Improving the positive impact of disability services on the lives of Aboriginal and Torres Strait Islander people with disabilities in remote Australia: insights and recommendations from the work of Ninti One

Steve Fisher[1], Georgia Lennon[1], **Maureen Abbott**[1], Freya Kinden[1]
[1]Ninti One Ltd

Background and purpose

Aboriginal and Torres Strait Islander (ATSI) people face complex challenges in gaining consistent access to the range of services required to live successfully in remote Australia. Geographical distance from urban centres, environmental extremes, high costs and cross-cultural considerations are key barriers to appropriate access to services. For people with disabilities, accompanying ill-health, limited transport and low levels of community understanding of their situation are additional obstacles.

For twelve years, Ninti One has been working to improve access to services for remote communities. We commenced by focussing on technical services such as housing, energy, water and telecommunications. In recent years, our emphasis has shifted towards the needs of vulnerable groups, including people with disabilities and their carers, for social and human services. This paper presents insights Ninti One has gained on ways that services for people with disabilities can be more effective in achieving a long-term and positive impact on their lives.

Conceptual thinking on access to services for people with disabilities

The effective design of services can be improved by the use of conceptual frameworks relevant to policy and practice. In the field of disability, conceptual frameworks draw on the work of disabled peoples' organisations, researchers and governments, both in Australia and internationally. This section outlines the key conceptual frameworks applied in the field of disability in order to assist strategic thinking, based on existing knowledge and evidence.

Firstly, the role of **participation** and **inclusion** is considered. Given that the nature of disability is that it isolates people from others, the basic notion that 'presence without participation can be more isolating than no presence at all' [1 (p44)] is a powerful one. Both terms imply an active role for people with disabilities and a positive shift in awareness and practical facilitation by those around them. Effective processes of inclusion result in people with disabilities experiencing a greater sense of belonging to community and society. The notion of belonging has been taken up with some vigour in the 'Count Me In' public awareness campaign mounted by the Health Department of the Canadian Government. [2]

In recent years, through advocacy by the Australian Department of Foreign Affairs and Trade, the concept of **disability-inclusive development** has gained ground as a way of ensuring that people with disabilities are considered from the outset when investments are made in social, economic and human development. Disability-inclusive development seeks to enhance participation and empowerment, reduce poverty and improve equality for people with disabilities. [3 (p3)]

Strategically, a twin-track approach to disability-inclusive development is to combine targeted activities which enable people with disabilities to access services such as information, public spaces,

education and/or employment with mainstreaming efforts which ensure all projects consider the impact on and actively include people with disabilities. [4]

Inclusion is often confused with **integration**. While inclusion refers to a process of change that empowers an individual or group through respect for their rights to be included, integration describes the physical presence of a person with disability. Integration can refer to specialised classes or programs, segregated group activities or not enjoying the same social and learning outcomes as other class members. As such, integration falls short of the process of fundamental change required for inclusion.

However, people with disabilities have been careful not to see inclusion as a panacea. Without the full commitment to change required at a community and societal level, inclusion can become lip service to a goal rather than its genuine pursuit. As one wide-ranging study from the United States has shown, people with disabilities have become aware of the many tensions and contradictions in policy and practice surrounding genuine inclusion, the difference between activity and participation, decisional autonomy, the importance of physical access and participation enabling the expression of their own value rather than predetermined societal norms. [5] The study goes on to make the valuable observation that core participation values include active and meaningful engagement, choice and control, access and opportunity, personal and societal responsibilities and social connection, societal inclusion and membership.

The presence of **stigma** is a key barrier to meaningful participation and inclusion. The concept of stigma is relational, only thriving if the individual possessing the disability accepts their devaluation by the wider society. A case study from Ghana provides useful insight, revealing that among people living with a disability the shame associated with having a disability and fear of societal discrimination was a greater source of anguish than the lived reality of enacted stigma. [6] In Australian society relational stigma stems from the affected person's labelling, whether anecdotal, in the media or medically diagnosed. Official labelling constructs that person for society on a cognitive level, informing others how to behave towards them and interpret their actions, which then leads to social dispossession and isolation. [7]

The **rights of people with disabilities** rarely feature strongly in discussions about access to services. The United Nations Convention on the Rights of Persons with Disabilities provides the key international position on the subject through Article 29: Participation in political and public life, which states that parties shall guarantee to persons with disabilities political rights and the opportunity to enjoy them on an equal basis free from discrimination. [8]

The concept of **empowerment** is used frequently to describe the aspirations of minority groups. The strength of the ideas behind empowerment have been overlooked as the word itself has become over-used, but they remain relevant to the needs of people with disabilities. For Ninti One, empowerment refers to the voices of people being influential in places and processes where decisions are made that affect their lives.

For ATSI people, empowerment is a concept that is central to the history of their rights and interaction with the Australian state. Access to services is a critical part of this history and so empowerment includes effective ways by which the priorities of ATSI people can influence the design of services.

Aboriginal and Torres Strait Islander people in remote Australia; key facts on population and disability

The vast majority of Australia's population lives in the urban and regional areas that cover the country's coastal fringes. Remote Australia makes up 85% of Australia's landmass while accounting for only 2.6% of Australia's total population. [9] ATSI people represent 48% of the population residing in very remote areas, and 16% of the total population in remote areas. [10] The ATSI population in remote Australia is diverse, spanning 1,100 communities, a number of major towns and speaking 50 unique languages. [11] Given the isolated nature of many remote communities in this region, access to some of the most basic services including internet, transport and health care is generally poor, contributing to a range of problems faced by ATSI people living in remote Australia. [10, 12]

Only in recent decades has Australian ATSI Health Surveys (AATSIHS) been able to provide national statistics on the prevalence of disabilities in the ATSI population. However, data is based on self-reporting and thus it is important to recognise the way in which Aboriginal people consider disabilities. For example, long term health conditions such as diabetes or chronic asthma which restricts everyday activities can be considered as 'disabilities'. [13] In 2013 the AATSIHS reported that 35.7% of ATSI people had a disability or severely limiting long-term health condition. This makes ATSI people 1.7 times as likely as non-Indigenous people to be living with a disability. [13]

The most prevalent disabilities for ATSI people were physical impairments followed by sight, hearing, speech, intellectual and psychological disabilities. There is little difference in rates reported by males and females with disabilities across all types except for psychological disability, which is more common among women. [14] ATSI women living with a disability are also more likely than men to have caring responsibilities for children. [14]

Data on remote disability service providers is very limited. In 2012 only 13% of Aboriginal people accessing disability services nationally lived in a remote or very remote area. [12] Although a number of disability advocacy and health organisations provide services in remote Australia the majority of these are based in an urban setting and are controlled by non-Indigenous people. These outreach services (such as Anglicare and CarersNT) are periodic, only accessing communities weekly on a 'fly in fly out' or 'drive in drive out' basis.

A handful of services are Aboriginal controlled and operate full-time within communities. The most significant of these are Aboriginal Community Controlled Health Organisations (ACCHOs) and Local Council supported Aged and Disability Services. However in a remote based setting, none of these are dedicated solely to disability support, and include a range of services for infant, youth and aged health. [16]

Trends in policy and practice for people with disabilities

The purpose of this part of the paper is to provide an overview of strategic and conceptual developments in programs, policy and practice for people with the disabilities in order to inform our analysis of the situation in remote Australia. If we know what is happening elsewhere, then we can form a view on areas of improvement that could be achieved.

Initially, the work of disabled people's organisations (DPOs) must be considered. The post-war growth in the role of civil society in tackling social problems and promoting development in industrialised countries included non-government organisations established to improve facilities, services and equipment for people with disabilities Since then, the work of DPOs has modified its focus towards a

lead role in advocacy for people with disabilities as part of wider social change, promoting what Hammel et al refer to as 'personal and societal responsibility (based on) determination, advocacy and empowerment' considering 'common values associated with participation (as) shared, while the routes to their realisation are individualised.' [5]

Effective DPOs are critical to the achievement of inclusive societies and efficient economies. They know and understand disability issues better than any other group and are necessary advocates to governments and communities as experts to inform policy development and also as providers of services for people with disabilities. [4]

A major milestone in disability policy was the United Nations International Year of Disabled Persons (IYDP) in 1981. The celebration of IYDP across Australia in hundreds of events brought people with disabilities together on a scale and with a focus which had not previously occurred. The IYDP particularly emphasised the rights of persons with disability and their participation within society. At the time, this represented a major shift in personal and social consciousness of disability from understanding it in terms of individual pathology (the medical model) to an understanding based in human rights and a focus on the elimination of barriers created by society.

DPOs in some countries including Cambodia, India and the Pacific Nations are notable examples of active self-advocacy groups and networks. They are characterised by a focus on key themes of importance to their members, including democratic participation, reducing risks associated with natural disasters, drug and alcohol abuse and combatting stigma. In Australia, developments have followed a similar track with a major difference in that DPOs tend to be funded and contracted to provide services on behalf of the state. This role presents an underlying tension with any desire they have to advocate on behalf of their clients, since policy advocacy will most likely be directed towards government departments who are funding their services. Independent funding reduces these contradictory forces, but does not remove them.

This point having been made, it is also important to note the work of many organisations in this country with the strategic emphasis of working for ATSI people with disabilities, including; People with Disability Australia (PWDA), First Peoples Disability Network (FPDN), Disability Advocacy Service (DAS) Inc., Disability Advocacy New South Wales, Women with Disabilities Australia, Motivation Australia, Karrarendi Aged and Disability Program and Bindi (Australian Disability Enterprise). Their capacity-building and education work aims to promote a disability-inclusive culture which is applied in a practical way. Additionally, empowerment is a key goal for DPOs. They raise awareness among people with disabilities of the contribution education and skills make to an individual's ability to self-empower and self-advocate. Most organisations consider the context in which people live as being critical to their ability to achieve an improved quality of life and so invest in empowerment and advocacy on the one hand and community awareness on the other.

Strategies and principles for Disability Services in Australia and the NDIS

The National Disability Insurance Scheme (NDIS), implemented by the National Disability Insurance Agency (NDIA) develops individual plans for people living with a permanent disability in order to identify and fund the supports needed to live life fully and achieve personal goals. [16]

The NDIS seeks to support the outcomes articulated in the National Disability Strategy developed by the Council of Australian Governments (COAG) for the period of 2010-2020 which has strong links to

the National Standards for Disability Services, COAG's High-level Principles for a National Disability Insurance Scheme and the National Disability Insurance Agency's strategic plan (REF).

The NDIS Act 2013 [17] outlines 17 General Principles surrounding participation & inclusion, choice & control, equal rights and access, as well as asserting the importance of innovation & quality, the role of parents & carers and the role of advocacy throughout its legislation. Where the NDIS has taken a positive step in explicitly recognising the importance of advocacy it has done so on a generic scale that associates itself with the passive inclusion of the disabled person in question. What is absent from the principles of the NDIS, and consequently from its practical enactments, is the link between the principles of advocacy and empowerment and an active approach to self-engaged knowledge and inclusion. While the importance of this should be recognised and addressed on a nation-wide scale the engagement with such principles in a remote Aboriginal space requires even more concerted efforts.

Insights from the work of Ninti One

People are passive in their responses to service providers

Over the last decade, our research on the interaction between service users in remote communities and service providers has indicated a strong tendency for people living in remote communities to play a passive and non-influential role in service design and delivery. They are passive recipients of what is available locally and most likely determined from the nearest capital city. Hampered by language and cultural barriers with non-Aboriginal staff of service providers and unaccustomed to expressing a preference, disabled people and their carers are missing out on opportunities to shape services in a way that more closely matches their needs.

Community knowledge and education levels on disability are very low

Few people in remote Australia can count on the information and knowledge they require to respond adequately to disability. This observation applies to people with disabilities and their carers, as well as the wider community in which they live. Improvements in knowledge about the causes of disabilities, ways to manage them and potential pathways to recovery are the single biggest advance that could be made for ATSI people with disabilities. Greater awareness would help reduce fear and stigma experienced by people with disabilities and increase their prospects of greater social inclusion.

Benchmarks and standards relevant to remote communities are applied unevenly

Although there is no lack of willingness by local service providers to adapt mainstream practice to remote communities and many good examples exist, the overall picture is uneven. Standards exist, but people with disabilities have little information about them. The result is that people are again placed in a position of passive acceptance rather than active engagement.

Competencies to work cross-culturally are under-developed among service providers

The influence of culture is often under-described and therefore unappreciated. In practical terms it refers to the ways in which people address each other, the level of respect afforded to people of different social and cultural status, the values and priorities that individuals assign to aspects of their lives and conditions that apply to contact between men and women. Cultural norms do not apply only to ATSI people. Non-Indigenous Australians have their own cultural parameters that relate to the same subjects, but often in a different way.

Frequent feelings among people we have met during our research are that non-Aboriginal staff of organisations that serve them are often not attuned to the cultural aspects of work with clients causing

misunderstandings, embarrassment and feelings of disrespect. Most of the time, staff were doing their jobs according to their own ways of working and were unaware of the cultural sensitivities felt by clients. If culture is under-valued in service provision for ATSI people, then the effectiveness of those services is diminished.

Groups that work on empowerment and advocacy for people with disabilities are largely absent

Although our survey of organisations working with and for ATSI people with disabilities indicates the presence of many important initiatives and well-established programs, their reach to remote places is often limited.

For people with disabilities to achieve positive changes for themselves and in the community around them, long-term and permanent advocacy is required at a local level. This means they need to be able to represent themselves effectively to people who make decisions affecting their lives. They have to become active participants in positive change rather than passive recipients of services. This is a big challenge in remote places, but not one that is unachievable.

The design of services is transactional rather than transformative

All services, not just those relating to disability, are established according to a set of explicit or implicit performance standards. These standards tend to be operational in character, meaning they refer to practical delivery according to a schedule and a numerical measure, such as a number of visits provided or clients served. The tendency within service design is therefore to emphasise quantity of delivery, meaning that transactions between service providers and clients are the basic unit of currency. Of course, no person waiting for something important to arrive, such as a bus to a drop-in centre or a new wheelchair, would argue with that.

However, the over-valuing of service transactions, while fundamental to meeting basic needs, can mean that strategy is downgraded in the hierarchy of what an administrative system considers important. Services for people with disabilities must ultimately seek to change the lives of individuals who may be unwell, immobile, isolated, low in self-confidence and uncertain of the future. While caring about the transactional, services must also aim to be transformative.

Recommendations

- **Research**—Rigorous and meaningful research is undertaken which occurs alongside ATSI people in a remote setting in order to determine the reach, coverage and character of disability and services for ATSI people in remote Australia.

- **Raise Awareness**—Develop guidelines and methods for awareness initiatives that emphasise the role of the wider community in the lives of people with disability with the aim of tackling the local obstacles and stigma experienced by individuals and their carers. These methods should be harnessed in the service of community awareness of disability and improved social inclusion.

- **Culturally Appropriate Services**—Efforts are made to build and implement culturally appropriate services that are transformative and consistent with the outcomes of the amended National Disability Strategy and National Standards for Disability Services in order to guarantee the accessibility of disability services for ATSI people.

- **Advocacy and Empowerment**—Efforts are made to build the capacity of existing advocacy networks and new networks are fostered in order to encourage the empowerment of Aboriginal leaders. Processes are put in place to enable advocacy networks to be invited to advise on and contribute to better service arrangements for ATSI people in remote locations. People with a disability and their carers are supported and enabled to be active in their responses to service providers. For people with disabilities to become active participants in positive change they need knowledgeable advocates to help work out the best way to achieve it.

To conclude, we believe that the fundamental challenge for people with disabilities in remote Australia is how best to gain access to care and support services within a community environment that encourages social and economic inclusion. We recommend that further research, strategic, design and operational work is conducted to tackle the issues we have described in this paper.

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Presenters

Steve Fisher is the Director of Community Works, a small company that provides management consultancy and project management services to organisations in Australia and overseas. Community Works is a long-term partner of Ninti One Ltd and Steve contributes to a range of the company's work, including the Cooperative Research Centre for Remote Economic Participation, Stronger Communities for Children and work on improving health and disability services. For many years, a large part of his work has involved designing and using monitoring and evaluation methods for remote communities in many places across Australia. He has also worked extensively on mental health programs internationally, most recently for the World Psychiatric Association, BasicNeeds and mhNOW.