

# WEBWORDS 14

## Service delivery and consumer advocacy

Caroline Bowen

### Bad waiters

Speech-language pathology needs bad waiters. We don't need nice, patient, understanding waiters – we need consumers who are itching to address communication difficulties, in themselves, or in family members, and who will not put up with waiting lists, stop-gap minimalist services, untested “consultative” models, incomprehensible home programs they have not been given the skills to implement, group therapy where individual services would be more appropriate, or patchy, sketchy intervention delivered by under-resourced, clinicians who never have enough time for themselves on the road to burnout (<http://helping.apa.org/work/stress6.html>).

Imagine a well-organised band of vocal, articulate consumers, or would-be consumers, rallying with banners aloft and facts at their fingertips outside the-place-where-the-waiting-list-is-kept protesting their right to timely, appropriate, efficient and effective assessment and intervention. What's that they're chanting?

'What do we want?'

'Service!'

'When do we want it?'

'NOW!'

### Good-bye nice

Picture the bad waiters in cahoots with therapists behaving boldly. The bad (<http://www.macquariedictionary.com.au/p/dictionary/slang-b.html>) ones who bravely go out on a limb, ethics to the fore, accurate information, including TOMS (<http://www.speech-therapy.org.uk/toms.htm>), NOMS ([http://164.109.82.203/resources/noms/noms\\_data.cfm](http://164.109.82.203/resources/noms/noms_data.cfm)) and the latest clinical research ([http://members.tripod.com/Caroline\\_Bowen/webwords10.htm](http://members.tripod.com/Caroline_Bowen/webwords10.htm)) at the ready, to advocate for clients' needs – even when it might mean that the Wild Things further up the hierarchy will smile their terrible smiles, and gnash their terrible teeth, and write their terrible memos – to stop the badness RIGHT NOW!

Consider how powerful a group of well-disciplined, fully informed, energetic consumer advocates, liaising closely with members of the profession, could be in lobbying government and funding bodies to provide essential and adequate services for all communicatively impaired people in this, or any country.

Yes! I've imagined it all and thought about it a lot, and I've gone right off “nice”. From now on I'm on the side of bad! Really.

### Internet activists

Pure fantasy? Well, not quite. Protesters, advocates and lobbyists may not be physically beating down agency doors, badgering politicians, or chaining themselves to giant waiting lists to make their point: but there is a lot of activity going on, and nowhere is it more apparent than on the Internet.

Take for example The Ontario Association for Families of Children with Communication Disorders whose site includes a no-holds-barred document (<http://www.oafccd.com/factsheet/fact68.htm>) detailing the OAFCCD (<http://www.oafccd.com/>)

Service Delivery Model Analysis of School Speech–Language Pathology Ratios And Costs. Arguing the case for essential improvements to services, this lobby group of parents and professionals does not mince words:

Of the approximately 2 million students in Ontario Schools, roughly 50,000 students are serviced by school speech-language pathologists (School Health Support, 1993). This represents about 2<sup>1</sup>/<sub>2</sub>% of the estimated 10% of children who need speech and language service. (Beitchman, et al. 1986; Casby, 1989). Clearly the speech and language needs of our school age children are not being met.

Given that the schools presently employ roughly 300 speech-language pathologists to provide speech and language service, the current ratio is approximately 1:6666 school children. This overall figure, however, provides a misleading picture of the current situation because of the disparity in service from board to board, with some boards providing no service from speech-language pathologists ... the range of ratios is from 1:2250 to 1:10,000 for boards where services are available.

The OAFCCD people do not stop at agitating for better services. In common with many comparable groups, their real forte is providing information that empowers and helps consumers make the most of what is currently available via downloadable resources, newsletters, a message board, online chat, and related links.

### Professional voices

Our professional associations are taking up the cudgels too, on behalf of clients. In a document on the costs of a communication disability (<http://speechpathologyaustralia.org.au/pages/factsheets/factsheet1.5.html>), Speech Pathology Australia, and, you know, Speech Pathology Australia is its members, refers to itself as “the official body representing speech pathologists, the professionals who work with and advocate for people who have a communication disability.” The document goes on to refer to “long waiting lists and understaffing in government services”.

In the US, *Take Action* (<http://www.asha.org/takeaction/>) often assumes centre stage at the ASHA professional portal. It includes an online form that enables members to write to their state and federal legislators directly from the site.

The Canadian association, CASLPA (<http://www.caslpa.ca>) – have you *seen* their nice new site! – is replete with articles around the “demands [that] are being placed on speech-language pathology services, as evidenced by lengthy waiting lists and large caseload numbers.”

Montreal clinician-manager Robin Springer writes (<http://www.caslpa.ca/english/resources/cm005.asp>):

We have become obsessed with waiting lists in speech-language pathology. Perhaps it is the by-product of an era of increased public attention to the state of our health care and educational systems that is giving us our notoriety – finally. Waiting lists for many of us

have become a focus of what we think about, and appear to stand in direct competition with the combined intellectual passions and clinical dedications that to me are the hallmarks of a wonderful profession.

The Royal College of Speech and Language Therapists has a highly political news and press release (<http://www.rcslt.org/press.shtml>) section, quoting directly from the national media, for example:

On 22 August 2001, *The Guardian* published an article in its *Society* supplement on speech and language therapy, under the title "Lost for words". The article outlines the long wait for speech and language therapy experienced by some children with communication difficulties and the limited nature of therapy when available. ...The article points out that much of the problem is due to the profession's recruitment and retention problems....The Royal College of Speech and Language Therapists recognises that the shortage of therapists causes worrying problems for families. Together with the Department of Health and MSF (the union to which many SLTs belong), we are working to improve the recruitment and retention of therapists.

## Let's roll!

Right on, bad waiters! Good for you, SPA, ASHA, RCSLT and CASLPA! Individual therapists behaving boldly: go for it! Let's usher in a mood of zero tolerance for service delivery that is shackled by low staff retention rates and long waiting lists. Come on! What are we waiting for?

## References

Beitchman, J., Nair, R., Clegg, M. Ferguson, B., & Patel, P. (1986). Prevalence of speech and language disorders in 5-year-old kindergarten children in the Ottawa-Carlton region. *Journal of Speech and Hearing Disorders*, 51, 98-110.

Casby, M. W. (1989). National data concerning communication disorders and special education. *Language, Speech and Hearing in the Schools*, 20, 22-30.

School Health Support, Interministerial Committee (1993). *Speech and language services in Ontario schools*. Paper presented at the Education Symposium, December, Mississauga, Ontario.

Find the electronic version of Webwords 14, with live links to the sites mentioned here, at [http://members.tripod.com/Caroline\\_Bowen/webwords14.htm](http://members.tripod.com/Caroline_Bowen/webwords14.htm)



## MY TOP TEN RESOURCES

Susan Balandin

I work in the School of Communication Sciences and Disorders at The University of Sydney. I teach in the area of lifelong disability and augmentative and alternative communication (AAC). My research is focused on adults who are ageing with a cerebral palsy and complex communication needs. Prior to working at the university, I was a clinician for many years, working primarily with adults with lifelong disability. I also do some consultative work, mainly in the area of medico-legal assessments for people with cerebral palsy and teaching group home staff and other professionals about ageing with a lifelong disability and complex communication needs. These are the things I feel I can't live without – I can usually find books, and other material relevant to the context when I am there.

### 1 A laptop computer

With a laptop, I can work in just about any context.

### 2 A copy of Board Maker™

(Mayer Johnson)

With Board Maker™, I can quickly make up a board or overlay.

### 3 A laminator

To ensure that systems last – at least until the next update.

### 4 A range of light tech devices

Items such as community request cards, chat books, personal communication dictionaries, a book about me, and object symbol systems: these are great for demonstration and working with communication partners.

### 5 The Triple C

(Bloomberg & West, 1999).

This is a useful tool to encourage communication partners to look for communicative behaviours from adults who are functioning at a presymbolic level.

### 6 Peers who are natural speakers

How else do I know whether you say wicked, cool or fandabbadoozytastic!

### 7 A saved copy of every board and topic board

Sooner or later they get lost and no one remembers everything that was there!

### 8 A team!

I believe it is impossible to be an effective speech pathologist unless working as part of a team including the person who uses AAC, family members and, of course, an occupational therapist to help with access and all the other tricky bits.

### 9 An active listserv

Listservs are good to bounce ideas and get help. There are lots of good ones, including the AGOSCI listserv, Makaton, ACOLUG and the ciaforum <http://au.groups.yahoo.com/group/ciaforum/> that has a focus on autism.

### 10 An assistive technology team

I need to be able to refer many of the people I see to this team for assessment for high tech AAC devices, seating, and access.