

Many people would consider these policies are only commonsense; however, much ignorance and discrimination still prevail. When economic times are difficult the people who are most disempowered by society receive even less support. In Victoria, the years of the Kennett government demoralised disability services and minimised advocacy services. The recent 3-year commitment by the Brack government to provide better services for people with complex communication needs is encouraging. The struggle for effective communication continues and structures need to be developed in organisations to ensure that information goes both ways for the consumers. It is vitally important that those who have a lot to say but may take a long time to say it take an active part in decisions about their lives. If we, the natural speakers, are prepared to face the challenge of effectively communicating with people with a severe communication impairment, then we will be developing the vision of "creating opportunities that liberate human potential" (Mirenda, 1993).

References

Basil, C. (1992). Social interaction and learned helplessness in severely

disabled children. *Augmentative and Alternative Communication*, 8, 188–199.

Bink, M. (1993, August). *The role of consumers in improving service quality*. Paper presented at "My Day, My Choice" Conference, Melbourne.

Edwards, A. (1993). *Communication in the Spastic Society of Victoria*. St Kilda: Spastic Society of Victoria.

Light, J., Collier, B. & Parnes, P. (1985a). Communicative interaction between young nonspeaking physically disabled and their primary caregivers. Part I: Discourse patterns. *Augmentative and Alternative Communication*, 1, 74–83.

Light, J., Collier, B. & Parnes, P. (1985b). Communicative interaction between young nonspeaking physically disabled and their primary caregivers. Part II: Communicative functions. *Augmentative and Alternative Communication*, 1, 98–107.

Kravitz, E., Littleman, S. & Cassidy, K. (1992). *Meeting the communication needs of nonspeaking adults with mental retardation*. Paper presented at the ISAAC Conference, Philadelphia.

Mirenda, P. (1993). AAC: Bonding the uncertain mosaic. *Augmentative and Alternative Communication*, 9, 3–9.

National Joint Committee for the Communicative Needs of Persons with Severe Disabilities (1992). *Guidelines for meeting the communication needs*

of persons with severe disabilities. *ASHA*, 34 (March supp. 7), 1–8.

Patson, P. (1993). *Alternatively speaking in a talkist society*. Wellington, NZ: Winston Churchill Memorial Trust Board.

Pennington, L. & McConnachie, H. (2001). Predicting patterns of interaction between children with cerebral palsy and their mothers. *Developmental Medicine and Child Neurology*, 43, 83–90.

Spastic Society of Victoria (1995). *Policy and procedures manual*. St Kilda: Spastic Society of Victoria.

Spastic Society of Victoria (2000). *Annual general report*. St Kilda: Spastic Society of Victoria.

Sweeney, L. (1992). *Assessment of learned dependency among potential users of augmentative communication*. Paper presented at ISAAC Conference, Philadelphia.

West, D. & Strickland, A. (2000). *Human relations: Best practice report to Department of Human Services*. Melbourne: Department of Human Services.

Correspondence to:

Hilary Johnson

Severe Communication Impairment

Outreach Projects

Spastic Society of Victoria

PO Box 381, St Kilda, VIC 3182

phone: (03) 9536 4246

email: sciop@ssov.org.au

ACQ INTERNET COLUMN

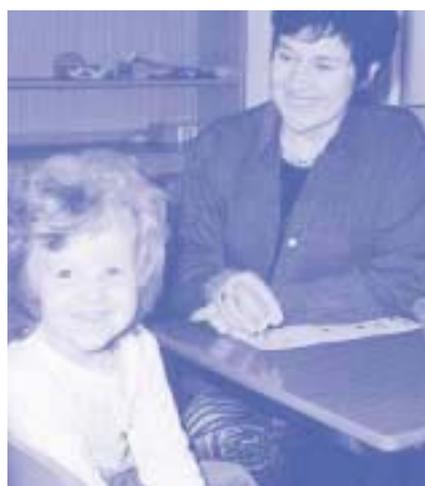


Webwords 9. The language of empowerment: Putting people first

Caroline Bowen

AAC users

Many of our clients would tell you, if they could, that their experience of communicating with others is anything but empowering. This is pointedly the case for people with developmental disabilities and severe communication impairments, including those who are AAC (alternative and augmentative communication) users. The Internet abounds with websites devoted to serving these populations, and not only in terms of their communication requirements. Some are commercially (<http://www.toby-churchill.com/>), research (<http://aac-rerc.com/links.html>) or leisure (<http://www.achievableconcepts.com.au/>) oriented, and others home grown in Australia, like the Internet's best kept secret, according to its hit counter, the AGOSCI (<http://members.iinet.net.au/~sharono/AGOSCI/index.html>) site with its vibrant *listserv* ([http://listmaster.](http://listmaster.iinet.net.au/list/agosci)



Morgan Taylor and Caroline Bowen

iinet.net.au/list/agosci). Others are politically (<http://www.hreoc.gov.au/index.html>) or industrially (<http://www.acrod.org.au/>) motivated, and an ever-increasing number are just plain helpful and encouraging (like the Life

Span Institute Home Page <http://www.lsi.ukans.edu/lsi/>).

What better place to start exploring these sites than the University of Nebraska – Lincoln AAC Links Page (<http://aac.unl.edu/AAClinks.html>), where we find at the top of their list the International Society for Augmentative and Alternative Communication (ISAAC) (<http://www.isaac-online.org/>). Then there is the SNOW (<http://snow.utoronto.ca/>) site in Toronto, emphasising the needs of school-aged students, and Ruth Ballinger's YAACK (<http://www.mauigateway.com/~duffy/yaack/>) geared to the younger AAC user like Morgan (pictured left).

Insights and information

Tucked away in the depths of my website is Insights from Parents ([130](http://</p>
</div>
<div data-bbox=)

members.tripod.com/Caroline_Bowen/ParentInsights.htm). It lists pages by people whose lives have been touched by having children with communication impairments. The unifying theme linking these sites is the generosity of families who willingly share the strengths and resources they have discovered in themselves, through the health and legal professions, from government sources, and via the Internet. These parents-turned-web-developers include Julio Ciamarra whose youngest son, Robert, born in October 1983, has cerebral palsy, epilepsy, and moderate developmental delay. Julio's Internet Resources for Special Children (IRSC) (<http://www.irsc.org/index.htm>) has won multiple awards, and accolades. Writing about it in glowing terms, high profile advocate for people with disabilities, Cincinnati writer Deborah Kendrick (<http://enquirer.com/columns/kendrick/>) aligned it with the (<http://www.empowermentzone.com/>) developed by Jamal Mazrui. Mazrui is a policy analyst for the National Council on Disability (<http://www.ncd.gov/>) in the US. The zone offers "information, ideas, and software related to empowerment: helping individuals and communities achieve self actualisation and full citizenship". There are a few dead links on his list – but not to worry! Try copying and pasting the "dead" page titles into a search engine (in quotes, of course) – that's how I found Mazrui's "Guidelines for language to use when writing about disability" (<http://www.nfbnet.org/bbsfiles/INFO/LANGUAGE.TXT>).

Person first?

Webwords 9 is coming along famously. The headings are in place, the information ties together nicely, all the links work, and I've had the pleasure of revisiting some of my favourite sites when my world crashes around me! My desktop wobbles like the screen-saver from Rolf Harris, and I am barely able to see my fingers through a haze of hotspots. Somehow, realising what is happening, I claw at my phone dialler and call Dr Mac. "Mac. Mac? I must see you immediately. I've got Late Onset Videopathic Exstrophy. You know, Love Syndrome ... what I've always dreaded ... I've become an LS sufferer!" Oh, no! With phonological representations strangely intact I hear my words coming back to me as meaningless CVCCCC and VCVVVVV strings. This is dreadful.

Dreamlike, I tear myself from the keyboard and by the time I reach the security of his waiting room the acute

phase has passed. I address the room. "How can I function as a speech defective speech pathologist?" Unaware that the first sign of LS is a severe loss of person first language, Maud the unflappable receptionist snaps unsympathetically, "You can't say that! You mean how can you work as a professional who is differently abled". It's a horrible syndrome: political correctness is the second thing to go. I'm getting louder. My pragmatics are disgraceful. "No I don't mean that! I mean I'm used to being NORMAL (http://www.vigormagazine.com/lib/Oth/Oth-People_with_Disabilities.htm). I don't want to be an LS victim with a mouth on me like a brainless retard". I think she's going to faint. She rallies. "There, there. You just feel challenged by the prospect of having the communication skills of a person who learns atypically. I do understand where you're at." No she doesn't. I'll kill her in a minute. "But," she's humouring me now, "Love's is just a word, not a sentence." I've done my linguistics and I can't argue with that. I take a different tack. Softly, persuasively. "Maud, try to understand? I'm a LOVIE, and I'm going to have to get used to people calling me that. Come on lovie, they'll say, we can't have you being down in the mouth. It's not that bad. But it is bad, and I hate it".

Suddenly Dr Mac is in our midst. Soothing, well-intentioned, reassuring, but – I haven't noticed this about him before – really, really patronising. The waiting room breathes a collective sigh of relief. "Around here", he murmurs, "the only label a person needs (<http://www.usd.edu/sduap/systems/primer/person%20first%20lang.htm>) is their name. Instead of giving you people labels, we try to think of ALL people in terms of their strengths and abilities". All I hear is "you people". Before I can release a suitable retort he is giving Maud a serve. "Maud, I don't want to hear you say 'Love's' or 'Love's Syndrome' ever again. It's Love Syndrome. Yes? No 's' and no apostrophe. Like Down syndrome."

"No apostrophe and no 's'", she repeats obediently. "No 's' and no apostrophe, no 's' and no apostrophe ..." the words float me away and next moment I am lying on the grass in Fitzroy Gardens. There's Libby Love. Looking zany. I'll have a word with her in a minute about this syndrome. Oh, and Sue Reilly. And there are all these fabulous women in period dress talking about how we were students together before the turn of the century. And ... and ... I can see Joy Carbone, Janine Clift, Bev Dodd, Liz Yewers, Jan

Mackenzie (she seems to be doing something with Jim), Marg MacCrae, Gail Crowe, Marj Conroy, Jenny Britten, and there's Martin Cameron searching for something. Our late friend Marion Lees is in our thoughts and so too are the people who couldn't make it to our 30-year reunion: Adrienne Evans, Barb Craig, Sharon Page, Leone Sanders, Howard Mould, Martin Cameron, Janin Silverman, Bill Annear, Maria Jackman. They missed a great night. I wake for a moment and then drop back to sleep in my conference hotel room. They must have put something in the food ...

Food for thought

In my searches for information about empowerment on the Internet I was struck by frequent references to age- and gender-fair person first language: and the fierce arguments for (<http://www.fmhi.usf.edu/cfs/dares/famteach/chooswords.htm>) and against its use. Katie Windsor (<http://www.a2z.org/pilot/person1st.htm>), whose daughter Julianne careers through the day in a bright red wheelchair, believes that "Person-first language is not a lofty idea or a construct to remain politically correct. It is a philosophy to focus on the person and then the disability". ASHA (<http://professional.asha.org/publications/folkins.htm>) and (your Bible and mine) the APA Style Manual (<http://www.apa.org/pi/cdip/portrayal.html>) too, are for it, particularly in academic writing. But then we get the opposing view, not from parents, caregivers and professionals, but from the "persons" themselves. Jim Sinclair (http://members.nbci.com/jimsinclair/person_first.htm) announces to the world, "I am not a 'person with autism'. I am an autistic person", and goes on to explain why this distinction matters to him. Blind woman (her preferred designation) Alyzza H (<http://www.geocities.com/EnchantedForest/Meadow/8921/person1.html>) (on the New Vision site <http://www.geocities.com/EnchantedForest/Meadow/8921/>) is offended by person first language, "the awkwardness of the structure 'woman who is blind' compared to 'blind woman' makes the disability stand out more. Further, it denotes shame on our parts about our disabilities when we use such language ..." It made me think that the key to empowerment really is recognition that all are entitled to their points of view. Including the embattled person first campaigners.

See Webwords 9 at:

http://members.tripod.com/Caroline_Bowen/webwords9.htm