

PLANNING FOR A BETTER LIFE IN REGIONAL, RURAL AND REMOTE AREAS UNDER THE NATIONAL DISABILITY INSURANCE SCHEME

ABSTRACT

Person-centred planning is a key NDIS process for identifying goals, supports and funding for people with disabilities. People in regional, rural and remote areas of Australia experience unique service access and service delivery challenges. An Australian Research Council funded project is investigating how planning is occurring for Aboriginal and non-Aboriginal people, including those with intellectual disability, in regional, rural and remote areas of Central Australia and Western NSW.

INTRODUCTION

Is person-centred planning with individualised funding different for people with disability who live in regional, rural and remote Australia compared to those in metropolitan areas? An Australian Research Council funded project involving researchers from The University of Sydney, the University of Canberra, Deakin University, and Centre for Remote Health, Flinders University in the Northern Territory, seeks to answer this question. In this article, we provide background as to why this research is needed and briefly outline what we plan to do.

PERSON-CENTRED PLANNING IN THE NATIONAL DISABILITY INSURANCE SCHEME

The Australian National Disability Insurance Scheme (NDIS) aims to provide people with disability with choice and control over the supports and services they need and want to live an inclusive life. Person-centred planning is a key process for NDIS participants to identify their aspirations and goals, the supports they need to achieve these, and determine the funding they will receive to engage services. Given the importance of planning, we asked ourselves how well the person-centred planning process was working for people living in regional, rural and remote geographic areas, including Aboriginal and Torres Strait Islander people, given additional factors previously identified for this group of Australians with disability. For the one third of NDIS participants who report having an intellectual disability there is evidence that some people lack previous experience of decision making and planning requiring additional time and the support of a highly skilled planner to engage fully in the planning process (Collings, Dew & Dowse, 2018). The need for additional planning support is likely to increase if the person with intellectual disability is living in a regional, rural or remote location.



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SUMMARY

- Person-centred planning is a key NDIS process for identifying goals, supports and funding;
- People in regional, rural and remote areas experience unique service access and delivery challenges;
- Some people with intellectual disability in regional, rural and remote areas lack previous experience of decision making and planning and need additional time and support from highly skilled planners to develop a good plan;
- Some Aboriginal and Torres Strait Islander people with intellectual disability from regional, rural and remote areas may experience lack of cultural understanding from service providers and policy makers;
- This research will examine how planning is occurring for these groups.

The focus of our research project is to understand planning for people with a diverse range of impairments, including those with intellectual disability, living in regional, rural and remote areas of Western New South Wales (NSW) and Central Australia. The NDIS Rural and Remote Strategy 2016-2019 (2016, p. 57) has a goal that “effective, appropriate supports [are] available wherever people live”. According to the March 2020 NDIS quarterly report to the Council of Australian Governments (COAG), of the 364,879 current NDIS participants 1.5% (n=5551) live in, or close to, our project region of Central Australia, Barkley, and Western NSW. Data on Aboriginal and Torres Strait Islander participants by region is not publicly available, however the latest report to COAG indicated that this group represented 6.9% of all NSW NDIS participants and half of those in the Northern Territory (National Disability Insurance Agency, March 2020).

CHALLENGES OF SERVICE ACCESS AND DELIVERY IN REGIONAL, RURAL AND REMOTE AREAS

Undoubtedly, all people with disability living in regional, rural and remote Australia have the same rights to receive supports and services as their peers in metropolitan areas; however, previous research conducted by our team highlights service access and service delivery challenges in these geographic areas. Service access challenges include: lack of required services due to “thin markets” where gaps in the market mean people cannot access what they need; limited availability of technology especially internet; high economic and social costs due to the need to travel long distances to access existing services available in larger regional centres or cities; and/or intermittent access to fly-in/fly-out or drive-in/drive-out services resulting in a lack of continuity and follow-through which is particularly important for people with intellectual disability and Aboriginal and Torres Strait Islander people with disability.

People with intellectual disability from Aboriginal and Torres Strait Islander backgrounds, and particularly those from remote communities, experience significant additional barriers associated not only with geographic isolation, but also due to a lack of cultural understanding on the part of planners, service providers and policy makers. Our previous work in very remote communities in Central Australia highlighted the disconnect between the strong desire of Anangu from the NPY Lands to remain living on their Country and perceived pressure for them to relocate to regional centres to access services (Dew et al., 2019). These concerns were also highlighted by family members of children, many of whom had intellectual disability. Families reported feeling that relocation to larger regional centres was necessary to access appropriate education, medical support, and other services not available in their geographically isolated

local communities (Ryall et al., 2019). There is widespread acceptance that moving off Country to access services adversely impacts on the physical, cultural, and emotional health and wellbeing of Aboriginal and Torres Strait Islander people.

Likewise, service providers working in regional, rural and remote geographic areas, including those working with Aboriginal and Torres Strait Islander communities, report specific challenges in *delivering* support. These challenges may include: additional costs associated with transport and accommodation; potentially low client numbers at a given location (contributing to “thin markets”); difficulties organising appropriate staff supervision and support; and high levels of staff turnover. Additionally, at the policy level, the geographic challenges experienced by people with intellectual disability, family members and service providers are rarely acknowledged or planned for.

NDIS PLANNING PROCESS

Early Childhood Early Intervention (ECEI) Coordinators, who work with the families of children with developmental delay up to the age of six years, and Local Area Coordinators (LACs), who work with all other eligible age groups, are employed by non-government organisations to assist people to navigate the NDIS including through the planning process. The National Disability Insurance Agency (NDIA), which administers the NDIS, employs planners who record an individual’s person-centred plan goals and make funding recommendations. Concerns have been expressed that some planners lack experience working with people with more complex needs including factors associated with rurality, intellectual disability, Aboriginal and Torres Strait Islander cultural considerations and complex communication needs. Following the NDIA plan approval, ECEIs and LACs work with the family/person to implement their goals within budget, drawing on available supports and services within their local community. As previously stated, this can be difficult to achieve in regional, rural and remote areas where required supports may be lacking. The planning process and workers’ roles have changed a number of times since the rollout of the NDIS resulting in lack of clarity and confusion. Additionally, the March 2020 NDIS dashboard report for COAG highlights significant underutilisation of allocated NDIS funds for those living in regional, rural and remote locations compared to the NDIS benchmark. The Northern Territory data indicates only 37% utilisation of the plans for people living in very remote communities and 66% for those in remote communities. Similarly, in NSW 36% of the plans of people from very remote areas and 51% of the plans of those in remote communities were utilised. Overall, for the areas included in our project, only 65% of the funding allocated to plans in Western NSW have been utilised, 46% in Barkley and



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66% in Central Australia (National Disability Insurance Scheme, March 2020). This underutilisation suggests that the plans themselves may not be fit for purpose for people in regional, rural and remote areas.

PROJECT TO UNDERSTAND PLANNING IN REGIONAL, RURAL AND REMOTE AREAS

The authors, who are all members of the research team, have collaborated on a number of other research projects in regional, rural and remote areas of Australia including in very remote Aboriginal communities in Central Australia and Western NSW. In this project, the team is led by Aboriginal academic and lead author, Associate Professor John Gilroy, and includes non-Aboriginal academics (the other authors) who work in partnership with Aboriginal community-controlled organisations using decolonisation principles and culturally appropriate data collection methods (e.g., Yarn Ups).

We will speak with Aboriginal and non-Aboriginal people with disability and their families or guardians, ECEIs, LACs and NDIA Planners. Our aim is to find out, from these different perspectives, how planning is occurring in the two identified areas which encompass regional, rural and remote communities. We will identify the skills, expertise and attitudes of the ECEI, LAC, and NDIA Planner workforce to engage effectively with people with a disability, both Aboriginal and non-Aboriginal from central Australia and north west NSW. As indicated in the evidence described previously, a well-prepared and trained NDIS workforce is essential to ensure that participants in regional, rural and remote areas, both Aboriginal and non-Aboriginal people with disability, and those with intellectual disability, are supported to develop, implement and fully utilise NDIS plans that meet their unique and potentially complex needs. Data collection has been impacted by the COVID-19 pandemic and will commence once social distancing restrictions are lifted.

If you are interested in knowing more about or participating in the project, contact John Gilroy on john.gilroy@sydney.edu.au

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