



Journal of Clinical Practice in
Speech-Language Pathology

Volume 18, Number 2 2016

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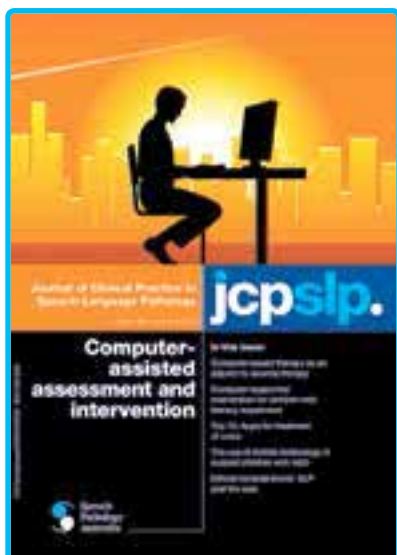
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Speech Pathology Australia

Level 1 / 114 William Street,
Melbourne, Victoria 3000
T: 03 9642 4899 F: 03 9642 4922
Email:
office@speechpathologyaustralia.org.au
Website:
www.speechpathologyaustralia.org.au
ABN 17 008 393 440 ACN 008 393 440

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Number 1, 2017
1 August 2016
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Number 3, 2016
17 August 2016
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(including GST). No agency discounts.

Reference

This issue of *Journal of Clinical Practice
in Speech-Language Pathology* is cited
as Volume 18, Number 2, 2016.

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From the editor

David Trembath

The advent of the National Disability Insurance Scheme (NDIS) represents a fundamental shift in the way in which services for individuals with lifelong disability are funded, accessed, and provided. In principle, the NDIS will see control of allocated funds shift from organisations to individual participants within the scheme, allowing them to choose from the range of services available in their location. For speech-language pathologists and other allied health practitioners, these changes present tremendous opportunities, but also challenges, which together are the focus of this issue.

Hines and Lincoln open the issue with a timely reflection on how the NDIS funding model might impact on the training, recruitment, and retention of SLPs in the disability sector. They challenge colleagues in both university and workplace settings to develop innovative clinical placement and continuing professional development models to ensure a sufficiently large and capable workforce. Simpson and Douglas review research examining the impact of self-directed funding models, similar to that being applied in the NDIS. They note that reported benefits (e.g., greater flexibility and autonomy) are off-set partially by associated challenges (e.g., administrative burden on families) and call for higher quality research examining the impact on individuals and families. Johnson and West present strategies for addressing key challenges to individuals with complex communication needs participating in the NDIS planning process.

Two articles address the issue of information access and accuracy, including associated impacts on practice. In the first, Anderson and Andres evaluate the relevance, scope, and credibility of online information about augmentative and alternative communication. Westerveld leads an article examining common misconceptions regarding reading development in children with autism spectrum disorder, arguing for alternative interpretations. Finally, Olsson and Johnson round out the set of articles relating to the NDIS theme by elucidating emerging ethical issues for SLPs working with participants in the scheme. A further three articles – examining phonological awareness of skills of higher education students, communication partner training for nurses, and prognostic and predictive factors in stuttering – along with regular columns complete the issue.

When I commenced work in early intervention services for children with disability 15 years ago, I never dreamt I would see the roll out of a national scheme, supported by all mainstream political parties, with the expressed purpose of giving power to individuals with disability and their families, within such a short amount of time. Again, the opportunities are tremendous, and as presented in the articles herein, we as a profession must be agile, creative, and inspiring in the way we embrace and shape the new way of working as experts in the field.



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Boosting the recruitment and retention of new graduate speech-language pathologists for the disability workforce

Monique Hines and Michelle Lincoln

KEYWORDS
CLINICAL PLACEMENTS
CONTINUING PROFESSIONAL DEVELOPMENT
DISABILITY WORKFORCE
NATIONAL DISABILITY INSURANCE SCHEME
UNIVERSITY STUDENTS

THIS ARTICLE HAS BEEN PEER-REVIEWED

New graduate speech-language pathologists (SLPs) will play an integral role in meeting the anticipated growth in demand for a highly skilled disability workforce under the National Disability Insurance Scheme (NDIS). However, NDIS implementation will have major implications for factors known to support new graduate recruitment and retention in the disability sector. In this article, we consider how the NDIS is likely to affect (a) clinical placements in disability while at university, and (b) access to clinical supervision and continuing professional development (CPD) in the workplace, and propose strategies to address these challenges.

The introduction of the National Disability Insurance Scheme (NDIS) will stimulate a rapid growth in demand for disability staff (Productivity Commission, 2011). It is estimated that full NDIS implementation will require the disability workforce to nearly double in size, with highest growth in demand expected for allied health (NDIS, 2015). Thus, a high-quality allied health workforce, including speech-language pathologists (SLPs), with requisite skills, knowledge, and values is a cornerstone to the realisation of the NDIS vision to improve the lives and promote community inclusion of people with disability.

New graduates of Australian allied health programs will undoubtedly constitute a key source of entrants to this expanded disability workforce. In order to work within the evolving disability sector, new graduate SLPs will need to demonstrate a range of foundation skills, knowledge and values that enable them to deliver supports that emphasise individual choice and control, participation, and inclusion (Breen, Green, Roarty, & Siggers, 2008). With NDIS principles emphasising access to mainstream environments and capacity development (NDIS, 2015), SLPs will need to adopt a range of roles in addition to direct service provision, such as consultants, educators, and indirect service providers. Working as a member of a transdisciplinary team in the disability sector will require strong communication skills and the ability to oversee therapy implemented by other team members. These service delivery models will mean that SLPs must learn to think differently about their primary clinical roles and practice accordingly. Adequate

preparation, orientation and support of new graduate SLPs to work under the NDIS will therefore need to reinforce aspects of clinical practice that will be essential within this new environment.

How will the disability sector change?

The disability service system within which future new graduate SLPs will practice will be markedly different to the previous one. Currently, disability services are provided predominantly either through government-based programs, or through of government block-funding contracts with not-for profit organisations. However, the NDIS will enable individualised and person-centred funding arrangements with the aim of enabling choice and control for people with disability over the supports they receive. It is anticipated that a wider diversity of providers will enter the disability sector. These will include private practitioners, for-profit organisations, and providers from other sectors, such as health and aged care who may not have a history of expertise in disability support provision (NDIS, 2015). The role of government-based providers will vary from state to state. For example, in New South Wales the existing provider of disability supports, Ageing Disability and Home Care, will cease operations before NDIS full implementation, resulting in disability service provision being available solely via not-for-profit and for-profit organisations and private practitioners.

This major shift in delivery of disability services will have far-reaching effects on all aspects of the sector, and has major implications for the preparation of new graduate SLPs. In this paper, we consider implications of the NDIS on two important factors known to influence recruitment and retention of new graduate SLPs in the disability sector: (a) clinical placements in disability while at university; and (b) access to clinical supervision and continuing professional development (CPD) in the workplace. Understanding how NDIS implementation will impact these domains will help to identify ways in which to best prepare new graduates for working in disability and ensure that there is a quality, NDIS-ready workforce ready by full implementation and into the future.

Clinical placements in disability Why are placements critical?

High-quality clinical placements are essential for the ongoing development and viability of the speech-language



Monique Hines (top) and Michelle Lincoln

pathology profession (Speech Pathology Australia [SPA], 2005). Clinical placements help to prepare students for the workplace by reinforcing concepts taught in lectures, and allow students to practise clinical skills and develop interpersonal skills and reflective practice (SPA, 2005). Learning facilitated by clinical placements can be generalised across workplace settings (Sheepway, Lincoln, & McAllister, 2014); however, there may be unique benefits of clinical placements within disability settings.

An essential component of preparation for working in disability is the development of positive attitudes towards people with disability (Balandin & Hines, 2011). In transferring learning about disability from lectures to clinical practice, Shakespeare and Kleine (2013) assert that students need time to critically reflect on their learning experiences and 'emotional reactions to disability' (p. 33), opportunities which may be provided by clinical placements within the sector. Placements also help to improve students' attitudes and level of comfort in working with people with disabilities (Karl, McGuigan, Withiam-Leitch, Akl, & Symons, 2013). Consequently, they are a critical factor in the recruitment of new graduates into the disability workforce, and in positioning this sector as their preferred employment option (Balandin & Hines, 2011; Johnson, Bloomberg, & Iacono, 2008). An effective workforce strategy for the speech-language pathology disability sector must address how to facilitate sustainable, quality clinical placements for students and address barriers to the availability of clinical placements likely to arise as a result of NDIS implementation.

How will placements be affected by the NDIS?

Availability of clinical placements is affected by changes to the speech-language pathology sector (McAllister, 2005). As SLPs focus on learning new skills and new ways of working themselves, they may be less likely to make themselves available to supervise students. Although clinical placements are beneficial for supervising clinicians (Thomas et al., 2007), it is not mandatory, so cutting clinical placements may be used to minimise pressure during times of significant change. Although it is not known what the actual impact of the NDIS on student placements will be, it is possible to anticipate effects on clinical placements, related to (a) funding, and (b) the nature of service providers under NDIS.

Funding

Under the previous disability service system, clinical placements in disability were primarily provided by government-based or large not-for-profit disability providers. Within this model, universities worked to organise clinical placements in partnership with disability service providers according to their capacity to take students. Funding for both student-delivered services and clinicians' time spent in supervision were covered by government block-funding arrangements. In some cases, government-based and not-for-profit providers developed student units that focused on promoting student learning in disability, including in the coordination and resourcing of clinical placements.

Under the current NDIS funding model, however, student supervision and clinical placements do not attract direct funding. Further, there is no separate pricing structure for student-delivered services, so there is presently no incentive for NDIS participants to consent to using their funding to

purchase student-delivered services at the same price as services delivered by experienced SLPs. To take students on clinical placement, it appears that service providers will need to build into their business models mechanisms that recover costs associated with clinical placements, including their own time spent in student supervision. This will be further complicated by challenges arising from the nature of disability providers under NDIS.

Who will provide clinical placements?

The move to individualised funding under NDIS will increase pressure on SLPs to maximise the number of billable occasions of service in order to maintain the viability of their positions in not-for-profit organisations or private practice. Private providers of disability supports are likely to proliferate under NDIS (NDIS, 2015), yet already face considerable challenges taking students for placements. These include supporting clients' rights to choose their clinician, ambiguous and inconsistent Medicare and health insurer requirements for rebates of student-delivered services, and ensuring adequate income is sustained while providing clinical supervision (McAllister, 2005). Without viable business models, SLPs may believe that time taken away from direct client contact in student supervision compromises their ability to produce billable hours for their employers or themselves. Despite research demonstrating that students on placement can increase productivity (Hughes & Desbrow, 2010; Ladyshevsky, Barrie, & Drake, 1998), such perceptions may have a negative impact on SLPs' willingness to offer clinical placements.

Potential solutions

Given the importance of clinical placements in disability for recruitment to the sector, new models of student placements are required that meet workplace and educational needs and are financially sustainable under the NDIS. Tools to support NDIS participants to make informed choice about student involvement are also needed to facilitate placements.

Emerging innovative models

Anecdotally, there are some emerging innovative models of clinical placements in private practice within speech-language pathology and in other disciplines. For instance, private practices may provide clients with incentives to choose services provided by students on clinical placement, such as providing them with longer or additional sessions. Some private practices agree to share students on clinical placements with another site to minimise the workload associated with clinical supervision. However, more needs to be done to ensure lessons learned from these models are communicated to encourage uptake and incentivise student placements across the sector. Universities in particular are well placed to showcase and share knowledge and experience in using innovative placement models in the disability sector.

Although there are challenges to the availability of clinical placements under NDIS, there are also opportunities for unique and nonstandard student placements supported by emerging roles. For instance, placements with NDIS planners may provide students with an opportunity to develop knowledge and skills required for working within the NDIS environment, including researching interventions and service options for participants, developing resources, and interacting with clients and caregivers. Similarly, placements with allied health assistants may provide unique opportunities for peer-to-peer learning and experience with

service delivery models that are likely to have a role in the evolving disability sector. Where such placements occur in rural and remote areas, clinical placements may also act to ensure coverage and continuity of service provision in areas that have historically faced considerable inequity (Dew et al., 2014). Rural and remote placements could be supported by telesupervision with SLPs at a distance (Wood, Miller, & Hargrove, 2005).

The viability of innovative clinical placement models will require significant support from both universities and the National Disability Insurance Agency to ensure supervisors have skills and resources to support optimal student learning. Additionally, for less intense models of supervision to be feasible, policies across NDIS, Medicare, and private health insurance need to be developed to clarify rebates for student-delivered services, and specify requirements for supervision for safe and competent practice in the disability sector.

Supporting participant choice and control

Aside from ensuring the sustainability of clinical placement models, attention must also be paid to supporting participant choice and control. Regardless of the model of clinical placements used, NDIS participants must be supported to provide informed consent to student involvement in delivery of their supports, and have the right to decline without it affecting the services they receive. To achieve this, person-centred tools are required that enable SLPs to negotiate with clients student involvement in their care. These tools may support uptake of student-delivered services.

Cost-benefit analyses

There is no evidence to suggest that one model of clinical education is superior to any other in terms of student learning outcomes (Lekkas et al., 2007). Research is required that provides a cost-benefit analysis of student placements for various models, and for different organisational settings. This information will ensure that disability providers are able to make evidence-based decisions regarding the financial and workplace implications of student placements, and may help to incentivise student placements for organisations concerned about the implications of activities not considered 'core business'.

Clinical supervision and continuing professional development

Why are they critical?

While Australian university speech-language pathology programs include units covering foundation disability concepts, and some students participate in clinical placements in the disability field as part of their studies, new graduate SLPs working in disability have traditionally required access to clinical supervision and CPD on-the-job to address essential clinical competencies. For instance, although transdisciplinary practice is a key feature of contemporary disability service provision (Dew, De Bortoli, Brentnall, & Bundy, 2014), it is not considered an entry level competency for SLPs in Australia (SPA, 2009). Likewise, although features of family-centred practice are expected competencies for entry level SLPs (SPA, 2011), new graduates are likely to require support to adopt family-centred philosophies into clinical practice in the complex area of disability (Espe-Sherwindt, 2008). SLPs also vary

considerably in their understanding of, and confidence with augmentative and alternative communication as a result of limited pre-professional training (Balandin & Iacono, 1998; Iacono & Cameron, 2009), and therefore require clinical supervision and CPD to facilitate effective practice. Consequently, workplaces have historically played a critical role in provision of support to SLPs to adopt the philosophies underpinning best practice in disability.

Studies also consistently underscore the importance of regular, quality supervision by experienced allied health professionals (AHPs) and guaranteed access to CPD as being influential in both recruitment and retention of new graduates to the disability sector. Denham and Shaddock (2004) found that the need for regular professional supervision, among other factors, had a vital influence on recruitment and retention of AHPs in disability. Similarly, Lincoln et al. (2014) found that access to CPD and supervision and mentoring from experienced AHPs was perceived to promote retention in the rural allied health disability sector in New South Wales. In particular, new graduates were attracted and retained in jobs where continuing CPD was guaranteed. Lincoln et al. (2014) found that retention and job satisfaction in the disability sector was threatened by embarrassment and frustration regarding the inability to meet the needs and expectations of clients, waiting lists, and lack of services, along with onerous management and administration systems. These findings suggest that strong mentoring may be needed to help new graduate SLPs cope with and adjust to the workplace context to prevent burnout and disillusionment.

Taken collectively, research suggests that clinical supervision from SLPs experienced in disability and access to CPD will be essential to attract new graduates to the disability sector, and to retain them in the workforce. Clinical supervision and CPD may pay dividends in terms of boosting the quantity and quality of the speech-language pathology disability workforce required to meet expected demand for services under the NDIS.

How will they be affected by the NDIS?

Access to clinical supervision and CPD will play an important role in development of a highly skilled speech-language pathology disability workforce. However, new arrangements under the NDIS have implications for (a) how clinical supervision and CPD is funded, and (b) who will provide them.

Funding

Historically, access to clinical supervision and CPD for new graduates has been largely dependent on the support of employer organisations or, for private practitioners, self-funded. Under block-funding arrangements, managers allocated funding or approved role release for new graduates and other employees to attend supervision or CPD. Government-based and larger non-government disability organisations have typically had the capacity for senior staff to supervise and mentor less experienced colleagues, though, not all not-for-profit organisations have had this capability (Lincoln et al., 2014).

Under NDIS, time or expenses to engage in clinical supervision for both supervisors and supervisees will not be funded. Moreover, when engaging in, providing, or travelling to CPD or clinical supervision, employees are not able to produce NDIS-billable hours for employers. It is likely that new graduates, being most dependent on access to clinical supervision and CPD, will have less time available to them

to produce billable hours for their employers and maintain the viability of their own positions. Further, the cost to organisations of releasing senior SLPs from their roles to provide clinical supervision to less experienced staff may be disproportionate to the potential billable hours they could generate for the organisation in the equivalent amount of time.

In many cases, CPD is the responsibility of individual clinicians as an investment in their own careers. However, access to CPD may help disability providers to ensure that their staff deliver quality supports. Long-term investment in staff through CPD may also support retention of expertise within disability service organisations. There needs to be careful attention to the development of viable business models that provide new graduates, and indeed all employees, with ongoing access to quality supervision and CPD. This is particularly important for rural and remote areas where the cost of attending CPD is greater due to travel.

Who will provide clinical supervision and CPD?

Access to disability expertise will become essential for the delivery of frontline supports consistent with best practice and capacity development of new graduates. However, as government-based providers leave the disability sector prior to full implementation of the NDIS, there is a risk that the sector's most experienced members may similarly leave the sector rather than transition to not-for-profit or private providers (NDIS, 2015). This potential drain of expertise from the sector may have a variety of impacts, not limited to lack of access to individuals able to provide new graduates with the necessary supervision and support they require.

New graduates may face additional challenges to accessing clinical supervision and mentoring depending on the type of employer organisation. While employees of larger not-for-profit organisations with a long history of disability service provision may have ready access to experienced colleagues, the increased entry of providers without specific expertise in disability (NDIS, 2015) may make these avenues of support more difficult to source. The increased casualisation of the disability workforce, with AHPs increasingly working under contractual arrangements, may result in new graduates not having timely access to training, supervision and mentoring. New graduates may become increasingly responsible for their own CPD, yet may not have the knowledge, skills and connections within the field to meet these needs.

Potential solutions

Sustainable solutions for provision of clinical supervision and CPD are required to support development of a fit-for-purpose speech-language pathology disability workforce. There are various examples of innovation that have the potential to be developed and become integral elements of disability service design under the NDIS.

Communities of practice

Communities of practice (CoPs) have been described as "groups of people who share a concern or a passion for something they do and learn how to do it better as they interact regularly" (Wenger, 2015, p. 1). When applied to speech-language pathology, CoPs provide SLPs with learning structures and connections to their peers that allow them to engage in shared learning and promote good practice. New graduates may need to be supported to identify CoPs that match their CPD goals. It may also be necessary to establish and support new CoPs focused on

specific practice areas, such as transdisciplinary practice. CoPs can be developed face-to-face or virtually via online forums and digital hubs. This feature highlights a further potential solution to clinical supervision and CPD: accessible, technology-enabled disability resources.

Learning and teaching resources in disability

SLPs, both new graduates as well as established clinicians entering the disability sector, require accessible CPD and resources to assist them to develop foundational skills, knowledge, and attitudes required to deliver quality supports under the NDIS. Technology-enabled CPD, such as resources accessible via centralised online repositories, online courses, and webinars, not only ensures that new graduates have timely access to targeted resources, but may help to ensure equity in access for SLPs working in disability in rural communities. Accessible disability resources may help to minimise time away from billable clinical hours by eliminating the need to travel to attend training.

There are numerous examples of accessible resources in disability that may help organisations support CPD of new graduate SLPs but these are often fragmented and numerous gaps exist. The need for ongoing disability resource development highlights a unique opportunity for disability organisations to capitalise on their expertise as providers of CPD for new graduates across the sector.

Development of alternative models for clinical support provision

New graduate SLPs employed across a range of organisations will require access to quality clinical supervision. Schemes that provide access to senior clinicians via videoconferencing may support new graduates employed in organisations without experienced senior SLPs, and may be a mechanism by which expertise within the sector is recognised and distributed.

Disability service providers will need to ensure business models are sustainable and take account of costs associated with clinical supervision and CPD, including time spent engaging in these activities. Innovative models of workforce support and development for private practice need to be considered. Examples that may have merit for speech-language pathology are business models where principal clinicians subcontract work to individual private providers, and provide subcontractors with training and support in evidence-based practice. This model, previously reported for occupational therapy (Goldenberg & Quinn, 1985), allows a consortium of evidence-based practitioners to build over time. Other similar business models may similarly have potential for the disability speech-language pathology sector.

Conclusion

SLPs play important roles in supporting people with disability to maximise their potential and live the best life possible. Yet, without attention to strategies that support recruitment and retention of new graduate SLPs to the disability sector, there may not be a highly skilled workforce in place to provide these necessary supports. Specially, strategies that enable (a) clinical placements in disability while at university, and (b) clinical support and CPD will be essential to boosting the quality and quantity of new graduate SLPs in disability. Innovations in these areas are emerging, and must continue to be explored and developed with full implementation of NDIS in mind.

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Dr Monique Hines is a speech pathologist and postdoctoral research associate at the Faculty of Health Sciences, The University of Sydney. **Prof Michelle Lincoln** is a speech pathologist, researcher, and deputy dean at the Faculty of Health Sciences, The University of Sydney.

Correspondence to:

Dr Monique Hines

Faculty of Health Sciences, The University of Sydney

phone: +61 2 9351 9050

email: monique.hines@sydney.edu.au



An examination of the impact of self-directed funding models on children with disabilities

Andrea Simpson and Jacinta Douglas

In this paper, we report the results of a systematic review to examine self-directed funding (SDF) models specifically in the context of families with children with disabilities. The review identified 12 studies of relevance to the question of interest. The overall quality of the studies reviewed was relatively poor as rated by quality appraisal tools, with all papers receiving scores in the low-to-moderate range. However, papers were fairly consistent in reporting that SDF schemes provided families with a greater sense of flexibility and autonomy, as well as greater social participation. The potential for greater administrative burden, a lack of available information in what to choose or how to spend funding, and a limited number of services on which to spend funding were also major themes. However, despite the popularity of SDF models, the research-based evidence supporting the usage of these models on families of children with disabilities has not yet been established.

Self-directed funding (SDF) models for persons with disabilities refers to individuals being assigned responsibility for managing a personalised support package. The recent implementation of the National Disability Insurance Scheme (NDIS) in Australia is one example of a self-directed approach to disability funding.

By far, the biggest advantages of SDF programs appear to be that they provide greater choice and greater flexibility. The autonomy in deciding what support services are needed, when they are needed, how often they are needed, as well as the ability to select and hire personal carers have been frequently cited as reasons for the high levels of satisfaction with SDF models (Mahoney, Desmond, Simon-Rusinowitz, Loughlin, & Squillace, 2002). Although outcomes for SDF models have been fairly comprehensively researched in adults (Caldwell & Heller, 2003; Glendinning et al., 2009; Glendinning et al., 2008; Heller, Miller, & Hsieh, 1999), the question of how self-directed funding impacts on children and young people with disabilities has been largely overlooked.

The authors were interested in what, if any, impact SDF has had on the way families with children with disabilities functioned. A systematic review of the published literature on SDF in families of children with disabilities was carried out with particular reference given to outcome-based, rather than descriptive studies. The review attempted to answer the following research questions:

- What is the impact of SDF support models on families with children with disabilities? and
- What is the research-based evidence that underpins SDF support models for families with children with disabilities?

The results of the review together with an analysis of findings are reported below.

Method

A systematic literature search was conducted using the following databases: Medline (Ovid), CINAHL (EBSCO), Proquest, the authors' university's library search engine, Google, and Google Scholar. A hand search of reference lists from articles of interest was also completed. Exact search terms entered into the databases included the following:

- Concept 1: Population: "children with disability*" OR "child* with a disability*" OR "disabled child*" OR "child* with special needs" OR "child* with complex needs" OR "child* with additional needs" OR "handicapped child*" AND
- Concept 2: Intervention: "individual budget*" OR "self-managed fund*" OR "self-directed support*" OR "direct funding" OR "individual* fund*" OR personal*ation OR "personal budget*" OR "cash for care" OR individual*ation OR "person cent* care" OR "person cent* plan*"

In order to be included in the review, papers had to meet the following criteria:

- the paper included families or caregivers of dependent children or young adults with disabilities with the age of the children or young adults in the study stated as having a mean age of under 21 years at the time of publication;
- the full article was available in English; and
- the paper described at least one impact or outcome of SDF models on families of children or young adults with disabilities.

Table 1 shows the databases searched together with results. Potential studies were appraised for eligibility by the first author. A second reviewer examined the abstracts of

KEYWORDS

CASH FOR CARE

DISABILITY

INDIVIDUAL BUDGETS

PERSONALISATION

SELF-DIRECTED FUNDING

THIS ARTICLE HAS BEEN PEER-REVIEWED



Andrea Simpson (top) and Jacinta Douglas

these studies independently to determine if they met the inclusion criteria. Both the first author and reviewer needed to agree on including a study, with a total of 12 studies selected for final analysis.

Table 1. Results from search strategy (search by keyword, abstract and/or title)

Database	No. of initial papers/articles	No. after removing duplicates and applying inclusion criteria	After reading in full
MEDLINE (Ovid)	8	2	1
CINAHL (Ebsco)	8	3	–
Proquest Central	29	1	–
Google Scholar	63	11	4
University library search engine	130	9	3
Google.com.au site:gov.au	31	4	–
Google.com.au site:edu.au	25	2	–
Google.com.au site:gov	24	1	–
Google.com.au site:gov.uk	199	3	–
Hand search	7	7	5
Total	524	43	13

When assigning a quality score for each paper, the checklist developed by Downs and Black (1998) and recommended by West et al. (West et al., 2002) was chosen for quantitative and mixed-method study designs. For qualitative study designs, the Critical Appraisal Skills Programme (CASP) checklist for qualitative research was selected (CASP, 2014).

For each of the 12 studies, the first author and an independent reviewer worked through each checklist and assigned a rating for each paper independently with an average rating assigned to each paper. If the two reviewers differed in ratings, an average rating was calculated if the reviewers' independent rating values were no more than plus or minus two points of each other. If the difference between the two reviewers' rating values was greater than plus or minus two points, the authors discussed the paper and agreed on a rating.

Results

Results from the 12 studies are shown in Table 2. Methodologically, quality ratings were low for all studies. Ten of the studies obtained a quality score of less than 50 per cent and only one paper scored above 50 per cent. For the quantitative and mixed-method studies, only one of the 5 studies provided a statistical analysis of results. A control group was used in only one of the studies and no consideration to blinding or randomisation was given in any of the studies. Of the 5 qualitative studies, only 3 reported evidence of thematic data analysis and planning. A number of studies were also carried out by organisations with a

vested interest in SDF models which may have influenced the outcomes. First, the objective in carrying out the study may have been purely for operational or evaluative needs which may have narrowed the research question. Second, researchers would have had difficulty in being able to interpret findings objectively due to the context in which they worked. Overall, the current published evidence on the impact of SDF was found to be weak.

Despite the limitations of individual studies, when viewed together, a number of themes emerged, which are further described below.

Autonomy, flexibility and control

Families reportedly experienced benefits of greater involvement in decision-making for their child in 8 of the 12 studies. The most consistent reported positive benefit was families being able to choose what specific supports were best suited to their needs. This is best illustrated by Weaver (2012):

"It has been positive for the family in that we can be more flexible with Andrew's respite hours and we can utilise this as and when we need it. We no longer have the frustration of wasted allocated hours because we are in control."

Well-being and quality of life

Seven of the 12 studies reported an improvement to the well-being and quality of life either for carers or the children themselves. Robinson et al.'s (2012) study involving 37 families receiving funding through SDF found carers' average scores on the Personal Well-being Index (Cummins, Eckersley, Pallant, van Vugt, & Misajon, 2003) were on par with the general population and higher than a control group of carers not receiving SDF. As one caregiver describes: "Before the pilot he was very depressed and often spent much of the day in bed ... now he is tinkering in the garage all day ... it's giving him ambition and drive" (Robinson et al., 2012). Heller and Caldwell (2005) also reported favourable findings in favour of SDF models whereby families using SDF were significantly less likely to place their children in institutional care when compared to families on the waiting list to begin using SDF schemes.

Social participation

Eight of the 12 studies reported that families using SDF models had some positive outcomes in their social lives. Major areas identified were improved family relationships (e.g., Johnson et al., 2010), greater opportunities for carers to have a social life outside of caring (e.g., Robinson et al., 2012), and more openings for children to socialise in a variety of contexts (e.g., Crosby, 2010). This last benefit was attributed as a by-product of the flexibility SDF models gave families. Studies inferred that by having greater control over their daily life and what activities appealed to them, families were able to generate new opportunities for social networking for their children outside of the traditional service model (e.g., Blyth & Gardner, 2007).

"I do feel bad that I can't spend a lot of time with his sisters. It's tough for them but having the direct payments means I can take them shopping whilst he goes out with his uncle to play football. I love to see the girls so happy when they are enjoying themselves and not having to worry about their brother. It's a good release for them as well as me." (carer 28, Blyth & Gardner, 2007, p. 238)

Table 2. Summary of the 12 studies included in the review in order of study strength

Citation	Aim	Location	Sample size	Study design	Main findings	Strength/quality
Quantitative and/or mixed-methods study design						
Heller & Caldwell, 2005	To determine whether SDF decreases out-of-home placement, particularly institutional placement	Illinois, USA	N = 301 families with children with disabilities receiving SDF versus N = 835 families waiting to receive SDF	Statistical comparison of living arrangements of children with disabilities between those receiving SDF and those on waitlist to receive SDF	After controlling for minority status and age, individuals with disabilities receiving SDF were significantly less likely to be moved into an out-of-home placement ($p < .01$). 16% of participants on the waiting list were placed in institutional settings compared to 10% of participants receiving SDF	15/28 <i>Major weaknesses:</i> – Limited information on groups studied – Limited outcome data presented
Prabhakar, Thom, & Johnson, 2010 and Johnson et al., 2010	Evaluation of English national pilot program implementing SDF	<i>United Kingdom</i> Sites in Coventry, Derbyshire, Essex, Gateshead, Gloucestershire, and Newcastle	126 parents of children (aged 0–18 years) with a disability	Pre-post research design Purposefully developed survey Qualitative focus group interviews	<i>Parent outcomes (change pre- to post):</i> – Felt more informed (+23%) – Greater involvement in decision making (+24%) – Autonomy/control – flexibility (+51%) – Felt more supported (+40%) – Greater access to social care services (+53%) – Better quality of life for the child (+22%) – Improvements in parents' social life (+24%) and quality of life (+22%) <i>Challenges:</i> – Positive changes were dependent on socio-economic status – Administrative burden – Families not aware of all options	11/28 <i>Major weaknesses:</i> – No statistical analysis of results – No control group
Robinson et al., 2012	Evaluation of newly implemented SDF program	Sunshine Coast & Brisbane, Queensland, Australia	N = 37 families with children (aged 0–7 years) with disabilities	Personal Wellbeing Index (PWI) survey results at program entry and every 6 months thereafter including program exit Qualitative focus group interviews (N = 10)	<i>Outcomes</i> <i>PWI:</i> Mean score of 84 (comparisons given as the Australian general population mean score = 75, Australian carers = 59) <i>Qualitative themes: Increases/improvements in:</i> – Physical well-being & independence – Family members' resilience and independence – Autonomy/control – Social participation – Family participation – Access to mainstream services	11/28 (3.5/10 on CASP) <i>Major weaknesses:</i> – No control group – No randomisation – No blinding

Table 2. Summary of the 12 studies included in the review in order of study strength (continued)

Crosby, 2010	Evaluation of SDF for 'In Control' – an English non-profit organisation	Newham, England, United Kingdom	N = 47 parents of children with disabilities	In-house evaluation questionnaire	<i>Strongest outcomes, SDF "helped" or "helped a lot" in:</i> – Fit and healthy (78%) – Feelings and Emotions (85%) – Enjoying childhood (81%) – Taking part in school life (81%) – Household finances (73%) – Support in parenting role (78%) – Quality of life (73%) – Relationship with children (78%)	4.5/28 <i>Major weaknesses:</i> Methodological details missing, no statistical analysis, no blinding of participants/researchers, no control group
Crosby, 2011	Follow-up to Crosby (2010): Evaluation of SDF for 'In Control' – an English non-profit organisation	Various sites, England, United Kingdom	N = 67 parents of children with disabilities	In-house evaluation questionnaire	<i>Strongest Outcomes, 50% + improvement reported for (*individual results not provided):</i> – Fit and healthy – Feelings and Emotions – Enjoying childhood – Taking part in school life – Household finances – Support in parenting role – Quality of life – Relationship with children	5/28 <i>Major weaknesses:</i> Methodological details missing, no statistical analysis, no blinding of participants/researchers, no control group
Qualitative study design						
Dew et al., 2013	Evaluation of the impacts of SDF for people living in rural and remote areas	Rural western New South Wales, Australia	N = 8 mothers and 2 fathers of 14 children aged 2–8 years) with disabilities Five carers had 2 children with disabilities 13/14 children were diagnosed with autism, 1/14 children was diagnosed with cerebral palsy	Qualitative focus group interviews Grounded Theory Approach	<i>Four themes identified as barriers:</i> – Lack of information/advice – Limited availability and choice in local service options – Complexity of managing funds – Higher costs and fewer services	4.5/10 <i>Major weaknesses:</i> – Lacked justification for research design
Ottmann et al., 2009	Longitudinal evaluation of newly implemented SDF program	Melbourne, Australia	N = 12 parents of children (aged 0–20 years) with disabilities	Longitudinal qualitative participatory action research at the points in time: 6 months, 36 months, and 48 months post-enrolment	<i>Major themes identified:</i> – Greater sense of autonomy and independence – Improved flexibility and quality of care – Over time, felt greater sense of isolation, particularly at crisis points – Administrative burden and confusion – Perceived overall less funding available than prior to SDF	4.5/10 <i>Major weaknesses:</i> – Limited information on recruitment of participants

Table 2. Summary of the 12 studies included in the review in order of study strength (continued)

Blyth & Gardner, 2007)	Explore contributing factors leading to SDF take-up	North-west England, United Kingdom	N = 7 parents of children with disabilities	Qualitative semi-structured interviews Grounded theory approach	Major themes identified: – Reducing caregiver stress – Greater sense of autonomy & control – Greater sense of choice and flexibility in selecting additional supports – Greater social participation	4/10 <i>Major weaknesses:</i> – Limited information on data analysis
Weaver, 2012	Evaluation of SDF by the Integrated Disability Service, a support service for people with disabilities	Warwickshire, England, United Kingdom	N = 10 families with children aged 0–19 years) with disabilities	Qualitative semi-structured interviews	<i>Anecdotal reports of:</i> – Autonomy/control, confidence and independence – Greater social participation – Improved family and social relations – Improved emotional well-being – Not aware of available options to spend budget on – Limited choice on what to spend budget on	3.5/10 <i>Major weaknesses:</i> – Limited information provided on findings – No analysis of results
Welch et al., 2012	To explore families' motivations for and experiences of using SDF	United Kingdom Participants recruited from 21 Aiming High for Disabled Children Pathfinder authorities; and 2 Change Champion authorities	43 families who had received SDF subsample from N = 93)	Open-ended questions from self-administered questionnaire	Benefits to using SDF – Increased flexibility – Autonomy/control Process difficulties – Information – Eligibility – Assessment – Administration	3/10 <i>Major weaknesses:</i> – Unclear how the sample was selected – Methods of data collection unclear – Qualitative data analysis lacked rigour
Cowen, Murray, & Duffy, 2011	Evaluation of the use of SDF for young adults with complex needs exiting secondary school	Sheffield, United Kingdom	N = 23 young adults with complex needs and their families	Qualitative case studies	<i>Anecdotal reports of:</i> – Autonomy/control – Greater social participation – Employment gains	1/10 <i>Major weaknesses:</i> – Limited information on study design, recruitment and analysis
Donnelly & Brooke-Mawson, 2008	Pilot evaluation of the use of IBs for young adults with learning disabilities exiting secondary school	Bradford, Yorkshire, United Kingdom	N = 6 young adults with learning disabilities and their families	Qualitative case studies	<i>Anecdotal reports of:</i> – Greater sense of autonomy, control, and flexibility – Reduction in stress – Improved quality of life – Time management and cost a challenge – Limited choice of what to spend money on	0.5/10 <i>Major weaknesses:</i> – Limited information on study design, recruitment and analysis

Note. SDF = self-directed funding IB = Individual budgets

Administrative burden

Six of the 12 studies identified that the administrative process of managing SDF was a source of stress for families. The process was generally reported to be time-consuming and complex (e.g., Prabhakar, Thom, & Johnson, 2010), and resulted in feelings of confusion and frustration (e.g., Johnson et al., 2010). As quoted in Ottman et al. (2009, p. 471): "It is time-consuming finding out about activities and organizing them – the work of a case manager ..."

Lack of information and choice

Half of the 12 studies reported that while SDF offered families greater flexibility in how to spend funding, there was a very limited number of service options to spend it on. Options were particularly limited if families were based outside of major metropolitan hubs (e.g., Dew et al., 2013). Families also reported they received inadequate information on the options available to them at the time of receiving their funding (e.g., Dew et al. 2013).

Four of the 12 studies discussed how the positive outcomes associated with SDF were dependent on contextual variables. These variables include socioeconomic status, minority group status and geographical location, with poorer families, minority groups and families based rurally achieving poorer outcomes using SDF models. As stated by Dew et al. (2013, p. 437):

"the trend towards client directed funding [is] a great model [and] I think everyone supports it in principle, providers and consumers alike. In the metropolitan areas [there are] many, many different agencies to refer to, great choice for the consumer ... [but] in the real remote areas ... there might only be one provider in town."

Discussion

Generally, the results from this review are consistent with findings on SDF models on adults with disabilities. Numerous studies on SDF in the United States and United Kingdom have reported that users of these schemes report greater autonomy with SDF when compared to more traditional models of funding (Glendinning et al., 2009; Head & Conroy, 2005; Poll & Duffy, 2008). This review has found that for families with children with disabilities, the gains of autonomy and independence provided by SDF play out within the family dynamic. For caregivers, they are able to "purchase" respite breaks when needed and have greater involvement in the allocation of caregiving assistance. Caregivers are able to select activities that are more tailored to their child and family's needs. This perception of greater choice and control reportedly leads to other benefits, such as greater socialising, less tension within the family unit, and a higher sense of satisfaction with services.

In terms of offering greater choice, SDF models are reported as being moderately successful. However, greater choice has a flipside. There is some evidence to suggest that the more affluent a family is the more they will benefit from greater choice (Johnson, Thom & Prabhakar, 2010). Those families with children with disabilities in more affluent areas were more likely to rate their sense of control with SDF as higher than poorer families (Johnson, Thom, & Prabhakar, 2010). In addition, although providing choice reportedly provided a perception of freedom and autonomy, Schwartz (2004) has cautioned that too many choices can feel like a burden and create a sense of anxiety for families.

A number of studies in this review reported that the added administrative burden of managing choices with SDF was experienced as stressful and time-consuming (Johnson et al., 2010; Ottmann, Laragy, & Haddon, 2009).

In the context of this review, not all environments of SDF provided families with "meaningful" choices. For instance, two papers (Dew et al., 2013; Weaver, 2012) reported that families had limited options available to them on what to spend their funding on, and many of these options were already within the scope of what had been previously provided. In one study (Dew et al., 2013), these limitations were largely due to where families lived, with families in rural and remote areas having both limited choice in, and limited access to, disability services. Finally, meaningful choice was also highly influenced by information and the way such information was framed. Two papers (Johnson et al., 2010; Weaver, 2012) found that families of children with disabilities reported a general lack of information when it came to SDF. Caregivers were unsure what options and services were available to them, which impacted negatively on their ability to make the best use of their funding.

Conclusions

This article presents a systematic review of the literature on self-directed funding and families of children with disabilities. Across all studies the major reported positive themes for families using SDF were a greater sense of flexibility and autonomy, as well as greater social participation including improved relations within the family unit. A smaller number of studies reported additional benefits of gains in health, well-being and employment. Most studies were also fairly consistent in the types of challenges SDF produced for families. These challenges included the potential for greater administrative burden and the stress and time associated with this, a lack of available information in what to choose or how to spend funding, and finally a limited number of services on which to spend funding. However, the overall quality of the studies reviewed was relatively poor as rated by quality appraisal tools, with all papers receiving scores in the low-to-moderate range. Across the 12 studies reviewed, there was generally a lack of well-controlled methodological designs.

The findings of this review have a number of potential implications for practice. First, the research-based evidence supporting the outcomes of SDF on families of children with disabilities is relatively poor. Further rigorous research into the area is needed, particularly looking at comparing SDF against more traditional forms of service usage for these families. Second, knowledge and information will be an ongoing challenge as SDF models progress. Families will be under more pressure to obtain information themselves on what is available for their child and family as opposed to relying on professional referrals or advice. A question for families and services alike is how individuals will navigate through the plethora of information available in a digital age and which sources they will choose to trust and act upon.

Conflict of interest

The authors know of no conflict of interest in reporting this work. This work has not been presented at any meetings or conferences. Funding for this work was supported by internal funding at the corresponding author's institution.

Acknowledgements

The authors would like to thank Dr Carly Meyer for her time in independently reviewing the papers included in this study.

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Dr Andrea Simpson is a senior lecturer in Audiology with La Trobe University, Melbourne, Australia. **Professor Jacinta Douglas** is an internationally recognised researcher in the field of disability following brain injury based at La Trobe University, Melbourne, Australia.

Correspondence to:

Dr Andrea Simpson

School Allied Health

La Trobe University

Kingsbury Drive, Bundoora, Victoria, 3086, Australia

phone: +61 (03) 9479 1821

email: a.simpson@latrobe.edu.au



Meeting the planning needs of people with complex communication needs

Hilary Johnson and Denise West

KEYWORDS

ADULTS

COMPLEX COMMUNICATION NEEDS

NATIONAL DISABILITY INSURANCE SCHEME

PLANNING

THIS ARTICLE HAS BEEN PEER-REVIEWED

The introduction of the National Disability Insurance Scheme (NDIS) in Australia is changing service provision for people with disabilities. The scheme has been operating at trial sites since 2013 and will roll out nationally in 2016. The aims of this paper are to explore some of the current challenges presented by this scheme in the provision of services for adults with complex communication needs and provide recommendations for change. Examples of lifestyle planning are outlined and essential elements highlighted to ensure adults with complex communication needs successfully identify their goals and receive the reasonable and necessary individualised supports they require in order to achieve life goals. Recommendations for the NDIS include specialised training for planners and inclusion of the person with complex communication needs in the process. Recommendations for speech pathologists include developing appropriate communication tools and resources for planners, individuals with complex communication needs, and advocates.



Hilary Johnson (top) and Denise West

Service provision for people with severe disabilities is rapidly changing within Australia due to the National Disability Insurance Scheme (NDIS). The National Disability Insurance Agency (NDIA) is an independent statutory agency, whose role is to implement the NDIS. A Commonwealth Government initiative, the NDIS was set up to redress the inequities people with disabilities face in receiving supports that have been described as “inequitable, underfunded, fragmented, and inefficient” (Productivity Commission, 2011, p. 2). The NDIS aims to improve outcomes for people with a disability through what was initially termed a three-tiered model. Tier 1 is aimed at all Australians to create more inclusive opportunities for people with a disability (Productivity Commission, 2011, p. 11.) Tier 2, now renamed Information, Linkages and Capacity Building (ILC), targets approximately 800 000

people with a disability. The ILC aims to build community awareness and capacity building, assist primary carers or families to obtain information or referrals for service through mainstream services and community support groups, and provide local area co-ordination. Tier 3 is focused on providing individualised funded packages (IFPs) to enable eligible people with disability to receive the *reasonable and necessary supports* to achieve life goals. Funding will be provided to 460 000 people with a disability who need specialised individualised supports determined through a planning process (New South Wales Government, 2015). The IFPs have been piloted for eligible participants since July 2013 at various sites across Australia, with the full scheme scheduled to progressively roll out across New South Wales, Victoria, Queensland, South Australia, Tasmania and Northern Territory from July 2016 until 2019. Many of the participants targeted to receive individual support packages in the NDIS have complex needs and cognitive difficulties.

The NDIS estimate that 60–70 % of participants have an intellectual disability (Bigby, 2014; Bonyhady, 2015). In Australia 2.9% (668 100) of the population have an intellectual disability, of which 417 100 people (or 62%) have a profound or severe core-activity limitation. Of these people with profound or core limitation, 67.3% have speech difficulties (Australian Bureau of Statistics, 2012). Not all of these people will be eligible for the NDIS as people who acquire a disability after the age of 65 years will receive funding for services through the aged care sector. The NDIA’s 2015 report of the trial data demonstrated that people with cognitive and associated impairment constitute a large number of those with established plans which reflects the population data (NDIA, 2015). For instance, “Autism and related disorders represent the highest proportion of approved plans overall, at 31%. The second highest proportion is represented by participants with intellectual disability (including Down syndrome and other intellectual/learning disability) at 25%” (NDIA, 2015, p. 29). As many participants will require communication supports (as clearly reflected in the top two diagnostic groups with completed plans), Speech Pathology Australia has recognised that the NDIS will have an impact on service provision and established a project officer, based at national office, dedicated to inform the profession and oversee developments (Olsson, 2015; Speech Pathology Australia, n.d.). Speech-language pathologists (SLPs) have commenced providing services in the trial sites, with some reporting positive outcomes. For instance, there have

been requests for service from adults with disabilities who have previously not received speech pathology services. The aim of this paper is to consider some of the changes the NDIS will bring to SLP services and how SLPs, in ensuring adults with complex communication needs, can meaningfully participate in the planning process and identify life goals. This will ensure that they receive the reasonable and necessary supports required for improved social and economic participation.

The introduction of NDIS is challenging disability service providers to change established business practices that have previously relied on state and/or federal block funding to one where there is greater individual choice of providers in a competitive market (Foster et al., 2012), set fee schedules, and mandatory reportable outcome measures. Disability service providers need to reorientate their services from providing a suite of services based on goals developed in partnership with individuals and their supporters to one based on delivering individual goals that were developed in an external planning process. This paradigm shift is both economic and attitudinal. Under the NDIS, service providers will be contracted to deliver a service that is outcome based and time limited. The economic drivers require SLPs to account for their time but may not fund the time involved in selecting, prescribing, and setting up augmentative and alternative communication (AAC) systems and keeping abreast of technological advances. SLPs recognise the importance of developing ongoing respectful relationships with both the individual and key supporters in order to maximise communication opportunities and promote skill development. Johnson et al. (2012), in a grounded theory study of positive relationships between people with severe intellectual disabilities and their key partners, reported that developing trust and spending time together were essential components of relationship building. Thus a tension exists in delivering an individual time-limited goal and promoting and building positive relationships to achieve the best outcome.

Planning

The NDIS planning process allocates funding based on the supports deemed reasonable and necessary to achieve an individual's life goals. People with disabilities are not new to lifestyle planning processes which have been fundamental to receiving services since the 1980s; however, each planning process differs. Lifestyle planning encompasses a range of planning types such as educational, individual or whole of life person-centred planning. Independent of the plan type, the desired outcome is to clearly articulate goals which meet an individual's needs. These goals have not always been reflected in plans and in some disability services, individual program plans (IPPs) have been developed based on what the service could offer, rather than being matched to an individual's needs (Kaehne & Bayer, 2014). An alternative approach is person-centred planning (PCP), which commenced in the United States over 40 years ago and was adopted in Australia and the United Kingdom over the last 15 years. PCP requires a switch of focus from what the service can offer to what the individual requests or needs. In addition, a person-centred plan purports to be aspirational and requires a collaborative planning process, led by the focal individual, to identify and enable the focus person's dreams to be realised (O'Brien, 1987; Sanderson, 2000). PCP can be distinguished from other planning types by requiring both the presence of the person for whom the plan is being prepared and his or her

key supporters as essential to the process (Mansell & Beadle-Brown, 2004). As many adults with severe intellectual disabilities have small social networks mainly consisting of family and paid workers (Clement & Bigby, 2010), there are challenges in engaging key personnel who can adequately support the decision-making process (Watson, 2016). O'Brien (2014) referred to nine frequently used approaches (e.g., personal futures planning, essential lifestyle planning, person-centred thinking tools) each of which can be used singly or in combination to facilitate the process. These approaches allow for flexibility and can be adapted to meet the needs of people with severe communicative and cognitive limitations.

There is a growing body of evidence to support the impact of PCP for adults with intellectual disability (Espinier & Hartnett, 2011; Kaehne & Bayer, 2014; Robertson et al., 2007). Robertson et al. examined the impact of PCP on 93 adults with intellectual disabilities through interviews and document analysis and found that the commitment of the plan facilitator to the process was the most important predictor in ensuring a person received an appropriate plan in which goals were enacted. In addition, the active involvement of the focal individual positively affected his/her ability to make choices and develop relationships.

Espinier et al. (2011) in a small qualitative study of 10 people with an intellectual disability and three key supporters reported similar findings but also highlighted the importance of the focal person being listened to and heard, being adequately prepared for the planning meeting, and having information in accessible formats. A qualitative Australian study involving people with cognitive and complex support needs and over 100 practitioners determined various elements of effective planning (Collings, Drew, & Dowse, 2015). The researchers emphasised the need to allow time in the pre-planning stage in order to develop trust and to attend to any barriers at the individual, service, and systems levels. Furthermore, they highlighted a requirement to develop planner attributes and job competencies and embed reflective practice in to the service system.

The current evidence for people with an intellectual disability suggests that to achieve meaningful outcomes, person-centred planning needs to actively involve the individual for whom the plan is being prepared, take the time required, and be supported by a committed and skilled plan facilitator who monitors and facilitates the achievement of goals. While recognising disability activists use the catch phrase "nothing about us without us", collaborating to develop a plan with a person with severe or profound intellectual disability can be challenging for planners. Nonetheless, the presence of the person with a disability is a grounding experience for those involved and could assist the planners to write the necessary communication goals. As the supports funded through the NDIS rely on goals identified through the planning process, implementing evidence-based characteristics of effective planning is vital to achieve economic and social inclusion for participants.

NDIS planning

Collings and colleagues (2016) highlighted the complex process for participants in establishing their eligibility for the NDIS and developing goals and aspirations. For those participants whose communication, literacy, and /or cognition are limited, the initial disadvantage may continue into the planning process unless supported by skilled planners. From the commencement of the pilot, NDIS has

had an ambitious timeline for delivering plans. Not surprisingly planners have been under time and resource pressures and anecdotal evidence from people with complex communication needs without intellectual disability suggests some NDIS planners were unsure of how to accommodate the needs of a person who communicated using AAC. As service providers were initially excluded from planning meetings, there were few opportunities to impart specialist AAC knowledge to planners. SLPs were infrequently asked for any input, resulting in some communication needs of an individual being ignored or erroneously identified. In addition, there have been reports that people with severe intellectual disabilities were not always present at planning meetings and thus a supported decision-making process was not utilised. Collings et al. (2016) also reported a tendency to provide a “quick fix” rather than a carefully crafted individualised plan. In one trial site it appears that recommendations for communication aids have been overrepresented through the provision of IpadTM with technological solutions seen to be superior to non-electronic communication aids. Yet researchers have reported that some adults who use AAC equally value their non-technological AAC solutions (Iacono, Lyon, Johnson, & West, 2013). In addition, the knowledge and skills of planners are varied and frequent staff turnover has impeded the establishment of trusted relationships. Although some service providers and people without an intellectual disability who use AAC have expressed concerns, NDIS participant satisfaction ratings have consistently rated the planning process highly (95%). This rating is collected after the planning process, independent of the planner but the mode and format of the survey may preclude people with an intellectual disability responding.

Throughout the trial process the NDIS has actively sought feedback from participants and provided opportunities for face-to-face meetings across the country to assist participants and their families understand the NDIS (NDIA, 2015). The NDIA’s June quarterly report noted difficulties that NDIS participants experienced in understanding what to apply for and how to engage in the planning process. In part these difficulties have been attributed to the complexity of the written information and the lack of advocates and no or limited pre-planning support. The NDIS is attempting to address the identified barriers for people with cognitive and literacy difficulties by providing information in multiple formats. This includes translating key documents into Easy English and making those available both on-line and in hard copy (<http://ndisrights.org.au/fact-sheet/easy-english>). In addition, the NDIS has developed a range of pre-planning documents to assist individuals and families prepare for the planning meeting.

In 2015, the NDIA have attempted to address the lack of input to the scheme by people with an intellectual disability by establishing an intellectual disability reference group to advise the Agency. The reference group is focusing on identifying modifications required to the scheme that will enable people with intellectual disability to receive the supports they need for a “good life” (NDIS, 2015a). Nonetheless, for all NDIS participants with communication disabilities there remain many issues that still need to be addressed, such as involving key supporters who know the person well (this may be a paid worker in the absence of a family member or an independent communication support worker), allowing increased time for planners to build a relationship with participants, ensuring planners understand how people communicate using their chosen AAC systems

and ensuring appropriate planning tools and resources are available for people with complex communication needs.

The role of SLPs

SLPs are experts in communication and readily understand the link between communication competency and the possibilities for social and economic participation. Their skills may minimise a possible *implementation gap* (Mansell & Beadle-Brown, 2004) in which plans are prepared and documented but little change ensues for the individual involved. NDIS financial restraints will restrict SLP hours of service delivery and lower cost solutions such as utilising allied health assistants are being considered (National Disability Service, 2015). SLPs are attempting to positively influence the NDIS through individual interactions, participating in organisational feedback opportunities, liaising with advocacy bodies and peak bodies such as Speech Pathology Australia. Although the trials so far have only implemented IFPs the ILC framework paper suggests there are opportunities for SLPs to support community capacity building, and community engagement and inclusion outcomes (NDIS, 2015b, 2016). The ILC framework will also provide an alternative avenue to IFPs for the provision of information and education to people in the community to effectively engage with people with complex communication needs. There are several ways in which SLP expertise can be utilised to facilitate the social and economic inclusion of participants: (a) to train planners, local area co-ordinators (LACs) and advocates in recognising the range of AAC systems and their application; (b) to provide tools to engage people with complex communication needs to ensure they meaningfully participate in the planning process; and (c) to provide clear information on AAC resources through apps, blogs and websites.

Training planners

Planners come from a range of professional backgrounds and may have limited experience communicating with people whose speech is difficult to understand or providing supported decision-making to people with a profound disability. They may also have an incomplete understanding of the range of AAC resources available. These issues may also be true for disability advocates. The pre-planning process is a vital time to establish relationships and interactions and to involve the SLP or key person (if there is no family member) to assist with preparing appropriate communication tools and resources, ensuring an individual has access to appropriate vocabulary to communicate their life goals, understanding the Easy English information and formulating initial goals. For people with profound disabilities, using graphics such as photos and symbols or written words may not be as helpful as using a supported decision-making process (Watson & Joseph, 2011). Watson (2016) emphasised the importance of a key support person’s responsiveness to subtle communication cues that included recognising and acknowledging idiosyncratic means of communication, but also ensuring that the interpreted choices are acted upon. In the absence of a skilled planner or key supporter, independent communication assistants could be utilised (Communication Rights Australia, 2016). Encouraging planners to directly involve the person with a disability (if even for a short time) in the process will enhance the planners’ skills in communication and be beneficial for both the planner and the focal person. The authors would endorse the possibility

of the NDIA outsourcing the planner role for participants who have complex communication needs to specialist services who have experience supporting people with disabilities.

Providing tools

A practical set of tools could be provided for all planners. Basic communication aids could be developed representing the life domains of the planning process to assist the involvement of people with severe cognitive difficulty to engage in the process. In addition, a set of images expanding vocabulary options in each domain could allow for a deeper discussion, perhaps supported by the use of the Talking Mats™ approach (Murphy & Boa, 2012; Murphy & Cameron, 2008). A non-technological approach that allows picture cards to be manipulated and placed along a visual continuum to indicate preference (e.g., like a lot, a neutral, dislike) is more applicable for some participants than on-line resources such as picture my future (<http://picturemyfuture.com>) which may be useful for other individuals.

Providing information

There is a plethora of information about AAC on the web; however, planners and plan supporters would not be aware of the process of feature matching for aids or the support needed to implement communication aids effectively. As there is little researched evidence of the most effective ways to inform planners about AAC, a multi-pronged approach may be necessary. One method to convey information would be the development and maintenance of an easily navigated website with commonly referred to resources/links. This could be developed through a co-design process engaging the NDIS, planners, SLPs, LACs and people with complex communication needs. It would provide planners, families, participants with useful communication tools and strategies that could be updated monthly. SLPs could build the capacity of individuals with communication disabilities to engage in aspects such as writing blogs and moderating forums that would provide opportunities for social and economic participation. Project funding for these activities may be available through the ILC, but funding sources for this type of activity would need to be finalised.

Conclusion

This paper has attempted to highlight some of the current issues that present barriers for adults with cognitive and communication difficulties when developing a plan through the NDIS. The authors recognise the speed with which the NDIS has progressed and while applauding NDIS' willingness to implement changes, we would recommend a number of adaptations to the NDIS to ensure greater participation by people with complex communication needs. Currently, individualised goals seem to focus on acquiring tools, especially technological aids; however, for people with cognitive and communication difficulties time to trial different communication aids is vital. Supports must be funded to enable participants to develop new skills, provide time to develop trusting relationships with planners and provide welcoming and inclusive communities. The pre-planning stage for individuals with cognitive and communication difficulties will be critical to ensure that they have the opportunity to fully participate in the planning process and effectively communicate their goals, dreams and aspirations. The principles underpinning the NDIS focus on increasing an individual's independence and

community participation; thus, it is reasonable and necessary that the voice of all people including those with complex communication needs are heard and their choices respected throughout the planning process.

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Dr Hilary Johnson is strategic projects advisor for Scope's Communication and Inclusion Resource Centre. **Denise West** is manager of scope's Communication and Inclusion Resource Centre.

Correspondence to:

Hilary Johnson

Scope

phone: 0417 126 471

email: hjohnson@scopevic.org.au



Googling AAC: Exploring the relevance, scope, and credibility of online information about augmentative and alternative communication

Kate L. Anderson and Paul Andres

Under the National Disability Insurance Scheme (NDIS), Australians who use alternative and augmentative communication (AAC) and their support networks can increasingly expect to make decisions about technology, intervention, and service providers. Knowledge is key to informed choice and agency, and yet little is known about the quality of online information available to people who use AAC and their support networks. This study analysed the relevance, purpose, and credibility of 300 webpages resulting from 15 AAC-related keyword searches in Google. Eighty-one per cent of the sites were judged to be at least somewhat relevant to AAC. Search results included sites for commercial marketing and sales, independent reviews, service networking, and implementation guidance, and varied greatly between general and product- / diagnosis-specific searches. The presence of credibility indicators was also variable. Based on the findings of this and other studies, we suggest strategies for improving accessibility and uptake of high quality on-line AAC information. Areas for future research and development are also flagged.

As the National Disability Insurance Scheme (NDIS) is rolled out, people with disability, including people who use augmentative and alternative communication (AAC), will gain greater control over the type, context and providers of their support, and many will self-manage their support budgets. One focus objective of the NDIS scheme falls within the category of “information, linkages, and capacity building” (ILC), which includes knowledge and capacity building for individuals with disability, and for the broader communities they are part of (Disability Reform Council, 2015). ILC supports have particularly high relevance to the Australian AAC community, whose individual members will be expected to make informed decisions about intervention approaches, goal-setting, and assistive technology. As a complex and rapidly evolving field, such decisions necessitate the availability of current, high-quality information. Indeed,

Australian parents of children who use AAC have described several information priorities, including well-timed advice about AAC services, products, and home implementation (Anderson, Balandin, & Stancliffe, 2014). Nonetheless for many, time and logistics are major barriers to in-person consultation or training (Anderson et al., 2014).

As an alternative, information may be presented on-line, either synchronously (e.g., webinars, on-line product demonstrations, and real-time social media), or in asynchronous formats (e.g., webpages and discussion boards). Relatively little is known about the utility, scope, and quality of asynchronous on-line information sources pertaining to AAC. In general, health consumers and their families report a range of benefits to on-line health-information access including privacy, convenience, and the breadth of available information (Roche & Skinner, 2009), yet it is important to note that not all information seekers benefit equally from on-line information, and not all on-line information is equal. For instance, individuals without internet access or on-line capability are frequently excluded from the same health information access as on-line peers (Blackburn & Read, 2005).

Even on-line, health consumers may face additional hurdles to information access. Parents in Roche and Skinner’s study (2009) cited a range of access barriers to on-line health information, including a lack of search confidence, Internet knowledge, or necessary technology, while 85% of parents in Blackburn and Read’s study (2005) reported difficulty in finding the specific information they required. Given the written complexity of most on-line health information, searchers with intellectual disability or low literacy skills are at an additional disadvantage (Zaidman-Zait & Jamieson, 2007), and for those with physical disability, lack of assistive technology provisions may be an additional barrier to access. The Internet also creates potential risks for misdirection and information overload. Still, 74% of health-information seekers report feeling reassurance at the information they find (Fox, 2006), suggesting that the Internet is a valued knowledge source among people with illness or disability. Before we can critique existing asynchronous on-line information for AAC consumers specifically, it is first important to understand typical approaches to health-information searching on-line.

What do we know about health-information seeking on the Internet?

On-line asynchronous health information reaches the typical searcher through a number of routes. In a US survey, 77%

KEYWORDS

AUGMENTATIVE AND ALTERNATIVE COMMUNICATION (AAC)

AUSTRALIA

CAPACITY BUILDING

HEALTH-INFORMATION SEEKING

INTERNET

NATIONAL DISABILITY INSURANCE SCHEME (NDIS)

THIS ARTICLE HAS BEEN PEER-REVIEWED



Kate L. Anderson (top) and Paul Andres

of health-information searchers reported starting at a general search engine (Fox & Duggan, 2013), with Google being the most preferred by far. Thirteen per cent started at a familiar health hub (e.g., WebMD), while others follow recommendations from friends or family (Fox & Duggan, 2013).

In a review of search trend research from 1997 to 2003, Spink and Jansen (2004) reported that around 1 in 3 web searchers used only one search term, and that 2 in 3 web users did not reformulate or modify their terms after an initial query. Few searchers make use of advanced features, such as Boolean operators. Users on average viewed only 5 documents per query, and most did not look beyond the second page of results (Spink & Jansen, 2004). Finally, only a quarter of health searches consistently check for the source and recency of on-line information (Fox, 2006). While it would appear that the search strategies of the average user are not sophisticated, there are certain exceptions. Parents of children with disability or health conditions, for instance, exercise greater caution on average than other on-line health searchers. Parents of children with hearing impairment interviewed by Porter and Edirippulige (2007) expressed a desire for more unbiased, objective, and evidence-based information available to families on-line. Parents spent longer on each search than non-parents, visited multiple sites, and were more likely to check their findings with a health professional (Porter & Edirippulige, 2007).

The on-line search behaviours of parents have been examined extensively. Parents of children with genetic disorders interviewed by Roche and Skinner (2009) reported high rates of health-related internet use, with 83% of parents receiving on-line information about their child's condition, and 69% searching for this information themselves. Like most health searchers, parents typically begin their searches in engines, using keywords relating to their child's symptoms or diagnostic label (Porter & Edirippulige, 2007; Roche & Skinner, 2009). Their reasons for searching the Internet vary greatly. In a UK survey of 788 carers of children with disability, 72% of those who had used the Internet had searched for general information on benefits, services, or their child's medical condition, while 36% had used it to locate and make contact with specific service providers (Blackburn & Read, 2005).

While many parents report success in locating relevant information, their success often depends on the type of guidance being sought. For some parents in Roche and Skinner's study (2009), Internet searches about their child's condition resulted in unwanted clinical images, genetic information or prognostic predictions, while guidance around broader issues such as inclusion was scant. As one parent reflected: "[The Internet] doesn't really have what I'm looking for. I know what it's like to be the parent of [an affected] child. I need to know [how to] help them succeed, help them be productive citizens" (p. 124). In Porter and Edirippulige's study (2007), parents of Australian children with hearing loss wanted more on-line information on topics such as education, intervention, and technology options, and guidance around family support services, as well as personal stories from other families. Parents of children who use AAC technology have described similar information needs (Anderson, Balandin, & Stancliffe, 2016).

In their review paper concerning parents of children with disability, Zaidman-Zait and Jamieson (2007) stress that professionals should be: "aware of the Web sites most likely to be accessed by the parents with whom they work ... parents may be accumulating both information and misinformation" (p. 20). The same could easily be said for

AAC consumers, and yet there is a dearth of research into the on-line information search behaviours of people who use AAC and their support networks. Further, despite the large amount of AAC information available on the web little is known about its visibility and accessibility to naïve stakeholders (i.e., first-time AAC searchers). The aim of this study was to examine the range, relevance, and credibility of AAC information retrieved as the result of conducting a series of keyword searches, using the popular search engine Google.

Research questions

The study sought to answer the following questions, using descriptive analysis of search-engine results:

- When a naïve (first-time) keyword search relating to AAC is performed:
 - what percentage of the resulting websites bear relevance to Australian AAC stakeholders?
 - what is the primary purpose of resulting websites, and how does this vary based on the type of search performed?
- For sites with the primary purpose of information or knowledge translation:
 - which populations and ages does the information focus on?
 - how do the sites perform against common credibility measures?
 - is there any relationship between these credibility measures?

Method

To sample the range of asynchronous AAC resources available, we conducted a targeted English-language search from an Australian location, using the popular engine Google (www.google.com.au). Our method was largely borrowed from the field of search-engine optimisation (SEO) research. Engines such as Google employ a set of rules (search algorithms) to determine the placement of websites in the resulting hierarchy. These algorithms are based on a number of factors (e.g., the number and source of links to the site, the number of social media shares, and the frequency of traffic), with some factors weighted as more important than others. In the current study, SEO keyword methods were applied to predict the public search behaviours associated with a specific concept (AAC).

Selection of search terms

When a member of the general public is looking for information on AAC, which keywords are they likely to search? We probed this initial question using the free keyword research tool from SEOBook: <http://tools.seobook.com/keyword-tools/seobook/>. This tool shows the approximate usage frequencies of keyword search strings, based on data published by Google and Yahoo. Two keyword branches (*communication and communication device*) were used as starter strings for this investigation. Table 1 lists the first five AAC-related terms that appeared in the top-100 keywords containing these two search strings. In addition to these 10 terms, the acronym "AAC" and three terms relating to diagnostic populations who frequently use AAC (aphasia, autism, and cerebral palsy) were included. A final term, *communication app*, was also included. Although this term did not appear within the top-100 keywords for communication, the recent rise in mobile AAC technology warrants its use in this study. The full list of terms and their usage frequencies can be seen in table 1.

Table 1. AAC-related search terms containing the words *communication* or *communication device*, in order of search frequency

Search term	Estimated monthly	Estimated daily (Google)
Containing the term "communication"		
augmentative communication	1560	43
facilitated communication	1560	43
picture exchange communication system	1560	43
communication board	1200	33
communication devices	1200	33
Containing the term "communication device"		
augmentative communication device	168	5
tech talk communication device	60	2
go talk communication device	60	2
dynavox communication device	60	2
springboard communication device	48	1
Diagnosis-specific terms		
aphasia communication	24	1
autism communication	252	7
cerebral palsy communication	24	1
Additional terms		
AAC	39 720	1 103
communication app	No data available	No data available

Search strategy

One factor that features heavily in a search engine's algorithms is the individual searcher's prior search behaviours and browsing history. As a consequence, a parent of a child with newly diagnosed autism and an experienced AAC clinician may in fact receive different results from the same keyword search. To ensure results were not influenced by the researcher's own search history, searches were conducted using an anonymous browser setting, and new sessions were launched for each search. Given Spink and Jansen's 2004 findings that most searchers do not look beyond the second page of results, we restricted the number of harvested results to 20 (2–3 standard Google results pages), which were then transferred as URLs to an Excel spreadsheet for later analysis. Google-generated definitions, sponsored websites, advertisements, and other suggestions (e.g., "images" and "scholarly articles") were not included on this list.

Search result analysis

The first 20 results harvested for each term were rated in Excel, according to the following criteria:

- purpose of the website;
- relevance to AAC and Australian location;

- focus of site content (population, age);
- credibility indicators (including the presence of citations, date of posting / update, and domain type).

These metadata were only collected for the page directly linked to the Google search result. The full coding schema has been included in the Appendix. Findings underwent descriptive statistical analysis in Excel. Inter-rater coding was performed by the second author on 20% of the sample. Cohen's Kappa statistic was used to calculate inter-rater reliability (Hallgren, 2012), with an average Kappa score of 0.42 (moderate strength). Kappa values for each criterion are presented in Table 2.

Table 2. Inter-rater reliability for each criteria, calculated using Cohen's Kappa

Criteria	Kappa value	Strength
Relevance	.42	Moderate
Purpose	.23	Fair
Citations	.73	Substantial
Recency	.47	Moderate
Domain	.96	Near perfect
Location	.45	Moderate
Population	.41	Moderate
Age	.48	Moderate
Average	.50	Moderate

Note: Cohen's Kappa compares the observed agreement against an agreement level that could be expected by chance. A score of 1 would indicate perfect agreement between raters, while a score of -1 would indicate perfect disagreement. Any scores between 0 and 1 indicate agreement at better-than-chance levels (Hallgren, 2012).

Results

Search results were analysed as a group, and then in separate groupings according to their keyword, purpose, and domain types. The analyses are presented below.

Viability, relevance and format

The total search set was analysed according to link viability and relevance of the page to AAC (see table 3). Nine of the resulting links (3%) led to expired or password-protected pages, and were excluded from analysis. Of the remaining 291 sites, 204 (70%) were judged "mostly relevant", 32 (11%) were judged "somewhat relevant" (for example, listing AAC strategies among other communication strategies or interventions), and the remaining 55 were found to have no relevance to AAC (19%). For four search terms (*augmentative communication*, *augmentative communication device*, and *communication board*) all viable top-20 results were judged "mostly relevant"; product-/technique-specific search terms also yielded high numbers of mostly relevant results. By comparison, the search terms *communication app*, *AAC*, *communication device* resulted in high numbers of non-relevant pages (12, 11 and 9, respectively), typically concerning mainstream computing. Diagnosis-specific searches tended to result in somewhat-relevant sites that mentioned AAC among a range of other diagnosis-specific intervention techniques and strategies, for example, the use of gestures in combination with other language strategies for adults with aphasia.

Table 3. Website viability and relevance to AAC

Search terms	Website relevance to AAC			
	Mostly	Somewhat	Not at all	Total relevant (%)
Total websites	300 (100%)			
Total viable sites	291 (97%)			
Generic terms				
AAC	8	1	11	45
communication app	7	1	12	40
augmentative communication	20	0	0	100
communication board	20	0	0	100
communication devices	11	0	9	55
augmentative communication device	19	0	0	100
Technique-specific terms				
facilitated communication	18	2	0	100
picture exchange communication system	18	0	0	100
tech talk communication device	19	0	1	95
go talk communication device	19	0	1	95
dynavox communication device	18	1	0	100
springboard communication device	17	0	0	100
tech talk communication device	19	0	1	95
Diagnosis-specific terms				
aphasia communication	1	10	9	55
autism communication	3	7	9	53
cerebral palsy communication	5	10	3	83

Location data were analysed for pages dealing with services or sales, to determine their specific relevance to Australian consumers. Eighteen (26%) of sites offering purchase options were based in Australia, and five (42%) of sites describing AAC services (e.g., therapy centres, groups, or training) were also Australian-based. In total, 37% of service or commercial sites were based overseas, and irrelevant for Australian consumers.

Site purpose

The search terms were divided into three categories: generic, technique-specific, and diagnosis-specific (see Table 3 for groupings). We then examined the purpose distributions for each search category (see Figure 1). Perhaps unsurprisingly, commercial pages such as manufacturer and distributor sites dominated the technique-specific category (41%). In addition, technique-specific terms produced 30 overviews of products or techniques (27%), and ten opinion or news articles for a mainstream audience (9%), mostly concerning facilitated communication. The product-specific searches produced only four sites providing implementation guidance (4% of all relevant results), mostly consisting of device manuals. Conversely, pages resulting from the generic AAC searches were populated largely by product and technique overviews

(41; 47%), followed by commercial sites (21; 24%) and sites offering implementation guidance and resources (19; 22%).

Site purpose varied greatly for diagnosis-specific searches. The majority of AAC-relevant sites from the *aphasia communication* search offered guidance around implementation (9 of the 11 sites), typically listing AAC strategies such as picture symbols, gesture, and drawing among other communication partner strategies. AAC-relevant sites for autism spectrum disorder and cerebral palsy mostly offered information on available products or techniques (9/11 and 8/15 respectively), for example picture-exchange based communication systems, communication apps, and assistive technology. Table 4 contains a breakdown of the purpose data for each keyword category.

Characteristics of information sites

Additional analyses were performed on all sites coded as P/T (product or technique overviews, such as non-commercial information on available AAC products), G/R (AAC implementation guidance, home practice ideas, communication partner strategies, and resource repositories), and OPN (opinion pieces or news sites). The majority of information on these sites was generic, although 23% specified an age-group (adult, child, or both).

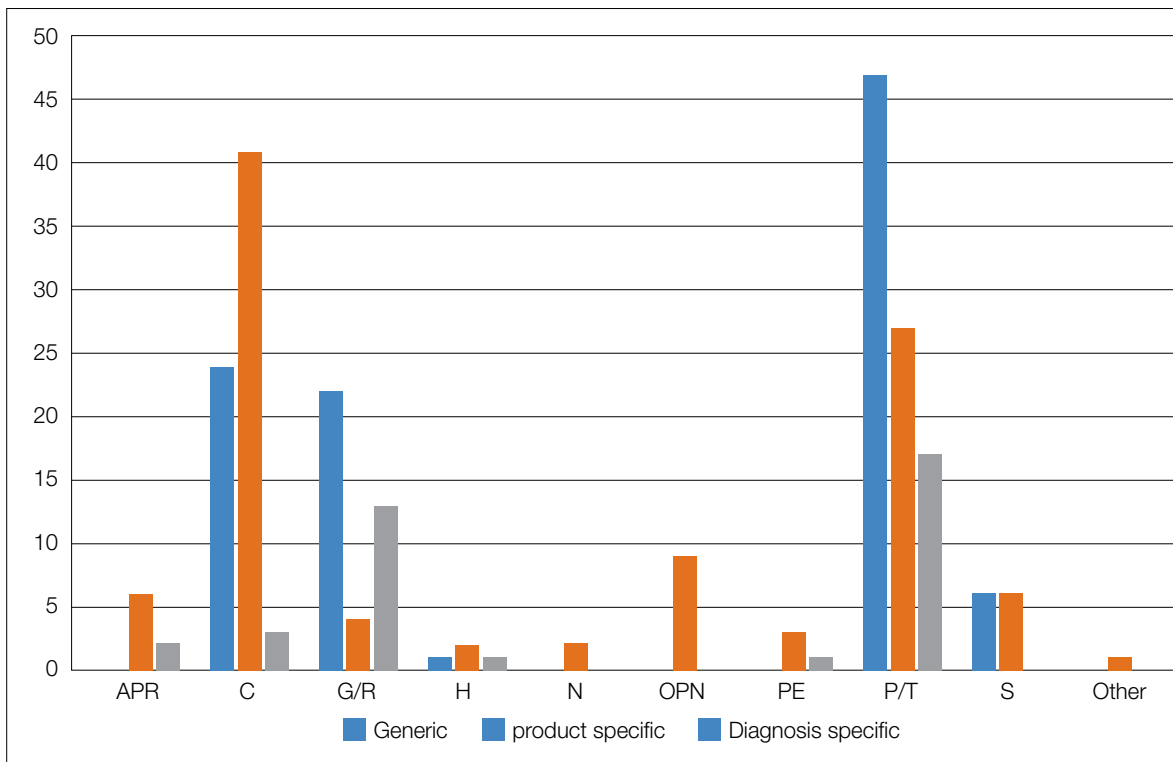


Figure 1: Number of websites for each site purpose, across search categories.

Note: APR = academic publication or report; C = commercial; G/R = guidance or resources; H = information hub; N = networking; OPN = Opinion or news sites; PE = personal experience; P/T = product or technique overviews; S = services.

Website purpose	Generic search	Technique search	Diagnosis search
Academic	0 (0%)	6 (6%)	2 (5%)
Commercial	24 (24%)	41 (41%)	3 (8%)
Guidance and resources	22 (22%)	4 (4%)	13 (35%)
Information hub	1 (1%)	2 (2%)	1 (3%)
Networking	0 (0%)	2 (2%)	0 (0%)
Opinions and news	0 (0%)	9 (9%)	0 (0%)
Personal experience	0 (0%)	3 (3%)	1 (3%)
Products/techniques overview	47 (47%)	27 (27%)	17 (46%)
Service directory	6 (6%)	6 (6%)	0 (0%)
Other	0 (0%)	1 (1%)	0 (0%)

We then examined the apparent credibility of websites in each purpose category. Kunst and Khan (2002) define credibility of on-line information as: “the power of inspiring belief ... credible websites should offer reasonable grounds for being believed” (p. 44). Three common credibility indicators were evaluated: the domain of the website (commercial vs. non-commercial), the presence of references, and the page’s currency. OPN sites demonstrated the highest presence of references by far (representing 80% of all websites with citations). These articles, pitched at the general public, frequently concerned ethical and legal issues in facilitated communication.

Breakdowns for these three variables can be seen in Tables 5 and 6. In terms of domain, P/T overviews were the pages most likely to occupy non-commercial sites (51%). Non-commercial sites represented 47% of the combined information search results, with the remaining hosted on commercial or non-specified sites. Finally, 47% of the total information sites indicated recency (first posting/latest update). OPN sites were again the most likely sites to include this metadata (90%).

Chi-squared analyses of the three credibility indicators showed a strong relationship between the presence of citations in the work and statements of recency ($\chi^2 = 13.361, p < .001$). A very weak association was noted between domain type and recency ($\chi^2 = 2.8, p = .096$), with commercial sites stating recency slightly more often than non-commercial sites (54% versus 40%, respectively). This may be due to the large number of blog posts within the commercial category, as blog posting dates are typically auto-generated. The type of domain (commercial vs. non-commercial) had no predictive value for the presence of citations ($\chi^2 = 0.126, p = .723$).

Discussion

This research raises a number of issues concerning access to, and dissemination of, on-line information for AAC consumers and their support networks. These are discussed below, with reference to similar research across a range of health care domains.

Finding the “right” information

In general, relevance of results to AAC was highest when the names of specific approaches and brands were included in the search. It is unclear whether naïve searchers will know to use these terms however, and a lack of definitive terminology is a recognised barrier to searching for health information on the web (Roche & Skinner, 2009).

Table 5: Presence of recency statements and citations for each type of information site

Purpose	Recency				Citations present	
	None	>5 yrs	<5yrs	Total Stated	N	Y
Guidance/resources	20	3	14	17 (46%)	32	5 (14%)
Product/technique overview	50	7	31	38 (43%)	64	24 (27%)
Opinions and news	1	2	7	9 (90%)	2	8 (80 %)
Total	71	12	52	64 (47%)	98	37 (27%)

Table 6. Domain types for each category of information site

Purpose	Non-commercial			Total	Commercial		Other	Total	N/S
	.edu	.org	.gov		.com/.co	.net			
Guidance/resources	1	12	3	16 (43%)	19	1	1	21 (57%)	0
Product/technique overview	4	37	3	44 (51%)	24	7	11	42 (48%)	2
Opinions and news	0	3	0	3 (30%)	6	1	0	7 (70%)	0
Total	5	52	6	63 (47%)	49	9	12	70 (52%)	2

Judging by our findings, it is likely that naïve searchers will encounter limited information about AAC simply through the use of generic terms such as *communication app*, but may be less likely to find this information when diagnosis-specific search terms are used.

Even when relevant to AAC in general, the specific focus of many websites returned through Google may be a poor match for those in search of practical advice. For instance, only 4% of results from device-specific searches addressed issues of implementation. Consequently, searching for a specific AAC solution may unearth a plethora of information on where to purchase it, but little on its suitability, viability, or optimal use. Many of the products and services advertised on-line were also inaccessible to Australian searchers. Availability of such information is critical to informed decision-making and implementation success, particularly under the new NDIS. In anticipation of this problem professionals should direct consumers to appropriate information sources (e.g., specific websites or information hubs) as necessary.

As on-line knowledge brokers, AAC service providers and support organisations can play an important role in supporting the NDIS's ILC domain by optimising the reach of quality on-line content. Particular attention should be paid to page titles and salient keywords, which can improve chances of search-engine retrieval. Internet-based health information is frequently inaccessible to people with disability and to those from non-English speaking backgrounds, and often requires high levels of reading proficiency (Greenberg, D'Andrea, & Lorence, 2004; Zaidman-Zait & Jamieson, 2007). Given that accessibility issues will affect a large number of NDIS service users, attention to these features in website design is of paramount importance. Guidelines on web content accessibility can be found at www.w3.org/WAI/intro/wcag.php. By attending to issues of accessibility and visibility, reputable knowledge brokers can help to improve access to local and high-quality information for Australian AAC consumers on-line.

Credibility and accuracy are not the same thing

The credibility of a website becomes particularly salient to those searching unfamiliar topics (Eastin, 2001). The indicators most strongly associated with seekers rejecting a website include a lack of authorship or source information, a heavy commercial focus, and the presence of information the seeker knew to be incorrect (Rice, 2006). Information websites evaluated in the current study showed high variability in their external credibility, with sites from several reputable organisations lacking both citations and recency statements.

Several researchers have pointed out the inherent limitation of putative credibility cues such as source and author attributions, which can increase apparent credibility but are no guarantee of quality (Eastin, 2001; Kunst & Khan, 2002). Other credibility cues such as levels of evidence and the presence of referencing present similar risks given that, without peer review, evidence and citations may be falsified or cherry-picked to support inaccurate information. Furthermore, common indicators of credibility have been shown at best to have only a weak correlation with each other (Kunst & Khan, 2002). This finding was mirrored in the chi-squared analyses from the current study for the credibility indicators of recency and references, suggesting that single measures may be insufficient predictors of a website's credibility or accuracy. In light of these findings, training AAC consumers and their families to "evaluate" on-line sources based on their apparent credibility alone may not guarantee the retrieval of reliable information. Given that approximately 35% of information seekers do not consult with their health professional about the information they find on-line (Fox & Duggan, 2013), it is important for AAC professionals with expert knowledge to initiate a dialogue about information seeking with health consumers and their families (Roche & Skinner, 2009; Zaidman-Zait & Jamieson, 2007).

At a broader level, official information hubs or wikis, such as the proposed Newell network or the NDIS hub (<http://www.ndis.gov.au>), could be used to disseminate evidenced-based information on communication disability, intervention techniques and available products, in addition

to reputable service providers. Trusted AAC advocacy organisations such as Agosci or the International Society for Augmentative and Alternative Communication (ISAAC) may play a role in this dissemination. With regards to content certification, third-party verification schemes such as MedCERTAIN have also been proposed to improve the reliability of on-line health information through the use of expert review processes and recognised “trustmark” seals (Eysenbach, Yihune, Lampe, Cross, & Brickley, 2000). Finally, user feedback may be valuable for webmasters of disability sites in tailoring their content to consumers’ needs and guiding the attention of other users (Greenberg et al., 2004). Indeed, facilities for users to rate the quality and usefulness of information were already present on several of the disability and parenting “hubs” included in the current study. Uptake of such quality-assurance practices by webmasters in the field of disability may further improve consumer knowledge and acumen.

Study limitations and future directions

Keyword research is modelled from patterns of established search behaviour in the general population, and yet little is currently known about the *actual* search strategies of AAC consumers and their support networks. Until these are ascertained, research into this area remains speculative. Future studies using interviews, focus groups, surveys, and/or user-observation methods will shed light onto the information requirements of AAC consumers, their approaches to information seeking, and their ILC support needs.

Like most exploratory research, this study raises more questions than it answers. We had limited capacity in the current project to evaluate the quality of on-line AAC information. Nonetheless, the measurement of content

quality remains an ongoing challenge in on-line health informatics (Greenberg et al., 2004), and should be a priority focus for disability in the NDIS era. Another valuable area for ongoing research is the role that AAC- /disability-specific forums, peer support, and social media play in networking and disseminating asynchronous information sources. Emerging research into the use of Twitter by people who use AAC (Hemsley, Dann, Palmer, Allan, & Balandin, 2015) indicates that, for some individuals, social media has become another important vehicle for information exchange and social connection.

Conclusion

In today’s digital world, it is safe to assume that many AAC consumers will turn to the Internet for information. Internet users researching AAC for the first time are likely to encounter high volumes of variable quality information, covering a range of agendas. As self-directed support becomes the norm, the ability of consumers to access and appraise information will become a pressing requirement. Improving digital literacy of health consumers is only one part of a complex puzzle; supporting professionals, service providers, and web content developers should also play a key roles as they consider issues around digital accessibility, readability, and search-engine optimisation. Future investments in this area by the general AAC community and/or NDIS service providers could include the implementation of a unified quality rating scale, and the use of centralised hub sites to guide information gathering by service users. In the meantime, AAC professionals can act as a conduit, guiding consumers towards quality on-line advice or resources, and assisting them to evaluate their findings.

Appendix. Full coding schema for website metadata	
Criteria	Coding
Relevance	M = Mostly relevant S = Somewhat relevant N = Not relevant
Purpose	P/T = general information about AAC/AAC products/ AAC techniques S = information about AAC-related services G/R = implementation guidance and resources N = networking members of AAC community (consumers, family, professionals) APR = academic publication or research (presenting, reviewing, or evaluating research findings) C = commercial marketing or on-line sales H = information hub (links to other information only) OPN = opinions and perspectives, news items, journalism PE = sharing personal experiences O = other (specify)
Citations	Do authors cite other publications or include references to support their content? (Y/N)
Recency	Year last updated (not copyright year) N/S = not specified
Domain	First order domain name (e.g., .com, .co, .edu., .org, .net) Specify also public repository sites: Youtube, Pinterest, etc. N/S = not specified
Country	Country of website sourced from domain name or other page information N/S = not specified
Population focus	Autism, cerebral palsy, aphasia, other N/S = not specified
Population focus (age)	Child, adult, or both. N/S = not specified

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Kate Anderson is a researcher and lecturer in disability and inclusion at Deakin University, Melbourne, Australia. **Paul Andres** is an occupational therapist and AAC consultant at Prentke-Romich Deutschland, in Germany.

Correspondence to:

Dr Kate Anderson

Deakin University

email: Kate.anderson2@deakin.edu.au



Ethics and the National Disability Insurance Scheme

Cathy Olsson and Trish Johnson

This article seeks to identify anticipated and emerging ethical issues and challenges for speech pathologists working with National Disability Insurance Scheme participants, and to facilitate exploration of the ethical decision-making for clinicians working within that funding environment.

Speech pathologists practise in a wide variety of environments and contexts, which result in the presentation of an equally wide variety of ethical issues and challenges. The diversity of clinical practice requires flexibility in ethical reasoning and decision-making, particularly when practising within a new context, such as the National Disability Insurance Scheme (NDIS), which is developing and changing as it expands.

As professionals, speech pathologists are bound to uphold high ethical principles and standards, described within the Speech Pathology Australia Code of Ethics (2010). We demonstrate ethical behaviour by being aware of the ethical issues inherent within daily practice, considering the ethical implications of decisions and integrating proactive ethical reasoning into our everyday work by applying those principles and standards. A current challenge for speech pathologists is to become confident in understanding and responding to the ethical issues that arise when working with participants in the NDIS, and to develop proactive strategies for managing those issues.

The National Disability Insurance Scheme – in brief

Many commentators describe the NDIS as the most significant social policy reform since the introduction of Medicare in 1975. The scheme entails a shift from state and territory government and non-government organisations receiving block grant funds to provide services to people with disability, to funds being provided directly to individuals themselves. In the previous model, as part of their service provision, disability provider organisations may have had restricted eligibility and rationed and prioritised services in an environment of significant unmet need. Under the NDIS, people with disabilities are able not only to determine their own goals and priorities, but also to exercise choice and control over who provides services and how they are provided. While the changed relationship between providers and participants that comes with the new funding model

brings many advantages and opportunities, it also brings some challenges.

The altered funding model is driving a range of changes in the service provider landscape and systems. Established service provider organisations which may have had a specialist focus are broadening the range of supports they offer (e.g., adding case management or accommodation) and their client group (e.g., children with autism spectrum disorder as well as children with physical disabilities). The increase in funding, and consequent demand for services, is leading to an increase in the number of speech pathologists who are expanding their skills set to work with children and adults with disabilities. Many new private practices are being established and existent practices are entering the arena as providers under the NDIS. Clinicians are required to have a broader personal scope of practice to provide for the heterogeneous needs of people with disabilities.

In addition to new players in the field, some long-term service provider organisations are being devolved or are no longer continuing to provide allied health services for people with disabilities.

“With the benchmarks for face-to-face contact I’m not getting time to write up my progress notes, let alone do the preparation for sessions or provide supervision to all the new staff.”

Speech pathologists face challenges to their professional autonomy, application of their clinical reasoning and standards of practice in relation to their service provision. These challenges are occurring in the context of changes in provision of clinical governance. It is more difficult under the individualised funding model for organisations to prioritise activities such as clinical supervision and support and targeted clinical professional development, particularly in a contestable market. Organisations which are new to allied health service provision and/or service provision to people with disability may still be developing their understanding of the need for and value of clinical governance, and the structures and systems to provide this.

Provider organisations are facing challenges to their financial viability, have had to shift to a more competitive mode and focus on marketing their services. Service managers who may have limited understanding of speech pathology service provision are now competitively contracting with individual participants to purchase

KEYWORDS

ETHICS

NATIONAL
DISABILITY
INSURANCE
SCHEME



**Cathy Olsson
(top) and Trish
Johnson**

services from their organisation. Participants whose understanding of speech pathology is limited may demand a type, frequency, duration or model of services which are not evidence based and which could have negative consequences.

“It is hard sometimes to help families understand that more isn't necessarily better, and that it's more about what I can support them to do, and a lot less about me being with their child.”

Providers have had to modify their service delivery as a result of the NDIS pricing and support, and rules around what activities can be included in billable hours. For example, the restrictions around payment for travel are creating a shift back to participants attending at clinics, and provision of services in segregated and central rather than community settings. Clinicians may have “quotas” of billable hours that have to be achieved per day or week. It is NDIS planners who are tasked to support participants to develop and articulate their participation focused goals. It is also planners who determine what and whether services are “reasonable and necessary” and represent “value for money”. From its implementation in July 2013, the NDIS identified the provision of trans-disciplinary support as the exemplar for early intervention services (NDIS, 2014). Family-centred practice, routines-based and strengths-focused intervention, and use of a key worker as a primary provider of interventions are core components of this model of service delivery (NDIS, 2013). These developments have provided a catalyst for the early intervention sector, including allied health providers, to explore and attempt to clarify our understanding of the terminology and best practice in early intervention, including the role and responsibilities of a key worker as a primary provider of interventions, issues around scope of practice and responsibilities, and boundaries around knowledge transfer and delegation. For example, when is it appropriate or necessary for a speech pathologist to take the key worker role? What knowledge and skills can be transferred to colleagues to enable them to provide holistic and integrated developmental support to a child's communication and oral eating and drinking and in turn model this to others? What knowledge and skills can be effectively transferred such that another early interventionist can effectively provide an intervention themselves? Are there some situations, or some interventions, where we should see our role as one of delegation to another team member, and if this is the case, what are our responsibilities for the quality of the intervention that those other members provide?

The NDIS has also had an impact on the interface and overlap between the disability, health and education sectors. While the expectation of the NDIS that mainstream services maintain provision of services to people with disabilities is reasonable, and seems very clear, the interactions and relationships between the sectors are different within and across jurisdictions. Arrangements at local, regional and state or territory levels have been developed between the education, health and disability sectors for pathways and processes for referral, continuity of care and provision of services at all levels within the International Classification of Functioning, Disability and Health (World Health Organisation, 2001). The changes in the funding have created the need to rework well-tested and effective processes where these have been in place,

and are requiring a review of the current service provider responsibilities and arrangements.

For example, in some jurisdictions the disability speech pathology service provider has been part of developing and providing a service within the state health system to provide instrumental assessments of swallowing for people with disabilities. The NDIS may provide a catalyst for the state-based public health services to decide that they will not provide instrumental assessment of swallowing such as a modified barium swallow for people with disabilities. Is it appropriate for these to be funded through the NDIS/disability sector? Should community-based speech pathologists who are providing support for dysphagia assessment and management provide the clinical support for private radiology services which may step into the breach and offer an MBS? What if speech pathologists are asked to work within the hospital setting to provide the clinical support to the radiologist who works within the hospital? Where does the responsibility lie to determine whether or not these services might be more appropriately funded and provided through the state health services? Where and how should the advocacy for this occur, and who should be doing this?

Ethical issues and challenges specific to NDIS

Since the introduction of the NDIS, Speech Pathology Australia (SPA) members have been raising concerns in relation to the NDIS about a range of ethical issues. Many of these are not new, but the changes brought by the NDIS mean that issues which previously may have been managed through existent structures and systems now require a response by individual members, as well as by the profession over all. Additionally, the NDIS is currently in a process of very dynamic evolution and development. The “rules of engagement” are constantly changing and it can be difficult to get clear and consistent information about what they are.

While many of the ethical issues may be familiar and possible to anticipate, it is important to be alert for new ethical challenges as they emerge in the NDIS environment. People with disabilities who have communication and swallowing difficulties are likely to have complex clinical and service delivery issues. It is commonly identified that this group are particularly vulnerable to abuse, including of their communication rights (ASHA, 1992). These complexities and vulnerabilities bring with them a responsibility for us to reflect on our competencies, and on our relationships and interactions with participants and their supports. We are required to be aware of, understand, use and advocate for the range of strategies and techniques (ASHA, 1992; SPA, 2012) which facilitate communicative rights, access and participation for people with disabilities. This includes their ability to take part in life situations where knowledge, information, ideas or feelings are exchanged (Eadie et al., 2006), using whatever modes of communication are available for them in order to successfully send and receive a message.

Speech Pathology Australia member feedback

A brief survey in December 2015 of Speech Pathology Australia members of the online SPA Disability member community demonstrated that speech pathologists working with NDIS participants are aware of a broad range of ethical issues arising from this clinical context.

Members were asked to identify whether the introduction of the NDIS is leading to an increase in the ethical challenges for practitioners, and if so, to identify the areas where those challenges lie. Seventy-seven responses were collected, and, in brief, 53% of respondents provide services in an NDIS trial site; and 86% of respondents anticipated or have experienced ethically challenging issues in speech pathology service delivery as a result of the introduction of the NDIS.

The survey asked respondents to identify where the ethical challenges lie, according to the professional principles and standards contained within the Code of Ethics (2010). All respondents identified ethical issues relating to provision of services for NDIS participants in at least two or three Standards of Practice. Table 1 sets out the issues most frequently mentioned by the respondents.

Table 1. Ethical issues identified and their relationship to the SPA Standards of Practice	
Duties to our clients and the community	Duties to our profession and ourselves
Service planning and provision	Professional standards
Professional competence	Supervision
Accurate and timely information	Development of your profession
Duties to our employers	Duties to our colleagues
Professional competence	Professional standards

Two case studies and working through challenges

Case study 1

Katie is an experienced speech pathologist who has been working in a not-for-profit disability provider organisation for more than ten years. There is a lot about the NDIS that she thinks is really great. The individualised funding model has empowered parents to make choices about how funds are used, and is allowing parents to prioritise and get greater access to speech pathology services. The flip side of the coin is that Katie now finds herself having to negotiate with families for the provision of evidence-based treatment approaches. The discussions have gone in all sorts of directions. For some parents, the only model that they know of for “therapy” is weekly sessions of one to one with the therapist sitting opposite the child at a table in a small room at a clinic. Of course, for some children that model is a perfect fit, but for lots of the children who Katie is being asked to see, it is not. Families are really wanting to do the best for their child and get value for the money that they are now able to access; they can’t see the value of all the “behind the scenes” teamwork that goes into ensuring coordinated, collaborative, cohesive, consistent supports. For some families, Katie has been trying to advocate for the provision of AAC interventions alongside coaching for parents to support them to provide early speech and language facilitation strategies, but they have wanted her to focus solely on direct speech interventions. The daily targets for NDIS funded face-to-face hours of service provision are also posing a challenge, as is the pressure from her manager to do all of her documentation and device programming while she is with the client. There seems to be a slightly different permutation for each family,

but the bottom line is that Katie feels pressured to provide an intervention that she isn’t confident will benefit some children and their family, and, as well, she feels unable to provide adequate time to provide a high-quality and effective intervention for some of her clients.

Case study 2

Jude graduated last year and was delighted to get a newly established position providing services to adults with disabilities for a residential accommodation provider. She hadn’t had a student placement in an adult disability setting, but she had loved the presentation by a guest lecturer about some of the emerging areas of practice with people with disabilities who use informal means of communication. The first priority of her employer was to assess all of the residents and provide them with mealtime guidelines. Jude was feeling daunted – she didn’t have any experience with assessment and management of dysphagia in people with complex life-long disabilities. Furthermore, the manager of client programs had told her that she was expected to assess all five residents in each house, write up their guidelines and then train one of the support workers how to follow them, so that they could then train the rest of the staff – all in five hours. When Jude hesitantly suggested that she would need more time, the manager informed her that the organisation had negotiated with the NDIS how much funding was available to provide speech pathology, and she just had to manage it within the funding envelope. Jude was just about ready to quit, but she had always enjoyed a challenge, and decided that this was the challenge that she had to have!

Using the Code of Ethics to work through the challenges

The ethical responsibilities of a speech pathologist in case study 1 include provision of accurate and timely information to educate parents or carers, to ensure they understand the evidence base behind an intervention and their decision-making is fully informed. Although it can be difficult to find the time to access the research, the speech pathologist’s responsibility includes provision of information regarding the evidence base for different types of service provision, including the more “traditional” scenarios that the family are comfortable and familiar with. Provision of this information is undertaken while also respecting their autonomy to make decisions regarding the types of intervention that are offered, timing, location, etc.

We have an obligation to “evaluate the services we provide on an ongoing basis to ensure that they are as effective as possible. We provide services only if our clients can reasonably expect to benefit from them” (SPA, 2010, Clause 3.1.6). By enacting these ethical responsibilities we can discuss with families the potential effectiveness of intervention and efficiency of use of funded time. This can include the benefits of all aspects of work involved in providing therapy, to ensure the family are aware of the behind the scenes work and its value to the overall program and contribution to progression towards achievement of goals.

Case study 2 highlights the obligation we have to maintain quality and safe care of our clients. While we strive to continually update and extend our professional knowledge and skills, we must also be aware of the boundaries of our professional competence, and practise professionally within the scope of our level of education, training and expertise. This means we need to seek

support as necessary, and be prepared and willing to discuss our requirements with our managers, employers and colleagues, as an ongoing commitment to providing high quality services for our clients. In this scenario, Jude has the responsibility to educate the manager regarding an appropriate timeframe for safe and effective service delivery and can seek support to do this from other more experienced members of her team.

Both case studies explore the potential effects of NDIS on the service delivery frameworks expected by employers and organisations. Also, NDIS participants with complex needs are seeking to maximise the effectiveness of the services they purchase. Our role, whether we are early career or more experienced clinicians, includes education for participants, managers, employers and other team members, including planners, regarding appropriate service delivery models for speech pathology services.

Response to ethical challenges

“For ethical problems to be effectively managed, they need to be identified, understood, and decisions need to be made about how to manage them” (Speech Pathology Australia, 2014, p.27). The complexities of the NDIS, due both to participant complexity and the funding environment, create the need to integrate proactive ethical problem-solving into our clinical practice. The Ethics Education Package (2014) is a resource available to SPA members, as a self-guided professional education tool that works through four different theoretical models. Examining the case studies through an appropriate theoretical approach may assist the speech pathologist who is managing ethical problems to identify the ethical issues and potential courses of action. For example, the Casuistry approach, which is grounded in the professional and clinical experience of the speech pathologist, may assist in case study 1 to identify the most important issues on this situation and how similar ethical challenges have been managed previously. The Ethics of Care approach would assist the new graduate in case study 2 to identify the needs of the clients, her role and responsibilities, the barriers that exist in the current situation and the resources required to provide appropriate management or improve the current situation.

Once the ethical issues and challenges within a particular clinical scenario with an NDIS participant have been identified, what happens next? The obligation to act and make proactive ethical decisions need not weigh heavily on the clinician’s shoulders; rather, ethical principles, standards and decision-making frameworks can be useful tools to identify where discourse should occur and what the key topics should be.

As suggested by Lindy McAllister, “like most professional skills, ethical and moral reasoning develop with experience, and ... this development can be supported through mentoring, workplace supervision and professional development programs” (McAllister, 2006, p. 79). Reflection and discussion of the ethical issues that arise in professional practice are key components to developing awareness of the ethical issues and potential courses of action.

In the above scenarios, the issues could be addressed in a number of ways:

- reflection on professional and ethical obligations and responsibilities
- discussion with the employer to describe where the issues sit and identify an appropriate course of action, such as identification of and participation in professional development activities to extend clinical knowledge and skills

- consultation and collaboration within local networks – work colleagues, team leaders, managers, professional supervisor, mentor, local interest groups, and the national speech pathology community through SPA online communities
- direct contact with the SPA NDIS project consultant and professional advisors
- presentation of appropriate information back to the NDIS, including clinical reasoning and evidence base for the recommended intervention. As an organisation, the NDIS has demonstrated a degree of consideration for well-formed arguments and responded to such discussions to inform the frameworks of the scheme.

Conclusion

Communication is an intrinsic human right, and as professionals working with clients presenting with complex needs within a new and, at times, challenging funding environment, speech pathologists have the responsibility to provide appropriate services for their clients. As professionals supporting communicative participation, we also have additional responsibilities to advocate for communication rights within complex systems which may have limited knowledge and awareness. Working within complex and challenging situations is a worthwhile endeavour. There is a range of ethical challenges associated with human service delivery, and speech pathologists provide meaningful services, making a difference to people’s relationships, their community and civil participation, their future and their quality of life.

Our responsibility as ethical practitioners is to utilise methods available to us to identify the ethical issues and challenges within our work, seek advice and support to explore appropriate responses, then work to ensure optimal services are available for our clients.

Disclaimer

The information in the quotes, vignettes and case studies in this article are an amalgam of many real-life scenarios, and were created for the purposes of this article by the authors. The person/s described in the discussion is/are not a real person/s. Any similarity to real people or organisations is coincidental.

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Cathy Olsson is the disability project consultant with Speech Pathology Australia, and is assisting members of the Association to navigate the National Disability Insurance Scheme (NDIS). **Trish Johnson** is the senior advisor ethics and professional issues at Speech Pathology Australia, and is available for support and advice for members experiencing ethical issues and challenges in their professional practice. The Ethics Board of Speech Pathology Australia is actively supporting members facing ethical challenges when working with NDIS participants.

Correspondence to:

Trish Johnson

Senior Advisor Ethics and Professional Issues

Speech Pathology Australia

phone: 1300 368 835

email: tjohnson@speechpathologyaustralia.org.au



Reading instruction for children with ASD

Getting the story straight

Marleen F. Westerveld, Jessica Paynter, and David Trembath

KEYWORDS

AUTISM SPECTRUM DISORDER
READING INSTRUCTION
LITERACY
SPEECH-LANGUAGE PATHOLOGY

THIS ARTICLE HAS BEEN PEER-REVIEWED

Speech-language pathologists (SLPs) have the specialist knowledge to promote children’s literacy learning, especially those at risk for difficulties in literacy acquisition and development. However, three common misconceptions may cause a failure to address the literacy learning needs of children with autism spectrum disorder (ASD). In this article, we question these mistaken beliefs and draw on the available evidence to explain why literacy activities should be incorporated into the SLP’s routine assessment and/or intervention practices for all children with ASD.

Literacy is a fundamental human right (UNESCO, 2008). Until recently, however, there has been little acknowledgement or awareness of the literacy needs of children with disabilities (see Keefe & Copeland, 2011, for a discussion). In fact, a number of assumptions have been documented in the literature about people with disability and literacy. For example, children with autism spectrum disorder (ASD) may be seen as “too cognitively impaired” or “not ready for” support in this domain (Mirenda, 2003). Alternatively, these children may also be thought to be competent in literacy when observed to show skills or strengths in one aspect (e.g., letter knowledge or word reading), but when in fact showing difficulties in other aspects of literacy (e.g., comprehension) (Ricketts, 2011). Such assumptions may lead to neglect of this important skill-set for children with ASD, and have the potential to impact on these children’s participation and achievement in education, the workforce, and society more broadly. This lack of attention to literacy learning may have important ramifications, as long-term outcomes of children with ASD are generally poor across all these areas (e.g., Howlin et al., 2015; Levy & Perry, 2011). Most children with ASD need some support at school, including assistance with learning and communication (Australian Bureau of Statistics, 2014). Moreover, these difficulties continue after school, with more than 80% of children with ASD not completing a post-school qualification (Australian Bureau of Statistics, 2014). The focus of this article is on providing insight and understanding into one aspect of academic achievement that may impact these outcomes: literacy for children with ASD.

ASD is characterised by impairments in social/communicative skills and the presence of restricted and

repetitive behaviours and interests (American Psychiatric Association, 2013). It is estimated to affect approximately 1 in 68 people (Centers for Disease Control and Prevention., 2014) and is associated with elevated rates of intellectual disability (e.g., Fombonne, 2003; French, Betrone, Hyde, & Fombonne, 2013) and challenging behaviour both compared to typically developing children and those with other conditions (e.g., Blacher & McIntyre, 2006; Eisenhower, Baker, & Blacher, 2005; McClintock, Hall, & Oliver, 2003). Although literacy difficulties are not explicitly part of the diagnostic criteria, challenges with literacy, particularly comprehension, are commonly reported (Ricketts, Jones, Happé, & Charman, 2013). Indeed, between 30 and 60% of children and adolescents with ASD are reported to show below average literacy skills (Arciuli, Stevens, Trembath, & Simpson, 2013; Nation, Clarke, Wright, & Williams, 2006; Ricketts et al., 2013). In addition, characteristics of ASD may make individuals particularly vulnerable to difficulties in acquiring literacy skills. For example, difficulties with joint attention, failure to follow pointing, oral language delays, and problems with social orienting, as described in diagnostic criteria (American Psychiatric Association, 2013), may hinder the acquisition and development of literacy. These areas are commonly addressed by speech-language pathologists (SLPs) and can form the foundation for addressing secondary, but related challenges such as literacy. However, literacy skills are typically not included in the remit of SLP interventions for children with ASD (Lanter & Watson, 2008). In this article we will address three common assumptions that may act as barriers to providing literacy support.

Assumption 1: Children with ASD show strengths in decoding

Children with ASD, especially those children who show average or above average intelligence, are frequently labelled as *hyperlexic*. Hyperlexia refers to an imbalance between the ability to read or decode words and the ability to comprehend the written text, with decoding exceeding comprehension (Frith & Snowling, 1983). As young children with ASD often show an interest in letters, and a proportion of children with ASD seem to learn to read without direct instruction, much research attention has focused on this puzzling phenomenon (Newman et al., 2007; Turkeltaub et al., 2004). As a result, in clinical practice, we may incorrectly assume that all children with ASD will have no difficulties developing their reading skills and that reading is in fact a relative strength. The evidence suggests otherwise.



Marleen F. Westerveld (top), Jessica Paynter (centre), and David Trembath

A “pure” hyperlexic profile is not the most common reader profile in ASD. For example Nation et al. (2006) assessed a group of 41 school-age children (age 6–15 years) with ASD who showed sufficient oral language skills to participate. Using the Neale Analysis of Reading Ability – II (NARA: Neale, 1988) to assess the participants’ reading accuracy and reading comprehension skills, only 20 children showed age-appropriate word reading skills, and 10 of these (~25% of the total sample) showed a hyperlexic profile. In addition, 9 children with ASD were unable to read at all, and a further 10 children showed difficulties in accurately reading the passages of the NARA. Taken together these results clearly show that we cannot assume that all children with ASD will develop adequate word-reading skills.

Furthermore, a large proportion of children with ASD who do become fluent decoders show difficulties in deriving meaning from written text (Arciuli et al., 2013; Huemer & Mann, 2010; Nation et al., 2006; Ricketts, 2011). For example, studies investigating the reading abilities of primary school-age children with ASD showed that between 53% (Arciuli et al., 2013) and 65% (Nation et al., 2006) of children showed reading comprehension difficulties. Similar results were found in a study of adolescents with ASD (Ricketts et al., 2013). Of the 100 adolescents who participated in the research, 60% showed reading comprehension difficulties as measured on a standardised reading test. This may not come as a surprise considering the oral language weaknesses that are core symptoms of ASD, but assessment and management of these reading comprehension difficulties may be overlooked in clinical practice. Considering there is emerging evidence for the effectiveness of reading comprehension intervention for students with ASD (El Zein, Solis, Vaughn, & McCulley, 2014), we urge speech pathologists to determine the reading abilities of their clients with ASD and provide intervention as needed.

Literacy learning, however, starts long before children commence formal schooling (Justice, 2006). Given children with ASD are at risk of oral language and literacy difficulties, emergent literacy skills are also important to acknowledge in young children with ASD. Although some evidence exists regarding the reading profiles of school-age children with ASD (see also Jacobs & Richdale, 2014), there is surprisingly little research investigating the emergent literacy skills in young children with ASD prior to school-entry (Westerveld, Trembath, Shellshear, & Paynter, 2015). Results from Westerveld et al.’s (2015) systematic review of the literature showed some evidence of specific early difficulties in development of print concept knowledge (e.g., reading from left to right and pointing to the words on a page). Westerveld et al. (2015) recommended including emergent literacy tasks into the routine assessment battery for preschool children with ASD (see also Lanter & Watson, 2008).

Assumption 2: Cognitive and/or severe communication impairment means children with ASD can’t learn to read

Just over a decade ago, several authors commented on the distinct lack of attention to the emergent and early literacy skills of children with ASD who have severe communication impairments (Koppenhaver & Erickson, 2003; Mirenda, 2003). Since that time, Google Scholar reveals 105 cites to Mirenda’s (2003) article as at 23 September 2015, indicating an increasing interest in this neglected area of academic achievement for children with ASD. Mirenda called for abolishing the “readiness model” of literacy instruction for children without functional speech, that is that literacy

instruction should only commence once students have sufficient verbal skills (e.g., to produce letter sounds) and demonstrate mastery of prerequisite skills such as letter knowledge and phonological awareness. Instead, Mirenda promoted “literacy instruction that incorporates the use of multiple instructional strategies that are carefully matched to the stages or phases of development through which all readers pass on their way from emergent reading to skilled reading” (p. 275). These levels of word learning involve (1) the pre-alphabetic phase, (2) the partial alphabetic phase, (3) the full alphabetic phase, (4) the consolidated alphabetic phase, and (5) the automatic phase (Ehri, 1995). Underpinning this approach is the importance of careful assessment of the student’s current literacy level. This includes children who have limited or no functional speech and rely on augmentative and alternative communication (AAC).

One method of reading instruction for students with severe cognitive abilities is sight-word instruction (i.e., level 1). A recent review of the literature into the effectiveness of sight-word instruction for students with ASD revealed nine small-scale studies involving students aged between 4 and 16 years of age (Spector, 2011). In general results were positive in that all children learned to read printed words by sight, even children who were nonverbal or who had received no prior reading instruction. Unfortunately no evidence was provided regarding generalisation of the results to oral language or more natural reading tasks, so further research is clearly needed. It is also important to point out that this type of instruction may not be suitable for “high-functioning” students with ASD or for students with ASD who demonstrate average word reading skills (Spector, 2011). For those children, as stated previously, we need to ensure literacy instruction is carefully matched to their phase of (reading) development (Mirenda, 2003).

Koppenhaver and Erickson (2003) introduced natural literacy learning opportunities into a preschool classroom for children with ASD and measured the effects on children’s emergent literacy development, including independent book exploration, spontaneous choice of reading- or writing-related activities, and emergent name writing. Some interesting findings emerged when the authors examined the progress made by three children with severe cognitive and communication impairments. First, the authors commented how easy it was to interest the children in literacy-related activities, although each child seemed to favour different types of activities (e.g., books vs. writing tools). Second, the incidental exposure (as opposed to structured systematic exposure) to literacy learning opportunities seemed sufficient for the children to make progress. These results clearly show the importance of exposing preschool children with ASD to literacy-related activities, even those children who have severe communication impairments.

In summary, despite an obvious increase in interest in literacy learning for children with ASD who show severe cognitive and /or communication difficulties, there seems to be little empirical research into literacy instruction for these students across the five different levels of word reading as identified by Ehri (1995). Heeding repeated calls that “all people are capable of acquiring literacy” (Keefe & Copeland, 2011, p. 97), we strongly advise SLPs to include literacy activities for all children with ASD, including those who require AAC.

Assumption 3: Learning styles and children with ASD

Given that learning to read is a fundamental goal of early childhood development, but a documented challenge for

many children with ASD, it is essential that literacy instruction methods accommodate the learning strengths and needs of children with ASD. For SLPs, this means adopting an individualised, theoretically driven approach to ascertaining and accommodating the motivations, learning strengths, and preferences of each client with ASD (Trembath & Vivanti, 2014). Kanner (1943), in his original article describing 11 children presenting with “autistic disturbances of affective contact”, noted that the children presented with a set of essential common characteristics (i.e., social-communication and behaviour impairments), but also “individual differences in the degree of their disturbances, the manifestation of specific features, the family constellation, and the step-by-step development in the course of years (pp. 241–242)”. Although it is uniformly accepted in research and clinical practice that children with ASD present with a spectrum of individual learning strengths and needs, there has been a propensity within the field at times over the past two decades to adopt a somewhat narrower view of children’s “learning styles”. This includes the commonly asserted notion that “children with ASD are visual learners” who are likely to benefit from picture-based instructional methods, despite a concerning lack of research evidence (Trembath, Vivanti, Iacono, and Dissanayake, 2015), and the fact that the notion of “learning styles” has been generally discredited in the broader educational literature (see Pashler, McDaniel, Rohrer, and Bjork; 2008). Such an approach, if adopted, places children at risk of being prescribed interventions, including literacy instruction, in a manner that is non-evidence based.

So how can clinicians accommodate, and where possible harness, the “learning styles” of children with ASD when it comes to literacy instruction? We propose that the first step is to be familiar with the known mechanisms of learning impairment in children with ASD, including difficulties with joint attention, social learning, and imitation outlined above (American Psychiatric Association, 2013). Speech pathologists, and the parents and others they coach to support children’s literacy development, should seek to ascertain children’s abilities in these areas and put in place additional strategies (e.g., extra cues to gain and maintain a child’s visual attention; providing ample opportunities and graduated scaffolding to support imitation) to account for any difficulties during literacy activities (such as shared book reading). The second step is to identify each child’s individual, at times idiosyncratic, motivations and learning strategies, and where possible to incorporate these into the intervention (Winter-Messiers et al., 2007). For instance, SLPs and others may infuse literacy instruction into a child’s particular interest (e.g., drainage systems or vehicle badges) in order to harness the child’s intrinsic motivation for learning on these topics. Above all, our third recommendation is to at all times assume that each child with ASD will present with individual differences in the way he or she learns most effectively, the need for which is clearly evidenced in the rapidly accumulating body of research documenting individual differences in response to interventions amongst children with ASD (e.g., Trembath & Vivanti, 2014).

Conclusion

Literacy skills in ASD are an important topic worthy of further attention. At present there are significant gaps in the literature describing the acquisition, development, and effective interventions for reading in children with ASD. We know that many children with ASD will encounter difficulties with literacy, and areas of strength (e.g., decoding), need

(e.g., oral language impairment), or assumed “learning styles” can lead to unhelpful assumptions. As a result, speech pathology intervention may neglect to incorporate literacy goals tailored to meet an individual child’s learning profile.

Until we have further evidence, we must draw upon the evidence-based practice frameworks by using the best available evidence combined with clinical reasoning and judgement (Hoffmann, Bennett, & Del Mar, 2013). The best available evidence at present includes an extensive literature base on typical development and language-impaired populations (e.g., Catts, Herrera, Nielsen, & Bridges, 2015). This knowledge can be interpreted in conjunction with ASD knowledge and assessment of the individual child to formulate appropriate interventions that include literacy related goals and activities (see Lanter & Watson, 2008, for further recommendations).

Speech pathologists, as part of an interdisciplinary team, are well positioned to address the literacy needs of young children with ASD with their expert knowledge of oral language development and its relationship with literacy development (Speech Pathology Australia, 2011). By including a focus on literacy we may help to bridge the education gap in children with ASD.

Author statement

The authors have no conflict of interest to declare. Dr David Trembath is supported by a National Health and Medical Research Council ECR Fellowship (GNT1071811). This article was processed, reviewed, and accepted under the Guest Editorship of Dr Chris Brebner. David Trembath’s name was withheld from all documents prior to acceptance by Dr Brebner.

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Dr Marleen Westerveld is a senior lecturer in speech pathology in the School of Allied Health Sciences at Griffith University. **Dr Jessica Paynter** is a researcher at the AEIOU Foundation, as well as a registered psychologist in Australia. **Dr David Trembath** is a NHMRC ECR fellow and senior lecturer specialising in the field of autism spectrum disorder at Griffith University.

Correspondence to:
Dr Marleen Westerveld
 Griffith University
 phone: (07) 5678 7658
 email: m.westerveld@griffith.edu.au



The phonological awareness skills of education and speech pathology higher education students during their first semester of study

Marleen F. Westerveld and Georgina Barton

KEYWORDS

HIGHER EDUCATION

PHONOLOGICAL AWARENESS

SPEECH PATHOLOGY

TEACHER PREPARATION

THIS ARTICLE HAS BEEN PEER-REVIEWED

Responding to the urgent call to address the need for appropriate preparation of professional teachers of reading, this preliminary investigation examined the phonological awareness knowledge of Bachelor of Primary Education and Master of Speech Pathology students in their first semester of study before and after their regular course work. This report outlines the results of the study and proposes ways of utilising this information to enhance tertiary teaching practices, with the ultimate aim of raising student performance in the area of phonological awareness.

The ability to read is an essential skill in today's world. Skilled readers not only need to recognise or decode the written words, they also need to understand what those written words mean. Results from the Progress in International Reading Literacy Study (PIRLS; Mullis, Martin, Foy, & Drucker, 2012) showed that Australian students scored significantly lower than 21 other countries, with 24% of the Australian year 4 students performing at the low or below low international benchmarks (Thomson et al., 2012). This is concerning and, accordingly, the value of teaching reading in our primary schools has been well recognised by the Australian government including departments of education. In 2005, the Australian government initiated a National Inquiry into the Teaching of Literacy and identified the importance of "teachers adopting an integrated approach to reading that explicitly teaches phonemic awareness, phonics, fluency, vocabulary knowledge and comprehension" to ensuring reading success (Australian Government, 2005, p. 11). A decade later, a report titled *Action Now: Classroom Ready Teachers*, also known as the TEMAG report (Australian Government, 2015), indicated a continuing necessity for quality and explicit practices to focus on the teaching of reading in the early years and throughout schooling.

Ferrari (2015), in a newspaper article summarising the views of Dr Louisa Moats, noted that "teachers' lack of basic understanding of how language works is the underlying problem of teaching reading in schools". In the last 20 years, Moats has been a keen advocate for improving the language-structure knowledge and skills (e.g., phonological, morphological, and syntactic

awareness) of literacy intervention specialists (Moats, 2014). The underlying rationale is that these professionals must have an explicit knowledge of language structure to teach their students to become capable readers (see Moats, 2014). This paper reports the preliminary phase of a planned longitudinal project aimed at improving the professional preparation of teachers and speech pathologists at an Australian university by tracking one aspect of their language structure knowledge, i.e., phonological awareness, during their first semester of study.

Phonological awareness can be defined as the ability to consciously reflect upon and manipulate the sound structure of spoken words, at syllable (e / le / phant = elephant), onset-rime (r / oom = room), and phoneme (c / a / t = cat) levels (Stahl & Murray, 1994). Phonological awareness is crucial for early reading and spelling success (Stahl & Murray, 1994), and research has clearly established that a large percentage of children with reading difficulties demonstrate poor phonological awareness (Carson, Gillon, & Boustead, 2013). Phonological awareness should not be confused with phonics. Phonics is a teaching strategy that addresses how sounds are mapped to letters or symbols (e.g., what sound does the letter /s/ make?), whereas phonological awareness refers to the ability to recognise and manipulate the sounds in spoken language (e.g., what sound does the word *snake* start with? or how many sounds (not letters) in the word *thought*? answer = 3) (e.g., Gillon, 2004).

Once children commence their formal school education, qualified teachers play an important role in young children's reading development. Teaching of reading has been and still is a large focus in curriculum and policy, both in Australia and internationally (Australian Government, 2005; 2015). Apart from teachers, speech pathologists address literacy development with a range of clients – for example when working with children with spoken language impairment – who are considered at risk of long-term reading difficulties (Catts & Hogan, 2003). Considering the fact that phonological awareness is best taught explicitly, especially with children who have difficulty in literacy acquisition (Gillon, 2004), it stands to reason that both teachers and speech pathologists should display strong phonological awareness skills themselves. Alarming, however, research suggests that education professionals, including early childhood educators and primary school teachers generally present with poor phonological awareness skills (Carroll, 2006; Carroll, Gillon, & McNeill, 2012; Moats, 2003; Spencer, Schuele, Guillot, & Lee, 2008). Although results from Carroll et al.'s (2012) and Spencer et al.'s (2008)



Marleen F. Westerveld (top) and Georgina Barton

research showed that speech pathologists performed much better than teachers or early childhood educators, variability in performance was observed, with some speech pathologists showing unacceptably poor levels of phonological awareness.

Considering that previous research has demonstrated the education professionals' relatively poor performance on phonological awareness tasks in particular, it is not surprising that research into the phonological awareness skills of pre-service teacher education students shows similar results (Carroll et al., 2012; Fielding-Barnsley, 2010; Purvis, McNeill, & Everatt, 2015). Overall, results suggest very low levels of phonological awareness at the phoneme (i.e., sound) level in pre-service teacher education students. Moreover, a recent study by Carroll and colleagues (2012) showed that although Bachelor of Education students in New Zealand improved their phonological awareness performance over the three years of study, their level of phonological awareness at the end of their 3-year degree course was still poor (e.g., mean score of 3.2/10 on the phoneme counting subtest). Research into the phonological awareness skills of speech pathology students is more limited. One fairly recent study of the phonemic awareness skills of speech pathology students was conducted by Robinson, Mahurin, and Justus (2011). A total of 43 undergraduate students in communication disorders completed subtests of the Comprehensive Test of Phonological Processing (CTOPP; Wagner, Torgesen, & Rashotte, 1999), during the first two days of class associated with a course in phonetics. Although these researchers did not report the range in scores, mean performance on the Segmenting Words subtest (requiring the student to segment words into phonemes) was 8.26 (standard score) with a SD of 2.70 indicating that a considerable percentage of the students obtained below average (i.e., $SS \leq 7$) on a test of phoneme segmentation.

The current study aims to address the important issue of adequately preparing our next generation of literacy professionals by investigating the phonological awareness skills of Australian Bachelor of Education and graduate-entry Master of Speech Pathology students at Griffith University. We aimed to (a) determine initial levels of performance at the start of the year, (b) evaluate whether these skills improved following exposure to their regular university courses during their first semester of study, and (c) determine what percentage of students would show mastery of skills at the end of the year.

Method

Ethics permission was obtained from Griffith University (EDN/16/14/HREC).

Participants

Students enrolled in English Education 1: Reading and Writing in the Early Years (across three campuses) and Communication and Swallowing Disorders 1 were invited to participate if they attended the tutorial during which the surveys were administered. Out of a total of approximately 450 Bachelor of Education students, 111 completed the survey at Time 1 and 68 at Time 2. A total of 30 (out of 35) Master of Speech Pathology students completed the survey at Time 1; at Time 2, there were 27 responses.

Data collection

Students were asked to complete a written survey (approx. 7–12 minutes) during class-time. There were two data collection points: (a) at the start of semester 1 (weeks 1 or 2) and (b) towards the end of the semester (weeks 12 or 13).

Survey

The survey, previously validated in a study by Carroll et al. (2012), consisted of a range of questions testing phonological and morphological awareness. For the current report, students' responses to four questions addressing phonological awareness (at syllable and sound/phoneme level) were analysed. The full questions are provided in the Appendix. The survey was given to the students at the start of the tutorial and no further instructions were provided. In contrast to the procedure used by Carroll et al. (2012), students were provided with multiple choice options (as opposed to open answer questions).

Regular class instruction

During their first semester of study, Bachelor of Primary Education students typically spend one 2-hour tutorial out of 12 focusing on phonics and one 2-hour tutorial on phonological awareness and teaching phonics (Hill, 2012, chapters 6, 10 and 11, respectively) in a course focusing on early years literacy. In the Master of Speech Pathology program, first-year students attend a 3-hour workshop that focuses on phonological awareness (including development, assessment, and intervention) during their first semester of study. In addition, the concept of phonological awareness is addressed in a problem-based learning case (in week 8) about a school-age girl with language-learning difficulties, who demonstrates poor phonological awareness skills.

Results

Student responses from paper copies of the survey were entered into Survey Monkey® by independent research assistants. Responses were downloaded from Survey Monkey into Excel and exported into SPSS (PASW, 2012). First, we wanted to determine the level of performance at the start of the year as well as the percentage of students who showed mastery of skills (i.e., performance of at least 80% correct on each skill) at Time 1. As shown in Tables 1 and 2, although students generally performed well on the syllable identification task (mean scores of 9.1–9.6 out of 10), a high percentage (43% to 88%) of the students struggled with tasks requiring the identification of the number of sounds in words (i.e., phoneme awareness).

To determine if there were significant differences in performance between the Time 1 and Time 2 scores, independent samples t-tests were used. The samples were considered independent as we did not gather data to match Time 1 to Time 2 responses. As shown in Table 1, students studying speech pathology showed significantly better performance on two measures: identifying the number of sounds in a word (Question 2), $t(55) = -2.485$, $p < .001$ and identifying the second sound in a word (Question 3), $t(55) = -2.218$, $p = .031$. No other significant differences ($p < .05$) in performance were found in either group of students.

Finally, we wanted to determine the percentage of students who showed mastery of skills at Time 2. As shown in Table 2, there seemed to be a noticeable increase in performance at Time 2 in the speech pathology students when asked to identify the number of sounds in a word.

Discussion

The results from this study showed that, at the outset of their respective training courses, cohorts of teacher education and speech pathology students demonstrated adequate levels of performance on tasks measuring identification of syllables in words and identifying the final sounds in words, with at least 73% of students

Table 1. Student performance (in number of items correct) at Time 1 and Time 2 with means (standard deviations) and ranges reported

Question		Education Time 1	Time 2	Speech pathology Time 1	Time 2
	<i>n</i>	111	68	30	27
1	No. of syllables (max 10)	9.1 (1.4) 1–10	9.5 (.92) 6–10	9.6 (.67) 8–10	9.3 (1.0) 7–10
2	No. of sounds (max 10)	2.6 (3.0) 0–10	2.0 (2.6) 0–10	5.4 (2.9) 0–10	7.9 (2.1)* 3–10
3	2nd sound in word (max 5)	1.7 (.94) 0–4	1.8 (.90) 0–4	2.8 (.86)* 1–4	3.3 (.81)* 1–4
4	Last sound in word (max 5)	3.8 (1.3) 0–5	3.9 (1.31) 0–5	4.0 (.89) 1–5	4.3 (.71) 3–5

Note: * indicates the students showed significantly better performance ($p < .05$) at Time 2.

Table 2. Percentage of students obtaining scores of 80% or higher

Question		Education Time 1	Time 2	Speech pathology Time 1	Time 2
1	No. of syllables	91.9%	92.6%	100%	92.6%
2	No. of sounds	11.7%	10.3%	26.7%	63%
3	2nd sound in word	1.9%	3%	20%	44.4%
4	Last sound in word	73.9%	72.1%	76.7%	85.2%

demonstrating > 80% correct on these tasks. However, lower levels of performance were found in both cohorts of students when asked to identify sounds in words (total number of sounds and second sound in a word). These results indicate that students' previous education had not been successful in promoting phonological awareness at sound-level (i.e., phonemic awareness). Of note, 85% of the education students had just completed year 12 of high school, whereas the Master of Speech Pathology students had all completed a bachelor degree. The performance of the education students is surprisingly similar to that found by Carroll et al. (2012). Carroll and colleagues measured the performance of 153 first-year New Zealand Bachelor of Teaching and Learning students and reported a mean score of 2.03 (SD 2.08) on the total number of sounds task. In the current study, performance of the education cohort measured 2.6 (SD 3.0). Taken together, these findings indicate that regardless of the education system (or country), phonological awareness at the phoneme level in university students is low (at least at the outset of their training course) and will need to be developed as part of their degree courses, particularly when the teaching of reading is emphasised in curriculum and policy (see also Fielding-Barnsley, 2010).

In response to our second research question, which posed whether exposure to their regular course work during their first semester of study would enhance students' performance in phonological awareness, we found no significant difference between education students' phonological awareness skills at Time 1 and Time 2. This is concerning as results from Carroll et al.'s (2012) study showed that third-year Bachelor of Teaching and Learning students did not show significantly better performance than their first-year peers. Different results

were found for the speech pathology students. Significantly better performance at Time 2 was seen on two tasks: (a) identifying the numbers of sounds in a word, and (b) identifying the second sound in the word. Although we did not set out to compare the phonological awareness skills across student cohorts, the difference in progress made by the two cohorts following one semester of university studies is striking. The most likely explanation is that the semester 1 tutorials related to phonetic transcription helped improve the speech pathology students' phonological awareness skills at phoneme level (see Robinson et al., 2011). Regardless, as shown in Table 2, the percentage of speech pathology students obtaining at least 80% correct on these two tasks was still low (63% and 44%, respectively). One possible explanation may be that the students need more time to consolidate their skills and re-testing the students on a yearly basis may help confirm if this hypothesis is true. Taken together, more explicit teaching of phonological awareness in both degree courses seems warranted.

Limitations

It is not clear if the results reflect the performance of the full Bachelor of Primary Education cohort. Future research should investigate ways of ensuring a higher percentage of students complete the survey (or self-quiz – see suggestions below). It is also not clear if the use of verbal instructions as opposed to written instructions would have influenced the results.

Recommendations and future directions

Based on the findings from this preliminary study, a change in the current course work is recommended to ensure an improvement in students' phonological awareness skills. Although there is limited evidence regarding the optimal model for teaching phonological awareness (see Carroll,

Gillon, & McNeill, 2015, for a review), suggested changes include:

- From the outset, providing students with an explanation of the importance of phonological (including phonemic) awareness to their future professional practice (Griffith University Learning and Teaching principle 3). This will help make the learning activity more accessible/understandable and will help build a realistic expectation of what the course's learning objectives, teaching and learning activities, and assessment tasks may entail (Myers & Nulty, 2009).
- Embedding a learning activity on explicit teaching of phonological awareness (at phoneme level) in one of the tutorials. Explicit teaching of phonological awareness has been found to be the most effective method for promoting phonological awareness in preschool children and in children with language and/or reading difficulties

(Gillon, 2004; Gillon & Dodd, 1995; Phillips, Clancy-Menchetti, & Lonigan, 2008).

- Developing an on-line task or module (including a quiz) to help students consolidate their phonological awareness skills. Completing this module and passing the quiz can be made compulsory, either as a hurdle task or an assessment task. Research clearly suggests that assessment tasks influence student learning (Biggs & Tang, 2011).

New cohorts of students will be surveyed at the outset of their training courses at the start of 2015 and following their first semester of training to determine the effects of these proposed changes to their course work on students' phonological awareness skills. In addition, current students' performance will be re-surveyed on a yearly basis to determine progress over time as a result of their regular coursework and educational/clinical placements.

Appendix: Survey questions (Carroll et al., 2012)

Instructions: This section involves questions regarding your knowledge of language structure. These questions require you to think about your responses. Give it your best shot!

How many SYLLABLES in each of the following words?

	1	2	3	4	5	6	7	>7
animal								
caution								
hastily								
catalyst								
revolution								
crustacean								
invincible								
inconceivable								
stealthily								
fortunate								

How many SOUNDS (not letters) in each of the following words?

	1	2	3	4	5	6	7	8	9	10
flag										
scone										
rust										
clump										
change										
straight										
chemist										
hiccup										
thought										
instrument										

What is the SECOND sound (not letter) in each of the following words?

	ie	i	r	w	ee	k	kr	h	other
bride									
whim									
scream									
queen									
thrive									

What is the LAST SOUND (not letter) in the following words?

	g	f	p	h	oa	e	other
laugh							
though							
giraffe							
crisp							
arrange							

Author acknowledgements and declaration

The authors have no conflict of interest to declare.

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Dr Marleen Westerveld is a senior lecturer in speech pathology in the School of Allied Health Sciences at Griffith University, Gold Coast, Australia. Marleen has been a practising speech pathologist for more than 25 years and has research and clinical experience in working with children with spoken and/or written language disorders. **Dr Georgina Barton** is a senior lecturer in the School of Education and Professional Studies at Griffith University, Brisbane, Australia. She has over 20 years experience working in schools as a teacher and literacy intervention leader. Her research focuses on the teaching of reading with a focus on multimodality as well as writing across curriculum areas.

Correspondence to:

Marleen F. Westerveld, PhD

Senior Lecturer in Speech Pathology
Griffith Institute for Educational Research
Griffith University, Qld 4222
phone: (07) 5678 7658
email: m.westerveld@griffith.edu.au



Communication partner training for nurses

A pilot study of an online learning program

Kathryn McKinley and Robyn O'Halloran

Communication partner training improves the communication skills of conversation partners of people with aphasia. Health care providers who work nightshifts or on weekends may not be able to access this training. This study investigated if an online education program was associated with improved nursing knowledge of communication strategies and improved perceived knowledge and confidence when communicating with patients with aphasia. This mixed method study found that an online education program significantly increased nurses' perceived knowledge about aphasia, knowledge of communication strategies, and perceived confidence communicating with patients with aphasia. Further research is needed to determine the effects of this training on interactions with patients.

Effective health care communication between patients and health care providers is a central tenet of patient-centred care (Bensing, Verhaak, van Dulmen, & Visser, 2000), and has been linked directly and indirectly to a range of positive health outcomes such as improved pain control, increased functional ability, and emotional well-being (Street, Makoul, Arora, & Epstein, 2009). Yet many patients with communication disabilities and their health care providers are unable to communicate effectively. Approximately half of all patients observed communicating with health care providers in acute stroke units were unable to communicate their typical health care needs (O'Halloran, Worrall, & Hickson, 2012). When asked, patients with communication disabilities describe a range of communication difficulties such as "difficulty remembering what to say, not being understood, feeling the doctor did not believe them, being rushed, and not following what the doctor said" (Murphy, 2006, p. 55). The inability to effectively communicate puts patients with communication disabilities at risk of a range of poor health outcomes including misdiagnosis (Hines, 2000), preventable adverse events (Hemsley, Werninck, & Worrall, 2013), inadequate pain relief and even death (Mencap, 2007).

Being unable to communicate effectively may be due in part to the nature and severity of a person's communication

impairment(s), as well as the number and type of barriers to communication in the health care environment. A 2012 meta-synthesis identified a range of environmental factors that influence health care communication. These related to the individual health care provider, such as the provider's knowledge and attitude, and hospital processes, such as opportunities for communicating (O'Halloran, Grohn, & Worrall, 2012). The lack of knowledge and skills of the communication partner has also been cited as a communication barrier specifically for people with aphasia (Parr, Byng, Gilpin, & Ireland, 1997). An observational study by Hersh, Godecke, Armstrong, Ciccone, and Bernhardt (2014) suggests that the lack of knowledge and skills of the communication partner continues to be barrier for patients with aphasia in hospital. In their study, three inpatients, two of whom had aphasia, were videorecorded continuously for 7.5 hours. The two patients with aphasia had few opportunities to engage in conversation with nursing staff and the nurses employed very few conversation strategies to support communication with them.

Communication partner training (CPT) is a proven intervention that focuses on enhancing the knowledge and skills of the communication partner in order to support the person with aphasia to participate in conversation more successfully (Simmons-Mackie, Raymer, Armstrong, Holland, & Cherney, 2010). CPT has also been extended to support communication with people with a range of different communication disabilities. Simmons-Mackie (2014) describes four levels of CPT training. The aim of level 1 training is to raise the awareness of communication partners about aphasia, how aphasia can impact on communication, and how communication support can help the person with aphasia communicate. Level 2 training aims to build awareness plus provide communication partners with strategies to facilitate communication in a specific activity, such as teaching a doctor how to use strategies to facilitate taking a medical history. Level 3 training builds on level 2 training and aims to develop the person's skills in facilitating communication across a variety of situations using a range of different supports and resources. Finally, level 4 training is directed towards teaching the communication partner how to train others.

CPT is needed at all levels and while CPT may be necessary for health care providers, it may not be sufficient in the hospital setting to ensure communicative access for people with aphasia (see Simmons-Mackie, Kagan, O'Neill Christie, Huijbregts, McEwen, & Willems, 2007). However, level 1 training that aims to raise awareness

KEYWORDS

APHASIA
COMMUNICATION PARTNER TRAINING
HOSPITAL
NURSES
ONLINE

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Kathryn McKinley (top) and Robyn O'Halloran

may be an important start because it has the potential to increase staff awareness of communication breakdowns (Simmons-Mackie, 2014) and awareness that patients may have communication impairment(s). It may also result in a willingness to try different kinds of communication supports to facilitate more effective communication and appropriate referrals to speech-language pathologists.



“Communicating with patients with aphasia” online training program

Online learning may be an effective way to increase health care providers' awareness of about aphasia, the impact of aphasia on communication, and how strategies can facilitate more effective communication. Online learning provides staff with the opportunity to access education at any time of the day or night and any time during the week, it is well suited to health care staff who work different shifts and on weekends (Purkis & Gabb, 2013). It also means that staff can access the same education several times if required. Although there are some excellent online resources available about aphasia, such as the Aphasia Stimulations (Aphasia Corner & Hinckley, n.d.) and Better Conversations with Aphasia (Beeke et al., 2013), there are no generic introductory online training programs available to raise the awareness of health care providers about aphasia.

Therefore this study had two main aims. The first was to determine if an online training program increased the awareness of nurses about aphasia and the strategies that may support communication with patients with aphasia. The second aim was to investigate the feasibility of providing online training about aphasia to health care providers in a health care setting.

Method

Design

A mixed method design was used to investigate (a) the effect of online training on nurses' knowledge of aphasia and communication strategies, and their confidence communicating with patients with aphasia, and (b) the feasibility of delivering this kind of training online. The effect of the online training on perceived confidence communicating with patients with aphasia was investigated by administering a survey before and after the training. The effect of online training on knowledge of communication strategies was investigated by administering a survey before and after training, and by asking nurses to identify appropriate strategies that they could use to communicate with a patient before and after training. The feasibility of online training was investigated by asking participants to

evaluate the training. Ethics approval was obtained from the relevant hospital and university committees prior to any data collection.

Participant recruitment

As this was a pilot study, all registered nurses working on the acute neurosurgical and stroke wards in a tertiary hospital in Melbourne were invited to participate. To increase the likelihood of obtaining complete data sets, casual employees were excluded from participating. The first author attended six nursing handover meetings and sent information about the study via email. Nurses who were interested in the study completed a participant information and consent form that was available on the ward. Information about the nurses who participated in this study is provided in the Results section.

Data collection

Basic demographic information about the nurses was collected. This included years worked as a registered nurse, years worked with patients with aphasia, and whether or not they had received any previous education or training in communicating with patients with aphasia. The nurses' knowledge and confidence in communicating with patients with aphasia was assessed before and after the training in a number of different ways (see below).

Knowledge of aphasia

Three measures were used to assess each nurse's knowledge of aphasia. The first and second measures assessed the nurses' perception of their understanding of aphasia and their knowledge of communication strategies respectively on 4-point ordinal scales. The third measure assessed each nurse's knowledge of communication strategies by asking the nurse to list communication strategies that would (a) enable respectful communication with a patient with aphasia; (b) facilitate the patient's understanding; (c) facilitate the patient's ability to express a message; and (d) check understanding of the message.

Confidence communicating with patients with aphasia

The nurses' confidence communicating with patients with aphasia and their confidence repairing communication breakdown was measured on separate 4-point ordinal scales from “not confident” to “fully confident”. All the measures of nurse knowledge and confidence were conducted via SurveyMonkey™, and are provided in the Appendix.

Feasibility

Quantitative and qualitative data were collected in the post training questionnaire to explore the feasibility of online training. Data on the number of nurses who enrolled in and participated in the online training was collected. Nurses were asked to provide any feedback or recommendations regarding the future development of the online training in an open comments section.

Materials

The *Communicating with patients with Aphasia online training program* was developed specifically for this research. The online training program consisted of background information on the incidence of aphasia post stroke and a description of the potential implications of aphasia on the patients' ability to communicate and participate in their health care in hospital. The online module also provided a description of different ways of supporting

patients with aphasia in conversation, drawing on materials that the first author had acquired from attending training at the Aphasia Institute in Canada and Connect in the United Kingdom. Information on ways to support patients with aphasia was separated into four categories: (a) health care professional behaviours that communicate a respectful, positive attitude towards people with aphasia; (b) communication strategies that help patients understand the message; (c) communication strategies to help patients get their message out, and (d) ways to check that the health care professional has understood the patient's message. The online training included video material of people with aphasia who described what it is like to have aphasia in hospital. There was also video material demonstrating how health care professionals might communicate with people with aphasia in supportive and less supportive ways. Pilot testing indicated that the online module took approximately 30 minutes to complete.

Data analysis

A Wilcoxon's Signed Rank Test was used to investigate changes in perceived knowledge and confidence when communicating with patients with aphasia. In order to investigate any changes to the number of appropriate communication strategies following training, the second author reviewed all the strategies that nurses listed, and categorised those strategies as appropriate or inappropriate for people with aphasia. For example, when asked to identify communication strategies that help the patient with aphasia understand you, one nurse provided the following strategies before training: "speak loudly", "speak slowly", and "speak clearly". The two strategies "speak slowly", and "speak clearly" were categorised as appropriate, and the communication strategy "speak loudly" was categorised as inappropriate. The first author then checked the categorisations. When any categorisation of a strategy was unclear to the first author, both authors discussed the categorisation until they reached agreement. A repeated measures t-test was used to investigate any change in the number of appropriate communication strategies identified before and after training using SPSS, version 22.0 (IBM, 2013). The feasibility of the online training program was analysed by calculating the number of nurses who enrolled in and completed the training program. Feasibility was also explored qualitatively by conducting a descriptive coding of the feedback provided by the nurses about the online training (Morse & Richards, 2002).

Results

Sample demographics

The pre training assessments were conducted between July and August 2013. Nurses completed the online training

in September and the post training assessments were conducted immediately afterwards in September and October 2013. A total of 34 nurses were recruited to the study. Twenty-eight completed the demographic and pre training assessments. Twenty nurses completed the online training and 19 completed the post training assessments. Each of the 19 nurses who completed all the assessments



Rating the videos observed in the online training program

and online training had worked as a registered nurse for less than a year to more than 12 years (mode 1–4 years). Similarly they had cared for patients with aphasia for less than a year to more than 12 years (mode 1–4 years). Seven of the 19 participants had completed some training in communicating with patients with aphasia prior to this study. No further details on the nature of this training were collected. The following results are based on analysis of the 19 participants who completed all the assessments.

Changes in knowledge of communicating with patients with aphasia

As described above, knowledge was assessed in three ways. The median score on "perceived understanding of aphasia" rating scale increased from a pre-training level of "basic understanding" to "good understanding" following training. Despite having fewer than 28 participants complete the training, a Wilcoxon Signed Rank Test indicated that this was a statistically significant increase, $z = -3.358, p < .01$, with a large effect size ($r = .54$). There was also a significant increase in the nurses' rating of their knowledge of communication strategies from a median score of basic knowledge of strategies pre training to a median score of good knowledge of strategies after training, $z = -2.887, p < .01$, with a moderate to large effect size ($r = .46$).

Table 1. Knowledge of appropriate communication strategies before and immediately after training

	Appropriate strategies before training (n = 19)		Appropriate strategies after training (n = 19)		p
	Range	Mean (SD)	Range	Mean (SD)	
Purpose of communication strategy					
To promote respectful communication	1–5	2.89 (1.29)	1–14	5.11 (3.32)	0.01
To help patients with aphasia understand the message	0–6	2.53 (1.35)	0–7	3.68 (2.16)	0.047
To help patients with aphasia get their message out	1–4	2.16 (0.96)	1–5	3.05 (1.22)	0.025
To check the nurse has understood	0–2	1.05 (0.62)	0–5	2.16 (1.3)	0.005

This increase in knowledge of communication strategies was also reflected in the number of appropriate communication strategies nurses identified before and after training to: (a) communicate a respectful, positive attitude; (b) help a patient understand the message; (c) to help patients get their message out; and (d) check that the nurse has understood the patient's message. Descriptive analyses and paired samples t-tests were conducted to compare the number of appropriate strategies identified before and after training. These are depicted in Table 1 and indicate a significant increase in the number of appropriate strategies identified by nurses across all four situations.

Changes in confidence communicating with patients with aphasia

There was also a significant increase in the nurses' reported confidence communicating with patients with aphasia following the online training. The median score prior to training was "somewhat confident" which increased to "mostly confident" after training and a Wilcoxon Signed Rank Test indicated that this change was statistically significant, $z = -3.419, p < .01$, with a large effect size ($r = .55$). There was also a shift in the median score on confidence using communication strategies when communication breaks down with patients with aphasia from "somewhat confident" to "mostly confident", which was also statistically significant, $z = -3.419, p < .01$, with a large effect size ($r = .55$).

Feasibility of online training

While 34 nurses expressed interest in participating in the study, 27 (79%) completed the pre training assessments and only 20 (58%) completed the training. Of the 19 nurses who completed the post training assessments, 18 (95%) agreed or strongly agreed with the statement that the online learning program met their needs. These nurses reported that the online learning program was easy to access day or night and was easy to use. They noted that the content was detailed, interesting, helped them learn new communication strategies, and was easy to understand. Six nurses made particular mention of the value of including videos of people with aphasia and that this helped them gain a greater understanding of the perspectives of people with aphasia in hospital, and how to use communication strategies in conversation with people with aphasia. Difficulties with the online learning training related to computers not working, limited access to computers with speakers, and finding a quiet place to listen to the training program. Several recommendations were made to improve the training. These included providing immediate feedback after the videos to highlight the communication strategies that were used, being able to print off a one page summary with key points to serve as reminders about the communication strategies, and having additional face-to-face in-services so that nurses could practise the communication strategies that had been learned. Other suggestions related to the availability of headphones in order to hear the videos more clearly.

Discussion

This pilot study explored the effectiveness of a specifically designed online education program to increase nurses' knowledge of and confidence in working with patients with aphasia, and the strategies that may support

communication with patients with aphasia. The results indicated that, as a group, nurses who completed the online education program experienced a significant increase in their knowledge of aphasia, appropriate communication strategies, and in their perceived knowledge and confidence in communicating with patients with aphasia. This study indicates that online training was associated with an increase in awareness of health care providers about aphasia and that strategies can facilitate communication with patients with aphasia. However, an experimental study with a control group would need to be conducted to determine if online training causes this increase in awareness.

While this study provides evidence only of an associated perceived increase in knowledge of aphasia, knowledge of communication strategies, and perceived confidence communicating with patients with aphasia, these may be important. One of the findings of the study conducted by Hersh and colleagues (2014) was that nurses often used closed questions with patients with aphasia and tended to limit conversation to aspects of physical care. It may be that feeling more knowledgeable and confident will help nurses engage patients with aphasia in conversation more. Further research is needed to determine if this is the case.

Further research is also required to determine if increased knowledge of communication strategies, increased perceived knowledge, and confidence communicating with patients with aphasia translates to the appropriate use of these communication strategies on the ward, and more importantly, whether they result in more successful communication between patients with aphasia and their health care providers. Direct observation like that conducted by Hersh and colleagues (2014) would be one way to explore this question.

Finally, while online delivery of education and training was feasible for most nurses, it was not suitable for all. Although 34 nurses expressed interest in undertaking the study and 27 completed the pre training assessments, only 20 nurses completed it. The scope of ethics approval did not permit identification of those nurses who did not complete the training. Future research needs to include this to better understand why some nurses did not continue with the training. In addition even though 18 nurses who completed the post training assessments reported that the training met their needs, one nurse reported that it did not. Furthermore, even though there was general support for online training, many nurses also wanted additional training opportunities to practise the communication strategies face to face. This perhaps is also a sign that the online education was effective in that the nurses were aware of the need to practise these communication strategies and interested to do so. Online training is associated with an increased awareness of aphasia and a greater understanding of communication strategies to support people with aphasia, and provides a small step towards creating a more accessible communication environment for patients in hospital.

Acknowledgements

Kathryn McKinley completed this project as part of a Masters in Health Administration, supervised by Adam Ferrier, Dr Priscilla Robinson and Dr Lindsay Carey. Thanks to the Jack Brockhoff Foundation for providing funding for this study.



Appendix. Confidence communicating with patients with aphasia questionnaire

Assessing perceived knowledge of aphasia

- Please rate your understanding of aphasia
No understanding – Basic understanding – Good understanding – Excellent understanding
- Please rate your knowledge of communication strategies
No knowledge – Basic knowledge – Good knowledge – Excellent knowledge

Assessing knowledge of communication strategies

- What can you do to facilitate respectful communication with people with aphasia?
- What strategies can you use to help people with aphasia to understand you (e.g., instructions, questions)?
- What strategies can you use to help people with aphasia to communicate their message?
- What strategies can you use to check you have understood what the person with aphasia is trying to communicate?

Assessing confidence communicating with patients with aphasia

- How confident are you communicating with someone with aphasia?
Not confident – Somewhat confident – Mostly confident – Fully confident
- How confident are you in using strategies and attempting to repair breakdowns in communication?
Not confident – Somewhat confident – Mostly confident – Fully confident

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Kathryn McKinley is the speech pathology manager at St Vincent's Hospital in Melbourne and completed this project as part of the Master of Health Administration at La Trobe University. **Dr Robyn O'Halloran** is a senior speech pathologist at St Vincent's Hospital and lecturer in Human Communication Sciences at La Trobe University.

Correspondence to:

Kathryn McKinley
Speech Pathology Manager
St Vincent's Hospital
41 Victoria Parade, Fitzroy, Vic. 3101
phone: +613 9231 3846
email: kathryn.mckinley@svha.org.au



Stuttering prognosis and predictive factors of treatment outcome: A review

Charn Nang and Natalie Ciccone

KEYWORDS

ONSET
PREDICTION
PROGNOSIS
RECOVERY
STUTTERING
TREATMENT OUTCOMES

THIS ARTICLE HAS BEEN PEER-REVIEWED



Charn Nang (top) and Natalie Ciccone

There is value in understanding the prognostic indicators of stuttering onset and stuttering persistence due to the associated negative life consequences. Stuttering therapy can be beneficial, but not all individuals respond equally to therapy. Knowledge of the factors relevant to treatment success is required to enhance client outcomes. This review summarises and compares the prognostic factors of stuttering, as well factors that predict treatment outcomes. Prognostic indicators for stuttering onset include positive family history, age, and gender; whereas for persistent stuttering they are gender, age of onset, time since onset, and family history of persistence. The most consistent factor for predicting treatment outcomes is pre-treatment stuttering rate. However, there is lack of data for predictive treatment factors. Overall, the findings of studies of prognostic and predictive factors of stuttering need replication, but with improved study design. In the meantime, a systematic review of existing literature is recommended to synthesise and quantify the strength of each factor.

Stuttering is defined as a disorder of speech production, specifically in the rhythm of speech (Bloodstein & Bernstein Ratner, 2008). Speakers know what they want to say but have difficulty in doing so due to involuntary disfluencies characterised as repetitions, prolongations, and cessation of sound. Negative consequences and feelings associated with stuttering may begin as early as the preschool years (Yaruss, 2010). For those with chronic stuttering, difficulty with producing fluent speech can negatively impact on all domains of an individual's life including education attainment (O'Brian, Jones, Packman, Menzies, & Onslow, 2011) and employment opportunities (Yaruss, 2010).

Prognostic and predictive factors

The importance of prognosis is emphasised in evidence-based practice where clinical decisions should be made

based on an integration of the current best evidence, clinician and client-based factors, and the service setting (Hoffmann, Bennett, & Del Mar, 2013). An understanding of which client factors may provide information on the individual's prognosis is required to improve client outcomes and to ultimately inform health policy.

As a broad term, *prognosis* means "foreseeing, predicting, or estimating the probability or risk of future conditions" (Moons, Royston, Vergouwe, Grobbee, & Altman, 2009, p. 1317), and the relevant factors are clinical or biologic characteristics that are objectively measured. They include factors such as an individual's age, gender, history, symptoms, signs, and diagnostic test results.

A more specific medical definition of a *prognostic factor* is a measurement that is associated with the natural progression of a disease, independent of therapy (Gordis, 2014). It provides information about the likely course of a disease or condition in an untreated individual. However, prognostic factors do not have to be specifically linked to an illness or presence of a health condition. They can also be used to predict the future of healthy individuals (Moons et al., 2009). Therefore, in stuttering the relevant prognostic factors are ones that can identify (a) subgroups of those who start to stutter and those who do not; and (b) within untreated individuals who stutter, subgroups of those who recover and those whose stutters persist.

On the other hand, a *predictive factor* provides a measurement of outcome (with response or lack of) that is associated with a specific therapy (Gordis, 2014). Valid and reliable predictive factors can be used to select the therapy with the highest likelihood of efficacy for the individual patient in order to inform tailor-made treatment. Accordingly, predictive factors can be used to identify subpopulations of patients that are most likely to benefit from a given therapy (Adolfsson & Steineck, 2000). Regarding stuttering, predictive factors are ones that can account for subgroups of individuals having different treatment outcomes, such as individuals who recover compared to those who persist with stuttering after some form of treatment, or those who maintain treatment gains compared to those who relapse.

As both prognostic and predictive factors are related to the outcome of an individual who develops a disease or health condition, the two concepts are related. Nevertheless, the extent of this relationship is unknown for stuttering. A prognostic factor may or may not also be predictive of treatment outcomes (Adolfsson & Steineck, 2000).

Aims of this review

A comprehensive systematic review of the prognostic and predictive factors of stuttering is beyond the scope of this article. Instead, the aim is to provide a synopsis of prognostic and predictive factors, and to present an argument for why there is a need for a comprehensive systematic review of the topic to be conducted. There are no previously published reviews of predictive factors of treatment outcomes of stuttering. In contrast, there are some previous published reviews of stuttering prognostic factors, for stuttering onset and for persistence of stuttering without treatment. For example, Yairi and Ambrose (2013) discuss the incidence, prevalence, natural recovery and persistency, and subtypes of stuttering in light of recent research advances. While the literature in this area has not changed dramatically in the past 25 years, more recent studies, including a prospective, community cohort study by Reilly and colleagues (Reilly et al., 2013), are contributing new insights into prognostic factors, outlined below.

Prognostic factors associated with stuttering onset and persistent stuttering

Stuttering onset

The onset of stuttering usually occurs between 2 and 5 years of age (Bloodstein & Bernstein Ratner, 2008). The prevalence of stuttering, or percentage in a particular population at a given time, is just below at 0.72% (Craig, Hancock, Tran, Craig, & Peters, 2002). Recent incidence data of the lifetime risk for stuttering indicate a rate of between 8% (Dworzynski, Remington, Rijdsdijk, Howell, & Plomin, 2007) and 11% (Reilly et al., 2013). Accurately predicting who will stutter is challenging given there is no single known cause. However, in recent years, there has been converging evidence to indicate that stuttering is a complex neurological disorder of speech motor control with genetic influences (Dworzynski et al., 2007).

Genetics

Regarding prognostic factors of stuttering onset, there is a tendency for stuttering to run in families, with approximately 30%–50% of people who stutter reporting a positive family history (Bloodstein & Bernstein-Ratner, 2008). Stuttering is more common in monozygotic twins (52%) than in dizygotic twins (12%) (Dworzynski et al., 2007), but the specific role of genetics in stuttering onset is still somewhat unclear. Linkage studies have analysed the genetic marker(s) for stuttering in affected and unaffected members in families (Yairi & Ambrose, 2013). Such studies have reported multiple genes that could be related to stuttering. However, the findings are inconsistent and need replication. In Reilly et al.'s (2013) study, logistic regression analysis found that being a twin was a significant prognostic variable and family history of stuttering was close to significant ($p = .07$) for predicting stuttering onset by 4 years of age.

Age

Age is a relevant prognostic factor for onset of stuttering. The older a child is, the less risk they have of beginning to stutter. Reilly et al. (2013) reported that the incidence for stuttering onset slowed markedly after 3.6 years of age. Similarly, Craig et al. (2002) found that a child of 6 years or older is 75% less likely to start stuttering when compared with younger children.

Gender

There are conflicting findings regarding gender as a prognostic factor. Yairi and Ambrose (2013) concluded that only small differences have been found between males and females for stuttering onset, whereas Reilly and colleagues (2013) reported that being male was a significant risk factor for stuttering onset by age 4.

Neurology

Neurological studies of factors associated with stuttering onset are emerging. To illustrate, brain scans of preschool aged children, taken soon after the onset of stuttering, have revealed deficiencies in left grey matter volume when compared to fluent controls (Chang, Erickson, Ambrose, Hasegawa-Johnson, & Ludlow, 2005).

Maternal education

Reilly et al. (2013) reported that by age 4 ($n = 1619$), higher maternal education was an additional significant prognostic variable for stuttering onset using logistic regression analysis. The authors speculated that this may be due to more reports of stuttering in children from mothers who are more highly educated and aware of stuttering.

Persistent stuttering

The difference between the incidence and prevalence rates has been attributed to the rate of natural recovery in a large proportion of people who stutter. Some disagreement as to the definition of natural recovery exists (Bloodstein & Bernstein Ratner, 2008), but it is generally considered to be recovery without clinical intervention (Yairi & Ambrose, 2013). Alternatively, treatment assisted recovery is sometimes referred to, and the distinction between this and natural recovery should be made clear in studies. At times it is not, and this can be problematic in defining relevant prognostic factors to predict those who recover or persist with stuttering without clinical treatment.

It has been suggested that up to 74% to 83% of children who start to stutter recover naturally (Ambrose & Yairi, 1999; Dworzynski et al., 2007), but this also means that approximately 1 in 5 of these children will develop a persistent stutter. It is of interest to be able to predict if a child who has started to stutter will naturally recover in order to accurately prioritise therapy services to those at greater risk.

Genetics

Persistent stuttering has been found to relate to positive familial history of stuttering (Yairi & Ambrose, 2013) with individuals who stutter and have a family member who stuttered but recovered being more likely to recover themselves (Dworzynski et al., 2007; Yairi, Ambrose, Paden, & Throneburg, 1996).

Gender

The sex ratio of stuttering indicates that gender in itself is a risk factor for persistent stuttering. Ambrose and Yairi (1999) conducted a longitudinal study of 147 children, collecting data from when the children were close to stuttering onset. They found that 84% females recovered versus 77% males, and that females who recovered did so at a younger age than males who recovered. Contrary to findings from Yairi and colleagues, Reilly et al. (2013) reported a higher rate of recovery within 12 months for males compared to females. However, as the number of recovered children was low ($n = 9$), the authors stated that they could not examine predictors of recovery appropriately.

Age at onset

Yairi et al. (1996), in comparing groups of children who recovered from stuttering with those whose stuttering persisted, reported that children who continued to stutter started stuttering 5 to 8 months later (onset at 39 months of age) than those who recovered (onset from 30 to 33 months of age).

Time since onset

The time since onset of stuttering has been found to be a prognostic factor for persistent stuttering, with the risk of persistent stuttering being greater in individuals who have been stuttering for more than one year than in those who have not (Ambrose & Yairi, 1999).

Neurology

Chang and Ludlow (2010) reported further neurological data to identify factors of persistence. Specifically, children who had a persistent stutter had reduced white matter integrity in the left hemisphere areas of the brain involved in speech compared to those who recovered.

Language ability

There are inconsistent findings for status of speech and language skills in predicting persistence of stuttering. For example, Yairi et al. (1996) reported that better speech and language skills may be related to recovery from stuttering, whereas Watkins and Yairi (1997) found that children whose stuttering persisted had typical to advance language skills.

Additional factors

Other behavioural factors that have been found to be different between children with persistent stuttering and children who recovered include differences in second formant transitions (Subramanian, Yairi, & Amir, 2003), higher variability of articulation rate for persistent stuttering (Kloth, Kraaamaat, Janssen, & Brutten, 1999), and poorer phonological and speech production abilities for persistent stuttering (Spencer & Weber-Fox, 2014). Howell and Davis (2011) found that symptom severity, as measured by the Stuttering Severity Index, of children who stutter at 8 years old was the only significant factor that was able to predict persistence of stuttering in the teenage years using logistic regression analysis. However, Yairi and colleagues (1996) did not find that initial stuttering severity predicted persistence in their study of younger children (under 6 years).

Interpreting risk and prognostic factors

In summary, common prognostic factors of stuttering onset and of persistent stuttering include positive family history of stuttering and age. An older child has less risk of stuttering onset, though if a child is older when onset does occur, the risk for the stutter to be persistent is higher. Additional factors associated with persistent stuttering (i.e., behavioural factors) have been identified; however, caution is required when interpreting such findings. For example, replication of findings is needed to establish reliable indicators of persistence, since current results are based predominantly on single or few studies, with many having small sample sizes (e.g., Chang et al., 2005, $n = 14$). A number of studies are retrospective in design and it is recommended that prospective studies are more appropriate to answer questions of prognosis (Moons et al., 2009). While there have been comprehensive reviews of prognostic factors of stuttering onset and persistence, none were systematic reviews. A systematic review would synthesis and evaluate available information on this topic

allowing for the interpretation of data from large bodies of information (Petticrew & Roberts, 2006).

Predictive factors for stuttering treatment

Findings from systematic reviews

There is much to learn from investigating the predictive factors of stuttering treatment outcomes. With improved measures of treatment outcomes encompassing the impact of stuttering on an individual's quality of life, as well as the more reliable identification and measurement of relevant client and clinician factors, it may be possible one day to develop predictive models of treatment success.

Previous systematic reviews of stuttering treatment include one by Bothe, Davidow, and Bramlett (2006). They conducted a qualitative systematic review of behavioural, cognitive, and related approaches to stuttering therapy across a range of age groups. The prolonged speech approach, treatment targeting self-management, and treatment using response contingencies were found to have the strongest evidence for adults who stutter (AWS). For early stuttering, the authors concluded response-contingent-based therapies had the strongest evidence.

Herder, Howard, Nye, and Vanryckeghem (2006) reported results from a systematic review and meta-analysis of behavioural stuttering treatments and concluded that treatments resulted in positive therapeutic gains, but there was no one treatment approach that was significantly better than the others. Subsequently, a systematic review by Nye and colleagues (2013) reported that the current best evidence for children who stutter up to 6 years of age was the Lidcombe Program (LP) developed by Onslow and colleagues. Of these systematic reviews of treatment in stuttering, none specifically addressed predictive factors of treatment outcomes. Nevertheless, the importance of finding out more about predictive factors was recognised (Herder et al., 2006; Nye et al., 2013). Nye et al. (2013) further acknowledged that there were limited data available to make any useful conclusions.

Herder et al. (2006) noted a lack of understanding of how each factor or sets of factors may impact on treatment outcome. Interestingly, they concluded that differences in the effectiveness of intervention approaches were unlikely due to the nature of the intervention strategies themselves or to participant characteristics. Instead they hypothesised that clinician impact could have played a role, stating that "it might well be that the clinician represents a helping individual who is perceived to have the knowledge and skills to bring about a change in the speech behavior of a person who stutters" (Herder et al., 2006, p. 70).

Adults who stutter

Results from the systematic reviews demonstrate that treatment for stuttering is generally beneficial. However, predicting which individuals will benefit most, as well as knowing how to support those who may have higher risk of regression, is a pivotal for clinicians prior to commencing intervention. The potential to relapse is of interest and concern in the provision of treatment to AWS, with up to 72% of adults relapsing post-treatment (Craig, 1998). Relapse is defined as "stuttering to a degree which was not acceptable to yourself for at least a period of one week" (Craig, 1998, p. 3).

Stuttering severity

The definition of a predictive factor provided at the beginning of this review stated that it relates to client

characteristics. The most consistent predictor of relapse or regression is pre-treatment stuttering severity, usually measured as percentage of syllables stuttered (%SS). This has been found in earlier studies as well as more recent ones of predictive factors of treatment outcomes in AWS (Block, Onslow, Packman, & Dacakis, 2006; Craig, 1998; Guitar, 1976; Huinck et al., 2006; Ladouceur, Caron, & Caron, 1989).

Of the more recent studies, Huinck et al. (2006) investigated subtypes of AWS ($n = 25$) based on pre-treatment scores of stuttering severity (mild or severe) and severity of negative emotions and negative cognitive thoughts (mild or severe). Only stuttering severity was found to be a predictor of treatment outcomes; people with severe stuttering demonstrated the largest gains in therapy but they also experienced more relapse as measured by %SS (Huinck et al., 2006).

Block and colleagues (2006) conducted a prospective investigation of predictive factors for treatment outcomes with short- and long-term (up to 5 years post-treatment) follow-up periods. Consistent with previous findings, pre-treatment stuttering rate (%SS) was found to be a predictor of short-term treatment outcome ($n = 78$). That is, AWS with mild stuttering achieved better treatment outcomes, as measured by %SS, at the 1-year follow-up and were less likely to relapse than adults with a severe stutter. In turn, the only predictor of long-term treatment outcome was the short-term stuttering rate at 3 months post-treatment.

Additional factors

Caution is required when interpreting the research literature, given that studies of factors to predict relapse other than stuttering severity have yielded inconsistent results, are based on single studies, and/or are based on weak evidence. As such, their ability to predict treatment success is currently questionable and the findings need replication. These factors requiring further investigation include those related to communication attitudes, locus of control (internal or external), social anxiety, personality profiles (Iverach et al., 2010), mental health disorders (Iverach et al., 2009), and resilience, which are the processes and mechanisms by which an individual deals with adversity in life (Craig, Blumgart, & Tran, 2011). Craig et al. reported that AWS who were more resilient had lower levels of health risk, were able to manage their stress levels better, had fewer physical as well as social limitations, and had more vitality and social support.

Factors found not to predict treatment outcomes

Factors that have been examined but not found to predict treatment outcome include the following: age, gender social status, neuroticism, extroversion, avoidance, reaction (e.g., negative reactions to stuttering), self-help activities, formal practice (booster/maintenance sessions), real-life assignment (practice of techniques in a functional setting), post-treatment speech naturalness, number of first-degree relatives who stutter, and whether or not previous treatment had been received (Block et al., 2006; Craig, 1998).

Children who stutter

Early stuttering

It is a surprise and a concern that very little data are available to provide information on the prediction of treatment outcomes for early stuttering. In 2000, Jones et al. stated that “almost nothing is known ... about factors that predict the responsiveness of early stuttering to treatment” (Jones, Onslow, Harrison, & Packman, 2000, p.

1441). Jones et al. investigated factors including age, time since stuttering onset, gender, and stuttering severity in 261 children that could predict treatment duration for the first stage of the LP. They found that stuttering severity at the first treatment session was the only factor that related to the how long it took for children to enter the second (maintenance) stage of the program. Children with more severe stuttering required more time.

There have since been more studies of factors predicting outcomes on the LP for early stuttering, with several studies consistently reporting that treatment takes longer for children who stutter more frequently or more severely pre-treatment (Jones et al., 2000; Kingston, Huber, Onslow, Jones, & Packman, 2003; Koushik, Hewat, Shenker, Jones, & Onslow, 2011). A follow-up investigation of the same children from Jones et al. (2000) found that majority of children treated with LP maintained their fluency gains (below 1% syllables stuttered) 5 years post-treatment (Jones et al., 2008). A minority of the children relapsed, but the authors stated that it was unknown if there were any predictors of long-term relapse after treatment with the LP as their analyses did not yield useful results regarding this.

More recently, a replication and re-analysis of the data from children treated by the LP (independent of the LP developers) was conducted by Guitar and colleagues (2015). The authors combined the data from two sets of children who had been treated with the LP ($n = 29$) to investigate predictors of long-term outcomes of treatment with the LP. They tested pre-treatment stuttering %SS and gender as factors, and found that both were significant predictors. They found that females had better long-term outcomes as measured by %SS and that this was independent of their pre-treatment %SS. For males, long-term outcome in %SS was positively correlated with their pre-treatment %SS.

Older children and adolescents

For older children and adolescents, pre-treatment stuttering severity has been found to be a predictive factor for treatment outcome (Cook, Howell, & Donlan, 2013; Hancock & Craig, 1998). Hancock and Craig (1998) ($n = 77$) found that trait anxiety post-treatment could also predict stuttering frequency 1-year post-treatment. Psychosocial measures and a language measure of lexical diversity did not predict stuttering severity following treatment (Cook et al., 2013).

Interpreting predictive factors

The most reliable factor in predicting treatment outcome is pre-treatment stuttering severity in AWS. To date, this seems to also be the case for children who stutter, although data is limited and has been reported mainly for the LP. Other client factors could be useful for predicting treatment outcomes, and more studies are required with improved research design and replication of results. Replication of results is also necessary across different sites independent of the original location and the program developers, for example, for programs like the LP (Guitar et al., 2015; Jones et al., 2000; Kingston et al., 2003; Koushik et al., 2011).

Conclusions and future directions

At present, the most consistent prognostic factors associated with stuttering onset – that is, factors to predict who is likely to start stuttering – are a positive familial history of stuttering, age, and gender (being male). The prognostic factors related to natural recovery – that is, who is likely to

recover from stuttering – are gender (females being more likely to recover), age of onset (the older age of onset, the lower likelihood of recovery), time since stuttering onset (the more time that has passed, the lower the likelihood of recovery), and familial history of recovery. None of these prognostic factors have been consistently reported to predict an individual's treatment outcomes. Instead pre-treatment stuttering severity is the most consistent predictor of successful stuttering treatment outcomes. Individuals with milder stuttering have better treatment outcomes. Stuttering severity has not been found to be a consistent prognostic factor for whether or not an individual continues to stutter or not.

There is unlikely a single factor that can reliably predict treatment outcomes. Rather, it is likely that a combination of factors – for example, combinations of stuttering severity rate and relevant client factors (e.g., communication attitudes, personality profiles) – will be more accurate in predicting treatment outcome (Craig, 1998; Guitar, 1976).

To improve the strength of the evidence in prognosis and predictive factors in stuttering, prospective studies are needed with appropriate statistical methods for analysing the data such as logistic regression analysis (Reed & Wu, 2013). The ideal study design for investigation of predictor factors is the randomised control trial and the ability of a factor to predict treatment outcome should be evaluated per specific treatment (Adolfsson & Steineck, 2000).

To confirm that a factor gives prognostic as well as treatment predictive information, a randomised study stratified for the factor in question is needed. Also, for each predictive marker, it is necessary to evaluate the level of evidence as specified by evidence-based practice models of hierarchy (Adolfsson & Steineck, 2000). As the systematic review of randomised controlled trials is considered to be the highest evidence available according to models of evidence-based practice (e.g., Hoffmann et al., 2013), it is recommended that systematic reviews are conducted in the areas of prognostic and predictive factors in stuttering.

The rigour expected for systematic reviews of treatment efficacy studies with methods such as the Cochrane Collaboration should be extended to studies of prognosis and predictive factors of treatment outcomes in the future. Systematic reviews of prognosis of health conditions are becoming more recognised. The Cochrane Prognosis Methods Group, established in 2004/5, aims to ensure the best use of prognostic evidence in Cochrane reviews and to conduct research to advance the methods of prognosis reviews and other types of reviews, where similar methods apply (The Cochrane Collaboration, 2015).

In the meantime, clinicians can continue to integrate the available data on prognosis of stuttering and predictive factors of treatment with their clinical judgment and patients' individual profiles to plan appropriate therapies. Clinicians should strive to continuously evaluate therapies, to establish therapeutic alliance and troubleshoot different problems of response with their clients (Bloodstein & Bernstein Ratner, 2008).

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Dr Charn Nang is a speech pathology lecturer and researcher at Edith Cowan University, Western Australia. **Associate Professor Natalie Ciccone** is the associate dean of Allied Health in the School of Medical and Health Sciences at Edith Cowan University.

Correspondence to:

Dr Charn Nang

Speech Pathology

School of Psychology and Social Science

Edith Cowan University

270 Joondalup Dr, Joondalup, WA 6027

phone: (08) 6304 5168

email: c.nang@ecu.edu.au



Webwords 55

Work, ethics, costs, and Australia's NDIS

Caroline Bowen

Go on with your work as usual, for work is a blessed solace. Louisa May Alcott

It's been a tough few months. Webwords has tasted what it is like to be a carer and, in the last little while, three of Speechwoman's colleagues have experienced serious loss. The first surrendered a teenager to cancer. The second grieved the death of a parent. The third made a split second transition from full-time work and full-on leisure to being a 55-year-old NDIS **candidate**¹, in a skull-shattering 2 metre tumble from a **ladder**², abruptly terminating a rash of DIY enthusiasm. This was an adrenaline-fueled abseiler, mountaineer and sometime stuntman, known for impromptu somersaults on Kilimanjaro, Kinabalu, and Kosciuszko, landing right-side-up, cheerful and unscathed; now grappling with wheelchair life, memory and emotional regulation problems, agitation, dependency, and depression – with no visible means of escape.

Work

The other two colleagues could escape to work, characterising it as a welcome, protective distraction. Its routine demands, comfortable predictability, focus on the intellectual tasks at hand, periods of intense concentration, and the privacy of not having to share waves of sadness with everyone around, were a haven and comfort. Unlike Speechwoman and her friends, Marmee in **Little Women**³ was of a religious bent, and she called work "a blessed solace". Did work help the two to navigate grief? They said it did, and that, of course, there was more to it than that – including actively remembering the missing loved one. In that connection, both mentioned Lucy Hone, a New Zealand academic involved in resilience psychology research, and the author of a powerful reflection called **Remembering Abi**⁴. Telling her story, Dr Hone recounts her use of remembering as a strategy, employing simple rituals around every day acts, to take some control of grieving for her 12-year-old daughter and to simultaneously get on with the business of living.

Stories and discussion

The Internet is rich in ideas and opinions about work, what it entails, what it means to us, and its role in our lives beyond the obvious ones of earning a crust and feeling useful. In a Guardian Health **series**⁵ of 89 "a day in the life of" stories of health sector professional practice, a clinical psychologist describes a typical work day and how she learns from her clients, and a music therapist explains how she can give people back the power to communicate. The stories hold useful insights into the work that colleagues do, particularly for NDIS primary service providers functioning under the key worker teamwork model, and for those involved in multi-, inter-, and trans-disciplinary **teamwork**⁶ (Moore, 2013).

There is no SLP/SLT story among the 89, but Speech Pathology Australia makes up for that! Its Facebook "closed group" **communities**⁷ provide opportunities for discussion between members interested in ageing, apps, developing communities, disability, education and training, the justice sector, mental health, private practice, rural and remote practice and SPA student-member networking. There is a wonderful sense of engagement within the SPA closed groups that is also evident in some of the more open and international

social media platforms, including Reddit in the **SLP subreddit**⁸, and in Twitter on the **@WeSpeechies**⁹ handle.

The SLP subreddit contains fascinating, supportive conversations whose topics range from what inspired SLPs to become SLPs, to sexism in the profession, to whether an introvert can be an effective clinician, to unmanageable workloads (prompted by incredulous 2016 comments on an article in CareerCast about SLP as a low-stress job). Unlike several of the snarling, snapping, argumentative SLP/SLT Facebook groups, the SLP subreddit is a well-moderated global discussion platform that welcomes qualified SLPs/SLTs, students and SLP assistants to discuss therapy ideas, share stories and informative links, and give general advice based on personal experience and research.

In Twitter, @WeSpeechies is a collegial environment that facilitates mutual colleague-to-colleague support and encouragement, helpful connections, sharing of peer-reviewed articles and relevant links to websites and blog posts, across all areas of SLP/SLT practice and beyond. At the time of writing, @WeSpeechies is approaching its 100th international Tuesday Chat, with an impressive record of engaging top academics and clinicians who curate for a week, Saturday to Sunday, and lead the week's one-hour chat on the #WeSpeechies hashtag. Newcomers to Twitter and/or @WeSpeechies are welcomed when they participate in discussions (as opposed to lurking), and "how to" advice on the ins-and-outs of Twitter, and curating for those who are interested to volunteer, is readily available.

Flipping ethics

A common theme in discussion threads is ethical dilemmas in clinical and professional practice, a @WeSpeechies topic led by Suze Leitão, 12–18 June 2016. A resource that was highlighted during the week was an 80-page open-access version of the **Journal of Clinical Practice in Speech-Language Pathology, 2015, 17 (Supplement)**¹⁰. The supplement comes in FlippingBook form, or, as Webwords, who prefers an actual book or a regular pdf would say, "in flipping FlippingBook form". It comprises ethics-related articles published in ACQ and JCPSLP over a decade, elucidating from many informed perspectives. The word "disability" is repeated 18 times, and "insurance" three times, but, because of the timing of this valuable resource, the National Disability Insurance Scheme (NDIS), not at all.

NDIS

Six years in the planning, and initiated by the Australian government in November 2012, the visionary National Disability Insurance Scheme (NDIS) Act was launched in July 2013, shortly after a leadership spill saw one of its fiercest proponents, Julia Gillard, lose leadership of the Labor Party and resign from the office of prime minister. Launching the scheme, Gillard told Parliament it was, "a reform that will deliver significant benefits to people with disabilities, to their carers and to their families and to the wider Australian community". The agency responsible for delivering the **scheme**¹¹ is the National Disability Insurance Agency, and its roll-out commenced when the first agreements were signed with two states (NSW and Vic) by Liberal Prime Minister Malcolm Turnbull in September 2015.

The NDIS has an official Twitter account, @NDIS¹², and the Every Australian Counts campaign @EveryAustralian¹³, under the auspices of National Disability Services Limited (NDS), is a valuable source of current information, as is the surprisingly advertisement-free (for now) Twitter hashtag #NDIS. In other social media there is the NDIS Grassroots (closed) discussion on Facebook under the Australian Federation of Disability Organisations (ADFO) banner, and @DisabilityLoop¹⁴, an NDIS information resource run by ADFO project staff. On the Speech Pathology Australia website is a dedicated page on the NDIS, and members can contact the Association's Disability Project Consultant, Cathy Olsson, if they have NDIS or other disability-related questions to ask or issues to raise.

Elsewhere on the web is @Clickability¹⁵, an Australian disability service directory which features ratings and reviews from the people who use the services, and @MyDisabilityMatters¹⁶ (MDM). The MDM website provides a news and article curation and republishing service to alert readers to stories published in the mainstream and disability media and disability niche blogs that relate to disability and disability advocacy. Again, ethical concerns permeate articles and discussions, particularly as they relate to children and adults on our caseloads who become involved with non-evidence-based complementary and alternative medicine (CAM) interventions and interventionists.

The good, the bad, and the ugly

In a good example of bad timing, the manuscript submission deadlines for Webwords 55 and the Bowen and Snow (2017) book¹⁷ almost coincide. The book, *Making Sense of Interventions for Children with Developmental Disorders: A Practical Guide for Parents and Professionals*, is about fad interventions for speech, language, literacy, fluency, voice, communication, behaviour and social connectedness. It is a detailed exploration of the good, the bad and the ugly therapies for children and young people, with an approximate 50:50 balance between interventions that work, and have a scientific evidence-base, and those that do not. CAM practitioners that are mentioned frequently are astrologers, chiropractors, healers, homeopaths, and unqualified "gurus" and "leading experts" operating in areas of communication, disability, education, health, hothousing, nutrition, parenting and psychology.

The authors have been immersed in it for months, growingly aware of the widespread use of ineffective, and sometimes dangerous practices, that are unsupported by research evidence, theoretically unsound and biologically improbable (or **ludicrous**¹⁸), and often aggressively marketed to the disability sector. Accordingly, the media furore over the possibility of unqualified providers registering with the NDIS came as no surprise. Two examples are **Report: NDIS concerned about chiro decision**¹⁹ (in the Australian Skeptics' blog) and **Autism: Parents targeted by pseudo-medical charlatans with bogus treatments**²⁰ (in the Daily Telegraph), and more such articles are expected over the coming months as the NDIS is rolled out nationally.

Costs

Ineffective interventions are costly, not only in terms of fees for services and the prices of pills, potions and "equipment", but also in terms of opportunity costs that adults and children with disabilities, and their families, can ill-afford. Financial resources are misdirected from legitimate interventions to those that achieve a placebo effect at best, and cause actual bodily harm at worst. Emotional reserves are squandered when people invest hope in useless "trainings" and "techniques" such as dolphin or horse boy therapy, facilitated communication, non-speech oral motor treatments, the rapid prompting method, and sensory

integration therapy. Emotional reserves are exhausted in the mop-up from the adverse, health-jeopardising consequences of chelation, chiropractic subluxation, the GFCF diet, homeopathic vaccination, and other forms of non-vaccination. Valuable time is wasted, even lost, in which clients could have engaged in evidence-based approaches more likely to yield positive long-term gains rather than a short-lived transcendental glow, or a trip to the emergency department.

Sometimes, in our professional and private lives, we have to stand up and be counted, and by its very key-worker, multi-, inter-, and trans-disciplinary nature, the NDIS will give us ample opportunity to do so. This will mean, when engaging with clients, families and colleagues, expressing informed views in ways that are candid, clear, courteous, and unapologetic. "That is unwise because of the risks" is candid, clear and courteous (with the right expression), and unapologetic; "That's not such a great idea" and "I wouldn't do that in your shoes" and "I'm not so sure about that", are not. It is not helpful if clinicians and service managers fudge, dither, "sit on the fence" and respond vaguely when asked about dangerous pseudo-scientific interventions, high-risk non-interventions, and unethical or inappropriate practices.

As members of an evidence-based profession, steeped in a proud tradition of ethical practice, Australian speech pathologists are well-poised to uphold our clients' interests in the exciting and dynamic new context of the NDIS, honourably and with professionalism.

Webwords 55 is at www.speech-language-therapy.com with live links to featured and additional resources.

Links

1. <http://www.ndis.gov.au/ndis-access-checklist>
2. <http://www.alfred.org.au/News.aspx?ID=553>
3. <http://alcott.thefreelibrary.com/Little-Women/1-16>
4. <http://linkis.com/essentialkids.com.au/Tyz5S>
5. <http://www.theguardian.com/healthcare-network/series/day-in-the-life-of>
6. <http://www.ndis.gov.au/document/factsheet-teamwork-early-childhood-i>
7. http://www.speechpathologyaustralia.org.au/spaweb/Document_Management/Public/Online_Member_Communities.aspx
8. <https://www.reddit.com/r/slp/>
9. <https://twitter.com/wespeechies>
10. <http://speechpathologyaustralia.cld.bz/JCPSLP-Vol-17-Supplement-1-2015-lores>
11. <http://www.ndis.gov.au/>
12. <https://twitter.com/NDIS>
13. <https://twitter.com/EveryAustralian>
14. <https://twitter.com/DisabilityLoop>
15. https://twitter.com/_clickability
16. <https://twitter.com/audisability>
17. http://www.speech-language-therapy.com/index.php?option=com_content&view=article&id=163
18. <http://www.thechildrenoftherainbow.org/episodes/>
19. http://www.skeptics.com.au/2016/04/22/report-ndis-concerned-about-chiro-decision/?utm_content=buffer1a65c&utm_medium=social&utm_source=twitter.com&utm_campaign=buffer
20. <http://www.dailytelegraph.com.au/news/nsw/autism-parents-targeted-by-pseudomedical-charlatans-with-bogus-treatments/news-story/4105baa831dac2ed4b82306d2119e6f7>

Reference

Moore, T. (2013). Teamwork in early childhood intervention services: Recommended practices. National Disability Insurance Scheme (NDIS). Retrieved from www.ndis.gov.au



Top 10

Janice Buckland

In January 2016 I clocked up 25 years of experience in the disability area. This area is not known for its abundance of resources and often, making do is the order of the day. In the Barwon Region, we have just entered our third year of the National Disability Insurance Scheme (NDIS). The extra resources have gone towards increasing services for the people we support, but it is yet to hit our resources' wish list! Therefore, on the smell of an oily rag, we are welcoming the biggest change to disability in recent memory. There has been an increase in the number of people now eligible to access more appropriate levels of service, so there is an abundance of work to be done in the speech pathology area. Our service has grown and we now have more speech pathologists than ever before. Despite this increase, time is still a limited resource so it is important to make use of the resources that we have.

1 Time

My appreciation of the value of time has grown tenfold. Time to reflect on good practice, future goals and resources required; time to mentor our new therapists and develop our skills; time to read and keep abreast of new developments. There never seems to be enough time. Funding is now much more transparent and we need to account for how each minute of our time at work is used. There is an expectation that we will get more done and that productivity will increase. With a better understanding of how long things take, we can then request an appropriate amount of time to achieve a goal. But how long does it take to program a communication device or conduct a mealtime review? These are the questions that we are gradually getting better at answering. Scope has put into place a structured practice support system to ensure that therapists still have time to develop their skills, and mentor other therapists. Improved systems will maximise the efficient use of time.

2 The Triple C Checklist of Communication Competencies

Any therapist working in the adult area in disability services will be very familiar with this assessment. It is a no-fail checklist that is completed by family and supports for adolescents and adults who communicate with fewer than 50 functional words or signs. It is my go-to assessment to determine a person's level of communication skill and I have found the revised edition containing an additional supplement even easier to use and follow. It is rare nowadays to come across staff in adult services who aren't familiar with this particular assessment. Team it up with the InterAACTION Manual and you have a raft of communication strategies that are easy to develop for every level of communication. It makes so much sense that I even find myself sometimes referring to it when I am thinking about the communication skills of the young children that I am involved with.

Bloomberg, Karen, West, Denise, Johnson, Hilary, & Iacono, Teresa. (2009). *Triple C kit*, Revised edition. \$110, available from <http://www.scopevic.org.au/shop/triple-c-kit/>

3 The InterAACTION Kit

Or Janice's box, as it is known at Shannon Park. It was developed to go with the InterAACTION manual and is a large box of examples of communication supports. It is invaluable for showing people what the communication supports we are trying to develop might look like. It makes a large difference if someone can be shown a communication support and they can see how it might work for them or the people they support. Some people want the product to be exactly the same while others use them as a starting point to design their own. My box has travelled with me all over the Barwon South West region of Victoria and has been added to over the years. The lid doesn't quite fit!

The InterAACTION kit as described above is no longer available but it is possible to purchase a kit of Everyday Communication Aids that includes the InterAACTION Manual (\$990.00) or the Communication Aid Creator (\$120.00) which is a USB stick with over 50 templates to make different types of communication aids. This allows you to make your own kit! Both of these resources are available from <http://www.scopevic.org.au>

4 A good team

I have worked with many wonderful speech pathologists, occupational therapists and physiotherapists over my career. This has shaped my practice as a therapist and has helped me see the overall picture for the person and not just focus on my own areas of interest. Therefore goals can be more functional. In the new environment, our team has grown and we now have many therapists working across these three streams. It is tempting for a lot of people to move into private practice within the NDIS model, but for me, I would miss the collegiality of such a wonderful team and working closely with others to achieve the goals of the people we support.

5 Enthusiastic therapy assistants

With so many resources to be made, we have always relied heavily on our wonderful therapy assistants, and now more so than ever. The NDIS is also opening up many opportunities for therapy assistants to be involved in therapy follow-up with the people that we support. At the moment we are lacking in people that have the skills and knowledge to fulfil this role, but numbers are gradually building and if we add them to our recommendations, with adequate time for training, we will gradually build their skills. I see this as a real growth area and if we are creative it will be of great benefit to the people we support. The Regional Communication Services, which are part of the CAN network across Victoria, have been developing communication coordinator networks by training one or two disability support workers from as many day and

accommodation services as possible. They are skilled up in a range of strategies to assess and provide communication supports for the people they are working with. They become champions of communication within their service and endeavour to foster a culture of communication. I envisage networks of therapy assistants who could be trained and then meet regularly to share ideas and develop skills to support people achieve their communication goals within the community.

6 My ipad

A few short years ago, it was unimaginable that we would be carrying these marvellous devices around with us everyday. I know they have their limitations, but they have literally changed the way we do things. I can access my emails and workplace network, take photos for communication, utilise any number of games and activities during sessions, and trial a range of communication apps with the people I support. Even if I know that they might benefit from a dedicated communication device, this is a great place to start and I have it all at my fingertips. Ipad's are mainstream and easily used by families and carers. I have also been amazed at the ease with which videos can now be used to practise conversational skills. Federation University Australia has developed a website to help people with fluency difficulties practise conversations. But I have found it just as useful for the people I support. Go to <http://www.scenariaid.com> to check out interview practice, ordering at a fast food outlet and many more typical scenarios. I attended a presentation by one of the developers at this year's "Having a Say" conference and he said that they were keen for ideas about relevant scenarios that others might require. This website has led me to develop my own conversational scenarios utilising the Pictello app on my iPad. I really can't believe how quick and easy it is to develop my own video resources. Pictello \$30.99, available via www.itunes.com.au

7 The Australian standardised labels and definitions for texture modified foods and thickened fluids

No doubt most people will be aware of this work that was done as a collaboration between the Dietician's Association of Australia and Speech Pathology Australia. The standards have become a mainstay of the work that we do on a daily basis. It has made supporting people with dysphagia easier and safer, not only by improving the consistency of therapists' language, but also in improving staff understanding of the appropriate terminology, and they are asking questions when things appear confusing. I am seeing a real change in the level of care and support around mealtimes and am interested in seeing how this is transferring to a better quality and life expectancy for people with disabilities. It is possible that this was the impetus behind the development of better quality thickeners, and it has improved the outlook for people with dysphagia. For more information, visit: <http://www.speechpathologyaustralia.org.au/resources/terminology-for-modified-foods-and-fluids>

8 Supportive managers

The NDIS is really changing the way services operate. Everywhere you go, there are marketing departments and business analysts. It is really important to ensure that we have managers who understand therapy and what we require to get the job done. In disability we work with such

a range of people with complex needs and I could never admit to knowing everything I need to know for every person I support, no matter how much experience I have. We require managers who understand the unique difficulties that we face. People often need information in an Easy English format and visual resources are often required to enable people to be a part of the conversation. Conversations often take time and we really need people to be part of their own plans. We need to ensure that the need for economic sustainability does not cause us to lose sight of all the things that we have learnt over the years about being person centred and allowing people to inform their own plans. Managers who understand these things are invaluable to our services.

9 SOS and Suzanne Evans Morris

I have recently been sucked back into the busy vortex that is early intervention. It had been several years since I worked in this area and I needed to brush up some of my skills. I was being asked to work with some children with very complex feeding issues and all the paediatricians kept asking about my credentials. Had I done SOS training or did I believe in the Graz approach? Very early in my career I had the good fortune to attend a live-in Suzanne Evans Morris training course as professional development (PD) here in Victoria, which has always formed the basis of how I approach feeding issues, but I decided it was now time to invest in some new PD. I spent a very intensive three days in Brisbane learning all about SOS and I am pleased to say I found it very useful. I was impressed by their emphasis on giving children time to overcome their early negative experiences with eating and drinking and to develop the skills that they require to eat and drink effectively. PD has increased my confidence and benefitted the people I support.

Morris, S.E., & Klein, M.D. (2000). *Pre-feeding skills: A comprehensive resource for mealtime development* (2nd ed.). San Antonio, TX: Therapy Skill Builders.

Suzanne's New Visions website is worth a look for anyone working with children and infants with feeding difficulties: <http://www.new-vis.com>

For information regarding SOS training, visit <http://www.feedingworkshops.com>

10 Wonderfully supportive businesses

Whenever I am assisting people to determine which communication device will be the best for them, we always make a list of each device that we have trialled and the pros and cons of each one. Within this approach I often think about who will be supplying the equipment and how much support we will receive after they have acquired their device. Suppliers, such as Zyteq, that get to know people with communication difficulties and make it easy for them to independently ring and troubleshoot difficulties are empowering for people we support. It is inevitable with technology that something will go wrong, and people can't always get hold of me, so to be able to go straight to the supplier is invaluable. I should also mention the wonderful support that we get from our Electronic Communication Devices Scheme staff at Yooralla. I don't know about other states, but when I look at how difficult it can be for our occupational therapists and physiotherapists to get equipment for people, I am grateful that I am a speech pathologist!

For information about Zyteq, visit www.zyteq.com.au

For information regarding the Electronic Communication Devices Scheme, visit <https://www.yooralla.com.au/>

services/Communication-and-Assistive-Technology/
electronic-communication-devices-scheme

10+1 Community request cards

I just had to list an “eleven” because request cards are my favourite! It is empowering for people to be able to independently interact with the wider community and have them interact back directly! Anyone can use them and we even took some on our family trip to Japan. Such a simple concept, but they have so many uses. I have one lady that I support who has a set with such diverse comments as “I am just browsing. I will let you know if I require some help” and “Does that product come with a warranty?” right down to “Can I get a \$20.00 top up on my Vodaphone please?” She told me that when she goes into Priceline, she has staff racing all over the place finding things for her. She feels

wonderful and never has to ask her father to purchase personal products for her any more. Sometimes the simple things in life really are the best!

Author statement

Janice is employed by Scope which publishes some resources mentioned in this Top 10. She has no commercial interest in any of the resources presented or businesses mentioned.

Correspondence to:

Janice Buckland, speech pathologist

Scope Shannon Park, Victoria

phone: 03 5221 5444

email: jbuckland@scopevic.org.au

Around the journals

Plesa Skwerer, D., Jordan, S. E., Brukilacchio, B. H., & Tager-Flusberg, H. (2015). **Comparing methods for assessing receptive language skills in minimally verbal children and adolescents with autism spectrum disorders.** *Autism*. Advance online publication. doi:10.1177/1362361315600146

Amelia Edwards

Assessing the receptive language of minimally verbal children with autism spectrum disorder is both a challenge for clinicians and an area that has not been widely explored within existing literature. This study compared and contrasted several different assessment approaches, including standardised direct assessment of receptive language, caregiver reporting, eye-tracking assessment, and a computerised touch-screen assessment. Although all of the participants within the study were considered “minimally verbal”, the results of the study indicated that there was significant variation across the participants in terms of receptive language skills. There was also significant heterogeneity in performance across the various assessment methods, with the authors highlighting that there was not a clear assessment approach that presented clear advantages given the variability of performance across participants. While the computerised tasks (touch-screen and eye-tracking assessments) are still considered experimental, and further research is required, this study highlights the exciting possibility of combining computerised assessment of receptive language with more traditional assessment measures (e.g., standardised formal assessment and caregiver report). Ultimately, if computerised tasks can be implemented into assessment practices in the future, they may provide clinicians with a more comprehensive understanding of the receptive language skills of individuals on the autism spectrum.

Radford, J., Bosanquet, P., Webster, R., & Blatchford, P. (2015). **Scaffolding learning for independence: Clarifying teacher and teaching assistant roles for children with special education needs.** *Learning and Instruction*, 36(1), 1–10.

Bonnie Kang

Increasing numbers of teacher assistants (TAs) working with children with special educational needs (SEN) bring new challenges and opportunities. This article uses a sociocultural approach to propose an effective scaffolding model for TA interaction during instruction for children with SEN. Conversational analysis of audio and video recordings taken from three UK studies of TA interactions with children with SEN during maths and literacy classes in mainstream schools revealed three effective scaffolding roles: (1) the repair role, in which TAs prompted and cued students to find solutions to breakdowns when they occurred, without providing the direct answer (e.g., a verbal cue to find a word); (2) the support role in which TAs used strategies (e.g., cuing, prompting, giving instructions) to gain and maintain students’ interest during learning activities; and (3) the heuristic role in which TAs modelled and encouraged students to use learning strategies to solve problems independently. The authors identify strategies for achieving best learning outcomes for children with SEN including ensuring teacher and TA discussion and planning, ongoing TA scaffolding training, and reviewing whether TA educational qualifications are consistent with TA roles and expectations. The authors also recommend that future research examine the impact of peer scaffolding on learning and learner contribution during scaffolding. This is an insightful article that would interest speech pathologists working in school settings.

JCPSLP notes to authors

The *Journal of Clinical Practice in Speech-Language Pathology* is the major clinical publication of Speech Pathology Australia. Each issue of *JCPSLP* aims to contain a range of high quality 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)	Theme*
Number 1, 2017	1 August 2016	Advancing speech pathology services for Aboriginal and Torres Strait Islander peoples
Number 2, 2017	1 December 2016	To be announced. Check website for updates
Number 3, 2017	13 April 2017	To be announced. Check website for updates

* 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.

Ethical approval

All manuscripts in which information about a person and/or organisation is presented must be accompanied by evidence of approval by an authorised ethics committee. This includes clinical insights, ethical conversations, manuscripts presenting the results of quality assurance and improvement activities within workplace settings, and research manuscripts.

Themes

Each issue of *JCPSLP* contains a set of articles relating to a particular theme, as well as a selection of articles reflecting broader speech pathology practice. The Editorial Board selects a theme for each journal, and these themes can be suggested by members of Speech Pathology Australia at any time. Manuscripts on any topic relevant to speech pathology practice can be submitted to *JCPSLP* at any time.

Length

Manuscripts must not exceed 3500 words (including tables and a maximum of 30 references). Longer manuscripts may be accepted at the discretion of the editor. It is highly recommended that authors contact the editor prior to submitting longer manuscripts.

Types of Submissions

When submitting your article to *JCPSLP*, please indicate the type of submission:

- Tutorial: Educational/narrative discussion on topics of interest to clinicians. This should include a brief overview of the current literature, as well as a section containing clinical implications.
- Review: Critical appraisal of the research literature in an area of research-practice that is relevant to practising speech pathologists.
- Clinical Insights: Articles that may be of primary clinical interest but may not have a traditional research format. Case studies, descriptions of clinical programs, and innovative clinical services and activities are among the possibilities.
- Research: Research articles with clear clinical relevance. These submissions will be judged on the review of the literature (including a rationale), methodology, statistical analyses, and a clear discussion directed to a clinical readership.

Peer review

Manuscripts submitted to *JCPSLP* undergo a double blind peer-review process. Regular columns (e.g., Webwords, Top 10, resource reviews) undergo editorial review. For peer-reviewed articles, *JCPSLP* uses a double-blind peer-review process, in which the anonymous manuscript is sent to two reviewers. The authors are provided with information from the review process. Often, authors are

invited to revise and/or resubmit their work, as indicated by the reviewers. Occasionally, the reviewers request to re-review the revised manuscript. In some instances, a paper will be rejected for publication. The editor's decision is final. The sentence "This article has been peer-reviewed" will appear after the title for all peer-reviewed articles published in *JCPSLP*.

Format and style

All submissions must be Word documents formatted in accordance with the following guidelines:

- All text should be 12 point Times New Roman, double spaced (except figures and tables), left justified.
- A maximum of five levels of heading (preferable 2-3 levels) should be used:
 1. Centered, boldface, uppercase and lowercase heading
 2. Left-aligned, boldface, uppercase and lowercase heading
 3. Indented, boldface, sentence case heading with a period. Begin body text after the period.
 4. Indented, boldface, italicised, sentence case heading with a period. Begin body text after the period.
 5. Indented, italicised, sentence case heading with a period. Begin body text after the period.
- Please use the terms 'speech-language pathology' and 'speech-language pathologist' (abbreviated to SLP) throughout article.
- Do not include images within the text of the article – send photos as separate attachments, digital images should be of high quality and preferably be sent as uncompressed TIF or EPS images.
- Use only one space after punctuation, including full stops.
- Use a comma before 'and' in a series of three or more items (e.g., "The toys included a ball, bucket, and puzzle")
- Clear and concise writing is best. Use short sentences and paragraphs and plain English. Please reduce bias in language as much as possible (i.e., avoid stereotypical terms, refer to participants, rather than subjects, and be sensitive to racial and ethnic identity).
- 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 key references only, must follow the American Psychological Association (APA, 6th edition) (2009) style. For further details on correct referencing, visit <http://owl.english.purdue.edu/owl/resource/560/01/>
- Tables and Figures: If there are to be tables or figures within your article, these should be presented on separate pages with a clear indication of where they are to appear in the article (in text indicate where the figure or table should be inserted). All tables and figures should be numbered. Figures should be presented as camera-ready art. Please ensure figures and tables appear at the end of your article with each table or figure on a separate page.

Documents to be submitted

1. Manuscript featuring:
 - a. Title
 - b. Author names and affiliations (will not be forwarded for peer review)
 - c. Up to 6 key words
 - d. Abstract (maximum 150 words)
 - e. Main body of text (**main body must not include any identifying information**)
 - f. Reference list (maximum 30)
 - g. Tables (if relevant)
 - h. Figures (if relevant)
 - i. Appendixes (if relevant)
 - j. Acknowledgements if relevant (will not be forwarded for peer review)
2. Author submission form (to be downloaded from *JCPSLP* website)
3. A colour photograph of each author (to be included in manuscript if accepted for publication)

Submitting your manuscript

Articles should be submitted electronically to the Editor, David Trembath at jcpslp@speechpathologyaustralia.org.au

