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Hard to Reach: Examining the National Disability Insurance Scheme Experience - A Case Study in Wollongong

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Hard to Reach: Examining the National Disability Insurance Scheme Experience - A Case Study in Wollongong

Abstract

We report on interviews conducted to examine the effectiveness of the Australian National Disability Insurance Scheme (NDIS). Our aims were to assess the effectiveness of the NDIS in communicating with people with disabilities who are socio-economically disadvantaged, to consider the types of assistance required, and to provide recommendations to improve the NDIS. Our interviewees are characterised as 'hard to reach', a cohort that is missing out on benefits they might receive under the NDIS because of the socioeconomic disadvantage that compounds their disability hardship. Some of our key findings were that many of our interviewees were unaware of the NDIS, the application process was overwhelming for them, and that the vast majority lacked family and friends to help them apply. We propose a number of measures that will help to bring the 'hard to reach' population within the ambit of the NDIS. Recommendations: 1. That the NDIA revise its communication strategy to socioeconomically disadvantaged groups with disabilities. 2. That resources are allocated to providing advocacy support for socio-economically disadvantaged groups with disabilities. 3. That the classification and eligibility criteria used to access the NDIS are reviewed. 4. That further research is undertaken into specific geographic, economic and social cohorts, particularly where the potential for sub-optimal outcomes from the NDIS exists.

Keywords

national, disability, wollongong, study, examining, case, insurance, reach:, scheme, hard, -, experience

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A Case Study in Wollongong

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in collaboration with

St Vincent de Paul Society
(Wollongong Central Council)

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Foreword

This report considers the narratives, ideas, and experiences of people with disability and their carers' in Wollongong NSW. A sample of socio-economically disadvantaged people living with a disability, who had sought and received assistance from the St Vincent de Paul Society between July 2017 and June 2018, were profiled and analysed. The research presented in this report is not intended to provide a comprehensive analysis of issues related to the NDIS, but rather has a deliberately narrow focus on the experiences of a particular group of potential participants one year after the roll out of the NDIS in the region.

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List of Abbreviations

CALD	Culturally and Linguistically Diverse
DSP	Disability Support Pension
NDIA	National Disability Insurance Agency
NDIS	National Disability Insurance Scheme
SVDP	St Vincent de Paul Society
SVDP WCC	St Vincent de Paul Society Wollongong Central Council
UOW	University of Wollongong

Executive Summary

We report on interviews conducted to examine the effectiveness of the Australian National Disability Insurance Scheme (NDIS). Our aims were to assess the effectiveness of the NDIS in communicating with people with disabilities who are socio-economically disadvantaged, to consider the types of assistance required, and to provide recommendations to improve the NDIS. Our interviewees are characterised as 'hard to reach', a cohort that is missing out on benefits they might receive under the NDIS because of the socio-economic disadvantage that compounds their disability hardship. Some of our key findings were that many of our interviewees were unaware of the NDIS, the application process was overwhelming for them, and that the vast majority lacked family and friends to help them apply. We propose a number of measures that will help to bring the 'hard to reach' population within the ambit of the NDIS.

Recommendations:

1. That the NDIA revise its communication strategy to socio-economically disadvantaged groups with disabilities.
2. That resources are allocated to providing advocacy support for socio-economically disadvantaged groups with disabilities.
3. That the classification and eligibility criteria used to access the NDIS are reviewed.
4. That further research is undertaken into specific geographic, economic and social cohorts, particularly where the potential for sub-optimal outcomes from the NDIS exists.

Section One: Overview

Many people who should be receiving support under the National Disability Insurance Scheme (NDIS) are missing out. This was the conclusion of researchers from the University of Wollongong (UOW) who undertook a study with the aim of assessing the effectiveness of the NDIS in communicating with people with disabilities who are socio-economically disadvantaged. A large proportion of these individuals are not receiving any support from the NDIS. They miss out on NDIS support for a variety of reasons, many of which were uncovered during interviews.

Interviews were undertaken with people receiving disability support pensions who had been assisted by the St Vincent de Paul Society (SVDP). Many of those interviewed in this pilot study knew very little, or nothing, of the NDIS. Some had heard of the NDIS but could not access it as they found it too complicated to apply without assistance. Only 12% of those interviewed could count on close friends or family to assist them with their application. Additionally, many of the interviewees suffer from more than one disability and desperately need assistance. From our study, it is clear that there is a large gap in the NDIS system and that some people – those who are 'hard to reach' – are falling through that gap. There is a need for dedicated helpers who can go out into the community to identify these individuals and help them to access the NDIS.

The NDIS, established by the *National Disability Insurance Scheme Act* (Australian Government, 2013), is the first legislative reform in disability service provision in Australia in almost three decades since the *Disability Services Act* (Australian Government, 1986). Underlying the creation of NDIS was the ideal of increasing social inclusion and participation among people with disabilities and their families and carers. Moving away from a block- or service-focused funding model, the NDIS aims to provide individually tailored support packages. The NDIS intends to offer people with a disability 'choice and control' over the selection and delivery of the support services that are required (NDIS, n.d.-f, p.3). These initiatives help to shift the responsibility for service provision away from the state and to the individual through 'mutual obligation' (Carney, 2008). The scheme was trialed in Tasmania during 2013, before being introduced in other states.

Our preliminary results are supported by a recent Queensland study. In Queensland the NDIS was rolled out in July 2016. Lakhani et al (2018) studied participants' knowledge and expectations of the NDIS in South-East Queensland by examining the responses of 70 people with a disability and their families or carers. They indicated that there was a lack of understanding of the NDIS by people with intellectual or cognitive disabilities, especially with respect to the self-directed approach to disability support. They also found that most people with a disability expected that a family member or friend would make most of the decisions about their NDIS plan with their existing service provider. They identified the importance of providing training in budgeting skills in order for participants of the NDIS to undertake self-directed health programs.

In Wollongong, the NDIS rolled out from July 2017 (see Figure 1). Many of our interviewees failed to access the NDIS due to factors outside their control, such as a lack of family or friends support, illiteracy, mental illness and unemployment. The people we interviewed are all recipients of the disability support pension (DSP) and, therefore, are *prima facie* eligible for the NDIS. However, when a disability is overlaid with the marginalisation that comes from socio-economic disadvantage, as is the case with this cohort of interviewees, the capacity for people with a disability to participate in a complex program like the NDIS becomes problematic. The issues faced by the SVDP clients examined in this study do not have a single root cause for their disability, but are intertwined with other problems including social exclusion, lack of education, lack of community integration and support, or negative associations with authority.

The 'choice and control' offered by the NDIS aims to enable access to 'reasonable and necessary support' in order that people with disabilities can participate meaningfully in society (Frisch, 2013). For our socio-economically disadvantaged interviewees, however, the very nature of what they consider 'necessary' amounts to electricity, food, transport, and secure housing. For many, accessing services to assist with disability management was simply not something that had been considered, or, at most, was secondary to basic living needs. The complex needs of the group we examined do not appear to be being met by this Scheme.

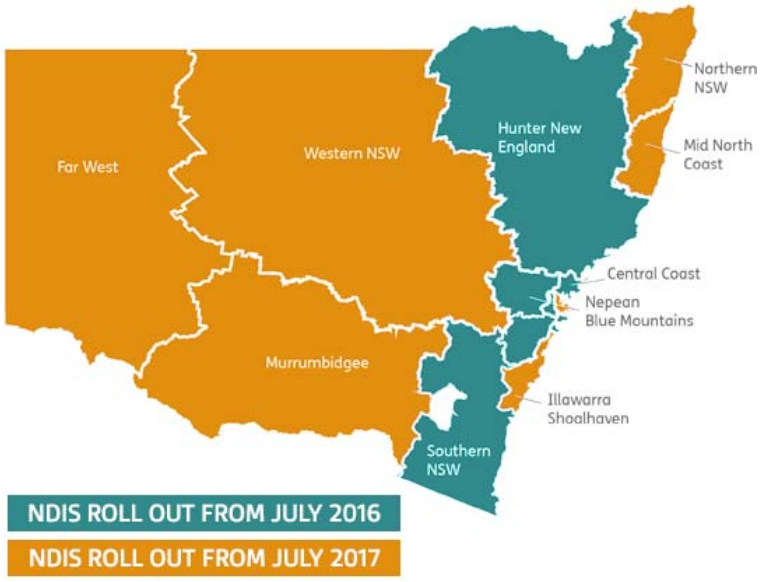


FIGURE 1 NSW regions rolling out the NDIS

Source: NDIS website (http://www.everyaustraliancounts.com.au/a-z-of-the-ndis-roll-outs-in-nsw-and-victoria/

The NDIS is based on an assumption that people with a disability who require NDIS support have the knowledge and capacity to interact with the system. This is not necessarily the case. It seems that a number of people with mental illness, for example, do not have their needs met under the NDIS. This may be because those suffering mental illness are unaware of their disability/condition, making this a particularly problematic group given that they do not see the need for special support (Lysaker *et al.*, 1994; Gulliver *et al.*, 2010). This problem requires adaptive solutions that are tailored to work in the local setting. These should be implemented by a group of local stakeholders who are well-versed in the organisational culture and who are familiar with the particular needs of this marginalised group of people. The recommendations that we propose focus on NDIS-related communication and advocacy, as well as further research into ways of supporting people with disabilities who are also socio-economically disadvantaged.

Section Two of this report provides background to the National Disability Insurance Agency (NDIA), along with detailed discussion of the NDIS and its associated eligibility criteria. Section Three follows with an introduction to our research partner, SVDP, and a description of our research method. The sample of people assisted by the SVDP that were interviewed is also presented, along with a profile of their demographic information, disabilities, and

support services currently accessed. Section Four presents our findings from the interviews, categorised into four key areas: awareness of the NDIS, understanding of the NDIS, methods of managing funding, and the types of support needed. Lastly, recommendations are offered in Section Five.

Section Two: The National Disability Insurance Scheme

2.1 The National Disability Insurance Agency

In July 2011, the Productivity Commission released the results of a public inquiry into a "National Disability Long-term Care and Support Scheme" (Productivity Commission, 2011, p.IV). This inquiry was the result of many years of discussion over the need to reform disability services in Australia. A significant finding from the Productivity Commission Inquiry Report (2011, p.2) was that Australia's support system for disability is "underfunded, unfair, fragmented, and inefficient, and gives people with a disability little choice and no certainty of access to appropriate supports". A key recommendation was for a national scheme that provides insurance cover for all Australians in the event of significant disability: "funding of the scheme should be a core function of government, just like Medicare" (Productivity Commission, 2011, p.2).

In response to the inquiry and Productivity Commission's report, the National Disability Insurance Scheme (NDIS) was launched in 2013. The scheme was trialled over three years and, from 1 July 2016, a national roll out of the Scheme began (NDIA, 2017). With the passing of the *NDIS Act* in 2013, the National Disability Insurance Agency (NDIA) was given responsibility for delivering the Scheme. The NDIA is an "independent Commonwealth entity responsible for implementing the NDIS" (NDIA, 2017, p.16). According to the NDIS *Service Charter* the NDIA will:

- provide choice and control in accessing the most appropriate supports and services;
- provide support to become more independent and included in the community;
- recognise and uphold informal support and care arrangements;
- welcome, respect and value feedback; and,
- raise awareness and knowledge in the community of how to support people with disability (NDIS, n.d.-e, p.4).

Importantly to those with a disability, the NDIA "makes decisions about who can access the NDIS based on the information they [person with a disability] provide about their disability and how it impacts on their day-to-day life" (NDIS, n.d.-f, p.3).

Noted in the NDIS *Service Charter* is the role of the NDIA to "connect people with information and resources" (NDIS, n.d.-e, p.3). The NDIA uses its Annual Reports as a way of communicating its successes and outcomes. For example, demonstrating that it has connected people with information and resources, the NDIA claimed in its 2016-2017 Annual Report that "a major focus was placed on community engagement through hundreds of events and information sessions, along with the launch of NDIS TV and interactive webinars" (NDIA, 2017, p.19).

The NDIA have acknowledged that, so far, raising awareness and knowledge in the community has been one area that has been challenging. Dr Helen Nugent, Chairman of the NDIA, reports that for 2016-2017: "[the] complex picture of where to seek such assistance is not clear for many individuals, particularly those with psychosocial disabilities. We are working to eliminate this source of frustration in the lives of people with disability, their families and carers" (NDIA, 2017, p.8). The role that NDIA plays in delivering the NDIS is further discussed in the following section.

2.2 The NDIS

The NDIS is "a social insurance scheme, not a welfare system" (NDIS, n.d.-c) and is based on insurance principles that enable the Scheme to take a life-time approach. Under the *NDIS Act 2013*, the Scheme "will provide all Australians with a permanent and significant disability, aged under 65, with the reasonable and necessary supports they need to live an ordinary life" (NDIS, n.d.-c). 'Reasonable and necessary supports' in this context are those deemed to "help participants live as ordinary a life as possible, including care and support to build their skills and capabilities, so they can engage in education, employment and community activities" (Productivity Commission, 2017, p.3).

The NDIS as a social policy is "concerned with the allocation and distribution of financial and non-financial" disability services and benefits (Foster *et al.*, 2016, p.28). In order to make decisions about allocation and distribution, the principle of 'reasonable and necessary' will guide those decisions once an applicant is successful. The NDIA determines "the scope and level of services that are necessary, but which are also reasonable in terms of cost and

benefits" (Foster *et al.*, 2016, p.28). Additionally, according to the Productivity Commission (2011), determining 'reasonable and necessary' will need to take into consideration a level of care provided by family members.

It is only after a participant successfully applies for NDIS funding and receives their NDIS funding based on the 'reasonable and necessary' principle that they have the power to exercise 'choice and control'. Choice and control gives participants the "flexibility to ensure you [participants] can choose how to spend your [their] funds to live the life you [they] want" (NDIS, n.d.-a, p.1). The concepts of 'reasonable and necessary' and 'choice and control' are discussed further in section 2.3 and 2.4 respectively.

2.3 Eligibility and approval for NDIS funding

To be eligible for the NDIS, a person must first meet the access criteria: be under the age of 65, be an Australian citizen or permanent resident and "satisfy **either** the disability requirements or the early intervention requirements" (NDIS, n.d.-c). A person receiving a disability support pension (DSP) is not automatically entitled to NDIS funding (NDIS, n.d.-f).

In addition to these access criteria, the NDIS provides a checklist for eligibility regarding a disability (NDIS, 2015) that contains five specific criteria that must be met:

- Criteria 1: The applicant must have a disability that is intellectual, cognitive, neurological, sensory or physical or impairments resulting from a psychiatric condition.
- Criteria 2: The disability must be permanent but also does not need to constantly be impacting on functional capacity (ie, the severity could be fluctuating).
- Criteria 3: The impairment(s) must affect the person's capacity for social and economic participation.
- Criteria 4: The applicant requires support under the NDIS for their lifetime.
- Criteria 5: The impairment(s) must substantially reduce functional capacity or psychosocial function to undertake activities.

There are also criteria for those classified as children (0 – 6) who will need a parent to apply on their behalf under the Early Intervention Requirements. Overall, at each stage evidence (for example diagnostic information) must be supplied to support the criteria.

Psychosocial disability[1] is another category for which NDIA gives specific attention. The area of psychosocial disability is one that has been described by the NDIA as "complex" (NDIA, 2017, p.56). In 2016-2017 the NDIA put forward a strategy to reach those with a psychosocial disability. The NDIA launched a "website project focussed on supporting people with severe and persistent mental health issues to better understand the NDIS" (NDIA, 2017, p.56). The project was titled 'Reimagine: Mental Health, My Recovery and the NDIS' and the free website Reimagine.today was used to explain how to apply for NDIS.

Reimagine (n.d.) notes that "while not everyone living with a mental health condition will experience psychosocial disability, those who do are much more likely to experience significant disadvantages including:

- unemployment,
- poor health,
- poor relationships,
- poor housing and homelessness."

The Reimagine website is an important resource for those who have a mental health issue and who want to consider accessing support that can help in those times when their health issues are at their worst. However for people living with a psychosocial disability, accessing a website to seek help may not be feasible. They may be less likely to think they need help (Gulliver *et al.*, 2010), or to seek out online support.

The NDIA has also acknowledged that the socio-economically disadvantaged population is "hard to reach", and a group that the NDIA needs to strive to connect and communicate with. In its 2016-2017 Annual Report (NDIA, 2017, p.59), NDIA state:

> Throughout 2016 and 2017 the Agency has further progressed the development of specific strategies for other population groups with disability including:

[1] See definition at Section 3.5.2

- culturally and linguistically diverse (CALD) populations;
- the lesbian, gay, bisexual, transgender, intersex, queer, asexual (LGBTIQA+) community; and
- people who are 'hard to reach' due to their social, health and welfare circumstances.

In the NSW region, CALD populations were targeted for information sessions (NDIA, 2017, p.25). In an effort to reach the LGBTIQA+ group, NDIA representatives participated in the 2017 Sydney Mardi Gras Parade (NDIA, 2017).

Those who are 'hard to reach' because of social, health and welfare circumstances are at risk of becoming further disadvantaged because of their limited ability to be informed of the scheme. Those who receive DSP are likely to have very little money left to access the internet, due to the costs of data usage and costs to own a digital device (such as a computer). Since NDIA information is provided mostly online, any strategies that are put in place to communicate with potential applicants or participants to the Scheme are likely to be ineffective for this cohort, given that they cannot readily access the internet.

Once an applicant is successful in their request to access NDIS funding, they become a Scheme participant and need to prepare an NDIS Plan. This stage requires the participant to be able to discuss detail in regards to: current supports and services they use on a daily basis (eg, important people in their lives who help, such as family and friends); and short, medium and long term goals (NDIS, n.d.-d). This process may also be difficult for socio-economically disadvantaged participants because of limited education and access to social support structures.

As mentioned in section 2.2, the NDIA will determine what is 'reasonable and necessary' when approving a participant's plan. To determine whether the support or service is 'reasonable and necessary', five criteria must be met. The support or service (1) must be related to a participant's disability; (2) cannot include day-to-day living costs that are not related to the disability; (3) must represent value for money; (4) will likely be effective and work for the participant; and, (5) should take into account support already given by other government services and the participant's family, carers, networks and community (NDIS, n.d.-f).

2.4 Choice and control

The NDIS states that "people with disability have the same right as other Australians to determine their best interests and to have choice and control over their lives" (NDIS, n.d.-f, p.3). This means that participants can choose who will provide their support, and how to live their lives. This level of flexibility comes when the participant has had their plan approved.

From the 2016-2017 NDIA Annual Report (p. 12):

> Participants are deeply involved in making decisions around how their funds are spent, and how their supports are delivered. Participants are able to choose and move between disability providers rather than having providers contracted for them. In this way, participants are empowered to own their goals and aspirations, and to have a say in how they attain improved social and economic outcomes.

Australia is one of many countries who have introduced this concept of individualised funding where participants are able to direct the way in which their funds will be used (Dickinson *et al.*, 2014).[2] The assumption underlying individualised funding, as is the case with NDIS, is that "specifying an individual's budget and allowing the individual to decide how this is spent should enhance control, choice and flexibility" (Dickinson *et al.*, 2014, p.418). However this model also assumes that the individual is able to exercise choice and control. Given that this study focused on a socio-economically disadvantaged segment of the population, with many of those interviewed having either a psychosocial disorder as their primary disability or secondary disability, the concept of 'choice and control' is problematic.

The NDIS explains that control means having the ability to self-direct, defining self-direction as having control "over your supports and how they are provided" (NDIS, n.d.-b, p.9). The concept of choice is enabled when the participant is able to choose the providers they want to deliver the services they need (NDIS, n.d.-b). Both concepts assume a level of competence in making these decisions, and where that is not possible, that others may be elected to make the choices on their behalf.

[2] Similar schemes have been developed in the UK, Netherlands, Canada, Belgium, France, Austria, Finland, Sweden and Germany (Dickinson *et al.*, 2014).

2.5 Summary

This section of the report has discussed the NDIS as an Australian government response to dealing with a disability funding system that was in need of reform. The NDIA was described as the agency in charge of administering the scheme and ultimately the body that determines what is 'reasonable and necessary' support as well as the services to be funded under the scheme. However, as discussed in this section, in order to even get to the stage where a Plan can be made under the Scheme, there is an assumption that potential participants are aware of the Scheme, that they understand the eligibility criteria, and that they have the capacity to engage with a lengthy application process that may not be open and clear (or in fact inclusive). In the section that follows, we examine how the NDIS has been communicated and understood in the Wollongong area, particularly among a socio-economically disadvantaged cohort.

Section Three: A Case Study of the NDIS in Wollongong

3.1 The project

This joint research project involved a team of UOW researchers and SVDP staff. This project was a pilot study that aimed to explore the effectiveness of the NDIS in the Wollongong community, in particular as it related to recipients of the DSP who had received some support from SVDP Wollongong Conference.

The SVDP is a lay Catholic charitable organisation that provides a range of financial and non-financial assistance to those in need (St Vincent de Paul Society, 2017). Many of these people in need are DSP recipients and potentially eligible to apply for NDIS support. As such, the SVDP (Wollongong Conference) was a point of contact for identifying people in the Wollongong community who may have had some experience with the NDIS. Potential interviewees were invited to discuss NDIS awareness and experiences.

The project team interviewed 32 people assisted by the SVDP, mainly at the SVDP retail stores at Fairy Meadow and Corrimal, but also at the homes of some of the participants or via phone. Each interview lasted approximately one hour, and interviewees were asked a range of open ended questions concerning their personal situations, support needs and the NDIS. All interviewees were provided with a food voucher in recognition of the time that they gave to the interviews.

Appropriate ethics clearance for the project was obtained from the University of Wollongong Human Research Ethics Committee (2017/466), and appropriate authorisation to access the SVDP database was granted by SVDP Wollonogng Central Council (WCC) executive representatives. Given the sensitivity of these interviewees and respect for confidentiality, all written and phone communication was via a SVDP representative.

3.2 St Vincent de Paul Society

SVDP is a lay Catholic charitable organisation that operates in 150 countries around the world (St Vincent de Paul Society, 2017). It began its operation in Australia in the 1850s (Pedemont, 1993) and currently provides a range of support services to people experiencing some form of disadvantage. Its programs are designed to promote social justice and raise awareness about the causes of poverty and inequality.

In Australia, the organisation is headed by the National Council, which convenes three times a year as a forum for State or Territory Councils to report on their activities, discuss matters of common concern and make decisions on action to be taken[3]. On a more local level, Councils are formed to provide a link between grass roots groups within the Society[4]. The SVDP Wollongong Central Council (WCC) spans from Glenfield to Ulladulla, and is broken into six regions Campbelltown, Camden/Wollondilly, Southern Highlands, Wollongong, Central Illawarra, and the Shoalhaven. In the Wollongong region there are eight Conferences; Thirroul, Corrimal, Bulli, Fairy Meadow, Gwynneville, Unanderra, Wollongong and West Wollongong. The role of Conferences and their members is to provide grassroots support by visiting people in their homes and by providing financial assistance to people in need. The combined Wollongong based conferences comprises 82 members and has provided assistance to over 3000 people during 2018. More specifically, it has assisted 110 people with a disability during that time. Given the experience and local knowledge of the members of the Wollongong Conference, it was an important link to individuals in the local community who are in need, living with a disability, and who may be eligible for support under the NDIS.

3.3 Project scope

As already indicated, this project was a pilot study to investigate how the NDIS is experienced by people in the Wollongong community, with a particular focus on a cohort of people who experience some form of socio-economic disadvantage. As such, the scope of this project was limited to recipients of SVDP assistance in the Wollongong area, referred to

[3] https://www.vinnies.org.au/page/About/Our_Structure/National_Council_of_Australia/
[4] https://www.vinnies.org.au/page/About/Our_Structure/Councils_-_Regional_Central_and_State_or_Territory/

as SVDP clients, details of whom are maintained in a manual database in the Wollongong office. This database consists of a collection of individual client records detailing name, address, contact phone number, gender, relevant welfare support (for example, DSP), and the types and dates of assistance provided by SVDP (for example, home visits, electricity subsidies, emergency food hampers, food vouchers). Potential interviewees were contacted by mail and/or phone, inviting them to an interview. The interview transcripts, along with relevant notes, form the main data set that was used to explore the NDIS roll out in the Wollongong area.

3.4 Research method

The Wollongong Conference database was reviewed and all SVDP recipients of assistance who had received support from SVDP during 2016, 2017 and 2018 and who were supported financially by the DSP were selected as potential interviewees. People assisted who were aged 65 or over were omitted because their age disqualified them from participating in the NDIS. A list of 103 potential interviewees was compiled, noting relevant details such as name, address, age, and phone number. At this point we noted that the addresses recorded for many of the people in the sample referred to temporary accommodation (such as Piccadilly Wollongong or City Beach Hotel), so we had some doubt about whether or not the invitation to interview would be received by many of the intended recipients. It was decided that where a client failed to respond, an SVDP staff member would make a follow up phone call to invite the client to an interview. This fact also points to the difficulty in contacting this cohort of people in terms of NDIS information and support.

Invitations were sent to each potential interviewee along with a participant information sheet, a consent form and a stamped self-addressed envelope for return mail. An acknowledgement in the form of a food voucher was offered to potential interviewees, along with an offer of financial support for transport if needed. The SVDP interviewees who agreed to an interview were contacted by an SVDP representative, and provided with a choice of interview dates and venues (either SVDP Fairy Meadow retail store, SVDP Corrimal retail store, their own home or phone interview). All interviews were coordinated by an SVDP staff member, and in many instances reminder phone calls were made. Interviews

were scheduled over a six-week period (14/6/18 to 24/7/18) and each lasted for about an hour.

Interviews were semi-structured and conducted by two members of the research team, one from SVDP and one from UOW. At the beginning of each interview, the interviewers clarified the purpose of the interview and confirmed key points that had been noted in the UOW participant information sheet and the consent form, namely that: participation was voluntary, the interviewee could ask any questions about the research, the interviewee could decline to answer any questions, the information would be kept confidential, all identifying information would be removed prior to publishing, and that the interview would be recorded and transcribed. If requested, the interviewee could ask to see a copy of the transcript.

Interviewees were asked a range of open-ended questions drawn from a pre-prepared list, loosely grouped around personal details and circumstances, nature of disabilities, support currently accessed or required, use or otherwise of the MyGov website, knowledge around the NDIS and, if applicable, their experience with the NDIS. However, after the first few interviews it became apparent that very few of the participants were aware of, or had experience with, the NDIS. Questions were therefore reframed around their understanding of the NDIS and support required. In most cases there was some digression from these questions in order to better engage the participant or to respond to their individual stories.

Interviews were recorded and later transcribed using Google Translate. Notes were also taken during each of the interviews. The interview transcripts and notes formed the primary data set for the project. Transcripts were reviewed by the UOW research team, with relevant details transferred to an Excel spreadsheet for analysis, and supplemented with notes in cases where the recordings were unclear. Data was analysed in terms of themes, and attention was given to the more nuanced responses of individual participants. A discussion of aggregate and individual responses is presented in Section Four.

3.5 The sample

As indicated, 32 people participated in semi-structured interviews with the research team. A brief outline of the interviewees is provided in the following sections.

3.5.1 Demographic details of the sample

Figures 2 and 3 show the age and gender profiles of our interviewees. Over 80% were 35 years or older, with a substantial portion (25%) in the 55-64 age bracket. Given that the NDIS is outside the reach of older citizens (ie those aged 65 years or over), there appears a strong need to engage with this cohort as early as possible to ensure appropriate access to the NDIS.

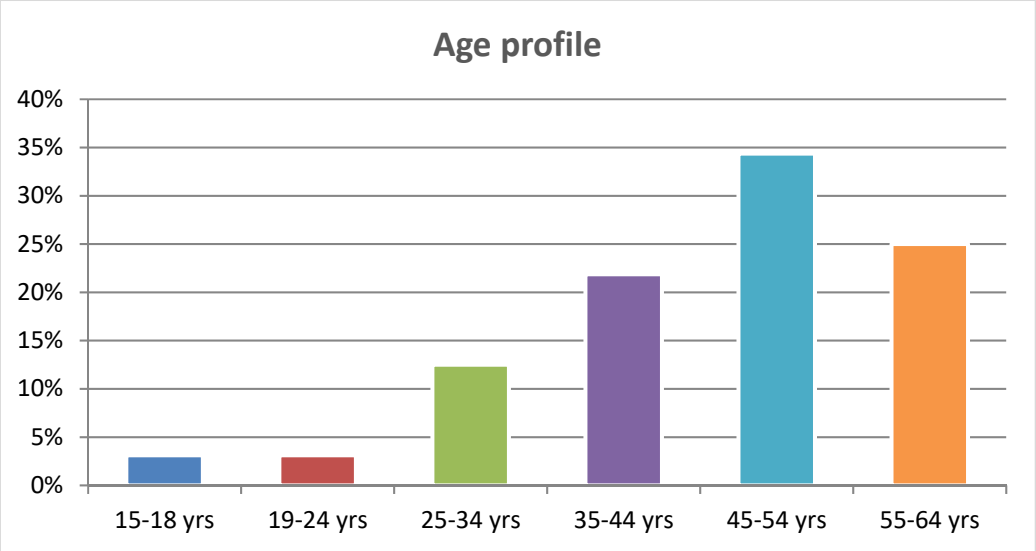


FIGURE 2 Age profile of interviewees

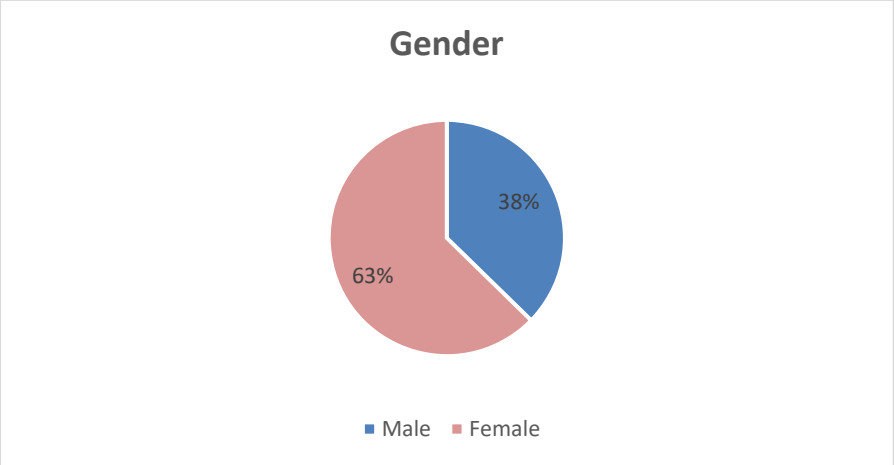


FIGURE 3 Gender profile of interviewees

Figure 4 points to the CALD (Culturally and Linguistically Diverse) status of interviewees, with 6% falling within this category. While statistics on CALD status in the Wollongong region vary depending on the instrument used, the 2016 census reveals that 22% of the Wollongong population were born overseas, and 17% speak a language at home other than

English[5]. The relatively low representation of CALD people in our sample suggests that this cohort may not be aware of, or not have the skills to reach out to, charities such as SVDP.

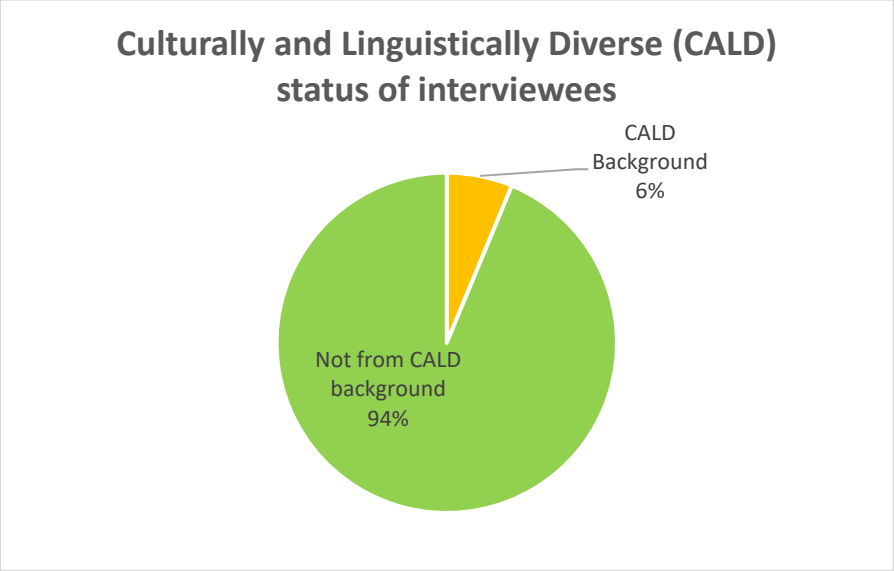


FIGURE 4 CALD status of the interviewees

Figure 5 reflects the type of accommodation used by our interviewees. Almost 60% of the participants depend on public housing, while a further 19% access temporary housing. As noted earlier, the temporary housing status of our cohort presents a significant problem in terms of NDIS outreach: these people simply do not have a regular address and as such efforts to contact them via mail are likely to be fraught.

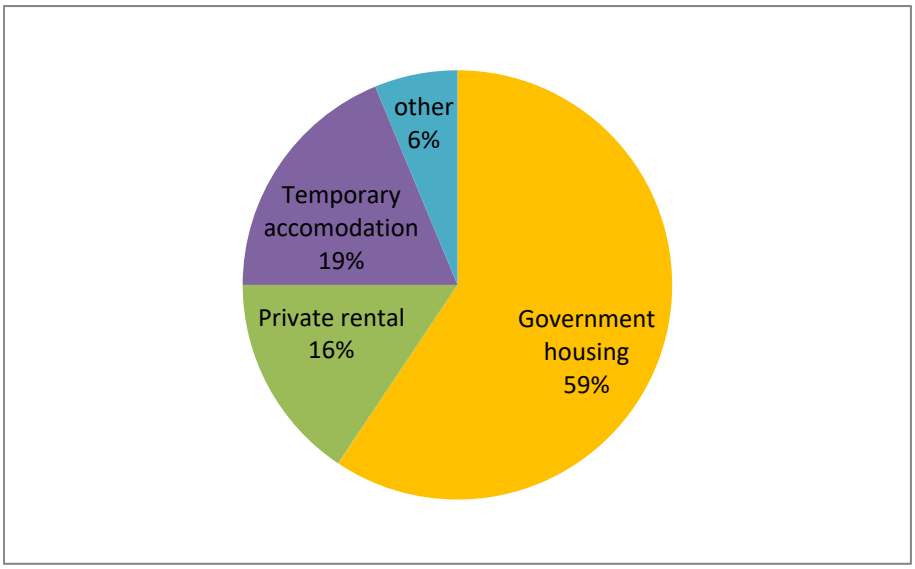


FIGURE 5 Accommodation status of the interviewees

[5] https://profile.id.com.au/wollongong/highlights-2016

3.5.2 Types of disabilities of participants

Figures 6 and 7 respectively show the type of primary and secondary disabilities of our interviewees. These figures show that the most significant disability related to some form of psychosocial disability, with over 60% of interviewees acknowledging this as either their primary or secondary disability. The NDIS uses the term 'psychosocial disability' to describe:

> …the experience of people with impairments and participation restrictions related to mental health conditions. These impairments can include a loss of ability to function, think clearly, experience full physical health, and manage the social and emotional aspects of their lives. Psychosocial disability relates to the social consequences of disability - the effects on someone's ability to participate fully in life as result of mental ill-health. Those affected are prevented from engaging in opportunities such as education, training, cultural activities, and achieving their goals and aspirations.[6]

While over 15% of the participants acknowledged this as their primary disability, almost 47% acknowledged it as their secondary disability. As discussed later in the report, many of our interviewees referred to their inability to participate fully in life as a result of their disability, and, when taken in the context of the NDIS, it was apparent that this translated into a lack of awareness of the NDIS or the necessary means to apply for the scheme.

The most significant primary disability, at almost 40%, related to back or spinal cord injury. These injuries were acquired by the interviewees in a number of ways, including a motor vehicle accident, workplace injuries or physical injury resulting from drug abuse or as a victim of crime. What is clear from the interviewees is that back injuries severely hamper their ability to actively participate in life, and many of them were in need of basic support such as transport, as well as assistance with shopping and home care (see further discussion in Section Four).

[6] An internationally recognised term under the United Nations Convention on the Rights of Persons with Disabilities https://mhaustralia.org/general/getting-ndis-right-people-psychosocial-disability (accessed online 28 August 2018)

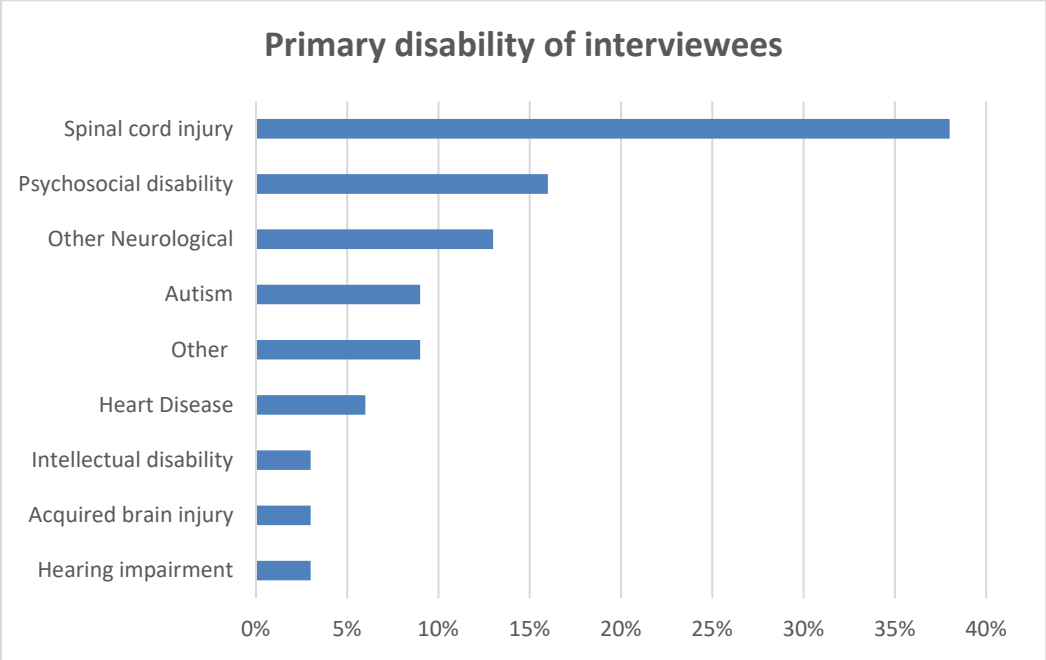


FIGURE 6 Primary disabilities of the interviewees

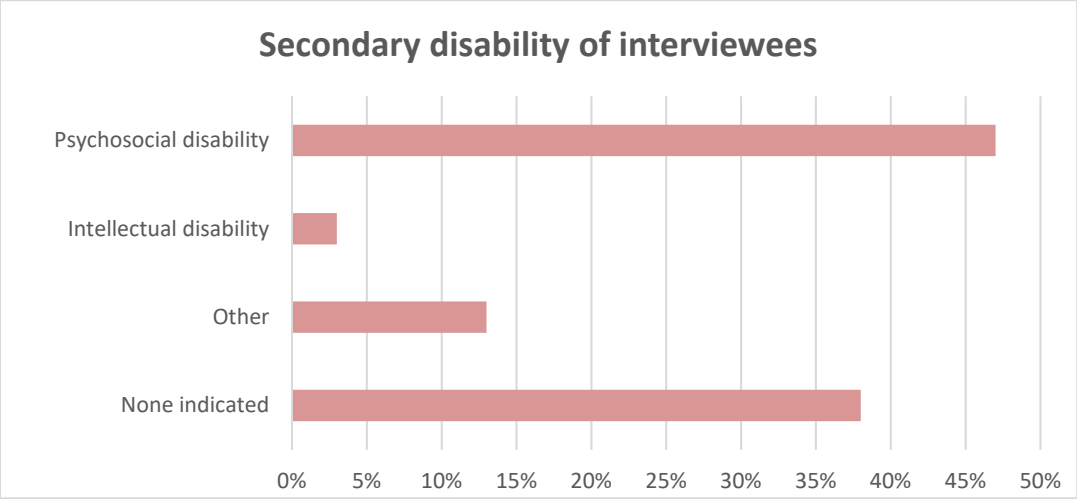


FIGURE 7 Secondary disabilities of the interviewees

3.5.3 Support services

Figure 8 indicates the support groups currently accessed by our interviewees. Sixty-six percent of the SVDP interviewees we interviewed seek support from a range of charities, such as SVDP, Anglicare, Barnados, West St (Wollongong) Support group, Illawarra Multicultural Services, Homeless Hub, Lifeline and Wesley Mission. The nature of the support that could be provided by charities is discussed in Section Four, however given their high level of contact with disadvantaged people, it seems that workers within these

organisations, given sufficient training and support, are in an excellent position to identify and support potential NDIS applicants. Further, 16% of the participants secure assistance from service providers, again pointing to an avenue for identification of potential NDIS participants.

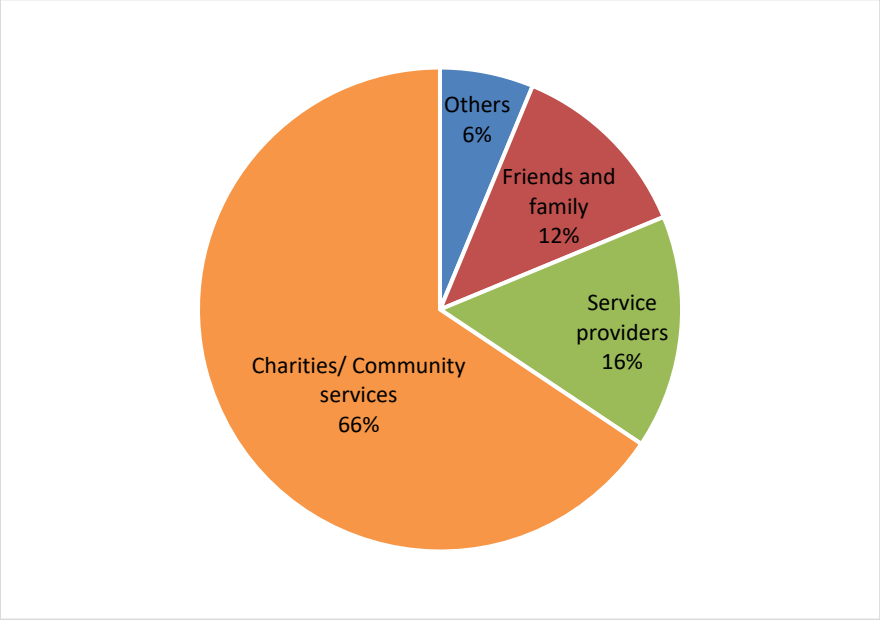


FIGURE 8 Support groups currently accessed by the interviewees

Perhaps the most surprising detail of the research was that only 6 of our interviewees (19%) were actually receiving NDIS support. Given that our sample selection specifically targeted people on the DSP, there was an expectation that this would translate to participation in the NDIS perhaps not universally, but certainly at a level higher than 20%. Further analysis of this is provided in Section Four.

3.6 Summary

This collaborative project between SVDP staff and UOW led to the interview of 32 people drawn from the SVDP Wollongong Conference data base. These interviewees are currently receiving the DSP and, on face value, may be eligible to apply for the NDIS. However, only 6 out of 32 are currently receiving support under the NDIS. While our interviewees experience a range of physical and mental disabilities, around 62% are affected in some way by a psychosocial disability. When combined with a lack of permanent housing, a picture is

created of a group of people who do not have the capacity to know about, much less apply for, the NDIS. The participants in our sample draw on a fragmented range of support services, most notably those provided by some form of charity. Given this, NDIS awareness or support programs might be more effectively implemented if initiated through selected charities.

The interview responses are analysed in greater detail in Section Four.

Section Four: Findings

Our interviews revealed a number of emergent themes around the effectiveness of the NDIS for people who are socio-economically disadvantaged. Our findings focus on four key areas, which include,

- Awareness about the NDIS
- Understanding of the NDIS
- Methods of managing funding
- Types of support needed

In the sub-sections that follow, we discuss our findings in detail, beginning with NDIS awareness.

4.1 Awareness of the NDIS

An interesting finding from our study is the lack of awareness of the NDIS, or, if interviewees were aware of the NDIS, there was confusion as to the purpose of the Scheme or who might be eligible to participate in it. This is contrary to the NDIA's claim that its "major focus" for 2016-17 was on community engagement via interactive webinars, and community events and seminars (NDIA, 2017, p.19) (refer Section 2.1).

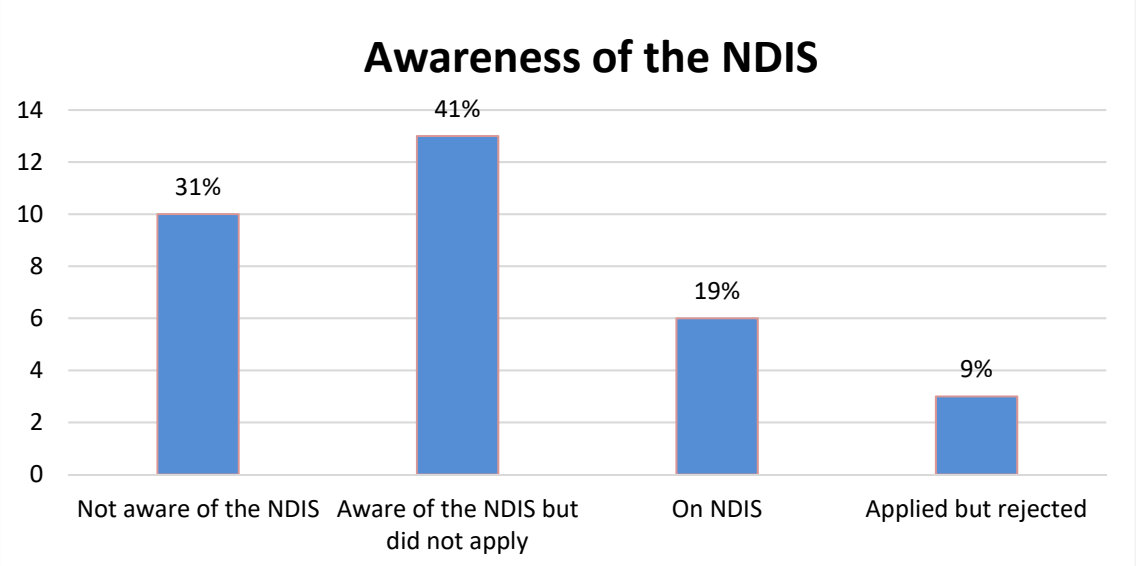


FIGURE 9 Awareness of the NDIS among Wollongong SVDP clients interviewed

As noted, all of our interviewees, as DSP recipients, were potential NDIS participants, but 31% had not even heard of the NDIS (see Figure 9). Social isolation appears to be a key factor that limited the sharing of NDIS information, and this was compounded by a lack of financial independence, which combined to keep people housebound and away from social interactions. An absence of structured support networks limited information flow. Psychological barriers were identified, which often arose from physical health complications, with depression being a common reason for extended isolation.

> *I don't have any income, and because there's no income I don't ... until the bills are paid, I don't have any money to do any leisure or pleasure. There's no leisure or pleasure, do you know what I mean? (Interviewee no. 4)*
> *I got a mate, sometimes he'll get me my packet of smokes, something if I need it. But nothing, there is nowhere I go. (Interviewee no.24)*

> *I'm pretty self-sufficient. I've been brought up self-sufficient. I can cook. I wash my clothes and that…I don't get out much and talk to many people. (Participant no.8)*

> *I have a lotta issues getting myself to doctors and getting myself ... like I need to get to a psychiatrist at the moment or a psychologist I can't remember which one. I think both but, I've been literally putting that off for two months. Like I need sort of someone to not come and get me, but sort of just to push me along with it 'cause otherwise I just get in too much of a bad head space and I just shut down and sit at the house. (Interviewee no. 25).*

A considerable number of interviewees, 41%, stated that they had heard about the NDIS but decided not to apply (see Figure 9). These interviewees indicated that they have been informed about the NDIS from multiple sources. For the majority, family and friends were the main source of information about the NDIS. Some participants mentioned seeing advertising about the NDIS on television. A small group were informed by the service providers. A few people mentioned their medical practitioner informed them about the NDIS, while others received information from other community services. Figure 10 presents the source of information on the NDIS among the participants.

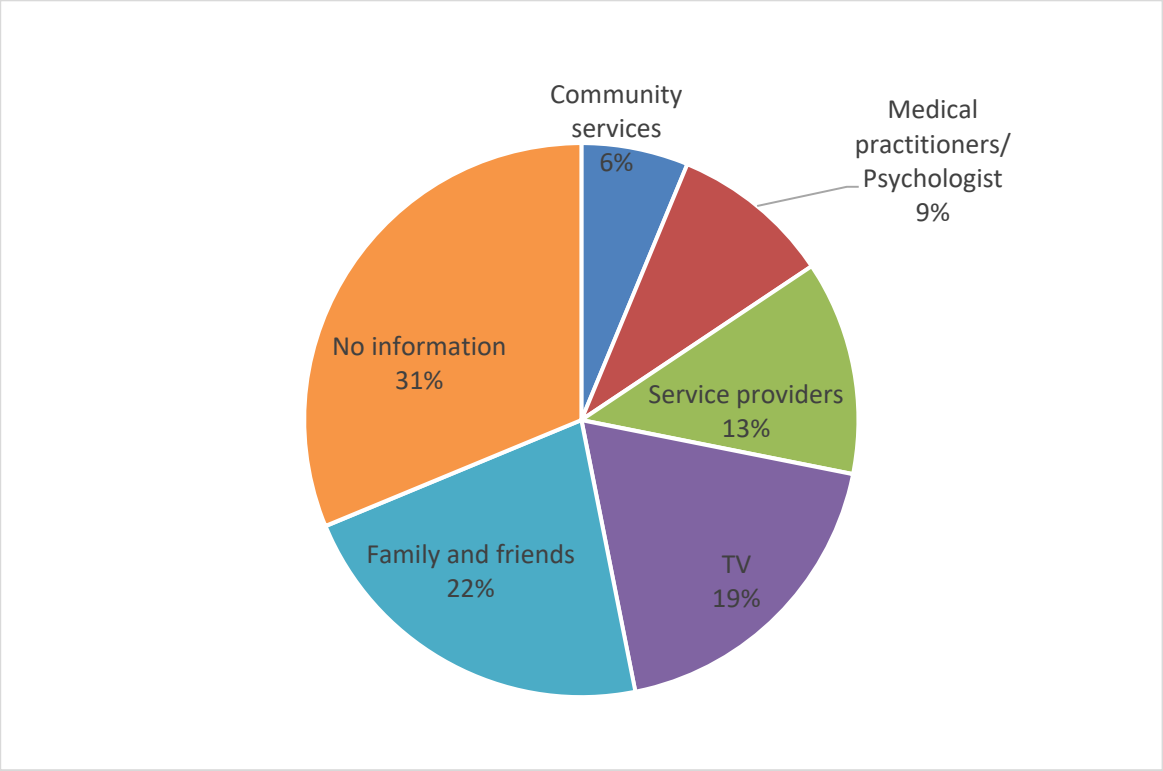


Figure 10 Source of information about the NDIS

Although this group of interviewees had heard of the NDIS, they had chosen not to apply. The inaction of this group of interviewees was attributed to a lack of skills, a lack of assistance, discouragement from their doctor, as well as uncertainty around their eligibility for the NDIS. Isolation was also a significant barrier in taking the step towards applying for the NDIS. The irony for some of these interviewees is that it is their disability that is inhibiting them from accessing disability support. From participant no. 23:

> *Maybe, 'cause the autism blocks me from working stuff out with the internet, like if I have to go somewhere. It's, like, recently some link wants me to go on to myGov and, I'm sitting there thinking, "How do I do that?" And then they're saying, "Link your myGov with something" I'm like, "Huh, that's not explaining it.*

Another participant suffering from depression and anxiety stated that:

> *That [the application process] freaks me out. That freaks me out. I get anxiety, I get anxiety and I tremble. Extended forms like: "Name, Address, Phone Number, How many Kids?" Real straight-forward stuff. (Interviewee no. 5)*

There was a group of participants who were willing to apply, but required assistance. As stated by Interviewee no.17:

> *I'd like someone to do it for me because I can't fill the forms out. Even with Centrelink, I had to tell them I need someone to help me all the time. Because I can't fill forms out and things like that.*

Also from Interviewee no. 13:

> *I don't even know where to apply to or how to go about getting on it.*

Some participants denied that they needed any support. They responded that: "*It's not like I'm invalid*". (Interviewee no.27). Another participant in this group stated that:

> *I'm very independent. I mean, yeah, I'm actually highly qualified, just … I've just got a bit of personality disorder on top of the other stuff. (Interviewee no. 7)*

One indicated that their doctor had not been supportive and had discouraged an application for the NDIS.

> *I talked to my doctor, my psychiatrist who I've seen for 29 years, and he didn't give me much information back as if to say he didn't really want me to do it, to go through it. (Interviewee no.1)*

Once we had established that there was limited awareness of the NDIS, the next theme to explore was the level of understanding that existed among our interviewees who were aware of the NDIS. The following section reports on responses regarding interviewees' understanding of the NDIS.

4.2 Understanding of the NDIS

In Section 4.1, we established that 41% of interviewees had heard of the NDIS but had decided not to apply; 19% were currently participating in the NDIS; and 9% had applied for the NDIS but had had an application rejected. The balance, 31%, had never heard of the NDIS. The 69% of interviewee responses that we consider in this section generally reveal a limited understanding of the NDIS.

4.2.1 Understanding: Aware without action

As noted, 41% of our interviewees were aware of the NDIS but had decided not to apply. This decision was, generally, based on an inadequate or incorrect understanding of the NDIS.

Responses included:

> *I've heard of it, yeah. But I don't know what it's about. (Interviewee no.13)*
>
> *[I heard] when they were talking about it because I leave the news channel on, but I don't know who it's for and what it's for (Interviewee no.17)*
>
> *I've heard of it, but I don't know much about it. (Interviewee no.19)*

Other participants in this group believed that the NDIS is limited to a certain disability:

> *I think it's more for Down Syndrome. (Interviewee no.18)*
>
> *I just thought maybe it's more for disability people, like with severe disabilities, you know, that are in homes and stuff. (Interviewee no.29)*

Some of our interviewees who had heard of the NDIS believed that its purpose is to facilitate transition to the workplace:

> *I actually went down to NDIS and approached the receptionist to find out more information... What I got from the receptionist is it's mainly a place for you to get back into the work area. (Interviewee no.1)*

Other interviewees indicated that the NDIS would change their disability funding under the DSP and care plan:

> *It's more to do with the funding ... what was explained to me was - I was with the Partners in Recovery organization and the government pays them. Well, now it's worked differently to how they're gonna be paid but they can't continue this work unless everyone's on the NDIS program. (Interviewee no. 5)*
>
> *That it's to serve as an individualized care plan for whoever needs it with their unique issues, conditions. (Interviewee no.7)*

4.2.2 Understanding: Interviewees on the NDIS

Nineteen percent of our interviewees were NDIS participants. These interviewees who had NDIS plans in place were asked about their understanding of the NDIS. Interestingly, even though these interviewees had been through the entire process, not all had a clear understanding of the NDIS. Responses included:

> *I know that it's quite good for the people that have got disabilities that can't go shopping on their own. (Interviewee no. 3)*

> *It's for, like a thing to help you for funding to get help… like it pays for my counselling. (Interviewee no. 22)*

Due to the lack of understanding of the NDIS and the planning process, some interviewees in this group were not utilising their plans. Interviewees stated:

> *Personally I haven't taken many of the activities. I'm not sure if I'm going to continue to seek the same activities as I put down originally in the plan. (Interviewee no. 21)*

> *We didn't use it [the plan] at all because we don't know what [to do]. Some people said we have to make contact…if you want to become their client. But my son is different so I'm just thinking [how]can we use it. (Interviewee no. 28)*

> *I didn't really use the support services except for the transportation. And it was basically because I felt like I wasn't using all the time, but I kind of felt kind of like I felt guilty for accepting services because I wasn't doing the right thing. (Interviewee no. 31)*

It became apparent that for this group of interviewees, the lack of understanding of the NDIS impacted their NDIS plan. If the services required are not articulated clearly, the NDIS plan is ineffective. Interviewees stated that

> *I couldn't get the transport… All I want is transport. (Interviewee no. 21)*

> *All my funding [is] with the place I go to. I didn't get enough funding to go out on the weekend and get support or anything like that. (Interviewee no. 22)*

As a result, half of our interviewees who are participating in the NDIS are not satisfied with their plans.

> *The concept is not bad, but considering what he used to have and what he gets now, he's behind the eight ball… Now the NDIS has come in, he's worse off, because now instead of going on a trip somewhere and it costing him nothing, now he goes on trips that cost him money, but the care he gets there for nothing. (Interviewee no. 3)*

> *I'm still given choices, but the control seems to be lax a bit. Lax because it's not doing the job it was supposed to, and maybe they can't do the job. (Interviewee no.21)*

> *I find it quite difficult to use at the moment and I can't do anything really because when I want to do something I have to go to the NDIS coordinator, you know even though there's not enough funding there for me. I can't do what I want to do because I've got no money there. It's all gone. (Interviewee no.22)*

4.2.3 Understanding: Applied but rejected

A small group, 9%, of our interviewees had applied for the NDIS but had their applications rejected by the NDIA. This group of participants understood the NDIS as a support system for people living with a disability. However, they did not fully understand the reasons why their applications were rejected. Interviewees stated:

> *They said you get rejected because they accept the people who they're born with a disability, not get a disability in the future. (Interviewee no. 9).*

> *I was ringing like three times a week, and ….[a] gentleman called me and said I didn't have enough proof. And I said, "Well, it clearly states I have multiple fractures, I have severe osteoporosis, I'm nearly 62. Do you really think that it's going to get better? It's not, it's going to get worse." And he said, "Well, I can't see you." And I said, "But my doctor's clearly stated on the forms." He said, "But that's not enough." I said, "Well what more do you need?" He said, "I need more letters, more proof." (Interviewee no. 11)*

> *Basically because I wasn't suffering too much. I didn't have a disability that concerns them too much. They basically said I wasn't, I didn't have this much disabilities to ... for them to cover. (Interviewee no. 15)*

With awareness and understanding of the NDIS examined, our attention turned to the financial implications of the NDIS. In the planning stages of this project, we had envisioned this study to be about how NDIS participants budget for and manage the amounts they receive as part of their NDIS plans. We had not foreseen that 72% of our interviewees would

not be participating in the NDIS due to being unaware of the Scheme or having a limited understanding of it. More critically, we had not imagined that we would be confronted with a cohort of people so socially and economically disadvantaged that funding available to them under the NDIS is significantly less important than money needed to fund basic living expenses. The following section details responses regarding the methods used by our interviewees to manage the funding they have, and the types of support that are needed.

4.3 Methods of managing funding

This section will discuss how our interviewees manage their finances. It is important to note that all of our interviewees identify the DSP as their main source of income, and all have received some assistance from SVDP. This positions our interviewees as socio-economically disadvantaged, meaning they often struggle to cover weekly living costs.

A common theme among interviewees is the financial stress they experience. Reasons for financial stress include debt to family and government, as well as the rising cost of living.

> *There's school food, you know, that's the first thing I do, making sure that I've got them the meat, you know, for every day and if I've got enough, then they can have a few little treats. But my mum, on my off week, because I get paid fortnightly, the week that I don't get paid, she's been lending me three hundred dollars. I'm in over two and a half thousand dollars debt with her at the moment. (Interviewee no. 29)*

> *I literally ... me and my family got into a 20,000 debt in that time. Because we couldn't get by. The only way that we were gonna get by is to take loans. (Interviewee no.25)*

> *Our money gets us through week by week but we run out what, a day before, sometimes two days before pay for certain things. (Interviewee no. 32)*

Due to their financial situation, interviewees sought support from charities and not for profit organisations in the form of vouchers, food and cash for medications.

> *The only support that I usually get, if I'm struggling with a bit of food, then I ring up Vinnie's. That's the only one I believe, that's the only one I trust and I feel comfortable with them. (Interviewee no.2)*

> *I went to Anglicare just recently, they gave me some money for medication. And then gave me a food voucher of like ... I was going to that place in Wollongong, what's it called? Because I was homeless for a while, homeless hub. I went there for a couple of months (Interviewee no.20).*
>
> *We sometimes use them [Anglicare] for food help or the community soup kitchen, which we now have discovered does food parcels. So we get help in the way of food but not our disability-wise. (Interviewee no.23)*
>
> *I've never usually got much left by the end of the fortnight, but you know I get there. And it, in this area, if you really, really starving you can get a feed. You know what I mean? And then at Mangerton, there's the caravans there, they make hamburgers and stuff, some of the places are okay. There's a few around. Darcy House is at Port Kembla, and Wesley Mission is in here in Wollongong. There is a Lifeline church that gives dinners on Thursday night, so you can get a feed. So you're not going to starve. You go alright. (Interviewee no.24)*

Despite their financial situation, some of our interviewees stated they still managed to live day to day.

> *We all struggle but I just seem to get through every fortnight. (Interviewee no. 24)*
>
> *So I would say that with the combination of public housing, that actually does help a long way in being able to afford things. I think if it was part rental I just couldn't do it. (Interviewee no. 30)*

Interviewees clarified how they manage to meet their everyday cost of living by emphasising their budgeting and financial management skills.

> *I like to eat and I don't like to eat rubbish. But sometimes I've got to eat ... you can only eat what you can afford to buy, which is the way it is. (Interviewee no. 4)*
>
> *I'll pay all my bills first. That's the first thing. I have rent. Food's the last thing. So whatever I've got left, I'll buy something. If I've got money left. (Interviewee no.17)*
>
> *Rent. So I pay that straight away. As soon as I get paid I pay that, and then the rest of it I work out. Electricity comes out before I get the payment. Whatever I have left over is gonna pay my pharmacy bill, my food, phone bill and that's it. (Interviewee no.19)*

> *When you got a certain threshold of money you're not going under. You're sort of buoyant and you're just balancing all the things as they come in, goes out. (Interviewee no.27)*

> *Now it's just learning that, you know, I can't afford this, so I can't get that or you know, like this is what I can afford so, instead of getting this, we'll have to get this and then maybe when we get some more money, then we can get that. (Interviewee no.29)*

The financial hardship and focus on meeting basic and day-to-day needs appeared to prevent our interviewees from considering the support services that they might be able to access under the NDIS. Many seemed to be unaware of services that they might be able to access, for example, community activities, because of their overriding, and understandable, concern for meeting essential needs. When asked about the types of support that would improve their circumstances, the majority of interviewees indicated that the major hardship they face was in meeting daily living costs. Responses included:

> *Necessities, bills and things like that. (Interviewee no.12)*

> *Electricity I suppose, I mean electricity's a big one man. (Interviewee no.20)*

> *When it comes to maybe assistance with food. (Interviewee no.5)*

> *My electricity bills …, because I'm learning to make bread, and learning to make bread, and those things, well certainly the electricity, six hours on, you know? (Interviewee no.7)*

> *About three months ago I needed help with one of my electricity bills. They weren't sending my electricity ... I've got electric and gas and I thought they were both in one because I'd never received a gas bill. So, when I went to get help for my electricity bill, they said on the phone "you've got an outstanding $400.00 gas bill" and I was like "Oh". (participant no.29)*

Interviewees were also asked about the types of support they could potentially expect from the NDIS. Interviewees who were not aware of the NDIS and those who decided not to apply could not name any item of support. Responses included:

> *I don't know what I'd utilise there. I'd have to think about it. (Interviewee no.19)*

> *We don't know what it's about and what it's for. (Interviewee no. 17)*

I honestly can't think of that right now mate (Interviewee no.26)

Others indicated they needed support with transport to perform their daily activities.

I need transport I know that. Transport's a big thing. (Interviewee no.20)

You can get community transport. But that's really hard to get into because I did try to get in when I was having this dental work where I fractured me back, and they were just booked solid. (Interviewee no. 11)

…you can get a coach between Lismore to Twin Heads. But I've done that, and it's not good with my back. My back, it's 16 hours. I had the money to just book in advance and pay the $90, I'd be there in one hour, fly. But it's all money, I haven't got the money. (Interviewee no. 4).

One indicated that support with socialising would be beneficial:

Like helping with my bi-polar, get me out there and not be afraid of other people. (Interviewee no.26)

Some interviewees indicated they needed support to help them use technology:

Maybe, the way technology's going, maybe some sort of assistance to guide me with computers and how to keep up to date with computers and how they work. (Interviewee no.30)

…I need a good technology training with computers, how to edit a video, how to make a movie. And I'm in the entertainment biz…. cause I got my channel and I have no idea how to continue that at the moment. (Interviewee no.23)

Another group indicated they needed support with house work:

I have no social worker. I am just on my own here,…housework, everything, and work. (Interviewee no.1)

Showering, house cleaning and trips to the doctor. (Interviewee no.15)

Another interviewee requested assistance with the cost of medication:

Well you see my medication's quite expensive. It's not PBS. It's hard because it costs me about 70 bucks a month. So you know, on a pension, that's difficult….I went to see a private neuropsychiatrist. It was every other

> *medication was making me tremor and sick. So I went on to that one which is expensive. (Interviewee no.31)*

4.4 Summary

This section has summarised the responses received from our 32 interviewees. We have found that a majority of the interviewees were either not aware of the NDIS or had decided not to apply for it. The findings further revealed that the lack of awareness was mainly due to the social isolation that is often associated with living with disability. For this cohort, however, social isolation and disability was compounded with socio-economic disadvantage, further complicating the circumstances of these people. The NDIS is promoted and facilitated through service providers, community programs, and technological platforms. The socially isolated population, which includes many people with disabilities, but especially those suffering socio-economic disadvantage, are missing out. In effect, the lack of socialisation limits the "hard to reach" populations' awareness and understanding of the NDIS. This suggests alternate means of connection may need to be developed to better align "hard to reach" community needs. Financial disadvantage was also noted as a barrier to NDIS application. The majority of our interviewees could not afford internet connection, and some did not have the skills to use a computer. This also suggests that these people are not readily able to access online information about the NDIS.

For those whose NDIS plan was approved there were other issues. While some interviewees were not utilising their plan at all, others had applied for a review of their plan. The latter often occurred mainly due to a lack of awareness and understanding of the NDIS and the support that it can provide at the time of application.

All of our interviewees indicated that they experience financial stress. This resulted in a heavy reliance on charitable organisations to meet their needs, such as a need for food and utilities. As explained in the interviews, the people that the SVDP had assisted had become accustomed to living on very little money and had learnt to focus mainly on their essential needs. Many interviewees indicated that they self-manage their finances. One result is that living day-to-day meant that "hard to reach" populations had a limited capacity to pursue other types of support. As such, the majority of interviewees were unable to consider the detailed and meaningful type of disability support that they could access under the NDIS

and instead limited their considerations to everyday living expenses and general transportation.

In the final section of this report, we propose four recommendations.

Section Five: Recommendations

The NDIA has publically recognised that the socio-economically disadvantaged segment of Australia's disabled population is 'hard to reach'. In response to the experiences of our interviewees, we propose the following recommendations.

5.1 Communication

The NDIA needs to improve communication with potential participants, particularly those from socio-economically disadvantaged groups. Our findings indicate that many potential participants are unaware of the Scheme. A lack of access to information was a common theme among our socio-economically disadvantaged interviewees. To promote a greater use of the Scheme requires that the NDIS leverage its use of potential partners such as Centrelink and GPs to transfer knowledge about what is offered. We advocate the creation of promotional materials such as posters or leaflets that could be placed in locations potential participants may gather.

5.2 Disability advocates

People with disabilities and who are socially and economically disadvantaged have limited access to advocacy support due to their financial status and social isolation. The employment of advocates, particularly those associated with outreach services (e.g. Uniting Care, Salvos, SVDP) would provide an opportunity to leverage the charity-based assistance and knowledge that already exists within the community and would facilitate NDIS knowledge sharing. This would bring some assurance that socio-economically disadvantaged people with disabilities (especially those with a psychosocial disability) who are not participants in the NDIS can effectively engage with the NDIS by helping to bridge the knowledge gap between the individual and the NDIS.

5.3 Clarification of eligibility criteria

Many of our interviewees were unsure of the purpose of the NDIS and its intended targets. The current eligibility criteria could be improved to provide greater clarity for both potential participants and their family and carers. Currently there is not a publicly available assessment tool to use when assessing the eligibility of people for the NDIS. While we have

emphasised socio-economic status, homelessness and other issues, this is of particular importance for those with multiple disabilities that include a psychosocial disability. Greater clarity around eligibility criteria will assist with consistent application of assessment criteria processes.

5.4 Further research

We have reported on a pilot study of 32 people that the SVDP have assisted. We have interviewed a specific cohort of individuals, with particular demographic characteristics. This pilot study could be expanded to other SVDP Conferences in other parts of NSW and/or Australia to examine for similarities or differences. Research might also examine the needs of potential NDIS participants who, for example, have multiple disabilities, are from culturally diverse backgrounds, are experiencing homelessness, or are illiterate. We have limited evidence to suggest that it is vital for NDIS planners to be able to assist this particular cohort of potential participants to plan for expenses beyond their day to day living needs and budget for services that will go some way to improving their lives. Research that investigates the NDIS planning processes will be helpful as the NDIS roll out continues. Interesting comparisons might also be made by interviewing NDIS participants who have been accessing the Scheme for some time, or who are accessing the Scheme on behalf of their children or someone in their care. With the NDIS in relative infancy, the potential for research in this area is significant.

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