

NEWSTART, POVERTY, DISABILITY AND THE NATIONAL DISABILITY INSURANCE SCHEME

Dr Louise St Guillaume

E.G. Whitlam Fellow 2019,
The Whitlam Institute within
Western Sydney University

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List of acronyms

CaLD	Culturally and Linguistically Diverse
DEEWR	Department of Education, Employment and Workplace Relations
DES	Disability Employment Service
DHS	Department of Human Services
DSP	Disability Support Pension
DSS	Department of Social Services
ICESCR	International Covenant on Economic, Social and Cultural Rights
ILC	Information, Linkages and Capacity Building
JSA	Job Services Australia
NDIA	National Disability Insurance Agency
NDIS	National Disability Insurance Scheme
NEDA	National Ethnic Disability Alliance
NES	Non-English Speaking
NF	Neurofibromatosis
NSA	Newstart Allowance
NSW	New South Wales
OECD	Organisation for Economic Cooperation and Development
PCW	Partial Capacity to Work
POS	Program Of Support
PWDA	People with Disability Australia
UK	United Kingdom
UN	United Nations

Executive Summary

This paper presents the findings of a small qualitative pilot study which broadly examines the lived experience of people with disability in Western Sydney on Newstart Allowance (NSA) and whether they are eligible for disability supports through the National Disability Insurance Scheme (NDIS) and the Information, Linkages and Capacity Building (ILC) tier of the NDIS.

The research draws attention to the fact that people with disability experience difficulty with the application process for the Disability Support Pension (DSP), including the need to provide medical evidence and meet the Program of Support (POS) requirements. It also found that people with disability ineligible for the DSP live in poverty on NSA and are unable to afford basic necessities such as food, baby formula and sanitary pads. The low rate of NSA additionally means that people with disability could not afford medication, to attend medical appointments, medical aids and equipment. This hampered their attempts to apply for the DSP because they could not provide the required medical evidence or in some cases be assessed as diagnosed, treated and stabilised. Furthermore, people with disability found it difficult to meet their mutual obligations requirements which they must in order to receive NSA and felt unsupported by Services Australia (formerly Centrelink)¹ and employment service providers. Participants also drew attention to barriers which they experience to employment such as disability, race and age discrimination and felt that they were regulated by a social security system which placed able-bodied expectations on them. This is despite the fact that almost all participants wanted to participate in the labour market. For many of the participants, their impairment/s were exacerbated, or a secondary condition was acquired while living on NSA. For people from Culturally and Linguistically Diverse (CALD)/ Non-English Speaking (NES) backgrounds with disability, their experiences of applying for the DSP, on NSA and meeting their mutual obligations was often more complex, particularly when English was not their first language.

With regards to the NDIS and ILC, investigations revealed that most participants did not have and would be unlikely to be eligible for an individualised package to purchase disability supports through the NDIS. For the one participant who did have an individualised funding package and was on NSA she was confused at this policy intersection. Nevertheless, it was found that people with disability on NSA would in theory be eligible for support under the ILC. However, because the ILC is still being implemented and is mainly administered through grants which fund programs and initiatives which could have their own eligibility requirements, it was unclear what supports people with disability on NSA would be able to access. It was also unclear whether their participation in programs funded by the ILC would contribute to their mutual obligations. Given that there are grants funded to improve economic and community inclusion and participation of people with disability, it could be valuable for people with disability on NSA to participate in these initiatives. Yet it might not be possible for them to as well as uphold their mutual obligations.

Therefore, this research makes a significant contribution to the academic and policy discussions on people with

disability, NSA and the NDIS. Given that there is very little research on how social security (i.e. NSA) and disability care and support policy (i.e. NDIS) intersect to govern the lives of people at this intersection; there is a lack of exploration of the lived experience of people with disability on NSA in Western Sydney, and; the experience of people from CALD/ NES backgrounds with disability on NSA, the evaluations and conclusions provided in this pilot research are important and worthy of further investigation.

Ultimately then based on the findings of this research, **it is recommended that the eligibility criteria for the DSP be reviewed and revised, that the rate of NSA increase, the mutual obligation expectations placed on people with disability on NSA be reviewed, that people be provided with personalised and individualised support in the social security and employment service system, that structural barriers to employment be addressed for people with disability and that clear consideration is given to how NSA and the NDIS intersect to govern people's lives so that people with disability on NSA are provided with the opportunity to take advantage of relevant aspects of the NDIS. All these recommendations should be informed by the voices and experiences of people with disability.**

¹ Centrelink's name changed in February 2020 to Services Australia. As such, Services Australia and Centrelink are used interchangeably in this paper.

1. Introduction

Since 2006 there have been significant policy reforms by various Australian Federal governments to the eligibility criteria for the Disability Support Pension (DSP) (Fitts & Soldatic, 2018). These changes have meant that for some people with disability who would have previously been eligible for the DSP they no longer are. Instead, they have to apply for an alternative payment should they require income support. These people are categorised in the social security system as 'people with a partial capacity to work' (PCW). Although people with a PCW can apply for and receive Parenting Payment Single or Youth Allowance (other), most people with a PCW receive the unemployment payment, Newstart Allowance (NSA). As at September 2019 there were 295, 889 people with PCW on NSA (Department of Social Services (DSS), 2019). This is approximately 43% of the NSA population.

This attempt to shift people with disability who have an assessed capacity for employment from disability-specific payments in the income support system into formal paid work has also occurred in other global contexts, such as Canada and the United Kingdom (UK) and has been supported by the Organisation for Economic Cooperation and Development (OECD) (2003). Although there are local variations, this positions Australia as part of a global trend in the Anglosphere to restructure the social security system (Chouinard, 2010; Chouinard & Crooks, 2005; Grover & Piggott, 2010; Hyde, 2000; Roulstone, 2000).

The reforms are described as part of a neoliberal trend where the market is positioned as the place from which people can satisfy their welfare needs (Gardner, 2017). Furthermore, high rates of unemployment, an economic recession, a growing ageing population, increasing DSP numbers (increasing by approximately 400 per cent between 1974 and 2004)² and claims of a population dependent on welfare justified the austerity measures with attempts to curb welfare spending and shift people into the labour force (Daniels & Yeend, 2005; Fitts & Soldatic, 2018; Galvin, 2004; Goggin & Newell, 2005; Harris, Owen, Fisher & Gould, 2014; Humpage, 2007; Mendes, 2008). This has meant policy changes which subscribe people with disability to conditions, obligations and responsibilities in return for income support. Scholars have argued, and this research shows, that the reforms have constrained the implementation of human rights for people with disability (Harris et al., 2014; Soldatic, 2011) and are causing physical and mental harm.

Alongside reforms to the social security system affecting people with disability, there have been changes to the disability care and support system in Australia. The National Disability Insurance Scheme (NDIS) uses an individualised funding model (Buckmaster & Tomaras, 2013) and is a significant shift in the provision and funding of disability supports in Australia (National Disability and Carer Alliance, 2014). Underpinned by the principles of choice and control and seeking to support people with disability to live an 'ordinary life' and participate in their care and support decisions, it provides individualised funding packages to those people with disability who meet the eligibility requirements

including having a significant and permanent disability. The NDIS also includes an Information, Linkages and Capacity Building (ILC) component which seeks to link people with disability who have and do not have individualised funding packages with support services and information. It also seeks to break down some of the barriers experienced by people with disability to social inclusion and participation.

This small-scale, qualitative, pilot research is positioned at the intersection of these policy systems governing people with disability in that it sought to understand the lived experience of people with a PCW on NSA in Western Sydney and determine whether people with a PCW are eligible for disability supports under the NDIS. Soldatic (2011) suggests that Australia is at a "critical and contradictory moment in the history of Australian disability policy". The shift in the provision of disability care and support, although critiqued for its failure to deliver on increased choice and control for people with disability (see for example, Knaus, 2018; Morton, 2018), operates alongside changes which have "result[ed] in diminish[ed] citizenship and human rights to a group of people with disabilities who no longer seem "disabled enough" to qualify for government support" (Soldatic, 2011). Yet, while there has been some research in this area, very little scholarly research has examined the experience of people at this policy intersection nor how the policies operate at this intersection. Furthermore, policy makers and service providers have not yet examined or considered this policy intersection or the experience of people at this intersection. For example, a NDIS service provider denied that people with a PCW would be eligible for an individualised funding package, and recent data on the employment outcomes of NDIS participants produced by the National Disability Insurance Agency (NDIA) has not yet captured people with disability on NSA as participants in the scheme (Australian Federation of Disability Organisations, 2020), yet this qualitative research has interviewed a person with a physical impairment who sits at this policy intersection, that is, has an individualised funding package and receives NSA. As such, this research is significant.

It is also significant because it contributes to the lack of research on the experience of people from Culturally and Linguistically Diverse (CALD)/ Non-English Speaking (NES) backgrounds with disability on NSA. "Western Sydney is one of the most diverse areas of Australia, with 38% of the population speaking a language other than English at home, and up to 90% in some suburbs" (Glen, 2015). 43% of the participants in this research required an Arabic interpreter.

As well as exploring this, the research considers how former Australian Prime Minister Gough Whitlam's disability social policy legacy could inform policy recommendations in this space. The Whitlam government proposed the National Accident Compensation Scheme (similar to the NDIS), enacted the United Nations (UN) International Covenant on Economic, Social and Cultural Rights (ICESCR), increased the rate of the Invalid Pension and the Unemployment Benefit, created a Social Welfare Commission and continued the Henderson Inquiry into Poverty in Australia. In addition, more broadly with regards to social security, the Whitlam government was underpinned by values of equality, dignity and fairness. While there are many texts which outline, name or mention the

² It is worth noting that Fitts and Soldatic (2014) argue that DSP often served "as a way to hide real structural unemployment for those individuals excluded permanently from the labour market with neo-liberal restructuring of the Australian economy and the combined effects of labour market and social security law, policy and social programming".

Whitlam policies being explored in this research, very few texts have explored such policies in depth with the exception being the National Accident Compensation Scheme (Keeler, 1975; Luntz, 2003; Robinson, 1987) - or with regards to their relationship to the contemporary context. As such, this research works to extend the legacy of Whitlam's policy reforms in this space.

As such, what becomes apparent through the research findings is though it is possible for some people with a PCW on NSA to access disability supports through the NDIS through an individualised funding package or through ILC programs, their experiences on NSA in the social security system are not underpinned by human rights, equality, dignity and fairness. This research makes policy recommendations accordingly to rectify this.

This report begins by establishing the contemporary policy context relative to the reforms to the eligibility criteria for the DSP, the establishment of the PCW category and the NDIS. It then briefly examines existing literature in this area, including both scholarly and non-scholarly research. Following this, the method of the research is outlined, before presenting the research findings and discussion. Throughout the findings and discussion are a series of corresponding recommendations for policy makers. The report ends with a conclusion which summarises the recommendations and reflects on how Whitlam's legacy can inform this contemporary context.

2. Policy context: How did Australia get here and what does it look like?

People with disability on NSA

In 2006 under the Howard Liberal-National Coalition Government, the *Employment and Workplace Relations Legislation Amendment (Welfare Reform and Other Measures) Act (Cth)* was passed, making changes to the eligibility criteria for the DSP. Following the reforms, those people with disability assessed as capable of working between 15-29 hours per week were no longer eligible for the DSP. Instead, they had to apply for an alternative payment, such as NSA, the lower unemployment benefit.

In 2007 the Liberal-National Coalition Government was not re-elected, replaced by the Labor Government. Throughout the course of the Labor Government no increases were made to the rate of NSA (Morris & Wilson, 2014) and further changes were made to the DSP eligibility criteria making it increasingly difficult for people with disability to access the DSP. Through the Gillard Labor Government's *Social Security and Other Legislation Amendment Act 2011 (Cth)* the impairment tables, which are used to assess the impact of an applicant's impairment/s on their capacity for employment, were moved to a legislative instrument. This meant that the government could regularly update the tables, as previously to make changes to the Act a bill was required to be passed by both Chambers of Parliament (Daniels, Buckmaster & Thomas, 2011). This has resulted in the tightening of the impairment tables with some medical conditions removed (Fitts & Soldatic, 2018). Additionally, through the *Family Assistance and Other Legislation Amendment Act 2011 (Cth)* the program of support (POS) requirement was introduced as part of the

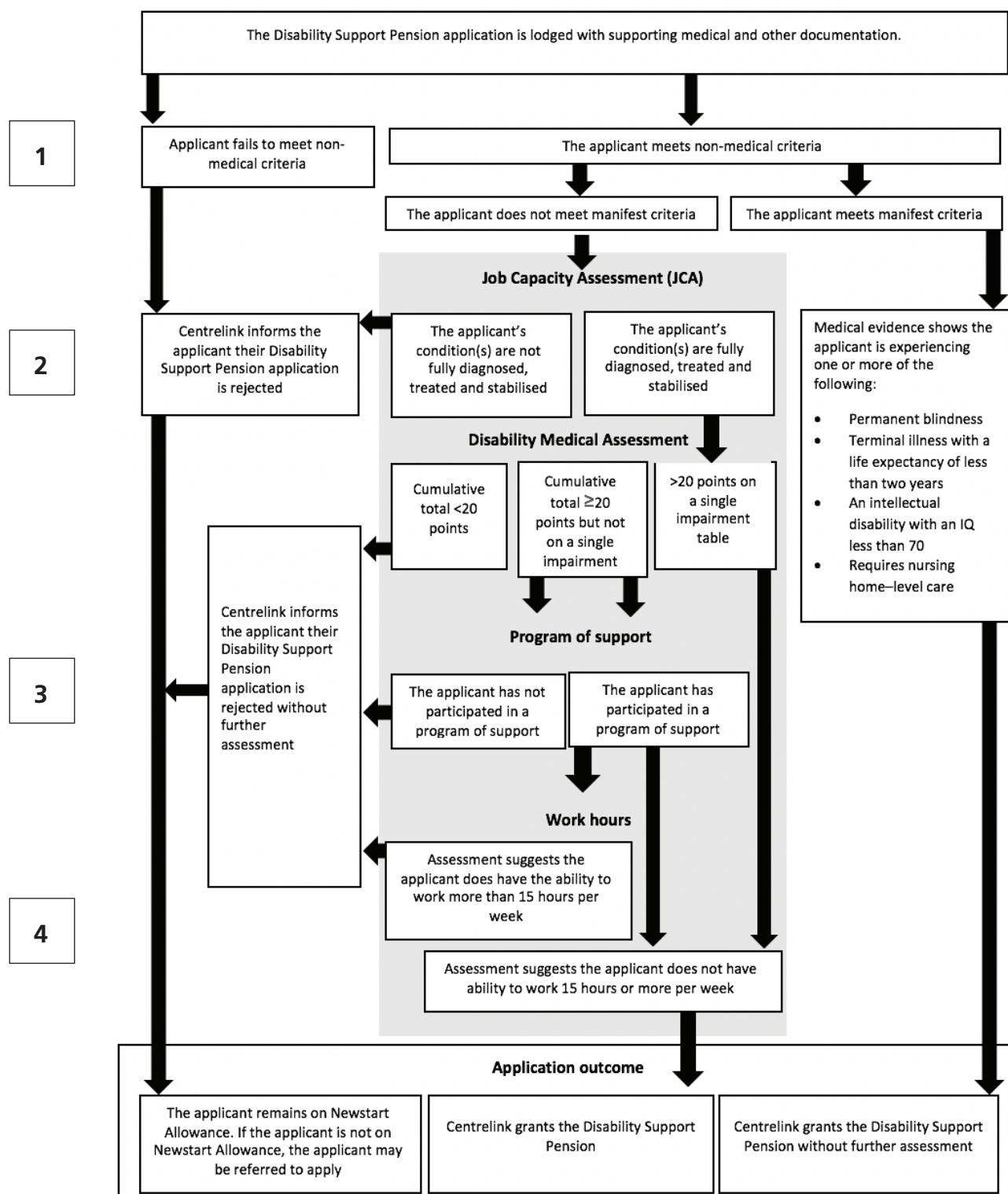
eligibility test. In order to assess whether an applicant without a 'severe' impairment had a 'continuing inability to work' they had to demonstrate that they had previously engaged with a POS, like a Disability Employment Service (DES). Active engagement with a POS was assessed as complying with the program requirements as well as being engaged with the program for 18 months within the three years immediately prior to claiming DSP (Australian Government, 2015). If a person could not prove that they had previously engaged with a POS then they were excluded from the DSP, had to apply for an alternative income support payment, such as NSA and engage with a POS for 18 months. The National Welfare Rights Network (2011) describe this change as requiring people to test their work capacity before becoming eligible for the DSP.

"A further key shift took place in 2011. Disabled people under 35 years of age with a capacity to work eight hours or more per week now had to wait for 36 months before they could access the DSP (only people with assessed 'severe impairment' in this age group immediately qualified for the DSP). During the waiting period, clients are placed on Newstart. In July 2012, Labor legislated that all DSP claimants under the age of 35 must undergo activity tests. Compulsory 'participation plans' and ongoing interviews are embedded throughout the new requirements. Access to the DSP for disabled people under the age of 35 became conditional on successive failures to find work over a two-year period" (Morris, Wilson & Soldatic, 2015, p. 48). However, it is worth noting that alongside this Labor made some other changes. Firstly, when those assessed as capable of working no more than 15 hours per week worked more than this, they no longer had their benefits cut. "Labor also committed to additional subsidies for employers hiring disabled people (a subsidy of AU\$3,000 per DSP recipient for providing 26 weeks' employment at 15 hours per week) and proposed compensation for productivity losses incurred by employing disabled people" (Morris, Wilson & Soldatic, 2015, p. 50). The changes affecting those under 35 were extended to those under 35 already on the DSP when the Liberal-National Coalition Government was elected in 2013.

Furthermore, "[f]rom July 1, 2015 medical reports from treating doctors were no longer required for any DSP claims (Australian Government 2018b). Instead, new applicants are now given a checklist of types of primary medical evidence that they wish to supply to support their application. The review process of this evidence has also changed" (Fitts & Soldatic, 2018).

As a result of these changes and others, applying for the DSP is a complex process for people with disability, particularly for people with disability who do not meet the manifest eligibility rules (see Australian Government, 2016). Instead, they must now meet several other eligibility tests under the general medical rules which are described and mapped in Figure 1 below.

Figure 1: Process for applying for the DSP (Fitts & Soldatic, 2018)



1. Job Capacity Assessment to determine whether condition is diagnosed, treated and stabilised.

A Job Capacity Assessment determines “a person’s level of functional impairment resulting from permanent medical condition(s) and [...] assess[es] a person’s ability to work” (Fitts & Soldatic, 2018). It is undertaken “by an allied health professional such as an occupational therapist, psychologist or social worker” (Fitts & Soldatic, 2018) who will assess the applicant and the medical evidence provided to understand their impairment/s (diagnosis), barriers to work and whether their impairment has been treated and stabilised. A person’s condition must be diagnosed, treated and stabilised for them to be assessed for DSP eligibility. A condition is diagnosed if it has been examined and diagnosed by an appropriate medical professional. To assess whether the condition is ‘treated’ assessors will examine the person’s previous and current treatment, whether further treatment is planned, the outcomes and suitability of any treatment plans and if there is medical evidence for why treatment is not possible. Finally, for a condition to be categorised as ‘stabilised’ an assessment is made on whether the person’s condition will improve or remain the same with further treatment and rehabilitation (Australian Government Services Australia, 2019a).

2. Impairment/s must have a rating of 20 points or more in one impairment table (Disability Medical Assessment).

A government-contracted doctor reviews the medical evidence provided by the applicant (Fitts & Soldatic, 2018) and gives the individual an impairment rating, that is, how a person’s impairment affects their ability to function daily which is assessed using the impairment tables. The impairment tables are used to assess those conditions which *have been* diagnosed, treated and stabilised (permanent) and the impact these conditions have on work capacity, assigning them an impairment rating (Australian Government Services Australia, 2019b). This rating is used to determine whether the general medical rules for a DSP claim are met. If a person’s impairment measures 20 points or more in a single impairment table their ability to work will be assessed. If they meet 20 points or more across multiple tables then they must also meet the POS requirement (detailed below). If their condition rates less than 20 points across the impairment tables they are not eligible for the DSP (Australian Government Services Australia, 2019b).

3. The POS must be met.

For those whose impairment is rated at 20 points or more across multiple impairment tables, they have to demonstrate that they have actively engaged with a POS, such as a JobActive or DES provider. “A program of support helps people with disability to prepare for, find and keep a job” (Australian Government Services Australia, 2020). This engagement must be for 18 months out of the three years prior to the claim or if an applicant has completed a similar program of less time this may count. Any time in which a person is not participating in the POS during this time does not count.

4. The continuing inability to work test must be met (Work hours).

The continuing inability to work test assesses future work capacity. It assesses whether a person’s impairment will stop them from working at least 15 hours per week in the next two years.

As suggested for those unable to pass these tests, they may apply for and receive NSA. Those people with a PCW on NSA, like those people without disability on NSA, have mutual obligation requirements which must be upheld such as reporting their fortnightly income to Centrelink (now Services Australia), attending job interviews or acting on job opportunities. They are also subject to demerit points and

placed in warning and penalty zones should they not adhere to their mutual obligation requirements which could result in a payment suspension or payment cancellation (*Social Security (Administration) (Non-Compliance) Determination 2018 (No. 1) (Cth)*). It is suggested in the Social Security (Administration) (Non-Compliance) Determination 2018 (No. 1) Explanatory Statement (Australian Government, 2018) that this provides jobseekers with strong incentives to remain in the ‘green zone’, achieved through meeting their mutual obligation requirements.

Employment support for people with disability on NSA

People with a PCW are generally expected to search for employment while on NSA. People with a PCW are eligible for employment support from JobActive (formerly Job Services Australia (JSA) or DES. DES provides help for people with disability, illness or injury to find and keep a job (Australian Government Services Australia, 2019c). It is the “primary employment service for Newstart Allowance recipients with a partial capacity to work” (Department of Education, Employment & Workplace Relations (DEEWR), Department of Families Housing & Community Services & Indigenous Affairs, Department of Human Services (DHS) & Department of Industry Innovation Science Research & Tertiary Education, 2012, p. 82). Job service providers operate to find people with disability employment but are also given the power to sanction participants should they fail to uphold their obligations and are required to as a condition of their funding by the federal government (Morris, Wilson & Soldatic, 2015).

People with a PCW fair poorly in transitioning to work. For example, “Only three per cent of the job placements achieved for Newstart Allowance job seekers since the start of JSA have been achieved for job seekers with a partial work capacity” (DEEWR et al., 2012, p. 72). “[Additionally, t]here is a strong correlation between partial capacity to work and long-term duration on payment. Average duration on payment for people with a partial capacity to work at the end of June 2012 was 257.7 weeks on payment or slightly less than five years, compared to 179.8 weeks for the general Newstart Allowance population” (DEEWR et al., 2012, p. 81). As at September 28, 2018, 176, 743 out of the 199,698 at that time included in figures for the PCW category reported no earnings (Answers to Questions on Notice SQ19-000048).

Rate of NSA³

Despite an active campaign to increase the rate of NSA (Business Council of Australia, 2019; KPMG, 2016a; Raise the Rate, 2019; Share the Pie Project, 2017-2018) which has fallen behind incomes in the broader community (Arthur, 2019), and a current Federal Government Inquiry into the adequacy of NSA and other related payments which is due to report in March 2020, the current rate of NSA as at February 2020 is \$599.00 per fortnight for a single person over 22 with no children (Australian Government, 2019). By comparison, the maximum basic rate for the DSP for a single person is \$850.40 per fortnight (Australian Government Services Australia,

³ NSA is due to be replaced by the JobSeeker Payment from March 20, 2020 which will be the main working age payment and will consolidate seven existing payments including, NSA (Australian Government Department of Social Services, 2019).

2019d). NSA has not been increased since the Labor Keating Government in 1994 (Arthur, 2019).

The payment rate of NSA is tied to the Consumer Price Index. Unlike rates for the DSP and the Age Pension which is linked to the full-time average weekly earnings of male workers (Morris & Wilson, 2014). Recipients of the DSP are able to access comprehensive supplementary assistance and concessions and more relaxed income and assets tests. The DSP also has higher taper rates (Morris, Wilson & Soldatic, 2015). Basing NSA on the Consumer Price Index does not take into consideration increased costs of living (Arthur, 2019).

The NDIS

The NDIS emerged as a 'big idea' from the former Labor Prime Minister Kevin Rudd's 2020 Summit in 2008 (Bonyhady, 2009; Soldatic & Pini, 2012) which was followed by an investigation by the Productivity Commission (2011) into the feasibility of a long-term care and support scheme for people with disability and a campaign, 'Every Australian Counts', for national disability insurance (National Disability and Carer Alliance, 2018). It sought to address problems identified with the previous disability care and support system in Australia (Buckmaster & Tomaras, 2013) which was described by the Productivity Commission (2011, p. 2) as "underfunded, unfair, fragmented and inefficient". Legislated in 2013 through the *National Disability Insurance Scheme Act 2013* (Cth), it provides a person-centred, self-directed approach to reasonable and necessary care for people with permanent and significant disability and is underpinned by the principles of choice and control. It began with trial sites across Australia testing different aspects of the Scheme before commencing in full, nationwide in 2018. The NDIS includes several tiers consistent with the Productivity Commission (2011) design; two of which were included in this research (Tier 2 and Tier 3). Tier 3 includes individualised funding packages for those with permanent and significant disability designed to provide disability supports. Tier 2 provides ILC to those with disability eligible and ineligible for individualised funding packages. Until recently there has been little focus on this tier. However, it has four focus areas: Information, linkages and referrals; Capacity building for mainstream services; Community awareness and capacity building and Individual capacity building (NDIA, 2019). From 2019, the NDIA began to implement programs outlined in the investment strategy (NDIA, 2019) by holding grant application rounds for each of the program areas. For example, in 2019 organisations could submit proposals for programs which would improve the economic and social participation of people with disability (Australian Government, 2020).

3. What is already known?

There is very little existing scholarly literature which examines the experience of people with disability living on NSA in Western Sydney, their experience with applying for the DSP and the experiences of Culturally and Linguistically Diverse (CaLD)/ NES backgrounds peoples with disability. Nevertheless, several scholars have explored the experience of living on NSA generally (for example, Morris & Wilson, 2014), and for sole parents (for example, Holdsworth, 2017; Jovanovski & Cook, 2019; McKenzie, McHugh & McKay, 2016), people with disability (for example, Harris et al., 2014; Humpage, 2007; Morris, Wilson & Soldatic, 2015) and Aboriginal and

Torres Strait Islander peoples with disability (for example, Fitts & Soldatic, 2018; Soldatic & Fitts, 2019). These sources consistently found that the payment rate of NSA is inadequate to afford basic needs (for example, Jovanovski & Cook, 2019; Saunders & Bedford, 2017), that employment services do not effectively support people into employment, that the application process for the DSP is problematic (for example, Fitts & Soldatic, 2018) and that the structure of the income support system for people who are underemployed or unemployed has significant impacts on peoples' health and wellbeing (for example, Darab & Hartman, 2011; Soldatic, 2018b). Additionally, Soldatic (2018a, 2018b & 2019) has found that the reforms to DSP eligibility have had a racialised effect particularly for Aboriginal and Torres Strait Islander peoples with disability.

Furthermore, answers to questions on notice can provide some insights on people with a PCW generally. Therefore, although **more data is required on the PCW category, particularly about people with disability on NSA**, answers to questions on notice indicate that as at June 28, 2019 most people with a PCW live in New South Wales (NSW) (approximately 31%) and the highest first recorded medical condition is a psychological/ psychiatric (approximately 42%) impairment followed by a musculo/skeletal and connective tissue (approximately 31%) condition (Answer to question on notice no. 867).

In addition to the lack of quantitative data in general, information on the experience of people with a PCW in Western Sydney and the experience of people from CaLD/ NES backgrounds with disability on NSA, there is a lacuna of studies which examine how the NDIS can intersect with unemployment policy to govern people's lives, and indeed little evidence which acknowledges that people with disability on NSA could also be NDIS participants. This research also contributes to filling this gap.

As such, this research not only is significant because of its contribution to policy and existing debates about NSA and the NDIS but it also contributes to an under researched and under theorised area in academia and social policy.

4. Method: How was the research conducted?

Research began in June 2019 and concluded in December 2019. Ethics approval was granted by The University of Notre Dame Australia's Human Research Ethics Committee and the project was funded by the Whitlam Institute within Western Sydney University with an in-kind contribution from The University of Notre Dame Australia. There were three key phases to this research which occurred simultaneously. Each phase sought to inform different aspects of the research and will be detailed below.

Phase 1: Whitlam's legacy

In order to understand Whitlam's disability social policy legacy, an analysis of key documents from the Whitlam Institute's Prime Ministerial Collection was conducted. As 'disability social policy legacy' was conceptualised to include documents and sites of interest which would be relevant to the contemporary notion and experience of people with a PCW on NSA, there were several actions, programs and initiatives of Whitlam and

the Whitlam government which informed the search terms for this section. This section included an analysis of documents associated with the National Accident Compensation Scheme, the increase to the Invalid Pension and Unemployment Benefit, the enacting of the UN ICESCR, the establishment and actions of the National Welfare Reform Commission and the continuation of the Liberal McMahon Government's Inquiry into Poverty. This analysis was supported by supplementary sources on Whitlam and the Whitlam government and a semi-structured interview with a key member of the Department of Prime Minister and Cabinet during Whitlam's leadership who was asked about Whitlam's policies and values and their relevance for a contemporary context.

Phase 2: The NDIS

To understand the NDIS and to determine whether people with a PCW on NSA would be eligible for disability supports, a policy analysis of relevant documents was undertaken. This included an analysis of the *NDIS Act 2013 (Cth)*. With regards to the ILC tier, key documents were analysed such as, the ILC Policy, the ILC Commissioning Framework, the PB ILC Outcomes Framework, Program Guidelines (2019-20-20 – 2021-22), Strengthening the ILC: A National Strategy towards 2022, the grant opportunity guidelines for each ILC grant round and the Development (CICD) Program – Implementing ILC.

To triangulate the findings of the policy analysis and add a deeper understanding, semi-structured in-depth interviews were conducted with experts on the NDIS. In total three interviews were conducted. Interviews averaged an hour. Participants were asked about how the NDIS operates and whether it would be likely that people with a PCW would be eligible for disability supports or support via the ILC. One participant in this phase straddled this phase and phase 3 in that he was able to give insights into the changes happening to the former services which provided ILC in NSW as an employee of such services. Yet, it was these very changes that resulted in concerns about his job security going forward, meaning that he anticipated losing his job, having to apply for NSA and being assessed with a PCW. Most participants in this phase reviewed the interview transcript.

Phase 3: People with a PCW on NSA

To understand the experiences of people with a PCW on NSA in Western Sydney, qualitative in-depth interviews were conducted with people with a PCW on NSA residing in Western Sydney. In total, 16 semi-structured interviews were conducted. Interviews ranged from 38 To 174 minutes and were completed at a mutually convenient location for the participants by the researcher or the research assistant. Seven of the participants required an Arabic interpreter. There were five males and 11 females and half of the participants were over 50. Participants had a combination of impairments such as anxiety, severe depression and schizophrenia, and physical impairments and injuries such as back injuries and heart conditions. One participant was in a wheelchair from having polio as a child and one participant had an intellectual disability. Many of the participants had comorbidities. For some, the implications of their physical impairments had psychological impacts, for example one participant said: "Yeah but the weight loss, the loss of appetite, the emphysema, the asthma, going to the toilet, passing urine and it's always full of blood, it's mind damaging" (Male, 53, Physical and mental impairment, cancer and other conditions). Most

of the participants had applied for the DSP and had been rejected, some on multiple occasions. Participants were asked about their experience on NSA, meeting their obligations, whether they knew of or were accessing the NDIS and how their impairment/s shaped their everyday life. Participants were provided with a \$50 Coles Myer gift card to recognise their time and contribution to the research and some of the participants reviewed the interview transcripts. Interview transcripts were coded in NVivo by the research assistant who created codes around emerging themes. These codes and themes were then checked by the researcher.

Participants were recruited via third party organisations, including disability employment organisations, community organisations, local councils, NSW health members, NDIS service providers and disability/ mental health support and advocacy organisations. Social media was also used to recruit participants, including through contacting the organisers of Facebook groups and through posting the call for participants on Twitter. The low response rate given the significant attempts at recruitment could be explained by a fear held by those eligible to participate in the research and the difficulty for some to participate in the research and uphold their mutual obligations so they would receive payment. In addition, some methods of recruitment favoured those who were computer literate, engaged with community service organisations, and read English. It could be assumed that this is not the case for all people with a PCW. Furthermore, the focus on the research in Western Sydney did limit the number of people who were eligible to participate in the research, in fact, the researcher was contacted on multiple occasions by participants who were out of area. The low response rate does not detract from the significance of the findings given that the purpose of qualitative research is quality not quantity and understanding peoples' lived experiences. This approach fits with the research question. Furthermore, as this is part of a pilot project which will be extended, a small sample size is to be expected.

To complement an understanding of the lived experiences of people with a PCW on NSA a policy analysis of relevant documents was also undertaken. Building on the researcher's existing analysis of the *Employment and Workplace Relations Legislation Amendment (Welfare to Work and Other Measures) Act 2006 (Cth)*, the *Social Security and Other Legislation Amendment Act 2011 (Cth)*, and the *Family Assistance and Other Legislation Amendment Act 2011 (Cth)*, the *Social Security (Active Participation for Disability Support Pension) Determination 2014 (Cth)* was also analysed as well as other documents.

5. Findings, discussion and recommendations

The research found that people with a PCW have trouble with applying for the DSP. On NSA they live in poverty and are unable to afford basic items, medication, doctors appointments, aids and equipment or meet their expenses as 'jobseekers'. They felt unsupported on NSA and felt that their mutual obligations were unrealistic. For many their impairment/s were exacerbated, or a second impairment was acquired while living on NSA. For people from CALD/ NESB with disability they experienced additional barriers and difficulties.

In relation to the NDIS eligibility, all participants except one did not have an individualised funding package and it would be unlikely that many would qualify for one under the NDIS disability eligibility requirements. Despite this, it was likely that they would receive supports under the ILC. However, no one has yet. Furthermore, because this tier is still being implemented it is unclear what these supports would be, how they would support people with a PCW and how they operate alongside mutual obligations.

This section begins by exploring the experience of participants on NSA which can be divided into two sections. The first is regarding problems that participants identified with applying for the DSP. The second relates to their experience on NSA. Following this, the experience of people with a PCW with the NDIS is explored as well as how the NDIS could support people with a PCW. Finally, this section summarises Whitlam's legacy with regards to disability and social security policy. Throughout this section, there are a series of corresponding recommendations which follow the explanation of the main findings and discussion for each subsection.

APPLYING FOR THE DSP

Participants raised problems with the eligibility criteria for the DSP. One participant raised problems with the expectation that those applying for the DSP should be diagnosed, treated and stabilised. She argued that this relies on engaging with medical treatment. She describes:

I think that's hard because – not that a person chooses to be unwell ... It's more to do with the nature of what condition you have and how that impacts on you being able to keep appointments. I've had a lot of trouble leaving the house ... I've had doctors actually tell me that I was pretty much wasting their time because the way I talked, or because I was just so restless or irritable that impacted on how I engaged with them. They were not really aware that I was unwell, and that I wasn't able to express or say that hey I'm unwell and I need help ... all those experiences just accumulate and then it's easier just not to go. (Female, 33, Schizophrenia).

While not in relation to the same criteria, sentiments made about how disability is assessed are echoed by another participant who spoke about the process of when he applied for the DSP. He explained how eight weeks after lodging his application he received a phone call where he was assessed over the phone. They asked about one of his conditions and he was dishonest, explaining to the interviewer how he did not want to sound desperate on the phone. Speaking to the interviewer he said:

I didn't want to tell how bad it was. I said I'm coping, but I wasn't coping.

He explained how he wanted to be assessed in person, not over the phone. While the Services Australia website states that assessments are usually in person, in some cases they are conducted over the phone (Australian Government Services Australia, 2019e). His application for the DSP was rejected because he did not meet the points criteria (20 points or more in one impairment table) and he did not appeal this decision. He stated:

I wanted to go back and say to her, look, my NF [neurofibromatosis] is worse than what I told you, but I

didn't. (Male, physical and mental impairment, cancer and other conditions)

There were also problems raised with the eligibility rules tied to the impairment tables. Specifically, the need to have impairment measured as 20 points or more in one table to move to the work hours assessment and bypass the POS requirements. The need to have 20 points or more in one impairment table was found to disregard the experience of those with co-morbidities whose impairments may significantly impact their lives.

Recommendation 1: The diagnosed, treated and stabilised part of the eligibility criteria for DSP must be revised.

Recommendation 2: The emphasis on 20 points or more in one impairment table needs to be revised so that people with 20 points across multiple impairment tables can access the DSP without having to complete the POS requirements.

Participants also raised concerns about the medical evidence requirements for DSP applications. As part of the reforms to the eligibility criteria for the DSP instead of applicant's treating doctors supplying medical reports, government-contracted doctors are used "to review 'raw' medical information" (Fitts & Soldatic, 2018). Treating doctors are also now expected to provide medico-legal letters which document how an impairment affects an individual's functional capacity and details all impairments including modes of treatment as opposed to completing a standard government approved form. According to Fitts and Soldatic (2018) this shift in the role and responsibilities of the applicant's treating doctor in the DSP application process, and the type of evidence that they are now expected to provide acts as a barrier to successfully awarding applicants with the DSP. This is because the medical evidence does not always consider functional capacity and doctors are not trained in the type of language required in supporting letters. Furthermore, this process is cumbersome for treating doctors and unclear particularly given that the criteria lacks clarity and the impairment tables regularly change to include or exclude certain impairments (Fitts & Soldatic, 2018). In this context, participants were cognisant of the need to have the 'right' medical assessment, paperwork and diagnosis to strengthen their DSP application and recognised that different types of medical evidence were assessed and valued differently by medical assessors. Yet they found this process confusing and fraught with contradictions including discrepancies between the reports of treating doctors and the assessments made by assessing medical professionals. This can be seen in the extracts below.

Even for myself, even though I identify with intellectual disability in that brain injury, I might not be eligible for a disability pension at this stage. It all comes down to the right type of specialist you see and the reports that are made on you and how that assessment is made with the information that they accept. (Male, 42, Intellectual disability and depression)

This is where the anxiety and everything comes up. Because even though my - clinical departments I guess the psychiatrists or whatever in their field say, yes this is

this. It's not that my psychiatrist has said you can work 20 hours. It's my GP who came up with that - well 15 hours while with my clinical people are saying, you're lucky to even get three hours in a week at this stage. (Female, 46, Depression)

Whatever you have in your hand, the report that you have in your hand, if he says you have 10 points and the other doctor, their doctor, said he have [sic] just 5 points, they don't care about this. This is nothing. They only care about what they say. (Female, 51, Depression, knee replacement, back condition)

Fitts and Soldatic (2018) note that the lack of detail in DSP outcome rejection letters also makes it difficult for participants and treating doctors to determine what needs to be done to improve the application so that it can be granted or to support applicants. While none of the participants in this research explicitly raised this, it contributes to their ambiguity around the application and rejection process.

The medical evidence requirements were also particularly difficult for participants from CaLD/ NES backgrounds. For some participants they were unable to access a medical history. Furthermore, Ibrahim and Ismail (2018) suggest that medical assessment tools can be culturally biased in their research on Muslims with disabilities and psychosocial reforms from an Islamic perspective. They stress the need to develop culturally sensitive assessment instruments.

Recommendation 3: A review of the medical evidence procedures for the DSP should be conducted to determine what will best serve people with disability and people from CaLD/ NES backgrounds with disability.

Recommendation 4: Clear reasons for rejecting DSP applicants need to be detailed including how applications can be improved and support services for those unlikely to qualify.

BEING ON NSA

Participants were either already on NSA while waiting for their DSP application to be processed or were not eligible for the DSP and so applied for NSA. On NSA they have to meet mutual obligation requirements. Many participants detailed problems with meeting these requirements and some had medical exemptions from them.

Medical exemptions

Many of the study participants were currently or had been medically exempt from some of their responsibilities as NSA recipients. For some they had been medically exempt from their mutual obligations for extended periods of time or on multiple occasions. Yet some were frustrated by the rules to seek a medical exemption, with a couple explaining that there was a limit to the amount of times they could write the same reason as their justification for seeking a medical exemption. This is consistent with the findings of Fitts and Soldatic (2018) and can be seen in the example below.

Well because it's got the same thing written on it three times in a row [I am unlikely to be eligible for a medical

exemption]. I said [to my employment service provider] so if my doctor is writing down the truth, chronic pain due to a workplace incident injury, has had physio, hydro - I've been through it all, now I'm on medications to control the pain. So now you want me to write down that I've had a leg amputated and I can't work because I'm dyslexic as well, you want me to lie in other words. She said well no, I don't want you to do that. Well you're telling me you can't accept it, I'm saying to you I can't write anything on it other than the truth so what do you want? She said well the point is once you give us the same one three in a row, we're now going to put you on Newstart [with obligations]. (Male, 50+, Lower back injury)

Medical exemptions are an important way for people with disability who receive NSA to get some relief from their obligations and tend to their medical needs. Yet if someone had a medical exemption from their job search obligations and their POS requirements then the time in which they are exempt does not count towards the required 18 months in a POS. This is required for DSP eligibility. Furthermore, denying a medical exemption overrides the expertise and knowledge of the treating medical professional who has decided that their patient is unfit for work (Fitts & Soldatic, 2018). This situation has resulted in NSA recipients, at least in the case of Fitts and Soldatic's (2018) research, failing to report their inability to meet their NSA requirements because of their medical condition to their treating medical professional which could undermine the need for medical professionals to provide a detailed record of how impairment impacts on functional capacity for DSP applications.

Recommendation 5: The POS requirements need to be revised to consider any time spent exempt from the POS due to a medical exemption.

Recommendation 6: The reasons for the medical exemption rules must be reviewed and potentially revised to reflect the likelihood that people with disability may require medical exemption due to their impairment/s on multiple occasions.

These recommendations should be implemented by striking the right balance between the need for a medical exemption and meeting the objectives of the mutual obligation – assistance with seeking participation in the labour market.

Discrimination in employment and inaccessible communities

Most participants without medical exemptions had to search for and apply for a certain number of jobs or hours per fortnight as part of their mutual obligations. Many of the participants referred to the possibility of prospective employers discriminating against them because of their disability or had experienced discrimination. For these participants it added a layer of confusion about how they were expected to find and maintain employment. As Harris et al (2014) note while there has been structural reform to the social security system in Australia, this has not addressed problems with disability discrimination in employment. Disability discrimination in employment is well-documented. For example, according to the

Australian Human Rights Commission's 'Willing to Work' report "[i]n 2014-15 the average proportion of disability discrimination complaints related to employment across all jurisdictions was 40.4%" (2016, p. 16). Additionally, in Australia people with disability are less likely to be employed (48%) than those without disability (79%) (Australian Institute of Health and Welfare, 2019). Experiences of and fear of discrimination was embedded in the responses of interviewees. For example:

... they found me a job. But because of my back, they wouldn't take me for the insurance. (Female, 52, Back injury and depression)

But it's hard. You go to an employer. If you disclose I've got stomach cancer, emphysema, kidney disease, they're not going to give you a job. If you don't tell them and then they find out, they'll – most likely ... terminate you ... because you're a liability ... it just doesn't add up to me. (Male, 53, Physical and mental impairment, cancer and other conditions)

It is worth noting that participants did not simply describe concerns of disability discrimination. For example, participants with workers compensation claims were concerned about the implications of disclosing this. Some were concerned about their medication impacting on their chances of employers hiring them, such as taking opioids. There were also concerns about age discrimination. For example, "plus the fact I'm 58" or "But once they see that we're older you don't get a look" and "Forty years old, no way. You're too old". Concerns about discrimination based on age are supported by the findings of the Australian Human Rights Commission report 'Willing to Work' (2016) and also of Hutton, Bohle, McNamara and Li who found that "older workers with a disability face multiple disadvantages when seeking employment" (2014, p. 1). Concerns about the intersection of race and disability discrimination in employment were also raised by those participants with disability from CaLD/NES backgrounds who noted language barriers to employment. The National Disability Ethnic Alliance (NEDA) (2014) has recommended change to employers' attitudes towards people from CaLD/ NES backgrounds with disability.

More broadly, scholars have drawn attention to physical barriers which impede access for people with disability such as inaccessible public transport and buildings. These barriers could also impede people with disability from meeting their mutual obligation requirements (Harris et al, 2014). Harris et al (2014) suggest that "The disconnect between mandated responsibility to participate in the labor market without supporting accommodations and equality, compromise[...s] the implementation of the reform policies. Individuals could not act on responsibilities in the labor market without the government taking concurrent steps to address discrimination, access, and

Recommendation 7: The system needs to recognise how disability discrimination in employment could be experienced by people with disability and shape their access to employment opportunities and outcomes. Furthermore, the system should recognise how disability discrimination can intersect with other forms of discrimination such as age and race to shape access to employment opportunities and outcomes.

The structure of employment

Furthermore, one participant alluded to the fact that the employment system is not designed to accommodate people with multiple health conditions which regularly require medical treatment and require them to attend appointments. This can be seen below.

Because if I was to go to work in - with all these illnesses and say my kidney disease got bad and I needed to go into hospital, how long will I last before I get fired? Then I'm going to have to apply for Newstart again, wait four or five weeks ... Not many employees [sic] are going to be lenient. It's not like I've only got one thing wrong. I've got half a dozen ... sometimes I could be seeing two, three doctors in a fortnight and who's going to give you time off to go see two or three different doctors a fortnight? (Male, 53, Physical and mental impairment, cancer and other conditions)

In circumstances such as those described above, if people with a PCW are expected to participate in the labour market then the structure and expectations of employers and employment needs to change and take into consideration the fact that some people may require considerable and/or unplanned time off due to appointments. Currently, the expectations assume a flexible employer who can appreciate that workdays or schedules may change to accommodate medical appointments or urgent treatment. Such considerations would also be valuable to people with episodic conditions.

Recommendation 8: No waiting/ processing period for those who may relapse and require income support.

Recommendation 9: Supported employment where employers appreciate that people with disability may require time off for multiple appointments or may relapse and require urgent, unplanned medical attention.

Inadequate support

Many of the participants recognised that the employment requirements of finding and searching for a certain amount of jobs or hours per fortnight to meet a certain capacity does not result in successful employment outcomes, particularly without adequate support. Many alluded to the fact that the obligations appeared to be 'busy work' for the sake of being busy but without any tangible productive outcomes. Morris and Wilson (2014) found this also and Harris et al (2014) suggest that without adequate support and wider labour market considerations it is unlikely that individualised tasks will result in employment for people with disability. This is despite the fact that the policy assumes that such obligations will improve recipients job chances (Morris & Wilson, 2014). An example of participants' opinions on the tasks can be seen below.

Interviewer: ... were those courses to get you to employment?

Participant: They were a joke. Sitting in a classroom just playing around with a computer, just filling in time. That's all it was ... How to write resumes. I've got excellent resumes.

(Male, 53, Physical and mental impairment, cancer and other conditions)

... where you turn up and they have a computer thing – age, name, have you looked for this, what are you interested [in] you know ... It didn't seem like they were really willing or able to assist me. (Female, 46, Depression)

Furthermore, one participant, was aware of the lack of employment opportunities in Australia and the challenge to 'traditional' employment posed by technology. He suggested that the government, particularly in the last ten years has lost touch with reality. Others argued that if young people or those with skills were finding it difficult to find employment then it was unlikely that they would be successful.

Therefore, people with disability need to be adequately supported into employment. While it could be argued that this is achieved through or the role of employment service providers, participants generally suggested that they were not adequately supported by their employment service provider (more below).

Recommendation 10: People with disability need to be adequately supported into employment.

Recommendation 11: Consult with people with disability to inform the best ways to support them into employment.

Recommendation 12: Provide opportunities which are likely to result in meaningful employment or effective outcomes (not simply 'busy work').

Recommendation 13: Job creation and investment by the government and large public and private entities.

In general, participants found that Centrelink did not support them. This was directly expressed by some participants.

I struggle with Centrelink sometimes because you tell them you need support, but I think because they're always asked, there's not anybody that you can be referred to that can take the time to sit with you and go through what it is you may need. Most of it's generalised ... I struggle with my reading and writing, I need that one to one communication (Male, 42, Intellectual disability and depression)

Generally, this gap was filled by others, but this was not always possible for some participants because they had no one to support them. For those that did have others to support them, support was usually provided by a family member or a different service provider. For example, one participant when asked does he ever apply for jobs by himself replied that his daughter would sit with him at the computer and help when his employment agency was unable to search for him. Others had their children report for them or organisations which helped them. For example, one

participant mentioned that Flourish Australia would send a worker to go with her to her appointments with Centrelink and another mentioned that someone from the Housing and Accommodation Support Initiative or a community health worker has gone with her to Centrelink. The participant who was eligible for an individualised funding package under the NDIS qualified for a support worker. Her support worker would often help her to complete her reporting requirements for Centrelink because she does not know how to use a computer and take her to appointments. However, her support worker acknowledged that this was not part of her role. The types of tasks required to remain eligible for income support individualise the problem of unemployment in that the individual and their drive, motivation and dedication to finding employment is framed as a problem, rather than the broader structure. Yet, individualised and personalised support is not provided to adequately support people. It must be questioned the extent to which the government is upholding their obligations to recipients and to what extent this is a 'mutual' exchange.

Recommendation 14: Adequate support as determined by their individual needs should be provided to people with disability accessing the income support system.

Employment service providers are responsible for assisting people with disability on Newstart into employment. People with disability on Newstart can access either JobActive service providers or DES for this assistance. While some had positive experiences with their employment service providers, others argued that they received little support or the jobs they were expected to take did not consider their capacities.

For those who spoke of positive and supportive experiences, they spoke of a service which was understanding and lenient. One participant spoke of how her case worker helped her to find a job. A job which understood her needs and ensured she would be looked after by her employers. Her case worker at the DES used her community links to set up a position for the client and knew that in doing this the client would be looked after and supported.

Yet many of the participants spoke of negative experiences with employment service providers. The problem with employment service providers in general and for people with disability specifically is well documented in existing literature. For example, while DES does achieve some outcomes for people with a PCW (see DEEWR et al., 2012, pp. 82-83), DES has been described as inadequate for finding long-term, meaningful employment for people with disability (Taleporos, 2014) and is criticised for "undermin[...ing] and dismiss[...ing] human potential" (Soldatic, 2009, p. 6). While DES is represented as assisting people with disability to reach their potential and capacities through employment, DES does not address the deprivation and economic and social exclusion which people with disability experience (Soldatic, 2009). Furthermore, People with Disability Australia (PWDA) have suggested that "DES focus on getting people with disability into jobs, not ensuring that those jobs are retained" (2013a, p. 2). Reports such as these are concerning for people with disability on NSA given that employment service providers are meant to support people into employment, and the fact that should a participant fail to attend an appointment

with their job service provider or refuse a reasonable offer of employment they could have their payments stopped. Additionally, research shows that the longer someone is unemployed the more difficult it is for them to be employed for various reasons (Morris & Wilson, 2014). Participants commented:

So I had to join up with a disability job provider ... They didn't do much for me with help. You had to attend because if you don't attend they give you a letter threatening ... we're not going to pay you. (Female, 46, Depression).

One participant was particularly aware of the outcomes based, privatized approach to employment services suggesting that organisations are simply going through the processes. Another noted that they did not receive much help because their employment service provider had too many clients. Like other scholars have noted, the design of the system impacts on the supports organisations are able to provide (Harris et al., 2014). For example, Morris, Wilson & Soldatic (2015) detail reforms to the funding of employment services where they became 'time limited' and outcome focused. Designed in such a way 'creaming' was encouraged where employment service providers placed the most able-bodied of clients with disability into jobs. The structure of the system including how contracts were issued and payment to providers made makes it difficult for employment service providers to genuinely support people with disability. One service provider was trying to organise petrol cards for their client which they had to justify to their manager. This made it difficult to support the needs of their clients which were beyond simply finding them a job. Concerns with the design of the employment service system have also been raised and experiences of 'creaming' and a lack of individualised support have been noted (Harris et al., 2014; Thomas, 2019); hence why there was an investigation into employment services by an Employment Services Expert Advisory Panel (2018) who made a number of important recommendations in relation to personalising support and reducing the workloads of employment service providers so that they could better support those accessing their services.

Yet employment support services also need to be culturally competent. It was clear from the interviews that job service providers achieved outcomes for people with disability from CaLD/ NES backgrounds when they understood peoples' culture because it meant that this was considered when placing or suggesting jobs for participants and when understanding why someone had been unable to uphold their obligations. Furthermore, employment outcomes were favourable when overseas qualifications, training or positions were taken into consideration. In discussions with the manager of a DES agency she described that it was crucial that she understood how people's culture shapes their lives. She gave the example of a client with a physical disability who had come from the Middle East and had worked as a journalist, explaining that it was crucial that she find a job which would allow him to connect to the Arabic community and maintain his status as a professional. She contacted her networks in the community and got him a job writing a small column in an Arabic paper. His role has now expanded. This had a positive impact on his self-confidence. NEDA (2014) also emphasises how important it is to take into consideration peoples' prior employment experiences, skillsets and qualifications. They found that with young migrants with disabilities, unemployment or gaining a position in Australia less skilled than their previous position impacted on their

mental health. Young migrants with disabilities would arrive in Australia with high expectations for their career. Long-term unemployment often leads to depression and suicidal ideation. Being aware of how culture shapes peoples' interactions with employment service providers is thus crucial to avoid intercultural gaps which can result in poor outcomes.

In addition, understanding how culture intersects with gender in this context is important. Ibrahim and Ismail (2018) describe how gender roles and expectations shape how willing and able people are to engage in educational opportunities and employment. For some participants their role in their family and society was as a caregiver, rather than as an employee. For others their role was as a 'breadwinner'. In both cases the expectation to find employment was difficult. For caregivers they felt that this expectation meant that they either could not adequately fulfil their role as caregiver, or they were restricted in terms of what jobs they could take because of their responsibility to their families. In some of these cases, these were families with multiple children or with complex family circumstances. For example, two young children from a Syrian refugee family exhibited symptoms of post-traumatic stress disorder, and for another woman her son and caregiver had been diagnosed with cancer. In addition, many caregivers had no previous employment history which meant that the types of skills they had were limited. Alternatively, for one participant the pressure from his role as 'breadwinner' was crippling and impacted on his heart condition and depression. He experienced pressure from the system to find employment and pressure to support his young family by the community.

The NEDA found that there are a "limited number of specialist DES providers who have expertise in working with people from CaLD and/or NESB communities with disability" (2014, p. 8). Hence, they recommended that the government investigate the effectiveness of generalist DES providers for achieving employment outcomes for CaLD/ NES backgrounds people with disability. They also suggested an investment in cultural sensitivity training.

Recommendation 15: The job service provider system needs to be redesigned, particularly to consider the needs of people with disability on NSA and people from CaLD/ NES backgrounds with disability.

Recommendation 16: Adequate, individualised and personalised support should be provided through the employment service system.

Recommendation 17: Employment service providers should be supported to support people with disability into employment even if this means attending to needs not directly related to employment outcomes.

The rate of NSA

As already extensively documented for several years by the media, scholars (Morris & Wilson, 2014), welfare and disability advocacy organisations, government inquiries (Education, Employment and Workplace Relations References Committee, 2012), and as currently being investigated by the Senate Inquiry into the Adequacy of Newstart Allowance, the rate

of NSA is inadequate. NSA has been extensively criticised by those on the left and right for being too low (Morris, Wilson & Soldatic, 2015). The OECD has also criticised the rate of NSA with it being one of the lowest unemployment payments in the developed world (Henriques-Gomez, 2019a). Furthermore, accountancy firm KPMG have suggested that the rate of payment is 'damaging' with people unable to meet their material needs (Henriques-Gomez, 2019b).

Participants found NSA insufficient to meet their needs. One participant suggested that this was one of the reasons she was applying for the DSP because of difference in the rate of pay. This difference in payment rates and how they are determined was highlighted as a problem in the report by the Reference Group on Welfare Reform to the Minister for Social Services (DSS, 2015). As part of the argument to simplify the income support system which was argued to "not provide clear rewards for work" the Reference Group suggested that the fact that "[p]eople with similar basic living costs and similar capacities to work may receive very different levels of financial support, and have different participation requirements [...] could] significantly reduce the effectiveness of the system and lead to incentives for people to try and qualify for higher income support payments" (DSS, 2015, p. 10).

Participants in this study spoke of financial stress on NSA. For example, they were unable to meet their costs of living including, rent, house repayments and strata fees. As such, one participant had his house repossessed. Morris and Wilson (2014) similarly found that for people living on NSA they were unable to afford satisfactory accommodation which meant people were living in inadequate or unsafe accommodation. This had mental and physical impacts on their health.

Additionally, participants could not afford basics such as food, toilet paper, sanitary products and baby formula as well as 'luxuries' such as tutoring for their children, money to go for coffee or lunches with friends and food and drinks for visitors. This is consistent with existing data which reports on the inadequate rate of payment (Morris & Wilson, 2014).

This impacts on the physical and mental health of participants because people are unable to meet the requirements of a healthy diet leading to poor health such as, Type II Diabetes, high blood pressure, anemia and dental problems (Morris & Wilson, 2014), and people are unable to afford to socialise and 'host' friends and family. The ability to socially interact is important for mental health and being socially included and connected. Furthermore, the feeling of not fitting in or able to participate in the same ways as others, that is, experiencing social deprivation becomes internalised, reinforces inequality and could lead to stigmatisation (Gardner, 2017).

In addition, many had concerns about the increasing cost of living such as increasing gas and electricity prices. This impacted on their ability to cool and heat their homes which had an impact on their health. For a participant in Morris & Wilson's (2014) research for example, while living on NSA he had his electricity cut off. With no heating he caught pneumonia which led to a virus which caused a bone to collapse under his eye. He now requires surgery which he cannot afford.

Furthermore, and as others have recounted (Morris & Wilson, 2014), people on NSA do not have enough money for unexpected costs. For example, one participant was worried

because the house she rents is for sale and she will need to move. She did not have the money to cover the cost of a removalist or the bond in a new place.

For one participant with depression, her debts have become exacerbated while on NSA as she does not have the money to pay them. She is also accruing more (for example, through tolls) and does not have the energy to engage with the people that she owes money to. As such, she is getting a bad credit rating. One of the debts she has accrued is because of a course she attempted to complete when she felt she could no longer look and apply for work as part of her role as a 'job seeker'. Her anxiety and depression prevented her from completing the course. Furthermore, because of her ongoing situation, she is also at the point where she is exhausted from asking family and friends for help.

Expectations central to their role as 'job seekers' were also expenses which they had to account for or were concerned that they would be unable to afford. For example one participant said, "you've got to have a mobile phone so that people can contact you if you've got a job ... Plus the internet at home" (Female, 52, Back injury and depression). Morris and Wilson also found that "the low payment made finding employment a lot more challenging" (2014, p. 202) and in fact contributed to 'scarring' for people on NSA. 'Scarring' refers to "the relative loss of income and employment access caused by unemployment, and in sociological terms, scarring involves wider losses of social esteem and networks" (Morris & Wilson, 2014, p. 203). 'Scarring' can limit work return (Morris, Wilson & Soldatic, 2015). For their participants for example, "[i]nsufficient income contributed to stress, and it added to circumstances which interviewees struggled to maintain their confidence in a job interview" (Morris & Wilson, 2014, p. 216). Morris, Wilson and Soldatic (2015) argue that people with disability on NSA are more likely to experience 'scarring' because they receive payment for extended periods of time. KPMG Chief Economist Brendan Rynne has also made the link between the low payment rate and employment arguing that "The low level of Newstart is actually forming a barrier to employment, as it is insufficient to allow unemployed people to actively conduct job search" (KPMG, 2016b).

Two participants also commented on societal expectations for women and their inability to meet these standards on NSA. They wondered how it would impact on their job prospects.

I've had grey hair since I was in my 20s. I need to dye it all the time ... I'll do it myself. But there's still that cost ... if women have grey hair, you kind of get overlooked. So I mean you've just got to have money there to look good to have good mental health to be able to go and get a job ... because people take one look at them, at the way they dress, that their hair might not be as clean as it needs to be because you can't buy shampoo.

Especially a lady. She's going to have make up of some sort. So where does that come from? (Female, 52, Back injury and depression)

Interviewees in Morris and Wilson's (2014) study similarly worried about their ability to be presentable at job interviews. The low rate of NSA does not seem then to encourage labour market search and participation, rather harms those receiving it, reduces them to a position in poverty and reinforces their inequality.

Recommendation 18: Increase the rate of NSA.

Recommendation 19: Recognise and mitigate the costs of being a 'job seeker'.

"Unemployed people are more likely to be in poor health" (Morris & Wilson, 2014, p. 213) and Morris and Wilson also found that the "lack of disposable income had severe health implications" for people on NSA (2014, p. 202). This is compounded for people with disability on NSA. For many of the participants the low rate of NSA meant that they could not afford medication, to attend medical appointments or hire or buy necessary specialist equipment. For one participant, she could not afford the recommended operation for her back pain which made her immobile, so a doctor did a temporary procedure in 2005. She is still living with the temporary solution because she cannot afford to be in a private health fund. For another participant it was recommended that she purchase a face mask for \$2000 to improve her sleep and breathing because she is unable to breathe at night. Although she hired one for two months at \$150 per fortnight which helped her, she had to return it because she could no longer afford to hire it. Being unable to afford appointments, treatment, medication, aids and equipment is also clear from the quotes below and is documented in other studies (Fitts & Soldatic, 2018).

That's another thing because with medication now I'm taking so many things that I can't afford all of it. So I just basically rely on just getting my medication for my depression. That's all I'm getting now. (Female, 46, Depression)

If I have to go to a specialist and his fees would be \$250 I can't afford that, number one, and number two, even if I can there is a follow-up visit or the time that I have to see him and that's more payment. For example, I had an issue with my ear. I went once; I paid the \$250; however, it didn't go anywhere and I'm still in pain because I can't afford to go again.

... I get 600 per fortnight. If I end up going to specialist I'll have to live on no food all fortnight. They didn't accept the family doctor's - the GP reports. (Female, 50+, High blood pressure, depression, anxiety back and neck injury)

Many participants found that the number of visits covered by Medicare to a psychologist in a calendar year was inadequate. Linked to this, is the need to pay upfront before being reimbursed and the restrictions placed on those who do not attend scheduled appointments. One participant explained how no one told her that if she failed to turn up to three appointments with her treating psychiatrist that she would need to pay for the next appointment. She states:

I said, look the reason why I couldn't attend the appointment is because my depression is so bad I was asleep. I can't tell you the day before because it just changes. But they said, oh if you want to go see him again you've got to pay the equivalent of about \$100 or something dollars. I thought where the hell am I going to get that money? So I haven't seen him since. (Female, 46, Depression).

There are further problems with the inability of people with disability to meet their medical needs while on Newstart, particularly if they are applying for the DSP. As already mentioned, in order to be eligible for the DSP one's primary condition has to be diagnosed, treated and stabilised. Many are unable to afford the required 'treatments' to stabilise their condition. Many are also unable to afford the necessary medical documentation to support their DSP applications.

Recommendation 20: Recognise the impairment/ medical costs of people with disability on NSA.

Recommendation 21: Review the costs associated with medical documentation requirements for people with disability applying for the DSP.

An ableist system

The expectations and obligations expected of people with disability who receive NSA are not designed for people with disability. Rather, the discipline and management experienced by individuals through demerit points and penalty zones for failing to uphold their mutual obligations is underpinned by a framework of compliance and coercion, not encouragement and support. As such, the system is not underpinned by a model which understands the lived experience of people with disability.

I think if I was really unwell, the reporting system might be overwhelming because you have to log in, and then go to the reporting page. It's very simple. It is a simple process, but when you're unwell it's not a simple process. There's just so much things going on in your head. Organising yourself to do this, and then remembering things is really difficult. If you didn't report, if that triggered something to help the person rather than a punishment, that would be good. It probably does say that that person's not travelling well, that's why they didn't report. (Female, 33, Schizophrenia)

It's not as simple as ... we're not going to pay you if you don't get out of bed. For me that's threatening ... I had to rock up. I was like ugh. I turned up and I said look, I'm just not ... coping. Oh well look after yourself. That's what I'm trying to do. I'm trying to do that. But I'm getting threatened. I'm getting attacked. I'm getting pitied. I don't want to be pitied. I want to be helped. I want to be understood. I want to be seen. (Female, 46, Depression).

It is clear by the quotes above and the points made previously that the system does not consider the needs of people with disability in the way it is designed and functions. The NEDA (2014) have also noted how the need to attend appointments to avoid penalisation or payment suspension ignores the episodic nature of some disabilities and how disability can vary daily. As such, it appears that the system is designed based on an able-bodied norm. This is further echoed in sentiments made by one participant who suggested that Centrelink assumes that someone can interact with them or with a job service provider, that they can have a phone conversation, leave the house, and make a phone call. She states: "These are skillsets that people ... develop and lose when they're unwell, or when they lose that capacity" (Female, 33, Schizophrenia).

The system thus requires people with disability to discipline and manage their minds and bodies to comply with the expectations of the able-bodied system because if they do not they can become subject to discipline.

... I also have trouble understanding people. That means I might not understand the letters that I get, or I might not understand what the DES person is telling me, or I might not understand what I'm supposed to act on. That's not because I'm trying to be difficult, it's because I actually don't understand. That fluctuates, and those are the things that get in the way of dealing with Centrelink, or dealing with NDIS. (Female, 33, Schizophrenia).

Furthermore, "according to the Survey of Disability, Ageing and Carers in 2009 for people with disability aged 15-64 years seeking work, the most commonly reported main difficulty in finding work was their own ill health or disability (35%). This was followed by their lack of the necessary skills or education (13%)" (Australian Bureau of Statistics, 2012). This needs to be taken into consideration.

Recommendation 22: A review should be conducted into the system to determine how it is underpinned by ableism. This review should include the voices of people with disability.

Recommendation 23: The system should be redesigned to recognise the barriers that people with disability experience to meeting their mutual obligations as a result of their disability/impairment. When a person does not meet their obligations and are risk of losing payment this should trigger assertive outreach not punishment.

People from CaLD/ NES backgrounds experienced additional difficulties when attempting to uphold their mutual obligation requirements. Participants are required to report their job searches and fortnightly income to Centrelink. Yet participants found that the online system was in English and as such, did not know what information was required or how to complete the requirements. For one participant with a physical disability who does not speak English and is computer illiterate, she has entered her information into the form incorrectly on multiple occasions causing her payment to stop. It is unrealistic for her to report in person as a mother of four children, who does not drive and relies on her NDIS carer to take her to appointments. Her NDIS carer describes:

She's made mistakes before and they've cut her off - they've cut off her payment. I remember already twice since she's been with me. She's like I don't know what's going on, I don't know what I have to do. Then I think it got blocked I think at that time and she had renew the email address and I had to take her to Centrelink, had to see Centrelink at that time and I told her you have to do it by yourself. I can't do it for you. It was just - yes. I ended up making her a new email address and then getting into myGov account and then putting her report again. That was a big thing. I did everything for her. This is the second time it's happened. (Female, 50+, Syrian, Physical and mental disability).

For another NES background participant, who is computer illiterate she cannot apply for jobs online. As such, she walks from shop to shop in her local area asking if they will hire her. Asked has she been successful, the translator stated:

She's going there but deep down inside her, she is 100 per cent sure they're going to reject her because she doesn't have English, she doesn't have good health. So, she went there and she knows the answer already and that's what makes me angry, too, and sometimes I laugh, sometimes I cry. So, I don't know what I can do. I know what's going to happen, but I can't do anything about it. I have to do it. (Female, 51, Iraqi, Depression, knee replacement and back condition).

Recommendation 24: The system needs to recognise how disability intersects with other factors to create difficulties for those accessing income support and attempting to keep their obligations. Effective support should be provided to address these difficulties. This should be informed by consultation with people with disability.

Creation and/or exacerbation of impairment through expectations

For some participants their impairments were exacerbated by the expectations placed on them by Centrelink. This is consistent with Morris and Wilson's research where based on interview data they concluded that for people with psychiatric disability "Newstart intensified their disability" (2014, p. 214). Scholars such as Soldatic (2018b; Morris, Wilson & Soldatic, 2015) have documented how the experience of people with disability on NSA has created secondary impairments. This can be seen below in quotes from a participant.

There was one time when I did go for [a job interview]. It sounded promising ... But when the crunch came they decided to go internally. So I had another breakdown then. I couldn't cope.

... because I knew I wasn't ready for a job. I thought, well I can study instead ... When I started I couldn't - that anxiety of needing to impress to be at your best came all flooding back by 10 fold ... So when I had to give it up a few months later it once again brought me back down because I felt like a failure.

I think I made my situation worse, applying for the job or looking for jobs and trying to study when I couldn't study. (Female, 46, Depression).

What also became apparent for this participant was that she was already self-critical. In fact, her psychologist noted in a letter when she was applying for DSP that even if she was to get a job it would be difficult for her to fulfil the obligations because she is so self-critical, and yet the system reinforced and perpetuated her supposed incapacities and failures through making her apply for jobs which she did not get, and holding her to expectations which were difficult to achieve without adequate support. She said "So it's bad enough when you're already pinpointing yourself. You're a failure. You're pathetic. You shouldn't be alive. You're already doing that to yourself. [But when you have that double layer]. It's no

wonder you become even worse through it" (Female, 46, Depression).

Other participants also commented on the ways in which the system created stress or anxiety or through the expectations and obligations placed on them their impairment could become exacerbated. For example:

... so when I found out that I was suspended, I think my heart was racing and I was in a different space, a very heightened space. I didn't go into such a heightened space that I couldn't do anything, whereas people would ... to just think your world is over. (Female, 33, Schizophrenia)

... where I want to go to ask about work ... if I don't do ... they're going to stop the payment ... how can I pay the rent, how can I pay the food for the children ... so it's very stressful. (Male, 33, Heart condition, shoulder injury and depression)

For one participant it was clear how the system impacts on her existing depression and anxiety. This was not just clear when she responded to the question 'how do you imagine your life would be different without Centrelink's expectations?' but also throughout the interview. This can be seen through the various extracts below.

My anxiety and depression would be a bit less. Because you wouldn't have that pressure on your shoulders all the time.

If you don't do it [report], they can cut off your payments. I got so anxious not this last month, the month before. I forgot to do it ... now ... I've got a demerit against me ... it's just so stressful for me trying to look for work.

I've still got this big exclamation mark in big red bold where I have to report saying this demerit thing on it. So that makes my anxiety even worse.

I do it [apply for a job] all online now because I can't face it ... it's just the anxiety that comes with me actually applying [for a job].

So this was this anxiety, me trying to get out of work on time to get to the Bankstown office before it closed to report. (Female, 52, Back injury and depression).

Rather than supporting, encouraging and motivating people into employment it is clear that the system operates in a way which causes physical and mental harm to individuals with disability.

Recommendation 25: An immediate review of the system is required to determine the extent to which it creates or worsens impairment. Any practices where there is evidence to suggest this should be stopped.

The value of employment

Despite the problems with the system, many recognised the value of employment or valued the job they had. Employment was described as providing structure, therapeutic, providing necessary income for holidays and family improvement as well

as part of being 'normal', as a distraction and as an avenue for being socially included.

People with disability wanted the opportunity for meaningful employment.

I want a job that gives me some meaning ... But if you wake up because you need to do it because the government tells you ... it will come out in whatever you're suffering mentally. I have to find something that makes me want to get out of bed. (Female, 46, Depression).

This supports the existing scholarly and non-scholarly evidence which consistently acknowledges that people with disability want to work (Morris & Wilson, 2014) and that employment is important for physical and mental health, building social connections, individual welfare and economic security (Australian Human Rights Commission, 2016). The right to employment is also enshrined in various human rights instruments including the Universal Declaration of Human Rights, the ICESCR and the UN Convention on the Rights of Persons with Disabilities.

PEOPLE WITH DISABILITY ON NSA AND THE NDIS

Although many of the study participants were not accessing supports through the NDIS, it is worth exploring whether they could in theory be eligible for support. This section will begin by exploring this in relation to Tier 3. Following this, is some consideration of whether they would be eligible for Tier 2.

Tier 3

Eligibility for Tier 3 supports is dependent on whether people with disability on NSA meet the eligibility criteria. Through informal discussions with NDIS providers there was some confusion about whether people with disability on NSA would be eligible for Tier 3 supports. This was further complicated with the release of the NDIA report on employment outcomes which did not capture any current NDIS participants on NSA, just participants on DSP or in employment (Australian Federation of Disability Organisations, 2020). Despite this confusion, one of the study participants was eligible for Tier 3 supports. Through her current package she has access to a social support worker who takes her to appointments and a cleaner. She was also hoping to get access to a support worker to bathe her. This participant was confused about why she was eligible for disability supports under the NDIS and yet subject to mutual obligation requirements as a NSA recipient and not eligible for the DSP.

Another participant had tried to access the NDIS but was rejected because her medical evidence was not provided by a treating medical profession in a timely manner.

Based on the NDIS eligibility requirements it would be unlikely that other participants would qualify for the NDIS.

Tier 2

Although the ILC is currently being implemented, and it is difficult to determine who has and will access the supports provided, it is likely that most people with disability on NSA would be eligible for this tier. Yet as ILC currently operates

through awarding grants to initiatives and programs, it would depend on which organisations, initiatives and programs were awarded grants, and whether the programs funded had eligibility requirements which must be met as to whether people with a PCW would benefit. Inadvertently however, the work done through parts of the ILC could assist people with a PCW. For example, community awareness and capacity building endeavours could create improvements which could help people with a PCW to meet their mutual obligation requirements with the government and/ or find employment.

Despite this, there are no clear guidelines on how the ILC works alongside the expectations placed on people with disability with a PCW. For example, if someone with a PCW participates in a program funded through the economic and community building grants round, are they still required to meet their mutual obligation to find, search and apply for employment and could a program serve as meeting their POS requirements?

In addition, a note of caution is required on the ILC as one participant was at risk of losing his current job because his role was being replaced through the ILC and he was assessed as unable to perform in his role as it transitions into the ILC. He was interviewed during this assessment process and was concerned that he would require NSA. This case raises some serious concerns.

Recommendation 26: As the NDIS continues to be implemented, it is important that people with a PCW on NSA are recognised as potential participants for Tier 3 and Tier 2.

Recommendation 27: Assertive outreach should be used to ensure that they are able to access the supports which they require through the NDIS and are assisted with and supported to apply for the Tier 3 if eligible.

Recommendation 28: That careful consideration is given to how the income support and disability support systems intersect and govern people with disability, and how they both seek to enable social and economic participation.

WHITLAM'S LEGACY

The overarching values of the Whitlam government and Whitlam himself were equality, fairness, dignity and human rights. These general principles could begin to inform the treatment of people with disability on Newstart. In addition, examining the policy proposals of the Whitlam government including the National Accident Compensation Scheme, establishing the National Commission on Social Welfare (Social Welfare Commission), continuing the Henderson Inquiry into Poverty, increasing the Invalid Pension and the Unemployment Benefit, and enacting the ICECSR can inform how his legacy can support recommendations in this contemporary context.

Whitlam's leadership was underpinned by a policy of full employment. While there has been a shift away from this ideology contemporarily, this policy acknowledges that there is some social responsibility for unemployment. This could be translated into the current context through recognising that

many of the barriers experienced by people with disability to employment are structural and systemic. Therefore, the structural and systemic barriers to the social and economic participation of people with disability need to be acknowledged and addressed.

Whitlam also raised concerns with only providing cash payments to those receiving welfare. In a speech on Poverty in Australia delivered at the Lyceum Theatre Sydney on May 28, 1972 he stated:

If the one million poor ... are to break out of the interminable poverty cycle, it will not be by providing cash payments alone, but also by providing advice, counselling, training and retraining and services by social workers in the home, in the neighbourhood.

Recommendation 29: The structural and systemic barriers to the social and economic participation of people with disability need to be acknowledged and addressed.

Recommendation 30: Consider the inadequacy of cash payments alone and consider other ways which can genuinely support people out of poverty. This could be through a co-ordinated approach.

6. Conclusion

People with disability have difficulty applying for the DSP and meeting the eligibility requirements. They live in poverty on NSA and have their impairment exacerbated or acquire a secondary impairment while on NSA. They are also subject to obligations which are not reciprocated through providing structural reform to the employment system, society and social attitudes, and the problem of unemployment is individualised and they are required to manage and discipline their bodies and minds to comply with ableist norms. For people with disability from CaLD/ NES backgrounds it's more complicated.

Furthermore, the relationship between people with disability on NSA and the NDIS is complex and most people with a PCW in this research are yet to see any benefit from the Scheme. Nonetheless, the ILC holds potential. However, the evidence and recommendations here should be taken into consideration.

Finally, Whitlam's legacy of equality, dignity, fairness and human rights provides a valuable lens to reify the problems with the current system for people with disability on NSA and inform a way forward. This way forward should be informed by people with disability because as Joan Child (ALP) stated in the Second Reading Speech in the House of Representatives on November 27, 1974: "All too often we hear about States rights and Federal rights in this area and community needs. But nobody ever speaks much about the wants of [...] people with disability] themselves. They [...] have ideas of their own" (cited in People with Disabilities ACT, 2016).

Therefore, this small-scale, qualitative pilot study makes a number of important recommendations, contributes to discussions on NSA and the NDIS, and contributes to under researched and theorised areas. Further research would

benefit from expanding the study to other regions and states; capturing a more diverse range of people with a PCW and by conducting interviews with service providers. Further research should also be conducted into the experiences of CaLD/ NES backgrounds people with disability on NSA.

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T +61 2 9685 9210
F +61 2 9685 9110
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