Disability terminology: Are we listening?

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As audiologists we sometimes have to spend time persuading individuals that a member of their family does actually have a hearing disorder and isn't just wilfully unresponsive. How often have you heard a significant other say of their partner with a sensorineural hearing loss "He can hear if he wants to. He just doesn't listen."? Part of aural rehabilitation with adults being fitted with hearing aids for the first time is to educate their families about hearing impairment, perhaps playing them a recording of filtered speech to emulate a high frequency hearing loss, so as to help them understand that their family member has difficulties with hearing rather than listening.

And how often do teachers misread an auditory processing disorder (APD) in children? After we fitted a young girl with a remote microphone hearing system for her APD, and her classroom behaviour, participation and performance were transformed, the teacher was gracious enough to confess "I really thought Mary was just a naughty little girl".

Describing someone's hearing disorder as a listening difficulty is loaded with negative connotation, or at least the insinuation that it is within their control to remediate. Yet "listening difficulty" is the term being proposed in some academic circles to encompass or replace the term "auditory processing disorder".

Hearing difficulties referred to collectively as APD are the result of a mix of causes, some specific to the central auditory system and some involving both the central auditory system and higher order functions (Peelle, 2018; Peelle & Wingfield, 2016). Use of the term "listening difficulties" has been suggested so as to convey that cognitive processes not specific to hearing may be involved in auditory processing disorders. Indeed cognitive processes are involved in most aspects of seeing and hearing yet it's not customary to avoid words such as "auditory", "hearing" or "seeing" just because cognitive processes play a part.

There are however good reasons to review terminology used to describe different types and degrees of APD. Diagnoses of APD encompass a mix of different subtypes of hearing disorders ranging in severity. Different terminologies would be helpful for different cases, especially since the various criteria used to diagnose APD are arbitrary. It's also not usually clear whether the problem will persist following treatment. Sometimes the term "disorder" may be an overstatement and perhaps an unfair label with which to burden a child. At such times audiologists might talk about auditory processing weaknesses or deficits rather than using the "disorder" label. Educational psychologists tend to talk about a child's strengths and weaknesses rather than "disorders". On the other hand parents are sometimes pleased to have a diagnosis of a disorder to explain their child's difficulties, to encourage their child's

school to provide special educational assistance, or to qualify for funding for hearing assistive technology.

More delineation of sub-types of APD (e.g., spatial processing disorder, amblyaudia) is needed but this can only occur as research uncovers better understanding of processes that may be affected in APD. For example measures and terminology to describe various types of temporal distortions in APD would be useful. One type of temporal distortion might be atypical temporal jitter which has been demonstrated in mice with central auditory deficits (Kopp-Scheinpflug & Tempel, 2015) and might be analogous to the inconsistent neural responses to speech measured in children with dyslexia by Hornickel et al (2012). If suitable measures can be devised, another "temporal" sub-type of auditory processing disorder might be the fascinating temporal processing deficit in speaking rate perception recently reported by Gabay et al (2019).

We also need to be able to classify degree of disability in APD. While there are descriptors for severity of conductive and sensorineural hearing loss, there are none for APD. One of our research projects at the University of Auckland is to find measures to describe degree of functional disability in individuals with APD using questionnaires, performance on functional measures, and/or z scores derived from the diagnostic test battery.

Wilson (2018; 2019) addresses questions of terminology in the area of auditory processing disorders. While his inclusion of "listening difficulties" might be challenged by some, Wilson suggests APD could be considered a spectrum disorder, encompassing a range of terms to describe different "levels" and sub-types of APD. Wilson also suggests terminology to distinguish APD *associated* with a comorbid disorder, from APD *co-existing* with a comorbid disorder. This approach is likely to find favour with clinicians in search of more descriptive and flexible terminologies to suit individual cases.

Moore (2018) promotes the term "listening difficulties" and asserts that it is "gaining traction" in place of APD, but does not report any evidence nor consultation process with people with APD in this claimed change process. It would be surprising if groups representing people with APD were accepting of an overarching term that could be taken to imply the absence of a hearing disorder and a lack of listening effort by their members.

In WHO terms APD is an impairment that can cause a disability. It's important that members of disability groups have a say in regard to key or overarching terminologies that affect them. Members of Deaf culture choose to describe themselves as Deaf (capitalised), and some people with autism spectrum disorder choose to describe themselves as Autistic (capitalised). Hard of hearing people have rejected the term "hearing-impaired" and reclaimed the historic term "hard of hearing".

Foisting disability terminologies from the ivory towers of academia is not the consultative approach required in the 177 countries which have ratified the United Nations Convention on the Rights of Persons with Disabilities (UN CRPD). In addition to principles such as autonomy, dignity, inclusion, and full and effective participation (General Principles), Article 29 requires us to promote actively an environment in which persons with disabilities can

effectively and fully participate in the conduct of public affairs, without discrimination and on an equal basis with others.

Discussion of APD terminology is to be encouraged, and while the discussion process may need to be initiated by academics, it is vitally important that we involve and listen to people with APD and the clinicians responsible for diagnosing and labelling individuals' particular impairments and disabilities.

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