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Augmentative and Alternative Communication Supports for Adults with Autism
Spectrum Disorders

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**Abstract**

Many adults with Autism Spectrum Disorders (ASD) have complex communication needs and may benefit from the use of Augmentative and Alternative Communication (AAC). However, there is a lack of research examining the specific communication needs of these adults, let alone the outcomes of interventions aimed at addressing them. The aim of this study was to explore the views and experiences of support workers and family members regarding the outcomes of providing low-tech communication aids to adults with ASD. The participants were six support workers and two family members of six men and women with ASD who had received low-tech communication aids. Using semi-structured, in-depth interviews and following thematic analysis, the results revealed strong support for, and the potential benefits of, AAC for both adults with ASD and their communication partners. The results also revealed inconsistencies in the actions taken to support the use of the prescribed AAC systems, pointing to the clinical need to address common barriers to the provision of AAC support. These barriers include organisational practices and limitations in the knowledge and skills of key stakeholders, as well as problematic attitudes.

**Introduction**

The term Autism Spectrum Disorder (ASD) refers to a group of lifelong developmental disabilities which impact on the ability of children, adolescents, and adults to successfully access and participate in life activities at home, in education and workplace settings, and community activities. Yet despite the lifelong nature of ASD, research has focused primarily on understanding and supporting the needs of children; there has been little regard for the experiences, needs, preferences, and priorities of adults with ASD and important people in their lives (Iacono et al., 2009, Howlin et al., 2004). This disparity represents not only an imbalance in research funding and effort, it also creates a substantial barrier for family members, therapists, support people, and agencies seeking to meet the long term needs of adults with ASD (Howlin, 2008).

The limited longitudinal data on outcomes for children with ASD as they move into adolescence and adulthood point to the need for ongoing services and support. In fact, even adults within the near-average, or average, range of intellectual functioning tend to require continued support from their families or services, experience ongoing communication and literacy difficulties, have small social networks, and experience high levels of unemployment (Howlin et al., 2004, Billstedt et al., 2011). Not surprisingly, the challenges are even greater for adults with a performance IQ below 50, who are likely to have complex communication needs and are at greater risk of developing behaviours of concern (Nordin and Gillberg, 1998). These adults require

effective communication support, often in the form of Augmentative and Alternative Communication (AAC), in order to maximise their independence and participation at home and in the community (Iacono et al., 2009).

AAC is an area of clinical practice that compensates for the impairment and disability patterns of individuals with severe communication disorders, including adults with ASD (Beukelman & Mirenda, 2005). There are two types of AAC strategies: aided strategies requiring external assistance in the form of picture cards, electronic speech devices, or alphabet boards; and unaided strategies requiring no external device, and including manual signs and gestures. Both strategies are used to support comprehension and expressive communication rather than to replace the use of natural speech (Beukelman and Mirenda, 2005), and may be useful to adults with ASD. To illustrate, it has been suggested that (a) the visual representation of language in AAC may appeal to strengths in visual processing of information reported amongst individuals with ASD (Mirenda and Schuler, 1988); (b) the concrete, non-transient representation of language may support comprehension (Ganz et al., 2012); and (c) the use of recognisable communication symbols may also help communication partners interpret and respond to an individual's communicative attempts (Loncke and Bos, 1997). Despite the potential benefits, little is known about the real-life outcomes of using AAC to support the communication of adults with ASD.

Research in which AAC supports for adults with ASD have been examined has tended to focus on Functional Communication Training, whereby new communicative behaviours are taught (often through AAC) in order to replace behaviours of concern (see Sigafoos et al., 2009). In only one study, by Hines, Balandin, and Togher (2011), has the broader role that AAC can play in supporting adults with ASD been examined. Hines et al. conducted a qualitative study of the lived experiences of 16 parents supporting their adult sons and daughters with ASD, including their views towards, and use of, AAC. Although the parents identified their son's and daughter's communication difficulties as a key barrier to independence and participation at home and in the community, as well as to the establishment and maintenance of positive relationships, only two parents had attempted to implement AAC. These two parents highlighted the potential for AAC to help adults with ASD who have complex communication needs to indicate preferences, tolerate changes in routines, and reduce the need for behaviours of concern, but also noted the difficulties they faced in accessing appropriate AAC services (Hines et al., 2011). Although the findings were limited by the small number of participants with direct experience of AAC, they nevertheless indicate the need for further research into its potential benefits for adults with ASD, as well as the barriers to successful AAC provision and solutions to address them.

The advent of a government-funded low technology AAC scheme in Victoria, Australia, provided an avenue through which to examine the outcomes of providing

AAC support to adults with ASD. The Non-Electronic Communication Aid Scheme
(NECAS) was implemented to enhance communication, participation and independence
for people with communication difficulties (West et al., 2012). Since beginning in 2005,
the scheme has provided services to approximately 1338 adults with complex
communication needs, of whom approximately 206 had a diagnosis of ASD. The key
benefit of conducting research tied to the NECAS, as opposed to recruiting through a
community sample, is that all participants received an equivalent service in terms of the
level of information and advice provided. Variables related to knowledge, skills, level
of support, service delivery, and AAC design are all known to impact on AAC
outcomes for individuals with complex communication needs, and would otherwise
introduce further variability to the study of individual outcomes.

West et al. (2012) conducted a telephone survey of 54 people who had requested
communication aids through NECAS in order to evaluate program outcomes. They then
completed face-to-face interviews with 15 adults who had received communication aids
through NECAS, in order to explore their first hand experiences and outcomes, reported
in Iacono, Lyon, West, and Johnson (2012). Seven of the participants completed the
interviews independently; for four participants, support people provided occasional
information; and for a further four participants, a parent, spouse, or support person was
the primary respondent. These adults included one woman with ASD, Kim. The results
for all participants highlighted the valuable role AAC can play in not only meeting

individual wants and needs, but also in reducing frustration and anxiety, increasing

independence, and enhancing social engagement and interaction with others. Kim's

mother, for example, reported that Kim's 'book about me' made it easier for new people

to get to know her, thus facilitating her relationships with others and reducing the

anxiety she would experience when unfamiliar people did not know how to

communicate with her. The results also provided evidence or the value of multimodal

communication, the need to continuously review communication aids to ensure they

meet current and future needs, and the importance of including all key stakeholders

(mostly importantly the adult themselves) in the decisions and process of selecting and

implementing communication aids.

West et al.'s (2012) findings highlight the potential value of combining the

personal reports of adults who use AAC, with the reports of others who know them

well, in exploring the outcomes of AAC service provision. Such combined information

is needed not only because having complex communication needs is likely to make it

difficult for many adults with ASD to relate their experiences, but also because NECAS

records indicate that most referrals for adults with ASD come from support workers and

family members (Iacono et al., 2011, West et al., 2012). Consequently, their views,

actions, and experiences are likely to be central to understanding the outcomes of AAC

service provision. Therefore, our aim in conducting this study was to explore the views

and experiences of support workers and family members regarding the outcomes of providing low-tech communication aids to six adults with ASD.

## Method

### Ethics Approval

The study was approved by the Human Research Ethics Committees of [withheld for peer review].

### Design

We used a qualitative design. Semi-structured interviews involving adults with ASD, support workers, and family members were recorded and transcribed. Thematic analysis (Braun and Clarke, 2006) was conducted to explore the participants' views and experiences.

### Participants

The participants were four men and two women with ASD who had accessed the NECAS at least 6 months prior to the study, and seven support workers and two family members (mother and sister) who knew them well. Our intention in including both the adults with ASD and people who knew them well in the study was to provide the adults with ASD the opportunity to report on their own experiences of accessing AAC to the greatest extent possible, while benefiting from the input of key people in their lives. However, given that it eventuated that the support workers or parent were necessarily the primary responders in all interviews, analysis focused on their views and

experiences. Support workers were selected for inclusion in the study either by the adults with ASD directly, or on the basis that they knew the adults with ASD for at least six months and had knowledge of the communication aids they had been provided (that is, met this selection criterion).

The adults with ASD, whose experiences of accessing AAC through the NECAS were the focus of the study, were aged between 20 and 60 years, and had complex communication needs as evidenced by having severe or profound difficulties in understanding and being understood by others, thereby making them eligible for access to NECAS. All participants had previously received a clinical diagnosis of an ASD, which was documented in their individual client service records as confirmed with support workers and family members at the beginning of the interview. These reports were consistent with the first author's observations during the interviews that all participants displayed clear behavioural characteristics that were consistent with a DSM-IV-TR diagnosis of Autistic Disorder. All participants attended 'community day programs,' were not in paid employment, and required substantial support across activities of daily living (e.g., personal hygiene, transportation in the community).

Due to ethical constraints, we did not complete formal measures of cognition, communication, or other adaptive behaviours. A particular constraint arose from the fact that recruitment occurred through a follow-up of a clinical service for adults with complex communication needs in which such assessments had not been conducted by

the service providers. Indeed, such lack of assessment was the result of limited funding

for the service, a shortcoming addressed by Iacono et al. (2013). However, in

descriptive terms, the adults with ASD who had the most effective communication were

able to express their needs, wants, and interests using simple sentences, but were unable

to engage in reciprocal conversation of more than one turn. Those with the least

effective communication rarely spoke and instead communicated mostly through their

actions or vocalisations. A summary of the participants with ASD's demographics and

experience with AAC is provided in Table 1. Pseudonyms have been used and only

broad descriptions are provided to protect the participants' identities.

[Insert Table 1 about here]

**Materials**

Interviews were recorded using a Sony™ digital voice recorder. The recordings

were transcribed using Microsoft Word™.

**Interviews**

The first author completed a semi-structured interview with each participant

dyad, comprising one adult with ASD, and his or her family member or support worker,

at their chosen location. Five interviews (those involving support workers) were

conducted at the community day programs attended by adults with ASD and the

remaining two were conducted in the participants' homes (one a community residential

unit and the other in the family home). At the start of each interview, the first author

explained the aim of the study, his role, and the purpose of the interview. He explained that the study was not aimed at evaluating NECAS, but rather to examine the provision of communication supports to adults with ASD, and he encouraged them to contribute any information they felt relevant to the topic.

Two hours were allocated to each interview in order to allow for discussion of the study, breaks, to examine the AAC supports provided, and answer any questions. The total recorded interview time for participants ranged from 35 to 53 minutes, with an average of 43 minutes. A semi-structured question guide was used to ensure a range of issues were discussed, including (a) the type of AAC requested and used; (b) the benefits and barriers to using AAC; and (c) the extent to which the AAC supports complemented the strengths, needs, and learning style of each person. The interview guide is provided in Appendix A.

**Data Preparation**

Each interview was audio recorded and then  transcribed verbatim by a research assistant, and checked by the first author for accuracy against the audio recordings. Following each interview, the first author made additional field notes regarding the interview, issues discussed, emerging themes, the relationship between the new information and that gained from previous interviews, and issues to be discussed in future interviews with other participants.

**Analysis**

Analysis was conducted according to the procedures outlined by Braun and Clarke (2006). This approach focuses on abstraction, as opposed to description, of the data and involves iterative cycles of data collection and analysis (Creswell, 2007). The process is based on the principles of Grounded Theory (Strauss & Corbin, 1990), but constitutes a systematic and robust qualitative method in its own right (Braun & Clarke, 2006). Following each interview, the first author recorded his reflections including key issues requiring further exploration in future interviews. Once the interview recordings were transcribed, he read each transcript five times and documented his impressions. In doing so, preliminary codes, representing ideas, incidents, or recurring topics in the data, were then generated in a systematic manner and applied to the data using a constant comparative method (Crewell, 2007). This method entails comparing old data with new, in iterative cycles of data collection and analysis, in order to identify codes and then allow for categories and themes to emerge to account for the participants' experiences. A quote, for example, in which Carol explained that she felt the use of picture-based AAC systems helped adults with ASD understand language, was coded as 'supporting comprehension.' Through further analysis of subsequent interview transcripts, this code was then grouped with related codes to form the category 'Benefits for Self,' which in turn combined with the category 'Benefits for Others' to comprise the theme 'Proven Potential.' The themes were then reviewed and refined by the first

and second authors, in relation to the preliminary codes, the entire data set and the categories.

**Credibility**

To help ensure credibility through the research process, an audit trail of recordings, reflections, memos, and coding was created to enable the second author to review the process of enquiry (SAGE, 2006). In addition, we adopted Chiviotti and Piran's (2003) recommendations for ensuring credibility in qualitative research, which include (a) the need to specify the research aims, the basis on which participants were selected, and contexts in which data were collected; (b) the use of the participants' own words, where possible, to create codes, categories, and themes; (c) discussing the results with reference to the research literature; and (d) articulating the perspectives the research team brought to the study. To this end, the first and second author are both speech pathologists who work in the field of disability and believe that adults with complex communication needs have a right to effective communication supports, which may include assistance to develop natural communication skills (e.g., spoken language and gesture), augmentative communication, and/or communication partner training and environmental modifications. The third and fourth authors, who were not involved in analysis, but contributed to all other aspects of the manuscript, are also speech pathologists and involved in the delivery of the NECAS and are strong advocates for previous research examining the outcomes of the scheme.

**Results**

Two themes, comprising 5 categories, emerged to account for the participants'

experiences of AAC. The first theme, '*Proven Potential*,' emerged to account for the

benefits AAC reportedly provided, not only to the participants with ASD, but also to

their communication partners in everyday interactions. The second theme, '*Inconsistent*

*Action*,' accounted for the different, and at times contradictory, views and approaches of

those supporting the AAC implementation. In essence, the analysis revealed that

although support for AAC was common, uptake and support for AAC in everyday life

was inconsistent. The two themes, along with their associated categories are presented

in Figure 1 and described below using the participants' own words.

[Insert Figure 1 about here]

**Theme 1: 'Proven Potential'**

In analysing the transcripts, a common and consistent theme to emerge was the

potential for AAC to benefit not only adults with ASD, but also their communication

partners. Consequently, two categories - *Benefits for self* and *Benefits for others* –

emerged to capture the positive role AAC reportedly played in increasing independence,

supporting comprehension, and reducing anxiety amongst the adults with ASD, while at

the same time helping their communication partners understand, and better respond to,

their communication.

***Benefits for self***

The most common and frequently reported benefit of AAC identified by the support workers and family members was its role in supporting the comprehension of the adults with ASD. Carol, for example, explained that a visual timetable had helped Mary organise her thinking around activities that were due to occur on a given day or into the future.

> *Mary likes to know every month if there's a birthday, Anzac day, Valentines' Day. If she didn't have that [the timetable] she wouldn't know what's ahead. So she knows she's got to go to the doctor or the dentist. It's got when she goes to the gym… All that information, it keeps her happy. She knows what she's going to be doing on Saturday and Sunday. It's fantastic.*

Alex expressed a similar sentiment, in commenting on the positive role she felt a visual timetable had played in supporting Shane's comprehension.

> *He does this and it gives him order in his mind because it's structure, in a way. I think seeing the pictures too, helps him to confirm things in his mind that are going to happen. When you tell people, sometimes they [the instructions or explanations] are probably far too fast. It's too much information at times, but with this it's simple because this is what's happening today, and that's what I'm doing, and there's no confusion about it.*

When Carol was asked why she thought Mary found the visual timetable particularly useful, she suggested that the visual representation of language supported her comprehension.

> *People with autism don't understand spoken language and that's why we've got the little picture there.*

Adam, too, made a similar comment, in explaining why he felt the visual representation of language on Luke's visual timetable support his comprehension.

> *Adam: The difficulties Luke has is that he'll want to go to a coffee shop, but there's been problems, where they'll go down to a crowded shopping centre or a main street and say, 'pick your coffee shop'. It overwhelms him and he can't make a choice. He gets very funny about it and sometime gets aggressive.... Having those visual options in front of him, so he can make a decision, provides something more tangible to him. Basically, things that are more specific to his life.*
>
> *INT: What is it about having it in front of him?*
>
> *Adam: I think visual cues are more simple to him, something that is more tangible in his mind. A lot of the time I'll try to explain things to him but he just doesn't understand it. He doesn't get concepts of time like here and now. You'll tell him, 'in two days time', and he'll*

*think it's the next day. It's about having visual, simpler cue to*

*him.*

However, when asked if they felt the benefits of visual support are specific to adults with

ASD, both Carol and Adam disagreed.

*I think that would apply to all disabilities. I think anyone with*

*developmental delay, it wouldn't just be autism. (Carol)*

*I think people with disabilities in general do that… In this house I would*

*say everybody to some level, without having a diagnosis, has autistic*

*tendencies. They ask repetitive questions every day. Who's on tonight?*

*What are we doing? When are we going for coffee? And you'll answer*

*them and they'll ask you again half an hour later. It's reassurance*

*knowing what's coming with their day. (Adam)*

Through supporting comprehension, many of the support workers and family

members reported that the introduction of AAC had also helped to address the high

levels of anxiety experienced by the participants with ASD. Polly, for example,

explained that Susan had received a visual timetable as part of a broader plan to increase

her independence at home and reduce frequent behaviours of concern.

*Polly:  It's just wonderful now. Hardly any incidents reports, despite very*

*challenging times with some of them in the house. What would*

> *have driven her nuts before, she's coping really well with. Her*
> *tolerance is much greater.*

> *INT:*    *What role has the communication support played in those*
>         *changes?*

> *Polly:*  *She has reassurance, something that she can go to, and we can*
>         *redirect her to. We use it daily. She makes it up at night. You do it*
>         *at night time don't you Susan?*

> *Susan:*  *Yeah.*

> *Polly:*  *...It's reassurance for Susan that it's there. Her day is basically*
>         *trying to keep her anxiety levels down with reassurance.*

Janet reported a similar benefit for Greg, noting that the introduction of a chart displaying photos of staff rostered to work at his Community Access Service each day, had reduced his anxiety.

> *It benefits him by reinforcing. When he comes in he knows what he's*
> *going to do. He generally knows that, say, Wednesday is gardening.*
> *When there are staff or program changes it takes him a little while to get*
> *used to that. He would have different behaviour issues that he might try*
> *out on that [new] staff member. It's good having it, when there is a*
> *change in staff, to reinforce what you're doing.*

Although most of the participants' focused on the benefits of AAC in supporting comprehension and reducing anxiety, Alex also noted the positive impact that Shane's AAC supports had made on his confidence and independence. Shane had been provided with a set of community request cards, designed to support him to interact with staff and fellow patrons in shops, restaurants, and bars.

> Alex:   *I think that sort of gives him a feeling of being more independent*
>
> *because we're not having to do all this for him. He can sort of do*
>
> *it himself and he can pace himself and they're all learning steps*
>
> *for Shane to feel that he can do things for himself. Isn't that right*
>
> *Shane?*
>
> Shane: *(Shane nods his head in an affirmative gesture)*

To further explore the impact, Alex was asked how the same interactions might proceed if Shane did not have his cards when they walk up to order a drink at a bar.

> *Sometimes he [the person behind the bar] will look at me and I will say*
>
> *that Shane wants a drink, so then they change their focus on Shane. Then,*
>
> *sometimes when he [Shane] says he wants things, it's not quite clear*
>
> *[what he has said]. That's when I will have to step in if he hasn't got the*
>
> *cards to say that he'd like a beer. When we go with the card, I don't have*
>
> *to say that because he will say it, and I'll make sure he's got the card*
>
> *ready to show it. He usually gets a big smile.*

In demonstrating the way in which she believes AAC has increased Shane's independence and confidence, Alex also identified the potential for AAC to help unfamiliar communication partners engage in successful communicative interactions. Other support workers and family members expressed similar sentiments, leading to the emergence of the category '*Benefits for others*.'

### Benefits for others

Like Alex, Janet highlighted the potential for AAC to benefit the communication partners of adults with ASD. She recounted her recent experience of developing a set of request cards, based on those received from NECAS for Greg, to support another gentleman with ASD who attended Greg's community access service.

> *Recently, we made him some of those flip cards because a couple of*
> *times, we went into the butcher's and his plan was to buy a sausage roll*
> *or a burger to cook. Recently, we've made up, with Boardmaker™, a*
> *couple of different things on a key-chain. So he can show them to get*
> *across what he wants. That's something visual for the people across the*
> *counter.*

Sarah, on the other hand, focused on the positive role AAC can play in helping communication partners to recognise, understand, and respond to the communicative behaviours of adults with ASD, including signs of anxiety.

*This book, although Michael can use it to talk or to look through with*

*staff, but it's more about getting the staff all doing the same thing. At the*

*time, we didn't have regular staff so they would read this with him. It's*

*quite brief and the most important things are at the front. At the time, he*

*was really hurting people and being aggressive, so there were things they*

*needed to know straight away, like medical information and his*

*communication dictionary.*

When asked to elaborate on the ways in which Michael's chat book had been used, she explained that although it had the potential to help him share his interests and experiences (e.g., through photos of family, holidays, interests), she felt Michael tended to avoid social interactions.

*This is more beneficial as a staff aid rather than an aid for Michael*

*because he is not really that interested in sitting down and talking to*

*people. He chooses to be away from people. When we're all having a cup*

*of tea he'll take it away from the table and not have it with the other*

*people. So basically, it was more for the staff than it was for Michael. But*

*it was really important for Michael at the time. He really needed staff to*

*be doing the same thing and reacting quickly [when he was becoming*

*anxious].*

In summary, the support workers and family members identified a range of potential, and in many cases proven, benefits of AAC for the adults with ASD in this study and their communication partners. In particular, they highlighted the potential for AAC to support comprehension, reduce anxiety, and increase independence and confidence; while at the same time helping communication partners to recognise, understand, and respond to their communicative attempts. However, despite the common positive sentiments, the participants' reports also highlighted a range of inconsistencies in the views and actions of those responsible for supporting the adults with ASD in this study to utilise their AAC supports at home and in the community. These inconsistencies emerged to form the second theme: Inconsistent Action.

**Theme 2: 'Inconsistent Action'**

In analysing the support workers' and family members' accounts, it became clear that the adults had experienced very different paths towards accessing effective communication support, with inconsistent outcomes. Many of the differences, such as the degree of support provided and the extent to which communication aids had been updated, appeared related to time, knowledge, and skill barriers. These barriers, and in some cases solutions to them, were reflected in two related categories: '*Finding the time*' and '*Knowing what to do.*' Other differences, however, appeared to be more related to the individual views and attitudes of those involved in supporting the implementation of AAC. The differences in opinions, and actions, expressed by support

workers and family members regarding the role of AAC and its application in everyday settings, were captured in the third category: '*Lack of consensus.*'

### *Finding the time*

Although Sarah expressed strong personal support for AAC for adults with disability in her role as a support worker, she noted the practical challenge that comes with finding the time to develop and implement the aids. She singled out the important role Michael's mother played in helping to ensure he received his communication aids.

> *The main thing was the time it took. From the time we started thinking about getting an aid, it took quite a while, a few weeks, to get it done, and most of it was done by Michael's mum. If she hadn't have been there it probably wouldn't have been done.*

Indeed, when asked if other adults in Michael's house had received communication aids through NECAS, Sarah indicated that this had not occurred due to time constraints.

> *Michael is the only one that's got an aid from NECAS. It's more about how much paper work I've got, and how much time it takes. Everyone here could probably have an 'All about me' book. All of the guys here could use NECAS, but we haven't done it because there's not enough time. There's so much paperwork, so that's why.*

Although other support workers did not raise the issue of time specifically, many pointed to the difficulties associated with the rapid turnover of staff in disability

services, and the fact that many new staff lacked the knowledge, skills, and confidence necessary to effectively support the use of AAC.

***Knowing what to do***

Adam, in explaining that support for the use of Luke's communication aid had declined over the past four years, cited staff turnover and a lack of experience as key determining factors.

> *They (the aids) were made in 2007. I remember at that time they were used quite consistently at the start. Then they stopped being used as much. Newer staff that have come in over the past 5 years aren't as equipped to deal with this sort of stuff. They don't know what it means or understand its importance or relevance.*

Adam suggested that better, hands-on, training is needed to help new staff learn to support the use of AAC amongst adults with ASD.

> *I think it's useful showing people how to use it. Not just how, but why to use it…. It would be showing staff the importance and how it relates to the individual. For instance, talking to a staff member and relating to this individual, say to Luke, and talk about autism and why it's important, how it's important, what its benefits are.*

Sarah expressed similar sentiments, highlighting the importance of appropriate support, but also noting the difficulties she faced in accessing it.

*There's one speechie [speech pathologist] at [organisation name*

*withheld] and I put a request in recently but she hasn't called me back.*

*It'd be good if they had a speech therapist who would be able to come out*

*and meet the person and talk to staff to see what the person's needs are.*

Together, the support workers' reports indicate that the frequent turnover of staff, inadequate training, and inadequate support had a clear bearing on the extent to which the adults with ASD in this study were supported to use AAC, leading to inconsistent support, and at times, abandonment of AAC. However, their reports also indicate that the individual attitudes of those in a position to support their use of AAC also played a key role in determining the level of support provided.

### Lack of consensus

The participants' comments revealed a lack of consistency and consensus regarding the support provided to the adults with ASD to use AAC within and across different contexts, both at home and in the community. During the interview with Adam and Luke, for example, it was observed that a choice board had been stuck to the wall, presumably for the benefit of all residents requiring communication support. Yet, as Adam indicated, only some staff supported its use.

> INT:    *I notice you've got a choice board on the wall there. Is using*
>
>         *visual supports something that you've done throughout the house?*

*Adam: It depends on the staff. Some staff do that, who are better*

*equipped to do it.*

For Mary, a change of management at her community access program meant that the aids she was using were suddenly withdrawn, leading to inconsistency in support across settings and increased anxiety.

*There was a change in the organisation and there was a new manager,*

*they started changing everything. They thought clients didn't need*

*timetables anymore. I was against that because even though Mary knows*

*what's happening, if she feels anxious she always needs a backup. The*

*reason they stopped doing it was it involves time…. They don't think it's*

*important to have pictures. It's just crazy. (Carol)*

Polly suggested that a simple lack of interest may have been behind the decision not to support Susan's use of AAC at her work placement.

*They don't use a board there. They said it's not a problem. Perhaps they haven't*

*been interested in doing it.*

The results also suggested that, even as individuals, the support workers we interviewed were at times inconsistent in their views and support towards AAC. That is, while some expressed strong support for one mode of AAC, they were reluctant to consider other possible modes for the adult with ASD they supported due to their

personal views and judgements. Alex, for example, spoke of her preference towards simple activity-specific aids, rather than comprehensive communication supports.

> *We want things that are practical that you can take out into public*
> *without looking too ridiculous. You don't want to be out with a big folder,*
> *sticking things on. Little cards are very suitable because the person can*
> *have them in their wallet and because they're always there you've got*
> *them with you. The little cards are excellent because they're convenient.*
> *And if you keep them in that place they get used a lot more than the other*
> *things I'd say.*

When asked whether or not it might be helpful for an adult with ASD who uses little functional speech to have access to a comprehensive communication aid, Alex elaborated further, citing several practical reasons as well as the possible impact a 'bulky' AAC system might have on the way others viewed Shane.

> *I've seen those. I've seen people in McDonalds with these. We're trying to*
> *integrate people into the community. To me that's not the best way of*
> *doing it. But then again it might just work for that person. I feel for Shane*
> *this works better. I think he wouldn't like taking a big book with him. He*
> *would find that a nuisance. I think those cards are great because they are*
> *all on one key ring, all together, just excellent, especially out in the*
> *community. At home we've got books and different things so we can spell*

*it on the table. I think that's great. But in the community it has to be user*

*friendly. If Shane had to carry a book he would lose it or leave it*

*somewhere. And often I might not just have one person [to supervise], but*

*I might have five and everybody's got a bag and it could easily get lost.*

*It's just not practical.... It doesn't work. And because we're so big on*

*integration in the community and being part of the community you want*

*to be able to blend in a little bit too. That's a big thing for people as well.*

*I don't know where you draw the line. It's like putting labels on people*

*when you come with these big books…. Sometimes with the best of*

*intentions, we can actually put people in a more difficult position. It's*

*important to be more natural, something other people relate to more*

*easily.*

Janet also emphasised her preference towards keeping aids simple, to make it easier for

staff to support their use.

*They usually should be easy, shouldn't they? …You want it to be*

*something really simple. Easy to read and easy to use.*

## Discussion

The aim of our study was to explore the views and experiences of support

workers and family members regarding the outcomes of providing low-tech

communication aids to adults with ASD. Their views and experiences provide insights

into potential benefits and challenges associated with adults with ASD accessing AAC supports, and have implications for clinical practice.

The results revealed many potential, and some realised, benefits associated with the use of AAC. Findings were consistent with those of Iacono et al. (2012) from interviews of 15 adults with various types of disabilities who had accessed the NECAS, of whom many were able to participate in interviews themselves. Particular similarities were the benefits for the adults with ASD reported by support workers and family members in this study, including increased comprehension, reduced anxiety, and greater independence and confidence. Communication partners and staff reportedly benefited from the use of AAC, because the aids helped them to better understand the communication needs of the adults with ASD, and helped facilitate communicative interactions (e.g., ordering drinks at a bar) in the community. An important finding of this study was the emphasis placed on the use of AAC to support comprehension and to reduce anxiety, rather than to support expressive communication. Although only a small study, the findings both highlight the potential value of AAC in supporting the comprehension of adults with ASD, but appear to also point to a lack of support for these adults' expressive communication.

The results suggest several possible explanations for the support workers and family members focusing on the value of AAC in supporting comprehension. First, they were able to provide clear examples of where relatively simple strategies (e.g., use

of a visual timetable) had led to a dramatic reduction in anxiety and behaviours of

concern. Similar findings abound from research examining the outcomes of Functional

Communication Training, whereby new communicative behaviours are taught in order

to replace behaviours of concern (Sigafoos et al., 2009), and were also documented by

Iacono et al. (2012) following their interviews of adults about their experience of

NECAS aids. In essence, the results of this study provide support in the form of

qualitative data for previous empirical findings that AAC can provide a fast and

effective means for addressing problem behaviours.

      The fact that support workers and family members focused on the value of AAC

in supporting comprehension may also relate to suggestions by two support workers that

AAC aids should, in essence, be simple and easy to use. Presumably, learning to use

and to support the use of a visual timetable is easier than learning to support the use of a

comprehensive expressive communication system, particularly in the context of rapid

staff turn-over, inadequate staff training, and a lack of external support as reported by

participants. Communication partner instruction is known to be a critical component in

successful AAC intervention (Kent-Walsh and McNaughton, 2005), and although the

NECAS was co-ordinated by speech pathologists with expertise in AAC, they were

unable to provide direct assessments of the individual needs of each person referred to

the scheme or direct follow-up training (Iacono et al., 2011). The fact that key support

workers and family members focused on the benefits of comprehension supports may,

in part, simply reflect their preference for simple and easy to use systems in the absence of comprehensive assessments, and adequate training and support to implement the aids.

A third possible explanation for the focus on supporting comprehension, as opposed to expressive communication, may be inferred from Sarah's observation that Michael's chat book was used more for the benefit of staff, than for Michael, because he generally avoided social interactions. It may be that the inherent difficulties with social-communicative interactions experienced by individuals with ASD have the potential to lead communication partners, including family members and staff in disability services, to focus more on supporting comprehension (what others want to share with adults with ASD) than on working to provide them with an effective communication mode. While social-communication difficulties are a core feature of ASD (American Psychological Association, 2000), Mirenda (2008) argued that interventions aimed at supporting the social-communication interactions of individuals with ASD should be based on a presumption of the potential for competence, rather than assumptions regarding an individual's interests or abilities. In the context of this study, such an approach could mean expanding the AAC aids provided to the adults with ASD to include comprehensive communication supports.

**Clinical Implications**

The results reinforce the adage that simply providing communication aids is not enough, and that any attempt to support communication through AAC must also occur

with consideration of barriers relating to organisational policies and practices, as well as the knowledge, skills, and attitudes of all key stakeholders (Trembath et al., 2010, Kent-Walsh and McNaughton, 2005, Mirenda, 2008). Further, the results provide a new perspective on these issues, given that all participants received communication supports through the same scheme, and delivered by speech pathologists with expertise in AAC, albeit being limited in the extent to which they could provide supports (i.e., the funding does not include direct assessments or follow-up, see Iacono et al., 2011). The different outcomes for individual participants illustrate the impact of barriers to using AAC: Luke rarely used his communication aid, Alex had used his community request cards just a couple of days before the interview, and Mary had access to communication aids only at home but not her work place. They also highlight the ongoing value of professional support, training and education, the importance of consensus building, and the need for advocacy in order for adults with ASD to have access to effective, reliable, and sustained communication support: that is, beyond the receipt of an AAC aid.

**Limitations**

In considering the clinical implications for the study, care must be taken due to the small sample size. In qualitative research, the findings are intended to account for the participants' experiences, not to be generalised to the wider population. Nevertheless, important considerations are that the issues and experiences reported in this study may be unique to this group of participants, and not necessarily reflect those of other adults

with ASD in the wider community. Furthermore, despite the fact that we explicitly set out to capture a range of views and outcomes regarding AAC interventions for adults with ASD, both positive and negative, it is possible that the people who volunteered to participate in this study did so because of their positive views and experiences.

A further potential limitation of the study was our need to rely on reported diagnostic status based on previously documented assessment, rather than our own formal assessment that would provide current details of the participants with ASD's cognitive, communication, or adaptive behaviour skills. This lack of detailed information on participant skills further restricts potential to generalise beyond the current study. We also note that while the findings present the views and experiences of support workers and family members who knew the adults with ASD very well, the key limitation of this study is that we were unable to capture the individual perspective of the participants with ASD, due to their complex communication needs.

**Future Research Directions**

In considering possible future research directions, there is a clear need for a more comprehensive study investigating the provision of AAC supports to adults with ASD. Based on our findings, key issues requiring further exploration include (a) the factors influencing the decisions of family members, staff, and professionals in choosing from the range of communication aids available, particularly with respect to their role in supporting receptive versus expressive communication; (b) whether or not

there are particular learning style characteristics in adults with ASD, that may be particularly amenable to AAC; (c) the identification of factors that predict the best, and worst, outcomes of AAC provision to adults with ASD, and (d) the development and evaluation of strategies aimed at addressing these factors. A key challenge will be to develop strategies for better supporting the active involvement of adults with ASD in this research, through the provision of more effective communication support and the use of multiple sources of data, including interviews of multiple key stakeholders and observations where appropriate. Clearly, the ultimate goal of such research will be to develop practical strategies aimed at ensuring that adults with ASD themselves are able to make informed decisions about the communication supports they require, with only the level of support they desire.

**Conclusion**

This and previous studies indicate the likely benefit of low-tech AAC for adults with ASD. These aids have the potential to  support their comprehension and expression, as well as facilitate their interactions with family, friends, colleagues, staff in services they access, and members of the wider community. The views and perspectives expressed by support workers and family members in this study provide examples of the *Proven Potential* for AAC to have a positive impact on the lives of adults with ASD and others, but also the ways in which *Inconsistent Actions* can result from, and also lead to, barriers that impact on the long-term use and outcomes of AAC

for adults with ASD. The results highlight the need for a better understanding of the

benefits of, and barriers to, the provision of AAC supports to adults with ASD, as well

as the development and evaluation of strategies aimed at further improving outcomes.

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Table 1. Participant Characteristics

| | Mary | Michael | Greg | Susan | Luke | Shane |
|---|---|---|---|---|---|---|
| Chronological age group (years) | 30-40 | 30-40 | 30-40 | 50-60 | 20-30 | 30-40 |
| AAC prescribed | Activity schedule Calender Chat book | 'Book about me' | Visual timetable | Visual timetable | Visual timetable Staff photo board | Community request cards Weekly calendar |
| Living arrangements | At home with parents | CRU* | CRU | CRU | CRU | CRU |
| Interview partner/s | Mother | Support Worker | Support Worker | Sister and Support Worker | Support Worker | Support Worker |
| Community access program? | Yes | Yes | Yes | Yes | Yes | Yes |
| Description of communication modes and skills | Mary was able to answer yes/no or 'closed' questions on familiar topics (e.g., did you go to the theatre?) using mostly single words. However, she did not ask questions, make comments, or engage in reciprocal social communication. | Michael used a small number of words to respond to, but not to initiate, interactions. However, his responses to yes/no questions were inconsistent and he displayed behaviours of concern (e.g., biting) that staff believed were communicative. | Greg was able to provide brief answers to questions on familiar topics (e.g., where are you going tomorrow?) and made comments about his preferred interests (e.g., favourite singer). However, he did not engage in multi-turn reciprocal conversations. | Susan was able to provide brief answers to familiar questions (e.g., Where did you go on holidays?), but was inconsistent in her response to yes/no questions and she rarely initiated, or engaged in reciprocal, social conversations. | Luke responded to questions using 1-2 word phrases but was inconsistent in his response to yes/no questions. Throughout the interview, he repeatedly asked the same question to the interviewer and frequently made statements using stereotyped language. | Shane attempted to respond to yes/no and 'closed questions' (Did you help make your picture cards?) using a small number of words but did so inconsistently. Shane did not make any social overtures using language during the interview. |

* CRU = Community Residential Unit

Figure 1. The relationship between categories and themes accounting for the views and experiences of support workers and family members regarding the outcomes of providing low-tech communication aids to adults with ASD.
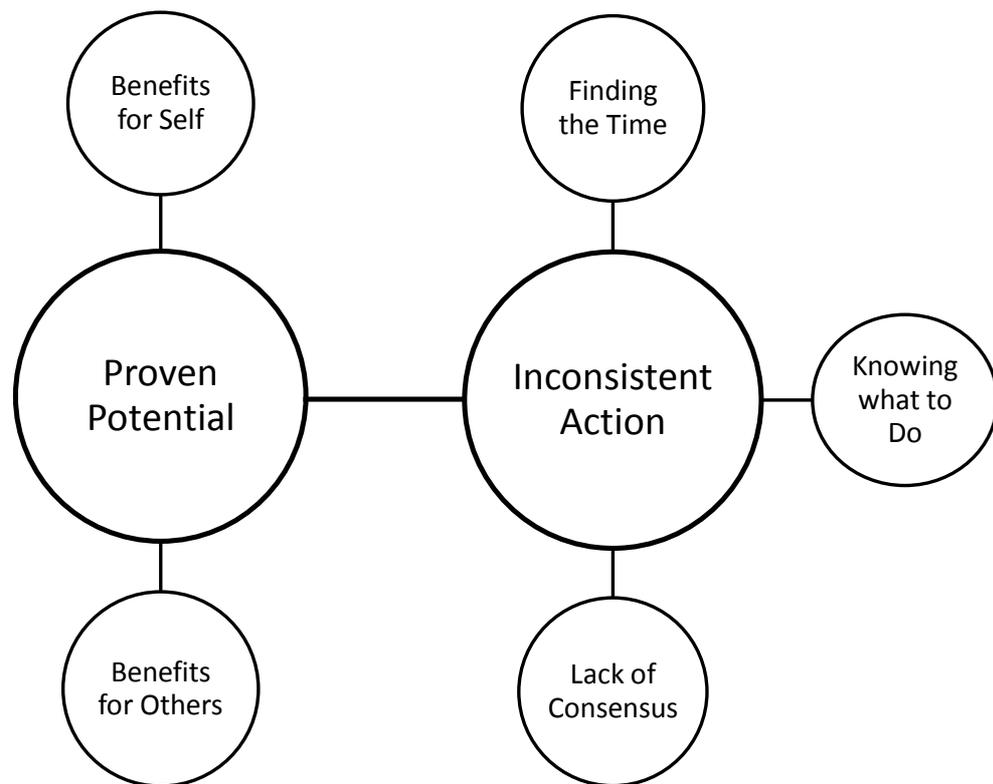
Appendix A

Semi-Structured Interview Guide

1. How long have you had this aid?
2. Do you have any other communication aids that you use?
3. When or where do you use the aid you got from NECAS?
4. Who do you use it with?
5. Can you tell me about when it seems to be really useful? Tell me about a time when its really been good to use it?
6. What about times when its not so useful? Tell me about a time when it just hasn't worked for you?
7. Overall, tell me about what having the aid has meant for you?
8. Would you like to see any changes to the aid? What sort? Why?
9. Would you like a different aid? What sort? Why?
10. How involved were you in choosing the aid you received? In its design (i.e., the vocabulary/ messages, how the messages were represented and size, how many messages there were)?
11. Does the communication aid fit your learning style? How?
12. What makes it easy to use?
13. What makes it hard to use?
14. If you were to have another aid requested from NECAS, would you want the process to happen differently? In what way?
15. Overall, can you talk about the difference, if any, having an aid from NECAS has made to your life?