



Webwords 55

Work, ethics, costs, and Australia's NDIS

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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