

‘I’ve never done anything like this before’: Integrating reflective practice, research, community and clinical service delivery to build the evidence base in culturally responsive AAC with First Nations families

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Short Abstract

The development of culturally responsive multilingual AAC systems and culturally safe supports is an emerging area of AAC practice. Developing AAC in remote northern Australia with First Nations families presents many challenges and requires extensive collaboration between stakeholders.

In this presentation we share reflective and creative insights from our collaborative and intercultural clinical research processes, as we learn from each other and work together to develop Anindilyakwa AAC systems with *Warnumamalya*, First Nations peoples from the Groote Eylandt archipelago living with Machado-Joseph Disease.

Drawing on our different ways of knowing, being and doing, across roles, organizations and locations we have developed a research team, aims, methodology, and protocol to share skills and insights through collaborative data collection and analysis. As we weave our clinical, linguistic, cultural and research expertise we build our relationships and learn from each other, individually and collectively.

We reflect on intercultural, clinical research collaborations in AAC – what it takes, what we can learn from each other, previous work, and what we can achieve when we bring our whole selves to work in vulnerable, creative, flexible and responsive ways - prioritizing the perspectives and values of the families with whom we work, grounded in place, connected to country, drawing on community and clinical expertise and the existing research evidence.

Long Abstract

Certified practicing speech language pathologists (SLPs) must demonstrate a commitment to contributing to evidence-based practice to ensure quality service provision for clients and families. Evidence-based practice requires the integration of the highest quality research evidence; clinical expertise; client perspectives; and knowledge of contextual factors (SPA, 2021). Accumulation of clinical expertise, consideration of client perspectives and contextual knowledge are all driven and underpinned by reflective practice. For SLPs collaborating across cultures in rural and remote, low-resource and underserved regions where research evidence is often pieced together and applied in indirect ways, reflective practice is paramount to

problem solving and supporting culturally responsive and safe SLP services and lifelong learning.

MJD, or spinocerebellar ataxia 3 (SCA3), is an autosomal dominant neurodegenerative disease with a very high prevalence amongst First Nations Australians in remote communities in the Northern Territory (NT) (Carr et al., 2019). Early symptoms of the disease include ataxic gait, spasticity, muscle weakness, nystagmus and dysarthria (Saute & Jardim, 2015). Later presenting symptoms include double vision, dysphagia, vocal cord paralysis, sleep, bladder and thermoregulation disturbances, cramps, fatigue and chronic pain (Pedroso et al., 2013). Depression, anxiety, executive and visuospatial impairment are also described, but severe cognitive decline is not associated with disease progression (Pedroso et al., 2013).

Communication difficulties experienced by First Nations people living with MJD are the highest clinical and research priority for families living with the disease (MJD Foundation, 2023). Progressive dysarthria, the impact of miscommunication, being separated from family, feeling not listened to, and others not understanding their needs has a the most significant impact on mental health and quality of life for First Nations people living with MJD (MJD Foundation, 2023).

First Nations families living with MJD across remote communities in the NT have had access to very limited and intermittent SLP services over the last 10-15 years, which have remained so, despite the introduction of the NDIS in the NT in 2017 (Amery., 2023). SLP services have incorporated swallowing assessment and recommendations, speech and voice therapy exercises, with some individuals trialling AAC systems in English with limited uptake and use.

The challenges experienced by First Nations families living with MJD are compounded by high rates of disability and chronic disease, low rates of bilingual literacy, limited access to health services, infrastructure and accessible housing (Carr et al., 2019). Great demands are placed on individuals and families, with many people with severe-stage MJD needing to move hundreds of kilometres away from their families to supported independent living (Carr et al., 2019). There are also many challenges that impact remote allied health service delivery, including geographical isolation, cost of travel and accommodation, recruitment and retention of staff, and profound linguistic and intercultural communication differences (Lowell, 2013).

The development of culturally responsive multilingual AAC systems and culturally safe supports is a growing area of SLP practice. However, comprehensive AAC systems in languages other than English, and research in AAC implementation and evaluation in non-English contexts is still grossly inadequate compared to the need (Tönsing et al., 2018). Existing research includes an emphasis on family perspectives, and family interactions with educators using descriptive, qualitative, and single-case study designs (Kulkarni & Parmar, 2017; Pickl, 2011). There is also growing evidence related to considerations for and development of vocabulary lists for AAC in languages other than English (Mngomezulu et al., 2019; Soto & Tönsing, 2023;)

In recent years, a team of SLPs, linguists, First Nations researchers, and cultural advisors, together with clients, family members and staff from the MJD Foundation developed the first prototype AAC systems in traditional Aboriginal languages to support Yolŋu living with MJD (Amery, Wunungmurra, Raghavendra, et al., 2022; Amery, Wunungmurra, Bukulatjpi, et al., 2022). While this research was conducted with Yolŋu families, many research aspects have the potential to be transferred and inform the development of AAC systems in other First Nations

languages. Of particular interest, is the culturally responsive, collaborative, mixed methods participatory action research process.

Warnumamalya, First Nations peoples from the Groote Eylandt archipelago have been living with Machado-Joseph disease (MJD) for generations. There are currently 26 people living with a diagnosis or monitored symptoms, and more than 180 people at risk of developing the disease. The archipelago is located 43 kms east of the Arnhem Land coast of the Northern Territory, and consists of over one hundred islands (Clarke, 1994). Anindilyakwa is spoken by at least 1,500 people across the archipelago, with *Warnumamalya* from all generations speaking Anindilyakwa as their first language (Bednall, 2019). Anindilyakwa is one of the few Australian Aboriginal languages that is still being acquired by children with increasing speaker numbers over the last century (Bednall, 2019). *Warnumamalya* hold strong perceptions and attitudes to their language and language variations (Bednall, 2019).

Since June 2024, a new research team has been developed to plan and design culturally responsive communication research with *Warnumamalya* living with MJD. The team is comprised of *Warnumamalya* MJD clients, extended family, community linguists, SLPs, MJDF staff; and SLP and linguist academics. Together they have designed a research project drawing on learnings from AAC research with Yolŋu living with MJD, the existing evidence base, experience from other local research projects and clinical programs with *Warnumamalya*. Most significantly the research is grounded in a deep respect, trust and prioritisation of relational accountability to long-term relationships with *Warnumamalya living with MJD*, Anindilyakwa language, culture, and connection to country around the Groote Eylandt archipelago.

Developing new research projects from the ground up takes time, resources, flexibility, creativity and openness to doing things differently and learning from each other across our differences. When reciprocal relationships are prioritized and teams work together, new knowledge and resources can be developed to support First Nations peoples living with MJD, encouraging and inspiring other people living with MJD and communication support needs across the world.