



# Kent Academic Repository

Iacono, Teresa, Bould, Emma, Beadle?Brown, Julie and Bigby, Christine (2019) *An exploration of communication within active support for adults with high and low support needs*. *Journal of Applied Research in Intellectual Disabilities*, 32 (1). pp. 61-70. ISSN 1360-2322.

## Downloaded from

<https://kar.kent.ac.uk/71771/> The University of Kent's Academic Repository KAR

## The version of record is available from

<https://doi.org/10.1111/jar.12502>

## This document version

Publisher pdf

## DOI for this version

## Licence for this version

CC BY-NC-ND (Attribution-NonCommercial-NoDerivatives)

## Additional information

## Versions of research works

### Versions of Record

If this version is the version of record, it is the same as the published version available on the publisher's web site. Cite as the published version.

### Author Accepted Manuscripts

If this document is identified as the Author Accepted Manuscript it is the version after peer review but before type setting, copy editing or publisher branding. Cite as Surname, Initial. (Year) 'Title of article'. To be published in *Title of Journal*, Volume and issue numbers [peer-reviewed accepted version]. Available at: DOI or URL (Accessed: date).

## Enquiries

If you have questions about this document contact [ResearchSupport@kent.ac.uk](mailto:ResearchSupport@kent.ac.uk). Please include the URL of the record in KAR. If you believe that your, or a third party's rights have been compromised through this document please see our [Take Down policy](https://www.kent.ac.uk/guides/kar-the-kent-academic-repository#policies) (available from <https://www.kent.ac.uk/guides/kar-the-kent-academic-repository#policies>).

# An exploration of communication within active support for adults with high and low support needs

Teresa Iacono<sup>1</sup>  | Emma Bould<sup>1</sup>  | Julie Beadle-Brown<sup>2</sup>  | Christine Bigby<sup>1</sup> 

<sup>1</sup>Living with Disability Research Centre, La Trobe University, Bendigo, Vic., Australia

<sup>2</sup>Living with Disability Research Centre & Tizard Centre, University of Kent, Canterbury, UK

## Correspondence

Teresa Iacono, Living with Disability Research Centre, La Trobe University, PO Box 199, Bendigo, Vic., Australia.  
Email: t.iacono@latrobe.edu.au

## Funding information

Australian Research Council, Grant/Award Number: LP130100189

## Abstract

**Background:** The aim was to explore the relationship between quality of active support and communication support for people in group homes with high and low support needs.

**Methods:** Data from 182 service users, 20–81 years (mean = 40), 89 with high support needs, were observed to have either good ( $n = 142$ ) or poor ( $n = 40$ ) communication support. Measures were of quality of active support, engagement and staff contact; field notes provided examples of good and poor communication supports.

**Results:** We found a relationship between the quality of communication support and active support. Receiving good communication was associated with higher levels of engagement. Field notes included some examples of appropriate communication supports, but limited use of augmentative and alternative communication (AAC).

**Conclusions:** Staff show limited use of appropriate communication with people having high support needs who require AAC. Strategies to improve quality of practice are discussed.

## KEYWORDS

active support, augmentative and alternative communication, engagement, intellectual disability, supported accommodation

## 1 | INTRODUCTION

Adults with intellectual disability often have complex communication profiles. For adults with severe to profound disability, in particular, communication can vary from unintentional behaviours (i.e., no evidence of a goal or being directed towards another person), but which can be interpreted as being communicative, demonstrated through body movements and facial expressions, to limited symbolic skills, demonstrated through the use of spoken words, pictures or signs (Iacono, Bloomberg, & West, 2005; Iacono, West, Bloomberg, & Johnson, 2009; Johnson, Douglas, Bigby, & Iacono, 2011; Ogletree, Bartholomew, Wagaman, Genz, & Reisinger, 2012). As a result, supporting their experience of meaningful interactions requires skill in interpreting and responding to communicative behaviours that may or may not be in a conventional form. In terms of the support provided in

disability services, Mansell (2010) noted that “Staff need to be able to recognise and respond to the full range of communication, including eye-movements, facial expression and body language” (p. 12).

The extent to which disability support staff are able to provide communication support to adults with severe to profound intellectual disability has been explored in previous research. Staff have been found often to be unresponsive to the communication attempts of people who rely on non-speech or non-symbolic communication (Schepis & Reid, 1994). Further, they can find it difficult to adjust their communication to the needs of the people they support (Bradshaw, 2001; Zilber et al., 1994), but may derive only limited benefit from training to increase their responsiveness (Bloomberg, West, & Iacono, 2003; Purcell, McConkey, & Morris, 2000).

On the other hand, there has been some research to indicate that at least some staff demonstrate skilled and/or sensitive

This is an open access article under the terms of the Creative Commons Attribution-NonCommercial-NoDerivs License, which permits use and distribution in any medium, provided the original work is properly cited, the use is non-commercial and no modifications or adaptations are made.

© 2018 The Authors. *Journal of Applied Research in Intellectual Disabilities* Published by John Wiley & Sons Ltd.

interactions with adults who have limited or no speech, even without training. Antonsson, Astrom, Lundstrom, and Graneheim (2013) provided examples of skilled communication support. They described disability support staff adjusting their language to the individual, ensuring that their communication was directly relevant to an ongoing activity, and using signs and body language to facilitate understanding. Similarly, Johnson and colleagues (Johnson, Douglas, Bigby, & Iacono, 2012; Johnson et al., 2011) observed some disability support staff adjusting their own communication to meet the needs of people with limited communication. Johnson et al. (2012) followed a grounded theory approach with data from extended observations and interviews for six adults with severe intellectual disability and people with whom they shared positive relationships (mostly family and staff). They found that adjusting communication was part of being willing to connect with the individual. Such willingness to connect was also observed by Antonsson et al. (2013), who further noted that staff were attentive to the adult they supported, showed genuine interest in them as individuals and the activity in which they were engaged, and demonstrated interpersonal warmth.

According to Mansell and Beadle-Brown (2012), supporting a person with intellectual disability to engage in social interactions is a feature of active support. Using this approach, disability support staff are trained to increase the quality of supports they provide throughout each day by focusing on enabling service users to engage in meaningful activities and relationships (Mansell & Beadle-Brown, 2012). A growing body of research has shown improvements in quality of life domains for service users through the consistent use of active support, particularly in increasing rates of engagement to ameliorate the almost total lack of activity reminiscent of institutionalized care (Jones et al., 2001; Mansell, Beadle-Brown, Whelton, Beckett, & Hutchinson, 2008; Mansell, Elliott, Beadle-Brown, Ashman, & Macdonald, 2002; Stancliffe, Harman, Toogood, & McVilly, 2007, 2008).

Being trained in active support includes learning to communicate at a level appropriate for each service user, and ensuring access and opportunity to use various forms of augmentative and alternative communication (AAC), such as gestures, signs, objects and pictures (Mansell & Beadle-Brown, 2012; Mansell, Beadle-Brown, Ashman, & Ockendon, 2005). In fact, the Active Support Measure (ASM) used in many studies to determine the quality of support provided by staff (see Mansell & Beadle-Brown, 2012) includes items of direct relevance to communication. These address the extent to which the speech of staff matches the developmental needs of the service user, and staff responses to the communicative behaviours of service users. Also included in the ASM are items (i) addressing the interpersonal warmth of disability support staff, reflecting positive interactions and respect for the service user; and (ii) opportunities for choice, relating to self-determination in everyday activities and requiring a means to indicate choice. The ASM is completed at the end of a 2-hr observation period, during which a momentary time-sampling measure of engagement in meaningful activities and

relationships (EMAC-R) (Mansell & Beadle-Brown, 2005) is used to determine the level of service user engagement and staff contact, including simple contact (e.g., pushing someone's wheelchair, giving medication) and assistance with the aim of engagement in meaningful activity and relationships (e.g., prompting a person to place an item in a dishwasher). The availability of appropriate communication supports, such as pictures or objects of reference, or use of signs by service users is also noted by observers.

Bradshaw, Beadle-Brown, Leigh, Whelton, and Richardson (2014) conducted the only previous study that focused specifically on communication support in houses in which active support was being implemented. They found that good active support was associated with the provision of appropriate communication supports for service users, including those with high support needs. Bradshaw et al. reported that of the service users who had severe to profound intellectual disability, 76% were reported by staff not to use speech and 26% not to understand spoken communication. Observational data showed that during only 28% of the time, staff directed speech to service users that matched their communication abilities, and they consistently responded to the communication of less than half (43%) of service users. In houses with good active support, defined according to exceeding a threshold of 66.66% (of a maximum score of 45) on the ASM (see Mansell, Beadle-Brown, & Bigby, 2013), staff communication was consistently appropriate. In contrast, in houses with mixed or weak active support, staff communication was appropriate less than 50% of the time. In relation to AAC, it was used effectively in interactions between staff and service users only a third of the time, even in houses with good active support, and rarely (0.9%) in houses with mixed or weak levels of active support (Bradshaw et al., 2014).

It would seem from Bradshaw et al.'s (2014) data that the provision of good active support may be reliant, at least to some extent, on the skill of disability staff in supporting the communication of people with severe to profound intellectual disability. Although their findings suggest that training in active support can enhance this ability, the difficulty of the task was still evident. In the majority of houses with good active support, the provision of good and appropriate communication supports was not consistent, even though the complexity of communication directed by staff was reportedly appropriate to the communication level of the service users.

Exploring the potential difficulties in providing skilled communication support may go some way towards understanding findings that service users with severe to profound levels of intellectual disability, who are in greater need of support, are less likely to receive facilitative staff contact than are more able service users (Jones et al., 1999; Mansell et al., 2008; Mansell et al., 2013). From the work of Bradshaw and colleagues (2014), the provision of communication support relies on staff providing service users with access to a means of communication, and being sensitive and responsive to service user communication. Appropriate forms of communication for service users with limited or no speech skills includes various types of AAC. Furthermore, Mansell and Beadle-Brown (2012) noted the complementarity of a

total communication approach to active support, whereby all means of communication are responded to and used by support staff.

In this study, we explored the potential role of communication in active support for service users with high and low support needs using data from a current Australian longitudinal study, first reported by Mansell et al. (2013) and more recently by (Bigby, Bould, & Beadle-Brown, 2017; Bould, Beadle-Brown, Bigby, & Iacono, 2018a, 2018b). We addressed the research question: Are there relationships between measures of service user engagement and contact from staff, quality of active support, and staff provision of appropriate and effective communication support. In addition, examples from field notes were included to further understanding of communication supports provided by staff.

## 2 | METHOD

### 2.1 | Participants and settings

Data were available for 182 of a total of 246 service users from 54 houses, each of which accommodated 1–9 service users. These houses were from nine disability organizations that had agreed to participate in the longitudinal study. They were from four Australian states: Victoria, New South Wales, Queensland and South Australia. The data included were collected during one year of the study (2015) and were from 84 males and 98 females, aged 19–81 (mean = 44). Following previous active support research (see Mansell & Beadle-Brown, 2012), service users were classified as having high or low support needs on the basis of their scores on the short form of the Adaptive Behaviour Scale (SABS) Part 1 (Hatton et al., 2001). Of the service users, 89 (49%) had high support needs (i.e., a score of less than 151); they were aged 19–78 years (mean = 48). The remainder 93 (51%) participants had low support needs (i.e., score of 151+ on the SABS); they were aged 20–81 (mean = 40). Approval for the study was obtained from La Trobe University Human Research Ethics Committee.

### 2.2 | Measures

Of relevance to this study were the results of a number of measures completed for the longitudinal study in relation to each service user. Adaptive behaviour, measured using the SABS, provided an overall score used to determine level of support needs (Hatton et al., 2001). Data from two specific items indicated general receptive and expressive communication skills according to staff report. The EMAC-R provided a measure of service user engagement, as well as contact by staff in the form of either assistance to engage in meaningful activity and relationships, or other simpler forms of contact by staff or other service users. Over a 2-hr period, each consenting service user present at the time of the observation was observed in rotating 5-min blocks by trained observers. At 1-min intervals, the researcher coded according to three activity categories (e.g., social interactions), two staff contact categories (contact or assistance) and four categories

of challenging behaviour (self-stimulatory, self-injurious, aggressive or destructive and other challenging behaviour, such as inappropriate sounds or social approaches). The ASM provided a measure of the quality of active support according to observer judgements. It included 15 items addressing the opportunities staff provided service users to be involved in meaningful activities and relationships, and the skills of staff. It was completed at the end of the observation period for the EMAC-R. Further details on the ASM and EMAC-R and their administration can be found in (Bigby et al., 2017).

An audit questionnaire package completed by staff also contained items about service user communication, including whether they used speech or any form of AAC (from a checklist). Finally, at the end of the 2-hr observation after completion of the ASM, observers also made an overall judgement of the extent to which staff used communication that was (i) appropriate to the communication level of the individual, either through their use of speech or non-speech means, in particular AAC (i.e., signs, pictures, gestures, photos or objects of reference); and (ii) effective in terms of whether the service user response indicated his/her understanding. A rating scale of 0–4 was used, anchored by no communication was appropriate and effective, and all communication was appropriate and effective. Good communication was defined as the combined ratings of 3 and 4 (most and all communication appropriate and effective); poor communication was combined ratings of 1 and 2 (no or some).

Observations were conducted by a team of four observers, including the second author who, along with the third and fourth authors trained the others. Just over half (51%) the observations were completed by one person. Inter-rater reliability on the 13 EMAC-R categories was available for 206 min and was shown to be high (Kappa 0.94, range 0.80–1.00). Percentage observer agreement on the ASM was 66% on average (range 20–100%,  $n = 15$ ), and the average Kappa was 0.55 (range 0.33–1.00). While agreement was low for some ASM items, a percentage of the maximum score (45) was calculated for each observer across all 15 items, and there were no significant differences found for the overall ASM scores,  $t(19) = 0.975$ ,  $p = 0.85$ . In terms of the observer judgement about the nature and appropriateness of staff communication level, inter-rater reliability was available for 15 service users observed and percentage agreement was 80% (Kappa = 0.62).

Additional data were from field notes made by the observers at the end of the observation and scoring period. These provided example descriptions of interactions, including how disability support staff responded to and supported service user communication. They also provided details of any communication supports, including forms of AAC, available to and used by service users.

### 2.3 | Procedure

Consent was gained from service users, or, for those without capacity for consent, from a person who usually made decisions for

them as approved by the HREC, and typically included a parent or senior staff member of the service. In addition, questionnaires were sent to each service for a staff member who knew the individual well to complete. Pre-paid envelopes were provided for direct return to the research team. A researcher visited each service to conduct the EMAC-R observation and the ASM. The researcher also recorded judgements about whether during this observation staff communication to each service user was appropriate and effective.

## 2.4 | Analyses

Data were entered into IBM SPSS Statistics 23. Differences in quality of support and engagement, and associations with the provision of appropriate and effective communication support were analysed using both descriptive and inferential statistics. Differences were explored according to whether service users had high (ABS below 151) or low (ABS of 151+) support needs.

## 3 | RESULTS

### 3.1 | Communication

#### 3.1.1 | Staff report on the SABS

Data from staff responses to items on the SABS about receptive and expressive communication are presented in Table 1. These data

**TABLE 1** Staff reported (SABS) communication of service users according to level of support needs

	High support needs (151 or less on SABS)		Low support needs (>151 on SABS)	
	<i>n</i>	%	<i>n</i>	%
Receptive communication				
Unable to understand simple communication	16	20.0	0	0
Responds correctly to simple phrases	28	35.4	2	2.2
Answers simple question	20	25.3	20	21.7
Understands information involving a series of steps	14	17.7	49	53.3
Understands complex information involving a decision	1	1.3	21	22.8
Expressive communication				
Communicates with sounds or is nonverbal	50	59.5	1	1.1
Speaks in simple sentences	25	29.8	24	26.1
Asks questions using words	7	8.3	31	33.7
Sometimes uses complex sentences	2	2.4	36	39.1

show that most service users with low support needs were reported to be able to understand sequential or complex communication, and most used speech to communicate. In contrast, over half the service users with high support needs reportedly could understand only simple phrases or questions, with many unable to understand simple communication; over half did not use speech to communicate.

#### 3.1.2 | Communication modalities

Presented in Table 2 are summary data for the communication modalities used by services users as reported by staff on the audit questionnaire and observed during data collection. These modalities were speech, gestures and various forms of AAC (objects of reference, signs, and symbols, including on communication aids). It is evident from this table that a variety of means other than speech were both reported and observed to be used by service users with both low and high support needs. Differences are evident across reported and observed use of various modalities, with the exception of service users with high support needs who used speech only or signs. The nonparametric measure of difference between proportions (i.e., percentages), the McNemar test for measures repeated across reported and observed, was conducted (Siegel & Castellan, 1988). Bonferroni's adjustment for familywise error (i.e., a *p* value of 0.05 was divided by 6, the number of comparisons made) was applied, to reduce the likelihood of a chance finding of significance (Pallant, 2007). As shown in Table 2, significant differences were found, such that staff reported more support service users with high support needs used gestures, symbols and signs than were observed to use these modalities. Significant differences for support service users with low support needs were found in the use of gestures and objects of reference, and, while significance could not be determined for symbol use, over half were reported to use them, but none were observed using them. It was also noted by observers that for 10 service users in this group, no communication interactions were observed during the 2-hr period.

Summary data for observer ratings of the communication used by staff with service users are also presented in Table 2. It is evident that almost all service users (*n* = 89; 96%) with low support needs received good communication, while 60% (*n* = 53) of those with high support needs did so.

### 3.2 | Quality of active support, levels of engagement and staff contact

Table 3 provides the mean and range for the ASM scores for service users provided with good versus poor communication, across the groups with high versus low support needs. It is evident that levels of active support were higher for service users with high and low support needs when good communication was provided (mean ASM of 63% and 72, respectively). Using a conservative *p* of 0.01 in the light of the multiple comparisons (i.e., to control for familywise error), the difference in the ASM scores when good

**TABLE 2** Staff reported communication modalities and modality and appropriate communication use observed by researchers according to service user level of support needs

	High support needs (n = 89)					Low support needs (n = 93)				
	Reported		Observed		McNemar	Reported		Observed		McNemar
	n	%	n	%	p	n	%	n	%	p
Gestures	54	60.7	33	37.1	0.001*	40	43	12	12.0	0.000*
Objects of reference	19	21.3	6	6.7	0.007	16	17.2	3	3.2	0.002*
Symbols	53	59.6	2	2.2	0.000*	54	58.1	0	0	NC
Signs	32	36.0	4	4.5	0.000*	14	15.1	5	5.4	0.049
Speech only	21	23.6	21	23.6	1.0	83	89.2	72	77.4	0.019
Staff communication appropriate <sup>a</sup>	-	-	53	59.6	-	-	-	89	95.7	-

Notes. NC: not computed because of violations of requirements for the McNemar.

<sup>a</sup>Observed only.

\* $p < 0.005$ .

**TABLE 3** Quality of active support, overall levels of engagement (including percentage of time spent in social and non-social activity) and percentage of time receiving contact from staff, for service users with high and low support needs by level of communication support

		High support needs (151 or less on SABS)			Low support needs (>151 on SABS)		
		Good communication (n = 53)	Poor communication (n = 36)	Statistical comparisons	Good communication (n = 89)	Poor communication (n = 4)	Statistical comparisons
ASM score	Mean	63%	42%	$z = -4.768$	72%	49%	$p = 0.037$
	Range	18%-100%	13%-78%	$p = 0.0001$	25%-92%	18%-74%	
	SD	18%	19%		15%	23%	
Time spent engaged overall	Mean	46%	22%	$z = -4.916$	77%	48%	$p = 0.035$
	Range	3%-92%	0%-88%	$p = 0.0001$	16%-100%	17%-82%	
	SD	21%	23%		20%	29%	
Social activity	Mean	15%	3%	$z = -4.425$	21%	12%	$p = 0.183$
	Range	0%-63%	0%-12%	$p = 0.0001$	0%-61%	0%-35%	
	SD	15%	4%		16%	17%	
Non-social activity	Mean	32%	19%	$z = -3.285$	61%	36%	$p = 0.052$
	Range	0%-92%	0%-79%	$p = 0.001$	9%-100%	6%-60%	
	SD	23%	23%		22%	23%	
Staff contact	Mean	25%	23%	$p = 0.789$	20%	15%	$p = 0.628$
	Range	0%-66%	0%-52%		0%-68%	3%-35%	
	SD	19%	16%		17%	14%	

Note. z scores are reported only for significant comparisons.

vs. poor communication was provided was found to be significant for the high support needs group only using the nonparametric Mann-Whitney test for independent samples (Siegel & Castellan, 1988).

Also presented in Table 3 are summary data for levels of engagement and staff contact (including assistance), as measured on the EMAC-R. These data show that time spent engaged for service users, overall, and specifically in social and non-social activity, was least for service users with high support needs with poor communication

provided, and most for those with low support needs provided with good communication. Staff contact varied relatively little across the groups in terms of means and ranges of percentage of time in which service users received contact from staff. The difference across service users provided with good versus poor communication was significant for those with high support needs, only, according to the Mann-Whitney test. Further, this difference was significant for time spent engaged, and engagement in social and non-social activities, but not for staff contact.



### 3.3 | Field notes

The quantitative data indicate a pattern of higher active support and engagement when staff used appropriate communication. In order to understand reasons for these patterns, we turned to the field notes for the following information: the use of AAC or other means of communication support; the level of communication directed to service users by staff, and staff responsiveness to service user communication attempts; and indicators of warmth in support staff–service user interactions. Entries into field notes providing both good and poor practices along these parameters were extracted. To ensure confidentiality, all names of service users and staff have been de-identified and all genders referred to as male.

### 3.4 | Supporting communication

Most examples of good communication supports were in the use of objects of reference from which a service user could make a choice, usually by pointing or reaching for the object, and mostly to choose between two food or drink items, as in the following example:

*[Service user] was offered a choice of two drinks, milk or orange juice, placed in front of him. This was effective as [service user] pointed to the one he wanted.*

However, this method of offering choice was not effective for all service users as illustrated in the following example:

*[Service user] was asked to choose a DVD, and two DVDs were put in front of him. He did not seem able to make a decision.*

There were other examples of staff members adjusting the communication used when it appeared the service user did not understand what was being asked. In the following example, the staff member combined speech with gestures and objects of reference to facilitate understanding:

*[Service user] was asked whether he wanted to assist with making a salad now or after the TV show, however, it was unclear if he understood because he did not respond. However, soon after, the staff member began pointing to his watch as well as the TV to supplement the verbal question. He also bent down to get to [service user's] eye level to make eye contact, at which point [service user] nodded when the staff member asked again if he wanted to make the salad now. When the staff member asked [service user] what he wanted to put in the salad, this question was not answered. The staff member then followed this question by leading [service user] to the fridge, opening the fridge and the fridge drawers and asking*

*"anything else?" At this point [service user] was able to pick out another vegetable that he wanted to add to the salad.*

In the following example, a staff member demonstrated paying attention to a service user's non-verbal signals to support him to choose a drink: "okay, smile if you want to have tea." In the following field note, a staff member supported a service user in an activity, providing spoken and non-verbal prompts:

*The staff member pointed to different parts of a puzzle and gave some prompts "do you know where that one goes, that one?" And also some encouragement—"you can do it." [Service user] occasionally stopped and looked at the staff member for further prompts. The staff member communicated at one point "where does that one go, you show me, you can do it."*

In another field note, the staff member kept conversations short (<20 s), and asked questions so that the service user was able to respond yes or no, and this seemed to be effective. There were also some examples of staff responding to service user behaviours that may have been communicative:

*A staff member in the kitchen asked "would you like some music on [service user]?" However, given the staff member needed to see his arm movement to know whether he had responded yes or no, the staff member then walked over to him and asked the question again, and on raising his hands said "you would" and wheeled him over to the stereo at the end of the dining room.*

In another field note, it was noted that a service user had access to a communication aid, and while the staff member used some signs to ask the service user "do you want a drink?" there were missed opportunities to further the interaction:

*[Service user] yelled out during the observation and the researcher observed him to spell out words using a plastic QWERTY keyboard. A couple of times the staff member went over and spoke with [service user] after he yelled out, though at other times he was ignored or not acknowledged.*

There were other examples of poor communication that did not address the service user's needs:

*[Service user] repeatedly asked who was on sleepover tonight. There was a "whose here today board," and the staff member kept directing him to that. However, there was no picture of tonight's staff member, there was just his name on a card. As [service user] cannot read, this was likely to be of no assistance to him. No*

*other attempt to answer [service user's] question was made.*

Little use of other AAC was evident with some service users who were non-speaking. There was one exception—a staff member working with a service user who was deaf used signs and other forms of communication supports:

*A staff member signed to [service user] on his arrival, explaining who the observer was. [Service user] signalled something and the staff member said “oh, you want your board” referring to the Etch a Sketch™ he had. The staff used this as another means to communicate with [service user].*

The lack of access to or ineffective use of AAC, including objects of reference, appeared to detract from choice making. Some staff provided too many options when offering choices, with no objects of reference to clarify and the service user being unable to respond. In the following field note, it is evident that the staff member was looking to the service user to make a choice, but without providing the means to do so by failing to use an appropriate level of language for this service user with high support needs:

*After [service user] came into the house, the staff member went over to him and asked “what would you like to do, go for a walk, or have a drink?” [Service user] is non-verbal so there was no way he could answer this question.*

There were also examples of disregarding clear communication, including use of AAC. In the following example, the staff member failed to respect a choice being made by the service user:

*[Service user] handed staff a communication card with a pictured headphone, to which the staff member said “you can have your iPod™ after dinner.”*

Also noted in field notes was a reliance on spoken communication, when gestures and demonstrations for instructions could have been beneficial, and there was sometimes a tendency to provide too much information or instruction. Such verbalization often was beyond the communication level of the service user, with the potential to also disrupt the service user's ability to participate in an activity, as illustrated in the following example:

*Staff were providing hand-over-hand assistance to [service user] to chop fruit, but there was too much chat from the staff member, and lots of unnecessary explanation, for example “okay, I'll leave you with that spoon and I'll get another spoon ... you need to have a little taste and see what you think.” At this, without notice, the staff member spooned some of the fruit/yogurt snack into [service user's] mouth.*

Good examples of communication supports appeared associated with interpersonal warmth between staff and service users, such as sharing through both communication and sensory means, for example:

*[Service user's] wheelchair tray had yes/no symbols which were used by a staff member when asking if he wanted to help get the clothes off the line outside. [Service user] put his hand up to indicate “no.” The staff member then asked “do you want to come and sit outside and watch me?” The staff member then wheeled [service user] outside, and as he was taking clothes off the line, he held clothes to [service user] to touch and asked “do you think it is dry?” The staff member talked to [service user] all the time, and put the folded clothes on his tray.*

*The staff member was reading [service user's] communication book, and although he was not able to read the communication book, the staff member was creating conversation to engage with [service user], demonstrating great rapport. The staff member was very expressive and showed enthusiasm and excitement, which [service user] was observed responding to with lots of smiling and laughter.*

Conversely, there were examples of poor communication and lack of warmth on the part of staff, for example:

*[Service user] was told by a staff member to “sit ... siiiiiit!!” The staff member then held up an index finger and instructed the service user to “staaaay” while the staff member went inside. On returning with a bowl of jelly and fruit, the staff member asked the service user “what do you say?” and pulled the bowl away. This action was repeated until the service user signed “thank-you” by tapping on his chin.<sup>1</sup>*

## 4 | DISCUSSION

Exploration of data collected about communication supports in Australian group homes as part of a larger study about active support suggest that skilled communication support was only infrequently apparent. This was especially the case for people with high support needs who relied on non-speech modes of communication. Mansell et al. (2008) suggested that changing a person's quality of life must be addressed through skilled support. For people with the most severe disabilities, a focus on supporting communication may be in order. There was some evidence from our data that active support and levels of engagement are better when appropriate communication support is received; the causality dilemma is which came

<sup>1</sup>In accordance with the ethical regime of the study, this and other examples of staff behaviours judged to cross over the boundary between poor and abusive practice, were reported directly to the Chief Executive Officer of the organization.



first, better active support or more appropriate communication support? Or perhaps the two are so closely intertwined to render them inseparable in support worker practice: that is, good communication support is an integral part of good active support.

We found evidence of a relationship between having good communication support, and both quality of active support and level of engagement. This relationship was most evident for service users with high support needs, such that those receiving poor communication supports also received poor active support and were less likely to be engaged overall. A similar, but non-significant pattern was evident for service users with low support needs. Of note was a tendency for staff to report much greater use of non-speech modes of communication, including informal (non-symbolic) objects of reference and gestures and more formal AAC, in the form of signs and symbols, than was observed. This difference may reflect simply a lack of opportunity to demonstrate use of varied forms of communication. But limited opportunity would seem a direct outcome of poor support and engagement, especially for service users with high support needs, 10 of whom were not observed to communicate at all with a staff member during the two hours of observation. A further explanation may be a tendency of staff to over-report the use of varied non-speech forms of communication. The agreement across reported and observed use of speech only and not for other modalities, evident for the service users with high support needs in particular, suggests that staff may be more attuned to spoken than other forms of communication (Schepis & Reid, 1994). This better attunement to speech, in turn, may contribute to better support of and engagement with service users with low support needs who almost all relied on speech.

The quantitative data provide support for the argument by Bradshaw et al. (2014) that skilled active support is associated with the ability to support the communication of service users with the greatest need. Our quantitative data and field notes provide some insights into the availability and effective use of AAC. We found examples of effective use of objects of reference, largely in relation to creating the opportunity and means with which to choose between food and drink options. There was, however, limited evidence of access to varied types of AAC, no doubt contributing to a failure to observe their use. A tendency to abandon or forget to provide access to AAC that has been designed for an individual is well-known anecdotally and in the AAC literature (Iacono, Lyon, West, & Johnson, 2013). Notable, however, was the example of sign use with a service user who was deaf. This example may point to associating signs with the Deaf community, thereby increasing the willingness of staff to learn and engage in signed interactions, but without realizing their potential use and benefits for others with severe intellectual disability (Johnson et al., 2012).

A further pattern evident from the field notes was staff failing to detect and/or respond to service user communicative behaviours, perhaps because of a combination of not recognising them as communicative, not knowing how to interpret them, or choosing not to respond. Certainly, interpreting the possible meaning of unconventional communicative forms demonstrated by people with severe to profound intellectual disability can prove challenging (Bloomberg et al., 2003; Bradshaw, 2001; Purcell et al., 2000; Schepis & Reid, 1994). Fortunately, there were

examples of staff engaging in problem solving (e.g., eliminating options as a service user rejected them until a final choice was made) and in being aware of idiosyncratic communicative behaviours (e.g., looking for a service user's arm movements to signal rejection).

## 4.1 | Implications

Overall, findings from this study revealed a pattern whereby active support and engagement levels were better when appropriate communication support was received. This finding would suggest more attention needs to be paid to helping staff develop their skills in using various forms of AAC and informal non-speech modes (e.g., gestures) within the context of supporting engagement in real, easily available activities: that is, as part of the active support. Staff also need to be creative and think differently sometimes about what AAC might look like. Training in active support may need to emphasize more strongly strategies for supporting communication. The following principles are recommended: (i) ensure access to varied forms of AAC through their visible presence throughout the house, (ii) provide service users with the help and opportunity to use them regularly as a means of supporting engagement, and (iii) respond to the message communicated. Hence, observed examples of poor practice, such as providing options that cannot be honoured, can be corrected to good examples, such as offering only genuine options that staff are in a position to respect. These principles are already embedded in active support (Mansell & Beadle-Brown, 2012), but may need a greater focus in practice with adults with high support needs in order to optimize the potential for improvements in their quality of life, thereby fulfilling the ultimate goal of this intervention.

As is the case with other forms of practice-based approaches, training is only one part of the solution. Staff also need to see people as worthwhile communication partners (Antonsson et al., 2013; Johnson et al., 2012) and have ongoing support and motivation to continue to use methods of AAC that have been found to work for individuals they support. The need to provide the models, support and motivations has implications for the focus and skills of those providing practice leadership.

## ACKNOWLEDGMENTS

Thanks are extended to the disability services participating in this study, and to research assistants Samuel Murray, Emma Caruana and Lincoln Humphreys. Funding support was from the Australian Research Council Linkage Grant LP130100189 and partner disability services. Parts of this study have been presented at the International Association of Scientific Study into Intellectual & Developmental Disabilities European Congress (Vienna, 2014) and Americas Regional Congress (Honolulu, 2015).

## CONFLICT OF INTEREST

The authors report no declarations of interest.

## ORCID

Teresa Iacono  <http://orcid.org/0000-0002-7988-9951>

Emma Bould  <http://orcid.org/0000-0003-3108-2072>

Julie Beadle-Brown  <http://orcid.org/0000-0003-2306-8801>

Christine Bigby  <http://orcid.org/0000-0001-7001-8976>

## REFERENCES

- Antonsson, H., Astrom, S., Lundstrom, M., & Graneheim, U. (2013). Skilled interaction among professional carers in special accommodations for adult people with learning disabilities. *Journal of Psychiatric and Mental Health Nursing*, 20, 576–583. <https://doi.org/10.1111/j.1365-2850.2012.01934.x>
- Bigby, C., Bould, E., & Beadle-Brown, J. (2017). Implementation of active support over time in Australia. *Journal of Intellectual and Developmental Disability*, <https://doi.org/10.3109/13668250.2017.1353681>
- Bloomberg, K., West, D., & Iacono, T. (2003). PICTURE IT: An evaluation of a training program for carers of adults with severe and multiple disabilities. *Journal of Intellectual and Developmental Disability*, 28, 260–282. <https://doi.org/10.1080/1366825031000150964>
- Bould, E., Beadle-Brown, J., Bigby, C., & Iacono, T. (2018a). Measuring practice leadership in supported accommodation services for people with intellectual disability: Comparing staff-rated and observational measures. *Journal of Intellectual and Developmental Disability*, 43(2), 174–182. <https://doi.org/10.3109/13668250.2016.1259466>
- Bould, E., Beadle-Brown, J., Bigby, C., & Iacono, T. (2018b). The role of practice leadership in active support: Impact of practice leaders' presence in supported accommodation services. *International Journal of Developmental Disabilities*, 64(2), 75–80. <https://doi.org/10.1080/20473869.2016.1229524>
- Bradshaw, J. (2001). Complexity of staff communication and reported level of understanding skills in adults with intellectual disability. *Journal of Intellectual Disability Research*, 45, 233–243. <https://doi.org/10.1046/j.1365-2788.2001.00318.x>
- Bradshaw, J., Beadle-Brown, J., Leigh, J., Whelton, B., & Richardson, L. (2014). Quality of communication support for people with intellectual and developmental disabilities living in supported accommodation settings. Paper presented at the 4th IASSID Europe Congress, Vienna, Austria
- Hatton, C., Emerson, E., Robertson, J., Gregory, N., Kessissoglou, S., Perry, J., ... Hilery, J. (2001). The adaptive behavior scale-residential and community (part I): Towards the development of a short form. *Research in Developmental Disabilities*, 22, 273–288. [https://doi.org/10.1016/S0891-4222\(01\)00072-5](https://doi.org/10.1016/S0891-4222(01)00072-5)
- Iacono, T., Bloomberg, K., & West, D. (2005). A preliminary investigation into the internal consistency and construct validity of the Triple C: Checklist of Communicative Competencies. *Journal of Intellectual and Developmental Disability*, 30, 139–145. <https://doi.org/10.1080/13668250500204059>
- Iacono, T., Lyon, K., West, D., & Johnson, H. (2013). Experiences of adults with complex communication needs receiving and using low tech AAC: An Australian Context. *Disability and Rehabilitation: Assistive Technology*, 8, 392–401. <https://doi.org/10.3109/17483107.2013.769122>
- Iacono, T., West, D., Bloomberg, K., & Johnson, H. (2009). Reliability and validity of the revised Triple C: Checklist of Communicative Competencies for adults with severe and multiple disabilities. *Journal of Intellectual Disability Research*, 53, 44–53. <https://doi.org/10.1111/j.1365-2788.2008.01121.x>
- Johnson, H., Douglas, J., Bigby, C., & Iacono, T. (2011). The challenges and benefits of using participant observation to understand the social interaction of adults with intellectual disabilities. *Augmentative and Alternative Communication*, 27(4), 267–278. <https://doi.org/10.3109/07434618.2011.587831>
- Johnson, H., Douglas, J., Bigby, C., & Iacono, T. (2012). A model of processes that underpin positive relationships for people with severe intellectual disability. *Journal of Intellectual and Developmental Disability*, 37, 324–336. <https://doi.org/10.3109/13668250.2012.732221>
- Jones, E., Felce, D., Lowe, K., Bowley, C., Pagler, J., Strong, G., ... Kurowska, K. (2001). Evaluation of the dissemination of active support training and training trainers. *Journal of Applied Research in Intellectual Disabilities*, 14, 79–99. <https://doi.org/10.1046/j.1468-3148.2001.00064.x>
- Jones, E., Perry, J., Lowe, K., Felce, D., Toogood, S., Dunstan, F., ... Pagler, J. (1999). Opportunity and the promotion of activity among adults with severe intellectual disability living in community residences: The impact of training staff in active support. *Journal of Intellectual Disability Research*, 43, 164–178. <https://doi.org/10.1046/j.1365-2788.1999.00177.x>
- Mansell, J. (2010). *Raising our sights: Services for adults with profound intellectual and multiple disabilities*. London, UK: Department of Health.
- Mansell, J., & Beadle-Brown, J. (2005). *Engagement in meaningful activity and relationships: An observational measure*. Canterbury, UK: Tizard Centre.
- Mansell, J., & Beadle-Brown, J. (2012). *Active support: Enabling and empowering people with intellectual disabilities*. London, UK: Jessica Kingsley.
- Mansell, J., Beadle-Brown, J., Ashman, B., & Ockendon, J. (2005). *Person-Centred Active Support: A multimedia training resources for staff to enable participation, inclusion and choice for people with learning disabilities*. Brighton, UK: Pavilion.
- Mansell, J., Beadle-Brown, J., & Bigby, C. (2013). Implementation of active support in Australia: An exploratory study. *Journal of Intellectual and Developmental Disability*, 38(1), 48–58. <https://doi.org/10.3109/13668250.2017.1353681>
- Mansell, J., Beadle-Brown, J., Whelton, B., Beckett, C., & Hutchinson, A. (2008). Effect of service structure and organization on staff care practices in small community homes for people with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities*, 21, 398–413. <https://doi.org/10.1111/j.1468-3148.2007.00410.x>
- Mansell, J., Elliott, T., Beadle-Brown, J., Ashman, B., & Macdonald, S. (2002). Engagement in meaningful activity and "active support" of people with intellectual disabilities in service user care. *Research in Developmental Disabilities*, 23(5), 342–352. [https://doi.org/10.1016/S0891-4222\(02\)00135-X](https://doi.org/10.1016/S0891-4222(02)00135-X)
- Ogletree, B. T., Bartholomew, P., Wagaman, J. C., Genz, S., & Reisinger, K. (2012). Emergent potential communicative behaviors in adults with the most severe intellectual disabilities. *Communication Disorders Quarterly*, 34, 56–58. <https://doi.org/10.1177/1525740112456201>
- Pallant, J. (2007). *SPSS survival manual*, 3rd edn. Sydney, Australia: Allen & Unwin.
- Purcell, M., McConkey, R., & Morris, I. (2000). Staff communication with people with intellectual disabilities: The impact of a work-based training programme. *International Journal of Language and Communication Disorders*, 35(1), 147–158.
- Schepis, M., & Reid, D. H. (1994). Training direct service staff in congregate settings to interact with people with severe disabilities: A quick, effective and acceptable program. *Behavioral Interventions: Theory and Practice in Service User and Community-Based Clinical Programs*, 9, 13–26. [https://doi.org/10.1002/\(ISSN\)1099-078X](https://doi.org/10.1002/(ISSN)1099-078X)
- Siegel, S., & Castellan, N. J. (1988). *Nonparametric statistics for the behavioral sciences*. New York, NY: McGraw-Hill.
- Stancliffe, R., Harman, A., Toogood, S., & McVilly, K. (2007). Australian implementation and evaluation of active support. *Journal of Applied Research in Intellectual Disabilities*, 20, 211–227. <https://doi.org/10.1111/j.1468-3148.2006.00319.x>

- Stancliffe, R., Harman, A., Toogood, S., & McVilly, K. (2008). Staff behaviour and service user engagement before and after active support training. *Journal of Intellectual and Developmental Disability, 33*, 257-270. <https://doi.org/10.1080/13668250802318284>
- Zilber, D., Shaddock, A., Dowse, L., Rawlings, M., Guggenheimer, S., & Browne, F. (1994). Communication patterns in services for people with severe intellectual disabilities: Function, form and responsiveness. *Australian Journal of Human Communication Disorders, 22*, 84-98.

**How to cite this article:** Iacono T, Bould E, Beadle-Brown J, Bigby C. An exploration of communication within active support for adults with high and low support needs. *J Appl Res Intellect Disabil.* 2019;32:61-70. <https://doi.org/10.1111/jar.12502>