

'Hard yakka': living with a disability in the West Kimberley



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July 2014

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ACKNOWLEDGEMENTS

We acknowledge the people of the West Kimberley region interviewed for this study and thank them for their willingness to share their experiences with us.

We also acknowledge Marie Shinn and Marlena Kahika at the Kimberley Disability Advocacy for all their work and support in facilitating the interviews with the research participants during 2011 and 2013.

We would also like to thank Jenny Au Yeong, former CEO of Ethnic Disability Advocacy Centre, for her vision, commitment and energy for disability advocacy for social justice and equality, and Wendy Rose, new CEO of EDAC, for maintaining this commitment.

Finally, special thanks to Jenny Au Yeong who collated a number of documents for the background research of this report.

The research underpinning this report was funded through an Australian Research Council Discovery Grant: DP 110102719.

The research for and the writing of this report were funded by an Early Career Researcher DECRA grant awarded to Dr Karen Soldatic in December 2013 from the Faculty of Arts and Social Sciences, UNSW Australia.

Citation:

Soldatic, K., Spurway, K. and Meekosha, H. (2014) “‘Hard yakka’: living with a disability in the West Kimberley”, UNSW Australia: Sydney.

ISBN: 978-0-7334-3498-3

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**Hard yakka* is an Australian slang term to denote the strenuous physical grind of rural working-class labour. According to informal sources, *yakka*, originally from an Aboriginal language group now extinct, means ‘work’. We have named this report ‘Hard yakka’ in recognition of the hard, ongoing work that West Kimberley Aboriginal residents with disabilities must do to maintain a basic standard of living, their health, wellbeing and economic security in the face of increased social insecurity caused by inadequate government support.

Disclaimer: Information presented in this report represents the views of the **authors** only, and not the ARC, CI/PIs involved in the larger national study who are not authors of this report, UNSW Australia, nor Kimberley Disability Advocacy.

Turn the anger into fire in the belly for social justice.

Marie Shinn, KDA Advocate, Broome
July 2013

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ABBREVIATIONS AND ACRONYMS

ABS	Australian Bureau of Statistics
AHL	Aboriginal Hostels Limited
AHMAC	Australian Health Ministers Advisory Council
AHRC	Australian Human Rights Commission
AIHW	Australian Institute of Health and Welfare
ALGA	Australian Local Government Association
AMA	Australian Medical Association
ATSI	Aboriginal and Torres Strait Islander
CAFCA	Communities and Families Clearinghouse Australia
CALD	culturally and linguistically diverse
COAG	Council of Australian Governments
CRPD	Convention on the Rights of Persons with Disabilities
CRS	Commonwealth Rehabilitation Service
DIA	Department of Indigenous Affairs
DPRWG	Disability Policy and Research Working Group
DSC	Disability Services Commission (WA)
DSS	Department of Social Services
FPDNA	First Peoples Disability Network Australia
HACC	Home and Community Care
KAMSC	Kimberley Aboriginal Medical Services Council
KIFSA	Kimberley Individual and Family Support Association
NIAF	National Indigenous Access Framework
NATSISS	National Aboriginal and Torres Strait Islander Social Survey
NDIS	National Disability Insurance Scheme
NDS	National Disability Strategy
PATS	Patients Assisted Travel Scheme
PCHRIS	Primary Health Care Research and Information Service
PWDWA	People with Disabilities Western Australia
SDAC	Survey of Disability, Ageing and Carers
WACHS	WA Country Health Service



BACKGROUND

This report investigates the lived experiences of Aboriginal people with disabilities living in the West Kimberley region of Western Australia, covered by the local government shires of Broome and Derby–West Kimberley. The major population centres in the West Kimberley are the towns of Broome, Derby and Fitzroy Crossing.

Both local government areas have low populations scattered across vast areas with poor infrastructure and under-developed built environments, which make travel and daily living especially challenging. The town of Broome is located 2,230 kilometres north of Perth; Derby is 2,383 kilometres and Fitzroy Crossing more than 2,500 kilometres to the north-east (Shire of Broome, 2014; Shire of Derby–West Kimberley, 2014). Broome Shire has a resident population of 15,857 people living in an area covering 56,000 square kilometres (Shire of Broome, 2014). Derby–West Kimberley has 8,941 inhabitants living in an area of 118,560 square kilometres (Shire of Derby–West Kimberley, 2014).

The region has a large Aboriginal population. Between one-third and one-half of the population is of Aboriginal or Torres Strait Islander origin (Shire of Broome, 2014; Shire of Derby–West Kimberley, 2014). There are over 100 Aboriginal communities of various population sizes throughout the region and nearly 100 properties servicing the pastoral industry.

The West Kimberley has a diverse economy, with mining, tourism, agriculture and pearling, all of which are major contributors to the economic output of the area. Geographically, the region has very diverse terrain and geographical features from arid desert areas, gorges and river valleys to long pristine coastlines, highly developed coastal resorts and beaches, in addition to extensive rainforest areas and cave systems (Shire of Broome, 2014; Shire of Derby–West Kimberley, 2014).

Both Shires have significant transportation challenges during the cyclone season, between November and April each year. The ‘great wet’ leads to road closures with the majority of roads being unsealed, gravel or unformed (Shire of Broome, 2014; Shire of Derby–West Kimberley, 2014). This makes travel impossible without access to off-road or four-wheel drive vehicles, further isolating remote communities and restricting access to health, education and other services, including disability support services.

DISABILITY AND INDIGENEITY IN AUSTRALIA

People with disabilities are among the most socially and economically disadvantaged groups in Australia, with disability being both the cause and consequence of disadvantage (Biddle et al., 2013). Disability affects educational attainment and employment opportunities as well as financial security and access to community and social services, all of which reinforce socioeconomic inequality and its associated health risks, lowering health outcomes and overall wellbeing (Biddle et al. 2013). In a cyclical interaction, low socioeconomic status may produce disability, leading to further negative outcomes for Australians with disability. This is particularly evident in the interaction between Aboriginal disadvantage and disability, as is highlighted in this report.

The Australian Bureau of Statistics’ *2012 Survey of Disability, Ageing and Carers* (SDAC) showed that nearly one in five (18.5%) Australians have some kind of disability, with similar

rates recorded for men and women. Physical impairment was the most common type of disability (84%) with a further 16% of Australians having a mental or behavioural impairment (ABS, 2012a). People with disabilities have fewer educational opportunities and a reduced rate of participation in social and community activities (ABS, 2012a). For example, the 2012 SDAC found that people with a disability aged 15 years and older living in households were less likely to have achieved a bachelor degree or higher (13%) than the general population (25%). In addition, the SDAC showed that people with disabilities rely heavily on family, carer and community support with nearly two-thirds needing assistance with at least one everyday activity (ABS, 2012a).

Aboriginal people comprise about 2.5% of the total Australian population, according to the Australian Bureau of Statistics (2010). Almost half the Aboriginal population (49%) is below the age of 20 years and only 3% is aged 65 years or older. Overall, the rate of disability in the Aboriginal population is substantially higher than for the non-Aboriginal population (ABS, 2010). The *2008 National Aboriginal and Torres Strait Islander Social Survey* (NATSISS) reported more than two in five (41.9%) Aboriginal people with a disability of some kind compared with an Australian average of less than one in five people (Biddle et al., 2013). NATSISS reported that nearly 8% of Aboriginal people also reported having a profound or severe limitation (Biddle et al., 2013).

In general, there is a clear correlation between the age of an individual and the likelihood of having a severe or profound impairment (Biddle et al., 2013). The older you are, the more likely you are to have a disability of some kind, with people aged over 65 reporting more profound disabilities. In Australia, the proportion of Aboriginal people reporting a profound or severe disability increases significantly from age 35, with more than a quarter of Aboriginal people reporting such a disability (Biddle et al., 2013). This contrasts with the non-Aboriginal population where, even though the rate of profound or severe disability does increase from the mid-thirties, a substantial increase in profound or severe disability is not evident until after 60 years of age (ABS, 2010). Profound and severe forms of disability occur more frequently among Aboriginal and Torres Strait Islanders of all age groups, however, with the highest rates among those aged 40 and older (Biddle et al., 2013).

Aboriginal Australians tend to have a disability or develop chronic health problems at an earlier age and the disability tends to be more serious than in the general population at the same age. The interaction between poor health and disability is complex for Aboriginal Australians; poor health may lead to disability in ways not seen in the broader community. After accounting for age differentials, Aboriginal people aged 15 years and older were half as likely to report having excellent or very good health compared to non-Aboriginal people (ABS, 2014a, 2014b). In addition, the number of Aboriginal people reporting only fair or poor health was at least twice as high as in the non-Aboriginal population (ABS, 2014a, 2014b).

Nationwide, Aboriginal people also reported having poorer health outcomes and overall wellbeing (AMA, 2014). The gap in health and life expectancy between Aboriginal and non-Aboriginal Australians is significant and well recognised by government and service providers. There is a real and immediate need for considerable and sustained interventions to improve the health and wellbeing of Aboriginal Australians, which involves addressing the complex interaction of contributing factors, including poverty, low educational attainment, disability,

and lack of employment opportunities as well as substandard housing and overall living conditions (AMA, 2014).

Aboriginal Understandings of Disability

Aboriginal understandings of 'disability' are different to mainstream conceptions (Gilroy and Donnelly, forthcoming). The First Peoples Disability Network Australia, a national peak body representing Aboriginal and Torres Strait Islander people with disabilities, their families and carers, highlights the fact that many Aboriginal Australians do not identify with mainstream conceptualisations of disability, due in part to different cultural perceptions of disability but also a strong reluctance to adopt additional 'labels of disadvantage' (FPDNA, 2013). People with disabilities tend to be supported by their families and communities, owing to a sense of cultural obligation, and are likely to mistrust the intentions of government agencies due to the long-term historical relations of colonisation (Gilroy and Donnelly, forthcoming). Research that aims to improve and refine understandings of Aboriginal experiences and cultural concepts related to disability, such as this study, should help to inform national policy approaches, such as the National Disability Insurance Scheme.

HEALTH, INDIGENEITY AND DISABILITY IN WESTERN AUSTRALIA

The remote and rural nature of the West Kimberley makes life more complex for the Aboriginal people with disabilities who live in the region. This is in addition to the racism, discrimination and socioeconomic disadvantage related to being Aboriginal and disabled in Australia.

Aboriginal Australians face significant barriers to accessing disability programs and support services in part because the majority live in remote and very remote areas, such as the West Kimberley. Not only are disability and mainstream services lacking in these areas, but of the services that do exist, most are not responsive to the needs of Aboriginal people with disabilities in terms of their cultural, linguistic and material contexts. Due to the high rate of socioeconomic disadvantage, Aboriginal people with disabilities face additional barriers such as low incomes and lower levels of literacy and numeracy than the non-Aboriginal population (Biddle et al., 2012).

The *ABS 2007-2008 National Health Survey* (ABS, 2009) found that increased disadvantage in certain geographic areas, such as remote and rural townships and communities, was strongly associated with poor health and wellbeing for people living in these areas. These groups have higher risk factors for certain diseases and use preventative health services less frequently than other groups with relative socioeconomic advantages (PHCRIS, 2013). The ABS survey also highlighted the variety of reasons why people living in disadvantaged areas of Australia, such as remote and rural communities, experience poor health. ABS (2010) gives the example of people with chronic conditions, which may include disability, who have low employment opportunities and whose family members reduce their working hours or leave their jobs in order to care for them. This situation results in a decrease in household income overall and forces families to move to low-cost housing in more disadvantaged areas. In addition, low educational attainment can lead to an inability to obtain information about preventative and appropriate health services (ABS, 2010).

The *ATSI Health Performance Framework 2012 Report: Western Australia* produced by the Australian Institute for Health and Welfare (AIHW, 2013) provides the latest information on

health system performance and the health status of Aboriginal and Torres Strait Islander peoples in Western Australia. The framework shows that there are areas of improvement in the health of Aboriginal people living in Western Australia. Over a 20-year period, from 1991 to 2010, there was a decline in overall mortality; a decline in deaths due to circulatory disease; a decline in infant mortality rates with a significant narrowing of the gap between Aboriginal and non-Aboriginal Australians; a significant increase in health assessments recorded through Medicare; a near equalising of immunisation rates for Aboriginal children to those for non-Aboriginal children by age two; an increase the number of Aboriginal primary health-care service providers; and improvements in literacy for Aboriginal students in Years 3 and 7.

However, AIHW's 2012 Framework Report also noted some areas of concern in terms of the health of Aboriginal people living in Western Australia. Half of those aged 18 years and older in non-remote areas have a disability or long-term or chronic health condition. Aboriginal people in Western Australia have nine times the mortality rate for diabetes and twice the rate for circulatory diseases than non-Aboriginal people. There has been no improvement in incidence rates for treated end-stage renal disease, which is currently 12 times that of the non-Aboriginal population. Aboriginal people in Western Australia also have high rates of hospitalisation and death due to assault, suicide, transport accidents and other injuries. More than one-quarter (29%) of Aboriginal Australians aged 15 years and older lives in overcrowded housing. In addition, there continue to be barriers to culturally appropriate health care with Aboriginal people having lower access to hospital procedures. The Aboriginal health crisis in Western Australia is taking place in the context of extreme socioeconomic disadvantage and inequity, evidenced by the fact that 15.1% of Aboriginal people are unemployed compared to the national average of 5.8% (ABS, 2014a, 2014b).

POLICIES AND LEGAL FRAMEWORKS

Nearly all the social and economic inequalities faced by Aboriginal people with disabilities documented in the research outlined above are strongly associated with persistent and structural racism that manifests in the ineffective, inadequate and inappropriate delivery of supports and services. This is despite the raft of ongoing legislative and policy frameworks designed to address either disability or Indigenous discrimination.

There is a range of federal, state and local government policies that directly and indirectly impact upon the health, wellbeing and participation of Aboriginal people with disabilities living in the West Kimberley region.

International Conventions

The Australian Government has signed and/or ratified a number of international agreements that are of direct relevance to Aboriginal people with disabilities which are designed to address the structural and persistent discrimination and disadvantage faced by this group.

The *Convention on the Elimination of All Forms of Racial Discrimination* is one of the earliest relevant human rights treaties. This was adopted by the United Nations General Assembly on 21 December 1965 and entered into force on 4 January 1969 (AHRC, 2014a). Australia ratified the Convention on 30 September 1975, obligating it to condemn racial discrimination and to pursue by all appropriate means and without delay a policy of eliminating racial discrimination in all its

forms. According to the AHRC (2014a), “Under the Convention, racial discrimination is where a person or a group is treated differently because of their race, colour, descent, national origin or ethnic origin and this treatment impairs, or is intended to impair, their human rights and fundamental freedoms”.

The Australian Government has signed and committed itself to implementing the principles of several other UN instruments that relate to the human rights of people with disabilities and Aboriginal people as well as the elimination of racial discrimination. In signing these, the Australian Government has committed itself to implementing human rights principles in accordance with the various articles within each document. The main instruments and their principles relevant to this report are summarised below.

Australia ratified the *UN Convention on the Rights of Persons with Disabilities* (CRPD) on 17 July 2008 and the Convention entered into force on 16 August 2008. The CRPD commits Australia to respecting and protecting the rights of people with disabilities and to ensuring that they are able to enjoy human rights fully and on an equal basis with other Australians. The principles of the CRPD have been integrated into policy and legal frameworks at all levels of government in Australia and government authorities are constantly under review in terms of compliance (AHRC, 2010).

In September 2007, the *UN Declaration on the Rights of Indigenous Peoples* was adopted by the UN General Assembly. Although Australia initially voted against it (along with the USA, Canada and New Zealand), with a change of government, Australia reversed its position and signed on 3 April 2009. The Declaration recognises the unique contribution of Indigenous culture to global culture and common heritage. The government’s obligations are to ensure the rights of Aboriginal people in terms of self-determination and the establishment of their own institutions, to protect Aboriginal culture, to safeguard Aboriginal people’s land, and to ensure Aboriginal participation in decision-making at all levels of policymaking (Wiessner, 2009: 4-6).

Commonwealth Policies and Frameworks

The Australian Human Rights Council (AHRC, 2014b) is a statutory body mandated by the federal government to take the lead on the promotion and protection of human rights in Australia. According to the AHRC (2010), the main legislative instruments and policy frameworks relating to disability, Indigeneity and discrimination are:

Racial Discrimination Act

The *Racial Discrimination Act 1975* (RDA) is the central piece of legislation to directly address racial discrimination in Australia. The main objectives of the Act are to promote equality before the law for all people, regardless of their race, colour or national or ethnic origin, and make discrimination against people on the basis of their race, colour, descent or national or ethnic origin unlawful (AHRC, 2014c). The RDA was established as an outcome of Australia’s ratification of the *Convention on the Elimination of All Forms of Racial Discrimination*. In recent years, the Australian Government has suspended a number of the RDA’s provisions, weakening its purpose and intent.

Disability Discrimination Act

The *Disability Discrimination Act 1992* (DDA) is the foundation of disability legislation and policy in Australia. The Act makes it unlawful to directly or indirectly discriminate against anyone on the basis of disability in terms of employment, education, access to premises, goods provision, services and facilities, accommodation, estate disposal, membership of clubs and associations, sport and administration of federal laws and programs. The DDA applies to federal, state and territory governments, and to the private sector. In addition, the *Human Rights (Parliamentary Scrutiny) Bill 2010* established a parliamentary committee to investigate and report on the compatibility of legislation with the CRPD and other human rights frameworks.

National Disability Strategy

The state and territory governments under the Council of Australian Governments (COAG) and the Australian Local Government Association (ALGA) developed the *National Disability Strategy: 2010-2020* (NDS) in order to meet the nation's obligations under the CRPD (COAG, 2011). The NDS is a nationwide policy framework that seeks to improve service provision, disability-inclusive emergency management, equal rights before the law, the security of person, and safeguards to prevent abuse and exploitation; to increase the visibility of people with disabilities; to address the barriers faced by them; to enhance the accessibility of transport and premises, participation, justice, liberty and educational opportunities; and other basic human rights as set out in the CRPD and other international and national legal and human rights frameworks (COAG, 2011).

According to COAG (2011: 3), the “National Disability Strategy is the first time in Australia’s history that all governments have committed to a unified, national approach to improving the lives of people with disability, their families and carers, and to providing leadership for a community-wide shift in attitudes”. The NDS aims to establish a coherent national policy framework that will guide government at all levels in relationship to mainstream and disability relevant public policy; improve mainstream service delivery and outcomes for people with disabilities; make disability more visible to ensure they are integrated into mainstream public policy and drive leadership towards more inclusive policy and practice for people with disabilities.

National Indigenous Access Framework

The *National Indigenous Access Framework* (NIAF) is one of the priority areas within the NDS that aims to ensure Aboriginal and Torres Strait Islander (ATSI) people are included in national disability policy and their needs are addressed at all levels of government and the private sector. The framework is based on the National Indigenous Reform Agreement established by federal, state and territory governments to support collaboration and coordination in order to close the gap on Aboriginal and Torres Strait Islander disadvantage (DPRWG, 2013). The NIAF aims to “ensure the needs of Indigenous Australians with disability are addressed through accessible and appropriate service delivery arrangements” (DPRWG, 2013: 1).

The NIAF contains seven principles to guide government in reducing barriers, building trust, ensuring accessibility and improving the experiences of ATSI people with disabilities:

1. Provide information using various media, proactive engagement and outreach with ATSI with disabilities in culturally appropriate ways

2. Use person-centred approaches, based on early intervention and a funding continuum that is holistic and considers ATSI people's complex set of needs
3. Establish common principles based on equity, cultural sensitivity, sustainability, flexibility and responsive, people-centred approaches
4. Ensure holistic, coordinated and transparent decision-making that allows for evaluation, based on ATSI needs and priorities and accessibility for all service users
5. Provide services that are culturally appropriate and flexible, encouraging ATSI ownership and participation in service design and delivery, with ATSI employment being facilitated and services integrated with other mainstream services that complement ATSI daily needs, such as housing, education and employment
6. Tailor service provision to the needs of ATSI people, ensuring participation, cultural appropriateness, participation and ownership in service delivery
7. Undertake collaborative and common planning across relevant government departments to create holistic and integrated services that ensure effective and efficient service delivery for ATSI people with disabilities. (DPRWG, 2013: 5-11)

Western Australian Government Legislation and Policies

The majority of policies relevant to the daily lived experiences of Aboriginal people with disabilities are set at the state level with the Western Australian Government being the primary implementer of policy, funding and service provision targeting the community, people with disabilities and Aboriginal support and assistance.

The Government of Western Australia has two key legislative frameworks which relate to ensuring that the rights and needs of people with disabilities are met in the state. These are the *WA Equal Opportunity Act 1984* and the *WA Disability Services Act 1993*.

The *WA Equal Opportunity Act 1984* makes it illegal to discriminate on the basis of race or impairment. The Act also specifies that it is illegal to discriminate on the grounds of sex, sexual orientation, marital status, pregnancy, religious or political conviction, age, family responsibility or family status, and gender history (AHRC, 2014c).

The *Disability Services Act 1993* established the state's Disability Services Commission (DSC) as the primary agency responsible for advancing the opportunities, community participation and quality of life of people with disabilities in Western Australia (DSC, 2013). The Commission directly provides services and support as well as funding non-government providers for people with disabilities, their families and carers (DSC, 2013).

The Disability Services Commission's *Reconciliation Action Plan: 2012-2014* acknowledges Aboriginal people as the original inhabitants of Western Australia (DSC, 2011). The DSC (2011) also states it respects and values the culture and contributions of Aboriginal people with disabilities, their families and carers to the broader community. In the Plan, the Western Australian Government commits to meeting the needs of and developing relationships with Aboriginal people with disabilities, their carers and families. The government further commits to developing strong relationships with Aboriginal people through "cultural recognition,

awareness and respect” as well as working with Aboriginal people with disabilities to ensure that programs and services are culturally appropriate and accessible (DSC, 2011).

Service Delivery

According to the WA Disability Services Commission, 1,216 Aboriginal people access disability services in Western Australia. This is significantly less than national data that suggests approximately 9% of Aboriginal people over the age of 15 have some kind of disability (Stopher and D’Antoine, 2012). This indicates that a large number of Aboriginal people with a disability who are eligible for disability services do not use them for whatever reason. In order to address their complex needs we also need to understand the characteristics of the Aboriginal population, the relevant policy environment, the nature and incidence of disability among Aboriginal people, and the nature of access to disability services in WA (Stopher and D’Antoine, 2012). Understanding why Aboriginal people with a disability, their families and carers do not utilise services necessitates developing an understanding of the complex interaction of an Aboriginal person’s individual and community characteristics with the existing policy and disability services environment.

According to the AIHW (2013), a large proportion of Aboriginal Australians (23.3%) reside in remote or very remote areas in comparison with only 1.7% of non-Aboriginal Australians. Economies of scale and the relative isolation of some Aboriginal and Torres Strait Islander populations affect the cost of delivering health goods and services. These factors can have a large impact on the level of health expenditure, and the quantity and quality of goods and services provided to particular population groups such as Aboriginal people with disabilities in West Kimberley (AIHW, 2013).

Aboriginal and Torres Strait Islander people living in rural and remote Western Australian communities have long been denied access to a range of allied health care and disability support services due to such issues as sub-optimal models of service delivery; differing cultural values and beliefs; access impeded by limited transport and timely communication; and high turnover of staff (WACHS, 2014a).

Indeed, the effective provision of allied health and rehabilitation services to rural and remote Aboriginal communities encounters significant barriers, including:

1. **Health service workforce issues:** such as difficulties in attracting and retaining health staff, high stress and large workloads
2. **Sub-optimal allied health service delivery models:** models are based on institutions and outreach services that fail to reach Aboriginal people and do not address their needs effectively due to lack of trust and rapport
3. **Cross-cultural issues:** an inability to understand and incorporate Aboriginal cultural frames of reference into service provision models
4. **Limited local knowledge of services:** remote communities often have limited knowledge of the types of services available to them
5. **Limitations on accessing services:** clients cannot access services due to poor transportation, limited access to public facilities and vast distances. (WACHS, 2014)

A 2013 report from the COAG Reform Council found that the proportion of people using state or territory disability support services remained low, but increased nationally from 32.4% to 34.9% from 2008-09 to 2010-11, although with a high degree of variation between jurisdictions.

Increased usage was negligible, however, for people in regional and remote areas at 1%, compared with a 3.5% increase in inner regional areas and 2.4% in major cities. Usage rates remained at less than 30% in outer regional/remote areas although the rate of use of these services by Aboriginal and Torres Strait Islander people had increased more rapidly than for the general population. In outer regional/remote/very remote areas, Aboriginal and Torres Strait Islander people used disability support services at more than double the rate of Indigenous Australians in major cities, at 61.1% and 26.4% respectively (COAG Reform Council, 2013).

Housing

Under WA's *Affordable Housing Strategy 2012-2020*, the Department of Housing has committed to making housing available, affordable and appropriate to the needs of the individual. Housing assistance is provided to people who are unable to obtain housing through the private market. The Housing Department provides public, Aboriginal and regional housing and also provides private rental assistance for low-income families and groups, such as Aboriginal people and people with disabilities who have difficulties accessing housing in the private market (Department of Housing, 2013). The Department sets income limits that apply to the primary householder but income assessments are also applied to other people living at the property. The Department maintains a waiting list and applicants are assisted according to the date of application with the waiting list reviewed annually (Department of Housing, 2013).

The Department of Housing, also known as Homes West, commits itself to compliance with the *WA Equal Opportunity Act 1984*, the *International Convention on the Rights of the Child*, and the state and federal anti-discrimination Acts in the allocation and management of public housing and rental assistance. Housing is allocated according to need and family size, and in keeping with an applicant's medical status. The Department has the discretion to allocate additional bedrooms to meet cultural considerations and needs, such as those related to extended Aboriginal families. Housing applicants are given one valid offer of accommodation in the area or town of their choice and, unless the applicant has a valid reason (e.g. inadequate bedrooms or otherwise not meeting their needs), they have to accept this offer (Department of Housing, 2013).

Public housing rents are assessed based on the total, gross household income of all household members. The Minister for Housing decided in 2010 that the base rate for subsidised rent in public housing would be set at 25% of gross household income for all tenants (Department of Housing, 2013).

Families and seniors can have transfers arranged based on their eligibility. Transfers can be mutually decided between two tenants if both tenants are eligible for the accommodation in question. If there is an urgent need, such as a medical emergency, domestic violence or racial harassment, then priority transfers can be arranged. Due to the limited housing options in regions such as the West Kimberley, however, this may be more difficult to arrange (Department of Housing, 2013).

The Department also subsidises eligible applicants to acquire private rental accommodation in areas where public housing is not freely available or where there is a substantial waiting list, such as in remote and rural areas. Private rental applicants must meet all the criteria and follow the same regulations as apply to public housing. A Bond Assistance Loan is made available to applicants to assist in the payment of the accommodation security bond (Department of Housing, 2013).

The Patient Assisted Travel Scheme

The Patient Assisted Travel Scheme (PATS) subsidises the cost of travel and accommodation for patients and their approved carers or escorts travelling from remote or rural areas to a specialist medical service. PATS is a health travel subsidy scheme where patients, carers or escorts are partially reimbursed for their travel costs to Perth to receive medical care and services. The subsidy scheme has been implemented as many necessary health and medical services are not provided in rural and remote areas, or the services that are available may be inappropriate for the level of medical care and expertise required. Specialist medical services include medical imaging, mammography, dialysis, assisted reproductive treatment (IVF), deceased applicant or escort, refractive surgical procedures, wheelchair applicants, child birth, and drug and alcohol treatment referrals, to name a few (WACHS, 2013).

Applicants must live in a WA Country Health Service region, such as the West Kimberley, and have to travel more than 100 kilometres to the nearest specialist medical service, including Telehealth. Country people who have to travel more than 70 kilometres each way for cancer or dialysis treatments, or who are frail and/or disabled, are also eligible for PATS if the medical facility cannot provide transportation. To apply for PATS, patients must ask their referring doctor to complete an application form and then lodge it with a regional health service (WACHS, 2013).

Certain conditions are applied to each type of travel under PATS (road, air, taxi) and accommodation. For travel by road, PATS covers only 16 cents per litre and only one claim can be made per vehicle. When travelling in a minibus or group transportation, the subsidy is 25 cents per litre. PATS pays a \$20 subsidy to cancer or dialysis patients required to travel more than 70 kilometres. For remote regions such as the West Kimberley, PATS covers air travel if the nearest specialist is more than 16 hours surface travel away or the trip is subject to excessive connections and stops. If cancer patients have to travel more than 350 kilometres by road, they are eligible for commercial air travel (WACHS, 2013).

PATS subsidises people who live more than 100 kilometres away and have to spend the night for medical treatment or due to distance or transportation schedules. The subsidies are \$20 a night for private accommodation or \$40 if travelling with a carer, and in commercial accommodation up to \$60 per night or \$75 a night if travelling with a carer. PATS provides additional assistance for taxi or airport shuttle services if recommended by the referring doctor. Taxi vouchers are provided only in limited and exceptional circumstances, however (WACHS, 2013).

METHODOLOGY

The interviews drawn upon for this report were conducted as part of a large national study funded by the Australian Research Council Discovery Grant: DP 110102719. The national project was led by Prof. Barbara Pini, Griffith University, alongside collaborating researchers Dr Karen Soldatic, A/Prof. Helen Meekosha and Prof. Carol Thomas. The overall project covered four states in Australia: Queensland (Prof. Pini), Western Australia (Dr Soldatic), Tasmania (A/Prof. Meekosha) and Victoria (A/Prof. Meekosha).

The aim of the national study, as outlined within the ARC grant, was to document the lived experience of people with disabilities living in rural and remote Australia, drawing upon the field of disability studies.

In rural Australia 21.2 per cent of the population has a disability while in remote areas the number is 22.1 per cent yet rural disabled people are rarely heard in policy debates. This study, mapping the experiences of disabled people in non-metropolitan Australia is consequently of critical importance to government and disability advocacy groups.

(ARC DP 110102719, 2011)

The research contained in this report is restricted to only those interviews conducted by Dr Soldatic in the West Kimberley region during two research trips to the area in October 2011 and June 2013. The information collated in this report represents the position of the stipulated report authors only and, therefore, the findings here cannot be extended to the field work undertaken by the other CIs on the project.

This report focuses on the in-depth qualitative interviews conducted with Aboriginal people with disabilities residing in the West Kimberley. The report does not, therefore, encompass all the interviewees in the West Kimberley region who participated in the study. The interviews incorporated into this report are from the three major towns in the region: Broome, Derby and Fitzroy Crossing.

While most of the adult participants self-identified as having a disability and of being of Aboriginal descent, some participants were parents of a child (including adult children) with a disability who were actively involved in the day-to-day provision of support and/or care. One of the case studies featured here includes the voice of a parental carer of an adult child with a disability.

To illustrate the issues identified in the interviews, a number of in-depth case studies are included to illustrate the particular issues faced by Aboriginal people with disabilities residing in the region. Pseudonyms have been used to respect the privacy of the participants. The aim of these case studies is to capture the ways in which the main thematic findings of economic, health and food insecurity intersect to create extreme forms of structural disadvantage. The selected case studies are thus representative of the general experience of all the Aboriginal research participants with disabilities in the West Kimberley interviewed as part of this study.

FINDINGS

Over the last ten years or so, as noted in the background section of this report, the impact of disability on the lives of Aboriginal people has gained greater attention and, in turn, a number of new policy initiatives has emerged to address this issue in the West Kimberley region. As documented in the Policies and Legal Frameworks section, a raft of legislation and policy has been designed specifically to address the service and support needs of the people of the West Kimberley. While these initiatives are welcome, there is a range of shortcomings in policy and practice in the area.

The findings of this report are grouped into three areas of social life:

1. Economic insecurity
2. Health insecurity
3. Food insecurity.

As the interview participants describe, while there are a range of public policy measures to address these issues, the vast majority of these policies are extremely inadequate, due to their low levels of payment and the stringent, restrictive criteria used to determine eligibility. It should be noted that, based on the interviews conducted, there has been no marked increase in overall wellbeing of the research participants involved in this study over the two-year period.

In government policy, particularly in emerging policy around the NDIS, it is assumed that advocacy support for people with disabilities is mostly associated with access to disability services only. As the sample of participants in this study articulate, advocacy has been absolutely essential to highlight broader issues associated with economic, health and food insecurities.

Aboriginal people with disabilities residing in rural and remote areas face extreme forms of racism, discrimination and exclusion from key areas of public policy. It has been only through the support of strong advocacy, which they receive as a person with a disability, that they have received necessary supports. This very advocacy highlights the systemic failure of key areas of public policy.

The direct consequence of such public policy failures is persistently high levels of chronic poverty, exacerbating the ongoing health and disability concerns of Aboriginal people living in the West Kimberley.

Economic Insecurity

In this study, the daily lived experience of economic insecurity was the primary theme to emerge from the interviews with the research participants. All the interview participants described severe levels of economic insecurity as the daily lived experience of being an Aboriginal person with a disability or a family member of an Aboriginal person with a disability living in the West Kimberley. All the interviewees described the severe negative impact of economic insecurity on their daily lives and clearly identified food insecurity, affordable and appropriate housing, and affordable transport as recurring or ongoing issues.

Economic insecurity is mostly experienced by population groups who are already located in a position of structural disadvantage (Western et al., 2012). This includes Aboriginal people and people with disabilities, as their life-long development has been hampered by structures of direct and indirect discrimination (Green et al., 2005; Karmel et al., 2014). This life-long discrimination denies them opportunities to develop their capacities in order to advance and acquire social mobility on par with other groups (Fraser, 2005). For example, discrimination from a young age too often results in poor educational attainment which in turn leads to poor labour-market opportunities to secure well-paid, highly regulated employment (Karmel et al., 2014). Compounding this, in many instances employers may hold social attitudes that deny access to secure, highly regulated employment.

For the participants of this study, economic insecurity was a constant feature of their lives due to the interstice of disability and Aboriginality, resulting in heightened and persistent forms of discrimination and racism endured daily. The experience of severe economic insecurity and deprivation left many of the research participants with feelings of despair as, despite their best efforts, they were unable to provide the necessary economic means to sustain a minimum standard of wellbeing.

The primary reasons for the severe levels of economic insecurity experienced by the research participants include, but are not limited to:

- inadequate centralised government income support and pension schemes
- highly restrictive state government concessions and subsidies with extremely low cut-off rates;
- restricted availability of public and social housing with lengthy waiting periods
- increased living costs associated with rural and remote locations.

These factors do not operate in isolation, but dynamically interact in the lives of the research participants. For example, participants with disabilities who did not qualify for the Disability Support Pension due to its restrictive disability criteria were placed on a general income support payment, such as the Newstart Allowance. This payment is substantially lower than the Disability Support Pension. Further, Newstart recipients do not have access to many state government concessions or subsidies. This resulted in higher levels of economic stress for these participants.

For those who were working in the open labour market, their earnings did not cover the full costs of living in the area. After accounting for private housing rental, the costs of running a car (a necessity due to the extreme lack of readily available public transport) and utilities, many of the participants interviewed were unable to extend their earnings to cover the cost of the weekly household groceries, including basic food items. These participants rarely qualified for any state government concessions or subsidies as the threshold cut-offs were restrictive. After general household expenditure was accounted for, they frequently required support from a range of charities to supplement their income in order to maintain basic wellbeing.

Our first case study, Julie, the working mother of a young child with a profound disability, illustrates the common experiences of economic insecurity among the research participants. In fact, Julie and her child's case emphasises the inter-relationship between the money economy and the social economy, even though she is 'earning' within the money economy.

Case Study 1

Julie described her experience as an Aboriginal parent of a child with a disability as one of economic despair and destitution. Julie was the primary carer for her young son, who had a congenital disability. Julie worked full time in a local store in the main centre of Broome. Given her work in the retail industry her annual salary was extremely low, which meant that she initially qualified for the WA Department of Housing priority list for an appropriate accessible house for her son. Julie had been on the priority waiting list for approximately 18 months at the time of the interview; however, just before the interview, she was advised by the WA Department of Housing that she was no longer eligible for priority housing as she had had a small wage increase and, therefore, would be placed on the 'regular' waiting list (reported earnings were just over the eligibility cut-off threshold by \$40.00).

Julie has been in full-time employment for a long period of time and has been renting over the last couple of years. Her private rental was about to increase from \$570.00 per week to \$600.00. She was desperate to leave the rental as she could no longer afford it and the rental was situated in an area that was inappropriate for her son. At the time of the interview, Julie had already exhausted the annual allowance of food vouchers (a maximum of three per year) from the local charity and was unable to access any more until the next year (2014). In addition to the rent, Julie had commitments to a car loan. The car was vital for her emotional wellbeing and her son's disability care as it was the only reliable transport she had to get her son to and from school, hospital and local health-care appointments, and herself to and from work and free community events around town. Given this level of economic insecurity, despite being in full-time paid employment, there are clear implications for her son's disability care, along with her own.

"You know I got to the stage where my rent's twelve hundred a fortnight, my car payment is three hundred and seventy six and I pay that on my own – so I've got to the stage now where I probably couldn't fly to Perth if they wanted me to because I can't pay for my accommodation when I get down there. Yeah I got a constant battle trying to get myself some housing for him. I've been on the Homes West priority housing for a year and a half and in Broome it's a three year wait. I had them ring me the other day telling me I was forty dollars over so they had to reassess my housing application."

As Julie and her son's story illustrates, the relationship between enduring economic insecurity and health insecurities is acute. Julie articulates the impact of economic insecurity in the types of choice she must make about the future care of her son. In Julie's case, she must balance time off work for medical appointments (and the consequent decrease in income) with the cost of care associated with those appointments.

The association between economic insecurity and poor health outcomes is well documented within the literature, particularly in the area of Aboriginal health in Australia (see pages 1-3 of this report: 'Disability and Indigeneity in Australia' and 'Health, Indigeneity and Disability in Western Australia'). Health insecurities arise when broader, structural economic insecurities place a greater burden on citizens to individually carry the costs of health care (Catalano, 1991). As Stuckler and Basu (2013) have clearly documented, as governments shift the economic burden to individuals, households and the community, through retracting supports within the social economy, individuals are forced to make choices about health care that they can ill afford.

It is recognised in national and state policy that Aboriginal people residing in rural and remote regions are at a significant health disadvantage due to the issues associated with the ineffectual provision of public health services in these regions. As noted on page 10 of this report ('The Patient Assisted Travel Scheme'), the PATS financial support scheme does provide a small amount of funding to cover travel costs; however, the subsidy is inadequate as it does not cover the full travel costs. In fact, as many of the participants of this study have found, it risks placing them into greater economic insecurity as they need to borrow funds from family to supplement the scheme.

Further, the scheme does not recognise that Aboriginal people with disabilities are not in a position to pay upfront costs and then seek reimbursement on returning home, such is their situation of extreme poverty. As a result, the research participants described situations where they did not seek the health interventions they required as they could not afford them, or they would forgo essential items that had an impact on their health, such as high-quality food, in order to pay for the necessary health services in Perth.

Health insecurities are therefore structurally located within a public policy regime of inadequate local health care, exacerbated by unaffordable costs for individuals and family members needing to travel to Perth to receive vital health and disability support services, which are only partially offset by a negligible travel subsidy system. This creates an extensive and persistent economic burden for those families who are compelled to travel to Perth for life-saving treatment, surgical procedures and specialist care.

Our second case study, Maggie, best exemplifies these critical failures in public health policy and the economic imposition that they create for Aboriginal people with disabilities and their households. Maggie is the primary carer of an adult child with multiple disabilities and is forced to travel regularly to Perth to ensure that her daughter receives appropriate treatment and support. Both Maggie and Clarissa are in the social security system and have little financial funds they can draw upon in medical emergencies which require travel to the primary hospitals in Perth.

Case Study 2

Maggie, the mother of a young woman with multiple disabilities, has had to travel to Perth on three occasions in the previous two years due to her daughter developing a range of conditions in addition to her primary disability. Maggie's daughter, Clarissa, has an acquired brain injury alongside a mental health condition and recently had a heart attack due to a blocked artery. As a result, Clarissa requires assistance in negotiating her own care and relies heavily upon the support of her mother. Clarissa requires a support person with understanding who is able to respond appropriately to information presented in either written or oral form. Therefore, a family member is required to attend hospital and medical appointments to ensure that Clarissa understands the issues raised within the clinical environment.

Additionally, due to the complex nature of Clarissa's conditions, she regularly attends medical appointments for treatments and specialist care in Perth. Some of the travel costs for Clarissa are subsidised by the WA Government's PATS; however, for many of the items, Clarissa is required to pay upfront and then receive reimbursement on her return to Broome. This is extremely difficult as Clarissa is on a Disability Support Pension and has almost no savings once housing and associated expenditure is accounted for.

To undertake these medical trips, Clarissa relies heavily on her mother, both economically and emotionally. As Clarissa is the adult child of Maggie, there is no guarantee that Maggie will be able to access the scheme as her informal carer, despite Clarissa's need for support, particularly when hospitalised.

"I said to him, 'Can you write me a support letter to PATS so I can go down there?', you know. So I only had a couple of hours to get on this plane. I had to go to Centrelink and arrange some money for myself and [Clarissa] – 'cause she had no toiletries, nothing you know, everything just happened so quickly. And I came back to the hospital and asked PATS for my air tickets, they said the doctor said, 'It wasn't necessary for you to go down.' So I said, 'Where is this doctor?' They told me he was still on ... so I went down there and pulled him out and I said in front of everyone, I said, 'Excuse me,' I said, 'my daughter just had a heart attack. I'm her mother and her carer.'"

Maggie is the primary carer for Clarissa and receives a Carer Payment. This reliance on an inadequate social security payment means they do not have the financial resources to pay upfront hefty travel costs, and when they travel to Perth for hospitalisation and medical care, they rely heavily on charity to subsidise their stay.

"Mmm. [Charity] help us to pay the other half but if they can't, we have to do it ourselves. See and sometimes we go down on an off-pension week and it's bloody hard, I tell ya. We gotta be runnin' around Perth lookin' for food vouchers you know, let alone getting Clarissa to the hospital."

A recurring theme in the interviews with participants involved in the 2011 and 2013 research was food insecurity. In fact, the research participants interviewed in 2013 only, alongside those research participants interviewed on both occasions (2011 and 2013), placed greater emphasis on food insecurity when compared to the research findings of 2011 alone.

Only 5% of Australians experience food insecurity; however, certain groups are more susceptible to food insecurity (CAFCA, 2011). According to the Communities and Families Clearinghouse Australia (2011), the following groups experience food insecurity at a higher rate than the wider Australian population: Indigenous people (24%); unemployed people (23%); single-parent households (23%); low-income earners (20%); rental households (20%); and young people (15%). Other groups in the community are also more susceptible to food insecurity, such as culturally and linguistically diverse (CALD) groups, including refugees; people with no access to private and/or public transport; and people who are disabled, unwell or frail (CAFCA, 2011).

To add to the disadvantage experienced by Aboriginal people with disabilities in terms of food security, remote and rural areas can also suffer from a lack of food security, availability and access (CAFCA, 2011; AHMAC, 2012). This is despite over 90% of the country's food production being in rural areas and nearly 50% of the people employed in producing food living in these areas (AHMAC, 2012). The cost of basic nutritional food is approximately one-third higher in rural areas in Australia, however, with the cost of food increasing with the degree of remoteness (AHMAC, 2012). In addition, people in the country travel further than their city counterparts to shop for food at a local supermarket: 90% of city dwellers travel only 5 kilometres or less while nearly a quarter of country people travel more than 10 kilometres. Further, rural and remote Australia has limited, if any, public transport, thus restricting rural people's choices to small local stores with high prices (AHMAC, 2012). People who cannot access healthy food tend to eat less healthy and cheaper food (AHMAC, 2012).

Aboriginal people living in regions such as the West Kimberley also have poor health and nutritional status due to the loss of access to healthier, traditional food alternatives; their replacement with western food types that are energy dense; and a limited availability of nutritious, perishable food (Office of Aboriginal Health, 2003). There is a substantial body of evidence that a healthy diet leads to better health outcomes and prevents chronic diseases such as diabetes, cancer and heart disease (Office of Aboriginal Health, 2003; AHMAC, 2012).

Level of income also determines the kinds and amount of food Australians can afford to purchase. People living in areas of socioeconomic disadvantage tend to eat foods with higher calorific values but with lower levels of essential vitamins and minerals compared with people living in areas of relative affluence (Office of Aboriginal Health, 2003). Such remote areas and rural townships can be found in the West Kimberley and Aboriginal Australians living here thus have a double disadvantage: lower incomes combined with higher food and living costs (Office of Aboriginal Health, 2003). In 2003, for example, census data showed that nearly half the Indigenous population of the Kimberley region had incomes of less than \$8,000 annually compared with only one in five non-Indigenous inhabitants. In addition, more than 80% of Aboriginal people in the Kimberley earned less than \$20,000 compared with only 42% of non-Indigenous people (Office of Aboriginal Health, 2003).

Our third case study, Robert, exemplifies the imposition of food insecurity, which was a consistent theme throughout the research findings. Disadvantage is multiplied in the case of Aboriginal people with disabilities who frequently fall into several categories of disadvantage simultaneously with high rates of unemployment or low incomes, and overall socioeconomic disadvantage as well as disability. As a result, even those in employment are trying to juggle a range of complex social support systems that interact to increase their structural position of marginalisation, precarity and insecurity.

Case Study 3

Robert, a local Indigenous man with an acquired brain injury living and working in Broome, was both employed and accessing food vouchers. Robert was employed by several organisations on a permanent part-time basis over many years; however, due to the cost of living within Broome Shire, he frequently required food vouchers as his earnings did not cover the daily costs of living once housing, transport and health care were accounted for.

One of Robert's employers learnt that he was reliant on food vouchers and so increased his pay. However, this resulted in an increase in the cost of his public housing unit and diminished the availability of the energy subsidy he received. Due to the extreme temperatures in the West Kimberley, many people with disabilities are heavily reliant on cooling systems within the home to maintain wellbeing, which has an impact on their participation in the labour market. His employer's generosity, specifically designed to address Robert's economic insecurity, had the adverse effect of reducing any of the potential financial benefits intended by the wage increase.

Robert's experiences clearly highlight the limited support available to those people who sit within a 'threshold' of earnings, making their economic existence more precarious and insecure, and increasing a range of other insecurities. As Robert describes, there is an intensity of economic insecurities for Aboriginal people with disabilities who must negotiate part-time low-paid employment, an inadequate disability pension system, and other dimensions of the social economy, all of which are vital to maintain a level of personal stability and wellbeing:

"[My employer] started giving me extra money just to keep me going, because I used to go and get food voucher. I had to go to Centrelink and try to get a food voucher and they used to send me to [Charity] and [Charity] send me to somewhere to get a thing – because I still had to pay Centrelink and Home West. Home West took my rent, my electricity – everything went up on me. 'Cause I was working and that – Centrelink didn't help much for any area if you had part-time or casual job.

The area of economic insecurity has become a national and international concern. A burgeoning body of research has thoroughly documented the implications of economic insecurity for individuals and the households in which they live.

As a global trend, economic insecurity has been on the rise. Governments have or are implementing public policies that radically diminish a range of social supports which have been critical to ensuring household stability and wellbeing with the onset of economic insecurity. Australia has been particularly affected by such diminished public policies and consequently household economic insecurity has been on the rise (ILO, 2004). And it is rural and remote regions that have most sharply felt its presence (Tonts and Haslam-Mackenzie, 2005).

Research in the area clearly identifies a number of structural supports that can alleviate economic insecurities. In particular, the research identifies well-structured labour markets and public pension support schemes as pivotal to ensuring an individual and the household in which they live access to economic security.

Bruce Western (2012) and colleagues define economic security as the risk of economic loss faced by workers and households as they encounter the unpredictable events of social life (p. 341). Public policies, such as unemployment benefits and disability pensions, alongside social policies around public housing, health care and education, can alleviate the impact of negative economic shocks on individuals, their families and communities (Western et al., 2012).

To ensure the long-term stability and wellbeing of individuals, households and communities, economic security can be established by providing:

1. labour-market and job security
2. highly regulated public pension schemes
3. public provisioning of a range of social services
4. subsidised housing
5. universal health care. (Western et al., 2012)

Economic security is thus the relationship between the ‘money economy’ associated with government-regulated public pension schemes, regulated labour markets and job security, and the ‘social economy’ which encompasses a range of public assistance programs in health, disability, support, transport and housing (ILO, 2004).

Economic security is the outcome of the interaction between these two spheres – the economic sphere and the social sphere. To assure citizens a life of security, dignity and respect, governments are required to play an active role in ensuring the wellbeing of individuals and the households in which they live, regulating markets associated with the money economy, and providing well-developed and supported schemes within the social economy.

The interaction between insecurities within the money economy and social economy cannot be emphasised strongly enough. Individuals and households are protected from the losses within the money economy via the depth and strength of the social economy.

The factors contributing to economic insecurity for the residents of the West Kimberley interviewed in this study show the critical importance of understanding the relationship

between the money economy and the social economy. That is, the experience of the participants identified the ways in which failures to provide appropriate supports within the social economy acutely undermined security within the money economy. The effect is extreme forms of economic insecurity which were felt most acutely in the areas of health and food security. The interstice of dual forms of discrimination – racism and disableism –both direct and indirect, increased the threats, risks and experiences of economic insecurity throughout the lives of the research participants.

The clearest example of this surrounds the inadequate provisioning of local health systems and the denial of universal access to health through the highly stringent cash transfers involved in health travel subsidies. The imposition of this meant that those who were working faced ongoing threats around job loss due to long and/or frequent periods of leave required to travel to/from Perth for health care, alongside the loss of income from extended periods of unpaid leave. Those on an income support payment, such as Newstart or the Disability Support Pension, experienced additional debt which they could not afford as the full costs of the travel burden were not upfront payments. As the travel cash health subsidy did not cover the full costs of travel, accommodation and other items associated with forced health-care travel to Perth, research participants faced an additional monetary burden, resulting in greater personal debt.

It is well acknowledged within the international literature that having a disability substantially increases all risks associated with economic insecurity, either with the advent of disability in adult life or with disability an existing condition prior to entering the labour market (UN, 2008). For people with disabilities, economic insecurity is heightened by the enduring structural discrimination embedded within the labour market (ILO, 2014). Despite national and state legislation and policy to address issues of disability discrimination, labour-market participation for people with disabilities has remained persistently low, staying at approximately 53% over the last ten years (ABS, 2012b).

Additionally, it is well recognised that due to direct and indirect forms of racism, Aboriginal Australians face particular barriers to achieving economic security via labour-market participation and associated earnings. The persistence of these extensive forms of racism has significant implications for Aboriginal health, illness and disability and, in turn, heightens exposure to economic insecurity when compared to the non-Aboriginal population (Cooperative Research Centre for Aboriginal Health, 2008). When Aboriginal people are employed, they have lower earnings as their employment is structurally located at the low end of precarious labour markets (see AHRC, 2008).

The relationship between Indigenous discrimination and disability discrimination is most acutely felt in rural and remote regions. As Australia has continued to retract supports within the social economy, Aboriginal people with disabilities are increasingly required to expend a large percentage of their income on critical and essential items. This situation is exacerbated in rural and remote areas, such as the West Kimberly, as individuals are required to travel vast distances to receive disability supports and health care that is readily available in urban centres, such as Perth. Many of these services are critical for their survival, and are not luxury or elective health-care procedures. This restriction on expenditure is compounded by limited labour markets which do not provide Aboriginal people with disabilities with secure, stable and highly regulated wages to cover the full costs of living.

The research participants' chronic economic insecurity was thus exacerbated due to the increasing restrictions placed on public policy developments within the money economy of regulated labour markets and pension/income support schemes coupled with a retracted social economy, illustrated by the diminished public housing stock, the privatisation of health care, and the increased reliance on private transport due to inadequate public transport, alongside government policy that has deregulated regional labour markets and greatly restricted income support payments.

Disability advocacy has been critical to ensuring a basic standard of economic security for Aboriginal people with disabilities, particularly in the face of systemic racism and disableism. It is therefore essential that funding for disability advocacy remains a permanent commitment from governments, outside any individualised disability support scheme, particularly as these policy endeavours assume that disability advocacy is focused on disability supports. Disability advocacy must be funded as a separate public policy disability program outside of any disability support system. Individuals should not have to choose purchasing advocacy to address broader structural exclusions above the support and service requirements specific to their disability.

CONCLUSION

As the case studies illustrate, life in the West Kimberley is highly complex for Aboriginal people with disabilities. Managing life as an Aboriginal person with a disability requires all-round hard yakka to navigate unfair, under-resourced and highly inadequate systems of economic, medical and social support. These poorly directed and under-resourced policy responses to the needs of West Kimberley Aboriginal residents with disabilities directly affected their access to appropriate housing, health and disability services, and, most concerning of all, food.

The primary underlying driver was, and remains, an inadequate income support payment that does not reflect the real costs of living a life with dignity for Aboriginal people with disabilities, coupled with ineffective cash health transfer systems that do not cover the full costs of travel and living expenditure related to accessing urban-based health-care systems.

The experience of this extreme level of economic insecurity illustrates the ways in which an inadequate concessional system that does not recognise the dynamic intersection of Aboriginality and disability compounds insecurity, such as labour-market discrimination, poor educational inclusion and resulting outcomes for rural and remote populations who live at this intersection. This created extreme forms of economic insecurity for all the research participants, even for those who were actively engaged in the labour market, earning incomes well above government income support payments.

Many of the federal and state government benefits, concessions and support systems use rudimentary cut-off eligibility criteria that do not recognise the extremely high costs of living in the region, nor the structural disadvantages faced by Aboriginal people with disabilities and their families and carers. When Aboriginal people with disabilities and their family members did work, they were adversely affected as even small earnings would put them into a higher assessed income bracket, resulting in a loss of state and federal concessional benefits.

As shown in the three thematic case studies, many local residents with disabilities were placed under constant economic strain and insecurity, as they had an additional range of daily living,

health-care and support costs, unrecognised within the current public policy framework of support. In some instances, many Aboriginal people and their families/carers were having to forgo the necessary health care that was vital to their overall wellbeing.

Moreover, to offset the additional costs associated with the health care and disability supports they needed, many of the research participants would forgo food to ensure they could afford to access these supports. In turn, a large number of the participants relied upon food vouchers as a means to subsidise the travel costs associated with the necessary hospital care.

The accumulated debt from such ill-directed policies is more likely to create an ongoing debt burden, rather than alleviate debt, for the individual concerned and their families. The long-term likely impact of such policies is increased and enduring economic insecurity, which Aboriginal people with disabilities can ill afford.

Since the writing of this report there has been a number of federal government announcements that are directly related to the key findings: economic insecurity, health insecurity and food insecurity.

These are most clearly outlined in the May 2014 Federal Budget announcements and the interim McClure report released in June 2014. The two policy areas of immediate concern to the findings of this report include the proposed co-payment charges to access the Australian health-care system under Medicare, and the restriction of eligibility to the Australian Disability Support Pension scheme. The McClure report recommends that the DSP be reserved only for those with no capacity to work, and that those “who have current or future capacity to work could be assisted through the tiered working age payment to better reflect different work capacities” (Commonwealth of Australia, 2014: 9). These government releases assume that labour-market participation is the principle means for economic security. Such an assumption misinterprets the critical relationship between the money economy and social economy, and their interactive dynamic to assure economic security.

Given the findings of this research, if such changes proceed, the daily experience of insecurity endured by the research participants of this study will intensify as the minimum protections that currently exist will be radically diminished.

There is also likely to be a compounding effect. The additional costs associated with health-care access will be experienced most by those who will be affected by the proposed tightening of the Disability Support Pension. Many Aboriginal people with disabilities will no longer qualify for this payment – a higher payment than the general income support payment under Newstart. In addition to the DSP being a higher income support payment, it also provides greater access to state and territory government subsidies, such as housing and transport subsidies, and local health services. The compounding effects of such emerging policy will result in enduring structures of Indigenous inequality and disadvantage, rather than addressing the extreme forms of insecurity which Indigenous Australians currently negotiate on a daily basis.

For the research participants of this study, a fair assessment of these policy directions suggests that, if these announcements are fully implemented as planned, their experience of economic insecurity is only likely to be further intensified in the future, leaving them with few, if any, emotional, social or economic responses to live a life of dignity, respect and participation.

Levels of economic and social insecurity have become further heightened as Australia has continued to retract supports within the social economy alongside the legal framework which assures legal protections against direct and indirect forms of discrimination, which also work to strengthen the effects of the social economy. Aboriginal people with disabilities are increasingly required to expend a large percentage of their income in areas within the social economy that were once provided by the state. This pushes them into greater levels of poverty and economic insecurity. As a result, many Aboriginal people with disabilities will never be able to achieve or return to a position of economic security due to the inadequacy of such policies.

The research participants’ experiences of the failings of the current system are a strong warning against the national trend to further diminish strong social protections within the money and social economies for Aboriginal people with disabilities residing in rural and remote Australia.

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