

Communication Assistants in Queensland: A survey of their engagement in conversations without speech.

Dr Jane Remington-Gurney
Speech Language Pathologist and Director
Options Communication Therapy & Training Centre Pty Ltd.
Brisbane, Queensland.

This article was published in InFocus, a publication of the Australian Group of Severe Communication, Winter 2018, 43(1), 10-14.

Communication Assistants in Queensland: A survey of their engagement in conversations without speech.

CONVERSATIONS WITHOUT SPEECH

Needing to have a conversation without the use of speech can occur to any of us at any stage in a lifetime. The Australian Institute of Health and Welfare (AIHW, 2010) has identified that 6.6% of Australians experienced severe or profound core activity restriction. Of this group, 10% experienced the restriction in the area of communication. The numerical significance of this is that approximately 48,000 Australians have a CCN. Subsequently, it would be reasonable to expect that a person with complex communication needs requires the reliable assistance of at least one other person in their support network. Further, that for sustainability and quality of life, that this 'other person' have some knowledge and skill in AAC. The literature uses the generic term 'communication partner' to refer to this other person irrespective of their AAC knowledge, skill, experience, competence or confidence. As a clinician I was interested to examine the strategies that were used in conversation with people with complex communication needs from the perspective of the person offering interaction support. Therefore, in 2017 I completed a Queensland based, qualitative PhD research study that was staged in three phases. The study has provided demographic and descriptive statistics, produced a glossary of over 70 conversation strategies and identified at least seven styles of conversation. The three phases of the study were as follows:

- Phase 1. A survey providing demographic information and descriptive statistics. The mean survey completion time was 12.57 mins and included three open questions.
- Phase 2. Use transcription (writing down and coding spoken and non-spoken language) to identify conversation strategies from six video-recorded conversations.
- Phase 3. Applied thematic coding to the analyse of written narratives from participants responding to the question ‘what makes having a conversation with someone who has a CCN, tricky or easy’.

This article shares information from the first phase of the research and begins by clarifying two key terms that were integral to the research design.

Conversation - Meaning-making within a rule-based structure, adhering to social conventions and intricacies that extend beyond the boundaries of a linear stimulus–response or question–answer exchange.

Communication Partner – someone with little or no knowledge, skill or experience in AAC. As the research aim was to identify strategies used by the communication partner, a decision was made to invite adult participants who did have some knowledge and skill in AAC and who therefore might demonstrate and report on a wider spectrum of conversation strategies. These participants were self-identified for their AAC knowledge and skill and were referred to as Communication Assistants.

Within the article I have noted a number of provocations or actions that aim to incite interest and other feelings such as anger and inspiration. This has been done to draw attention to research work that remains to inform the literature and bridge gaps in understanding.

The research study was launched on a disability accessible web platform [www.conversationswithoutspeech](http://www.conversationswithoutspeech.com) and made manageable by restricting the investigation to conversations with people from three developmental disability types. Namely, Down syndrome, rett syndrome and cerebral palsy. These genotypes were selected to increase the likelihood of communication assistants experiencing a broad range of AAC approaches such as key word signing, hearing impaired speech, eye gaze and pointing to high and low tech tools.

Provocation 1. How do the results of phase 1 compare with the experiences of communication assistants who converse with people from other disability backgrounds?

The adult communication assistants who completed the Phase 1 survey identified themselves as having some knowledge and skill in AAC. Their responses to open questions are shown in quotation marks and italics and the participant response values are shown as a percentage figure.

Phase 1: The Survey

After piloting the twenty-question survey with a large organisation in the Brisbane CBD and making minor changes to the wording of some questions to improve clarity, the survey was distributed to 1919 disability facilities throughout Queensland using mail and email methods of distribution. The large distribution hoped to yield a good response rate however, despite researchers reporting in the literature that a response rate of between 25% and 45% can be anticipated in disability research (Simeonsson, Carlson, Huntington, Sturtz McMillen, & Brent, 2001), the response rate for this study was a very disappointing 5.2% (n=74). Gatekeeping mechanisms including ethics procedures for organisations external to the University supervising the study, and dysfluency in communication channels were identified as some of the barriers to inviting people to participate.

Provocation 2. It can be difficult to distinguish between conscious gate-keeping practices that aim to exert a degree of control over information for dissemination and bureaucratic or organisational road blocks. McNaughton et al. (2012) refer to a quotation by Gibson (2003), that 'the future is already here—it's just not evenly distributed' and that this is 'especially true in the area of augmentative communication' (p. 51). Therefore, is there a way to improve access to research for people whose voices could be instrumental in improving the quality of life for individuals with complex communication needs?

The LIME survey tool was used because it is free, secure and able to collect unlimited responses (unlike Survey Monkey or Survey Gizmo). Unlike Question Pro and Smart Survey, there was the capacity with LIME to send bulk email invitations and reminders as well as download to other statistical analysis tools. It also had capacity to accommodate 50 other languages—an important consideration for future research, particularly if the host country is multicultural.

Four measures were used to identify who participants were, how they acquired and applied their AAC knowledge and skill, and their perceptions of conversation using AAC.

1. Demographics. This section contained seven closed questions and revealed that 89% female participants, that 92% were over the age of 30 years, and that 66% had a dual role as a care provider. There was no participation from people north of Mackay. Most of the participants in Phase 1 had at least six years' experience as communication assistants.

Provocation 3. Was there a reason for no one contributing to the survey north of Mackay? Is there a feeling of separation between AAC services that are available in the capital versus Central and North Queensland?

2. Knowledge and skill. The five closed questions in this section indicated that 30% of participants acquired their AAC knowledge and skill from a speech language pathologist versus 41% from the workplace and 16% from the user of AAC. Only 2.7% of participants obtained their AAC knowledge and skill from university programs. Participants identified themselves as having knowledge in areas other than AAC; for example, 24% reported that they had a trade and 54% reported that they had a qualification. The acquisition of AAC knowledge came mainly from face-to-face instruction rather than by using electronic or paper mediums and

sixty-five per cent of participants reported that they sourced this face-to-face instruction from people they perceived as having an existing relationship with the person who had CCN e.g. the family of the person with CCN. This finding appears to complement the literature finding that parents are increasingly being required to perform as experts in their child's welfare.

Provocation 4. The literature notes that 'partner instruction should be viewed as an integral part of AAC assessment and intervention' (Kent-Walsh et al., 2015, p. 280) but that as a key stakeholder group, speech language pathologists appear to have inadequate capacity to meet the needs of people with CCN at an intervention and Communication Partner Training level (Beukleman & Mirenda, 2005; Costigan & Light, 2010; Johnson, Ingelbert, Jones, & Ray, 2006; Ratcliffe, 1999; Ratcliffe & Beukleman, 1995; Ratcliffe et al., 2008; Sutherland et al., 2005). In their comprehensive overview of AAC training and a presentation of the results of a survey of speech language pathologists Ratcliffe et al. (2008) conclude that:

'The lack of clinical experience in the area of AAC as reported by respondents to this survey is a serious concern, as it will negatively affect service delivery to the population with AAC needs and will perpetuate the knowledge and skill barriers that limit services to people who could use AAC' (p. 55). Therefore, is the time ripe for design and development of the Specialist role, that is perhaps not restricted to SLPs and that includes AAC and Assistive Technology as a specialist service?

3. Language and communication. In three closed questions participants acknowledged a difference between communication (linear question-answer) and conversation. When referring to the language they used in conversation they noted their initiation (39%) and closing (8%) of the interaction, their use of small talk

strategies (54%), open (43%) and closed question strategies (36%) and co-construction strategies (20%).

When asked about the speech acts used by the person they supported there appeared asymmetry in conversation. For example, 25% of people with CCN were reported to be able to open or close a topic of conversation, 30% could use past and future tense language and less than 50% were able to ask questions.

Provocation 5. The literature reports that conversations with people who have complex communication needs can be monologic, asymmetric or dominant. However, is asymmetry built from a negative use of power and status, or is it a natural and necessary characteristic of conversations where AAC is used? Similarly, does it change over time and is dependent upon environmental, contextual, cultural and relationship factors?

4. Application. Dynamic Systems Theory (Smith and Thelan, 2003) was selected as the overarching metatheory to guide the research study. In this measure, participants reported on their understanding of the needs of the person with CCN in seven areas. In rank order, results were as follows: cultural needs (90%), motor needs (88%), communication needs (85%), social needs (81%), sensory needs (75%), intellectual needs (74%) and technological needs (67%). In terms of their use of AAC participants reported that they were most confident with aided communication methods such as the use of photographs (38% of respondents) and unaided methods such as the use of gesture (41% of respondents) and body language (49% of respondents). This suggests that for these participants multimodal communication was likely to be not formally AAC-specific.

Provocation 6. What is the ultimate goal in delivery of AAC interventions....communication or conversation?

In this last measure there were also three open ended questions that asked what made having a conversation tricky or easy, and what could make a communication assistant's job easier. The responses were analysed using a key word, colour coding approach and NVivo data analysis software (Bandara, Furtmueller, Gorbacheva, Miskon, & Beekhuyzen, 2015). The perceptions of what made having a conversation easy or tricky were first linked to one or more of five interaction systems and then reviewed to identify elements that might be accelerators or distractors to system stability (Thelan, 2005). Examples include:

Language: *'If their other carers have also been practicing Makaton with them.'*

Human agency: *'That I am not in a hurry'*

Relationship: *'Being familiar with what they have done during the day or who their family are.'*

Culture: *'If they have been taught to use and have AAC devices or knowledge.'*

Environment: *'Quiet environment, fewer distractions, ability to take time for responses'.*

It was noteworthy that the multidimensional nature of time was often seen in the data.

When asked what would make their job easier, participants strongly identified Training as an element that often had linkage to Time and Technology. For example, there were suggestions that AAC training *'be compulsory'* with steps to *'EDUCATE the educators'* and to encompass *'the development of communication'* to requests not just for *'training'* but *'more training'*. Although historically some AAC methods were associated with specific disability types, in this study each of the three groups made reference to common aided and unaided approaches (see Fig.1).

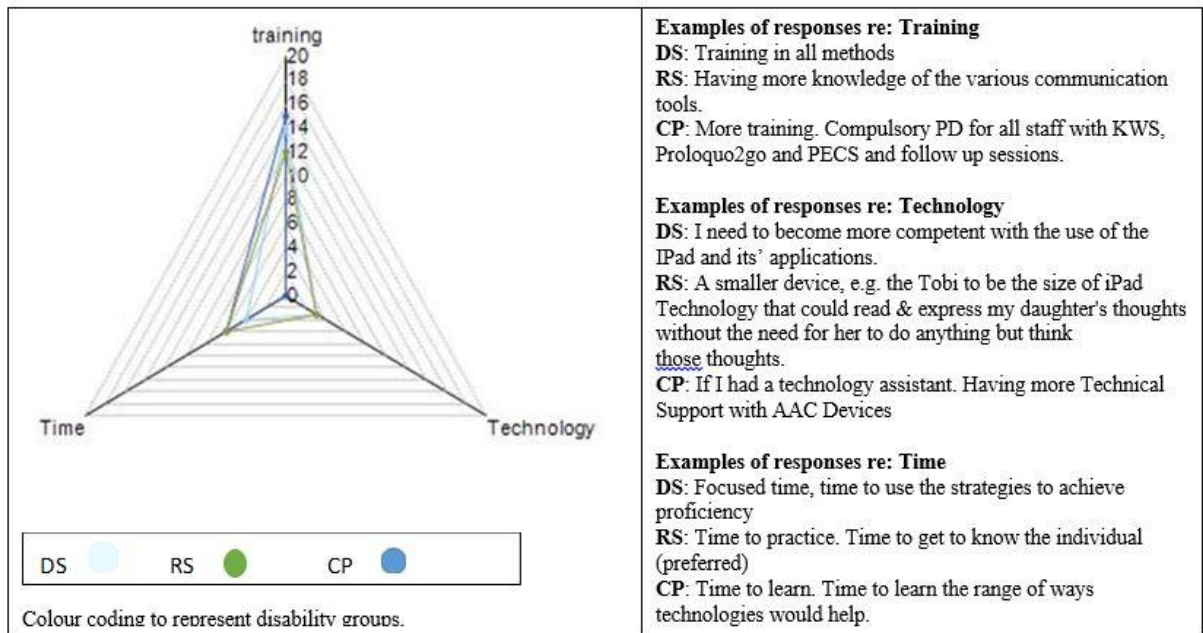


Fig. 1. Factors identified as accelerators. 'What would make your job easier?' (n= raw numbers)

Conclusion

The short survey provided a stepping stone to conversation strategies being transcribed for analysis from observation data (Phase 2) and from written narratives (Phase 3). With an absence of demographic and descriptive statistics concerning the people who provide interactional support in Queensland, the first step in the research study *Conversations Without Speech* was to provide an insight into who these individuals were and their perceptions of the conversation strategies they use.

Research studies aim to answer questions to bridge knowledge or create new knowledge. In addition to create questions for future research. In this article only one phase of the complex research methodology and findings has been discussed. Yet within the data and the provocations is a deep valley of unknown and uncharted areas. I hope that the provocations will stir interest in further research in this area.

References

- AIHW (2010). Health of Australians with disability: Health status and risk factors. AIHW bulletin no.83. Cat. no.AUS 132. Canberra. AIHW. Viewed December 2016 www.aihw.gov.au/publication-detail-/?id=6442472401
- Bandara, W., Furtmueller, E., Gorbacheva, E., Miskon, S., & Beekhuyzen, J. (2015). Achieving rigour in literature reviews: Insights from qualitative data analysis and Smith, L. B., & Thelan, E. (2003). Development as a dynamic system. Trends in Cognitive Sciences, 7(8), 2003. tool-support. *Communications of the Association for Information Systems*, 37(1), 8.
- Beukleman, D., & Mirenda, P. (2005). *Augmentative and alternativve communication: Supporting children and adults with complex communication needs*. (3rd ed.). Baltimore: Brookes Publishing
- Costigan, F. A., & Light, J. (2010). A review of preservice training in augmentative and laternative communication for speech language pathologists, special education teachers, and occupational therapists. *Assistive Technology*, 22, 200-212.
- Gibson, C. (2003). Cultures at work: Why culture matters in research on thecultural industries. *Social & Cultural Geography*, 4(2), 201-215.
- Johnson, J. M., Ingelbert, E. A., Jones, C., & Ray, J. (2006). Perspectives of speech language pathologists regarding success versus abandonment of AAC. *Augmentative and Alternative Communication*, 22(2), 85-99
- Kent-Walsh, J., Murza, K. A., Malani, M. D., & Binger, C. (2015). Effects of communication partner instruction on the communication of individuals using AAC: A meta analysis. *Augmentative and Alternative Communication*, 31(4), 271-284.
- McNaughton, D., Bryen, D. N., Blackstone, S., & Williams, M. (2012). Young adults with complex communication needs: Research and development in AAC for a "diverse" population. *Assistive Technology*, 24(1), 45-53.
- Ratcliffe, A. (1999). Augmentative and Alternative Communication: Challenges at the pre-service level. *Perspectives on Augmentative and Alternative Communication*, 8, 2-18.
- Ratcliffe, A., & Beuklelman, D. (1995). Pre-professional preparation in augmentative and alternative communication: State of the art report. *Augmentative and Alternative Communication*, 11(2), 61-73.
- Ratcliffe, A., Koul, R., & Lloyd, L. (2008). Preparation in augmentative and alternative communication: An update for speech language pathology training. *American Journal of Speech Language Pathology*, 17(1), 48-59
- Simeonsson, J., Carlson, D., Huntington, G. S. , Sturtz, J., McMillen, L.J. & Brent, R. (2001). Students with disabilities: A national survey of participation in school activities. *Disability and Rehabilitation*, 23(2), 49-63. (p.54).
- Sutherland, D. E., Gillom, G. G., & Yoder, D. E. (2005). Use and service provision: A survey of New Zealand speech language therapist. *Augmentative and Alternative Communication*, 21(4), 295-306
- Thelan, E. (2005). Dynamic systems theory and the complexity of change. *Psychoanalytic Dialogues*, 15(2), 255-283.