

Participation of Indigenous children with disabilities in remote communities

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Background—disability and participation

One of the core purposes of allied health interventions for people with disabilities is to promote ‘participation’ or active involvement in all areas of life, including home, school, work and the community (1). It is widely recognised that active participation and involvement in life activities at a personal, social and societal level are important to a person’s health and wellbeing (2). For children, active participation enables them to learn new skills, develop relationships, express themselves and become self-determined (3).

The International Classification of Functioning, Disability and Health (ICF) was developed by the World Health Foundation to provide a common language and universally applicable framework for discussions around health and disability (4). It is internationally recognised and used in clinical practice, teaching, research and policy development (5). The ICF provides a framework to explore components of human function and its restrictions, as well as contextual factors that impact on function (6). In the ICF, body structure/function, activities and participation are all components of ‘functioning’, with ‘disability’ occurring when impairments, activity limitations or participation restrictions are present (7). The ICF recognises that health and disability are also influenced by contextual factors, associated with the individual person and how they experience disability, as well as the broader physical and social environment. Participation is a core component of this model and defined as ‘involvement in life situations’ (6). Participation, as defined by the ICF is both a key contributor to wellbeing and a universal human right (8).

Promoting participation of people with disabilities is a primary goal of disability supports and services, including those provided under the National Disability Insurance Scheme (NDIS). The NDIS is currently being trialled at a number of locations across Australia, with the primary aim of improving supports available to eligible persons with permanent and significant disabilities (9). Core aims of this scheme are to support the participation of individuals with a disability in their local community, as well as promoting independence, access to education, employment and health and wellbeing (9). The NDIS recognises individual differences and acknowledges that each person has unique aspirations, which impact on what their goals look like. Through the scheme, participants have a support plan developed, which encourages and enables the person to participate in home, work and community activities (10).

Given participation is a guiding principle for disability policies and programs like the NDIS, it is important for allied health professionals to understand factors which impact on participation and how these factors may vary in different contexts. For children, it is acknowledged that patterns of participation are significantly influenced by the sociocultural environment, which impacts what children choose to do, how often and in what environments (11). A broad understanding of participation and its determinants enables allied health professionals to develop interventions and supports which promote participation (12). Hence research in this area is important to guide service provision for allied health professionals working in disability, particularly in the important early childhood years. As childhood participation is strongly influenced by the sociocultural environment, it is important that research occurs across a number of different populations. For disability services working with remote Indigenous populations in Australia, there is currently very little research to guide allied health practice in this area.

Background—participation of Indigenous children with disabilities

There is a scarcity of literature about childhood disability in the Indigenous population (13). Indigenous people in Australia experience significantly higher rates of disability, with the prevalence double that of the non-Indigenous population (14). Despite there being a significantly higher rate of disability amongst Indigenous Australians little has been documented about the day to day experiences of Indigenous children with a disability and their families. The lack of published research means that

there is little to guide the work of service providers in delivery culturally safe, evidence based practice to this population.

Office of Disability - Top End Remote (OoD-TER) is one of a small number of services available to Indigenous people with a disability living in remote areas of the Top End. The team provide a range of services to individuals across the lifespan and travel broadly to remote Indigenous communities across the region. Children with disability and developmental delay comprise 30% of the team's overall caseload and promoting community participation is one of the primary goals of service provision for this group. The lack of available research about Indigenous children with disabilities, particularly in remote and very remote areas, poses a significant challenge for programs such as OoD-TER and makes it difficult to deliver culturally appropriate, evidence based services. In December 2014, a literature review was conducted by OoD-TER staff to review current evidence around participation of children with disabilities in the remote context.

Literature review

The aim of the literature review was to summarise past research about participation of children with disabilities living in remote Indigenous communities, both in Australia and internationally. Pubmed and Medline databases were searched using the following search terms: Oceanic Ancestry Group, Indig*, Aborig*, First Nations, Native American, Maori, Child*, youth, kids, pediatric*, paediatric*, participat*, disabilit*, Cerebral Palsy, Physical Ther*, Physiotherapy, Allied health, Occupational Ther*.

Results

Only a small number of studies ($n = 4$) were located using the above search terms, with further studies located by reviewing reference lists and grey literature ($n=5$). In the handful of studies identified, a number of key themes were identified.

Disability and participation

Disability is a concept that does not exist in many Indigenous cultures and there is often no single word to describe disability in Indigenous languages (15). Western definitions of disability are based on a biomedical model of health and do not take factors such as culture, history and gender into account (16). These definitions also fail to incorporate social factors associated with disability, with the person's experiences often medicalised and health being the primary focus (17). Some studies have attempted to explore Indigenous understandings of disability and suggest that there is a strong focus on identifying the person with a disability in terms of what they are able to do (15, 16, 18). The literature review did not locate any papers that described community participation or explored the concept of participation for Indigenous people with disabilities.

Barriers to participation

A small number of studies explored the barriers to participation for Indigenous people with disabilities both in the urban and remote context (15, 17, 19). Key themes included transport, housing, employment and education. Unique barriers exist for Indigenous people with a disability living in remote areas, with some factors associated with the person's disability and others to do with broader environmental, cultural and social factors (i.e. shame, attitudes towards education, community infrastructure) (19). For the Yolngu people of East Arnhem Land, major barriers to participation have been identified as access to assistive technology, transport, housing and access to public buildings (15).

Disability services for Indigenous Australians

The literature review also highlighted a number of issues for disability providers working in this area. Service providers often have few resources to draw on, particularly around understanding attitudes, customs and beliefs (16). This contributes to a lack of cultural competency, which impacts on the development of meaningful relationships and effectiveness of services being provided. A number of other factors are associated with reduced effectiveness of service provision in the remote context, including high turnover of staff, communication difficulties and lack of information translated into language (15).

The literature review highlighted a number of barriers to participation, issues around service provision and issues with adopting Western definitions of disability for Indigenous people with disabilities. To date, there has been no published research about participation of Indigenous children with disabilities, both in the urban and remote context. This raises problems for current and future service providers, who need to understand the meaning, barriers and enablers of participation for children and families in order to provide culturally appropriate, client centred services.

Planned research

To address the gap in knowledge around participation in the remote context, a small pilot study is being planned in one Top End community. The goal of this initial study is to provide data around participation and involvement in daily activities for children with disabilities in a remote Indigenous community. While it is acknowledged that further research is needed to guide allied health professionals working with Indigenous persons with disabilities across the lifespan, this project is focussing on a small sample of children (2-18 years) from one specific community. Participants will be from across the age range and include children with both physical and intellectual disabilities, as well as children living in both in the main community and in the smaller and more remote outstations.

The study will use a qualitative methodology to explore participation of children with disabilities at home and in the community. Ipads will be used by families to capture images and videos of their child's daily life and involvement in their local community. Using the video footage as a reference, in-depth interview techniques will be used with families to gather information about social and cultural expectations around participation, how 'participation' differs from children without disabilities and activities which are common for children to be involved in. The project design includes the use of local co-researchers and interpreters, who will assist in guiding how the project is implemented and will play an important role in interpreting (both language and culture) and facilitating the in-depth discussions with participants.

Project scoping and initial community consultations commenced in January 2015, with a number of key learnings already emerging. Consistent with the literature review, our discussions with community members have found no single word for disability in any of the local languages. Rather than an umbrella term for disability, multiple words and phrases exist that refer to specific activity limitations or impairments. Some examples, translated into English include 'can't walk', 'cripple or maimed', 'can't speak well', 'don't think or learn right', 'don't listen' and 'can't hear'. Children or adults with these impairments do not appear to be viewed as a homogenous group hence the Western definition of disability is difficult to interpret. It has also proven difficult to translate the concept of 'participation', which also has no equivalent in any of the local languages. Specific examples of children's participation have been useful to introduce families to this concept, with individuals then able to draw upon similar examples from their lives. Grouping these examples together appears to be the most effective way of explaining this concept and significance of the proposed research. Unique examples of children's participation have already been identified by families, including hunting, fishing, participating in ceremony, visiting outstations and spending time with extended family networks.

Policy recommendations

It is anticipated that there will be an increasing number of service providers working in remote Indigenous communities over the next few years, with the progressive rollout of the NDIS. To provide culturally appropriate, evidence based services, it is essential for individuals and organisations to understand the meaning, barriers and enablers of participation for children and families in remote areas. This information is necessary to provide effective supports for children, families and communities. For this to happen, further research is needed to understand how participation is understood and what it means for families of children with disabilities in remote Aboriginal communities.

It is hoped that information from this pilot study can be used to inform service providers currently or planning to work in the remote context. This research will also provide background knowledge and guidance for similar research projects within the broader population of Indigenous Australians living in remote communities. While this project aims to increase knowledge in this area, it is recommended that further research be undertaken to develop the evidence base around community participation in

remote and very remote areas, particularly for those segments of the population not covered in this initial study.

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Presenter

Felicity Pidgeon graduated from Charles Sturt University in 2002 with a Bachelor of Health Science in occupational therapy. Following graduation she worked in a small multi-purpose rural health service in Orbost, Victoria. She has been working with the Northern Territory Department of Health Service for the past nine years in the Top End Remote Disability Services Team. In this role she travels to Indigenous communities around the Top End region, working with clients across the age range. Her diverse case load covers early intervention, school aged, disability and aged care services. Felicity completed a Masters in Remote Allied Health Practice through the Flinders University in 2012. In 2013 she was awarded with a Churchill Fellowship which allowed her to visit allied health teams servicing Indigenous persons living in very remote areas in Canada and the USA to compare service provision and models and to share ideas and resources.