

deeble institute



issues brief

Deeble Institute for Health Policy Research

no: 30

date: 23 April 2019

Title **Improving access to housing for Aboriginal and Torres Strait Islander renal patients with complex care needs**

Authors **Stefanie Puszka**
PhD Candidate
Menzies School of Health Research
Charles Darwin University; and
Centre for Aboriginal Economic Policy Research
Australian National University
Email: stefanie.puszka@menzies.edu.au

phn
BRISBANE NORTH
An Australian Government Initiative

This paper was developed as part of a Jeff Cheverton Memorial Scholarship undertaken at the Deeble Institute for Health Policy Research, Australian Healthcare and Hospitals Association (AHHA).

phn
NORTH WESTERN
MELBOURNE
An Australian Government Initiative

The Jeff Cheverton Memorial Scholarship has been established by the Australian Healthcare and Hospitals Association (AHHA), together with Brisbane North Primary Health Network and North Western Melbourne Primary Health Network, to honour the memory of Jeff Cheverton.

deeble institute


We connect researchers, policy makers and practitioners to promote research that informs national health policy

ahha

australian healthcare &
hospitals association

1 Contents

Key messages	4
Executive summary	5
1 End stage kidney disease amongst Aboriginal and Torres Strait Islander people	7
2 Housing needs of Aboriginal and Torres Strait Islander renal patients	8
2.1 ESKD, physical impairment and housing accessibility requirements	8
2.2 Economic disadvantage and needs for affordable housing	9
2.3 Psychosocial impairment and needs for culturally appropriate housing and accommodation	9
3 Housing exclusion amongst Aboriginal and Torres Strait Islander renal patients	10
3.1 Access to public housing amongst Aboriginal and Torres Strait Islander renal patients	10
3.2 Risk of homelessness amongst Aboriginal and Torres Strait Islander renal patients	12
3.3 Addressing housing needs created by health service delivery models	13
3.4 Delays in income support payments contribute to risk of homelessness	14
3.5 Aboriginal Hostels Limited accommodation - affordability and accessibility concerns	15
4 Eligibility of renal patients for the National Disability Insurance Scheme (NDIS)	17
4.1 Assessing disability amongst ESKD patients	17
4.2 The accessibility of the NDIS for Aboriginal and Torres Strait Islander people	18
4.3 Recognising the impairments of Aboriginal and Torres Strait Islander renal patients through the NDIS	19
5 Developing comprehensive policy responses to address the housing and support needs of renal patients	20
5.1 Patient needs and preferences	20
5.2 Collaborative approaches and governance structures	20
5.3 A new care package scheme	22
6 Conclusions and recommendations	22
7 Appendix 1: National Disability Insurance Scheme Act 2013 (Cwth) s24.....	26
8 Appendix 2: Proposed new care package scheme	27

Acknowledgements

This Issues Brief emerged from the findings of my PhD research, an ethnographic study of the meanings and expectations of care of Yolŋu (Indigenous Australians from north east Arnhem Land) with end stage kidney disease.

Firstly, I would like to acknowledge and thank the participants in my research for welcoming me into their lives and sharing their experiences of end stage kidney disease with me, including those who have experienced homelessness and insecure housing. I would especially like to express my gratitude to Yinin Dhurrkay and the late Mr B Dhamarrandji, who worked alongside me as co-researchers and advisors over the course of 14 months of fieldwork. I have learnt much from them.

I would like to thank the indefatigable Dr Rebecca Haddock for nurturing the development of this Issues Brief; and Alison Verhoeven, Dr Linc Thurecht and Dr Chris Bourke for reviewing drafts and providing advice and encouragement; and all of the staff at the Australian Healthcare and Hospitals Association (AHHA) for insights into Australian health policy. A scholarship offered by AHHA, Brisbane North Primary Health Network and North Western Melbourne Primary Health Network made this work possible.

Thanks are also due to representatives of Purple House, NT Shelter, the National Aboriginal Community Controlled Health Organisation, First Peoples Disability Network, Kidney Health Australia and stakeholders from several Commonwealth and Northern Territory agencies, who provided advice on the development of this Issues Brief.

Finally, I would like to thank Dr Paul Lawton, Gill Gorham and Professor Alan Cass at Menzies School of Health Research for providing content expertise and guidance in approaching a highly complex policy problem; and Dr Katie Curchin at Australian National University, for providing feedback on my ideas and for encouraging me to take up this opportunity.

Key messages

- Aboriginal and Torres Strait Islander people living in remote Northern Territory communities experience extremely high rates of end stage kidney disease (ESKD). As renal services are limited in remote areas, most patients must relocate permanently to urban areas for treatment.
- Despite improving access to remote services, it is likely that some patients with complex care needs will continue to relocate for treatment for logistical and medical reasons.
- Patients with complex care needs require affordable, accessible and culturally safe housing and accommodation. However, as a consequence of social housing shortages in urban areas, patients experience housing exclusion and risk of homelessness.
- The Commonwealth and Northern Territory Governments should consider an integrated care package that addresses the broader care needs of renal patients, including housing needs, in partnership with patients, families, Aboriginal Community Controlled Health and Housing Organisations, Aboriginal Medical Services and other stakeholders.
- Options for addressing patients' needs through an integrated care package include:
 - Interpreting NDIS eligibility criteria to recognise the impairments sustained by renal patients; and/or
 - Developing a new care package specifically targeted at Aboriginal and Torres Strait Islander renal patients.

Executive summary

Aboriginal and Torres Strait Islander renal patients experience multiple layers of disadvantage, partly as a consequence of the ways in which government services are provided.

In remote Northern Territory communities, rates of end stage kidney disease (ESKD) are 15 or more times higher amongst Aboriginal and Torres Strait Islander Australians, in comparison to non-Indigenous Australians of the same age and sex, and are rapidly increasing. Current models of care for ESKD result in approximately 80% of all patients undertaking dialysis being required to permanently relocate from remote communities to urban areas for treatment.

While access to remote renal services is improving through recent initiatives including a new Medicare item for remote dialysis, several logistical and medical barriers will continue to prevent many patients with complex care needs from accessing remote services.

Patients with complex care needs require access to affordable, accessible and culturally safe housing and accommodation. This Issues Brief synthesises the evidence regarding the impairments sustained by Aboriginal and Torres Strait Islander renal patients, and how impairments may impact on housing needs. It shows that while the experience of ESKD will vary from person to person, patients are likely to be living with impairments that may be unrecognised, undiagnosed and unsupported. It highlights the important role of carers and the need for housing and accommodation that reflects Aboriginal and Torres Strait Islander people's practices of care.

This Issues Brief investigates access to housing and accommodation amongst Aboriginal and Torres Strait Islander renal patients who relocate for treatment. It finds that a lack of appropriate, accessible and affordable housing, poorly targeted housing strategies, and delays in income support payments can result in housing exclusion and risk of homelessness amongst patients. Failure to address the housing and accommodation of renal patients can also lead to inefficiencies and wastage in health services.

Holistic, integrated and collaborative approaches are recommended to meet the complex care needs of Aboriginal and Torres Strait Islander renal patients who relocate permanently to urban centres for treatment, as well as the needs of their carers. An integrated care package scheme is proposed to address the housing and support needs and preferences of each patient and their family, with an emphasis on providing choice.

Options for addressing patients' needs through an integrated care scheme include:

- Interpreting the National Disability Insurance Scheme (NDIS) eligibility criteria to recognise the impairments sustained by renal patients; and/or
- Developing a new scheme specifically targeted at Aboriginal and Torres Strait Islander renal patients

Collaborative approaches are essential for improving the coordination and targeting of programs and schemes. Future policy responses should involve partnerships between health and housing agencies, patients and carers, Aboriginal Community Controlled Health and Housing Organisations, Aboriginal Medical Services and other stakeholders.

1 End stage kidney disease amongst Aboriginal and Torres Strait Islander people

Aboriginal and Torres Strait Islander renal patients experience multiple layers of disadvantage, partly as a consequence of the ways in which government services are provided.

In remote Australian communities, rates of end stage kidney disease (ESKD) are 15 or more times higher amongst Aboriginal and Torres Strait Islander people than amongst non-Indigenous Australians of the same age and sex (Australia and New Zealand Dialysis and Transplant Registry, 2016, Cass et al., 2001). The high and rapidly increasing incidence of ESKD is most marked in the Northern Territory (Lawton, 2017). Chronic kidney disease, the precursor to ESKD, is associated with markers of socio-economic disadvantage amongst Aboriginal and Torres Strait Islander people across northern Australia (Ritte et al., 2017).

Access to dialysis treatment outside of urban areas is poor and current models of care result in approximately 80% of all dialysis patients in the Northern Territory (NT) relocating from remote communities to urban areas (Gorham, 2001, Gorham et al., 2018). It is projected that by 2022, more than 800 people will be receiving haemodialysis in the Northern Territory (You et al., 2015). Displacement to urban centres for medical treatment produces a range of social, psychological and economic consequences for patients and places increased pressure on other government services (Devitt and McMasters, 1998a, Cass et al., 2011c, Hughes et al., 2018). Relocation, the demands of treatment and living with a chronic illness can reduce the ability of patients to undertake paid work, as well as fulfilling other social roles (Krishnan, 2019, Hughes et al., 2018).

Commonwealth, state and territory governments and Aboriginal Community Controlled Health Organisations (ACCHOs) have attempted to expand access to remote renal services through several initiatives. The Western Desert Nganampa Walytja Palyantjaku Tjutaku Aboriginal Corporation (Purple House) was established from community-generated funding, and provides dialysis to patients in remote Central Australia on a permanent and reverse-respite basis (Rivalland, 2006). Purple House also provides patient support services in Central Australia and Darwin, and has assisted other ACCHOs to establish their own dialysis services. However, nurse-supported haemodialysis (the most common form of treatment for ESKD in the Northern Territory) remains unavailable in most remote NT communities.

A new Medicare Benefits Schedule (MBS) item for remote dialysis provides a funding stream for primary healthcare providers, including Purple House and other ACCHOs, to deliver dialysis. This new MBS item is likely to result in greater availability of remote dialysis services in future and opportunities for some renal patients to return to their home communities.

However, dialysis facilities may not become available in all remote communities due to a range of logistical constraints, and improved remote access may be offset by the ongoing trend of growth in the incidence and prevalence of renal patients in the Northern Territory (You et al., 2015). It is not known what proportion of patients will have access to remote renal services over the medium term. It may not be possible to establish renal services in some remote communities due to poor water

quality and power unreliability. It is likely that some patients will continue to be required to relocate to urban centres for dialysis in the medium term as medical protocols require unwell patients with complex co-morbidities to be treated at hospital-based renal wards. Socio-economic disadvantage, serious illness and permanent relocation can combine in complex ways to result in intersectional disadvantage (Avery, 2018), complex care needs and poor patient outcomes amongst Aboriginal and Torres Strait Islander people with ESKD. In the context of insufficient housing and support services, this patient population is at high risk of housing insecurity and homelessness (Cass et al., 2011a, Habibis et al., 2011).

Holistic, integrated approaches are required to meet the housing and support needs of relocating renal patients. Integrated policy responses should take place through partnerships across relevant government agencies and with renal patients, Aboriginal Community Controlled Health and Housing Organisations, Aboriginal Medical Services and other stakeholders.

2 Housing needs of Aboriginal and Torres Strait Islander renal patients

2.1 *ESKD, physical impairment and housing accessibility requirements*

The relationship between ESKD, dialysis and physical impairment is complex and under-investigated. There is strong evidence showing that bone disease can be a consequence of ESKD, and that diabetes mellitus, which can lead to limb amputations, can be a precursor to ESKD (Thomas et al., 2008, Stumpers and Thomson, 2013). While a link between ESKD, frailty and functional limitation has been established, the evidence is of poor quality (Klang and Clyne, 1997, Vischini et al., 2011, Lee et al., 2017, Tsutsui et al., 2009, McAdams-DeMarco et al., 2013). A small number of studies have also reported a link between dialysis, anaemia and fatigue (Klang and Clyne, 1997, Tsutsui et al., 2009). These factors are likely to impair the functional mobility of patients.

Renal patients are likely to have special accessibility requirements for wheelchairs and walkers due to physical disabilities related to ESKD. It is imperative that housing for renal patients comply with national Building Accessibility Standards (Home Modification Information Clearinghouse, 2019). Stakeholders involved in the refurbishment of public housing for renal patients in Alice Springs and Tennant Creek advise that accessibility should not come at the cost of living in areas that facilitate care and sociality, for example, by retrofitting separate living spaces for renal patients, apart from other residents. Patients and stakeholders should be consulted about designs for new or refurbished housing to ensure that their needs are met.

2.2 Economic disadvantage and needs for affordable housing

People with ESKD are regularly prevented from full participation in paid work. Patients with ESKD undertake treatment three times a week, for four to five hours per treatment, and are generally restricted from carrying out full time work, leading to a loss of income (Krishnan, 2019). Relocation for treatment of EKSD patients can also lead to loss of employment (Devitt and McMasters, 1998b, Hughes et al., 2018). Analysis of census data shows that Aboriginal and Torres Strait Islander people who migrate from remote to urban areas have lower rates of employment compared to those who remain in remote communities (Biddle, 2010).

Private rental properties are largely outside of the financial means of renal patients receiving Centrelink pensions and payments. Taking into account eligibility for Commonwealth Rent Assistance and Family Tax Benefits, Anglicare Australia found that no private rental properties in the Northern Territory are both affordable and appropriate for recipients of Newstart Allowance, Single Parenting Payment, Disability Support Pension or Youth Allowance or those receiving an Aged Pension and living alone (Anglicare Australia, 2018). In addition, only 19 properties in the NT were affordable and appropriate for couples receiving the Age Pension (Anglicare Australia, 2018).

2.3 Psychosocial impairment and needs for culturally appropriate housing and accommodation

The impact of permanent relocation on Aboriginal and Torres Strait Islander renal patients' fulfilment of social roles and responsibilities, and capacity for social participation, is extensively documented. Aboriginal and Torres Strait Islander patient experiences of dialysis treatment in urban environments across Australia overwhelmingly describe a sense of displacement from family, country and identity (Devitt and McMasters, 1998a, Devitt and McMasters, 1998b, Anderson et al., 2012, Rix et al., 2014, Rix et al., 2016, Burnette and Kickett, 2009a, Burnette and Kickett, 2009b, Cass et al., 2011b, Rivalland, 2006).

Aboriginal and Torres Strait Islander renal patients have described relocation to urban centres as impacting on their social and familial roles and obligations. This may include caring for and teaching children, ceremonial roles and responsibilities and intergenerational knowledge transmission (Devitt and McMasters, 1998a, Burnette and Kickett, 2009a, Anderson et al., 2012, Rix et al., 2014, Hughes et al., 2018). Unfulfilled social and familial obligations are described as negatively impacting on physical health (Anderson et al., 2012, Rivalland, 2006), on personal autonomy and ability or willingness to engage with treatment regimens (Anderson et al., 2012, Burnette and Kickett, 2009a, Burnette and Kickett, 2009b, Devitt and McMasters, 1998a, Willis, 1995) and on resilience and ability to cope in new circumstances (Devitt and McMasters, 1998a, Rix et al., 2014).

People with ESKD face multiple stressors. End stage kidney disease is associated with psychiatric illness, and depressive symptoms are common amongst renal patients (Cukor et al., 2007, Kimmel et al., 1993, Palmer et al., 2013, Kimmel and Peterson, 2006, Kimmel et al., 1998, Kimmel, 2001).

Evidence suggests that ESKD can lead to premature aging and cognitive impairment (Chiu et al., 2019, Tian et al., 2019, O'Lone et al., 2016).

While psychosocial impairment amongst Aboriginal and Torres Strait Islander renal patients cannot be comprehensively addressed through appropriate access to housing, it highlights the need for culturally safe housing options that facilitate Aboriginal and Torres Strait Islander practices of domestic care and domestic living arrangements. Social participation and inclusion have been shown to improve the quality of life of Aboriginal and Torres Strait Islander people with disabilities (Avery, 2018).

Houses are places in which social activity and domestic care take place. Aboriginal and Torres Strait Islander practices of care are described as a key dimension of personal identities and social roles, and as processes for recognising the authority of and instilling respect for elders (Hill et al., 2016, Myers, 1986, McCoy, 2008). Aboriginal and Torres Strait Islander people's practices of care may involve several relatives caring for elderly or unwell people, who may rotate from time to time. Some evidence suggests that renal patients who have carers and stable places of residence may be admitted to hospital on fewer occasions compared to those who do not (Puszka, 2018). Responses to the housing needs of renal patients should also address the housing needs of carers, and housing and accommodation providers should have flexibility to accommodate fluctuating numbers of carers.

Dialysis Models of Care project – Menzies School of Health Research NT

The [Dialysis Models of Care project](#) (Menzies School of Health Research) investigates the broader financial, health and social costs borne by Aboriginal and Torres Strait Islander patients, families, communities and governments (Gorham et al., 2017). Findings show the broader costs of relocation borne by patients and governments.

3 Housing exclusion amongst Aboriginal and Torres Strait Islander renal patients

3.1 Access to public housing amongst Aboriginal and Torres Strait Islander renal patients

Access to appropriate housing can be an important determinant of health outcomes, including for Aboriginal and Torres Strait Islander people (Bailie, 2007, Pholeros et al., 1993, Taylor, 2018). Access to appropriate housing improves sanitation and hygiene in living environments, reduces the risk of infectious diseases and can serve as primary prevention for ESKD (Cass et al., 2004).

Aboriginal and Torres Strait Islander renal patients who relocate permanently for treatment require housing and accommodation close to renal services, however a lack of appropriate, accessible and

affordable housing can result in housing exclusion. The Northern Territory Government Patient Assistance and Travel Scheme provides accommodation for up to 8 weeks for relocating patients, after which patients are responsible for making their own arrangements (Northern Territory Department of Health, 2017a).

Renal patients who relocate to urban centres for treatment generally leave their home in public housing, which is often the only form of housing available in remote communities, to contend with public housing waiting lists in urban centres. Public housing stock across Australia is trending in decline (Groenhart and Burke, 2014). In Darwin, the stock of public housing declined by 23% between 2003-4 and 2014-15; while during the same period, the number of households on the public housing waiting list increased by 69%. In Alice Springs, housing stock declined by 38% while the wait list grew by 82%. The total number of urban public housing properties in the Northern Territory fell by 669 properties during this period (NT Shelter, 2016)¹.

The waiting list for a one bedroom public housing unit in Darwin is currently 6 – 8 years, a period longer than the average survival rate of Northern Territory renal patients (6 years) (Northern Territory Department of Housing and Community Development, 2018c, Northern Territory Government, 2017a).

While renal patients are often eligible for priority public housing through medical eligibility criteria, the average wait times for priority public housing are still 3 – 4 years (Northern Territory Department of Housing and Community Development, 2018c). Local non-government organisations (NGOs) managing the allocation of transitional and other forms of social housing in Darwin also report wait lists of 12 months or more (Puszka, 2018). From 2011-12 to 2016-7 there was a 40% increase in Northern Territory specialist homelessness service usage and over 4,000 unmet requests for assistance in 2016-17 (Northern Territory Department of Housing and Community Development, 2018a). While social housing, including public housing, is allocated on a needs basis, the under-investment in housing is resulting in exclusion amongst some groups with high needs, including renal patients.

The Commonwealth Government has provided funding to the Northern Territory Government for the refurbishment of a small number of family-centric public housing properties for renal patients in Alice Springs and Tennant Creek, including retrofitting facilities for people with physical impairments (Northern Territory Department of Housing and Community Development, 2018b). This small-scale initiative consists of only 10 properties and is unlikely to be extended to other regions. Central Australian renal services are responsible for determining which patients are allocated these houses and while this initiative has improved access to appropriate housing for a small number of patients, their carers and families, policy responses that provide limited housing and accommodation choices for patients, and that are administered by health professionals who are also providing care to

¹ The decline in public housing stock reflects the sale of properties to private developers and the transfer of some properties to social housing providers.

patients, risk disempowering patients. Policy initiatives to improve access to housing for patients should enable patients to make choices about where and with whom they live.

Improving access amongst Aboriginal and Torres Strait Islander people to appropriate and affordable housing is a priority of the Close the Gap Steering Committee (Close the Gap Steering Committee, 2019) and a key draft target of the Closing the Gap Refresh (Australian Government, 2019). Public housing programs should be appropriately resourced by Commonwealth, state and territory governments to address chronic shortages.

3.2 Risk of homelessness amongst Aboriginal and Torres Strait Islander renal patients

Amongst Aboriginal and Torres Strait Islander people who move between remote and regional communities and urban centres, renal patients are a group at high risk of homelessness (Habibis et al., 2011). In Alice Springs, 15-20% of renal patients are estimated to have no access to secure housing, and housing accessibility is further complicated by carers and other relatives accompanying them (Cass et al., 2011c). Up to five family members may follow a single relocating patient (Cass et al., 2011a).

Failure to address the housing needs of renal patients not only places patients at risk of homelessness and poor health outcomes but can also create inefficiencies and wastage of healthcare resources (Case Study 1).

Case Study 1: Royal Darwin Hospital

Recognising health services' duty of care to patients, the Royal Darwin Hospital has implemented a patient discharge policy of 'no exit to homelessness' (Northern Territory Government, 2017b). Due to the lack of suitable housing, Royal Darwin Hospital staff have operationalised this policy by keeping renal patients at risk of homelessness as hospital inpatients, placing pressure on hospital beds and resulting in delayed discharge (Byrne, 2018). In 2018, there were three extended periods of delayed discharge, in which all elective surgery was cancelled (Northern Territory Government, 2018). Patients impacted by delayed discharge have included other renal patients waiting to have catheters inserted for peritoneal dialysis, a form of dialysis that can be undertaken in remote community settings and enable patients to return home.

The Commonwealth and Northern Territory Governments should make urgent investments to increase the supply of crisis and temporary accommodation options.

3.3 Addressing housing needs created by health service delivery models

Northern Territory housing and homelessness policy targets people with mental illness, people experiencing domestic violence, young people leaving out of home care, and people exiting the justice system. While new visitor parks providing low-cost cabin and camping facilities are planned to accommodate Aboriginal and Torres Strait Islander people from remote communities who visit urban centres temporarily, the needs of people who relocate to urban centres permanently, such as people with ESKD, are not addressed (Northern Territory Government, 2017b). Housing and homelessness strategies must address the housing and accommodation needs created by health service delivery models that result in patients relocating to urban centres.

As access to remote renal services improves, patients returning to remote communities are also likely to require appropriate housing in communities. Public housing waiting lists are significantly longer and rates of overcrowding amongst Aboriginal and Torres Strait Islander households are significantly higher in rural and remote areas (North Australia Aboriginal Justice Agency, 2016, Australian Institute of Health and Welfare, 2015).

Severe shortages in affordable housing are a structural problem in the Northern Territory and can have significant consequences for vulnerable groups including renal patients. Policy responses to the housing needs of renal patients must address the urgent demand for affordable housing.

Commonwealth, state and territory governments should address chronic public housing shortages in urban and remote areas by investing in the social housing sector at sufficient levels to ease wait lists. Housing strategies should explicitly address housing needs created by health service delivery models that require people to relocate for long periods or permanently in order to access treatment. Investing in non-government providers, including Aboriginal Community Controlled Housing Organisations, may reduce the costs of housing to state and territory governments through eligibility of tenants for Commonwealth Rent Assistance, tax concessions and efficiencies within non-government organisations, and may result in greater tenant satisfaction (NT Shelter, 2019).

3.4 Delays in income support payments contribute to risk of homelessness

It is common for renal patients to wait for up to 6 months, and sometimes over a year, to have their Disability Support Pension applications approved by Centrelink (Puszka, 2018). Aboriginal and Torres Strait Islander ESKD patients have been known to become homeless while waiting for pensions to be approved due to lack of income (Puszka, 2018). Patients may receive other Centrelink benefits in the interim such as Newstart Allowance or Special Benefit, however these payments may not cover accommodation costs (see Section 3.5). There are, however, no data on Centrelink payments received by renal patients. Centrelink should urgently review application processes and reduce the timeframes for processing Disability Support Pension applications.

A bridging payment, at equivalent rates to the Disability Support Pension, should be made available by the Department of Human Services for people waiting to have Disability Support Pensions assessed, for those likely to be found eligible, for example, by satisfying conditions associated with impairment described in impairment tables such as end stage organ failure (Social Security (Tables for the Assessment of Work-related Impairment for Disability Support Pension) Determination, 2011).

Improving Centrelink benefit application processes

Centrelink processing times can result in delays to approving Disability Support Pension applications and Aboriginal and Torres Strait Islander renal patients often experience difficulties in the application process itself.

For example, people applying for Centrelink benefits are generally required to supply several forms of documentation from other Commonwealth and state or territory government agencies. Since Aboriginal and Torres Strait Islander people often have a variety of names that they are known by² and therefore possess various forms of identification with different combinations of these names, they often experience difficulties in proving their identities and providing relevant legal documentation (Banking Code Compliance Monitoring Committee, 2017). Some Aboriginal and Torres Strait Islander people are required to legally change their names to access Centrelink benefits.

Improving the cultural safety of Centrelink application processes will assist Aboriginal and Torres Strait Islander renal patients to access housing and accommodation, in addition to Centrelink benefits for which they are eligible. Centrelink should develop the capacity to assist clients to prove their identity and obtain forms of documentation from other government agencies needed for benefit applications, particularly when clients do not speak English as a first language. A majority of Aboriginal and Torres Strait Islander people in the Northern Territory speak a language other than English at home (Australian Bureau of Statistics, 2016a). State and Territory Registries of Births,

² Aboriginal names, English names, family names, skin names and clan names

Deaths and Marriages should waive change of name fees for clients changing their names in order to access government benefits.

3.5 Aboriginal Hostels Limited accommodation - affordability and accessibility concerns

Aboriginal Hostels Limited (AHL)

AHL is a not-for-profit company wholly owned by the Australian Government with an independent non-Executive Board of Directors appointed by the Australian Government and positioned within the portfolio of the Prime Minister and Cabinet. AHL offers accommodation and three meals a day in properties located across urban and regional Australia.

AHL receives funding to address the gap between expenses and revenue received through nightly tariffs. AHL also receives revenue from state and territory governments, to subsidise the accommodation costs of Aboriginal and Torres Strait Islander people who temporarily reside away from home for medical treatment (Aboriginal Hostels Limited, 2018a). The Northern Territory Government only subsidises the accommodation costs of relocating renal patients for a maximum of 8 weeks, on commencement of dialysis (Northern Territory Department of Health, 2017a).

AHL accommodation was originally designed to meet needs for culturally appropriate, affordable short-term accommodation amongst Aboriginal and Torres Strait Islander people. However these hostels attract a large number of long-term residents, many of whom are renal patients (Aboriginal Hostels Limited, 2018b).

A small number of AHL properties have been designated as renal hostels, in which renal nutritionists provide advice on hostel menus. These specialised properties can have long wait lists and renal patients are routinely referred to other hostels by staff based in renal units and wards.

Renal patients also reside at a small number of government-funded hostels operated by NGOs and Aboriginal and Torres Strait Islander organisations, which tend to have similar facilities and pricing models to AHL (Puszka, 2018).

Residents of AHL properties have limited disposable income and limited control over the food they consume and the times that it is served. Renal patients residing in hostels describe these factors as leaving them with little control over their lives and as contributing to experiences of AHL properties as institutionalising environments. AHL has been described as accommodation of last resort by some renal patients (Puszka, 2018).

At a flat rate of \$31 per night, AHL hostels charge below-market rates for accommodation and despite no rate increase since 2014 (Aboriginal Hostels Limited, 2019), this rate remains unaffordable for recipients of the Newstart Allowance or Youth Allowance. Additionally, this rate does not meet the national benchmark of rental affordability³ (Anglicare Australia, 2018) with

³ NB, the national benchmark of rental affordability does not take into account meal costs

residents who receive Newstart Allowance being left with around \$8.70 per day, while those receiving Youth Allowance retaining approximately \$1.50 per day (Table 1).

Renal patients are generally considered eligible for the Disability Support Pension (Australian Government Department of Human Services, 2018), making hostel accommodation more affordable, leaving recipients with around \$29.30 per day. In practice however, Disability Support Pension recipients, including those with ESKD, are faced with financial deductions from their pensions. These deductions can include, for example, repayments on Centrelink Centapay advances, loan repayments, phone bills and fines, all of which impact on disposable income (Puszka, 2018).

The AHL pricing model also prohibits patients’ partners, carers and other relatives who are not receiving a Carer Payment, Disability Support Pension or Age Pension from residing with them.

Table 1: Aboriginal Hostels Limited accommodation costs and Centrelink benefits (Centrelink, 2019)

AHL fortnightly rate	Newstart Allowance, Special Benefit ¹	Youth allowance ²	Disability Support Pension ³	Age Pension ⁴	Carer Payment ⁵
\$434	\$556	\$455	\$844	\$844	\$844

1. Fortnightly rate for a single person with no dependent children
2. Fortnightly rate for a single person aged 18 or over living away from their parents’ home
3. Maximum basic fortnightly rate for a single person aged 21 or over
4. Maximum basic fortnightly rate for a single person or a couple apart due to ill health
5. Maximum basic fortnightly rate for a single person

Established in the 1970s, some older AHL properties may not meet the accessibility requirements of people with physical impairments. This can create mobility constraints and safety risks for residents who require wheelchairs and walkers, or who are frail, and can lead to further housing and accommodation exclusion. Although AHL has partnered with Purple House, renal services and other stakeholders to improve facilities in Alice Springs and the Kimberley (Aboriginal Hostels Limited, 2019), this has not occurred in a systematic manner, and facilities remain unfit for purpose in other locations.

Government policy responses to the housing and accommodation needs of Aboriginal and Torres Strait Islander people should enable residents to make genuine choices about where and with whom they reside. AHL should develop a new accommodation model that meets the requirements of a changing resident demographic (Aboriginal Hostels Limited, 2018b), including accommodation options to meet the needs to renal patients and other long term residents with medical needs. This should occur in partnership with stakeholders including Purple House, Northern Territory renal services and local Aboriginal Community Controlled Health Organisations.

Greater investment is required to ensure that AHL can continue to realise its charter of providing affordable accommodation to Aboriginal and Torres Strait Islander people. New investment should enable AHL to reduce tariffs so that hostels can continue to provide affordable accommodation to all

social security recipients. A consortium of peak Aboriginal and Torres Strait Islander organisations should be commissioned to undertake a review of AHL's pricing structure, and address whether AHL's flat rate of tariffs addresses equity considerations.

4 Eligibility of renal patients for the National Disability Insurance Scheme (NDIS)

4.1 *Assessing disability amongst ESKD patients*

Disability is a Western medical concept that may not necessarily resonate with some Aboriginal and Torres Strait Islander people's experiences of impairment. Aboriginal and Torres Strait Islander languages tend to lack equivalent terms for 'disability' (Avery, 2018). Although this suggests that Aboriginal and Torres Strait Islander people may not necessarily adopt personal identities associated with disability, some localised studies have describe expectations of care and treatment within families and communities, and from healthcare services, amongst those with impairments and illnesses (Sansom, 1982, Puszka, 2019).

The World Health Organisation (WHO) adopts a biopsychosocial model of disability that synthesises individuals' personal impairments and dimensions of local environments and broader society that translate impairments into disabilities, through disruption to social and economic roles and by failing to be inclusive of human diversity. The International Classification of Functioning, Disability and Health (ICF) has been adopted by all member states, including Australia, for the standardisation of data (World Health Organisation, 2002). The Australian Bureau of Statistics adopts the ICF framework in its disability datasets (Australian Bureau of Statistics, 2016). The ICF has been used to assess disability amongst renal patients internationally (Tsutsui et al., 2009).

Assessment of impairments and care and support needs amongst Aboriginal and Torres Strait Islander people should take place through sensitive discussions between patients and carers, and Aboriginal and Torres Strait Islander health professionals or health professionals who have received tailored cultural awareness training. Assessment processes should adopt a holistic approach to considering patients' functioning within their social and physical environments, which may be culturally mediated, and impacted by intersectional marginalisation (Avery, 2018). Assessment of disabilities should determine needs for care while avoiding potentially stigmatising approaches. The ICF should be used to assess disabilities amongst Aboriginal and Torres Strait Islander renal patients.

4.2 *The accessibility of the NDIS for Aboriginal and Torres Strait Islander people*

National Disability Insurance Scheme (NDIS)

The NDIS was established in 2013 to provide support and services to people with impairments that impact on their functional capacities, including participation in social and economic roles.

Accordingly, the NDIS provides reasonable and necessary supports and services, including housing supports and services, to people who have a disability (National Disability Insurance Agency, 2019).

Poor access to disability supports and services for Aboriginal and Torres Strait Islander people eligible for the NDIS

Results from the independent evaluation of the NDIS have shown that the current scheme may not adequately address the needs of Aboriginal and Torres Strait Islander people, nor the circumstances of Northern and Central Australia (Mavromaras et al., 2018). People at risk of receiving lower levels of support include:

- Aboriginal and Torres Strait islander people;
- People who do not speak English as a first language;
- People with disabilities who are unable to advocate for themselves; and
- Those experiencing difficulties navigating the NDIS system.

The National Disability Insurance Agency (NDIA) is currently developing alternative pathways to accessing the NDIS for:

- Aboriginal and Torres Strait Islander people;
- People with complex care needs;
- People living in remote communities;
- People with psychosocial disabilities; and
- People with culturally and linguistically diverse backgrounds.

New referral pathways may address some of the accessibility problems identified in the NDIS evaluation. Referral pathways for Aboriginal and Torres Strait Islander clients could be further improved by providing information about the NDIS in clients' first languages and by employing greater numbers of Aboriginal and Torres Strait Islander staff as part of addressing cultural safety issues.

Case Study 2: Barkly Region, Northern Territory

The NDIS was pilot tested in the Barkly region of the Northern Territory between 2014 and 2017, in order to test the operation of the Scheme in rural and remote communities. The introduction of the Scheme led to an increase in demand for disability services, but due to difficulties in attracting providers in a remote, sparsely populated area, supply and participant choice did not improve. A pricing system which did not adequately reflect the costs of remote service delivery, nor include other essential work such as client engagement, case management and administration also contributed to the poor outcomes (Mavromaras et al., 2018)

There is a risk of thin markets for disability services in regional and remote areas, and for services designed for Aboriginal and Torres Strait Islander people (Productivity Commission, 2017). Urban centres such as Darwin and Alice Springs may have greater economies of scale and scope for service providers compared to the Barkly region (Case Study 2), however they also have relatively small populations and issues of thin markets and a lack of providers may still arise for highly specialised services. The NDIA must address the need for service providers in regional and remote areas. The NDIA should work with organisations delivering other similar services in these locations to assist them to engage with the NDIS. The NDIA should also review and appropriately adjust pricing structures to reflect the true cost of delivering services in regional and remote areas.

4.3 Recognising the impairments of Aboriginal and Torres Strait Islander renal patients through the NDIS

Renal patients are generally assessed as meeting eligibility requirements for the Disability Support Pension (administered by Centrelink) (Social Security (Tables for the Assessment of Work-related Impairment for Disability Support Pension) Determination, 2011). However, they are not considered eligible for the NDIS unless they have other extensive physical or intellectual disabilities meeting program requirements. Distinctions made by the NDIA between diagnostic categories of disability and long term illnesses do not recognise the impairments sustained by many people with long term illnesses, which can result in complex care needs. Such distinctions do not reflect the intention of the NDIS to provide necessary and reasonable supports to people with impairments and are likely to create further barriers to Aboriginal and Torres Strait Islander people accessing the NDIS.

The NDIA should recognise that serious long-term illnesses such as ESKD can lead to physical impairment under Section 24 1(a) of the National Disability Insurance Scheme Act 2013 (Cwth) (see Appendix 1). The NDIA should also recognise that people's experiences of physical and other impairments are culturally mediated, as well as mediated by medical treatment regimens; and that physical and cultural displacement can impact on people's abilities to undertake activities described in Section 24 1(c) of the Act. Interpreting the eligibility criteria of the NDIS to address the physical, economic, social and psychological impairments commonly experienced by Aboriginal and Torres Strait Islander people with ESKD reflects the intent of the NDIS and would enable their housing and support needs to be better addressed.

NDIS eligibility criteria were expanded after initial design work had commenced to include support for people with a psychosocial disability (Nicholas and Reifels, 2014). Further adjustment of the scheme, while it is in an implementation phase, is necessary to ensure that the NDIS is appropriately targeted, including for Aboriginal and Torres Strait Islander renal patients with disabilities. Expanding the NDIS to address the complex care needs of renal patients would enable governance structures, funding mechanisms and registered providers that already exist to be utilised, minimising the administrative burden of new policy initiatives.

Appropriately re-targeting a national scheme to address the needs of a specific group across Australia is not without challenges. Reforms are required to address systemic access barriers to the NDIS, as well as changes to the narrow interpretation of NDIS eligibility criteria, in order to provide

necessary and reasonable supports to Aboriginal and Torres Strait Islander renal patients with impairments.

5 Developing comprehensive policy responses to address the housing and support needs of renal patients

5.1 Patient needs and preferences

A national forum of Aboriginal and Torres Strait Islander renal patients held in 2017 called for patients to be given greater opportunity to be involved in their care (Hughes et al., 2018). Renal patients have differing preferences in living arrangements. Policy responses to the housing and accommodation needs of ESKD patients should reflect a patient-centred approach in which the housing needs and preferences of each patient and their family are considered, with an emphasis on providing choice.

Partnering with Aboriginal and Torres Strait Islander patients and communities provides a powerful opportunity to develop health and housing services which are meaningful to the intended beneficiaries; and which meet their needs (Australian Commission on Safety and Quality in Health Care, 2017). Any new schemes or expansions of existing schemes should take place in partnership with renal patients, Aboriginal Community Controlled Health and Housing Organisations, Aboriginal Medical Services and other stakeholders.

5.2 Collaborative approaches and governance structures

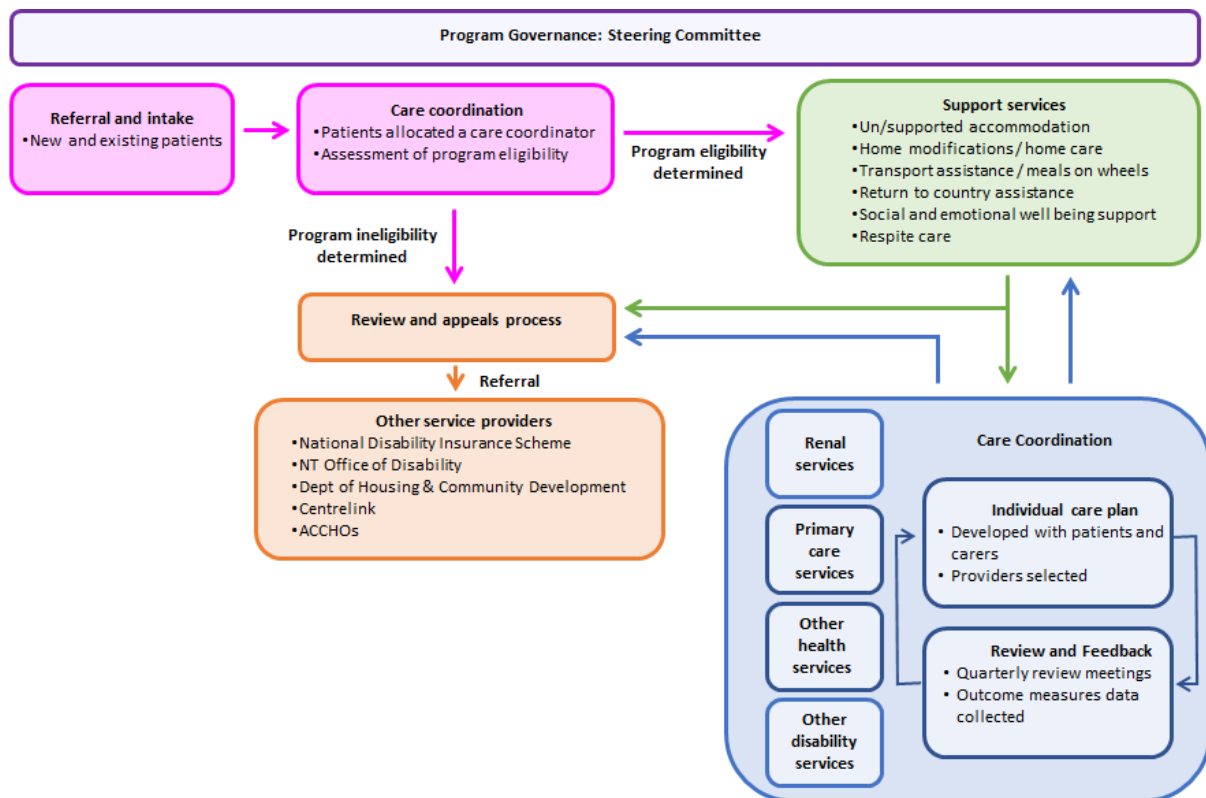
Health and housing policies can interact in complex and sometimes unexpected ways. Health policymakers may not have expertise in housing; and the direct administration of housing programs and supports for patients by health service providers may risk endowing health service providers with competing imperatives and excessive control over patients' lives. Greater dialogue across Government agencies, as well as with patients, Aboriginal Community Controlled Health and Housing Organisations, Aboriginal Medical Services and other stakeholders, is essential for improving the coordination and targeting of programs and schemes intended to assist patients.

The Northern Territory Housing Accommodation Support Initiative (HASI) may provide a model of coordinated healthcare and housing support that could inform future schemes targeted at renal patients.

Housing Accommodation Support Initiative NT

The [HASI program](#) provides integrated psychosocial support and care coordination to people with mental illness to assist them to continue living in the community and maintain public housing tenancies (Northern Territory Department of Health, 2017b). HASI operates under a partnership between government agencies and support providers, including the Northern Territory Department of Health, the Northern Territory Department of Housing and Community Development, Top End Mental Health Services and an NGO provider. It is led by a steering committee with representation from each of the partners and from patients, and is funded through the NT Department of Health. Participants are referred to the program by mental health services and receive support from a support worker based at the NGO provider. HASI is currently being independently evaluated by Menzies School of Health Research. The HASI model is likely to provide an appropriate governance arrangement for a new scheme addressing the needs of renal patients as service providers and referral processes would be similar (Figure 1).

Figure 1: Proposed care package referral pathway (adapted from HASI 2017)



5.3 A new care package scheme

A new integrated care package scheme could provide an option for addressing complex care needs of Aboriginal and Torres Strait Islander renal patients in a targeted way, as an alternative to providing support and services through the NDIS.

The new care package scheme would be administered by state or territory Departments of Health in partnership with patients, Aboriginal Community Controlled Health and Housing Organisations and housing and accommodation service providers, including hostels; and would reflect the local service delivery context.

Individual participants in the scheme would be assessed for their eligibility for specific supports and services. Similar to the NDIS, they would be allocated a budget to be spent on each support or service, and could choose to allocate their funds amongst registered service providers for each service or support area. The day to day management of housing and accommodation allocated to patients would take place at arm's length from health service providers.

The scheme could be implemented by working with existing service providers who may already have relationships with their clients and expertise in the local setting to enhance their capacity, including AHL. It may be possible for a new scheme to leverage current NDIS providers. Results from the NDIS evaluation suggest that enabling a greater range of choice in providers may need to be tempered with consideration of the capacity, quality and cultural safety of providers (Mavromaras et al., 2018).

Further details about the proposed new care package scheme can be found in Appendix 2.

6 Conclusions and recommendations

Aboriginal and Torres Strait Islander people with ESKD are likely to have complex care needs as a result of serious illness, displacement and intersectional disadvantage. A lack of policy response results in housing exclusion and risk of homelessness amongst this group. Limited evidence suggests a lack of appropriate accommodation and support can lead to increased levels of hospitalisation. Failure to address the housing and accommodation of renal patients can also lead to inefficiencies and wastage in health services.

Holistic, integrated and collaborative approaches are required to meet the complex care needs of Aboriginal and Torres Strait Islander renal patients who relocate to urban centres for treatment, including those of their carers. Integrated policy responses should take place through partnerships across relevant government agencies and with renal patients, Aboriginal Community Controlled Health and Housing Organisations, Aboriginal Medical Services and other stakeholders and should provide patients with housing and accommodation choices.

6.1 Recommendation 1. Housing policy frameworks should address the impact of health service delivery models that result in permanent patient relocation

Housing strategies should explicitly address housing needs created by health service delivery models that require people to relocate permanently to access medical treatment, such as renal patients. Housing strategies should be appropriately resourced by Commonwealth, state and territory governments to address chronic social housing shortages in urban and remote areas. This may include directly investing in public housing and providing grants and subsidies to Aboriginal Community Controlled Housing Organisations and other non-government providers.

Housing for renal patients should be appropriately designed or retrofitted to meet accessibility requirements in compliance with national Building Accessibility Standards, and the needs of carers. Housing eligibility requirements should recognise Aboriginal and Torres Strait Islander practices of care, which may involve multiple relatives providing care and fluctuating numbers of carers.

6.2 Recommendation 2. Aboriginal Hostels Limited should develop and pilot a new model of accommodation to meet the needs of long term renal/medical residents in partnership with stakeholders

AHL should respond to changing resident demographics by developing a new model of accommodation designed for long term renal/medical residents. The new model of accommodation could enable residents to participate in governance, provide greater flexibility and choice over meals, and facilitate an environment of belonging. The model should be developed in partnership with long term residents and stakeholders such as Purple House, renal services and local Aboriginal Community Controlled Health Services.

New models should enable AHL to continue to provide accommodation to renal patients, however policy responses to patients' housing needs should facilitate patients with a range of housing and accommodation choices.

6.3 Recommendation 3. Commonwealth investment in Aboriginal Hostels Limited should better enable AHL to meet its objectives of providing affordable accommodation

A consortium of peak Aboriginal and Torres Strait Islander organisations should be commissioned to review AHL's pricing structure and should specifically address accessibility and equity considerations of AHL nightly tariffs for Aboriginal and Torres Strait Islander people receiving different categories of Centrelink benefits. Commonwealth investment in AHL should enable AHL to adjust nightly tariffs based on the review findings.

6.4 Recommendation 4. Centrelink processing of Disability Support Pension applications should be urgently reviewed and improved

The Department of Human Services should conduct a review of the factors contributing to long processing times. Addressing processing times may require increasing resourcing to specific areas of Centrelink or its contracted service providers, such as service providers conducting medical assessments.

Centrelink should develop capacity to assist clients to prove their identity and obtain forms of documentation from other Commonwealth and state/territory government agencies needed for benefit applications, particularly when clients do not speak English as a first language.

State and territory Registries of Births, Deaths and Marriages should waive change of name fees for clients changing their names in order to access government benefits.

The Department of Human Services should make a bridging payment available to people waiting to have Disability Support Pensions assessed and likely to be found eligible, eg by satisfying conditions associated with impairment described in impairment tables such as end stage organ failure (Social Security (Tables for the Assessment of Work-related Impairment for Disability Support Pension) Determination, 2011).

6.5 Recommendation 5. Disabilities among Aboriginal and Torres Strait Islander renal patients should be appropriately assessed and supported

While it should be recognised that experiences of ESKD, dialysis and relocation will vary amongst Aboriginal and Torres Strait Islander renal patients, it is likely that some patients are living with unsupported impairments. Renal patients' impairments should be individually assessed and appropriately supported. Assessment processes should adopt a holistic approach to considering patients' functioning within their social and physical environments. Assessment of patients' needs should encompass the needs of carers. Assessment should take place through sensitive discussions between patients and carers, and Aboriginal and Torres Strait Islander health professionals or health professionals who have received tailored cultural awareness training.

6.6 Recommendation 6. Aboriginal and Torres Strait Islander renal patients with disabilities should be eligible for support through an integrated care package scheme such as the NDIS or a new scheme

The complex care needs of renal patients, including housing and accommodation needs, should be addressed through an integrated care package, reflecting a patient-centred approach in which the housing and support needs and preferences of each patient and their family are considered, and with an emphasis on providing choice. Commonwealth and Northern Territory health and housing agencies should work in partnership to address patients' needs, however the day to day management of housing and accommodation allocated to patients should take place at arm's length

from health service providers. Options for addressing patients' needs through an integrated care scheme include:

- Interpreting NDIS eligibility criteria to recognise the impairments sustained by renal patients; and /or
- Initiating a new care package scheme for relocating renal patients.

Reinterpreting NDIS eligibility criteria would enable policymakers to leverage the existing governance structures, funding streams and registered providers of the NDIS. However, reforms to the NDIS would be required to improve accessibility for Aboriginal and Torres Strait Islander people (Mavromaras et al., 2018).

A new relocation care package scheme could provide a targeted mechanism for addressing the housing and accommodation needs of renal patients reflective of the local service delivery context, while facilitating patient choice of service providers.

6.7 Recommendation 7. Policy responses to the housing and support needs of Aboriginal and Torres Strait Islander renal patients should take place in partnership with patients, Aboriginal Community Controlled Health and Housing Organisations, Aboriginal Medical Services and other stakeholders

Partnerships and collaborative approaches are essential for improving the coordination and targeting of programs and schemes intended to assist patients. An integrated care package scheme should involve partnerships between health and housing agencies, patients and carers, Aboriginal Community Controlled Health and Housing Organisations, Aboriginal Medical Services and other stakeholders

A lack of dialogue between Commonwealth, state and territory health and housing policymakers should be addressed through a permanent inter-agency forum with regular meetings.

7 Appendix 1: National Disability Insurance Scheme Act 2013 (Cwth) s24

(1) A person meets the disability requirements if:

(a) the person has a disability that is attributable to one or more intellectual, cognitive, neurological, sensory or physical impairments or to one or more impairments attributable to a psychiatric condition; and

(b) the impairment or impairments are, or are likely to be, permanent; and

(c) the impairment or impairments result in substantially reduced functional capacity to undertake, or psychosocial functioning in undertaking, one or more of the following activities:

(i) communication;

(ii) social interaction;

(iii) learning;

(iv) mobility;

(v) self-care;

(vi) self-management; and

(d) the impairment or impairments affect the person's capacity for social or economic participation; and

(e) the person is likely to require support under the National Disability Insurance Scheme for the person's lifetime.

(2) For the purposes of subsection (1), an impairment or impairments that vary in intensity may be permanent, and the person is likely to require support under the National Disability Insurance Scheme for the person's lifetime, despite the variation (National Disability Insurance Scheme Act 2013 (Cwth), s24)

8 Appendix 2: Proposed new care package scheme

A2.1 Referral processes and assessment of eligibility

Renal patients would be referred to the scheme by renal services. A two-step eligibility assessment process would determine patients' overall eligibility for the scheme, and their eligibility for specific support services. First, broader scheme eligibility would be assessed using standardised criteria reflecting WHO definitions of disability. Subsequently, eligibility for specific support services would be determined according to the 'necessary and reasonable' service and support benchmark established by the NDIS.

A2.2 Included support services

A range of support services would be made available to eligible participants through the scheme. Unsupported housing and accommodation providers could include hostels, social housing and private rental accommodation, providing participants with housing and accommodation choices. Assessment of the housing and accommodation needs of participants should include consideration of the housing and accommodation needs of carers, which may require some flexibility. Assessment processes should explore current housing needs of participants and carers, as well as likely future needs. The scheme should also provide respite for patients and carers.

The scheme could include return to country assistance, to enable access to reverse respite dialysis where available.

Reverse respite dialysis

'Reverse respite dialysis' refers to programs that support patients to return to home communities and continue receiving dialysis treatment for short bursts, in communities where dialysis facilities exist. Reverse respite dialysis may be made available when dialysis facilities in a community cannot accommodate all patients, and patients may take turns in rotating between an urban centre and their community. Reverse respite dialysis can also operate in communities in which dialysis facilities are normally unstaffed and often unused, when facilities are opened and staffed for short periods of time, sometimes coinciding with other events in communities such as funerals, ceremonies and festivals. Reverse respite dialysis is currently only available in a limited number of Northern Territory communities, but access is likely to expand in future.

Currently there are few avenues for patients to access funding to cover the costs of transport for respite trips. Patients and healthcare service staff confirm that some reverse respite dialysis services have been made possible through charitable donations and by patients self-funding their travel, however this can lead patients without access to funds to miss out. While reverse respite dialysis can significantly contribute to the quality of life of renal patients, the Northern Territory is yet to establish an avenue for funding such a program, as some other jurisdictions have done (Kidney Health Australia, 2016).

It is not recommended that a new scheme should include access to dialysis and other healthcare as it would not be appropriate to impose financial caps on access to healthcare services. However, patients' ongoing healthcare needs could also be integrated into their care package by their care coordinator, through liaison with renal services and other healthcare providers (Figure 2).

The new scheme should not include disability supports that are available through the NDIS or the Office of Disability, for eligible patients, however these services, if accessed by a patient, could also be coordinated by patients' care coordinators.

A2.3 Care coordination

Participants in a new scheme would be supported through case management and central coordination of a designated support worker, such as social workers and Indigenous Liaison Officers currently based in renal units and wards. It may be necessary to increase the ratios of social workers and Indigenous Liaison Officers to patients. Care coordinators will develop care plans in conjunction with patients and carers, review care plans with participants and carers quarterly, and reassess eligibility for support services annually.

A2.4 Supporting carers and families

Carers should be involved throughout the process, including during referral and intake, assessment, development of a care plan and in regular reviews with care coordinators (Figure 2). Care coordinators should ensure that all carers and other appropriate people are involved, in person or via teleconference or videoconference facilities.

A2.5 Registration of service providers

In order to ensure that service providers meet safety and quality standards, the scheme could adopt the assessment criteria and registration process utilised by the NDIA. The NDIS NT Quality and Safeguards Framework will assess service providers across the following domains:

- Governance and financial management
- Workforce planning and development
- Person-centred planning and practice
- Safeguarding
- Cultural safety, security and competency (National Disability Insurance Agency and Northern Territory Government, 2019).

Service providers that become registered for the NDIS would not need to register separately for the care package scheme. A similar process could be adopted for non-NDIS service providers. Alternatively, the registration process for non-NDIS providers may draw on standards, KPIs, and other program requirements already developed for similar services by the Department of Health and

the Office of Disability in order to minimise the administrative burden. Price guides for registered service providers may also draw on existing funding contracts for similar services.

A2.6 Monitoring and evaluation

The new scheme should include complaints handling, review and dispute resolution processes through independent mediators. The new scheme should be pilot tested, monitored and independently evaluated to assess the impact on participant access to support services, participant housing security and participant satisfaction. Data on the performance of the scheme should be routinely collected during quarterly reviews between care coordinators, patients and carers, and from service providers.

References

- Aboriginal Hostels Limited 2018a. Annual Report 2017-18. Canberra.
- Aboriginal Hostels Limited 2018b. Corporate Plan 2018-22. Canberra.
- Aboriginal Hostels Limited. 3 April 2019.
- Anderson, K., Cunningham, J., Devitt, J., Preece, C. & Cass, A. 2012. "Looking back to my family": Indigenous Australian patients' experience of haemodialysis. *BMC Nephrology*, 13.
- Anglicare Australia 2018. 2018 Rental Affordability Snapshot: Regional Reports and Snapshots. Canberra.
- Australia and New Zealand Dialysis and Transplant Registry 2016. 38th Annual Report. *38th Report*. Adelaide.
- Australian Bureau of Statistics 2016. Disability, Ageing and Carers, Australia: Summary of Findings, 2015. Canberra.
- Australian Commission on Safety and Quality in Health Care 2017. National Safety and Quality Health Service Standards user guide for Aboriginal and Torres Strait Islander health.
- Australian Government. 2019. *Closing the Gap* [Online]. Canberra: Department of Prime Minister and Cabinet. Available: <https://closingthegap.pmc.gov.au/> [Accessed 29 March 2019].
- Australian Government Department of Human Services. 2018. *Disability Support Pension* [Online]. Canberra: Centrelink. Available: <https://www.humanservices.gov.au/individuals/services/centrelink/disability-support-pension> [Accessed 5 April 2019].
- Australian Institute of Health and Welfare 2015. The health and welfare of Australia's Aboriginal and Torres Strait Islander peoples 2015. Canberra: AIHW.
- Avery, S. 2018. *Culture is Inclusion: A narrative of Aboriginal and Torres Strait Islander people with a disability*, Sydney, First Peoples Disability Network.
- Bailie, R. 2007. Housing. In: Carson, B., Dunbar, T., Chenhall, R. & Bailie, R. (eds.) *Social Determinants of Indigenous Health*. Crows Nest: Allen and Unwin.
- Biddle, N. 2010. Indigenous migration and the labour market: A cautionary tale. *Australian Journal of Labour Economics*, 13, 313-330.
- Burnette, L. & Kickett, M. 2009a. Dislocation and Dialysis in Aboriginal Patients with Renal Failure. *Aboriginal and Islander Health Worker Journal*, 33, 10-13.
- Burnette, L. & Kickett, M. 2009b. 'You are just a puppet': Australian Aboriginal people's experience of disempowerment when undergoing treatment for end-stage renal disease. *Renal Society of Australasia*, 5, 113-118.
- Interview with Age Discrimination Commissioner*, 2018. Radio. Directed by Byrne, C. ABC local radio Darwin.
- Cass, A., Brown, A., S, T., Snelling, P., Devitt, J., Thomas, M., Howard, K. & Mcgilvray, A. 2011a. Central Australian Renal Study: Part 3 Technical Report. Sydney.
- Cass, A., Brown, A., S, T., Snelling, P., Devitt, J., Thomas, M., Howard, K. & Mcgilvray, A. 2011b. Central Australian Renal Study: Part 3 Technical Report. Sydney.

- Cass, A., Cunningham, J., Snelling, P., Wang, Z. & Hoy, W. 2004. Exploring the pathways leading from disadvantage to end-stage renal disease for Indigenous Australians. *Social Science and Medicine*, 58, 767-785.
- Cass, A., Cunningham, J., Wang, Z. & Hoy, W. 2001. Regional variation in the incidence of end-stage renal disease in Indigenous Australians. *Medical Journal of Australia*, 175, 24-27.
- Cass, A., Feyer, A., Brown, A., Snelling, P. & Howard, K. 2011c. Central Australian Renal Study - Final Report. Sydney: Department of Health and Ageing.
- Centrelink. 2019. *Centrelink individuals* [Online]. Department of Human Services. Available: <https://www.humanservices.gov.au/> [Accessed 12 March 2019].
- Chiu, Y. L., Tsai, H. H., Lai, Y. J., Tseng, H. Y., Wu, Y. W., Peng, Y. S., Chiu, C. M. & Chuang, Y. F. 2019. Cognitive impairment in patients with end-stage renal disease: Accelerated brain aging? *Journal of the Formosan Medical Association*.
- Close the Gap Steering Committee 2019. *Our Choices, Our Voices: Close the Gap*. Melbourne.
- Cukor, D., Coplan, J., Brown, C., Friedman, S., Cromwell-Smith, A., Peterson, R. A. & Kimmel, P. L. 2007. Depression and Anxiety in Urban Hemodialysis Patients. *Clinical Journal of the American Society of Nephrology*, 2, 484-490.
- Devitt, J. & McMasters, A. 1998a. *Living on Medicine: A Cultural Study of End-stage Renal Disease among Aboriginal People*, Alice Springs, IAD Press.
- Devitt, J. & McMasters, A. 1998b. 'They don't last long': Aboriginal patient experience of end-stage renal disease in Central Australia. *Nephrology*, 4, suppl., S111-S117.
- Gorham, G. 2001. *Prevention and Treatment Options for Renal Disease in the Northern Territory (with particular reference to the Barkly Region)*. Darwin: The Cooperative Research Centre for Aboriginal and Tropical Health and Department of Health and Community Services.
- Gorham, G., Howard, K., Togni, S., Lawton, P., Hughes, J., Majoni, S., Brown, S., Barnes, S. & Cass, A. 2017. Economic and quality of care evaluation of dialysis service models in remote Australia: protocol for a mixed methods study. *BMC Health Services Research*, 17.
- Gorham, G., Majoni, S., Lawton, P., Brown, S., Dube, B., Conlon, T., Sajiv, C., Wood, P., Signal, S. & Cass, A. 2018. Interesting times — evolution of dialysis in Australia's Northern Territory (1980–2014). *Renal Society of Australasia Journal*, 14, 108-116.
- Groenhart, L. & Burke, T. 2014. Thirty years of public housing supply and consumption: 1981– 2011. AHURI Final Report No. 231.
- Habibis, D., Birdsall-Jones, C., Dunbar, T., Scrimgeour, M., Taylor, E. & Nethercote, M. 2011. *Improving housing responses to Indigenous patterns of temporary mobility*. Melbourne: Australian Housing and Urban Research Institute.
- Hill, T., Thomson, C., Raven, M., Wong, M., Cass, B., Yeandle, S. & Buckner, L. 2016. *Carers and Social Inclusion*. Sydney: Social Policy Research Centre, University of New South Wales.
- Home Modification Information Clearinghouse. 2019. *Legislation, Standards and Guidelines* [Online]. Sydney: University of New South Wales. Available: <https://www.homemods.info/resources/legislation-standards-and-guidelines> [Accessed 5 April 2019].
- Hughes, J., Dembski, L., Kerrigan, V., Majoni, S., Lawton, P. & Cass, A. 2018. Gathering Perspectives - Finding Solutions for Chronic and End Stage Kidney Disease. *Nephrology*, 23 supplement, 5-13.
- Kidney Health Australia 2016. *Budget submission to the Northern Territory Government*. Melbourne.

- Kimmel, B. & Peterson, R. A. 2006. Depression in patients with end-stage renal disease treated with dialysis: has the time to treat arrived? *Clinical Journal of the American Society of Nephrology*, 1, 349-352.
- Kimmel, P. L. 2001. Psychosocial factors in dialysis patients. *Kidney International Reports*, 59, 1599–1613.
- Kimmel, P. L., Thamer, M., Richard, C. M. & Ray, N. F. 1998. Psychiatric illness in patients with end-stage renal disease. *American Journal of Medicine*, 105, 214-221.
- Kimmel, P. L., Weihs, K. & Peterson, R. A. 1993. Survival in hemodialysis patients: the role of depression. *Journal of the American Society of Nephrology*, 4, 12-27.
- Klang, B. & Clyne, N. 1997. Well-being and Functional Ability in Uraemic Patients Before and After Having Started Dialysis Treatment. *Scandinavian Journal of Caring Science*, 11, 159-166.
- Krishnan, M. 2019. The Importance of Considering Total Patient Economics for Hemodialysis. *Kidney International Reports*, 4, 365-366.
- Lawton, P. 2017. Letter to editor: Response to An Expanded Nationwide View of Chronic Kidney Disease in Aboriginal Australians. *Nephrology*, 22.
- Lee, S., Yang, D. H., Hwang, E., Kang, S. H., Park, S., Kim, T. W., Lee, D. H., Park, K. & Kim, J. C. 2017. The Prevalence, Association, and Clinical Outcomes of Frailty in Maintenance Dialysis Patients. *Journal of Renal Nutrition*, 27, 106-112.
- Mavromaras, K., Moskos, M., Mahuteau, S. & Isherwood, L. 2018. Evaluation of the NDIS: Final Report. Adelaide.
- Mcadams-Demarco, M. A., Suresh, S., Law, A., Salter, M. L., Gimenez, L. F., Jaar, B. G., Walston, J. D. & Segev, D. L. 2013. Frailty and falls among adult patients undergoing chronic hemodialysis: a prospective cohort study. *BMC Nephrology*, 14.
- Mccooy, B. 2008. *Holding Men: Kanyirninpa and the health of Aboriginal men*, Canberra, Aboriginal Studies Press.
- Myers, F. 1986. *Pintupi Country, Pintupi Self: Sentiment, Place, and Politics among Western Desert Aborigines*, Berkeley, Los Angeles, London, University of California Press.
- National Disability Insurance Agency. 2019. *Housing and the NDIS* [Online]. Canberra: NDIA. Available: <https://www.ndis.gov.au/participants/housing-and-ndis> [Accessed 29 March 2019].
- National Disability Insurance Agency & Northern Territory Government 2019. Quality and Safeguards working arrangements for transition to the NDIS in Northern Territory (NT). Canberra.
- National Disability Insurance Scheme Act 2013 (Cwth).
- Nicholas, A. & Reifels, L. 2014. Mental health and the NDIS: A literature review. Melbourne.
- North Australia Aboriginal Justice Agency 2016. Response to the Housing Strategy Consultation Draft. Darwin.
- Northern Territory Department of Health 2017a. Patient Assistance Travel Scheme guidelines. Darwin.
- Northern Territory Department of Health 2017b. Trial of the NT Housing Accommodation Support Initiative (NT HASI) Service Model and Program Guidelines. Darwin.
- Northern Territory Department of Housing and Community Development. 4/5/2018 2018a.
- Northern Territory Department of Housing and Community Development. 2018b. *Central Australia renal accommodation project* [Online]. Available: <https://dlghcd.nt.gov.au/our-services/housing-development-opportunities/central-australia-renal-accommodation-project> [Accessed 27 Feb 2019].

- Northern Territory Department of Housing and Community Development. 2018c. *Public Housing Waiting List* [Online]. Darwin: Northern Territory Government. Available: <https://nt.gov.au/property/public-housing/apply-for-housing/apply-for-public-housing/waiting-list> [Accessed 23 September 2018].
- Northern Territory Government 2017a. Northern Territory Renal Services Strategy 2017-2021. Darwin.
- Northern Territory Government 2017b. Pathways out of homelessness: discussion paper. Darwin.
- Northern Territory Government. 2018. Departmental and agency media releases [Online]. Darwin: Northern Territory Government, . Available: <http://mediareleases.nt.gov.au/> [Accessed 27 Feb 2019].
- Nt Shelter 2016. Resetting the Homelessness and Housing Button for the Northern Territory? *Parity*, 29, 34-35.
- Nt Shelter 2019. More Efficient Service Delivery by Non-Government Organisations – A Case Study in Housing. *Budget Repair submission to the Northern Territory Government*. Darwin.
- O'lonc, E., Connors, M., Masson, P., Wu, S., Kelly, P. J., Gillespie, D., Parker, D., Whiteley, W., Strippoli, G. F., Palmer, S. C., Craig, J. C. & Webster, A. C. 2016. Cognition in People With End-Stage Kidney Disease Treated With Hemodialysis: A Systematic Review and Meta-analysis. *American Journal of Kidney Disease*, 67, 925-935.
- Palmer, S., Vecchio, M., Craig, J. C., Tonelli, M., Johnson, D. W., Nicolucci, A., Pellegrini, F., Saglimbene, V., Logroscino, G., Fishbane, S. & Strippoli, G. 2013. Prevalence of depression in chronic kidney disease: systematic review and meta-analysis of observational studies. *Kidney International Reports*, 84, 179-191.
- Phleros, P., Rainow, S. & Torzillo, S. 1993. *Housing for Health: Towards A Healthy Living Environment for Aboriginal Australia*, Newport Beach, Healthabitat.
- Productivity Commission 2017. National Disability Insurance Scheme Costs. Canberra.
- Puszka, S. 2018. Under serving citizens and contested moral economies of urban housing. Canberra: unpublished, Australian National University.
- Puszka, S. 2019. Sensibilities, interdependencies and spatialities of domestic care. Canberra: unpublished, Australian National University.
- Ritte, R., Lawton, P., Hughes, J., Barzi, F., Brown, A., Mills, P., Hoy, W., O'dea, K., Cass, A. & Maple-Brown, L. 2017. Chronic kidney disease and socio-economic status: a cross sectional study. *Ethnicity and Health*, 1-17.
- Rivalland, P. 2006. "It's more than machines and medicine - they should understand there's a Yanangu way": Providing kidney dialysis services to Yanangu, Indigenous people from the Western Desert, A report on the activities of Western Desert Nganampa Walytja Palyantjaku Tjutaku "Making all our families well". Alice Springs: Western Desert Nganampa Walytja Palyantjaku Tjutaku.
- Rix, E. F., Barclay, L., Stirling, J., Tong, A. & Wilson, S. 2014. 'Beats the alternative but it messes up your life': Aboriginal people's experience of haemodialysis in rural Australia. *BMJ Open*, 4.
- Rix, E. F., Moran, C., Kapeen, R. & Wilson, S. 2016. Building cultural bridges and two-way understanding: working with Australian Aboriginal people within mainstream renal services. *Renal Society of Australasia Journal*, 12, 12-17.
- Sansom, B. 1982. The Sick Who Do Not Speak. In: PARKIN, D. (ed.) *Semantic Anthropology*. London: Academic Press.

- Social Security (Tables for the Assessment of Work-Related Impairment for Disability Support Pension) Determination 2011. Minister for Families Housing Community Services and Indigenous Affairs. *In: Commonwealth (ed.)*.
- Stumpers, S. & Thomson, N. 2013. Review of kidney disease and urologic disorders among Indigenous people. *Australian Indigenous HealthInfoNet Reviews*. Perth.
- Taylor, L. A. 2018. Housing And Health: An Overview Of The Literature. *Health Affairs Health Policy Brief*. Bethesda, Maryland.
- Thomas, R., Kansa, A. & Sedor, J. 2008. Chronic Kidney Disease and Its Complications. *Primary Care*, 35.
- Tian, X., Guo, X., Xia, X., Yu, H., Li, X. & Jiang, A. 2019. The comparison of cognitive function and risk of dementia in CKD patients under peritoneal dialysis and hemodialysis: A PRISMA-compliant systematic review and meta-analysis. *Medicine (Baltimore)*, 98.
- Tsutsui, H., Koike, T., Yamazaki, C., Ito, A., Kato, F., Sato, H., Tawada, H. & Oshida, Y. 2009. Identification of Hemodialysis Patients' Common Problems Using the International Classification of Functioning, Disability and Health. *Therapeutic Apheresis and Dialysis*, 13, 186-192.
- Vischini, G., Tendas, A., Ferrannini, M., Scaramucci, M., Di Segni, G., Giovannini, M., Niscola, P. & Palumbo, R. 2011. Letter to the Editor: Motor Disability in End-Stage Renal Failure: An Epidemiological Study on Italian Dialyzed Patients. *Saudi Journal of Kidney Diseases and Transplantation*, 22, 1236-1237.
- Willis, J. 1995. Fatal attraction: do high-technology treatments for end-stage renal disease benefit Aboriginal patients in central Australia? *Australian Journal of Public Health*, 19, 603-609.
- World Health Organisation 2002. Towards a Common Language for Functioning, Disability and Health: The International Classification of Functioning, Disability and Health. Geneva.
- You, J., Lawton, P., Zhao, Y., Poppe, S., Cameron, N. & Guthridge, S. 2015. Renal Replacement Therapy Demand Study, Northern Territory, 2001 to 2022. Darwin.

Contact

Dr Rebecca Haddock
Director
Deeble Institute for Health Policy Research
Australian Healthcare and Hospitals Association

E: deebleadmin@ahha.asn.au

T: 02 6162 0780

Tw: [@DeebleInstitute](https://twitter.com/DeebleInstitute)

© Australian Healthcare and Hospital Association, 2019. All rights reserved