Complex communication needs

In this issue:

Experiences of intimacy by adults who use AAC

Communication in people with severe disabilities

Vocabulary use in children: Implications for children who use AAC

Ethical issues in alternative and augmentative communication

Speech
Pathology
Australia

Speech Pathology Australia

From the editors

Marleen Westerveld and Kerry Ttofari Eecen

Contents

THE EDITORSHIP OF THE *JOURNAL OF CLINICAL PRACTICE IN* Speech-Language Pathology (JCPSLP) brings many rewards. From a personal point of view, it not only encourages extensive professional networking, both nationally and internationally, it also enhances my knowledge across the speech pathology range of practice areas. The current edition of *JCPSLP* is a perfect example. Complex communication needs is an area of clinical practice I knew little about when Kerry and I set the topic back in July 2011. Since then, we have been in contact with specialists from around the country and New Zealand to gather up-to-date, evidence based, clinically relevant copy related to complex communication needs. We trust this edition of *JCPSLP* portrays just how complex some of our clients' communication needs can be and how we as speech pathologists may assist these clients in communicating their wants, needs, values, beliefs, and feelings.

Leigh, Sutherland, and Howe start with a thought-provoking study into the experience of intimacy and intimate communication by adults with acquired communication disorders who use augmentative and alternative communication (AAC); a topic that has not received much attention in the past. Johnson and colleagues remind us that every person, including people with severe–profound intellectual disabilities, has the human right to communicate. The authors highlight the importance of acknowledging "the inherent value of all communication, whether intentional or not intentional" (p. 67), and explain the clinical practice of collaborative transaction and intervention supports. Clendon and Westerveld emphasise the importance of vocabulary selection for children with complex communication needs who use AAC devices. Based on a comparison of databases of spoken and written language samples from typically developing children, the authors developed lists of the most frequently occurring words, two-word, and three-word phrases that may be useful to AAC professionals working with 5- to 7-year-old children.

Hemsley has done an excellent job in summarising some of the ethical issues clinicians may face when working in the area of AAC, and the informal writing style of the "Ethical conversations" makes her discussion a pleasure to read. As always, our "Clinical insights" articles provide us with examples of novel clinical practices. More specifically, McQueen explains a project aimed at "capacity building" for people with complex communication needs and Loh describes the introduction of Key Word Sign and Gesture in Singapore. Although these "Clinical insights" articles do not receive the official peer-reviewed label, the reader can rest assured that they do undergo an informal but stringent, blind peer-review process. As a result, only "Clinical insights" articles of the highest quality end up being published.

Thanks again to all our contributors, including the authors of "Around the journals", "Resource reviews", "Webwords", and the "Top 10" columns. We firmly believe that it is this mix of copy that will make *JCPSLP* stand out among the most popular speech pathology publications in the world.

The experiences of intimacy by adults with acquired communication disorders who use AAC

Angela Leigh, Dean Sutherland, and Tami Howe

THIS ARTICLE HAS BEEN PEER-REVIEWED

Angela Leigh (top), Dean Sutherland (centre), and Tami Howe

Augmentative and alternative communication (AAC) provides the mechanism for interpersonal communication for adults and children with complex communication needs. Research into AAC-use among adults with acquired communication disorders has typically focused on device selection, developing functional communication, acceptance and use of AAC, and caregiver support. The aim of this qualitative study was to explore the experience of intimacy and intimate communication from the perspective of individuals (and their partners) who have an acquired communication disorder and use AAC. Seven key themes emerged from the data, namely *effort, importance, time, closeness, adaptation, emotion, and identity*. Within these key themes participants discussed how AAC has been both beneficial and detrimental to their intimacy and intimate communication.

Intimacy has been described as a primary psychological need (Lippert & Prager, 2001) and according to some researchers, human beings require repeated, positive interactions with the people they are in caring relationships with in order to lead fulfilling lives (Miller & Perlman, 2009). Moss and Schwebel (1993) conducted a review of published definitions of intimacy and proposed the following definition: "Intimacy in enduring relationships is determined by the level of commitment and positive affective, cognitive, and physical closeness one experiences with a partner in a reciprocal (although not necessarily symmetrical) relationship" (p. 33). The quality of intimacy within personal relationships influences our overall health and well-being, reinforcing the importance of maintaining intimate personal connections (Miller & Perlman, 2009; Prager, 1995). Kouneski and Olson (2004) suggest communication as being vital in the development and evolution of intimacy. These researchers state that how a couple communicates is a crucial factor in intimacy, and communication needs to be assertive and respectful in order to promote intimacy. For the purpose of this study a broad definition of intimacy was used which combined Moss and Schwebel's (1993) affective, cognitive, and physical aspects with the communication component described by Kouneski and Olson (2004).

Although communication is central to intimacy, little research has investigated how intimacy is affected when people experience communication difficulties. Several studies have looked at intimacy and disability, with results indicating that strong intimate bonds and emotional connections between spouses lead to better quality of life outcomes and less stressful experiences for caregivers (Baikie, 2002; Wright, 1998). Communication between spouses or intimate partners is likely to be irreversibly altered after the onset of a neurological disease or disorder, a stroke, or traumatic head injury. For example, the ability to communicate using natural speech may be significantly reduced or lost and alternative methods of communication may be required in order to provide adequate levels of communication (Beukelman & Mirenda, 2005).

Strong interpersonal connections are important in the maintenance of intimate relationships when one partner acquires a disease or disability. Spousal acceptance and validation is vital for improving feelings of closeness and intimacy (Manne et al., 2004). However, little is known about the impact on perceptions of intimacy for adults with acquired communication disorders, particularly considering the central importance of communication to interpersonal relationships. While partner-responsiveness is critical, self-disclosure is also crucial to the interpersonal process model of intimacy (Manne et al., 2004). The ability to self-disclose is likely to be severely diminished as the result of an acquired communication disorder.

To date, research looking at adults with acquired communication disorders who are using AAC has focused on device selection, providing functional communication, acceptance and use of AAC, and caregiver support (Beukelman, Fager, Ball, & Dietz, 2007; Johnson et al., 2008). There is a lack of research that describes how AAC impacts the intimacy of relationships of adults with acquired communication disorders. There is a clear need to develop our understanding of intimacy and intimate communication for adults using AAC and their partners. This information will provide valuable insight into the needs of adults who use AAC and the strengths and weaknesses of existing AAC systems. Therefore the aim of this study was to explore the experience of intimacy and intimate communication from the perspectives of adults with acquired communication disorders who use AAC and their partners.[1]

Method

A qualitative research approach based on phenomenology was chosen for this study to allow for an in-depth exploration of the lived experience of peoples' intimacy in relation to AAC and acquired communication disorders from the insider's perspective (Patton, 2002).

Participants

Participants were recruited through support groups and speech-language therapists who worked with people using AAC. For inclusion in the study participants with an acquired communication disorder were required to: (a) be aged 18 years or over, with an acquired communication disorder; (b) be in a current long-term relationship with a spouse or partner who was also willing to participate in the study; (c) have had experiences using AAC some or all of the time as a mode of communication because of their acquired communication disorder; d) be able to participate in an in-depth interview in English using speech and/or AAC. Six dyads met the eligibility criteria for the investigation. One of these dyads initially agreed to participate, but then withdrew due to personal matters. Five participants with an acquired communication disorder and five partner participants participated in the study.

Sampling

Maximum variation sampling, a type of purposeful sampling, was used in this study. This involved identifying "diverse characteristics of particular interest in constructing the sample to maximise the variation in a small sample" (Patton, 2002, p. 235). Sampling was sought for these characteristics: gender (male/female), type of communication disorder (speech/language), and progression of communication disorder (degenerative/ non-degenerative). At least one participant who met the criterion for each category was recruited. Participant details with the maximum variation sampling characteristics, and full biographical details, are presented in Table 1. For full biographical details of the spouses/partners see Table 2.

Pseudonyms were used throughout the study in order to protect the identity of the participants. Participants and their partners ranged in age from 32 to 68 years and were of NZ European or English ethnicities. Additional identifying data such as occupation are not reported in order to protect participants' identity.

Interview procedure

Data collection involved joint and individual semi-structured interviews with the participants. The semi-structured interviews were transcribed and then provided to participants to read, edit, and confirm. This provided participants with the opportunity to modify the transcript, if required, to ensure that it was an accurate representation of their thoughts and experiences. This procedure endeavoured to verify the validity of the data. All participants were also offered the opportunity to supplement interviews with email responses to any of the questions from the topic guide.

Table 1. Biographical details of the five adults with acquired communication disorders

Participant*	David	Laura	James	Clive	Deb
Sex (Age)	Male (38)	Female (44)	Male (32)	Male (57)	Female (52)
Diagnosis	Motor neuron disease	Aphasia resulting from stroke	Locked-in syndrome resulting from traumatic head & neck injury	Locked-in syndrome resulting from brain stem stroke	Tracheal stenosis requiring tracheos-tomy, causing loss of voice
Spoken communication	No	Yes	No	Yes	Yes (mouthing)
Years since onset	1–3	> 10	>10	1–3	5–10
Length of relationship (years)	10–20	> 20	< 5 (18mths)	> 20	> 20
Time spent with partner per day (hours)	1–3	1–3	5–10 (online)	All day	All day
Types of communication used	Electronic – EZ keys, Gesture – vocalisa-tions, Head nods, Facial expression	Written, Spoken, Sign language, Gestures, Communication book	Perspex eye-gaze, Alphabet board, Email	Alphabet board, Spoken, Gestures, Email	Electrolarynx Nu-Vois III, Written, Gesture, Spoken (mouthing) Computer
Main communication with partner	MSN, Emails, Text message, Skype, Gestures	Spoken, Text message	Perspex eye-gaze, Alphabet board, Email	Spoken	Spoken (mouthing) Electrolarynx Nu-Vois III
Employment status	Retired	Retired	Not working	Working part-time	Not working
Living arrangements	Living with partner, with full-time carers	Living with partner	Living alone, with full-time carers	Living with partner, with part-time carers	Living with partner
Co-existing conditions	N/A	N/A	N/A	N/A	Meniere's disease

*All names are pseudonyms.

Table 2. Biographical details of the five partners/spouses of adults with acquired communication disorders

Participant*	Maggie	Steve	Hannah	Janet	Henry
Sex (Age)	Female (38)	Male (48)	Female (37)	Female (55)	Male (68)
Marital status	Wife	Husband	Partner/girlfriend	Wife	Partner
Employment status	Not in paid employment	Working full-time	Working full-time	Not in paid employment	Semi-retired

*All names are pseudonyms.

Joint interviews

Four of the five participants with an acquired communication disorder and their partners participated in a joint semi-structured interview that was conducted in their homes (Minichiello et al., 1990; Taylor & Bogdan, 1998). Because one member of couple 3 resided outside of New Zealand at the time of the study, it was not possible to conduct a joint interview with this dyad. The joint interviews ranged in length from 27 to 81 minutes with a mean of 56 minutes (SD = 23.6). The semi-structured interviews involved a conversation guided by open-ended questions from a topic guide about intimacy and intimate communication in relation to AAC use and acquired communication disorders (see Appendix A). All joint interviews were completed in one session.

Individual interviews

Participants with an acquired communication disorder

Individual semi-structured interviews were conducted with each of the five participants with an acquired communication disorder in their homes. The partner participant was not present during these interviews. Four of the participants supplemented their individual interviews with a series of email responses to the questions on the topic guide. Two of these participants advised that email was a commonly used AAC system for them due to the nature of their communication problems. A topic guide, involving the same questions asked during the joint interviews, was used for these interviews (see Appendix A). Length of individual interviews with participants with an acquired communication disorder ranged from 22 to 26 minutes with a mean of 24 minutes (SD = 2). The researcher followed practices recommended for communicating with individuals with language-based communication disorders during the interview with the participant with aphasia. (e.g., encouraging the person to use any mode of communication to respond to questions and verifying participants' communication [Kagan & Kimelman, 1995]).

Partner participants

Three of the five individual interviews with partner participants were conducted in the participants' homes, while one interview was conducted in a quiet private room at the participant's workplace. One interview was conducted over the telephone (due to the participant not residing in New Zealand at the time of the interview) following the practices recommended by Sturges and Hanrahan (2004). The telephone interview was supplemented with a series of seven email responses to the questions on the topic guide. All face-to-face interviews were completed in one session and were conducted without the presence of participants with an acquired communication disorder.

Data analysis

The data were analysed using thematic analysis based on the steps proposed by Braun and Clarke (2006). Thematic analysis is an inductive form of analysis for "identifying, analysis and reporting patterns (themes) within data" (Braun & Clarke, 2006, p. 79). The researcher began by reading each transcript several times, and then systematically examined the entire data set in order to identify initial codes. Related codes were then collated into themes. The themes were reviewed in relation to the entire data set, with ongoing analysis to refine the specific details of each theme. The primary researcher and two experienced researchers then reviewed and discussed the themes until consensus was reached. During these discussions, themes were considered and examined in relation to the aim of the study. Any differences in judgements between

appropriateness of themes or other aspects were discussed and revised as required. At this point, themes were defined and named, with all parties in agreement.

Results

Seven themes related to the experience of intimacy and intimate communication for adults with an acquired communication disorder using AAC and their partners, emerged from the data. These themes were: *effort, importance, time, closeness, adaptation, emotion, and identity*. Each of these themes is discussed below together with supporting quotations from participants.

Theme 1: Effort

Effort was a key theme in the study and included effort related to all aspects of the communication partnership. The theme of effort referred to expressions regarding the loss of fluidity in communication, or discussions about any extra lengths that either partner needed to go to in order to maintain their intimate communication. It also involved any difficulties or changes that the couples have had to overcome either by changing the way they communicate or by partners making communication easier for the person with an acquired communication disorder. The loss of ease and spontaneity of communication was commonly reported by participants with acquired communication disorder. Deb summed up the difficulty she had maintaining communication in most common situations:

Communication isn't easy you see for us. I mean a lot of people talk while they're doing the dishes or talk while they're cooking or talk while they're in the car, while we're in the car it's too noisy for him to hear my voice, and when I'm trying to cook I've only got two hands and it just puts extra barriers in communication instead of being easy and flowing; it's something we actually put a bit more effort into.

For the partner participants, it was the increased need for effort for both partners when communicating with an AAC device. Maggie commented:

So [AAC has] brought back more but it loses the banter that you have, that free flowing speech, and the banter and the quick bouncing off ideas, that sort of thing.

Hannah talked about the difficulty of using AAC in more intimate situations, and how the impracticality of some methods of AAC led to developing other methods in order to maintain a sense of intimacy:

It sometimes gets a little bit frustrating I think for both of us because he wants to [say] something and I have, you have to sort of get the board. I did make him a really small board for us to use when we're together because, cause it was getting in the way a bit … we mostly communicate through the board but obviously, um, like when we're in bed together he, he used to, he does like, gestures that, with his head, that I recognise for certain things.

Theme 2: Importance

The theme of importance referred to the re-evaluation of priorities and essential needs after the life-changing events involved in an acquired communication disorder, and included the need to prioritise communication, personal priorities, and relationship loss/gain. The aspect of prioritising messages and giving importance to communication in order to preserve energy and avoid wasting time was significant in most interviews. David expressed how with using AAC you have to:

Choose your words carefully … Intimate conversation still happens but in short and to the point.

For some couples, living with a communication disorder helped them prioritise other aspects of their lives and let them refocus on what they felt was truly important. For James, who had only recently begun his relationship with Hannah, his communication disorder and physical disabilities had given him time to re-evaluate his life and relationships; he commented:

I never really talked with my girlfriends before the [accident]… completely different now … thought lots about life after my accident (especially during my 2 years in hospital), what I want from my girlfriend, what makes a relationship healthy – COMMUNICATION, listening, expressing feelings, MORE COMMUNICATION… life's too short…more mature now, accident MAKES you grow up and think about life (what's really necessary/important/essential)…

Clive has also re-evaluated his life since his stroke and felt that:

Physical things don't seem so important. Like physical possessions.

Making communication a priority and only discussing the things that were important and crucial came through in several interviews. For Steve, it was evident that Laura's well-being and recovery have been his number one focus since her stroke 11 years ago. He reflected on the importance of this for him and his relationship with Laura, stating:

She was my priority, I think I made my point pretty well clear and I always, always have … that's what I was doing to filling in my time instead of being out in the garden and letting her stagnate in front of the TV, I was actually in there playing games, doing things, trying my best while the weeds were growing in the garden.

Theme 3: Time

The issue of time was identified as a significant concern for most partner participants. The theme of time incorporated time pressures and time-saving techniques employed to reduce effort for both partners. It also encompassed the need for special time to be put aside specifically for intimate communication and quality interactions that may not be have been possible otherwise. Some of the couples had made changes to the way they communicated in order to save time as Maggie explained:

You know how there's always that standard joke about married people and they finish each other's sentences ... that really came into effect and we actually had to tell people this is what we're doing and it's ok to do that ... but it just saved a lot of time and hassle.

For Hannah and James who communicated via email due to their long-distance relationship, time was very important and played a major role in the way they communicated, as Hannah explained:

On weekends we have, we do more emailing sort of because we have more time … obviously because he, he's slower at typing than me sometimes his responses aren't as detailed as mine and sometimes he'll, he'll just start a conversation thread and then I'll sort of put more detail in or whatever.

Theme 4: Closeness

The theme of closeness included the aspects of closeness and connection for couples, and physical closeness which had proved more difficult due to co-existing physical disabilities, but which was also seen by some as beneficial in developing the emotional connection in their relationship. For those couples who were in relationships before the onset of the communication disorder, most commented on

how their experiences through illness and upheaval had strengthened their relationships, although it had been reportedly difficult at times. Laura summed up her connection to Steve simply when she expressed her feelings about him:

Um, soul, soul mate.

Similarly, Clive discussed his feelings and what benefits he saw there had been for their relationship, by saying:

The stroke has probably strengthened our relationship … it's probably brought us, as I said, closer together, and I'm now more aware of her.

When asked about the meaning of intimacy, Maggie shared her feelings about her relationship and the loss that she and David have experienced since receiving the diagnosis of motor neuron disease (MND) and the subsequent changes they have experienced.

Intimacy means for us basically everything we've lost because of [MND] pretty much isn't it? So it is that closeness, it's, it's being able to communicate, it's being able to touch, it's being able to show facial expressions, and being able to be close to someone without any barriers.

Intimacy also encompasses physical closeness, and for some of the couples this had also been impacted by the physical and communication difficulties. After 35 years of marriage, one of the biggest obstacles to intimacy for Janet and Clive was the physical separation that they had to overcome. Janet discussed how this changed intimacy for them:

I knew it was going to be pretty tough but just try to talk to him about, for one thing, we were going to be sleeping in separate beds, and, I mean you can't really, it's not the same sleeping in a single bed and waking and having to cuddle where you have to make an effort to do those things … And so, sometimes we'd put our beds together so he could hold my hand, or rub my feet or whatever.

Theme 5: Adaptation

The theme of adaptation encompassed changing the method of expressing intimacy, AAC as a barrier to intimacy, and non-verbal communication. Adaptation included comments and discussions that centred on adapting communication methods in order to maintain effective and efficient communication, and also unsuccessful changes or difficulty with communication due to the inability to adapt. With the removal of natural speech as an option for communicating intimacy, couples have had to make changes to how they express themselves to each other. David explained how the adaptations had not taken away from their intimate communication:

[We] just [express ourselves] differently … quality is still the same it's just different way you put it across.

In contrast, the need to change methods of communication had a negative impact on other couples' intimacy, with the new methods not working sufficiently to replace natural speech. Deb talked about her experiences and how she felt her communication was still not adequate in some areas. She shared:

There is a way of communicating with not using words and that's missing in our sex life now, and I think that's affected [Henry's] sexual response cause [he's] not getting messages from me that I'm having a really good time.

For some of the couples, AAC systems and devices created barriers to intimacy and changed the dynamics of intimate communication in their relationship. For Henry the reduction of spontaneity in expressing a message played a big role in the fluidity of his communication with Deb:

You think of something that you want to say to your partner like Deb and then, you store up a number of questions whereas normal ah, a couple don't do that – it automatically comes out and it's solved at the time or you know, talked about or debated or whatever the case may be um, for us I think that it you know yes you build up a system of questions and then you can't find the voice, voice first, person second.

Henry also discussed the other side of AAC and how the introduction of the electrolarynx had been incredibly beneficial and had stripped away some of the barriers in their communication. He summed up his feelings about the device by saying:

The point is that this little electrolarynx is the best thing that ever came about because you know, it was really frustrating for me before that and it's much easier for me now even though I laugh and I make as though it, there are problems about it, and I do swear and curse because she'll leave it in the car and the phone goes or whatever, and, and it becomes a bloody curse sometimes, it's still the best invention out.

Theme 6: Emotion

Both negative and positive emotions came through strongly for the majority of the participants in this study. Within the theme of emotion, the negative aspects of arguing, frustration, and the meaning of intimacy were most significant. When asked about communicating with Steve, Laura expressed the emotions she felt when she was not able to communicate:

Um I, talking no talking, ah, ah frustrated, yeah frustrated.

Emotions were also a strong component of how the participants described what intimacy meant to them, both as a couple and as individuals. David described intimacy as:

Personal conversation between a couple … Touch and feelings are included as well.

In some of the interviews, the ability to express unhappiness or disagreement through arguing was indicated as being an important part of their relationship, and something that they still were able to do. Maggie summed up how arguing for her and David was still part of their communication, but had altered since the changes to David's communication:

Arguing is very mature we still argue ... but there's no, no chance of walking out and storming out because no one can chase you if that was ... but I would argue and then I would stand and wait for David to respond ... you can be really fired up and say something and then you think right, wait, wait, wait, wait, wait, wait ... it's just the sitting on the fence thing, I don't know you just sort of blank out and wait and then, you're back in again.

Theme 7: Identity

The theme of identity was made up from statements by participants about the loss or change to identity due to the onset of the communication disorder and the use of an AAC system or device. The loss of identity or sense of self came both from the participants with an acquired communication disorder and from the partner participants who expressed the loss of an important part of their partner. Deb summed up her feelings on losing her voice, expressing:

It's amazing how a voice distinguishing is not just our personality and our persona but our sex and it's yeah, it's weird how our voices are so magical and we take them for granted and we don't even appreciate how magical and complex and interesting and unique they are so, yeah oh to have it all.

The aspect of depersonalisation and how using an AAC device had meant David could no longer fulfil all aspects of his role as a father were discussed when Maggie shared:

…yesterday we were given a voucher for [daughter] and David to go and get a teddy bear made, and you can do a voice recording and you go into a booth and he could say something like "goodnight Suzy" so when she's cuddling the bear at night, she can squeeze it; but he can't do that so you have to look outside the box and think what can we do.

Discussion

The aim of this study was to explore the experiences of intimacy for adults with acquired communication disorders using AAC and their partners. As this was a qualitative study that attempted to gain an understanding of a small number of individual experiences related to different circumstances, it is not possible to generalise findings to a wider group. The study revealed seven themes: effort, importance, time, closeness, adaptation, emotion, and identity. Relationship loss and gain were expressed as the consequence of the onset of communication disorders and co-existing physical disabilities. The comment by Maggie (theme 4 – Closeness) relating to the loss of intimacy highlighted the devastating impact of an acquired communication disorder on an intimate relationship. Acting in the best interests of this population, it is crucial to address the importance of professionals being able to provide couples with ways to minimise the impact of sudden or gradual, life-altering changes on interpersonal and intimate interactions.

The negative impact of being unable to communicate effectively or spontaneously with a partner correlates with the findings reported by Manne et al. (2004). Using an interpersonal process model of intimacy, the researchers also found that partner responsiveness to self-disclosures was strongly linked to perceptions of intimacy. As there may be reduced opportunity for self-disclosure, due to the presence of paid carers or increased demands on time and emotions, the responses from their partner that would foster feelings of caring and understanding are also reduced, negatively impacting on perceptions of intimacy. When organising care for this population, professionals must support couples to spend time together without unwanted outsiders. Although carers are crucial for some couples, especially when physical disabilities are also present, the freedom to relax and communicate candidly or share personal moments is also important to the well-being of relationships.

Clinical implications

The findings from this study highlight several implications for professionals working with adults with acquired communication disorders who may use AAC and their partners. All of the participants in this study talked about areas that impacted on their ability to maintain intimacy within their relationships. While the factors were different for each couple, some general areas of concern emerged for all participants. The extra effort required to maintain intimate communication when using AAC was reported by all participants. Professionals working with this population should therefore consider intimate communication when setting up AAC communication systems. More focus may be required on light-tech and unaided AAC such as facial expressions and gesture, or pre-programming high-tech devices to include personal and relevant messages that support intimacy.

Previous research and findings from the current study indicate that couples with strong relationships have high levels of intimacy even when one partner has a communication disorder or disability. It is important for professionals to discuss the importance of maintaining a strong relationship and be able to provide support for couples appropriately. Couples need to be encouraged to continue to express themselves intimately and share their feelings with each other as it is through self-disclosure and partner responsiveness that intimate connections are maintained. Based on the findings reported here AAC devices may be of limited use during intimate communications. Therefore suggestions for alternative methods or ways of communicating may support maintenance of intimacy. Professionals such as speech-language pathologists may also require specific training in counselling or access to other support services in order to support clients' intimate relationships. Individuals must however be aware of the limitations of their training and experience and involve other members of the professional team such as counsellors and social workers as appropriate.

Conclusion

Intimacy and intimate communication are important aspects in the relationships of adults with acquired communication disorders and their partners. Being able to maintain a close and intimate relationship with the person closest to you could make the difference in recovery and quality of life after the onset of a traumatic life-changing disease or disability. It is important that professionals are aware of the potential need to support intimacy and intimate communication not only for the person with the acquired communication disorder, but also for their partner. Providing the support and means necessary for couples to preserve this aspect of their relationships requires dedication and commitment, and for professionals to work closely with couples to ensure they are able to communicate in the most effective and efficient manner.

1 For the purposes of this study, the term "partner" is used to refer to a significant other who is a spouse or considered to be a spousal equivalent by the individual with the acquired communication disorder.

Appendix A. Topic guide

The areas included in the topic guide were:

1. The meaning of intimacy for that individual/couple
   a. What is the meaning of intimacy for you as an individual?
   b. What is the meaning of intimacy for you as a couple?

2. The role of AAC in intimacy
   a. Does your AAC play a role in intimacy for you?
   b. What role does your AAC play in intimacy?

3. The role of the communication disorder in intimacy
   a. What is the role of your communication disorder in intimacy for you as an individual?
   b. What is the role of the communication disorder in intimacy for you as a couple?

4. The spouse/partner's role in intimacy
   a. What is your spouse/partner's role in intimacy?

5. The change to intimacy pre and post onset of communication disorder
   a. Have you noticed a change in intimacy since the onset of your/your partner's communication disorder?
   b. What was intimacy like before the onset of the communication disorder?
   c. How is intimacy different since the onset of the communication disorder?

References

Baikie, E. (2002). The impact of dementia on marital relationships. *Sexual and Relationship Therapy*, *17*, 289–299.

Beukelman, D. R., Fager, S., Ball, L., & Dietz, A. (2007). AAC for adults with acquired neurological conditions: A review. *Augmentative and Alternative Communication*, *23*, 230–242.

Beukelman, D. R., & Mirenda, P. (2005). *Augmentative and alternative communication: Supporting children & adults with complex communication needs* (3rd ed.). Baltimore, MD: Paul H. Brookes.

Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, *3*, 77–101.

Johnson, R. K., Hough, M. S., King, K. A., Vos, P., & Jeffs, T. (2008). Functional communication in individuals with chronic severe aphasia using augmentative communication. *Augmentative and Alternative Communication*, *24*, 269–280.

Kagan, A., & Kimelman, M. (1995). Informed consent in aphasia research: Myth or reality? *Clinical Aphasiology*, *23*, 65–75.

Kouneski, E. F., & Olson, D. H. (2004). A practical look at intimacy: ENRICH couple typology. In D. J. Mashek & A. Aron (Eds.), *Handbook of closeness and intimacy* (pp. 117–136). Mahwah, NJ: Lawrence Erlbaum.

Lippert, T., & Prager, K. J. (2001). Daily experiences of intimacy: A study of couples. *Personal Relationships*, *8*, 283–298.

Manne, S., Ostroff, J., Rini, C., Fox, K., Goldstein, L., & Grana, G. (2004). The interpersonal process model of intimacy: The role of self-disclosure, partner disclosure, and partner responsiveness in interactions between breast cancer patients and their partners. *Journal of Family Psychology*, *18*, 589–599.

Miller, R. S., & Perlman, D. (2009). *Intimate relationships* (5th ed.). New York: The McGraw-Hill.

Minichiello, V., Aroni, R., Timewell, E., & Alexander, L. (1990). *In-depth interviewing: Researching people*. Melbourne: Longman Cheshire.

Patton, M. Q. (2002). *Qualitative research & evaluation methods* (3rd ed.). Thousand Oaks, CA: Sage.

Prager, K. J. (1995). *The psychology of intimacy*. New York: The Guilford Press.

Sturges, K. E., & Hanrahan, K. J. (2004). Comparing telephone and face-to-face qualitative interviewing: A research note. *Qualitative Research*, *4*, 107–118.

Taylor, S. J., & Bogdan, R. (1998). *Introduction to qualitative research methods: A guidebook and resource* (3rd ed.). New York: John Wiley.

Wright, L. K. (1998). Affection and sexuality in the presence of alzheimer's disease: A longitudinal Study. *Sexuality and Disability*, *16*, 167–179.

Angela Leigh is a speech-language therapist with a particular interest in supporting adults with acquired communication difficulties. **Dr Dean Sutherland** is a senior lecturer at the University of Canterbury with an interest in AAC. **Dr Tami Howe**'s research and teaching is focused on adults with acquired communication disorders.

Correspondence to:
Dean Sutherland, PhD
Senior Lecturer
Health Sciences Centre
University of Canterbury
Christchurch, New Zealand
phone: +64 (0)3 364 2987 xt 7176
email: dean.sutherland@canterbury.ac.nz

Assessing communication in people with severe–profound disabilities

Co-constructing competence

Hilary Johnson, Jo Watson, Teresa Iacono, Karen Bloomberg, and Denise West

THIS ARTICLE
HAS BEEN
PEER-
REVIEWED

*Hilary Johnson
(top), Jo Watson
(centre) and
Teresa Iacono*

The recent focus on a human rights agenda in Australia has highlighted the vulnerability of people who have little or no speech in gaining access to their communication rights. This paper discusses the complexities of supporting communication for people with severe–profound disabilities within a framework of human rights. People with severe–profound intellectual disabilities are often considered not only unable to speak, but also unable to communicate. This preconception has been refuted and legislation enacted to protect the communication rights of people with severe–profound disabilities. In this paper we present an overview of good communication practices for people with severe–profound intellectual disabilities. Such practice consists of collaborative and transactional assessment and intervention supports, as exemplified in emerging models of supported and person-centred decision-making.

The United Nations' adoption and Australia's ratification of the Convention on the Rights of Persons with Disabilities (UNCRPD; United Nations, 2006) provided clear articulation of the rights of all people, including those with severe–profound intellectual disabilities, to communicate. The right of communication for all has also been recognised internationally, as demonstrated in the United States' Communication Bill of Rights (National Joint Committee for the Communicative Needs of Persons with Severe Disabilities, 1992) and The Montreal Declaration on Intellectual Disabilities (Lecompt & Mercier, 2007). These documents detail people's rights (a) to express themselves and be understood in all environments regardless of their cognitive and communication skills, (b) to receive interventions to improve their communication, and (c) for their communication to be treated with respect and dignity. These rights are also reflected in the ethical principles enshrined in professional codes of ethics and codes of practice by which Australian speech pathologists (Speech Pathology Australia, 2010) and other health care professionals practice (e.g., OT Australia, 2001).

In this article we discuss the issues and complexities of supporting communication for people with severe–profound disabilities within a human rights framework. The pertinent issues for speech pathologists include evaluating notions of communicative competence that incorporate models of good practice for assessment and intervention, person-centred approaches, and supported decision-making.

Human rights

Despite the appeal and vision of universal human rights, it is apparent that not everyone's rights, especially those with the most severe disabilities, are being realised (Brown & Gothelf, 1996; Stancliffe & Abery, 1997; Watson & Joseph, 2011a; Wehmeyer, 1998). Such views impact on the most disempowered in our community: people who are seldom heard, rarely named, infrequently counted, and largely ignored (Watson & Joseph, 2011a). Their disempowerment in part may be attributable to having multiple disabilities and complex health needs, and being unable to communicate formally with symbols (Grove, Bunning, Porter, & Olsson, 1999). Some of these people may have communication skills that are considered to be unintentional. That is, they lack awareness that their behaviour (including their communication) has an impact on others in their environment.

One reason for excluding people with severe–profound disabilities, and even denying their personhood, relates to the lack of acceptance and understanding of their unique needs and strengths, particularly in relation to communication. Clegg (2010), in stating that "we need to have a different way of respecting the inherent humanity of people with ID [intellectual disability]: not just different versions of ourselves because they are themselves" (p. 15), encouraged society to embrace diversity. Communication assessment processes for people with severe–profound intellectual disabilities should begin with an acknowledgement that their communication is complex and whether intentional or not, should be respected and valued. Such acknowledgement means that practitioners need to be skilled in recognising the individualised communicative signals of people with severe–profound intellectual disability, to ensure that assessment and intervention strategies have been chosen in recognition of these (often person-specific) signals. In addition, practitioners need to be able to support others to recognise the person's communicative signals so that the communicative rights of people with severe–profound intellectual disabilities are upheld.

Re-conceptualising communicative competence

Practitioners need to have a view of communicative competence that reflects the collaborative and dynamic nature of communicative interaction. Such a view shifts the onus of communicative competence from the individual with a disability to the environment of which they are a part. This approach is contrary to the candidacy model of augmentative and alternative communication (AAC) assessment that saw clinicians waiting for some prerequisite level of cognitive skill before introducing AAC options. The use of candidacy criteria, such as cognitive level or chronological age as the basis for exclusion from services, has been rejected explicitly by the American Speech-Language-Hearing Association (2005) and the National Joint Committee for the Communication Needs of Persons with Severe Disabilities (1992). In its place is the understanding that AAC, under the umbrella of multi-modal communication, reflects a continuum of communication that can range from simple social or turn-taking routines through to more sophisticated use of symbols (Wilkinson & Hennig, 2007, p. 64). Although it took a long time for policy to catch up, intervention became directed at supporting a person's communication regardless of his/her base level skills. Hence, the communication potential of all individuals, irrespective of their level of intellectual ability, was acknowledged. The clinician's aim, then, has become to gain a comprehensive understanding of what each person brings to the communication interaction so as to provide supports that enhance that interaction (Iacono & Caithness, 2009). This understanding is determined through assessment of skills rather than deficits in communicative competence, a concept that was originally defined according to standards based on the abilities of people without underlying intellectual impairment that impacted on functional speech (Light, 1989).

Communication competence is a construct best understood within a social interaction context, whereby the communication of each person contributes to the dynamic of the interaction utilising a transactional approach (McLean & Snyder-McLean, 1978). The bidirectional nature of interaction is such that the role and task of a communication partner will shift according to the contribution of the other communicator. Years of mother–child interaction research, for example, has shown that mothers will overcompensate for a child who rarely initiates interaction by being overly directive (Marfo, 1992). This directive style is also evident in carers of adults with disability (e.g., McConkey, Purcell, & Morris, 1999). An important component of intervention for people with severe communication impairment is to re-balance that interaction by improving the partner's ability to recognise and respond to the person's communicative or potentially communicative behaviours (Bloomberg, West, & Iacono, 2003). This re-balancing is achieved by sharing the focus of intervention between improving the skills of the person with communication impairment and creating a more able communication partner, who is supported to perceive the communicative competence of the person with the disability. This procedure involves learning to recognise and respond to the communicative or potentially communicative signals of a person with severe–profound intellectual disability (Bloomberg et al., 2003). This delicate balance of interpretation and feedback supports the co-construction of meaning, whereby communication partners collaboratively construct an interaction by recognising, interpreting, and responding to communicative attempts and then checking for signals that indicate the appropriateness of the response.

Assessment

According to a reconceptualised notion of communicative competence within the transactional model of communication, appropriate assessment is crucial in determining intervention targets and strategies that will support a person with severe–profound intellectual disability to participate in a social-communicative interaction (Carnaby, 2007). Iacono and Caithness (2009) described a model of assessment of relevance to people with severe–profound disability across their life stages. The model drew on dynamic, transactional, and participatory processes, also encompassed within the Participation Model that has guided AAC assessment for many years (Beukelman & Mirenda, 2005). The Participation Model provides a holistic approach to developing communication supports, in which assessment and intervention are intricately linked in such an ongoing and iterative process (Beukelman & Mirenda, 2005). Dynamic assessment is an ongoing process of observing communication within unassisted (as often occurs during formal testing) and assisted contexts (as is more typical in intervention). According to transactional approaches, communication is observed and assessed within social interactions in order to determine the reciprocal influence of both communication partners. Participatory processes involve a team of people significant to the person (e.g., family, support people, advocates), as well as the person with disability, working with professionals in the ongoing dynamic assessment.

Using the assessment model proposed by Iacono and Caithness (2009), formal measures such as tests or checklists provide data to supplement observations of the person within real-life contexts and meaningful interactions with regular interaction partners (Bloomberg, West, Johnson, & Iacono, 2009; Dewart & Summers, 1996; Rowland, 2010). For example, one checklist with established reliability (Iacono, West, Bloomberg & Johnson, 2009) is the Triple C – Checklist of Communication Competencies (Bloomberg et al., 2009). The developmental structure of the checklist provides a framework for intervention. Completion of the Triple C by multiple communication partners across environments is necessary to capture the complexity of the nature of interactions for the individual with complex communication needs. A specific assessment tool, such as the Triple C, when considered with other formal and informal strategies for assessment, contributes to an overall understanding of the person's communicative behaviours, learning and interaction styles, and preferred partners and contexts. The outcome of the entire assessment process is to reach an agreement about how the person communicates. The next step is to use the assessment data to inform strategies that will support the person's communication in multiple situations.

Informing intervention

The defining elements of a transactional approach to assessment described by Iacono and Caithness (2009) are inherent within current and emerging intervention models for people with severe–profound intellectual disabilities, such as person-centred and supported decision-making approaches.

Person-centred approaches differ from more traditional disability service approaches whereby people's goals were determined according to what a service could provide (O'Brien, 2007). Instead, a strength-based approach is adopted in which the primary consideration is recognising and valuing the person's individuality in order to mobilise resources and realise the person's aspirations. Implementation of person-centred approaches is fundamental to recognising and acknowledging the person and his/her unique circumstances, and precludes a focus on the person's disability.

Supported decision-making assists people with severe–profound disability in self-determination (Scott, 2007). In adopting this supported decision-making approach, the focus of individual competence, of relevance to skilled-based approaches, changes to that of co-constructed competence, whereby the onus of responsibility for communicative success is shared between the person and his/her communicative partners. A recent example of a supportive process for arriving at decisions about intervention is the supported decision-making framework developed by Watson (2011). Current thinking in relation to supported decision-making for people with severe–profound intellectual disability acknowledges that a person's ability to communicate and to have his/her preferences realised should not be related to a single measure of cognitive capacity, but rather to a range of factors including the degree of support available to the person (Pepin, Watson, Hagiliassis, & Larkin, 2010). Beamer and Brookes (2001) highlighted this view in relation to people with severe–profound intellectual disability, stating "where someone lands on a continuum of capacity is not half as important as the amount and type of support they get to build preferences into choices" (p. 4). Watson's (2011) supported decision-making model is characterised by five phases, each of which is implemented collaboratively: the identification of a decision to be made, listening closely to the individual and to everyone's opinions, exploring all available options, documenting the barriers and enablers in the process, and, finally, the making of a decision that reflects the person with intellectual disability's perceived preferences (Watson & Joseph, 2011b).

In any ethical decision about practice, the views of the person with a disability are important. An obvious but often ignored challenge is to ensure that decisions reflect the views of the person with intellectual disability, and not only the views of others involved in the interaction: that is, to ensure message ownership stays with the person being supported. People who feel they know someone with an intellectual disability well are bound to rely on inferences based on the context and their prior knowledge of the person. An obvious risk is that the meaning assigned to the communication may reflect the hopes, fears and desires of the communication partner, rather than those of the person with a disability (Carter & Iacono, 2002; Grove et al., 1999). Communication partners supporting people with severe–profound intellectual disability must remain ever vigilant to this risk that the person's "voice" in a decision is usurped or replaced by the hopes or dreams of others. Importantly, researchers have indicated that even the most well-intentioned communication partners may reflect their own views rather than the views of the communication of the people they support and that some support strategies are particularly open to this phenomenon (e.g., Mostert, 2010). In the case of Facilitated Communication, for example, communication partners may attribute communication to those who are unable to communicate intentionally without the intervention of a facilitator (see Mostert [2010], for a review of the literature on this phenomenon). Recognising that the process of supporting someone to participate in personal decisions is open to exploitation or abuse, any supported decision-making approach taken must as far as possible be a process that is transparent, systematic, and collaborative and that values any independent communication, whether intentional or unintentional, of the person with disability. An approach such as that proposed by Watson (2011) emphasises reliance on a team of supporters rather than a single individual functioning as a proxy decision-maker. Such an approach helps to ensure varied viewpoints are considered in reaching a consensus decision on the person's own views.

Determining positive communicative outcomes

Ensuring that people with severe–profound intellectual disability have communication systems and strategies that meet both their needs and the needs of their communicative partners is an ongoing process. In accordance with the International Classification of Functioning, Disability, and Health model (ICF) (World Health Organization, 2001), providing a means of communication that can be understood and supported by a range of communication partners in different environments for activity and participation in society is a primary goal. Speech pathologists, as professionals specifically trained in multi-modal and interpersonal communication, have a primary role to enact in ensuring this goal is met for people with severe–profound intellectual disability. However, speech pathologists are a scarce resource in the disability sector. As a result, they often take a consultative role with the aim of teaching and guiding others to provide daily support (Johnson, Douglas, Bigby, & Iacono, 2009). Speech pathologists need to provide recommendations that (a) are based on person-centred and dynamic assessment approaches involving various communication partners, and (b) provide strategies to enable a person's communication partners to interpret communication behaviours, establish consistent and reliable responses and support new modes of communication.

Initially, determining the most useful type(s) of communication supports involves a combination of strategies that include visual aids that document how to recognise and interpret ambiguous communicative signals (e.g., personal communication dictionary, multimedia profile); AAC aids that support expression (e.g., low technology aids) and/or systems that support both expressive and receptive communication (e.g., Key Word Sign) (Johnson et al., 2009). Each of these interventions requires input from the people who regularly interact with the person with severe–profound disability and such input will have been provided during the assessment process. Each strategy requires different levels of support and may not be used by all communication partners. For instance, developing a personal communication dictionary will need input and discussion from familiar communication partners in listing the relevant communication attempts and interpretations (Bloomberg, West & Johnson, 2004). Predominantly, the dictionary will be useful for clarifying the person's responses when communicating with unfamiliar communication partners. The role of a speech pathologist in supporting the implementation of communication strategies includes (a) ensuring resources and aids are

relevant to the needs and situation of the person so that they can be integrated into meaningful interactions and activities, and (b) providing practical communication support through initial modelling, ongoing advice, and a willingness to evaluate the intervention and re-instigate dynamic assessment strategies as needed.

Conclusion

A human rights framework, such as that outlined in this paper and enshrined in the UNCRPD, promotes the recognition of the diverse communication skills and preferences of people with severe–profound disabilities. A human rights framework for assessment and intervention is inclusive of individuals whose communication may be ambiguous or unintentional, and who may need extensive support to communicate. Providing communication support requires a commitment from all communication partners to be willing to suspend his/her own interests and consider those of the person with disability as distinct from the views of his or her communication partners. Suspension of one's own beliefs demands (a) relinquishing assumptions or beliefs about what a person with severe–profound disabilities can achieve, and (b) embracing a process of collaborative observation, interpretation, and development of intervention goals and strategies informed by principles of evidence based practice, the Association's code of ethics (Speech Pathology Australia, 2010), and ethical decision-making frameworks. Australian speech pathologists working with people with severe–profound disabilities are bound by obligations under the UNCRPD; hence our practice needs to acknowledge the inherent value of all communication, whether intentional or not intentional. In addition, our practice should be highly collaborative and transactional, as exemplified by incorporating models of person-centred practice and supported decision-making. In this way, we may work effectively towards people with severe–profound disabilities gaining access to their communication rights to participate in decisions that affect their lives.

References

American Speech-Language-Hearing Association (2005). *Roles and responsibilities of speech-language-pathologists in service delivery for persons with mental retardation/ developmental disabilities* [Position Statement]. Retrieved from http://www.ash.org/members/deskref-journals/ deskref/default

Beamer, S., & Brookes, M. (2001). *Making decisions: Best practice and new ideas for supporting people with high support needs to make decisions*. London: Values into Action.

Beukelman, D., & Mirenda, P. (2005). *Augmentative and alternative communication: Supporting children and adults with complex communication needs* (3rd ed.). Baltimore, MD: Paul H. Brookes.

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.

Bloomberg, K., West, D., & Johnson, H. (2004). *InterAACtion: Strategies for intentional and unintentional communicators*. Melbourne: Communication Resource Centre, Scope

Bloomberg, K., West, D., Johnson, H., & Iacono, T. (2009). *The Triple C: Checklist of communication competencies*. Melbourne: Communication Resource Centre, Scope.

Brown, F., & Gothelf, C. (1996). Self-determination for all individuals. In D. H. Lehr & F. Brown (Eds.), *People with disabilities who challenge the system* (pp. 335–353). Baltimore, MD: Paul. H. Brookes.

Carnaby, S. (2007). Developing good practice in the clinical assessment of people with profound intellectual disabilities and multiple impairment. *Journal of Policy and Practice in Intellectual Disabilities*, *4*(2), 88–96. doi: 10.1111/j.1741-1130.2007.00105.x

Carter, M., & Iacono, T. (2002). Professional judgments of the intentionality of communicative acts. *Augmentative & Alternative Communication*, *18*, 177–191.

Clegg, J. (2010). A moment of change. In C. Bigby & C. Fyffe (Eds.), *Fourth annual roundtable on intellectual disability policy* (pp. 12–18). Melbourne: La Trobe University

Dewart, H., & Summers, S. (1996). *The pragmatics profile of everyday communication skills in adults*. Windsor, Berkshire: NFER-Nelson

Grove, N., Bunning, K., Porter, J., & Olsson, C. (1999). See what I mean: Interpreting the meaning of communication by people with severe and profound intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities*, *12*, 190–203.

Iacono, T., & Caithness, T. (2009). Assessment issues. In P. Mirenda & T. Iacono (Eds.), *Autism and augmentative and alternative communication* (pp. 23–48). Baltimore, MD: Paul H. Brookes.

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*(1), 44–53.

Johnson, H., Douglas, J., Bigby, C., & Iacono, T. (2009). Maximizing community inclusion through mainstream communication services for adults with severe disabilities. *International Journal of Speech-Language Pathology*, *11*, 180–190. doi: 10.1080/17549500902825265

Lecompt, J., & Mercier, C. (2007). The Montreal Declaration on Intellectual Disabilities of 2004: An important first step. *Journal of Policy and Practice in Intellectual Disabilities*, *4*, 66–69. doi: 10.1111/j.1741-1130.2006.00098.x

Light, J. (1989). Toward a definition of communicative competence for individuals using augmentative and alternative communication systems. *Augmentative and Alternative Communication*, *5*, 137–144.

Marfo, K. (1992). Correlates of maternal directiveness with children who are developmentally delayed. *American Journal of Orthopsychiatry*, *62*, 219–233.

McLean, J., & Snyder-McLean, L. (1978). *A transactional approach to early language training* Columbus. OH: Charles E. Merrill.

McConkey, R., Purcell, M., & Morris, I. (1999). Staff perceptions of communication with a partner who is intellectually disabled. *Journal of Applied Research in Intellectual Disabilities*, *12*, 204–210

Mostert, M. P. (2010). Facilitated communication and its legitimacy: Twenty-first century developments. *Exceptionality*, *18*, 31–41. doi: 10.1080/09362830903462524

National Joint Committee for the Communicative Needs of Persons With Severe Disabilities. (1992). Guidelines for meeting the communication needs of persons with severe disabilities. *ASHA*, *34*(March, Supp. 7), 1–8.

O'Brien, J. (2007). Planning with open eyes and open hearts: An alternative to excessive positivism. *Research & Practice for Persons with Severe Disabilities*, *32*, 173–176.

OT Australia. (2001). *Code of ethics*. Retrieved from http://www.otaus.com.au/sitebuilder/about/knowledge/asset/files/1/codeofethics.pdf

Pepin, G., Watson, J., Hagiliassis, N., & Larkin, H. (2010). Ethical and supported decision-making. In K. Stagnitti, A. Schoo, & D. Welch (Eds.), *Clinical and fieldwork placement in the health professions* (pp. 263–280). Oxford: Oxford University Press.

Rowland, C. (2010). *The communication matrix*. Retrieved from http://www.communicationmatrix.org/

Scott, P. (2007). Rallying relationships: The role of positive visions and possible actions in person-centred planning. *Research and Practice for Persons with Severe Disabilities*, *32*, 181–183.

Speech Pathology Australia. (2010). *Code of ethics*. Melbourne: Author. Retrieved from http://www.speechpathologyaustralia.org.au/library/Ethics/CodeofEthics.pdf

Stancliffe, R., & Abery, B (1997). Longitudinal study of deinstitutionalisation and the exercise of choice. *Mental Retardation*, *35*, 159–169.

United Nations. (2006). *Convention on the rights of persons with disabilities*. Retrieved from http://www.un.org/disabilities/convention/conventionfull.shtml

Watson, J. (2011, June). *Listening to those rarely heard through supported decision making: A training package for informal communicators*. Paper presented at the Speech Pathology Australia Conference, Darwin.

Watson, J., & Joseph, R. (2011a). People leading lives they prefer through supported decision making: "Listening to those rarely heard". A powerpoint presentation. Retrieved from http://vimeo.com/23019913

Watson, J., & Joseph, R. (2011b). *People with severe to profound intellectual disabilities leading lives they prefer through supported decision making: Listening to those rarely heard. A guide for supporters*. A training package developed by Scope. Melbourne: Scope.

Wehmeyer, M. (1998). Self-determination and individuals with significant disabilities: Examining meanings and misinterpretations. *Journal of the Association for Persons with Severe Handicaps*, *23*, 5–16.

Wilkinson, K. M., & Hennig, S. (2007). The state of research and practice in augmentative and alternative communication for children with developmental/intellectual disabilities. *Mental Retardation & Developmental Disabilities Research Reviews*, *13*, 58–69.

World Health Organization. (2001). *International classification of functioning, disability and health*. Geneva: Author.

Hilary Johnson is a speech pathologist and manager at Scope's Communication Resource Centre. She is also a PhD student and lecturer in augmentative and alternative communication at La Trobe University. **Jo Watson** is a PhD student at Deakin University and a research fellow at Scope. **Teresa Iacono** is professor of Rural and Regional Allied Health at La Trobe University. **Karen Bloomberg** is a speech pathologist at Scope's Communication Resource Centre and a lecturer in augmentative and alternative communication at La Trobe University. **Denise West** is a manager and speech pathologist at Scope's Communication Resource Centre.

Correspondence to:
Hilary Johnson
Scope, Communication Resource Centre
830 Whitehorse Rd, Box Hill 3128, VIC, Australia
phone: +61 (0)3 9843 2001
email: h.johnson@latrobe.edu.au

Research note

Comparing spoken and written vocabulary use in typically developing children: Informing vocabulary selection for children with complex communication needs

Sally Clendon and Marleen Westerveld

This project used two datasets to compare the spoken and written vocabularies of typically developing 5-, 6-, and 7-year-old New Zealand children. Similarities and differences between spoken and written words and multiword sequences were identified, and word lists were generated that can be used to assist augmentative and alternative communication (AAC) professionals as they engage in selecting vocabulary to support both face-to-face and written communication of children with complex communication needs.

Vocabulary selection is one of the greatest challenges facing professionals in the augmentative and alternative communication (AAC) field (Clendon, 2006). Ensuring that children with complex communication needs have access to the rich and varied vocabularies that they need in order to develop mature language and literacy skills is a difficult and often overwhelming process (Clendon & Erickson, 2008).

Several authors have suggested that AAC professionals employ a variety of strategies to guide their decision-making around vocabulary selection (e.g., Beukelman, Jones, & Rowan, 1989; Fallon, Light, & Paige, 2001). One strategy is to refer to the word lists generated from research examining the vocabularies of typically developing children. A number of studies have examined the spoken vocabularies of typically developing children for the purpose of informing vocabulary selection in AAC (e.g., Ball, Marvin, Beukelman, Lasker, & Rupp, 1999; Banajee, Dicarlo, & Stricklin, 2003; Beukelman et al.,1989; Crestani, Clendon, & Hemsley, 2010; Fallon et al., 2001; Fried-Oken & More, 1992; Marvin, Beukelman, & Bilyeu, 1994; Trembath, Balandin, & Togher, 2007). These studies have elicited samples across a variety of linguistic contexts, such as playtime and mealtime, and in response to oral narrative tasks. None of these studies have included New Zealand (NZ) children.

In addition, three studies (Clendon & Erickson, 2008; Clendon, Sturm, & Cali, 2012; McGinnis & Beukelman, 1989) have examined the written vocabularies of typically developing children. In McGinnis and Beukelman (1989), the writing samples were taken from letter writing activities, science project assignments, and/or language arts assignments. In Clendon and Erickson (2008) and Clendon et al. (2012), the writing samples were on self-

selected topics. In the first few years of school, students are frequently asked to choose their own writing topics (Richards & Sturm, 2010). Research examining the vocabulary used when students write on self-selected topics provides insight into what students do naturally as beginning writers. One of these studies (Clendon & Erickson, 2008) included NZ children.

The current project used two datasets to compare the spoken and written vocabularies of typically developing 5-, 6-, and 7-year-old NZ children. This is the first project to compare the vocabulary used across the modalities for the purpose of informing vocabulary selection in AAC. The aim was to identify similarities and differences between spoken and written communication and to generate word lists to assist AAC professionals as they engage in selecting, prioritising, and organising vocabulary to support both face-to-face and written communication in children with complex communication needs.

Methodology

Written language database

The writing samples were obtained as part of the first author's dissertation research (see Clendon & Erickson, 2008). The participants included 106 children: 31 aged 5 years, 49 aged 6 years, and 26 aged 7 years. The children were recruited from three NZ primary schools. They were in the classrooms of teachers who provided regular (at least three times per week) opportunities for children to write about self-selected topics. All writing samples (*n* = 1225), produced during self-selected writing sessions over a 6-week period, were photocopied for analysis. The teachers were asked to provide translations of any handwriting or spelling attempts that were unclear or unconventional. The teachers were also asked to complete context logs with descriptions of events that may have influenced children's writing topics and vocabulary.

Spoken language database

The spoken samples were collected as part of a NZ database project (Westerveld, Gillon, & Miller, 2004). The participants included 216 children: 63 aged 5 years, 95 aged 6 years, and 58 aged 7 years. All children were seen at their kindergarten or school and engaged in a conversation with an adult using the Westerveld and Gillon Language Sampling Protocol (Westerveld & Gillon, 2002). In this protocol, prompts are used to encourage the child to talk about an object of his/her choice, family, and everyday activities.

THIS ARTICLE HAS BEEN PEER-REVIEWED

Sally Clendon (top) and Marleen Westerveld

Analysis and results

The analyses were conducted using the Child Language Analysis (CLAN, MacWhinney, 2009) program. The total number of words (TNW) and total number of different words (TNDW) are presented in Table 1. As shown in Table 1, the vocabulary used in the written samples was more diverse (type token ratio; TTR = 0.10), than that used in the spoken samples (TTR = 0.06). In both datasets, the most frequently occurring words accounted for a large proportion of the total words produced. As shown in Table 2, the proportions accounted for by the most frequently occurring 10, 50, and 100 words were very similar across the two datasets.

Table 1. Summary statistics for written and spoken samples

Measure	Written samples	Spoken samples
Total number of words	27,643	109,710
Total number of words / number of samples	23	508
Total number of different words	2799	6052
Type token ratio (TTR)	0.10	0.06

Note: TTR = Total number of words / Total number of words

Table 2. Proportion of total words represented by most frequently occurring 10, 50, and 100 words

Word list	Proportion of total number of words	
	Written samples	Spoken samples
Most frequently occurring 10 words	27%	32%
Most frequently occurring 50 words	52%	56%
Most frequently occurring 100 words	64%	66%

Tables 3, 4, and 5 outline the 20 most frequently occurring words, 2-word sequences, and 3-word sequences. The words marked with an asterisk occurred in the 'Top 20' lists for both written and spoken datasets. Eight of the Top 10 words were the same across datasets. These words were: *I, and, the, to, a, my, it,* and *we*. These were all structure words (pronouns, articles, conjunctions, prepositions) as opposed to content words (nouns, verbs,

Table 3. Twenty most frequently occurring words

Written samples		Spoken samples	
1. I*	11. on*	1. and*	11. you
2. and*	12. was*	2. the*	12. got
3. the*	13. am	3. I*	13. that
4. to*	14. went	4. a*	14. one
5. a*	15. are	5. to*	15. then
6. my*	16. in*	6. it*	16. of
7. is	17. she	7. my*	17. he
8. it*	18. have	8. we*	18. because
9. we*	19. me	9. in*	19. was*
10. going	20. like	10. on*	20. yeah

Note. * Word occurred in Top 20 for both spoken and written modalities. The Top 100 Word List can be obtained by contacting the first author.

Table 4. Twenty most frequently occurring 2-word sequences

Written samples		Spoken samples	
1. going to	11. in the*	1. and then	11. don't know
2. I am	12. it is	2. and I*	12. and it
3. and I*	13. she is	3. on the*	13. to the*
4. went to	14. are going	4. and we*	14. and he
5. I went	15. I got	5. in the*	15. and you
6. am going	16. on the*	6. and my*	16. my mum
7. to the*	17. I have	7. I don't	17. have to
8. it was*	18. and she	8. and the	18. go to
9. we are	19. and we*	9. it was*	19. and they
10. I like*	20. and my*	10. got a	20. I like*

Note. * Two-word sequence occurred in Top 20 for both spoken and written modalities.

Table 5. Twenty most frequently occurring 3-word sequences

Written samples		Spoken samples	
1. I am going	11. going to the	1. I don't know	11. and my mum
2. am going to	12. I have a	2. and then we	12. and my dad
3. I went to	13. and I got*	3. you have to	13. go to the
4. are going to	14. and it was*	4. and then I	14. and then he
5. we are going	15. and we are	5. we had to	15. play with my
6. went to the	16. going to play	6. and that's all	16. and we had
7. is going to	17. I had a	7. and I got*	17. play on the
8. and she is	18. it was fun	8. and then you	18. to go to
9. I got a	19. and I am	9. we went to	19. I've got a
10. going to have	20. in the weekend	10. and it was*	20. when I was

Note. *Three-word sequence occurred in Top 20 for both spoken and written modalities

adverbs, adjectives). Eleven of the Top 20 words, and 64 of the Top 100 words were the same across the two modalities.

Differences were found across the two datasets with words like *yeah* and *just* ranking much higher in the spoken samples than the written, and words like *today* and *birthday* ranking higher in the written samples than the spoken. The 2- and 3-word sequences also revealed differences with sequences like *I am going* and *I went to* ranking higher in the written samples than the spoken, and sequences like *I don't know* and *And that's all* ranking higher in the spoken samples than the written.

Age-comparisons using the Top 100 word lists for the two modalities revealed that the overlap was greatest for the 5-year-old children with 42 words shared across both word lists. The overlap for the 6-year-old children was 34 words, and for the 7-year-old children it was 33 words.

Implications and future directions

This study highlighted the similarities and differences in spoken and written vocabulary use in typically developing NZ children. The word lists generated can be used to support the face-to-face and written communication development of NZ children who use AAC. These word lists are particularly relevant for children in the first three years of formal schooling as it is likely that the vocabulary used

reflects a range of variables such as language level, classroom instruction, and interests. Although the word lists may also be useful for older children who have language skills at a similar level, as discussed, word lists must always be used alongside other vocabulary selection tools.

The most frequently occurring words should be prioritised for inclusion in children's AAC systems. The words that occurred with high frequency in both datasets should be targeted in interventions that address language and literacy simultaneously (see discussion in Clendon & Erickson, 2009). Future research should compare spoken and written vocabulary in students from other English-speaking countries and investigate children's spoken vocabulary use in other contexts, such as child–child dyads.

Acknowledgments

References

Ball, L. J., Marvin, C. A., Beukelman, D. R., Lasker, J., & Rupp, D. (1999). Generic talk use by preschool children. *Augmentative and Alternative Communication*, *15*, 145–155.

Banajee, M., Dicarlo, C., & Stricklin, S. B. (2003). Core vocabulary determination for toddlers. *Augmentative and Alternative Communication*, *19*, 67–73.

Beukelman, D. R., Jones, R. S., & Rowan, M. (1989). Frequency of word usage by nondisabled peers in integrated preschool classrooms. *Augmentative and Alternative Communication*, *5*, 243–248.

Clendon, S.A. (2006). *The language of beginning writers: Implications for children with complex communication needs*. Unpublished doctoral dissertation, University of North Carolina at Chapel Hill, USA.

Clendon, S. A., & Erickson, K. A. (2008). The vocabulary of beginning writers: Implications for children with complex communication needs. *Augmentative and Alternative Communication*, *24*, 281–293.

Clendon, S.A., & Erickson, K.A. (2009). Literacy instruction for individuals with complex communication needs. *ACQuiring Knowledge in Speech, Language and Hearing*, *11*(2), 77-80.

Clendon, S. A., Sturm, J. M., & Cali, K. (2012). *Vocabulary use across topics and genres: Implications for children with complex communication needs*. Manuscript submitted for publication.

Crestani, C. M., Clendon, S. A., & Hemsley, B. (2010). Vocabulary of narratives: Implications for children with complex communication needs. *Journal of Intellectual and Developmental Disability*, *35*, 268–278.

Fallon, K. A., Light, J. C., & Paige, T. K. (2001). Enhancing vocabulary selection for preschoolers who require augmentative and alternative communication. *American Journal of Speech-Language Pathology*, *10*, 81–94.

Fried-Oken, M., & More, L. (1992). An initial vocabulary for nonspeaking preschool children based on developmental and environmental language sources. *Augmentative and Alternative Communication*, *8*, 41–56.

Marvin, C. A., Beukelman, D. R., & Bilyeu, D. (1994). Vocabulary-use patterns in preschool children: Effects of context and time sampling. *Augmentative and Alternative Communication*, *10*, 224–236.

McGinnis, J. S., & Beukelman, D. R. (1989). Vocabulary requirements for writing activities for the academically mainstreamed student with disabilities. *Augmentative and Alternative Communication*, *5*, 183–191.

Richards, S., & Sturm, J. M. (November, 2010). *Writing instruction in primary classrooms: Implications for students with disabilities*. Poster session presented at the American Speech-Language-Hearing Convention, Philadelphia, PA.

Trembath, D., Balandin, S., & Togher, L. (2007). Vocabulary selection for Australian children who use augmentative and alternative communication. *Journal of Intellectual and Developmental Disability*, *32*, 291–301.

Westerveld, M. F., & Gillon, G. T. (2002). A New Zealand spontaneous language sampling protocol. Christchurch, New Zealand: Department of Communication Disorders, University of Canterbury. Retrieved from www.education. canterbury.ac.nz/documents/gillon/languageprotocol.pdf

Westerveld, M. F., Gillon, G. T., & Miller, J. F. (2004). Spoken language samples of New Zealand children in conversation and narration. *Advances in Speech-Language Pathology*, *6*, 195–208.

Sally Clendon is a senior lecturer at Massey University in Auckland, New Zealand. Her clinical and research interests are focused in the area of language and literacy development for children with complex communication needs who use augmentative and alternative communication. **Marleen Westerveld** is a senior lecturer at Griffith University, Gold Coast, Queensland. Her clinical research focuses on children's oral language skills that are needed to participate in daily activities.

Correspondence to:
Sally Clendon, PhD
Senior Lecturer
Speech Language Therapy Programme
School of Education at Albany
Massey University College of Education
PO Box 102 904, North Shore Mail Centre,
Auckland, New Zealand
phone: +64 (0)9 414 0800 ext 41488
email: s.clendon@massey.ac.nz

Peer-group consultation

Christa Carey-Sargeant and Lindsay Carey

THIS ARTICLE HAS BEEN PEER-REVIEWED

Christa Carey-Sargeant (top) and Lindsay B. Carey

The speech pathology profession acknowledges the need for professional development. Although there are well-established protocols and networks available for therapists seeking individual support, yet there has been minimal attention paid to professional group learning which is non-hierarchical. This paper explores the possible benefits and limitations of peer consultation in a group context – or *peer-group consultation* – as an alternative to customary forms of professional development.

In speech pathology, a therapist's "duty of care" to his/her colleagues means that we should "support our colleagues to reflect on their practice and professional conduct" and that we should "assist them to access relevant continuing education and support when required" (Speech Pathology Australia, 2010a, p. 3). Duty of care thus includes mentoring, postgraduate study, fulfilling professional self-regulation programs, or other continuing professional development curriculum (Hooper, 2007). While it is expected that employing organisations should provide processes to ensure that adequate professional development and supervision is occurring through such protocols as position descriptions, key performance indicators, and performance reviews (Hooper, 2007, p. 4), it is also expected that individuals will engage in their own ongoing professional development. This is because it is commonly recognised that a "practising speech pathologist requires additional specialist expertise beyond the competency based occupational standards (CBOS) entry level competencies required for admission to the profession" (Hooper, 2007, p. 10; Speech Pathology Australia, 2010b).

Although there is much literature concerning mentoring and supervision of new graduates (Carozza, 2011; Dickman et al., 2007; Rose, 2005), minimal guidance or reference appears within the speech pathology literature on how the process of mutual support between experienced speech pathologists should be established, practised and/or maintained. This paper will briefly review adult learning theory, issues of terminology, and peer-group consultation as a technique for professional development.

Adult learning theory

Since the 1970s the evaluation of adult learning styles has become increasingly popular. Knowles (1990) outlined six generally held *tenets* relating to adult education (summarised in Table 1). It can be argued that such tenets are just as important for adult peer consultation based on the assumption that professionals are social beings who need to connect, develop, and validate their behaviour through contact with other beings (Kombrink, 1985).

Table 1. Summary of Knowles' tenets of adult education
Adults
• have a need to know how to improve the effectiveness and quality of their lives
• have a self-concept developed early in life which influences his or her approach to learning
• draw on past learning experiences
• have a readiness to learn
• are motivated to learn if they perceive it will help them deal with and resolve real life problems
• The most powerful motivators for adults are internal pressures such as the desire for increased job satisfaction, self-esteem and quality of life.
Source: Knowles, 1990

Validation theory (among other theories) has also been acknowledged as important in understanding the adult education process. Friere (1983) suggested that adults follow a continuous three-pronged cyclical approach to learning comprising listening (reflection), dialogue (peer consultation), and action (collaboration). The central proposal of Friere's framework is the spiral of action–reflection–action pursued in the development of clinical reasoning skills. Engaging in dialogue with colleagues in a group context can also provide adults with opportunities to explore a variety of problem-solving tactics that are usually not as well developed simply through individual or one-to-one reflection. Hart (1995) also noted a number of potential benefits that adult learning through peer groups can achieve, which ultimately should lead to a better quality of care benefiting staff and clients/ patients (summarised in Table 2).

Interestingly, Kombrink (1985) identified that peer consultation in groups also had the potential for decreasing feelings of isolation, providing support in clarifying responsibilities, and helping members to express feelings and frustrations. In addition, peer consultation in groups potentially allows for members to cultivate innovative solutions for a variety of professional and personal issues.

Table 2. Summary of the potential benefits of adult learning through peer groups

1. Establishment of a non-threatening learning community
2. Decreased work-related anxiety
3. Self-discovery, insight, and personal growth on the part of the participants
4. Increased acceptance, validation, and support between group members
5. Recognition for, and promotion of, professional expertise
6. Enhanced self-esteem and increased confidence
7. Prompt evaluation of competency
8. Improved communication and information sharing
9. A more professional and client-centred approach to care
10. Improved staff morale
11. Improved quality of care

Source: Hart, 1995

The success of a group, however, would hinge upon group members understanding the characteristics, dynamics, and potential benefits of adult learning through peer groups in comparison to other strategies – some of which are described using similar terminology but are very different ideologically and pragmatically.

Terminology

Within the literature across business, education, medical, and psychological professions, terms such as peer mentoring, peer coaching, peer review, peer supervision, peer assessment, peer mediated instruction, peer modelling, peer monitoring, and peer assistance, are all used to describe colleagues working together as peers to improve professional practice. While the use of the word *peer* in these terms suggests equal sharing and learning, nevertheless the linking of the word *peer* with other words (e.g., supervision, assessment, monitoring) forms terms which subsequently can be interpreted and utilised by management to create a hierarchical or an uneven balance of power in workplace relationships.

Supervision

Within speech pathology a range of supervision models are noted such as one-to-one supervision, peer-group supervision, group supervision, co-therapy, or co-working supervision, live or audio/video supervision, or email-/computer-based supervision (Ferguson, 2005). The peer-group supervision in this context is defined as involving two or more members who supervise each other's work informally and are overseen by a formal supervisor. Hawkins and Shohet (2000) outline six advantages of peer-group supervision: (a) it is economically efficient, (b) it creates a supportive atmosphere among peers, (c) it is particularly advantageous for new staff, (d) it allows for feedback from a range of colleagues, (e) as well as the group supervisor, and (f) it allows the supervisor to test whether group members have the same response to material as him/herself. A group can also provide a wide range of life experiences allowing greater empathy to develop between colleagues, and group supervision allows for modelling of techniques including re-enactment to help solve clinical dilemmas. Given such advantages, group supervision has been noted to be beneficial for speech pathology (Horton, de Lourdes Drachler, Fuller, & de Carvalho Leite, 2008).

Group supervision, however, can have a number of disadvantages. These could include an unhealthy preoccupation with competitiveness and advice giving with members trying to outdo each other with a variety of "if I were you" solutions, or a focus on personal clinician needs to the exclusion of the client needs. In supervision groups, while it may be important for the supervisor (in terms of clinical education) to model reasoning and clinical skills, the supervisor can become dominant and hierarchical and do a poor job of leading beneficial group processes by continually showing off his/her expertise. Such supervision groups can also become over-collusive and inward looking and can ultimately fail to attend to the task of professional development (Hawkins & Shohet, 2000). Over the last decade, the use of electronic media, emails, Skype, and other forms of social networking have become increasingly popular for supervision (Carozza, 2011; Chambliss, 1996; Ferguson, 2005; Macklem, Kalinsky, & Corcoran, 2001). These forms of communication can be particularly valuable given time constraints and geographical isolation, however, there are confidentiality risks and a search of the literature failed to reveal evidence that "virtual" meetings are an effective substitute for involvement in face-to-face dialogue.

Mentoring

Another commonly used term is *mentoring*, usually involving direct professional assistance and role modelling plus emotional and psychological support by a more experienced and achieved mentor to a mentee (Jacobi, 1991). An example of this is ASHA's Student To Empowered Professional (S.T.E.P.) mentor program that can be implemented face to face or via electronic media to provide student support (Carozza, 2011, p. 151). Generally speaking, mentoring is considered a different process to supervision (given its explicit hierarchy involving power/assessment); nevertheless the power relationship in mentoring is still present but simply more subtle. The mentor is usually someone more experienced, knowledgeable and authoritative who will mentor someone, as distinct from networking or consulting. While it has been argued that *mentoring* can create increased job satisfaction, increased peer recognition, and potential career advancement for the mentee, and may even create rejuvenation in the mentor, it can also be argued that mentoring predominantly benefits the organisation where knowledge about the organisational culture is passed onto new employees to maintain the status quo (Carozza, 2011, p. 145ff; Limerick, Heywood, & Daws, 1994; Rose, 2005, p. 319ff) or is used to reduce attrition rates and increase staff productivity (Rolf-Flett, 2002).

Such dynamics may not initially be considerd a problem from a management perspective, however ineffective mentoring can lead to "role confusion and development of hostile relationships where power imbalances and complexities of confidentiality inside the workplace are compromised" (Rose, 2005, p. 317). Other difficulties associated with mentoring have included poor matching of mentor and mentee, unrealistic or incompatible expectations, and relationships that become too intense or exclusive and ignore other professional input (Enyedy et al., 2003). Interestingly, in a study comparing the terms mentoring to *networking* by Queensland women in senior management positions (Limerick et al., 1994), it was discovered that the term mentoring was perceived to have negative connotations for women. The preferred term networking, however, was viewed to describe strategic

alliances which depended on trust, support, reciprocity and communication and that networking, based on common interests and developing friendships, was found to be a more valued and utilised term and technique primarily due to its non-hierarchical nature (Limerick et al., 1994).

Peer consultation

Peer consultation was introduced during the 1980s in the nursing profession to foster adult learning and support for staff in the mental health arena (Shields, Gavrin et al., 1985). Staff members in this field of work found that breaking from traditional nursing roles meant that they required non-traditional methods of education and clinical supervision. Peer consultation in this workplace was seen as being more effective in a group context than an individual–supervisor or mentor one. Expertise was shared rather than being considered as that which is mastered by one practitioner alone. Colleagues met in a group to seek resolution of clinical or organisational issues where "a consultative response depended on cooperative group affiliations" (Shields, Zagata, & Zander, 1985, p. xv).

While there has been little empirical research exploring peer consultation in groups, Hart and colleagues (Hart et al., 2000) undertook a noteworthy quasi-experimental pre and post test study to evaluate an accelerated professional development program (APD) among mental health nurses (involving both peer consultation in a group combined with self-directed reflective practice) compared with peer consultation in a group (without self-directed reflective practice). The research explored *caregiver characteristics* (critical thinking ability, empathy, sense of hope, attitude), *service environment* (perception of nursing role, environment organization of nursing services) and *caregiver behaviour* (peer support, consultation, and performance appraisal).

The results indicated that participants from both groups reported significant improvements in their empathetic responses to patients, their sense of hope, their work performance, and their perceptions of the work environment. Hart and colleagues noted however that a significantly higher sense of hopefulness and greater confidence in their clinical work was reported by the APD program participants. Outcomes for participants of the APD program were more patient-care or clinically focused, compared with the peer consultation group alone which focused upon staff- and colleague-related factors. Either way, the research clearly indicates that peer-group consultation was beneficial as a professional development strategy. As Hart et al. (2000, p. 36) note:

> The value of such forums as a practical alternative to traditional one-on-one clinical supervision warrants consideration. The opportunity for peer consultation in both programs encouraged supportive and trusting relationships between colleagues and the focus on practice incidents ensured an orientation to patient care and personal development.

It is this strategy, peer consultations in a group context, more aptly and succinctly labelled by the current authors as *peer-group consultation* (PGC), which we believe would be beneficial for the speech pathology profession to encourage among experienced clinicians.

Peer-group consultation

Since the mid-1990s, there has been a growing interest in the development and implementation of peer consultation in groups reported in the literature from a variety of settings.

These have included: social work (Nurius, Kemp, & Gibson, 1999), tertiary settings (Cox, 1999), air force training (Millis, 1999), educational/school counsellors (Benshoff & Paisley, 1996; Garrett & Barretta-Herman, 1995; Logan, 1997; Wilkersen, 2006), Australian school principals (Beavis & Bowman, 1995), psychotherapy (Rozelle, 1997), and, most predominantly, nursing (Hart, Yates, Clinton, & Windsor, 1998; Nash et al., 1999).

Over the years, the literature indicates numerous attempts to define these group consultations. Generally, peer consultation in groups was usually defined as *case focused, problem-solving and brain storming*, versus other strategies such as peer supervision which predominantly have been hierarchical, one-to-one, clinician focused, skill based, and driven by a conceptual/theoretical model (Keys, Bemak, Carpenter, & King-Sears, 1998). Overall, it can be argued that peer consultation in a group context sought to marry the different types of professional learning (such as supervision and mentoring) within a non-hierarchical program, driven by the needs and/or goals of an individual but collaboratively considered by a professional group of peers.

Amid the varying definitions, we define the term *peer-group consultation* (PGC) as: **a non-hierarchical group of experienced peers and colleagues who intentionally and willingly network and consult together in a supportive and confidential setting, to collectively reflect and share their differing but equally valued expertise about clinical, professional, and organisational concerns, with the aim of considering possibilities, techniques, resources, and strategies to address and resolve issues**.

There are certain characteristics and advantages that clearly identify a PGC process compared to either mentoring or supervision strategies (refer to Table 3). This is to not to suggest that supervision or mentoring should no longer have a place in professional development – indeed it can be argued that such strategies are ideal for novices and inexperienced practitioners, plus it also needs to be acknowledged that PGC processes have been developed from a foundation in supervisory and mentoring experiences.

A PGC functions best when members approach the group not as supervisors or mentors but as equals, even though in practice the range of skills or years of experience may vary from person to person. Mondy, Sharplin, and Premeaux (1990) noted that group cohesiveness is established when members are from similar gender groups, age and experience, the group size is less than 15 and the needs of members are similar, the environment is conducive to group sharing, and there are few established threats. That is, a group that is cohesive is usually found to be more productive than one which is not.

Kovach (1985) states that power within a peer group should be distributed equally and there is no one leader. Rather than a *dominant* leader, the role of leader is assumed by members of the group taking turns. This role of leading, however, is confined to basic functions such as time keeping, scheduling and agenda setting. *Consultation* suggests that the professional elects to seek expertise without implied shared accountability.

As the professional competence and sophistication of a peer-group consultation increases, Shields et al. argue that individuals will increasingly seek less personal supervision and prefer greater collective creative resolutions and possibilities to solve complex personal, role-development, organisational or system issues (Shields, Gavrin et al.,

Table 3. Common characteristics of peer-group consultation compared with mentoring and/or supervision	
Peer-group consultation	**Mentoring/Supervision**
• Non-hierarchical	• Hierarchical
• Suitable for experienced clinicians	• Suitable for new graduates
• Power shared (even balance of power)	• Power over (uneven balance of power)
• Participants equal colleagues	• Participants mentored or supervised
• Shared/rotating leadership and responsibilities	• Appointed/dominant leader
• Participant volunteers/willing to be consultant colleague	• Participation often required/mandatory to be mentored/supervised
• Different expertise shared by multiple consultants and equally valued	• Expertise considered mastered by sole/dominant practitioner
• Collective reflection and breadth of resolutions/possibilities to solve issues	• Supervisor's and participant's reflection and resolutions/possibilities to solve issues
• Focus upon developing/considering new professional techniques/strategies	• Focus upon operating within and conforming to organisational status quo/culture
• Increases professional socialisation and outcomes	• Increases organisational socialisation and organisational outcomes
• Outward looking to numerous colleagues and external resources and support	• Predominantly inward looking to supervisor/mentor to solve/deal with issues
• Provides and encourages wider professional interaction and networking	• Provides and encourages more personal emotional/psychological support

1985). They identified quite rigid and structured boundaries for establishing a peer consultation group. They suggested that a regular time, place, and membership is necessary for the group to be successful. Shields et al. suggested groups hold between three and ten members who meet regularly (possibly monthly) in a consistent setting which suggests a business-like meeting but with sharing of drinks and food to create a feeling of informality before and after the meeting.

Wallerstein and Bernstein (1988) proposed a five-step plan to move group discussion from a personal or social encounter to a critical analysis and action outcome for clinical staff. Initially (Step 1) participants are invited to describe an incident from their clinical experience. Then all group members are involved in exploring the complexities of the problem (Step 2). Step 3 involves sharing of similar experiences. The group then identifies dynamics such as biophysical, psychosocial, cultural, religious-spiritual, economic, and political factors which contribute to the problem (Step 4). Collectively a care plan develops to address the problem (Step 5). Through the group experience, clinical reasoning skills are affirmed, and necessary changes to the individual's knowledge base or reasoning process are identified and encouraged.

Table 4. Summary of recommendations for establishing a PGC

- Recruit 8–10 members for a start-up group
- Decide on where and when to meet, length of meeting
- Plan a rotation of hosts and destinations for the year
- Decide who will provide refreshments
- Decide about social time: how much time before the meeting
- Discuss norms regarding attendance, commitment, absence
- Discuss group rules/expectations (e.g., confidentiality)
- Review phases of consultation
- Review roles of consultees
- Review roles of consultation
- Review roles of host, timekeeper, taskmaster
- Discuss a dinner meeting at the beginning and end of the year
- Discuss the idea of a retreat/professional development day.

Source: Hart, 2010

For those who would like to consider commencing a PGC, Hart (2010) made several useful recommendations for establishing a peer-group consultation model that can serve as a guide for speech pathologists (summarised in Table 4). Fundamentally, a PGC agenda is set with a different *consultee* each week who will present for approximately 45 minutes (or less) about a topic of their choice. Other members act as *consultants* providing feedback and suggestions for the consultee. Discussion may follow for 1 to 1.5 hours after the consultee's presentation. Hart-Smith (1985) noted a number of skills required of participants in a peer group relative to their role (consultant, consultee, attending member; see Table 5). Gavrin (1985) suggested that consultees need to address three areas of *preparation, presentation*, and *perpetuation* of the consultation process. Suggested components for each area are noted in Table 6.

Table 5. Summary of skills required of participants in a peer group

1. For a consultee:
   - an awareness of personal strengths and weaknesses (self-awareness)
   - an ability to state the problem/present case study/topic/issue
   - and ability to tolerate feedback (positive and critical)
   - an ability to structure the meeting (the presentation and discussion)
2. For a consultant/s:
   - an ability to listen carefully
   - an ability to ask questions that stimulate problem solving (insight oriented questions)
   - a style of communicating suggestions that leads to acceptance and mutual respect
   - an understanding of the theory of consultation and of group dynamics
   - an ability to let go of your suggestions, allowing consultees to proceed as they wish
3. For all members:
   - an ability to make a commitment to the group.
   - an ability to make the peer group a priority
   - an ability to share responsibility and achievement
   - a willingness to be proactive to assist each other

Source: Hart-Smith, 1985

Table 6. Summary of consultee preparation, presentation, and perpetuation

1. Preparation
   - develop awareness of yourself
   - choose your clinical case study/ topic/issue
   - put your material in context
   - consider evidence based research/ practice
   - formulate questions
2. Presentation
   - structure the meeting
   - deliver the formal presentation
   - prepare for self-disclosure
   - interact with peer group consultants
   - recognize societal/cultural influences
3. Perpetuation (of the consultation process)
   - take some time for review
   - evaluate whether your needs were met
   - consider long-term implications of individual presentation
   - plan future PGCs

Source: Gavrin, 1985

Topics of choice could vary from direct patient care, administration, professional relationships, and referrals, research in professional publications or work–life balance issues and even career changes. The consultee may identify the type of problem, briefly describe the background information, pose their concerns, give pertinent history of the problem, disclose pertinent personal experiences with the problem, and relate attempts made to address the problem, then open up the floor for group discussion. Following Friere's (1983) cyclical approach to learning (noted earlier), consultants would, after listening and reflecting, have a dialogue with the consultee to seek clarification and to actively respond as part of a group collaboration to consider possibilities, techniques, resources and strategies to address the consultee's issue. Based on Hart's (2010) model, examples of peer-group consultation scenarios involving speech pathologists are provided in Table 7.

It is beneficial, we believe, for each consultee and consultant, as a PGC collaboration, to commit to discussing their progress at subsequent meetings. It is wise, if agreed, that each PGC should begin by reflecting on the success or otherwise of the previous session's consultation (Hart, 2010).

Table 7. Examples of possible peer-group consultation scenarios

1. Consultation request: Clinical case

Consultee's question

"I have an ethical dilemma regarding another professional. I have a primary school student I recently assessed who has a language learning difficulty and behavioural issues. The family have tried many approaches in the past to address their child's needs. A professional involved (from another discipline) has recommended the family pursue expensive naturopathic treatment, but the literature indicates there is no evidence base for this treatment. I'd value the group's opinion. What would you do?"

Group consultants' clarification and responses

The consultants asked the consultee for more details regarding the background history of the student, the consultee's involvement so far and the additional management options trialled previously. Each consultant discussed treatment approaches used with their clients who had similar issues, focusing on those approaches that had been successful and had some research evidence of positive gain. In a subsequent PGC meeting, research articles that highlighted the lack of evidence for the particular naturopathic treatment were discussed. Discussion also occurred about the consultee's relationship with the professional involved. The pros and cons of approaching the other professional were discussed as was the duty of care to the student and the family.

Discussion

The consultee found the group was able to frame all the issues regarding this client in a way that the consultee was able to weigh up the issues and possible responses. The group considered that the consultee could approach the professional's training board for guidance as to best practice guidelines and present alternatives to the family that were evidence based and suitable for the student and school environment. The consultee thanked the group for their support and suggestions and committed to discussing progress at the next PGC.

2. Consultation request: Organisational issue

Consultee's question

"A member of our speech pathology staff has resigned and has not been replaced. The manager of allied health services reported that, due to government budget cuts, it was unlikely the member would be replaced and that the service delivery would have to change to cater for this change in staffing. As a speech pathology departmental manager I am unsure how to address the issue with management and with my speech pathology staff, who are now expected to have an increased case-load over and above their already excessive workload. I have tried 'all the strategies in the book' to have a replacement appointed but to no avail. I'd value the group's opinion. What would you do?"

Group consultants' clarification and responses

The consultants clarified details with the consultee about the workplace structure including staffing ratios and current levels of need. Consultants discussed service delivery issues such as core responsibilities versus non-core tasks and prioritisation of responsibilities of staff, expertise among staff, employment of an allied health assistant plus other strategies. Strategies for approaching management regarding the necessity for increased staffing were also discussed. Consultants reported on their own success or otherwise of negotiating with management. Engaging a third party to assist with negotiations was also discussed, with members sharing their experiences and offering to collaborate. The consultee made notes of discussion points, welcomed the collaboration and planned to look into the literature for other solutions.

Discussion

The consultee was quite frustrated and agitated initially. Once consultants shared their personal experiences and possible solutions, the consultee became visibly more relaxed. After thanking consultants for their input, the consultee promised to discuss progress at the next PGC.

Limitations

As noted earlier, there has been limited research evaluating the processes of peer consultation in groups. It seems logical, however, that PGCs will not suit all learner styles or gender groups. There may be clinicians who do not like to solve problems by group discussion but prefer to actively participate in individual learning activities (Kolb, 1984). Research suggests that women and men have different styles of communication, and different views of power and preferences for decision-making styles (Rose & Best, 2005). As outlined by Hart-Smith (1985), Enyedy et al. (2003), and Hawkins and Shohet (2000), there are also other difficulties groups may encounter. These could include blustering ("my group is bigger and better than yours") or lamenting ("isn't it awful working for this organisation"), or reinforcing feelings of powerlessness, avoiding disclosure by "patting each other on the back", entering a competition to be the "best contributor", or identifying a group member to play the role of patient allowing other members to avoid self-disclosure.

Personality conflicts, though not always a limitation, may nevertheless disrupt the flow and function of groups and thus group members may avoid giving constructive criticism to each other – hence the group needs to understand and deal effectively with personality and confrontation issues between group members (Sheehan, 1985). If the group has accepted group rules at the outset and developed a stable level of trust, members will not take confrontation personally, and as a result constructive criticism can be an effective part of developing participants' self-awareness and learning. In addition, if group goals are constantly held in mind, competition and conflict between members can be managed effectively. Additional practical matters such as poor group time management can also discourage group members. Lengthy or uninspiring presentations or defensive consultees could lead to members dropping out and cancellations of meetings may also discourage members (Hart, 2010). These difficulties can be overcome through pre-planning (refer to tables 5 and 6) and should disappear as trust develops between group members over time.

Another factor that can affect group cohesiveness and efficiency is in-depth personal sharing. Group members need to recognise that even though peer-group consultation may be cathartic and even therapeutic, it is not therapy. As the needs of group members change over time, group rules may need to be reviewed and/or reaffirmed. Members may also need to leave or join another group and thus all need to be mindful of the dynamics involved in these processes and to acknowledge members' feelings surrounding times of change and transition (Shields et al., 1985). Indeed, in the current economic climate, where people change jobs frequently, the ability of members to commit to a long-term relationship within a group may not be viable – not because of the group members per se, but due to the increasing lack of stability in the contemporary workplace. Given many of these potential limitations, there is a need to support evidence based research to help assess and improve the quality of professional development gained from peer-group consultations and to ensure that inappropriate and outdated practices are not perpetuated.

Future directions

This article discussed peer-group consultation (PGC), some of the known dynamics involved in running a PGC, and the advantages and limitations of its use. The speech pathology profession has clearly stated the need for clinicians to continue their professional development. PGC may be an effective model based upon adult learning theory and group process that can support professional development. The implementation and subsequent evaluation of PGCs would help provide evidence as to whether this model could be a beneficial option to assist professional development within the speech pathology profession.

References

Beavis, A., & Bowman, D. M. (1995). *The implementation of peer-assisted leadership in Australia: A means of spanning the chasms that divide*. Paper presented at the American Education Research Association, 1–22.

Benshoff, J. J., & Paisley, P. O. (1996). The structured peer consultation model for school counsellors. *Journal of Counselling and Development*, *74*(3, Jan–Feb), 314–318.

Carozza, L. (2011). *Science of successful supervision and mentorship*. San Diego, CA: Plural Publishing.

Chambliss, C. (1996). *Peer consultation on the net: The problem of ex-clients who stalk therapists*. ERIC Document No. ED393048. Pennsylvania.

Cox, M. D. (1999). Peer consultation and faculty learning communities. *New Directions for Teaching and Learning*, *79*(Fall), 39–49.

Dickman, G., Halloran, H., Cimoli, M., Gates, S., Shaw-Stuart, L., Stevens, A., & Stone, C. (2007). *Parameters of practice: Guidelines for delegation, collaboration and teamwork in speech pathology practice*. Melbourne: The Speech Pathology Association of Australia Limited.

Enyedy, K. C., Arcinue, F., Puri, N. N., Carter, J. W., Goodyear, R. K., & Getzelman, M. A. (2003) Hindering phenomena in group supervision: Implications for practice. *Professional Psychology*, *34*(3), 312–317.

Ferguson, K. (2005). Professional supervision In M. Rose & D. Best (Eds.), *Transforming practice through clinical education, professional supervision and mentoring* (pp. 309–323). London: Elsevier.

Friere, P. (1983). *Education for critical consciousness*. New York: Continuum Press.

Garrett, K. J., & Barretta-Herman, A. (1995). Missing links: Professional development in school social work. *Social Work in Education*, *17*(4), 235–243.

Gavrin, J. M. (1985). How to present to your peers. In J. M. Shields, J. M. Gavrin, V. Hart-Smith, L. Kombrink, J. S. Kovach, M. L. Sheehan, K. F. Zagata, & K. Zander (Eds.), *Peer consultation in a group context: A guide for professional nurses* (pp. 39–59). New York: Springer.

Hart, G. (1995). Teaching clinical reasoning in nursing: An environmental perspective. In J. Higgs & M. Jones (Eds.), *Clinical reasoning in the health professions* (1st ed.; pp. 289–300). Sydney: Butterworth-Heinemann.

Hart, G., Clinton, M., Edwards, H., Evans, K., Lunney, P., Posner, N., … & Ryan, Y. (2000). Accelerated professional development and peer consultation: Two strategies for continuing professional education for nurses. *Journal of Continuing Education in Nursing*, *31*(1), 28–37.

Hart, G., Yates, P., Clinton, M., & Windsor, C. (1998). Mediating conflict and control: Practice challenges for nurses working in palliative care. *International Journal of Nursing Studies*, *35*(5), 252–282.

Hart, V. A. (2010). Communication and peer group supervision. In V. A. Hart (Ed.), *Patient–provider communications: Caring to listen* (pp.283–308). Sudbury, MA: Jones and Bartlett Publishers.

Hart-Smith, V. (1985). How to create and manage a successful peer group. In J. D. Shields, J. M. Gavrin, V. Hart-Smith, L. Kombrink, J. S. Kovach, M. L. Sheehan, K.

F. Zagata, & K. Zander (Eds.), *Peer consultation in a group context: A guide for professional nurses* (pp. 25–37). New York: Springer.

Hawkins, P. S., & Shohet, R. (2000). *Supervision in the helping professions: An individual, group and organisational approach* (2nd ed.). Berkshire, UK: Open University Press.

Hooper, J. (2007). *The role and value of professional support*. Melbourne: Speech Pathology Association in Australia.

Horton, S., de Lourdes Drachler, M., Fuller, A., & de Carvalho Leite, J. C. (2008). Development and preliminary validation of a measure for assessment of staff perspectives on the quality of clinical group supervision. *International Journal of Language & Communication Disorders*, *43*(2), 126–134.

Jacobi, M. (1991). Mentoring and undergraduate academic success: A literature review. *Review of Educational Research*, *61*, 505–532.

Keys, S. G., Bemak, F., Carpenter, S. L., & King-Sears, M. F. (1998). Collaborative consultants: A new role for counselors serving at-risk youth. *Journal of Counseling & Development*, *76*, 123–133.

Knowles, M. C. (1990). *The adult learner: A neglected species*. (4th ed.). London: Gulf Publishing Co.

Kolb, D. A. (1984). *Experiential learning*. Englewood Cliffs, NJ: Prentice-Hall

Kombrink, L. (1985). Why join a peer group? In J. M. Shields, J. M. Gavrin, V. Hart-Smith, L. Kombrink, J. S. Kovach, M. L. Sheehan, K. F. Zagata, & K. Zander (Eds.), *Peer consultation in a group context: A guide for professional nurses* (pp. 1–7). New York: Springer.

Kovach, J. S. (1985). What is peer consultation in a group context. In J. M. Shields, J. M. Gavrin, V. Hart-Smith, L. Kombrink, J. S. Kovach, M. L. Sheehan, K. F. Zagata, & K. Zander (Eds.), *Peer consultation in a group context: A guide for professional nurses* (pp. 9–23). New York: Springer.

Limerick, B., Heywood, E., & Daws, L. (1994). *Mentoring: Beyond the status quo? Mentoring, networking and women in management in Queensland*. Brisbane: Queensland University of Technology.

Logan, W. L. (1997). Peer consultation group: Doing what works for counsellors. *Professional School Counselling*, *1*(2), 4–6.

Macklem, G. L. Kalinsky, R. & Corcoran, K. (2001). *International consultation, professional development and the internet: School psychology practice and the future*. Paper presented at the Annual Conference of the National Association of School Psychologists, Washington DC, pp. 1–21.

Millis, B. J. (1999). Three practical strategies for peer consultation. *New Directions for Teaching and Learning*, *79*(Fall), 19–28.

Mondy, R. W, Sharplin, A., & Premeaux, S. (1990). *Supervision* (2nd ed.). Boston: Allyn and Bacon.

Nash, R., Yates, P., Edwards, H., Fentiman, B., Deware, A., McDowell, J., & Clark, R. (1999). Pain and the administration of analgesia: What nurses say. *Journal of Clinical Nursing*, *8*(2, March), 180–189.

Nurius, P., Kemp. S. P., & Gibson, J.W., (1999). Practitioner's perspectives on sound reasoning: Adding a worker-in-context component. *Administration in Social Work*, *23*(1), 1–27.

Rolf-Flett, A. (2002). *Mentoring in Australia: A practical guide*. Frenchs Forest, NSW: Prentice Hall.

Rose, M. (2005) Mentoring in the health professions. In M. Rose & D. Best, *Transforming practice through clinical education, professional supervision and mentoring* (pp. 309–323). London: Elsevier.

Rose, M., & Best, D. (2005). *Transforming practice through clinical education, professional supervision and mentoring*. London: Elsevier.

Rozelle, D. (1997). Trauma and the therapist: Visual image making. Counter-transference and vicarious traumatisation. *Dissertation Abstracts International: Section B: The Sciences and Engineering*, *58*(4-B), 2136.

Sheehan, M. L. (1985). How to confront successfully. In J. D. Shields, J. M. Gavrin, V. Hart-Smith, L. Kombrink, J. S. Kovach, M. L. Sheehan, K. F. Zagata, K. Zander (Eds.), *Peer consultation in a group context. A guide for professional nurses* (pp. 81–99). New York: Springer.

Shields, J. D., Gavrin, J. M., Hart-Smith, V., Kombrink, L., Kovach, J. S., Sheehan, M. L., Zagata, K. F., & Zander, K. (Eds.). (1985). *Peer consultation in a group context: A guide for professional nurses*. New York: Springer.

Shields, J. D., Zagata, K. F., & Zander, K. (Eds.). (1985). Peer consultation in a group context: The cornerstone of sustained professional growth and development. In J. D. Shields, J. M. Gavrin, V. Hart-Smith, L. Kombrink, J. S. Kovach, M. L. Sheehan, K. F. Zagata & K. Zander (Eds.), *Peer consultation in a group context. A guide for professional nurses* (pp. xv–xvi) New York: Springer.

Speech Pathology Australia. (2010a). *Code of ethics*. Melbourne: The Speech Pathology Association of Australia Limited. Retrieved from http://www.speechpathologyaustralia.org.au/library/Ethics/CodeofEthics.pdf

Speech Pathology Australia. (2010b). *Competency based occupational standards (CBOS) for speech pathologists entry level*. Melbourne: The Speech Pathology Association of Australia Limited. Retrieved from , http://www.speechpathologyaustralia.org.au/library/CBOS%20Entry%20Level%202001.pdfhttp://www.speechpathologyaustralia.org.au/library/CBOS%20Entry%20Level%202001.pdf

Speech Pathology Australia. (2010c). Professional self-regulation (PSR) Program. Melbourne: The Speech Pathology Association of Australia Limited. Retrieved from http://www.speechpathologyaustralia.org.au/membership/professional-self-regulation-psr

Wallerstein, N., & Bernstein. E. (1988). Empowerment and education: Friere's ideas adapted to health education. *Health Education Quarterly*, *15*, 379-394.

Wilkerson, K. (2006). Peer supervision for the professional development of school counselors: Toward an understanding of terms and findings. *Counselor Education & Supervision*, *46*, 59–67.

Christa Carey-Sargeant is a senior speech pathologist with the Victoria Department of Education and Early Childhood Development and a PhD student with the Department of Audiology and Speech Sciences at the University of Melbourne. **Dr Lindsay B. Carey** is a lecturer and research fellow with the School of Public Health and Biosciences in the Faculty of Health Sciences, La Trobe University, Melbourne, Australia.

Correspondence to:
Christa Carey-Sargeant
BSpPath, MEd
Department of Audiology and Speech Sciences
University of Melbourne
550 Swanston St, Carlton, VIC, Australia
phone: +61(0)3 9035 5336
email: christa.carey@unimelb.edu.au

Clinical insights

Making Key Word Sign and Gesture happen in Singapore: Findings from a pilot study

Eva Wei-Lyn Loh

Eva Wei-Lyn Loh

Little is known about the use of Key Word Sign and Gesture (KWS&G) as an approach for persons with complex communication needs in Singapore. The current paper shares the findings from a pilot study that implemented KWS&G (Australia) within a special education school for children with intellectual disabilities, and trained parents and teachers in using KWS&G. The paper also reports the preliminary results from the pre- and post-pilot study questionnaire. After receiving training, parents and teachers found KWS&G (Australia) to be useful in facilitating communication between the child/ student and themselves. A supportive signing environment was also important in order for KWS&G to be embraced by staff. The team is looking into implementing KWS&G (Australia) as an interim common signing approach across the organisation, while looking forward to the possibility of developing KWS&G (Singapore) in the near future.

Background information

Key Word Sign and Gesture

Key Word Sign and Gesture (KWS&G), a form of augmentative and alternative communication (AAC), has benefits on facilitating understanding and expression for individuals with complex communication needs. It has been well documented that KWS&G has positive effects on speech development (Millar, Light, & Schlosser, 2000, cited in Cress & Marvin, 2003), vocabulary development, and social interaction (Kahn, 1981, cited in Cress & Marvin, 2003), as well as perceived speech intelligibility (Powell & Clibbens, 1994).

The KWS&G approach is not new and has been developed for individuals with multiple and severe disabilities, formally beginning in the United Kingdom in the 1970s with the introduction of Makaton (The Makaton Charity, 2012). Despite the fact that KWS&G (including Makaton) is used in over 40 countries worldwide to support the communication of hearing children/adults who are unable to speak or whose speech is difficult to understand,

little is known about the use of KWS&G in Singapore (Loh & Singh, 2011), and as a result, KWS&G has not been adapted to cater specifically to the needs and culture of our community.

Movement for the Intellectually Disabled of Singapore (MINDS)

Movement for the Intellectually Disabled of Singapore (MINDS, www.minds.org.sg) is one of the largest organisations that provides special education and training-employment services to children and adults with moderate-to-severe intellectual disability in Singapore. MINDS runs four schools, three employment development centres, three training development centres, and one residential home facility.

Typically within MINDS, there is one full-time speech therapist employed per school. Due to funding constraints, speech therapy positions initially only existed in MINDS

schools, not in the adult sector. Only recently, in 2011, were speech therapy positions created in the adult sector.

Historical use of signs in MINDS

In the past, manual signs from different signing systems were used in MINDS schools. School-based speech therapists, employed by MINDS, collated booklets and developed their own videos of basic functional signs and gestures as a medium for dissemination of information to involved parents and teachers.

The school's sole therapist, working with large caseloads, cited "time-consuming", "energy-exhausting" and "repetition of work" as factors accounting for the pitfalls in information dissemination (on manual signs) to the various people involved in caring for the clients. With respect to the adult sectors at MINDS, there was no system at all for dissemination of this kind of information. Indeed, several challenges were faced, particularly as our clients transitioned across settings: from schools to the adult employment-training development centres.

An initiative by the Allied Health Professionals Hub

In 2008, MINDS speech therapists acknowledged the need for an organisation-wide common signing approach. The implementation of a common signing approach was recognised as an essential step towards enhanced quality of service delivery to the clients at MINDS, aligning communication methods across the schools, adult sectors, and home (Loh & Singh, 2011). Approved by the organisation management (for financial years 2009–2011), the KWS&G Project was an initiative by the MINDS Allied Health Professionals Hub (made up of 11 multidisciplinary team members). Their aim was to look into the possibility of implementing a common signing approach within the organisation to cater to the communication needs of our clients within MINDS.

The learning and use of KWS&G may be compared to learning a language and/or embracing a new "culture" of communication. People need to be immersed in an environment where a common communication method is being used. Johnson, Douglas, Digby, and Iacono (2009) further highlighted that addressing attitudes of adult communication partners may result in persons with intellectual disabilities being supported more effectively. The communication partner's use of the AAC system signifies a valuing of the AAC system; it is through this that the communication partner promotes learning of the system by the AAC user, and everyday AAC-use to others in their environment (Johnson et al., 2009).

Interestingly, studies have found that staff caring for persons with intellectual disabilities were more likely to use verbal communication, irrespective of the mode of the communication of their communication partner or their perceived communicative competence (Bradshaw, 2001). The goal of an effective signing environment to support persons with intellectual disabilities cannot be pursued in isolation (Lodge-Miller & Elfenbein, 1994). Rather, commitment from many people (i.e., senior management, principals, teachers, parents) involved in the care of clients is essential to the successful implementation of a common signing approach within an environment.

The pilot study

Setting the scene

In Singapore, the sign language that is most commonly used by the deaf community is Signing Exact English which is adopted from American Sign Language. Prior to our involvement in the project, we knew little about KWS&G and thought that the approach consisted of a unique set of signs to be used specifically for persons with disabilities.

KWS&G is used by hearing children and adults who cannot speak or have speech that is difficult to understand. KWS&G typically borrows signs from the deaf community of the host country. While both speech and sign are used together, only the key words of a spoken sentence are signed (e.g., "Can *you help* me *open* the box"?).

As a first step, we investigated the uptake of KWS&G using Auslan (Australia) as an interim common signing approach to meet the immediate needs of the clients within a MINDS school as part of the pilot study for 2011. Auslan was chosen because we wanted to use training materials and resources related to KWS&G (Australia) that

were readily available to facilitate the pilot study, rather than reinventing the wheel. Indeed, the ultimate long-term intention of the MINDS Allied Health Professionals Hub is to develop Key Word Sign, incorporating Signing Exact English that could cater specifically to the needs and culture of our local context in Singapore.

Specifically, our project team was exploring the potential for creating a "culture" of signing environment as a long-term goal which, in this instance, was using KWS&G as part of a total communication approach when interacting with persons with intellectual disabilities. An action research framework (Morton-Cooper, 2000) was adopted for the pilot study, aimed to help us to critically reflect on our work practices and arrive at some consensus regarding the kind of services to better cater to our clients, and the reason(s) for providing the service(s) in a particular way.

Parents and teachers involved were trained using KWS&G via a train-the-trainer model, after one of the team members (a speech therapist) attended a KWS&G Presenter Training Course in Melbourne, Australia in 2009 to be Singapore's first qualified KWS&G Presenter (Scope, 2010). It was anticipated that the findings from the pilot study would help guide decisions with regards to KWS&G use within the entire organisation.

Aims

The pilot study aimed to explore 1) the attitudes and perceptions of teachers, parents, and students towards KWS&G use as part of a total communication approach, and 2) the willingness and abilities of teachers and parents to use KWS&G with greater accuracy, confidence, and frequency when communicating with their students/children, after having received training.

Method

Participants

Thirteen students (aged from 7 to 13) with limited speech and/or unintelligible speech were involved in the study, together with 18 parents, and 15 teachers from Lee Kong Chian Gardens School. All 13 students were assessed to be intentional communicators (Bloomberg, West, Johnson, & Iacono, 2009). A prerequisite for the student's involvement in the project was that at least one parent of the child attended the training sessions as scheduled. It was hoped that parents' involvement in the training would allow for follow-up and support to the child in the use of KWS&G at home.

Research design and data collection

Pre- and post-pilot study questionnaires were disseminated in January and October 2011, respectively, to parents and teachers who were in the pilot study. The pre- and post-pilot study questionnaires consisted of closed and open-ended questions, eliciting information on teachers' and parents' attitudes, knowledge, skills, and experiences with regard to using KWS&G, as well as the types of support that they would like to receive.

In order to do the pilot study, we engaged in a number of initiatives to create a signing environment, which are described here.

- *Train the trainer* A key component of the project's pilot study was training adult communication partners – in order to equip them with the fundamental knowledge and skills to be able to use Basic KWS&G effectively and efficiently. Specifically, the pilot study involved comprehensive and systematic in-service KWS&G workshops, targeted at teachers as well as parents of involved students. Both parent and teacher groups attended the training at separate sessions/timings. Training was conducted in three phases over a 5-month period, planned and led by the KWS&G presenter.
- *In-service training made available to other staff* Apart from the 15 teachers who were involved in the KWS&G Project, the Basic KWS&G Training Workshop was also made available as an in-service to other staff at the school. Attendance for the training was purely voluntary. In addition to the teachers involved in the pilot study, an estimated 70% of staff at Lee Kong Chian Gardens School received training on KWS&G.
- *Introducing Key Word Sign and Gesture at assembly* One or two key word signs were introduced to students and staff each week (Spragale & Micucci, 1990) during the assembly, and signs that were previously taught were practised during that period. Staff also verbally reported that the introduction of one or two new sign(s)

was easier for them to learn and remember, and hence considered the learning process as manageable.
- *Making our message loud and clear* Posters with the slogan "Sign with me – say it with signs" were also put up around along corridors of the school to promote the initiative, and highlight the benefits of key word signing to facilitate better language and communication skills with the students.

Results

Pre-pilot study questionnaire results

Prior to the commencement of the pilot study, parents and teachers were asked to fill out a questionnaire where they described their experiences when communicating with their child/students. Common themes emerged from both parent and teacher groups:
- They tended to use an eclectic communication approach (i.e., using words and gestures) when interacting with the individual child/student.
- There was an apparent concern about their child/ student exhibiting limited communication.
- There was uncertainty with regard to comprehension – whether the child could understand others and/or the parent/teacher could not understand the child's communication.
- Frustrations were noted in interactions between the child and communication partner(s).

When asked what additional tools/forms of AAC were used in the interaction between parent/teacher and child, common responses that were listed include Picture Exchange Communication System (PECS; Bondy & Frost, 1994), picture cards, gestures, and signing. Other responses included facial expressions, simplified speech, print, and high-technology devices (e.g., computer).

Interestingly, parents reported the use of signing as a predominant mode of communication with their child, in contrast to teachers who reported high use of pictures as an AAC tool within school. This difference could be attributed to parents having had previous exposure in signing when their child was in a different school in earlier years, as also reported on the questionnaire. Although a high proportion of parents and teachers reported instances of using signing with their child, the type of signing used appeared to differ between teachers and parents. Various types of signing which parents/teachers reported include: (a) signing (origin unknown) taught previously at a school, (b) conventional gestures, (c) KWS&G (Australia), and (d) American Sign Language. Parents, also tended to report on using other strategies (e.g., by asking close-ended questions, using slow speaking rate) to facilitate interaction with their child.

While one-third of the teachers' responses reported "no particular reason" for not using signing with the student, the common reason cited across both parent and teacher groups for not using signing with their student was the lack of training and knowledge-skills in this area. With proper training to be provided, a high proportion of parents and teachers ticked the options on the pre-pilot study questionnaires that they would use signing with their child/ student.

Other types of support that both parents and teachers selected on the pre-pilot study questionnaires that they would require included: (a) access to resources, (b) support from the speech therapist (modelling use of key word signing, direct intervention with child), (c) support from an occupational therapist, and (d) a signing environment (at both home and school).

Post-pilot study questionnaire results

When asked to list observable changes in the child's communication since the beginning of the project, one third of the parents reported that their child now used KWS&G to express themselves. Moreover, half of the teachers' responses indicated that they noticed improvement in their students' expressive communication using signs and speech. Some teachers also reported that they were better able to understand their students, suggesting fewer instances of communication breakdowns.

More than half of the parents indicated that they felt KWS&G was useful, particularly in helping them and their child to communicate, as well as fostering a better relationship between the parent and child. The parents also reported positive feelings (e.g., confidence, being happy, and proud of oneself being able to use KWS&G).

Similarly, teachers' reported views about using KWS&G after the training were positive. In particular, the teachers:

- felt that KWS&G was useful as it offered an alternative way for communication with their students;
- felt that using KWS&G was effective in communicating with their students;
- reported being confident in using KWS&G after the training.

In contrast, some teachers reported of instances where they confused KWS&G with other types of signing (due to previous exposure/learning) or forgot to use KWS&G in their interactions with their students.

Summary and conclusion

The questionnaire findings indicated a general positive attitude and perception of parents and teachers towards the use of KWS&G as a communication approach. After receiving a series of training sessions, both parents and teacher groups appeared to use KWS&G more confidently when communicating with their child/students, and found the approach to be a useful AAC.

The findings from the pilot study and concurrent initiatives taking place at the school suggest that a supportive signing environment is important in helping colleagues and the clients we work with to value and believe in the significance of the KWS&G as a communication approach. Such supportive measures may include introducing signs at assembly for clients and staff, having a sign of the week (Spragale & Micucci, 1990) within the workplace and, perhaps, through use of various mediums including posters, multimedia, and various visual reminders. Indeed, receiving training for a start is also essential in order for staff (as communication partners) to be acquainted with the appropriate knowledge and skills to be able to use KWS&G effectively with clients.

Unfortunately, the methodology employed in the current study does not allow for any firm conclusions to be drawn from the findings. It is also not clear if the positive attitude of the staff at the school that was involved in this pilot project reflects those of personnel in the other three schools within MINDS, and/or of other special education schools in Singapore.

Despite its obvious limitations, the findings from this pilot project have been encouraging. Currently, the KWS&G Project Team is looking into the next steps of realising the implementation of KWS&G as a common signing approach across the MINDS organisation. The project team looks forward to KWS&G being embraced as a total communication approach/practice to be used among all staff, clients, and their families/caregivers. While it is an interim measure, the team truly believes and advocates that KWS&G (Australia) can give our clients a "voice", empowering them and their significant communication partners and, thus, opening many doors of communication. Indeed, the team also looks forward to the possibility of developing KWS&G (Singapore) in the near future to better meet the diverse culture of our local context.

References

Bloomberg, K., West, D., Johnson, H., & Iacono. (2009). *The Triple C: Checklist of communication competencies*. Box Hill, Vic.: SCOPE.

Bondy, A. S., & Frost, L. A. (1994). The Picture Exchange Communication System. *Focus on Autism and Other Developmental Disabilities*, *9*(3), 1–19.

Bradshaw, J. (2001). Complexity of staff communication and reported level of understanding skills in adults with intellectual disabilities. *Journal of Intellectual Disabilities*, *45*, 233–243.

Cress, C., & Marvin, C. (2003). Common questions about AAC services in early intervention. *AAC: Augmentative & Alternative Communication*, *19*(4), 254–272.

Johnson, H., Douglas, J., Bigby, C., & Iacono, T. (2009). Maximizing community inclusion through mainstream communication for adults with severe disabilities. *International Journal of Speech-Language Pathology*, *11*(3), 180–190.

Lodge-Miller, K. A., & Elfenbein, J. L. (1994). Beginning signer's self-assessment of sign language skills. *Journal of Communication Disorders*, *27*, 281–292.

Loh, E.W-L., & Singh, R. (2011, June). *Sharing of a journey towards developing and implementing a common signing approach within an organisation for persons with intellectual disabilities in Singapore*. Paper presented at the Diversity and Development 2011 Speech Pathology Australia National Conference, Darwin.

The Makaton Charity. (2012). Makaton: The Makaton Charity website. Retrieved from http://www.makaton.org/international/international.htm

Morton-Cooper, A. (2000). *Action research in health care*. Oxford: Blackwell Science.

Powell, G., & Clibbens, J. (1994). Actions speak louder than words: Signing and speech intelligibility in adults with Down's syndrome. *Down syndrome: Research & Practice*, *2*(3), 127–129.

Scope. (2010). Singapore signs on. *Horizon Newsletter*, Issue 100, 26.

Spragale, D. M., & Micucci, D. (1990). Signs of the week: A functional approach to manual sign training. *AAC: Augmentative & Alternative Communication*, *6*(1), 29–37.

Eva Loh has been working as a speech therapist in the disability sector in Singapore since she first graduated from The University of Queensland, Australia, in 2003. She was recognised to be Singapore's first qualified Key Word Sign and Gesture Presenter in 2009, and was the Principal Investigator for the MINDS Key Word Sign and Gesture Project Pilot Study from 2010–2011. Eva also runs her own private practice.

Correspondence to:
Eva Wei-Lyn Loh
Speech-language therapist
Movement for the Intellectually Disabled of Singapore
MINDSville@Napiri
7 Lorong Napiri, Singapore 547533
phone: +65 6387 7662
email: evaloh.mv@minds.org.sg

Clinical insights

Capacity building and complex communication needs: Challenges and strategies

Andrea McQueen

Capacity building is a prevalent contemporary approach in health promotion and community development. In recent years capacity building methodologies have been applied to speech pathology services for people with complex communication needs. However there is minimal published information about this. This paper aims to identify the challenges of using a capacity building approach with people with complex communication needs, and suggests some strategies for maximising the success of this approach. Areas for future research are proposed.

Introduction of the terminology

Complex communication needs is defined as follows:

> *A person who has communication problems associated with a wide range of physical, sensory, environmental causes, that restrict/limit their ability to participate independently in society. They and their communication partners may benefit from the use of augmentative and alternative communication (AAC) methods, either temporarily or permanently. (Balandin, 2002, p. 2)*

Capacity building is widely used in health and community development, both in Australia and worldwide (Craig, 2007; Hounslow, 2002). Yet its application to the population with complex communication needs is recent and little studied. A survey of the peer-reviewed literature finds only one article that relates to this topic (McLennan et al., 2006).

What is capacity building?

Capacity building is a contemporary approach in health promotion and community services (Craig, 2007; Hounslow, 2002; Verity, 2007). Capacity building arose from the field of community development, and remains strongly linked to community development principles and practices (Craig, 2007). Capacity building is a process (Simmons, Reynolds, & Swinburn, 2011) aimed at predefined outcomes, such as health promotion or the empowerment of communities. The World Health Organization (WHO) defines capacity building as:

> *The development of knowledge, skills, commitment, structures, systems and leadership to enable effective health promotion. It involves actions to improve health at three levels: the advancement of knowledge and skills amongst practitioners, the expansion of support and infrastructure for health promotion in organisations, and the development of cohesiveness and partnerships for health in communities. (Smith, Kwok, & Nutbeam, 2006, p. 341)*

However, definitions of capacity building are context-dependent (Simmons et al., 2011). For practitioners working in a social model of disability it is useful to have a definition grounded in participation and social inclusion. One such definition was postulated by Britain's Charity Commission (2000): "Developing the capacity and skills of the members of a community in such a way that they are better able to identify and help meet their needs and to participate more fully in society" (p. 2).

Although most definitions of capacity building make mention of key components or characteristics of capacity building (Simmons et al., 2011), the exact components vary from author to author. The NSW Department of Health (2001) proposed a model of capacity building built on five key areas of work: organisational development, workforce development, resource allocation, partnership, and leadership.

Capacity building can occur at various levels. VicHealth (n.d.) identifies four levels of capacity building: individual, community, organisational, and systemic. Some researchers combine these levels under the umbrella term "community capacity building". This paper addresses capacity building at all four levels (individual, community, organisational, and systemic) and across the five areas of work (organisational development, workforce development, resource allocation, partnership, and leadership).

Capacity building and speech pathology

Capacity building is prevalent in health and disability services (Hounslow, 2002; Verity, 2007). The World Health Organization supports the use of capacity building through its Ottawa (WHO, 1986) and Bangkok Charters for Health Promotion (WHO, 2005). Various Australian states have policies and position papers advocating the use of capacity building approaches within health (Department of Health, 2011; Queensland Health, 2003) and disability (Queensland Government, 2011; Victorian Disability State Plan 2002–2012). However, there is surprisingly little published information about the use of capacity building in speech pathology.

In Victoria, a network of services for people with complex communication needs was established in 2003–04

Andrea McQueen

based on a "hub and spoke" model (McLennan et al., 2006). These services were established with capacity building as a core value and service model. This network is now known as the Communication Access Network (CAN), and comprises one central statewide service (the Communication Resource Centre) and 11 regional services. All these services have been involved in a range of capacity building projects over the past eight years, the results of which are currently largely unpublished. These projects have yielded useful information about the application of capacity building approaches to people with complex communication needs. Further information about some CAN projects is available from the Communication Access Network page on the Scope website (Scope Victoria, n.d. (b).

An example of a capacity building project

The Listening and Communicating with Everyone (LACE) project was undertaken in 2006 by a partnership of Glen Eira City Council (an urban council in South East Melbourne), the Inner South Communication Service and the Peninsula and South East Regional Communication Service. It illustrates some of the challenges of capacity building with people with complex communication needs. LACE aimed to improve the accessibility of local council offices to people with complex communication needs. The project arose after a local resident with complex communication needs complained at a council forum that the council offices were not accessible for him. LACE had two key components: (a) the provision of communication training to all Glen Eira customer service staff, and (b) the development of communication boards for use at the council customer service desks. LACE was evaluated using a "mystery shopper" model, whereby local residents with complex communication needs visited the council offices unannounced and provided feedback on the services they received.

The LACE project exemplifies some of the principles of capacity building. The NSW Health (2001) framework can be used to understand the components of the project. Key areas of work in this framework are organisational development, workforce development, resource provision, partnership, and developing leadership. In LACE, organisational development occurred through the change of customer service procedures following the introduction of communication boards. Workforce development was achieved through staff training. Resource provision was determined through the partnership, and included the costs of communication resources and backfill for staff attending training. The partnership between council and the communication services was essential to the success of the project. Leadership was targeted indirectly, through the skills and experience developed by the people involved in evaluating the project.

The outcomes of LACE were mixed. While the evaluation reports were generally positive, staff reported that there was minimal demand for the communication boards. It is interesting to reflect on why the communication boards have been so little used. It may be that the local council office is not a motivating place for many people with complex communication needs to visit. This project was instigated on the basis of the comments of one man with complex communication needs, but no further needs-analysis was undertaken prior to the project. A more informed project selection process may have led to a different outcome.

Another difficulty with LACE was that people with complex communication needs were not actively engaged in all stages of the project because of the difficulty of finding people with the requisite skills and interests to contribute. It could be hypothesised that closer collaboration with people with complex communication needs may have improved the outcomes of this project by building awareness and a sense of ownership of the new resources.

Informing people with complex communication needs about the availability of the new communication boards was challenging. Although this information was sent to a wide range of disability services, it is unclear whether it reached the individuals who could benefit from it (i.e., those with an interest in council services). Providing project information to people with complex communication needs can be difficult because of their communication difficulties and frequent isolation. Further challenges of capacity building with this population are described below.

Challenges of capacity building with people with complex communication needs

Capacity building often involves conflict (Atkinson & Willis, n.d.; Hounslow, 2002; Verity, 2007). Conflict may arise from the wide range of viewpoints and interests found within any community. In addition there may be conflicts between the values and expectations of professionals and the stated goals of community members. In some situations, there are disparities between the desires of communities and the evidence base. As people with complex communication needs form a heterogeneous community (with diversity of age, socioeconomic status, and aetiology of disability), conflict often arises from competing needs. For example, some literate adults may prefer not to be offered communication tools incorporating line drawings while for people without literacy these symbols are crucial for communication.

Capacity building often relies on unequal partnerships (Atkinson & Willis, n.d.; Verity, 2007). Community members are expected to volunteer alongside professional staff who may have different levels of education and authority, and who have the advantage of being paid for their time and skills. Furthermore, when community members and government agencies work in partnership, it is not always clear which party has the final say (Hounslow, 2002).

In many cases, such as Victoria's Communication Access for All (Scope Victoria, n.d. a) project, people with complex communication needs are now being paid for their contributions to capacity building work. This is important for addressing the imbalance of power, and for empowering people with complex communication needs. However, there are myriad issues relating to payment which need to be managed. Budgetary constraints may make it difficult to pay community members. Additionally, people in receipt of government benefits sometimes prefer not to be paid in money for fear of jeopardising their payments, or because of Centrelink's complex reporting system, which is not readily accessible to people with communication and other disabilities. Also, once a person is being paid for a service, there are issues of liability and insurance to be resolved.

Because the population of people with complex communication needs is small, with one in 500 people in Victoria (Perry, Reilly, Bloomberg, & Johnson, 2002, p. 2), and because of the small number of speech pathologists working in this field, people with complex

communication needs who are engaged in community projects frequently find themselves working with their own treating clinicians, past or present. This situation can have some advantages, in that partnerships can be built on established relationships. However, it can also exacerbate the power imbalance on project teams. Thus a higher level of sensitivity is required than might be the case in other capacity building projects.

A further complication arises from the fact that many people with complex communication needs have low social capital. Many (though not all) people with communication difficulties live in situations in which they have little autonomy, such as group homes, aged care facilities or the parental home. This can present an array of barriers to participation in capacity building activities. There may be a lack of practical supports, such as transport and attendant care, or a lack of confidence. People may be unaware of projects occurring in their neighbourhoods. Furthermore, limited life experience means that some people have little knowledge of what is possible in a healthy community, or what kinds of communication experiences they could strive for. Yet for capacity building to succeed, ideas and plans should ideally begin with the community itself (Hounslow, 2002), and excluding the most marginalised from this process is clearly problematic.

The communication difficulties associated with complex communication needs can affect the capacity to lead or participate in capacity building projects. According to Romanow and Bruce (2006), "The importance of communication in the building of social capital and social cohesion cannot be overstated" (p. 131). Yet people with complex communication needs may have difficulties with language, literacy and/or pragmatics which hinder their involvement in meetings and make partnerships more difficult to maintain.

Sustainability of capacity building projects is challenging (Lovell, Kearns, & Rosenberg, 2011). Maintaining communication resources and good communication practices after the completion of a project depends on ongoing relationships, which are difficult to maintain in the disability sector because of its high staff turnover.

People undertaking capacity building projects with people with complex communication needs are often speech pathologists with no training in capacity building. This has implications for the efficacy and efficiency of capacity building projects. Similarly, non-speech pathologists managing capacity building projects do not always have skills in working with people with complex communication needs.

Modern workplaces have a strong focus on evidence based practice. However the evidence base for capacity building within speech pathology is small. The absence of published data about the effectiveness of working in this model with people with complex communication needs can make it difficult for speech pathologists to advocate to management to adopt and maintain this approach.

In summary, capacity building for people with complex communication needs is complicated by issues arising from conflict, power imbalance, low social capital, communication difficulties, difficulties with sustainability, lack of training, and lack of evidence. The section below will provide some suggestions for managing these challenges.

Strategies for success

Using capacity building with people with complex communication needs is a relatively new phenomenon, and,

to the author's knowledge, there are no published data about strategies for success. The strategies offered here are based on clinical experience.

Conflict in a project can be reduced through the use of clear, explicit decision-making processes. Ensuring that partnership agreements and roles and responsibilities are recorded and understood can help to clarify decision-making. The VicHealth Partnership Tool (VicHealth, 2011) is a useful resource for planning partnerships and identifying what documentation may be required. In some cases it is necessary to make documentation available in alternative formats to ensure that it is accessible to all members of the project team.

Employing sound community engagement practices can be helpful in ensuring that all voices are heard and all contributions are documented. This can help to reduce conflict when community members do not get the outcomes they want. Victoria's Department of Sustainability and the Environment (2005) provides some useful community engagement tools, including ideas for engagement methods to suit diverse projects and populations.

In order to address the power imbalance in capacity building projects, finding ways to pay people with complex communication needs fairly for their work is vital. On an individual project basis this may mean having a flexible payment plan, allowing people to be paid in vouchers if monetary payments are problematic. An underlying issue here goes beyond any specific project, and there is a role for speech pathologists to lobby for appropriately valued and compensated roles for people with complex communication needs within the services which support them and the broader community.

Several factors contribute to the sustainability of any project. Tackling projects from both a "bottom-up" and a "top-down" approach is one strategy (Crisp, Swerissen, & Duckett, 2000). A "bottom-up" approach involves working with people at a grass-roots level (e.g., council customer service staff). This approach can facilitate commitment to the project and sense of ownership from the people who will be implementing it day-to-day. A "top-down" approach involves garnering the support of management and ensuring that organisational policies and procedures are changed to include new communication protocols. Using this approach assists in embedding good communication in the culture of a target organisation.

Regular project reviews help to keep the project on people's minds even after its official completion date. The Wellington Regional Communication Service in Gippsland (rural Victoria) employs people with complex communication needs to attend their local leisure centre on a weekly basis and ensure that all communication resources are in place. This approach keeps the communication strategies on the minds of leisure centre staff. It also ensures that people with complex communication needs are regularly attending the leisure centre and are performing a valued role within their community.

Building the social capital of people with complex communication needs is a big undertaking. Involvement in community projects is itself one way that people with complex communication needs can develop networks and skills and potentially improve their financial situations. In the meantime, there are supports which can be put in place to manage some of the barriers to participation arising from isolation. For example, providing transport and attendant care for community consultations and project meetings

can be helpful. Ensuring that meetings take place at times and venues that are convenient to attendees is also useful. Speech pathologists and project teams can work collaboratively with advocacy groups as well as disability support services in order to reach more isolated and less empowered community members.

Speech pathologists generally have many skills in facilitating the inclusion of people who have communication difficulties in community projects. In some cases it is necessary to have resources such as meeting agendas and partnership agreements in accessible formats. Depending on their experience, some project participants may benefit from training in meeting procedure and etiquette. Others may wish to attend meetings in an observer's capacity before being expected to contribute. It is often helpful to allow extra time for meetings and consultations, to permit people who use augmentative communication systems the time needed to have their say. Sending out meeting agendas in advance also allows participants to pre-program appropriate vocabulary into their communication devices.

Another way of involving people with diverse communication skills in a project is to have a range of roles available to cater for different skills and interests. Such roles may include project planning, trainer/co-trainer and evaluation assistant. Some projects, such as police training call for practice communication partners, where trainees have the opportunity to practise conversing with people with complex communication needs.

If speech pathologists are to undertake capacity building, relevant training needs to be available, either in entry-level courses, or through postgraduate study. Similarly, project managers from other disciplines need training in complex communication needs, to allow participation of people with complex communication needs in broader capacity building projects.

In order for capacity building to be valued and funded within speech pathology, there must be an evidence base to support it. Projects must have clear evaluations. There is a wide range of qualitative and quantitative evaluations which can be applied to capacity building projects (Simister & Smith, 2010). Whichever methods are selected, it is vital to audit the capacity building process as well as evaluating project outcomes. This will guide other practitioners in developing effective capacity building projects. Where possible project audits and evaluations should be published in order to increase the body of knowledge available to the profession.

Directions for future research

There is a great need for research into the applications and efficacy of capacity building with people with complex communication needs. In particular it would be useful to know what capacity building methodologies have been used with people with complex communication needs; the effectiveness or otherwise of these methodologies; and strategies for successful community engagement of people with complex communication needs. In addition there is a need for a broad needs-analysis to determine what projects have been undertaken to increase communication accessibility in the community; what further needs are identified by communities with complex communication needs, either locally or on a wider (e.g., national) scale; and what priorities are identified for future projects.

Conclusion

People with complex communication needs form a fragmented and diverse community with low social capital.

Their communication difficulties compound a lack of social infrastructure. This highlights an urgent need for capacity building.

There is a dearth of published information about the application of capacity building to people with complex communication needs. More research is needed into the efficacy of this approach as well as strategies and resources to assist in successful capacity building with this population.

The application of capacity building approaches to people with complex communication needs is a new and complex enterprise. Consideration should be given to how people with complex communication needs and speech pathologists can be adequately trained, resourced, and supported to undertake effective and meaningful community projects.

References

Atkinson, R., & Willis, P. (n.d.). *Community capacity building: A practical guide*. Paper no. 6. Hobart, Tas.: Housing and Community Research Unit, University of Tasmania. Retrieved from http://www.chs.ubc.ca/archives/files/Community%20Capacity-Building%20A%20Practical%20Guide.pdf

Balandin, S. (2002). Message from the president. *ISAAC Bulletin*, *67*, 2.

Charity commission. (2000). The promotion of community capacity building. Retrieved from: http://www.charitycommission.gov.uk/Library/guidance/rr5.pdf

Craig, G. (2007). Community capacity-building: Something old, something new...? *Critical Social Policy*, *27*, 335–359.

Crisp, B. R., Swerissen, H., & Duckett, S. J. (2000). Four approaches to capacity building in health: Consequences for measurement and accountability. *Health Promotion International*, *15*(2), 99-107.

Department of Health. (2011). *Integrated health promotion in action*. Retrieved from www.health.vic.gov.au/healthpromotion/steps/implementation

Department of Sustainability and the Environment. (2005). Effective engagement: Building relationships with community and other stakeholders. Retrieved from http://www.dse.vic.gov.au/effective-engagement

Hounslow, B. (2002). Community capacity building explained. *Stronger Families Learning Exchange Bulletin*, *1*, 20–22.

Lovell, S. A., Kearns, R. A., & Rosenberg, M. W. (2011). Community capacity building in practice: Constructing its meaning and relevance to health promoters. *Health & Social Care in the Community*, *19*, 531–540.

McLennan, F., Vickers, K., Mason, K., Bloomberg, K., Leadbetter, V., & Engel, M. (2006). Capacity building and complex communication needs: A new approach to specialist speech pathology services in rural Victoria. *Australian Journal of Primary Health*, *12*, 66–74.

NSW Health. (2001). A framework for building capacity to improve health. Retrieved from http://www.health.nsw.gov.au/pubs/2001/framework_improve.html

Perry, A., Reilly, S., Bloomberg, K., & Johnson, H. (2002). *An analysis of needs for people with a disability who have complex communication needs*. Melbourne: La Trobe University.

Queensland Government. (2011) Actively engaging people with a disability. Retrieved from www.qld.gov.au/web/community-engagement/guides-factsheets/people-disabilities/actively-engaging.html

Queensland Health. (2003). Integrating public health practices: A position statement on community capacity

development and the social determinants of health for public health services. Retrieved from http://www.health.qld.gov.au/ph/Documents/hpu/20426.pdf

Romanow, P., & Bruce, D. (2006). Communication and capacity building: Exploring clues from the literature for rural community development. *Journal of Rural and Community Development*, *1*, 131–154.

Scope Victoria. (n.d. a). Communication access. Retrieved from http://www.scopevic.org.au/index.php/site/whatweoffer/communicationresourcecentre/communicationaccess

Scope Victoria. (n.d. b). Communication access network. Retrieved from http://www.scopevic.org.au/index.php/site/whatweoffer/communicationresourcecentre/communicationaccessnetwork

Simister, M., & Smith, R. (2010). Monitoring and evaluation in capacity building: Is it really that difficult? Retrieved from http://www.intrac.org/data/files/resources/677/Praxis-Paper-23-Monitoring-and-Evaluating-Capacity-Building-is-it-really-that-difficult.pdf

Simmons, A., Reynolds, R. C., & Swinburn, B. (2011). Defining community capacity building: Is it possible? *Preventive Medicine*, *52*(3–4), 193–199.

Smith, B., Kwok, C. T., & Nutbeam, D. (2006). WHO Health Promotion Glossary: New terms. *Health Promotion International*, *21*(4), 340–345.

Verity, F. (2007) *Community capacity building: A review of the literature*. Adelaide: South Australian Health Department.

VicHealth. (n.d.). Capacity building for health promotion. Retrieved from http://www.vichealth.vic.gov.au/en/Publications/VicHealth-General-Publications.aspx?page=2

VicHealth. (2011). *The partnerships analysis tool*. Melbourne: Victorian Health Promotion Foundation.

Victorian Disability State Plan 2002–2012. Retrieved from http://www.field.org.au/legislation/responsibilities/state_plan.html

World Health Organization. (1986). *Ottawa charter for health promotion*. Retrieved from www.who.int/hpr/NPH/docs/ottawa_charter_hp.pdf

World Health Organization (2005). *The Bangkok charter for health promotion in a globalised world*. Retrieved from www.who.int/healthpromotion/conferences/6gchp/bangkok_charter/en/

Andrea McQueen works for the Inner South Communication Service, part of Victoria's Communication Access Network. She works with adults with complex communication needs in a role which combines clinical work and community capacity building.

Correspondence to:
Andrea McQueen
Speech Pathologist
Central Bayside Community Health Services, Victoria
email: amcqueen@cbchs.org.au
phone: +61 (0)408 701 671

Ethical issues in augmentative and alternative communication

Bronwyn Hemsley

Bronwyn Hemsley

In this "Ethical conversations" some common ethical issues and resources relevant to the provision of augmentative and alternative communication (AAC) or multi-modal communication in Australia are discussed. Guiding theoretical frameworks and Association documents are related to topical situations in speech pathology management in populations with complex communication needs. This paper is not intended as a review of the literature or as a guideline in relation to AAC practice which is forthcoming in the Association's Clinical Guideline on Augmentative and Alternative Communication. Rather, common issues that might confront clinicians in the dynamic field of AAC are discussed in the light of existing theoretical frameworks and Association documents. Bringing these issues to light at this time of rapid change in the field may help clinicians to arrive at good decisions to the benefit of people with complex communication needs and their families.

Guiding frameworks and principles

According to the St James Ethics Centre (n.d.), "Ethics is about answering the question 'What ought I to do?'" – a question that arises in any clinical decision, ideally well before any conflict or dilemma might arise. In recognition of the importance of ethical decisions in speech pathology, there are several resources pertaining to ethical practice (see Body & McAllister, 2009; Chabon, Denton, Lansing, Scudder, & Shinn, 2007; Speech Pathology Australia, 2002, 2010, 2012a) that are relevant in (a) assisting clinicians and all stakeholders to arrive at good, balanced, and evidence based decisions that are in the best interests of the person with complex communication needs, and (b) providing guidance to both prevent and resolve conflicts and establish positive working relationships among all those affected by a decision.

In the dynamic field of augmentative and alternative communication (AAC), the multi-modal communication

range of practice of the Competency-Based Occupational Standards (CBOS) for speech pathologists (Speech Pathology Australia, 2011), existing theoretical frameworks (e.g., participation model of AAC, the International Classification of Functioning, Disability, and Health [World Health Organization, 2001]), and the Speech Pathology Australia Clinical Guideline on Augmentative and Alternative Communication (2012b) are useful resources to help guide clinicians in arriving at good clinical decisions. If at all possible, at all stages in the process of providing AAC services (see the participation model of AAC, Beukelman & Mirenda, 2005), the person with complex communication needs and their communication partners are engaged in informing and making decisions on the course of action for intervention (Williams, Krezman, & MacNaughton, 2008). As do professionals in other areas of practice, speech pathologists will continue to be confronted with situations where the course of action might not be clear to all parties involved in the decision. Complexities arise in clinical decisions about communication interventions as people with severe communication disabilities frequently have high support needs owing to physical or cognitive impairments and many areas of life participation are affected.

Ethical decision-making with the person with complex communication needs or any other person responsible includes consideration of: the facts on assessment findings, all available intervention options and associated evidence, risks and benefits associated with each course of action, and values and beliefs of those involved in and affected by the decision. Tension might exist between doing what one *ought* to do and doing what one might be *able* or supported to do within the clinician's competencies and available resources, wishes of the client, and workplace or residential care policies. As such, it is important that speech pathologists apply not only the Code of Ethics of the Association (Speech Pathology Australia, 2010), but also a theoretically sound ethical decision-making framework (e.g., Speech Pathology Australia, 2002, 2012a; Markula Centre, 2012). Arriving at an ethical decision also requires consideration of a person's rights (see United Nations Convention on the Rights of Persons with Disabilities, 2006) and legal position, as well as risks or benefits relating to many other aspects of the person's life and preferences.

Other ethical considerations

In addition to the general principles and issues noted above, there are a number of ethical considerations relating

to AAC that all practitioners need to be aware of. These are:

- the ethical imperative to maintain and expand clinical competence in AAC
- a rapidly expanding field
- consenting to assessment and intervention
- ensuring that the AAC authentically represents the voice of the person
- ethical resource allocation in AAC: working within available resources, and seeking to expand resources.
- mobile technologies: an expanding range of AAC options
- risks to privacy and confidentiality in AAC communications.

The ethical imperative to maintain and expand clinical competence in AAC

Although speech pathologists will graduate with knowledge and skill in the range of practice of multi-modal communication (Speech Pathology Australia, 2011), there are many clinicians in the field who have had limited clinical experience in the area and who might actively avoid introducing AAC because of their knowledge limitations (Sutherland, Gillon, & Yoder, 2006). Indeed, few speech pathologists feel competent in advising on AAC interventions or developing AAC programs (Sutherland et al., 2006). Communication is a fundamental characteristic of human interaction (Kaiser & Goetz, 1993) and is recognised as a human right (see United Nations, 2006, Articles, 2, 3, 9, 16, 17, 21, and 24). People with communication disorders should not be denied the opportunity to communicate to the best of their ability and in their preferred mode(s). Therefore, clinicians meeting clients who would potentially benefit from AAC – that is, those who cannot rely upon spoken language to communicate – face an ethical imperative to maintain and extend their skills where a demand or need for a service exists. Their actions would include striving to practise the highest standards of professional competence and extending professional knowledge through professional development, consulting the literature, collaborating with more skilled members of the AAC team, and engaging the support of a mentor or supervisor in the field (see the Association's Clinical Guideline on Augmentative and Alternative Communication).

A rapidly expanding field

AAC is a dynamic and rapidly expanding field due to advances in technology and active international research endeavours. This situation has given rise to two important ethical issues for clinicians in the field. First, an untested but promising AAC intervention might be promoted directly to consumers through social media and accompanied by anecdotal evidence (e.g., blogs, YouTube videos) resulting in consumer uptake prior to a formal assessment. Once involved in assessing a person's communication needs, speech pathologists have an ethical responsibility to conduct a full assessment, and consider all available options and the potential risks and benefits of these prior to recommending intervention options. This includes consideration of options already selected by people with complex communication needs and their families prior to the assessment. Second, owing to the rapid expansion of available assistive technologies, it might not be possible or feasible for clinicians to keep abreast of all technological advances of tools for AAC, or for any expansion in

populations who might benefit. In order to reach an ethical decision in a rapidly expanding field, clinicians are reminded to appraise any new strategy on its theoretical foundations and evaluate these in relation to existing research and published evidence on AAC. Clinicians need to be mindful of the value of the full range of communication strategies and techniques that might be necessary in addition to any high technology options, including non-AAC intervention (e.g., training communication partners to interpret behaviours as communicative), unaided AAC (e.g., sign and gesture), and low or light technologies (e.g., communication boards, single message devices). A person's communication needs are not likely to be met with the provision of one type of communication aid, and often a range of multi-modal communication options need to be explored (Beukelman & Mirenda, 2005).

Consenting to assessment and intervention

According to the Speech Pathology Australia Code of Ethics (2010), clinicians "strive to ensure informed consent has been obtained from clients for the services we offer" (p. 2). Thus, people with complex communication needs must be given the opportunity to provide informed consent to a particular procedure or intervention, either directly or, in situations in which they have been assessed as being incapable of providing consent, through a proxy (primary support person or legal guardian). Some people with intellectual disability are deemed to be not competent in decision-making about services and interventions. As such, speech pathologists seek to gain informed consent from a person responsible, involve the person with disability to the level of his or her capacity, and strive to attain the ability to recognise when the person's assent is provided. Observing the person's behaviours and non-verbal communications can assist clinicians in determining the person's wishes, but these interpretations should be checked with people who know the person with disability well and are familiar with their communicative behaviours (see Goldbart & Marshall, 2011).

It can be difficult to determine a person's consent for a service when the person does not already have a functional method of communication. To address this problem, clinicians may need to establish a functional and effective method of communication with the person with complex communication needs for the process of obtaining consent for future decisions. Obtaining consent would involve providing information about decisions in formats that are accessible to people with communication difficulty – an ethical imperative according to the World Health Organization (2010). Communication supports for the process of ascertaining the person's willingness, assent, or consent to decisions include accessible information sheets and consent forms, information displays, schedules, appropriate photographs, pictographs, sign or gesture or objects to help the person participate in each decision to the extent that they are able or desire. Reliance upon a yes/no system is common in the early stages of an AAC assessment. However, the person with complex communication needs must have every opportunity to participate with more than a yes/no response wherever possible.

Ensuring that the AAC authentically represents the voice of the person

The ethical principles of *veracity* or truthfulness and *autonomy* also inform the design of AAC systems, which

necessarily involves the collaborative input of a range of stakeholders including the person with complex communication needs. However, the priorities over design and inclusion of topics and vocabulary should rest with the person's own needs and preferences and not only those of their communication partners (see McNaughton & Beukelman, 2010). All people have a right to communicate for themselves to the extent that they are able (World Health Organization, 2010; United Nations, 2006). Thus, each person's communication system should be validated as reflecting his or her own preferences and reflecting his or her own voice. Establishing autonomy in communication is of vital importance in the field of AAC, as people with complex communication needs often rely upon communication partners to set up a system that can be accessed by them without influence. Access to the system might also depend upon the involvement of a range of communication partners in determining the person's message (e.g., partner assisted scanning, encoded communication). Nonetheless, it is possible that a person with complex communication needs may have direct and/or indirect access to a communication aid, and continue to maintain independence or autonomy in communication.

Many technologies are now available and in development to support both direct and indirect independent access to computers and communication aids, and reduce reliance upon communication partners to assist in message selection (e.g., various new switch technologies, eye gaze technologies, brain computer interface technologies). Where the speech pathologist considers that a person's AAC system might not represent his or her true voice, or that the person does not have autonomy in expressing his or her own thoughts, they have an ethical responsibility to (a) raise these concerns with the person and their communication partners so that further actions may be taken to remove harms, and to help the person towards an AAC system that does reflect their own views and preferences; and (b) consult with the Speech Pathology Australia's Senior Advisor Professional Issues who would then advise if it was a matter to go to the ethics board, which involves a written complaint process.

Ethical resource allocation in AAC: working within available resources and seeking to expand resources

The ethics of resource allocation are highly relevant in the field of AAC. The demands for AAC services are likely to increase in line with increased survival rates associated with developmental and acquired disabilities, the ageing of the population, public awareness of AAC, and the possibilities afforded by new assistive technologies. Adolescents and adults with lifelong disabilities who use AAC are particularly vulnerable to the impact of increased service demands that are not matched with expanding resources, at a time when they are in transition and moving to a greater need for communicative autonomy (McNaughton & Beukelman, 2010). Ideally, clinicians strive to source the best available research evidence for the AAC intervention and instructional methods, and source resources that will be required for each treatment option. However, not all necessary resources might be available for all potential options. Thus, speech pathologists may be faced with knowing they can do *something* for the person with complex communication needs, while realising that they might not be able to do *everything* that might be necessary or of benefit to the

person. Applying the ethical principle of *beneficence* helps guide clinicians in determining whether their level of expertise and limited involvement might do the person good while avoiding any associated harms (principle of *non-maleficence*) (see also Speech Pathology Australia, 2010).

The influence of the environment and communication partners over the success or otherwise of any AAC intervention must be considered (see Beukelman & Mirenda, 2005; World Health Organization, 2001). An ethical dilemma may arise when a particular AAC intervention, such as the provision of a speech-generating device, requires accompanying service hours for effective use of the device which might not be available or covered by existing funding arrangements. It might not be considered ethical to conduct a full assessment, then trial of a range of devices, and obtain funding to purchase a device, if there is not also adequate follow-up support to ensure that the device is useful and is not abandoned through lack of support. Potential harms in such a situation of failure and abandonment include communication partners and the person with complex communication needs being reticent to attempt other interventions that might be better supported in the future (Williams et al., 2008). Nonetheless, potential benefits to the person of having the system available and the opportunity for improvements in the communicative environment to occur must also be taken into account.

Ethical dilemmas can also arise in relation to decisions based on the relative costs of each AAC option that might suit the person. Provision of a relatively cheap communication aid (e.g., mobile technology AAC system) might or might not be helpful if the communication aid has so few individualisation options that the person can only access some features of the device or only use it in some situations (AAC-RERC, 2010). Nonetheless, while a low-cost system might not meet all of the person's needs, it might provide some benefit as to warrant exploration as an option for intervention to meet some of the person's communication needs. Speech pathologists, therefore, have an ethical responsibility to (a) advocate on behalf of clients to funding bodies and governments to remove cost as a barrier to a person's best option in AAC, and (b) pursue follow-up support and training for the person and communication partners that can be obtained through distributors and manufacturers of the device, and also through formalised peer-mentoring systems if these can be arranged (Ballin et al., 2012). It is also important that clinicians who are aware of unmet needs in relation to multi-modal communication advocate for expanding resources available to meet those needs.

Mobile technologies: an expanding range of AAC options

The advent of mobile technologies (i.e., touch screen devices that connect to the Internet) with AAC software applications and switches to access mobile device AAC apps (see Farrall, n.d.; 2012) has been hailed a paradigm shift in the field and practice of AAC, owing to the much wider availability and recognition of AAC in the community and a much greater availability of speech aids to people who previously did not have access to these (AAC-RERC, 2010). The introduction and development of mobile technology AAC mean that speech pathologists and others need to consider a wider range of options than previously available in arriving at ethical decisions. Speech

pathologists have an ethical responsibility to work with families who desire mobile devices and provide unbiased information and advice in regards to the potential benefit to the person who uses AAC. However, mobile technology AAC does not currently provide all of the features and functions available within dedicated speech-generating devices, and it is important that all relevant AAC options be considered in a feature matching assessment (AAC-RERC, 2010).

Risks to privacy and confidentiality in AAC communications

A distinctive risk relating to privacy in the field of AAC is related to (a) the involvement of communication partners in supporting communication and thus being privy to what might otherwise have been treated as private conversations (e.g., consultations with the doctor or legal representatives), and (b) the potential for communications delivered by AAC to be captured and kept in a file (commonly called "history") within the speech-generating device or mobile technology app for AAC. It is recognised that collection of a history of the person's communications might be of benefit, but there may be less awareness of the potential harms arising from the storage and retrieval of messages in the history. The record or log of every keystroke, word, or phrase entered into an AAC system is akin to recording the person's voice. It should be treated as containing potentially sensitive and private communications and subject to the same restrictions and permissions prior to collection, storage, or release as audio or video recordings of the person.

As yet, there is no industry standard on the processes for designing a history feature of a speech-generating device or mobile technology app that takes into account all ethical issues pertaining to privacy, confidentiality of communications, freedom of choice and autonomy, and safety. An AAC system that does not enable the history feature to be switched on and off or to clear or delete messages potentially places the person at risk of breaches of privacy and confidentiality. Speech pathologists need to consider the potential harms of sensitive information shared with one person becoming known to people other than the intended communication partner. Risks to privacy posed by the history feature of a system is particularly pertinent to the situation where people with complex communication needs might wish to discuss personal issues or report abuse (see Bryen, Carey, & Frantz, 2003).

Conclusion

In summary, speech pathologists, being aware of ethical issues in AAC, have an important role in ensuring that AAC interventions are not only timely and effective, but also of greatest benefit and least harm to people who use AAC. Considering the range of options available, effective and ethical practice will rest heavily upon person-centred, collaborative, and evidence based practice. In this way, multi-modal communication services may truly improve the lives of people with complex communication needs, their families, and society as a whole.

References

AAC-RERC (2010). Mobile devices and communication apps. Retrieved from http://aac-rerc.psu.edu/index.php/pages/show/id/46

Ballin, L., Balandin, S., Stancliffe, R. J., & Togher, L. (2012). The views of people who use speech generating devices on mentoring new learners Disability and Rehabilitation. *Assistive Technology*, *7*, 63–74

Beukelman, D. R.; Mirenda, P. (2005). *Augmentative & alternative communication: supporting children & adults with complex communication needs* (3rd ed.). Baltimore, MD: Paul H. Brookes Publishing.

Body, R., & McAllister, L. (2009). *Ethics in speech and language therapy*. West Sussex, UK: Wiley-Blackwell.

Bryen, D. N., Carey, A., & Frantz, B. (2003). Ending the silence: Adults who use augmentative and alternative communication and their experiences as victims of crimes. *Augmentative and Alternative Communication*, *19*(2), 125–134.

Chabon, S. S., Denton, D. R., Lansing, C. R., Scudder, R. R., & Shinn, R. (2007) *Ethics education*. Rockville, MD: American Association of Speech and Hearing.

Goldbart, J., & Marshall, J. (2011). Listening to proxies for children with speech, language and communication needs. In S. Roulestone, & S. McLeod (Eds.), *Listening to children and young people with speech language and communication needs*. London: J&R Press.

Farrall, J. (2012). Switch accessible apps for ipad/iphone. Retrieved from http://www.janefarrall.com/html/resources/Switch%20Accessible%20Apps%20for%20iPad-1.pdf

Farrall, J. (n.d.) ipad/iphone apps for AAC. Retrieved from http://www.spectronicsinoz.com/article/iphoneipad-apps-for-aac

Kaiser A. P., & Goetz, L. (1993). Enhancing communication with persons labelled severely disabled. *Journal of the Association for Persons with Severe Handicaps*, *18*(3), 137–142.

McNaughton, D. B., & Beukelman, D. R. (Eds.). (2010). *Transition strategies for adolescents and young adults who use AAC*. Baltimore, MD: Paul H. Brookes Publishing.

Markkula Centre. (n.d.) *Ethical decision making*. Retrieved from http://www.scu.edu/ethics/practicing/decision/

Speech Pathology Australia. (2002). *Ethics education for Australian speech pathologists*. Melbourne: Author. 2002 version retrieved from http://www.speechpathologyaustralia.org.au/library/Ethics%20Education%20Package.pdf

Speech Pathology Australia. (2010). Code of ethics. Melbourne: Author. Retrieved from www.speechpathologyaustralia.org.au/library/Ethics/CodeofEthics.pdf

Speech Pathology Australia. (2011). *Competency-based occupational standards (CBOS) for speech pathologists*. Melbourne: Author.

Speech Pathology Australia. (2012a). Ethics education for Australian speech pathologists. Report in preparation.

Speech Pathology Australia. (2012b). Clinical guideline on augmentative and alternative communication. Report in preparation.

St James Ethics Centre. (n.d.). What is ethics? Retrieved from www.ethics.org.au/

Sutherland, D., Gillon, G., & Yoder, D. (2006). AAC use and service provision: A survey of New Zealand speech-language therapists. *Augmentative and Alternative Communication*, *21*, 295–307.

United Nations. (2006). UN Convention on the Rights of Persons with Disabilities. Geneva: World Health Organization. Retrieved from www.un.org/disabilities/convention/conventionfull.shtml.

Van der Meer, L., Sigafoos, J., O'Reilly, M. F., & Lancioni, G. E. (2011). Assessing preferences for AAC options in communication interventions for individuals with developmental disabilities: A review of the literature. *Research in Developmental Disabilities*, *32*, 1422–1431.

Williams, M. B., Krezman, C., & McNaughton, D. (2008). "Reach for the stars": Five principles for the next 25 years of AAC. *Augmentative and Alternative Communication*, *24*(3), 194–206.

World Health Organization. (2001). *International classification on functioning, disability, and health* (ICF). Geneva: World Health Organization. Retrieved from http://www.who.int/classifications/icf/en/

World Health Organization. (2010). *World report on disability*. Geneva: World Health Organization. Retrieved from www.who.int/disabilities/world_report/2011/en/index.html

Dr. Bronwyn Hemsley is a speech pathologist specialising in the field of augmentative and alternative communication and healthcare communication. She is currently undertaking postdoctoral research funded by the National Health and Medical Research Council and is a senior lecturer in the discipline of speech pathology at the University of Newcastle. Bronwyn is also the Australian representative to the Council of the International Society for Augmentative and Alternative Communication (ISAAC).

Correspondence to:
Dr. Bronwyn Hemsley
Senior Lecturer
Faculty of Education and the Arts, School of Humanities and Social Science
The University of Newcastle
University Drive Callaghan, NSW 2308, Australia
email: Bronwyn.hemsley@newcastle.edu.au

Webwords 43

Augmentative and alternative communication

Caroline Bowen

People with complex communication needs comprise a heterogeneous group who have difficulty communicating using speech alone. They rely to some degree on augmentative and alternative communication (AAC) strategies such as gaze, facial expression, body language, gesture, signs, symbols, pictures, non-speech sounds, writing, and low-tech and high-tech (electronic) devices.

An obvious but interesting thing about the various AAC modalities is that everyone uses some or all of them regularly in everyday exchanges as natural substitutes for speech or to supplement it. In fact, in highly charged emotional situations people who do not normally have to depend on AAC are more inclined towards non-verbal communication. We nod or shake our heads empathically in answer to another's sad news, clench and shake our fists in silent rage in response to perceived injustices, write words of sympathy when conversation would be too difficult, or surreptitiously give the *digitus infamis* (infamous finger) when a fellow road-user annoys.

Human rights

The **International Society for Augmentative and Alternative Communication (ISAAC)**[1] works to improve the lives of children and adults who use AAC, and the WC3 Web Accessibility Initiative (WAI).

ISAAC's vision is that AAC will be recognised, valued, and used throughout the world, while its mission is to promote the best possible communication for people with complex communication needs. In 2007, October was established as International AAC Awareness Month by ISAAC's LEAD Project Committee. Thirteen countries participated the first time it was celebrated, and events have been increasing in number and scope ever since. The month now has a Facebook presence with a remarkable photo and video gallery.

The **WC3 Web Accessibility Initiative (WAI)**[2] is directed by the Internet's founder Tim Berners-Lee who said in 2002, "Just as people differ in the language, characters and cultures to which they are used, so they differ in terms of their capacities, for example, in vision, hearing, motor or cognition. The universality which we expect of the Web includes making sure that, as much as we can, we make the Web a place which people can use irrespective of disabilities."

The WAI develops perfectionistic guidelines that are widely regarded as the international standard for web accessibility. It produces support materials to help developers to understand and implement web accessibility, and it provides resources through international collaboration. It welcomes participation from around the world from volunteers working alone and in work groups. There is much to explore in its extensive, no-frills site including the WC3 Accessibility page. The WAI principles have been embraced by the Australian Human Rights Commission – see for example its **World Wide Web Access: Disability Discrimination Act Advisory Notes**[3].

Caroline Bowen

Perfect

Dotted around the Internet are perfectly presented resources for clinicians who share ISAAC's vision and mission. Offerings from Canada include AAC A Way of Thinking from **Special Education Technology – British Columbia**[4], **Communication Assistance for Youth and Adults**[5], a **Visuals Engine**[6] that parents can use to make visual supports for their children, and the inspirational **Kilometres for Communication**[7] with its refreshing approach to accessibility and inclusion.

Across the border in Pennsylvania is **AAC-RERC**[8], a rehabilitation engineering research centre for AAC technology. The collaborators are from Duke University, **InvoTek**[9], Pennsylvania State University, the Children's Hospital Boston, the University of Nebraska, Lincoln, Oregon Health & Science University, and the State University of New York at Buffalo. David McNaughton develops and maintains the abundant AAC-RERC website and owns the associated Facebook page. The website includes scholarly publications, webcasts, a newsletter archive, and features on **Early Intervention**[10] and **Literacy**[11].

AbilityNet[12] in the UK provides a speech-enabled section on its website that uses innovative and quite entertaining Point software. This allows AAC users, their families and the people who support them to experience and compare a selection of AAC devices. It has its own Wiki in the form of a Global Assistive Technology Encyclopaedia (GATE) that anyone can help build – there is an "apply to be a writer" button on each page. The Communication section of GATE is of particular interest.

In Australia, Victoria's SCOPE website has a **communication aids and resources**[13] section with clear explanations of many aspects of AAC, and a well-illustrated overview of non-electronic low-tech communication aids. The Queensland government's Disability Information Service has published a 20-page **Complex Communication Needs**[14] brochure and a practical **Help Communicating – People with a Disability**[15] page. On the Royal Australian College of General Practitioners site there is an article
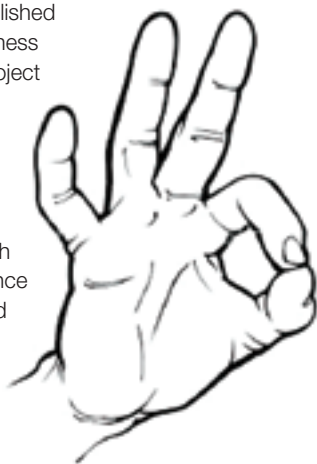
for doctors, **Patients with disabilities and complex communication needs: The GP consultation**[16], by Teresa Iacono and Hilary Johnson. The **AGOSCI**[17] Publications page and Publications Archive provide another rich source of information and practical resources accumulated since the group was established in 1981.

Quiet signs

The **National Relay Service (NRS)**[18] plays an important role in the lives of thousands of Australians who have hearing or speech impairments. Its resources page offers videos, fact sheets, posters and brochures, and **quiet signs of love**[19]. *Quiet Signs of Love* is a 15-minute video that promotes Internet relay to young deaf Australians while providing insights into the world of deafness.

Depicting the beginnings of a relationship between Daniel who is hearing, and Hannah who is deaf, the film was written and directed by Yannis Nikolakopoulos who collaborated with Brett Williams on the vibetrack – a soundtrack that focuses on vibrations for deaf audiences: music designed to be felt and heard. The page also has an interview with the actress Bethany Robinson who plays Hannah.

There are many other informational and resource sites relevant to people with complex communication needs and the people who live and work with them, as exemplified by the overwhelming Wikipedia **Augmentative and alternative communication**[20] page. However, for its reference list alone Webwords gave it the thumbs up with a clenched hand extended and the thumb vertically erect at 90°.

References

Berners-Lee, T. (2002). *The world wide web – Past present and future: Exploring universality*. Japan Prize Commemorative Lecture. www.w3.org/2002/04/Japan/Lecture.html

Brookes, M. (1967). *The producers*. Retrieved February 21, 2012 from www.dailyscript.com/scripts/producers.html

Links

1. www.isaac-online.org
2. www.w3.org/WAI
3. http://www.hreoc.gov.au/disability_rights/standards/www_3/www_3.html
4. http://setbc.org
5. www.cayabc.org
6. http://connectability.ca/visuals-engine
7. http://kilometresforcommunication.com
8. http://aac-rerc.psu.edu
9. http://www.invotek.org
10. http://aackids.psu.edu/index.php/page/show/id/1
11. http://aacliteracy.psu.edu
12. www.abilitynet.org.uk
13. www.scopevic.org.au/index.php/site/resources/communicationaidsresources
14. www.communities.qld.gov.au/resources/disability/community-involvement/communication/documents/complex-communitaction-needs.pdf
15. www.qld.gov.au/disability/adults/help-communicating
16. www.racgp.org.au/afp/200408/20040803iacono.pdf
17. http://www.agosci.org.au
18. www.relayservice.com.au
19. www.relayservice.com.au/quietsignsoflove
20. http://en.wikipedia.org/wiki/Augmentative_and_alternative_communication

Webwords 43 is at www.speech-language-therapy.com with live links to featured and additional resources.

Communication intervention for children with autism

Jeff Sigafoos, Dean Sutherland, Larah van der Meer, Debora Kagohara, and Donna Achmadi

There is general consensus that children with autism who do not develop speech should be taught to use augmentative and alternative communication (AAC) (Mirenda & Iacono, 2009). AAC options include manual signs, picture-exchange communication, and electronic speech-generating devices (SGDs). There is considerable debate, but little research, regarding which of these three options is best suited to children with autism. Comparative studies are few and have not compared the full range of AAC options. The few studies that do exist have revealed only small differences in terms of how quickly some children can learn to use these different systems (Mirenda, 2003; Sigafoos, O'Reilly, Schlosser, & Lancioni, 2007); However, the speed of acquisition of AAC systems has also been surprisingly quick in these studies, suggesting that the participants were relatively easy to teach. Overall, the limited data on this issue to date, suggest that while rate of acquisition may vary for different AAC systems, there may be other variables to consider, such as a child's preference for using different AAC options.

Pilot data indicate that individuals with autism and other developmental disabilities often show idiosyncratic preferences for using particular AAC options (e.g., Sigafoos et al., 2009). This raises the intriguing possibility that a child's preference for using one type of AAC option over others might be an important independent variable that could significantly affect progress in learning to communicate. Indeed, children may be able to "self-determine" the best and most effective AAC option.

Our current research project is comparing three methods of communication for children with autism who have very limited spoken language (i.e., less than 10 single words). The three methods are 1) manual signs, 2) picture exchange communication system (PECS), and 3) electronic speech-generating devices (SGDs – iPods®/ iPads®). The first of two studies is currently underway and is comparing these three methods of communication to answer the following questions:

1. Do children with autism learn to use one method of communication faster than the other two?
2. Do children with autism show a preference for using manual signs v. picture-exchange v. speech-generating devices?
3. Can such preferences be identified during the teaching (intervention) process?
4. Are preferences for different AAC options stable over time?
5. Does preference influence how quickly and efficiently children learn?
6. Does preference influence the extent to which children continue to use their newly acquired communication skills after the intervention has ended?

The key findings to date are:
- Seventeen out of 21 children successfully learnt to make requests (e.g., "I want more." "I want to play with a toy.")

as a function of the teaching (intervention) program. This finding suggests that our teaching methods were largely successful. For the remaining children, who have yet to reach the learning (or acquisition) criterion, we intend to provide more intensive intervention.
- For the 17 children who have so far reached the learning (or acquisition) criterion of 80% correct, we found that the speed of learning varied across the three methods of communication. Specifically, SGD use was learned the fastest (i.e., in the fewest mean number of teaching trials on average), followed by PECS and manual sign (see Figure 1). This finding suggests that SGDs may be an easier method of communication for children with autism to learn or an easier AAC system to teach.
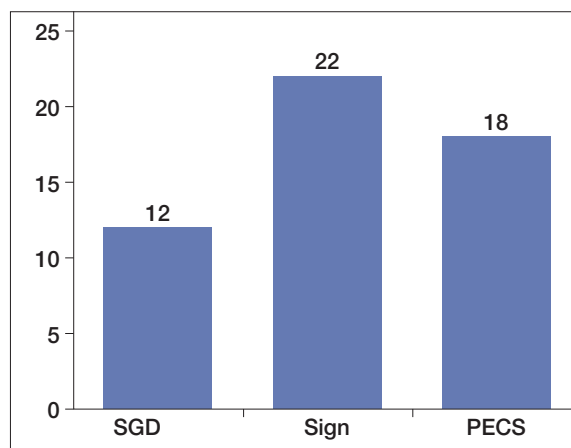

Figure 1. Mean number of teaching trials per AAC option to reach criterion

- The 17 children who have so far reached the learning (or acquisition) criterion have also participated in the preference assessment phase of Study 1. As part of this assessment, each of these 17 children received structured opportunities to choose which of the three communication methods they would like to use to make requests. The percentage of opportunities that each option was selected served as a measure of relative preference. On average, as shown in Figure 2, the SGD was chosen 50% of the time, followed by PECS (20%), and manual sign (11%). This finding suggests that the SGD is preferred over the other two methods. However, on 20% of the assessment opportunities that have so far been conducted, children did not make a choice. We are not yet sure how to interpret these "no-choice" responses. In addition, while children's preferences for different communication methods appeared consistent during the intervention stage of Study 1, it remains unclear how stable these preferences will be over time, hence the need for follow-up in 2012.
- Comparing Figures 1 and 2 suggests that children showed more rapid learning with the most preferred

(From the top) Jeff Sigafoos, Dean Sutherland, Larah van der Meer, Debora Kagohara, and Donna Achmadi
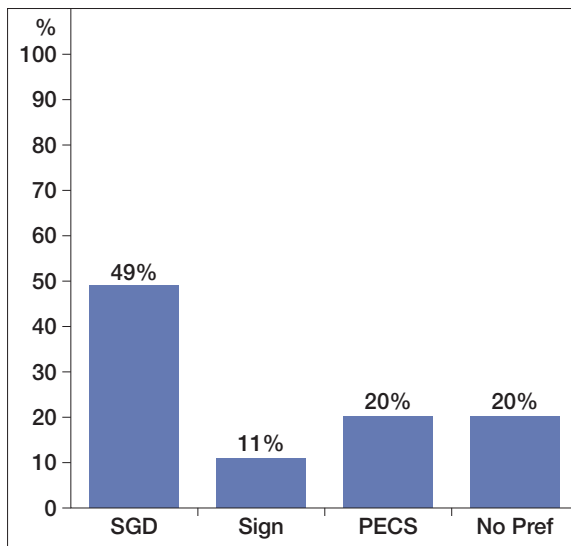
Figure 2. Mean percentage of opportunities each communication method was selected (n = 17)

communication method. This finding suggests that preference may influence how quickly children learn to communicate. We are undertaking further analyses to confirm any such relation between preference and speed of learning.

It is important to note that these key findings are so far limited to the teaching of communicative requesting, which is generally considered a more basic communication skill. A second study to commence later in 2012 will extend the present comparisons to more socially oriented communication skills.

In summary, these early data suggest that children with autism can learn to use a variety of AAC systems and that they are likely to indicate a preference for one mode of communication. However, it is not known how stable these preferences are over time or how these preferences may support the development of more complex communication.

References

Mirenda, P. (2003). Toward functional augmentative and alternative communication for students with autism: Manual signs, graphic symbols, and voice output communication aids. *Language, Speech, and Hearing Services in Schools*, *34*, 203–216.

Mirenda, P., & Iacono, T. (Eds.) (2009). *Autism spectrum disorders and AAC*. Baltimore, MD: Paul H. Brookes Publishing.

Sigafoos, J., Green, V. A., Payne, D., Son, S. H., O'Reilly, M., & Lancioni, G. E. (2009). A comparison of picture exchange and speech generating devices: Acquisition, preference, and effects on social interaction. *Augmentative and Alternative Communication*, *25*, 99–109.

Sigafoos, J., O'Reilly, M. F., Schlosser, R. W., & Lancioni, G. E. (2007). Communication intervention. In P. Sturmey & A. Fitzer (Eds.), *Autism spectrum disorders: Applied behavior analysis, evidence, and practice* (pp. 151–185). Austin, TX: Pro-Ed.

Acknowledgements

Jeff Sigafoos is a professor in the School of Educational Psychology at Victoria University of Wellington, New Zealand. He teaches in the area of special educational needs and undertakes research on augmentative and alternative communication for individuals with developmental disabilities. **Dr Dean Sutherland** is a senior lecturer in the Health Sciences Centre and College of Education at the University of Canterbury, Christchurch, New Zealand. His teaching and research interests include autism spectrum disorder, deaf education, and the use of augmentative and alternative communication by children and adults with significant communication difficulties. **Larah van der Meer**, **Debora Kagohara**, and **Donna Achmadi** are doctoral students at Victoria University, Wellington, New Zealand.

Correspondence to:
Dean Sutherland, PhD
Health Sciences Centre
University of Canterbury
Private Bag 4800,
Christchurch 8140, New Zealand
email: dean.sutherland@canterbury.ac.nz
phone: +64 (0)3 3642987

Activities and participation of children with cerebral palsy

Cristina Mei

Research investigating the speech and language abilities of children with cerebral palsy (CP) has to date largely focused on the impairment level. Yet emerging data highlight the functional impacts of communication deficits (Fauconnier et al., 2009; Hammal, Jarvis, & Colver, 2004; Morris, Kurinczuk, Fitzpatrick, & Rosenbaum, 2006). In light of this, researchers at the Murdoch Childrens Research Institute have recently commenced a study investigating the speech and language abilities of children with CP aged 5 and 6 years at both an impairment and functional level consistent with the International Classification of Functioning, Disability and Health for Children and Youth (ICF-CY; World Health Organization, 2007).

At the impairment level of the ICF-CY, children with CP may demonstrate a range of deficits relevant to speech pathologists that involve oral motor, speech, and/or language functions. Known functional impacts of communication disorders in children with CP at an activities and participation level include reduced number of social contacts and limited participation in community activities (Raghavendra, Virgo, Olsson, Connell, & Lane, 2011).

To measure children's activities and participation, the research team developed a questionnaire based on qualitative data. This qualitative study involved individually interviewing 13 parents of children with CP aged between 4 and 9 years. The interviews aimed to firstly determine parental opinions regarding their child's activities and participation and to secondly identify specific barriers and facilitators impacting on children's functioning. Interview questions were developed with reference to the ICF-CY. Parents' responses were then analysed to inform the development of questionnaire items, such as "my child is able to make choices or decisions" and "my child communicates to share information".

Results from the qualitative study indicated that children reportedly participated in a range of activities including communication-related activities (e.g., making choices), self-care tasks (e.g., eating), leisure activities (e.g., reading), assisting in household tasks (e.g., cleaning), school activities (e.g., group activities), and community-related activities (e.g., shopping).

In terms of factors impacting on children's activities and participation, parents reported the following facilitators: the child's characteristics (e.g., being determined or social), the support provided by others (e.g., family members, the school), the positive characteristics of communication partners (e.g., going to the child's level, understanding how to use the child's communication device), the child's environment (e.g., familiar setting, being around other children), and speech pathology services (e.g., receiving regular therapy and access to communication aids).

In contrast, reported barriers included the child's characteristics (e.g., being shy, behavioural issues), children's physical, communication, and feeding impairments, and the parent themselves (e.g., not providing the child with choices or opportunities to communicate). Further barriers experienced by children included the negative attitudes of others or others not understanding the child, the child's environment (e.g., noisy and crowded areas), and speech pathology services (e.g., lack of services, complexity of communication devices).

The developed questionnaire that is based on the above qualitative findings is currently being administered to a population-based sample of children with CP, as part of the author's PhD research. It is anticipated that this questionnaire will highlight differences between the activities and participation of children with CP with and without associated speech and language impairments. Furthermore, the data obtained via the questionnaire will assist in identifying key barriers and facilitators specific to children with CP with associated communication impairments. Given the present lack of assessments measuring the activities, participation, and influencing contextual factors of children with communication impairments, this information could be used by speech pathologists to assist in the assessment and management of children with CP.

Cristina Mei

Acknowledgements

References

Fauconnier, J., Dickinson, H. O., Beckung, E., Marcelli, M., McManus, V., Michelsen, S. I., … Colver, A. (2009). Participation in life situations of 8–12 year old children with cerebral palsy: Cross sectional European study. *British Medical Journal*, *338*, b1458.

Hammal, D., Jarvis, S. N., & Colver, A. F. (2004). Participation of children with cerebral palsy is influenced by where they live. *Developmental Medicine & Child Neurology*, *46*(5), 292–298.

Morris, C., Kurinczuk, J. J., Fitzpatrick, R., & Rosenbaum, P. L. (2006). Do the abilities of children with cerebral palsy explain their activities and participation? *Developmental Medicine & Child Neurology*, *48*(12), 954–961.

Raghavendra, P., Virgo, R., Olsson, C., Connell, T., & Lane, A. E. (2011). Activity participation of children with complex communication needs, physical disabilities and typically-developing peers. *Developmental Neurorehabilitation*, *14*(3), 145–155.

World Health Organization. (2007). *International Classification of Functioning, Disability and Health – Children and Youth Version*. Geneva: Author.

Correspondence to:
Cristina Mei
PhD Scholar
Murdoch Childrens Research Institute
50 Flemington Road, Parkville, 3052
phone: +61 (0)3 9345 5521

The Communication Access Network

Karen Bloomberg and Denise West

Karen Bloomberg (top) and Denise West

In 2002, the Department of Human Services in Victoria funded what was known as the "Speech Therapy Initiative". This initiative involved the creation of a "hub and spoke" model of service delivery consisting of the Communication Resource Centre as the "hub" (in metropolitan Melbourne) and 13 statewide Regional Communication Services as the "spokes". The regional communication services are located in 18 sites across Victoria.

This initiative recognised that Victorians who have complex communication needs have had limited access to specialist speech therapy services and support in their local communities. This situation arose in part because of the small number of therapists available with expertise in supporting people with complex communication needs. In addition, funding constraints and targets have historically focused on delivering individual services rather than promoting general community inclusion of people with a disability. The priority was to develop and provide a statewide model of service that was accessible and equitable for people with complex communication needs.

The term "Speech Therapy Initiative" was a misnomer as the focus of the initiative was not solely on providing direct speech therapy services. This innovative model of service delivery placed a greater emphasis on the role of speech pathologists to engage in projects and activities that support community capacity building. Indeed, the aim of the initiative is to make the community more accessible for people with little or no speech. With this aim in mind, the Communication Resource Centre and the Regional Communication Services developed under the "hub and spoke" model became known as the Communication Access Network (CAN).

This network supported the Victorian government's commitment to building more inclusive communities and the Victorian State Disability Plan 2002–2012 (Disability Services Division 2002) affirming the rights of people with a disability to live and take part in community life as citizens of Victoria. This has since been further endorsed by the National Disability Strategy 2012–2020 which calls for the removal of all barriers to the inclusion of people with disability in their communities (http://www.fahcsia.gov.au/sa/disability/progserv/govtint/Pages/nds.aspx).

The objectives of the CAN (Communication Access Network, 2010) include to:

- facilitate the participation and inclusion of people with complex communication needs in community life
- increase access to generic services for people with complex communication needs
- engage in capacity building for individuals and the general community

- raise awareness of communication as a human right
- provide opportunities for active participation and leadership by people with complex communication needs

To this end, the speech pathologists in the Communication Resource Centre and the Regional Communication Services have a two-fold focus. A minor proportion of their time is allocated to individual case-work. Where possible, this is done in collaboration with other speech pathologists seeking support in the area of alternative and augmentative communication (AAC). The majority of their time is spent in activities and projects that facilitate access and inclusion for people with complex communication needs.

Working in the CAN has been a rewarding experience but has not been without its challenges. Early work focused on community mapping. We needed to know where there were gaps and what resources and services were available across the state. In our search for that information we also began the process of developing new networks and working in partnerships so we could share expertise and value-add to work already being done in the community. Much of our work has involved addressing the opportunity barriers identified in the participation model described by Beukelman and Mirenda (2005). These include policy, practice, attitude, skills, and knowledge barriers.

In the last few years there have been two major objectives driving the CAN. One has been providing tertiary speech pathology services to people with lifelong disabilities. This has led to a train-the-trainer model of service delivery for support workers and communication partners living and working with people with complex communication needs. Staff participate in a comprehensive training package covering assessment of intentional and unintentional communicators, behaviours of concern, sensory-based activities, Key Word Sign, Boardmaker training, and developing functional communication strategies.

The training has been supported with access to resources such as *Getting Started with Key Word Sign* (Caithness, Brownlie, & Bloomberg, 2012), *The Triple C* (Bloomberg, West, Johnson & Iacono, 2009), *InterAACtion – strategies for intentional and unintentional communicators* (Bloomberg, West, & Johnson, 2004), NECAS (Non-electronic Communication Aid Scheme; http://www.scopevic.org.au/index.php/site/whatweoffer/communicationresourcecentre /necas), and other information and material on the Scope website (www.scopevic.org.au).

The second statewide objective has focused on projects and activities that support communication access and the

concept of a communication friendly state. There have been over 50 projects implemented statewide. It started with the "Libraries for all" project done in partnership with the State Library Network and VicNet. The State Library Network represents all public libraries across the state, and VicNet is a division of the State Library Network. VicNet helps the library to meet its goal of providing access to information for everyone and strengthening communities through the use of information technology. The "Libraries for all" project placed communication aids in all 262 public libraries.

After these developments came a series of projects with the theme of "Good Communication is Good Business". These involved partnerships with retailers such as Centro, Westfield, Stockland, and other smaller shops and cafes. In these projects, shops and services were provided with communication aids and tip sheets for serving customers with little or no speech. The Inclusive Leisure Initiative involved engaging gyms and aquatic centres in communication access. Communication aids were again provided, but disability awareness training was also included, co-presented by people with complex communication needs. Two transport initiatives were Talking taxis – providing communication aids to all M50 cabs (M50 cabs are the modified cabs able to carry passengers who use wheelchairs, scooters, and other mobility aids) – and Talking Transport, which makes bus travel in the Gippsland region accessible. The Talking Transport project involved developing a photo-based bus timetable. Each bus stop was represented by a photo or logo of a landmark unique to that stop. This allowed people with limited literacy to travel independently (http://www.wellington.vic.gov.au/Page/page.asp?Page_Id=2001&h=1). Resources for Talking Transport and Inclusive Leisure may be found on the Wellington Shire website (http://www.wellington.vic.gov.au/).

As the work of the CAN has progressed there has been an evolution in the involvement of people with complex communication needs. Some early projects just focused on community awareness and information about complex communication needs and communication access. For example, CAN produced fact sheets about complex communication needs and developed posters highlighting some of the projects mentioned earlier. Better planning of projects has led to more consultation with people with complex communication needs, with focus groups and surveys allowing us to better identify needs. Such developments have informed the direction of CAN and many projects now include people with complex communication needs on advisory groups and co-presenting workshops.

Working alongside people with complex communication needs and the challenges of creating sustainable communication environments highlighted the need for a common symbol to identify communication access. The symbol was ratified through a statewide consultative process which followed the Australian Standard AS 2342-1992 guide (Standards Australia, 1992). After much collaboration, the Communication Access Symbol was launched in Victoria on 17 November 2011. People with complex communication needs were instrumental in developing the criteria which define communication access. And in 2011 people with complex communication

needs were supported to deliver statewide forums on creating communication friendly environments. These are environments where people will:

- treat them with dignity and respect
- talk directly to them and not the person with them
- give them time to get their message across
- listen to their message
- be willing to use other methods of communicating.

Now in 2012 the Communication Access Network, in partnership with people with communication difficulties, will be working to promote the Communication Access Symbol and the concept of communication access across Victoria. Please visit the Scope website to see how you can make your service or facility communication accessible. www.scopevic.org.au

References

Beukelman, D. R. & Mirenda, P. (2005). *Augmentative and alternative communication: Supporting children and adults with complex communication needs*. Baltimore, MD: Paul H. Brookes Publishing Co.

Bloomberg, K., West, D., & Johnson, H. (2004). *InterAACtion: Strategies for intentional and unintentional communicators*. Communication Resource Centre: Scope, Victoria.

Bloomberg, K., West, D., Johnson, H., & Iacono, T. (2009). *Triple C: Checklist of Communication Competencies*. Melbourne, Victoria: Communication Resource Centre.

Caithness, T., Brownlie, E., & Bloomberg, K. (2012). *Getting started with Key Word Sign*. Key Word Sign Australia, Callaghan, NSW: University of Newcastle.

Communication Access Network (2010). *Communication Access Network Guidelines 2010*. Unpublished document.

Disability Services Division, (2002). *The Victoria state disability plan 2002–2012*. Melbourne Department of Human Services, Victorian Government. www.dhs.vic.gov.au

Standards Australia. (1992). *Development, testing and implementation of information and safety symbols and symbolic signs AS 2342-1992*. Standards Australia International Ltd: Sydney.

Correspondence to:
Karen Bloomberg
Consultant speech pathologist
Communication Resource Centre, Scopt
830 Whitehorse Road, Box Hill, VIC 3128
phone: +61 (0)3 9843 2000
email: kbloomberg.crc@scopevic.org.au

Our Top 10 resources for working with children with complex communication needs

Yooralla Early Childhood Services Speech Pathology Team

Yooralla ECS Speech Pathology Team

Yooralla Early Childhood Services (ECS) support families with children who have a disability or developmental delay prior to school entry (0–6 years). Yooralla's philosophy is one that embraces a family-centred approach recognising that families are children's first and most influential teachers. Support is provided within everyday settings and routines, through home visits and/or visits to community settings such as playgroup, childcare, and kindergarten. Families can, if they choose, also participate in parent support, siblings' and dads' groups. We aim to improve the quality of life for families who have a child with a disability.

In addition to speech pathologists, the Yooralla ECS team includes specialist early childhood teachers, physiotherapists, occupational therapists, program assistants, psychologists, and social workers.

1 Visual schedules

Visual schedules using pictures or photos are highly useful in assisting children and their families to be prepared, make choices, and plan routines and everyday activities. Visual schedules can increase a child's awareness of available activity choices and routines and can assist in reducing anxiety. They can enable children to be better prepared for any unexpected changes to routine and assist them to independently transition more easily between a greater range of activities. Visual schedules are often used at home as well as in community settings.

Parent-friendly information on transitions and schedules can be found in *Fine Motor Skills for Children with Down*

Syndrome: A Guide for Parents and Professionals (by Maryanne Bruni; Woodbine House, Bethesda, MD, 2006; pp. 186–187). The ACT-NOW fact sheet 32 "Using visual supports in the preschool environment: Timetables & schedules" also has useful, straightforward information on how to use visual schedules.
http://www.med.monash.edu.au/spppm/research/devpsych/actnow/download/factsheet32.pdf

2 Boardmaker

Where would speech pathologists be without *Boardmaker*? Boardmaker is a computer software program produced by Mayer-Johnson that allows the user to generate pictures for thousands of vocabulary items. Boardmaker is used extensively across Yooralla ECS not only by the speech

pathologists but by all staff. Visual prompts/cues are essential in our support of children with complex communication needs and Boardmaker plays a vital role in the development of communication books, communication boards, and other visual cues such as schedules, calendars, etc. Boardmaker also comes with a range of overlay templates for a myriad of electronic communication devices.

Boardmaker: Standard Australian/New Zealand Version 6 for Windows is available for purchase from Spectronics http://www.spectronicsinoz.com; cost: starting from $439.00.

3   Key Word Sign

Key Word Sign is a fantastic tool for language and communication development. It can be used with children and adults with a communication impairment, delay, or disorder to assist understanding, to assist with expression if speech is slow to develop, to supplement speech attempts, or as an alternative for someone with no speech. Key Word Sign can be used with children of any developmental level to facilitate communication and it is used widely across Yooralla. The most common vocabulary of words used was previously known as "Makaton", but is now known in Australia/Victoria as "Key Word Sign". There are a range of books available detailing the Key Word Sign Vocabulary as well as CD Roms that include video footage of how to do the signs. Key Word Sign Victoria also run regular basic workshops across Victoria. For further info see the Key Word Sign Australia website. http://www.newcastle.edu.au/research-centre/special-education/key-word-sign-australia/

4   Finish box / finish cloth

The black-and-white checked flag that represents "finish" can be seen across all Yooralla ECS. Using the "finish box"

(a box covered in the checked flag print) is a common and effective strategy. The child is encouraged to place any items in the "finish box" when they are finished with them (rather than throwing or discarding them) or the adult places items in the box to indicate that they are finished with. The finish cloth (a piece of black-and-white checked material) is used to cover items (often too big for the box) when they are finished. It is amazing how effective this symbol can be with children of all developmental levels, particularly with children who present with significant behavioural concerns. The "finish" symbol can also be used on placemats, as part of schedules, and as a picture symbol to be shown to children when they are finished.

5   The website Spectronics: Inclusive Learning Technologies

Spectronics is Australia and New Zealand's largest supplier of special needs software and assistive technologies. In addition to the thousands of products that they supply, Spectronics also provides a range of support and training for therapists. Their website includes an extensive range of information including blogs, information about products, support services, training, and conference information – a fantastic resource for all therapists working with clients with complex communication needs.
http://www.spectronicsinoz.com/

6   Hanen resources

In line with the family-centred approach that Yooralla embraces, the Hanen parent training programs such as "It Takes Two to Talk" and "More Than Words" and their associated resources are used widely across our services. Based in Canada, the Hanen Centre has led the way with family-focused early language intervention that supports parents, speech pathologists, and educators to develop language and literacy skills in preschool-aged children. Hanen provides research-based parent programs and resources (including books, DVDs, and handouts) as well as professional development in the areas of language development and delay, literacy, and autism spectrum disorders. Their programs/resources are extremely parent friendly and can be used with children at a range of communicative levels. Please see the Hanen website for more information www.hanen.org.

Hanen resources can be purchased in Australia from Dart Products (www.dartproducts.com.au).

7   The SOS Approach to Feeding

Children with complex communication needs often present with associated feeding/meal-time concerns. The SOS (Sequential Oral Sensory) Approach to Feeding is a trans-disciplinary program for assessing and treating

children with feeding and weight/growth difficulties. It was developed by Dr Kay Toomey and colleagues (including paediatricians, speech pathologists, registered dietitians, and occupational therapists) in Denver, Colorado. The SOS Approach integrates motor, oral, behavioural/ learning, medical, sensory, and nutritional factors and approaches in order to comprehensively evaluate and manage children with feeding/growth problems. It focuses on exploring and learning about the different properties of foods (i.e., texture, smell, taste, and consistency) in a safe and fun way. The SOS Approach is a developmental approach to feeding, which works through a hierarchy, beginning from tolerating to eventually tasting and eating foods. This approach was only recently introduced in some Yooralla ECS services, but has already shown a high level of success and effectiveness in working with our client population. On completion of the workshop participants were able to purchase CDs containing the forms and handouts that are used in Dr Toomey's clinic. These are a fantastic resource.

For further information on the SOS Approach and Dr Kay Toomey see the Sensory Therapies and Research (STAR) Center website www.starcenter.us/services-sos.htm or visit www.feedingworkshops.com/ for details of workshops in Australia & New Zealand. Queensland Children's Medical Research Institute (QCMRI) will be hosting workshops around Australia in 2012.

8 "One Day at a Time"

"One Day at a Time" is a resource developed by Scope, an organisation for people with a disability. It is a free resource that consists of a booklet, checklists, and activity sheets in four areas: 1) Moving around skills, 2) Using hand skills, 3) Communication skills, and (4) Play skills. These can all be downloaded from the Scope website: http://www.scopevic.org.au/index.php/site/resources/onedayatatime

The skills in the checklists are organised developmentally and the activity sheets provide ideas for developing the skills in everyday routines.

9 The BIGmack or Step-by-Step

The BIGmack and the Step-by-Step are basic single switch/button voice output devices. They are a great place to start when introducing augmentative and alternative communication (AAC) and can be easily programmed by staff and parents. The BIGmack is a single message device, while the Step-by-Step can be programmed to say a sequence of messages. They can be used for non-verbal or

unintelligible children to get attention, participate in group times, say their name, give a simple message about the day or participate in activities (e.g., to say "more" or perhaps a repetitive line in a book ["But where is the green sheep?"]). Both of these devices can also be used as a switch for toys, environmental controls, and other activities (e.g., a computer with a switch-adapted mouse). Step-by-Step and BIGmack are available from Technical Solutions http://www. tecsol.com.au; Big Step-by-Step or Little Step-by-Step $199.00, with levels $239.00, BIGmack or LittleMack $159.00.

10 iPad

The iPad has taken the world by storm and it is no different in ECS. The iPad has become a regularly used tool for many clinicians. There are a range of applications that can be downloaded to support language development and other educational needs, as well as voice output apps to support communication (e.g., proloquo2go), apps for visual schedules (e.g., first-then) and apps for social skills (e.g., Model Me Kids). The effectiveness of the ipad as a communication tool is still being evaluated; however, it has been found to be a fantastic motivator, distracter, and learning tool for many children. There are many websites now with lists and reviews of apps. See below:

- www.a4cwsn.com Apps For Children with Special Needs: a fantastic website where you can view a 5–10 minute demonstration of an application
- http://www.squidalicious.com/ website developed by a parent of a child with autism, with lots of information about ipad/apps, including her "Autism Apps Spreadsheet"
- www.bestkidsapps.com lists of apps for kids listed in age groups
- www.spectronicsinoz.com/article/iphoneipad-apps-for-aac Jane Farrall's list of current apps; includes descriptions, access, rating, and prices for each app
- http://www.spectronicsinoz.com/blog/apple/ Spectronics blog

Correspondence to:
Carla Gray
Clinical Advisor – Speech Pathologist
Yooralla Children's Services
phone: +61 (0)3 9808 6833
email: carla.gray@yooralla.com.au

Top 10 resources from Scope's Communication Resource Centre

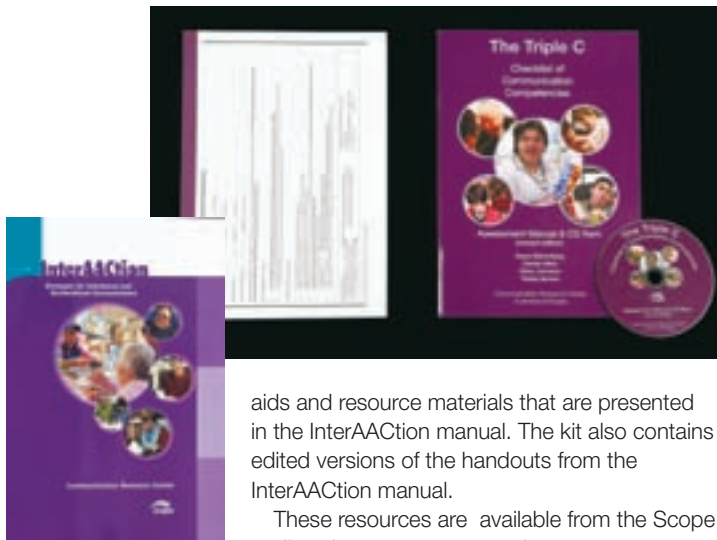*Some members of the Communication Resource Centre team*

The Communication Resource Centre is a service of Scope. The Communication Resource Centre provides information, advice, resources, and services relating to the many different aspects of communication disabilities. We aim to increase community awareness and the involvement of people with communication difficulties in their local and broader community. People with complex communication difficulties either cannot speak or they have speech that is difficult to understand. They use other ways of communicating (http://www.scopevic.org.au/index.php/site/resources/communicationaidsresources)

1 The Triple C (Checklist of Communication Competencies) and the InterAACtion resources (manual, DVD, and kit)

The Triple C (revised edition, 2009) by Karen Bloomberg, Denise West, Hilary Johnson, and Teresa Iacono is designed for use with adolescents or adults with little or no speech. It is a valid and reliable tool that makes it possible

to assess early communication, observable, and functional skills. This can be purchased from the Scope on-line shop at www.scopevic.org.au

InterAACtion: Strategies for Intentional and Unintentional Communicators (2004) by Karen Bloomberg, Hilary Johnson, and Denise West, are resources designed for people who work with adults who have complex communication needs. The InterAACtion manual provides a framework for introducing a variety of communication strategies to assist functional communication and extend or develop communication skills, where appropriate. It contains over 30 individualised communication strategies as handouts, which can be photocopied. The handouts include information about the strategy, who might use it, how to develop it, how to implement it, and how to adapt it for people with different communication skills. The worksheets are designed to assist communication partners to learn to observe communication skills and needs, and make decisions about appropriate communication strategies. The kit provides examples of the communication

three parts: Augmentative and Alternative Communication (AAC) processes, AAC intervention for people with development disabilities, and AAC for people with acquired disabilities.

aids and resource materials that are presented in the InterAACtion manual. The kit also contains edited versions of the handouts from the InterAACtion manual.

These resources are available from the Scope on-line shop at www.scopevic.org.au

2   Scope website

To find a range of useful resources and products go to the Communication Resource Centre pages or the Resources page. You will find information on human rights, grief, and loss, accessible information, gastrostomies, behaviours of concern, and much, much more!
www.scopevic.org.au

3   Symbol software and symbol sets

To make good quality communication aids and accessible written materials, you need a range of symbol sets and images at your disposal. These are some of the products we use every day: *Boardmaker: Picture Communication Symbols* (purchase from http://www.spectronicsinoz.com/), Compic (purchase from http://www.scopevic.org.au/), and Valuing People (purchase from http://www.inspiredservices.org.uk/). Good quality photos are also an excellent tool.
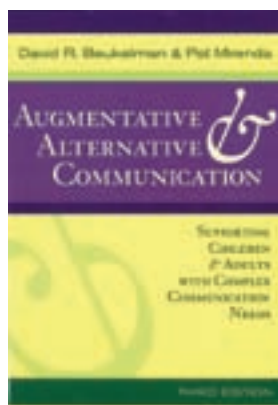
4   Cameras

Still images or video footage can be used in a variety of ways. Photos of a person completing tasks can be included on a person's visual schedule. Video footage can help with reviewing how a person communicates with different people and in varied environments. For quick and easy capturing and downloading, a USB flip camera is handy.

5   Augmentative and Alternative Communication: Supporting Children and Adults with Complex Communication Needs

Beukelman, D. R., & Mirenda, P. (2005) *Augmentative and alternative communication: Supporting children and adults with complex communication needs* (3rd ed.). Baltimore, MD: Paul H. Brookes Publishing.

The bible of AAC will be available in its fourth edition in September 2012. The current edition (3rd edition, published in 2005) includes

6   AGOSCI listserve

The AGOSCI listserve is an on-line forum for people with complex communication needs, family members, and carers. This is a thriving list serve where there is always an interesting conversation happening. It is also a great place to post a question and receive a range of responses from very experienced and knowledgeable people, who include AAC users, parents, teachers, speech pathologists, and other professionals. http://www.agosci.org.au/list.htm

7   The Pragmatics Profile of Everyday Communication Skills

Hazel Dewart and Susie Summers have created this tool and make it available on-line via http://wwwedit.wmin.ac.uk/psychology/pp/ There are different versions for use with children and adults. The tool enables communication partners to explore how a person communicates in everyday interactions. In the adult version, you can explore: communicative functions (i.e., attention directing), response to communication (i.e., understanding the spoken word), interaction and conversation (i.e., conversational repair), and contextual variation (i.e., person, place, topic).

8   Getting Started with Key Word Sign (2012)

This book is the newest resource from Key Word Sign Australia. It contains 100 key word signs, shown as line drawings with descriptions of how to do the signs. These 100 vocabulary items are also taught at Basic Key Word Sign workshops. You can purchase *Getting Started with Key Word Sign* and find out more about the workshops by going to www.newcastle.edu.au/KWSA.

9   AAC Journal

ACC Journal is published by the International Society for Augmentative and Alternative Communication http://www.isaac-online.org/english/publications

10   Scope's Delicious Page

The Delicious Page consists of weblinks bookmarked by the Communication Resource Centre's Accessible Information Service http://www.delicious.com/accessibleinformationservicescope Find everything from legislation to examples of Easy English and plain language documents.

Correspondence to:
Naomi Rezzani
Speech Pathologist
phone: + 61 (0)3 9843 2000
email: crc@scopevic.org.au
website: www.scopevic.org.au

Around the journals

Augmentative and alternative communication during music therapy sessions with persons with autism spectrum disorders

Gadberry, A. L. (2011). A survey of the use of aided augmentative and alternative communication during music therapy sessions with persons with autism spectrum disorders. *Journal of Music Therapy*, *48*(1), 74–89.

Carl Parsons

This interesting survey identified the need for speech pathologists to work together with music therapists who in turn work with clients with autism spectrum disorders (ASD) who use augmentative and alternative communication (AAC). The author conducted a survey of music therapists (in the USA). In order to be included in the study the music therapists needed to be working with clients ASD. The response rate was 49.6% (187/377).

The results indicated that only 14.6% of music therapists were consistently using aided AAC with clients who already had an AAC system. The author reported that only 33.8% of the music therapists used AAC in their music sessions. Of those music therapists using AAC in their sessions, 72.2% reported using aided AAC in the form of a picture schedule. A total of 65.1% used AAC while singing, 51.5% for giving directions, 47.3% for task schedules, and 38.5% for discussions. Only a few others were using AAC for choices, expressive communication, behaviour management, or receptive communication. Although the music therapists were aware that their clients were using aided AAC to work on expressive communication, many did not model how to use the aided AAC. Sixty percent of the music therapists working with clients with ASD indicated they had not received any training on the use of AAC. Only 15% indicated that they had referred individuals for evaluation to see if they were eligible for an AAC system with 57% indicating it was not part of their job description. The music therapists who had had some training at their workplace or had training by a speech pathologist were more likely to refer clients for evaluation for a possible AAC system or use AAC in their music therapy sessions. Finally, 73.9% of the music therapists indicated that they would benefit from training in AAC.

AAC systems are designed to allow the individual to interact and participate more fully in his or her environment. Thus, the use of AAC systems in all environments is recommended. The finding that less than half of music therapists who work with clients with ASD use AAC is problematic. In light of these results, speech pathologists have an important role in training other professionals who work with clients using AAC.

Learning action symbols with the use of animation

Fujisawa, K., Inoue, T., Yamana, Y., & Hayashi, H. (2011). The effect of animation on learning action symbols by individuals with intellectual disabilities. *Augmentative and Alternative Communication*, *27*(1), 53–60.

Carl Parsons

This project aimed to determine if (Japanese) students with intellectual disabilities learned action words more effectively with static symbols versus animated symbols. The concepts taught were: think, wash (one's face), talk, walk, wipe, stir, tidy up, fall over, look, smell, throw, get, up, ride, put, and spill.

The authors studied 16 students between the ages of 11;9–18;0 who had developmental ages between 3;2–6;11. They taught 16 concepts to each participant. Each participant was involved in learning eight concept words using only static symbols and the other eight were taught using animated symbols. The conditions were counterbalanced so that the items taught and the sequence in which they were taught was varied systematically.

In the training component of the project, both the static symbols and the animated symbols were presented to each participant using a notebook computer. The participants were shown the various symbols and asked to "label the symbol". If the participant did not respond correctly then the symbol was labelled for them. The amount of times the stimuli were presented is not clear from the study. However, the amount of time was equal for the two conditions. At the end of a one-week interval each participant was asked to name the 16 static symbols – the animated ones were not presented. The authors used a scoring system of 2 for a correct answer that clearly identified the action, a 1 if there was some proximity to a correct answer, and a 0 if the response was incorrect.

The ANOVA that was used to compare the two conditions demonstrated that the students learned the symbols/words more efficiently when the animations were presented. The authors also reported that the six participants who had developmental ages below 5 years performed the best on items that used animated symbols. The authors concluded that animated symbols facilitated the learning of static symbols and that animation may be beneficial to help students with intellectual disabilities comprehend action words.

Although there are a number of methodological limitations with this project (e.g., it is not clear how responses were recorded, nor why only static symbols were evaluated rather than evaluating both static and animated), it is interesting that an attempt has been made to document the advantage of using animations for the learning of verbs. The use of animations to support learning has been around for a long time. A few studies have appeared that suggest that animations and video modelling are useful to support learning (e.g., social stories, etc.) The present project extends the direction of this research. What we need to know is: who can best benefit from this learning? Is it more efficient? Is it more effective? Do the training effects remain? And what resources (time, money, human resources, expertise) are required to develop these resources?

While many speech pathologists in Australia will recognise that these findings are somewhat intuitive, the majority of speech pathologists still seem to be using one-dimensional static symbols in their teaching. With the use of Boardmaker Studio, you can create your own animated

symbols. You can do your own research to determine which is more efficient – static versus animated symbols.

Generalisation of PECS training to other communication situations

Yoder, P. J., & Lieberman, R. G. (2010). Brief report: Randomized test of the efficacy of Picture Exchange Communication System on highly generalized picture exchanges in children with ASD. *Journal of Autism and Developmental Disorders*, *40*, 629–632.

speechBITE rating 6/10

speechBITE review – Caitlin Winkelman and Tricia McCabe

Carry-over of learned skills and behaviours beyond the therapy room or training environment is the ultimate goal of speech and language intervention. Despite its worldwide recognition and extensive clinical use, there have been few studies investigating the generalisation of the Picture Exchange Communication System (PECS; Bondy & Frost, 1994). While some past research studying the efficiency of PECS has included generalisation measurements, these measures have failed to determine the extent to which PECS is generalised to contexts that are unlike the treatment conditions. The purpose of this study was to measure the "generality" of PECS, looking at whether the skill generalises to environments that are different from the environment where the behaviour was taught.

The authors used a sample of children from a study by Yoder and Stone (2006) that compared two different communication interventions for children with autism. In this study, 33 children with autism and 3 with a diagnosis of pervasive developmental disorder were randomly assigned to two treatment groups. The inclusion criteria required that participants were between the ages of 18 and 60 months, used fewer than 10 words, and had passed a hearing screening. One group was assigned to receive the PECS intervention, while the control group received the Responsive Education and Prelinguistic Milieu Teaching (RPMT; Yoder & Warren, 2002). The children were assessed using four different measures before and after treatment; however, the measure specifically reported in this paper was the Early Social Communication Scales-Abridged (ESCS-Abridged; Mundy, Hogan, & Doehring, 1996). The authors claimed this measure was a good indicator of generalisation because the examiner, setting, activities, and materials were different from that of the treatment sessions. The dependent variable examined from pre-treatment to post-treatment was the total number of picture exchanges.

The researchers found significant differences between pre- and post-treatment in the group that received the PECS intervention but not in the RPMT group. These findings suggest that the learned skill was generalised from the treatment context to the dissimilar context for those who received PECS, while there was not a strong indicator of generalisation for participants in the control group.

These findings are supported by a research design with strong internal validity through randomisation, blinding, comparable groups at baseline, and adequate follow-up. As a randomised control trial, participants were randomly allocated to either the PECS or RMPT groups. The study also had blinded assessors, which prevents biased results, as well as strong comparability of groups at baseline, assuring us that the post-treatment differences were not due to pre-treatment differences. The authors also provided adequate follow-up, certifying that sufficient data was available to support the results provided.

The demonstration of PECS, a trained behaviour, in an untrained context is now supported by this research. This research is important for clinicians and families of children with autism, because it reassures us that PECS will generalise to different situations outside of the therapy room. This generalisation of a skill to the many changing situations and environments of everyday life is the ultimate goal of intervention. We can now feel confident using the PECS intervention with children with autism in a clinical setting because the learned skills will transfer to other environments as well, such as the client's home.

References

Bondy, A. S., & Frost, L. A. (1994). *PECS: The Picture Exchange Communication System training manual*. Cherry Hill, NJ: Pyramid Educational Consultants.

Mundy, P. C., Hogan, A. E., & Doehring, P. J. (1996). *A preliminary manual for the abridged early social communication scales (ESCS)*. Coral Gables, FL: University of Miami.

Yoder, P. J., & Stone, W. L. (2006). Randomized comparison of twocommunication interventions for preschoolers with autism spectrum disorders. *Journal of Consulting and Clinical Psychology*, *74*, 426–435.

Yoder, P. J., & Warren, S. F. (2002). Effects of prelinguistic milieu teaching and parent responsivity education on dyads involving children with intellectual disabilities. *Journal of Speech, Language, and Hearing Research*, *45*, 1158–1174.

Home-based intervention for children with autism

McConkey, R., Truesdale-Kennedy, M., Crawford, H., McGreevy, E., Reavey, M., & Cassidy, A. (2010). Preschoolers with autism spectrum disorders: Evaluating the impact of a home-based intervention to promote their communication. *Early Child Development and Care*, *180*, 299–315. speechBITE rating 3/10

speechBITE review - Morin Beausoleil and Tricia McCabe

At-home communication-based intervention approaches for children with autism spectrum disorder (ASD) are common practice among parents and speech-language pathologists. But a couple of questions arise: how effective are these approaches? and, what developmental gains will the child make as a result of parental guidance and training?

This article evaluated the effectiveness of home-based interventions to preschool children with a confirmed diagnosis of ASD. The study used an early intervention program called Keyhole, that was based on the Treatment and Education of Autistic and Related Communications Handicapped Children (TEACCH) approach (Schopler, Brehm, Kinsbourne, & Reichler, 1971), as well as two other approaches aimed at promoting communication and interaction between parent and child, such as the Picture Exchange Communication System (PECS) (Charlop-Christy, Carpenter, Le, Leblanc, & Kellet, 2002) and the Hanen "More than Words" program (Pepper & Weizman, 2004). The current study also looked at parental perceptions of the therapy design and the effect of this Keyhole program.

The study included children from Northern Ireland between 2 and 4 years of age. Two speech-language

pathologists in different locations delivered therapy to an initial 40 families, with 35 families completing the program. Another 26 families were asked to act as a control group. The 26 families self-selected into two separate subgroups, 15 of the families received five home visits where general information on autism was discussed and educational toys were given, but no therapy was delivered. The remaining 11 families did not receive any visits or additional services.

The Keyhole intervention program (Crawford, Doherty, Crozier, & Cassidy, 2006) involved a speech-language pathologist, an educator, and a psychologist. Each visit lasted an average of 90 minutes, and there were three main phases of the study. Phase 1 included a maximum of four visits at weekly intervals in which the speech-language pathologist provided information about ASD, answered questions, and provided support to the family. Phase 2 included 10–12 visits at fortnightly intervals. Common goals for each family included (a) development of a consistent communication system for each child, (b) demonstration by each child of co-operation in learning of new skills, (c) development of the child's understanding of environments especially at home, and (d) development of parental skills in behaviour management and strategies to promote learning outcomes. During this phase, visual communication techniques were introduced to help the child's understanding and to manage behaviour. PECS's strategies were used to develop initiation and expressive communication skills. In Phase 3, families received one to four visits on a monthly basis to plan the withdrawal of visits from the speech-language pathologist and to discuss options for the child to attend a playgroup or nursery.

Results of this study were reported in two ways. The first measure was taken on the parents' opinions of the intervention program. To obtain this information, parents participated in semi-structured interviews and their answers were analysed thematically. A total of 34 mothers of the children receiving therapy were interviewed. All mothers reported that their child benefited from learning new things through the program, and 31 mothers (91%) reported that the family as a whole benefited from the program. A total of 30 mothers (88%) believed that the program helped them become more understanding of their child's difficulties and more patient when dealing with their child. On the other hand, 14 mothers (41%) did not like the video-recordings, 8 mothers (24%) wished there would have been more sessions, and 6 mothers (18%) were not satisfied with the withdrawal and transfer arrangement. In the end, all parents who completed the program said they would recommend it to other families.

The second set of outcome measures compared participants' scores before and after the program. Children were evaluated using the Psycho-Educational Profile – Revised (PEP-R; Schopler, Reichler, Bashford, Landing, & Marcus, 1990) which includes subscale tests in the following areas: imitation, perception, fine-motor, gross-motor, eye–hand, cognitive – non- verbal, and cognitive – verbal. The group that received therapy improved on all of these measures. Children also improved on the communication and daily living subscales of the Vineland Adaptive Behaviour Scale (Sparrow, Balla, & Cichetti, 1984), but some children showed more evident improvements than others. Children in the control group did not show similar improvements.

This study has a number of limitations, some of which the authors address. The amount of time mothers spent using the recommended therapy procedures was not specified and they did not keep any formal records of this information. This lack of specified time periods for the therapy may be the reason for the variation in progress within the group who received therapy. The study relied largely on parental assessment of progress, which may not have been an accurate source of evidence. The authors use the name "contrast group" instead of "control group" as the untreated group was not well controlled. Additionally, the mean age of the control group was higher than the mean age of the group receiving therapy.

This article confirms previous studies that home-based intervention approaches are beneficial to children with ASD, but fails to show how this program compares to other home-based approaches. Clinicians need to be aware that this study fails to outline the amount of time home-based intervention is needed for progress, and the many factors that may have played into the group receiving therapy. Further research needs to be done with a true control group, and with stricter guidelines for parents to follow.

References

Charlop-Christy, M. H., Carpenter, M., Le, L., Leblanc, L. A., & Kellet, K. (2002). Using the picture exchange system (PECS) with children with autism: Assessment of PECS acquisition, speech, social-communicative behaviour, and problem behaviour. *Journal of Applied Behaviour Analysis*, *35*, 213–231.

Crawford, H., Doherty, K., Crozier, B., & Cassidy, A. (2006). *The Keyhole Early Intervention Programme*. Belfast: Autism Northern Ireland.

Sparrow, S., Balla, D., & Cichetti, D. (1984). *Vineland Adaptive Behaviour Scales*. Circle Pines, MN: American Guidance Services.

Schopler, E., Reichler, R. J., Bashford, A., Lansing, M. D., & Marcus, L. M. (1990). *Psycho-Educational Profile-- Revised (PEP-R)*, Volume I. Austin, TX: Pro-Ed.

Speech pathology resources

Amaze (2011). *Picture my world*. Carlton South, Vic.: Author; Cards, display board, and information guide; A$70; www.amaze.org.au

Diane Jacobs

Picture My World is a series of 20 coloured picture cards comprising 10 different feelings and emotions (10 male and 10 female picture cards) that has been developed for use by individuals with limited communication skills and for individuals who exhibit difficulty expressing emotions. The picture cards are a good size (8 cm x 11 cm) and made from a sturdy laminate that should ensure durability. The aid also comes with an A3-sized board with plastic pockets that enables up to eight picture cards (those provided with the resource or a combination of the resource cards plus other cards tailored to the needs of the individual) to be simultaneously displayed.

While the 10 cards have designated emotions, they are not prescriptive, with flexibility for the pictures to be identified as other emotions. This is requisite as the reviewer and a peer could not agree upon all the emotions displayed within the picture cards. As such, when using the cards it will be vital to clarify each user's interpretation of the emotion cards in order to prevent communication breakdown.
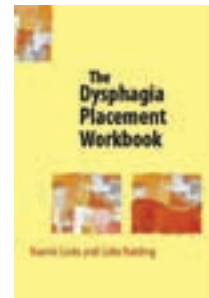
The cards come with an information guide identifying a non-exhaustive range of uses for the emotion cards. Additionally, the cards are colour coded with green being used to describe so-called "positive" emotions and red "negative" emotions. The reviewer is not convinced of the utility of such terminology and the concept that emotions such as "angry" and "scared" are "negative". Rather, encouraging and promoting the expression and communication of feelings and emotions as experienced by the individual per se is the goal, and these cards will be suitable for such a use by some adolescents and adults.

Overall, it is believed that the cards will be a useful adjunct to assist individuals with the understanding and expression of emotions. It is however recommended that inspection occurs prior to purchase to ensure that the cards are suitable for the identified client/s.

Cocks, N., & Harding, C. (2011). *The dysphagia placement workbook*. Croydon, UK: J & R Press; ISBN 978 1 907826 05 4; pp. 115; A$28.31 (£15) plus postage and packing; www.jr-press.co.uk

Julie Cichero

The Dysphagia Placement Workbook is a small, lightweight companion that will travel well from lectures to hospital ward. Careful design is evident with two pre-placement quizzes on general dysphagia knowledge, oral hygiene, and aspiration pneumonia. Provision is made for both UK and Australian speech language pathology students. Care has been taken to combine important information from the Royal College of Speech and Language Therapists and Speech Pathology Australia. In addition to pre-placement quizzes, the book contains 14 placement activities designed to educate and engage students, while also offering opportunities for reflection. Lined pages provide opportunity to write responses directly onto the book. No two books will be exactly the same, as students are required to reflect upon cases they have seen under supervision.

Each section begins with a list of resources in the form of journal articles and websites. Supervisors will benefit most from this book if they collate resource lists for students to read prior to observations or practical tasks. It is anticipated that students would need at least one hour to review the resource material prior to completing activities.

The workbook also makes use of role-plays in recognition that patient safety comes first. For example, in addition to completing an oro-motor assessment on a colleague prior to patient contact, students are prompted to reflect and write "if they had the opportunity to do the task again, what would they do differently?". Other novel learning techniques include: prompting to write a script with a colleague about how to deliver "bad news" (e.g., that the client can't eat or drink) after a videofluoroscopy. Although efforts have been made to include paediatric resources for many of the sections, the book is probably best suited for adult clients. It is not setting specific. The workbook is designed to operate in conjunction with a textbook by the same authors: *Developing Clinical Skills in Dysphagia: A Guide for Speech and Language Therapists*.

The 14 activities covered include essential elements such as general observation and communication status, mealtime observation, information gathering, oral motor assessment, oral trials, and information on thickened liquids, modified diets, and non-oral feeding. In addition, clinical documentation, management and working with others is covered. Instrumental assessment such as videofluoroscopy and fibreoptic endoscopic evaluation of swallowing is addressed. A dysphagia placement checklist completes the book, with a place for the supervisor to provide comment on each activity, sign, and date.

JCPSLP notes to authors

The Journal of Clinical Practice in Speech-Language Pathology (*JCPSLP*) is a major publication of Speech Pathology Australia and provides a professional forum for members of the Association. Material may include articles on research, specific professional topics and issues of value to the practising clinician, comments and reports from the President and others, general information on trends and developments, letters to the Editor, and information on resources. Each issue of *JCPSLP* aims to contain a range of material that appeals to a broad membership base.

JCPSLP is published three times each year, in March, July, and November.

Issue	Copy deadline (peer review)	Copy deadline (non-peer review)	Theme*
Number 1, 2013	3 August 2012	15 October 2012	Computer-assisted assessment and intervention
Number 2, 2013	6 December 2012	1 February 2013	Clinical education
Number 3, 2013	14 April 2012	30 June 2013	TBA refer to our website

* articles on other topics are also welcome

General

Material submitted must be your original work. Any direct quotations or material used from other sources must be credited in full. If copyright clearance is required to use material included in your article, please supply evidence that this has been obtained.

With rare exceptions, we do not publish material that has already been published.

Articles will be checked by a copy editor to ensure consistent presentation and standard of English.

Length

Articles should not usually exceed 3500 words (including tables and references). This is equivalent to approximately 11 double-spaced pages. Longer articles may be accepted, at the discretion of the editors. For further information go to http://www.speechpathologyaustralia.org.au

Format

The article should be submitted electronically via email (as an attachment). One hard copy and a copy on disk (preferably in Microsoft Word) is required if the article contains symbols (e.g., phonetic font).

The title page should contain the title of the article, the author's name, profession, employer, contact phone number, and correspondence address, as well as a maximum of five key words or phrases for indexing. Please provide brief biographical details (up to 15 words) for all authors.

The format must be double spaced with 2.5 cm margins, in a serif face (such as Times or Courier), each page numbered sequentially.

CDs must be clearly marked with file name, author's name and program used, including version number and whether PC or Macintosh (e.g., MS Word 2007). Each table or figure must be in a separate file on the disk. Do not incorporate figures or tables within the text of the article. Formatting must be kept to a minimum. Do not use tabs, bold, or other highlighting of the text. References must appear at the end of the article. The first line of each paragraph should be indented. Do not right justify the text. Use one space after punctuation, including full stops. Double quotes should be used.

Peer review

Articles submitted to *JCPSLP* generally undergo a double-blind peer-review process. The article will be sent to two expert reviewers. The authors will be provided with information from the review process and will be invited to revise and resubmit their work if this is indicated. The sentence "This article has been peer reviewed" will appear after the title for all peer reviewed articles.

Style

Clear and concise writing is best. Use short sentences and paragraphs and plain English.

Reproduce any quotations exactly as they appear in the original and provide the page number(s) for the pages you have quoted from.

References, which should be kept to a minimum, should follow the American Psychological Association (APA 6th ed.) style.

The title should be kept as short as possible (maximum 80 characters).

Headings should be short. Within the article a maximum of two levels of headings should be used. For first level headings use all capitals, centred with one line space above and one line space below. For second level headings use a capital letter for the first letter of the first word only, centred with one line space above and one line space below.

Tables and figures

If there are to be tables or figures within your article, these should be printed on separate sheets with a clear indication of where they are to appear in the article. All tables and figures should be numbered. Figures should be presented as camera-ready art. Do not incorporate tables or figures within the text of the article. Digital images should be sent as uncompressed TIF or EPS files.

Abstract

Please include an abstract of approximately 100 words describing your article.

Photograph

Please include a clear photograph of yourself. This can be a casual or formal shot. A good quality print or slide is acceptable. These should be labelled with your name on a sticky label on the back. To avoid impressions damaging the back of the photo, write on the label before it is attached to the photo. Digital photos should be JPEG files (>120kb).

Article submission form

If your article is accepted for publication, it will only be published if the "Article Submission Form" and "Copyright Warranty and Assignment" are completed and signed (please contact National Office for these forms) or go to

http://www.speechpathologyaustralia.org.au/publications/jcpslp

Send articles marked Attention *JCPSLP* Editor to:
Speech Pathology Australia
Level 2 / 11–19 Bank Place
Melbourne, Victoria 3000

Alternatively, send articles to the Editors:
Marleen Westerveld – m.westerveld@gmail.com
or Kerry Ttofari Eecen – k.ttofarieecen@gmail.com