measures to improve the clarity and focus of their exchanges.

Observations within the day centre provided a number of examples of incidents discussed in the focus groups, including challenging staff communication exchanges with clients about hygiene and client well-being. The observation of sessions away from the day centre, though, provided a very different snapshot of the dynamics of the centre's group activity sessions. While the integration of disabled individuals into mainstream society is important (Hamm & Mirenda, 2006), these external activities can be logistically problematic.

The apparent freedom of moving about a public environment, away from the centre, meant that the two staff members responsible for the six clients in these sessions spent much of their time managing the clients’ movements and exchanges with each other and members of the public. The safety of all participants became a priority, when clients displayed challenging behaviour toward each other, staff members and the public. Staff also had to guide clients away from potential hazards and some shops with particular displays.

Data in these sessions indicated that the amount of reprimands from staff greatly increased, from an average of less than 2 per session during group activity within the centre, to nearly 7 incidents per session away from the centre.

The potential for AAC development and use here would seek to address the need for clients to exhibit socially acceptable behaviour in public and be made aware of potential hazards and safety issues. Perhaps a mobile device or game that utilises global positioning or maps to plan journeys, identify obstacles and provide achievements for various aspects of the activity, walk or play would be beneficial.

3.1.4 Phone interviews with parents

The final part of data collection was phone interviews, conducted with parents of two day-centre clients. A total of six parents of clients (who staff had identified as possible interested participants) had been invited, but only two responded. Recall that the day centre is located in a suburb with high unemployment and predominantly blue-collar workers. Note also that both parents interviewed were mothers. The first interview with the mother of a male bipolar client with Autism, dyspraxia, an intellectual disability and Diabetes, took 68 minutes; the second, conducted with the mother of a female client with Prader Willi Syndrome, took 41 minutes. Prader Willi Syndrome is a genetic condition characterised by dysmorphic features, intellectual and behavioural dysfunction (Martin, State et al., 1998). Each parent was asked about communication difficulties with their child that they had experienced over the course of the child’s life. Each phone interview was audio recorded with permission and each conversation was transcribed verbatim.

Each parent gave a brief verbal history of their child, including diagnoses, support networks and examples of behavioural incidents and communication challenges throughout their child’s life. The topics described by the mother of the adult male included his safety, especially in public places, (such as when he travelled on the train by himself) any changes to his routine, and his behaviour being affected by his bipolar condition. Earlier in his life, the mother’s efforts concentrated on ensuring that his verbal skills were sufficiently well developed to enable others outside his immediate family to understand what he was saying.

The mother of the adult female mentioned her daughter's emotional state as being a particular challenge when communicating with her. It was difficult for her to find out why her daughter was upset or what she was feeling at any given time. Sensitive issues around puberty were another difficult issue, especially concerning physical changes and pain associated with those changes.

The data from the phone interviews also supported many themes emerging in the focus groups, including communication challenges about the well-being and safety of their children. Each parent described a broad range of AAC as extremely beneficial to his or her child's initial and ongoing development. The interest and advocacy of both parents as concerned guardians inspired both mothers to move into their current employment within the disability industry.

3.2 Results and discussion

Results from each investigative method provided useful data for various aspects of the state of AAC use in the disability day centre.
Documentation of AAC showed that photographic and illustrative picture cards were stored at the centre, but not used at any time during this research. Some public, generic, graphic-based information was displayed, but wasn’t tailored to adults with a disability. The only tailor-made AAC used was a picture/text based photocopied timetable, updated daily and made available to clients and staff. As the literature suggests that the use of AAC is beneficial for individuals with Complex Communication Needs, this limited use of AAC use in the centre was surprising.

Staff focus groups were very useful for identifying several themes of challenging communication between various groups in the centre. Potentially embarrassing personal issues, such as discussion about hygiene or one’s emotions, were outlined as problematic topics for both staff and clients. Appropriate behaviour, boundaries and safety were other issues staff found difficult to convey to clients. Information sharing was problematic, when staff were unaware of client conditions or a client’s recent history at home or at former day centres.

Observations confirmed many issues raised in the focus groups, but especially highlighted one aspect as being of more concern away from the centre. The challenges of managing client group movements and interactions in activities away from the centre meant that staff spent much of the time managing client movements and interactions to avoid behaviours of concern and potential safety hazards.

Finally, the data gathered from phone interviews outlined the benefits of lifelong advocacy from a guardian and the positive use of lifelong, dynamic use of AAC aids.

From these data, several possible directions for AAC development seem worthwhile, including discrete picture use, low-tech animation signage, GPS game design and interconnected, digital repositories for client information.

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