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SCIENTIFIC FORUM: COMMENTARY

“From your own thinking you can’t help us”: Intercultural collaboration to address inequities in services for Indigenous Australians in response to the World Report on Disability

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Abstract

Inequity in service provision for Indigenous Australians with communication disability is an issue requiring urgent attention. In the lead article, Wylie, McAllister, Davidson, and Marshall (2013) note that, even in the relatively affluent Minority World, including Australia, equity in service provision for people with communication disability has not been achieved. In remote communities in the Northern Territory (NT) almost all residents speak a language other than English as their primary language. However, there are no speech-language pathologists (SLPs) in the NT who speak an Indigenous language or who share their cultural background. Specific data on the prevalence of communication disability in this population are unavailable due to a range of factors. The disability data that are available, for example, demonstrating the high level of conductive hearing loss, indicates that the risk of communication disability in this population is particularly high. Change is urgently needed to address current inequities in both availability of, and access to, culturally responsive services for Indigenous people with communication disability. Such change must engage Indigenous people in a collaborative process that recognizes their expertise in identifying both their needs and the most effective form of response to these needs.

Keywords: *World Report on Disability, World Health Organization, Indigenous, collaboration, workforce issues.*

Introduction

In the lead article Wylie, McAllister, Davidson, and Marshall (2013) identify key issues for the profession to address with respect to the World Report on Disability (World Health Organization and The World Bank, 2011a). These issues include the lack of data on the prevalence of communication disability as well as barriers to availability and accessibility of services. These concerns are particularly relevant to service provision for Indigenous Australians with communication disability. In the Northern Territory (NT) of Australia 26.8% of the population is Aboriginal according to the 2011 Census data (Australian Bureau of Statistics, 2012). In remote areas the percentage is much higher. For example, in the East Arnhem region of the NT (the region on which this paper will primarily focus) 97.5% of the population is Aboriginal and only 2.1% of the population speaks only English at home (ABS, 2012). Across the NT, cultural and linguistic diversity is extensive, with more than a hundred languages and dialects spoken by Aboriginal people in the NT (Aboriginal

Interpreter Service – Northern Territory Government, 2012). Obtaining accurate prevalence data and provision of equitable services clearly present serious challenges in this population.

In this paper the barriers to equitable service provision for Indigenous Australians with communication disability, as well as strategies for improvement, are explored. Key points raised in the World Report on Disability and in the response to the World Report on Disability in the lead article (Wylie et al., 2013) will be discussed with particular reference to the concerns and ideas expressed by many of the Aboriginal people in remote areas of the NT with whom I have worked over more than 20 years. This work has included development and provision of services for Aboriginal people with communication disability as well as collaborative research and other projects with a focus on intercultural communication. It is hoped that this discussion will also have broader relevance to at least encourage reflection on the significance of the issues raised here to other Indigenous populations, both in Australia and elsewhere.

Prevalence of communication disability in Aboriginal populations in the Northern Territory

Australia might be considered a data rich country; however, it cannot be assumed this applies to the remote Aboriginal population. Wylie et al. (2013) refer to the challenge for people with communication disability to be heard—this challenge is compounded when they do not share the same language or cultural background as policy-makers and service providers. Factors that contribute to the lack of available data on the prevalence of communication disability in Aboriginal populations also include the absence of appropriate assessment tools in relevant languages or implementation of assessment strategies that might be effective. When there is limited or no access to a service consumers are unlikely to be aware that such a service exists or that they have a right to such a service, further contributing to the lack of information on actual need.

Relatively abundant data are available relating to other areas, such as ear health and hearing, which can provide some indication of the possible prevalence of communication disability in the Indigenous population. For example, a survey of young Aboriginal children in Northern and Central Australia found that 91% were affected by otitis media (Morris, Leach, Silberberg, Mellon, Wilson, Hamilton, et al., 2005). Extensive testing of Aboriginal children was also conducted through the Child Health Check Initiative (CHCI) introduced under the Northern Territory Emergency Response (NTER), which found that 30% had ear disease (Australian Institute of Health and Welfare and Department of Health and Ageing, 2009). A subsequent report on audiological and ENT services provided in response to the CHCI (Australian Institute of Health and Welfare, 2011) stated that 73% of children receiving an audiology service required further action. Although the report repeatedly mentions the effects of hearing loss on speech and language development and lists referral to a speech-language pathologist (SLP) as one option for follow-up, there is no mention in the report of any referrals to a SLP being made. This apparent absence of SLP involvement in identifying and responding to the service needs of a population with extremely high rates of early onset and persistent hearing loss, with obvious implications for language development, is just one indicator of under-servicing.

The World Report on Disability stresses the urgent need for “more robust, comparable and complete data collection” (World Health Organization and The World Bank, 2011a, p. 31). Accurate data on the prevalence of community disability in the Indigenous population is critical to achieve equity in availability of services. It is, however, only the first step.

Barriers to equitable service provision

Wylie et al. (2013) identify two key issues that must be addressed: service availability and service accessibility. They identify barriers to accessing services as structural, geographical, financial, and cultural/linguistic. These barriers provide a useful framework for exploring the factors contributing to under-servicing for Aboriginal people with communication disability. Each poses particular challenges to ensuring that appropriate services are available and accessible to the same extent as they are to other Australians.

In addition to inadequate levels of service, availability is also affected by high staff turnover and difficulty in recruiting staff. This is consistent across all areas of allied health in the NT (Campbell, Smedts, Lowe, Keane, & Smith, 2010). Geographic factors also limit service availability. In the NT, the term *very, very remote* has become popular in the allied health context as many communities are accessible only by light aircraft or many hours of travel in a four-wheel drive (4WD) vehicle. Most services are based in larger centres up to 1000 kilometres from where their Indigenous clients live, limiting access to services. Financial, as well as geographical factors, preclude access to private services: in the East Arnhem region, for example, the median weekly income is less than half the median income for Australia overall (ABS, 2012). Although specific information on the availability of SLP services to remote Aboriginal communities is difficult to obtain, lack of prevalence data resulting in an insufficient workforce, high staff turnover and difficulties in recruitment, as well as geographical and financial barriers, can all be expected to contribute to under-servicing for this population.

In addition to the barriers describe above, there are *profound cultural and linguistic barriers* to Aboriginal people with communication disability accessing equitable services. There are no SLPs who share the same language and cultural background as their remote Aboriginal clients in the NT. Although an Aboriginal Interpreter Service is available in the NT, the utilization of such services by health staff is far from optimal (e.g., Lowell, Maypilama, Yikaniwuy, Rapa, Williams, & Dunn, 2012). Cultural education for staff working with Indigenous clients is brief and general and it is unrealistic to expect staff to achieve the level of linguistic and cultural competence required for such a diverse client group.

The consequences of such barriers in the Canadian context have been described by Ball and Lewis (2005, p. 1):

Too often, language differences, and the cultural nature of raising children in Indigenous communities have been seen by outsiders as evidence of deficits and dysfunction, rather than of “differences” that contribute to the identities, cultural continuity and sense of belonging of Indigenous children and families.

Similar concerns have been expressed in relation to Indigenous Australians where “inappropriate assessment practices have been shown to result in the repeated misdiagnosis of communication differences as language or cognitive deficits” (Gould, 2008, p. 70). The potential for misdiagnosis was repeatedly demonstrated in research conducted in classrooms in a remote community school in the NT, for example, when culturally acceptable listening behaviour is interpreted by non-Indigenous observers as evidence of attention deficit (Lowell & Devlin, 1999).

Again in the Canadian context, Crago (1992) described the potentially serious consequences of cultural distance between service providers and their Indigenous clients:

Practitioners who are ignorant of, or refuse to alter their practices in ways that recognize the strength of cultural patterns of communicative interaction can, in fact, be asserting the hegemony of the mainstream culture and can thereby contribute, often unknowingly, to a form of cultural genocide of non-mainstream communicative practices (Crago, 1992, p. 37).

A disturbing example of this in Australia has been the introduction of foreign sign languages (e.g., Auslan) to remote Aboriginal communities by well-meaning professionals who are unaware that a highly functional and extensive sign language is already widely used and in which the child and her/his family are already highly proficient. The invisibility of cultural strengths and assumptions that interventions can be transferred from one cultural context to another is not uncommon. Yolŋu (Aboriginal people in Northeast Arnhemland) have long expressed concerns that their knowledge is unrecognized by Balanda (non-Indigenous people), for example:

We need teamwork before we go out—first we listen to each other ... How can it change—listen to Yolŋu people what they have—not always just follow (Balanda) ideas—Balanda have not been listening properly to Yolŋu (Lowell, Maypilama, & Birritjalawuy, 2003, p. 27).

Importantly, communication disability when it does exist can remain unrecognized by those from a different language and cultural background. This adds a further challenge for SLPs in addition to the potential for cultural and language differences to be interpreted as deficits and the invisibility of cultural strengths to outsiders. Despite these challenges it is possible—as well as ethically imperative—to improve access to equitable services for Indigenous Australians, and strategies to achieve this are explored in the next section of this paper.

Strategies to address inequities in service provision: Collaborative practice and shifting control

A term that recurs frequently in discussions with Yolŋu about service provision in their communities is *räl-manapanmirr djäma*. A turtle-hunting metaphor, in which the different role and expertise of each of the Yolŋu in the boat is essential to a successful outcome, is often used when Yolŋu explain this term. The closest equivalent in English appears to be “collaborative practice”—in which each of the participants is recognized for the essential contribution of their particular expertise in achieving the intended goal. “Working in partnership” is a term commonly used by non-Indigenous service-providers working within the Indigenous health context, but “partnership” implies equal power. Many Yolŋu, however, have argued that what is needed is a form of collaboration in which Yolŋu are in control and Balanda provide a support role:

Before Balanda used to walk first, we used to walk behind, but now we are working side by side; We’d like to ask Balanda to walk behind now (Lowell, Maypilama, & Birritjalawuy, 2003, p. 25).

In such a collaboration the unique skills and knowledge that Yolŋu bring are recognized as primary. As non-Indigenous professionals our expertise has limited application in isolation. An influential report released in 2007 strongly stated the “critical importance of ... genuine consultation with Aboriginal people in designing initiatives for Aboriginal communities ...” (Wild & Anderson, 2007, p. 21) and argued that interventions must be culturally appropriate and delivered with the involvement of the community. Over recent years there has been an influx of early childhood programs (although not speech-language pathology services) into remote communities as part of Australian Federal Government initiatives, purportedly in response to the report by Wild and Anderson (2007). However, a perceived lack of collaboration and increasing loss of control has been expressed by Indigenous community members in regard to some of these initiatives. For example, a group of Yolŋu women asked for their concerns about early childhood programs in their community to be videotaped. As Garrutju, a Yolŋu elder and educator, explains on the video:

We are not robots ... We are people with brains. People with vision and dreams. We are people with dignity. [Don’t] take over the responsibility ... We have brains to think. (We’ve) got eyes to see. Working together. Don’t take everything as if we are your people. We are Yolŋu—different. Different nationality, different background—I don’t know your background, you don’t know my background. I have to (be) born to be in your world, you have to be born in my world—to become 100% Yolgnu ... But you

Balanda, you take everything away from us. Everything ... But not the language. But not the way we live ... We all live in mistakes. But we have to solve it. You solve your problem. We solve our problem. You don't have to solve our problem. We can't say to you we can solve your problem, no—because we don't know what's your program, what's your background. But please from now on let's work together. [Don't] take responsibility. Help us to stand ... with our people ... (transcribed excerpt from *Yolŋu Concerns about Early Childhood Programs DVD*, Nyomba, Garngulkpuy, Garrutju, & Maypilama, 2011).

Wylie et al. (2013) suggest in the lead article that the speech-language pathology profession needs to make significant changes in how services are conceptualized, designed and delivered for under-served populations. There is little evidence that this has occurred with speech-language pathology services for Indigenous Australians. For example, Gould (2009, p. 72) contends that: "As a profession, speech pathology simply does not debate the issues involving communication and culture with the rigour and urgency required to sufficiently influence speech pathology practice". Engagement of Indigenous people in the process of change is crucial as "changes should be based on sound evidence, appropriate to the culture and other local contexts, and tested locally" (World Health Organization and The World Bank, 2011b, p. 18). This requires participation of people with disabilities and their families in processes to "determine priorities for change, to influence policy, and to shape service delivery" (World Health Organization and The World Bank, 2011b, p. 23).

Implementation of culturally responsive approaches to speech-language pathology service delivery for Indigenous people has not been sustained and/or transferred beyond specific contexts, even though attempts have been made to develop more effective approaches to service delivery. For example, in 1997 the then Territory Health Services funded a project to consult with remote communities about the development of a service for Aboriginal people with communication disability (e.g., Lowell, 1997). A key strategy identified through these consultations was the redistribution of the available funding to employ community-based workers to work with the SLP in the provision of services. A collaborative approach was proposed, arguing that "the needs of these clients and their families cannot be met unless both components of the service—specialist expertise in communication disability and specialist expertise in the client's culture and first language—are provided" (Lowell, 1997, p. 4). As with many other attempts to address inequities in service delivery, implementation of this model was not sustained.

Many allied health professionals working in remote Australia have recognized the need, and advocated for a collaborative approach involving Indigenous community members in service development and

delivery. Both Federal and NT legislation require that health and other services provide equitable access to services to people from culturally and linguistically diverse backgrounds (Northern Territory Government, 2009). Change has been slow, however, and the barriers to achieving equitable services for Indigenous Australians are not restricted to the field of speech-language pathology but affect many areas of healthcare. A report exploring cultural security issues in health services for Aboriginal people in the NT (Dunbar, Benger, & Lowell, 2009) identified a number of principles that are fundamental to embedding sustainable change in policy and practice. These principles can also inform action in addressing inequities in SLP services for Indigenous people in Australia and elsewhere. In summary they include the critical importance of:

- *Organizational commitment* to achieving culturally responsive services through implementation and monitoring of culturally and linguistically competent systems and practices at all levels (including policies, standards, guidelines, and protocols).
- *Community engagement* to ensure changes reflect the needs and aspirations of all consumers, and are responsive to their diverse and different cultural and linguistic needs.
- *Development of individual capacity*, including cultural education for all staff which goes beyond awareness to develop skills and knowledge (including cultural reflexivity; intercultural communication; understanding of power relationships; and institutional racism).
- *Sufficient resources* to enable effective implementation and monitoring of all of the above (Dunbar et al., 2009).

Wylie et al. (2013) argue that, to address under-servicing, new approaches to service delivery are needed that are "culturally relevant, holistic, accessible, sustainable and responsive ..." (Wylie et al., 2013, p. 9). This can be achieved for Indigenous people with communication disability: through co-ordinated action and commitment, engaging individuals, communities, organizations, and government. Most importantly, we must recognize the central importance of Indigenous expertise and control in determining the extent and form of support that is required.

Conclusion

In a country such as Australia with relatively abundant resources it is inexcusable that current inequities in services for Indigenous Australians remain largely unchallenged and unresolved. This inequity can and must be challenged—and resolved. Achieving equity requires collaborative action involving SLPs and Indigenous people in planning and implementing

strategies for change. Such an approach is essential to address the deplorable gap in our knowledge of the extent of communication disability experienced by Indigenous Australians. It will also ensure the relevance and sustainability of action to achieve equity in service availability and accessibility. A Yolŋu interpreter with extensive—and often distressing—experience of engaging with the health system illustrates why we must recognize the importance of Indigenous expertise and engagement in this process:

It's important that Yolŋu and Balanda work together and listen to one another ... if you want to help Yolŋu you have to help us the right way—with your own thinking you can't help us ...

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