Effect of the NDIS on Australian carers of individuals with an autism spectrum disorder

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Consent and Declaration

I certify that the work presented in this thesis is, to the best of my knowledge and belief, original, except as acknowledged in the text, and that the material has not been submitted, either in whole or in part, for a degree at this or any other university.

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Statement of Contribution of Others

The Statements of Contribution signed by co-authors can be found in Appendix 8.

Chapter 3 - Factors Mediating Dysphoric Moods and Help Seeking Behaviour Among Australian Carers of Individuals with Autism.

Chapter 4 - The National Disability Insurance Scheme: Effects on Australian Carers of Individuals with Autism Spectrum Disorder

The candidate, Matthew Snow, participated during all stages of the development of these papers and provided an overall contribution greater than that of any co-author. Matthew Snow designed the experiments, collected the data, ran the analyses, and wrote the first draft of the manuscripts which were revised with feedback from the co-author.

Signed
Candidate

Signed: ____________________________
Principle supervisor
**Additional Publications and Presentations**

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Abstract

Australian carers have previously reported lower levels of personal well-being and quality of life and elevated levels of dysphoric mood than the general population. It was believed the roll out of the National Disability Insurance Scheme (NDIS), the new model of disability support in Australia, may have a positive effect for carers. The purpose of this study was to monitor any effects the NDIS had on the personal well-being and quality of life in those caring for an individual with an Autism Spectrum Disorder (ASD carer). This longitudinal, online study was the first to control for the effect of carers’ state affect / dysphoric mood on a range of self-report measures. It was important to control for the variance across individuals in dysphoric mood as reporting on some psychometric measures, for example the Parenting Sense of Competency Scale, indicated a link between emotional state and thinking about oneself and carer experience. Notably, ASD carers reported higher levels of dysphoria at each time point so controlling for this difference was essential when comparing groups of carers on other variables.

Firstly, factors that may have limited help seeking behaviour prior to the NDIS roll out were investigated. Differences in reported levels of personal well-being and quality of life, between ASD carers caring for an NDIS participant (NDIS carers) and those caring for a Non-NDIS participant (Non-NDIS carers), were also identified. Finally, a longitudinal comparison of the same factors between ASD carers and those caring for individuals with other disabilities (Other carers) either participating, or not, in the NDIS was completed.

Stage one of the research indicated ASD carers reported slightly higher neuroticism and extroversion compared to the general population however they did not differ in their sense of parental competency. Personality, parental competency and geographic location, had no effect on ASD carers’ help seeking behaviour. In the second stage, NDIS-supported
carers reported lower personal well-being compared to Non-NDIS carers but both reported a similar quality of life. Time spent in the NDIS did not have any effect on any factors within carer type. Stage three indicated ASD carers reported lower quality of life and personal well-being than Other carers. Again, it was found that caring for an individual participating in the NDIS had no effect on either carer type’s reported level of personal well-being or quality of life.

The findings from this research suggest that all carers continue to report lower levels of personal well-being and quality of life than non-carers. Alarmingly, ASD carers reported the lowest scores in most instances. The failure of the NDIS to have a positive impact on the personal well-being and quality of life of Australians caring for those supported by the NDIS needs to be further investigated. The evidence for government efforts to reduce the number of individuals with an ASD supported by the NDIS, and the stigmatisation of ASD carers is provided and discussed. The current and long-term damaging effects on carers and for those for whom they provide essential care are linked to these misinformed characterisations by the media and public. The author argues from clinical and economic perspectives that NDIS-funded, carer respite be trialled, and research conducted to measure its effect on carer well-being and quality of life.
Acknowledgements

As Sir Isaac Newton once wrote “If I have seen further it is by standing on the shoulders of giants” and in that manner I wish to acknowledge the giants who have supported me throughout this project. Dr James Donnelly, Dr Alison Bowling and Dr Mitchell Longstaff, I thank you for your unwavering academic support and personal encouragement. The immeasurable hours of discussion, analysis, and inspiration you have given has enabled me to climb the PhD mountain. I will be forever thankful.

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Finally, my son and inspiration, Lachlan Brandon. You inspire me to be a better man every day. You have taught, and continue to teach, me more about life and myself than any other man. You are my left, my Beluga, my Gecko and my Axolotl.

Sadly, I won’t get to share this achievement with those I have lost during this journey – Simon Graham; Natalie Graham; Joe Mace; Alan and Betty Thacker; David Fagerlund; Larry Perry and Kevin Minotti. You all enabled me to complete this work and you are missed.
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Position of published article within the overall argument of this thesis.

Abstract

Keywords

Methods

Sampling

Participants

Dependents’ Demographics

Materials

Procedure

Results

Discussion

Conclusion
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List of Abbreviations

**ABA** - Applied Behavioural Analysis

**ABS** - Australian Bureau of Statistics

**ADHD** - Attention Deficit Hyperactivity Disorder

**ADI-R** - Autism Diagnostic Interview – Revised

**ADOS** - Autism Diagnostic Observation Schedule

**APGAR** - Appearance, Pulse, Grimace, Activity, Respiration

**AS** - Asperger’s Syndrome

**ASD** - Autism Spectrum Disorder

**ASPECT** - Autism Spectrum Australia

**AUD** - Australian Dollar

**BCBA** - Board Certified Behaviour Analysts

**BFI** - Big Five Personality Inventory

**CarerQoL** - Carer Quality of Life Scale

**CBT** - Cognitive Behavioural Therapy

**CGS** - Caregiver Strain

**CGSQ** - Caregiver Strain Questionnaire

**COAG** - Council of Australian Governments

**CP** - Cerebral Palsy

**DA_Tot** - Depression Anxiety Total

**DASS** - Depression Anxiety and Stress Scale

**DIG** - Disability Investment Group

**DISCO** - Diagnostic Interview for Social and Communications Disorders

**DS** - Down Syndrome
NDIS & Carers of Individuals with Autism

**DSM-IV-TR** - Diagnostic and Statistics Manual of Mental Disorders 4th Edition Text Revised

**DSM-V** - Diagnostic and Statistics Manual of Mental Disorders 5th Edition

**EIBI** - Early Intensive Behavioural Intervention

**LAC** - Local Area Coordinator

**MMR** - Measles Mumps and Rubella

**NA** - Negative Affect

**NDIA** - National Disability Insurance Agency

**NDIS** - National Disability Insurance Scheme

**PA** - Positive Affect

**PANAS** - Positive and Negative Affect Scale

**PANAS-Diff** - Positive and Negative Affect Differential

**PSOC** - Parenting Sense of Competency Scale

**PWB** - Personal Well-Being

**PWD** - Persons with a Disability

**PWI** - Personal Well-Being Index

**QoL** - Quality of Life

**SDAC** - Survey of Disability and Age Carers

**TD** - Typically Developing
Chapter 1. Introduction

Overview

The difficulties faced by all Australian carers has previously been highlighted in several studies, however the roll out of the National Disability Insurance Scheme (NDIS) was considered to present new opportunities and challenges for those in this group caring for an individual with a disability. In 2007, a research partnership was formed between Deakin University, Australian Unity, and Carers Australia. Their research aimed to estimate the subjective well-being of all Australian carers. After analysing Personal Well-Being Index (PWI) (International Well-Being Group, 2013), Depression Anxiety and Stress Scale (DASS) (Lovibond & Lovibond, 1995), and demographic data reported by 3766 carers, Cummins et al. (2007, p. 14) concluded that “Carers have the lowest collective well-being of any group we have yet discovered”. Also, more than a third of Australian carers have been shown to have stress levels in the ‘severe to extremely severe’ range when measured using the DASS stress subscale (Bellamy, Paleologos, Kemp, Carter, & King, 2014). Being a carer negatively impacts on a wide range of physical and mental health conditions (Johnson, Frenn, Feetham, & Simpson, 2011; Lee, Harrington, Louie, & Newschaffer, 2008; Schieve et al., 2011; Schuler, 2012; Siman-Tov & Kaniel, 2011; Smedje, Larsson, & Allik, 2006; Weitlauf, Vehorn, Taylor, & Warren, 2014; Yamada et al., 2007). Further, carer employment capacity or availability, and therefore income, savings and superannuation are all negatively affected (Australian Institute of Health and Welfare, 2014).

Those caring for individuals with a disability face further challenges as reported by the Department for Families, Housing and Community Services (2009). Along with the unique challenges related to caring for a person with a disability, their report highlighted significant problems in the system designed to support carers of those with a disability. The
author’s described Australia’s disability service system as “irretrievably broken and broke, chronically under-funded and under-resourced, crisis driven, struggling against a vast tide of unmet need” (p.19). A new paradigm of disability support, the NDIS, was heralded as offering all carers “certainty about the future” and “more respite and supported accommodation” (Productivity Commission, 2011, p. 12). However, those caring specifically for an individual with an Autism Spectrum Disorder (ASD) would hear from the Minister for Disability Reform, Jenny Macklin, that the NDIS would cover “most people with autism” (Aubusson, 2013 as cited in Ergas, 2013, p. 340) but who “most people” might include was undefined in the early stages of the NDIS. The lack of definition in various aspects of the NDIS, including who would be covered, what services would be covered, and who would actually deliver the services under the new scheme was seen by the current author as potentially concerning for carers, especially those who cared for those with ASD. Based on reports of difficulties faced by carers in the NDIS trial areas (Browne, 2014; Gibbs, 2014; NSW Carers Australia, 2014; Winter, 2014) it was believed monitoring how the NDIS affected the quality of life and personal well-being of ASD carers was warranted.

**Key Factors, Definitions, Demographics and History**

**Australian Carers**

The population of interest is defined by Carers Australia (2017, para. 1) as “people who provide unpaid care and support to family members and friends who have a disability, mental illness, chronic condition, terminal illness, an alcohol or other drug issue or who are frail aged”. It is important to note that formal carers (individuals who are employed as carers) are not covered by the definition. Data gathered by the Australian Bureau of Statistics (ABS) and for this research does not include data from formal carers. Also, ABS data
includes data for carers aged 15 years and over where data from the research in this thesis includes carers aged 18 years and over.

The Survey of Disability and Age Carers (SDAC), conducted by the Australian Bureau of Statistics (2016), identifies 3 main categories of carers as shown in Figure 1. Carers, aged 15 years and above, that live in the same household as the person with a disability for whom they care, and who provide the bulk of assistance to the person in terms of self-care, communication, and daily activities is identified as a primary carer. Carers, under the age of 15, or a carer who provides some informal assistance but is not identified as the primary carer is identified as a ‘other carer’. A person identified by a primary carer as someone who can take over caring duties should the primary carer become unavailable is identified as a ‘fall-back carer’. The SDAC also includes the categories ‘unconfirmed, primary carer and principal carer’. Unconfirmed, primary carers were defined as primary carers who were unable to attend a personal interview and thus could not be confirmed as primary carers. The term principal carer ceased to be used in all SDAC’s from 2009 onwards.

The Australian Bureau of Statistics (2016) divides the assistance provided by the carer into two categories; Core activities and Non-core activities. Core activities include assistance with self-care, communication and mobility. Non-core activities encompass, household chores, transport, reading and writing, health care, meal preparation, property maintenance and assistance with cognitive or emotional tasks.
Figure 1. All persons living in households, by carer status and whether they have a disability, 2015.

Note: 1 - Estimates have been rounded to nearest 100 persons, and due to rounding the sum of subtotals may not equal totals. 2 - ‘Living in households’ comprise all private dwellings and self-care retirement accommodation but excludes cared-accommodation. 3 – in this survey, a person under 15 years cannot be considered a primary carer. ABS Survey of Disability, Ageing and Carers, Australia: Summary of Findings—2015

Gender

The Australian Bureau of Statistics (2016) reported that carers made up 11.7% of Australia’s population in 2015. In 2015 female carers accounted for 68.1% (N = 583,004) of primary carers and 55.5% (N = 1,497,834) of all Australian carers. Persons who cared for their partner made up 40% (N = 1,079,520) of carers and importantly, females made up 88%
of carers who were the parent of the person they cared for. This statistic highlights one of the difficulties encountered when attempting to research male parent carers.

**Age**

In 2015 the average age for primary carers was 55 years. At the same time, other carers had an average age of 48 years and the Australian Bureau of Statistics (2016) reported a decrease in the number of carers under the age of 15 from 74800 in 2012 to 59100 in 2015.

**Employment**

The level of employment among Australian carers varies on 3 salient factors; the amount of time involved in providing care, carer type, and gender. Primary carers providing 20 hours or less of care per week reported a 69.4% employment rate (Australian Bureau of Statistics, 2016). This rate reduced to 45.6% for those providing care 20 to 39 hours per week and down to just 35.5% for those providing more than 40 hours or more of care per week. Primary carers aged between 15 and 64 years reported a participation rate of 56.3% in the labour force compared to a participation rate of 77.2% for other carers and 80.3% for non-carers. Female carers were less likely to be employed (60.8% compared to male carers (73%).

**Carers of Individuals with an ASD**

There is a lack of overarching demographical information about Australian carers of individuals with an ASD. An in-depth overview of this particular group and the many challenges they face will be covered in the literature review. An overview of the participants’ demographical data from each stage of this research will be presented in the discussions.
Carer Respite and Supports: Before and After the NDIS

Carer respite is defined as another person completing the carer’s duties while the primary caregiver has a break (Commonwealth of Australia, 2017). The break from the primary caregiver role could vary from a couple of hours to weeks in duration. Pre-NDIS carers were able to access funded respite and services such as those offered by the Commonwealth Respite & Carelink Centre Mid North Coast (2011). This funding could be used for entire family respite by means of respite for all family members including siblings, and even partial payment for a family holiday. Other services previously available, including emergency and after hours respite as well as assistance with organizing long term respite, are not funded under the NDIS. As stated in the obscurely located, Fact Sheets for Aboriginal People, Carers and the NDIS (National Disability Insurance Agency, n.d.):

“The NDIS is for people with disability. If you are a carer you can’t get a plan or support package for yourself. However, the person you care for might receive support from the NDIS and this might be good for you as well.”

Despite the obvious lack of support available to carers under the NDIS the National Disability Insurance Agency (NDIA) predicted that carers would benefit from it in two ways. “First, the NDIA suggested that supporting the participants to achieve goals would ‘directly and indirectly’ have a positive impact on carers, and secondly, this positive impact would occur due to information about, and linkage and referral to other service providers” (National Disability Insurance Agency, n.d. as cited in Snow & Donnelly, 2018, p. 2).

Unfortunately, this was not the case in the trial areas as revealed by reports in various media outlets (Browne, 2014; Winter, 2014). Current comments made by carers such as “Has anyone 'quit' the NDIS because it is all too stressful? I’m sick of it” on social media (Autism NDIS Support, 2017) publicly oppose the NDIA’s theory that carers are benefiting from the
NDIS. These comments are further supported by current media reports indicating carers, especially those caring for an individual with an ASD, are still struggling with the NDIS (Belot, 2015; Every Australian Counts, 2016; Morton, 2016; Naufal, 2016; Schumack, 2017). To the author’s knowledge, more formal, independent assessments of the effects of the NDIS on carers had not been reported before the current thesis.

National Disability Insurance Scheme

History

In 1974 a National Disability Insurance Scheme (NDIS), like the comprehensive insurance scheme New Zealand introduced in 1972, was proposed by Gough Whitlam (McDonald, 2013). The idea was due to be debated on the 11th of November 1975 however, the Whitlam Government was dismissed, and the Fraser Government shelved the idea (The Conversation, 2016) in favour of implementing Medibank (now Medicare). One group that was to be pivotal in reigniting the discussion of an NDIS was the Disability Investment Group (DIG). The group formed in 2006 after a meeting between Dr Bruce Bonyhady AM, the chairman of Yooralla (one of Australia’s largest disability support non-profit organisations) and Brian Howe, the former Minister for Health, Housing and Community Services under the Keating Labor government (Legge, 2013).

The DIG put forward an independent submission to the Australian 2020 summit meeting in 2008 outlining the need for fundamental change to disability support services. One year later, on the 22nd of September 2009, the DIG presented their report, “The Way Forward - A New Disability Policy Framework for Australia” to the Parliamentary Secretary for Disabilities & Children’s Services, Mr Bill Shorten (Steketee, 2013). This report, and numerous other submissions led to the Productivity Commission being “requested to
undertake an inquiry into a National Disability Long-term Care and Support Scheme” (National Disability Insurance Agency, 2016, para. 3).

The report found that Australia’s existing disability support arrangements were “inequitable, underfunded, fragmented, and inefficient and gave people with a disability little choice” (Productivity Commission, 2011, p. 5). The report recommended the implementation of the NDIS to provide Australians with, or in the event of, major disability the appropriate insurance cover. It further expressed that a core function of the government would be to fund the scheme in the same way it funds Medicare. Of considerable note was the report’s recommendation that the NDIS should have three main functions. Specifically, it should:

1. “cost-effectively minimise the impacts of disability, maximise the social and economic participation of people with a disability, create community awareness of the issues that affect people with disabilities and facilitate community capacity building. These measures should be targeted at all Australians”
2. “provide information and referral services, which should be targeted at people with, or affected by, a disability”
3. “provide individually tailored, taxpayer-funded support, which should be targeted at people with significant disabilities who are assessed as needing such support” (Productivity Commission, 2011, p. 63)

Introduction into Legislation

The implementation process of the NDIS accelerated in 2011 when the Council of Australian Governments (COAG) agreed with the recommendations from the Productivity Commission that a NDIS was needed to reform the current disability services in Australia (National Disability Insurance Agency, 2016). In October 2011, every Minister from the Select
Council on Disability Reform agreed to implement the foundations of the NDIS by June 2013. Even though this date was a full 12 months ahead of the Productivity Commission’s suggested timetable (National Disability Insurance Agency, 2016) in July 2012, the COAG agreed to launch the NDIS in South Australia (SA), Tasmania (TAS) and New South Wales (NSW). Other states would later agree to join the scheme except for Western Australia (WA).

On November 29, 2012, the National Disability Insurance Scheme Bill (2012) was put before the House of Representatives. Subsequently, on March 29, 2013 the National Disability Insurance Scheme Act (2013) received Royal Assent and became an official part of Australian Legislation.

**NDIS Management: The National Disability Insurance Agency**

Section 117 of the National Disability Insurance Scheme Act, 2013 (Australian Government, 2013) declared the formation of the National Disability Insurance Agency (NDIA) as the central agency responsible for administration of the NDIS. The original chairman of the board was Dr. Bruce Bonyhady AM, a father of two boys with cerebral palsy. Dr. Bonyhady and the NDIA Board were responsible for ensuring effective and efficient functioning of the NDIA as well as determining the strategies, policies and objectives of the NDIA (The Royal Australasian College of Physicians, 2016). The rest of the board (National Disability Insurance Agency, 2013) included:

1. Dr. Rhonda Galbally AO - contracted Poliomyelitis at a young age (ABC News, 2013)
2. Ms. Geraldine Harwood
3. Mr. John Hill
5. Mr. Martin Laverty
6. Ms. Fiona Payne
7. Mr. John Walsh AM – person with high-level quadriplegia (O'Reilly, 2011)

There was a level of concern expressed by the disability community as the board included just two people with disabilities, and two who had a child, or children, with a disability (The Conversation, 2015). The remaining board members came from disability, not-for-profit or insurance backgrounds.

**Western Australia’s variation of the NDIS**

From July 1, 2014, the Western Australian State Government began independently evaluating two different systems of disability support. The first was an extension of their current system, the WA NDIS My Way, run on behalf of the State Government by the Disability Services Commission. The second was the NDIS, NDIA- operated for the Commonwealth by the National Disability Insurance Agency (Disability Services Commission, 2014). This trial and evaluation period was expected to enable the WA Government to compare the cost and efficacy of both schemes over a period of two years.

In April 2016, the Disability Services Minister for WA, Donna Faraqher, and the Federal Disability Minister announced they would be extending the trial until July 2017 (Laurie, 2016). After completion of the trial the WA Sate and Commonwealth Governments signed a bilateral agreement to bring the NDIS to WA. However, while the WA model implemented is consistent with the national model it is to be administered by the state. To date, much controversy still surrounds the WA NDIS. Bonyhady (2017) criticized the intergovernmental agreement to implement a different state model as they reportedly failed to consult with people with a disability and their carers in WA.

The point of contention with the WA NDIS is consumer choice. Under the WA NDIS people with a disability must use a Local Area Coordinator (LAC) to contract the service providers they choose. If they are unhappy with that service provider, they must wait to
meet with the LAC who they were assigned to change the contractual agreement made with
the provider. Under the NDIS, the final contract is between the person with a disability and
the provider. They have the option to simply stop paying the provider and find a new one
where WA NDIS participants’ must wait for the LAC to address the matter (Laurie, 2016).
This has seen many people with disabilities and their carers waiting for lengthy periods to
engage or refine services that they require.

Implementation of Major Reform

In assessing the NDIS a key consideration is the fledgling status of the NDIS and its
sheer complexity. Australia’s history of introducing major reform, such as Medicare
(previously Medibank), illustrates the difficulties of such changes. Although Medicare is now
an accepted part of the Australian health system, there were significant complex
implementation issues when introducing such a major policy and social reform (Dickinson,
2017). Just 7 months after being introduced as Medibank on July 1, 1975, the Medibank
Review Committee was established in January 1976 to address all the unforeseen issues in
its implementation (Biggs, 2004). On May 20, 1976, the Australian Parliament announced
that in October of that year Medibank Private would replace Medibank after just 458 days of
operation. Again in 1984, after passing the Health Legislation Amendment Act 1983 and
amending several other Acts, it was announced that Medibank Private would be replaced by
Medicare. It became operational on February 1, 1984 (Biggs, 2004) and suggested reforms
and refinements to payment schedules and covered services continue to occur (Department
of Human Services, 2017). More comprehensive details about Medicare are available in
Boxhall and Gillespie (2013).

The 8 years and 7 months that it took for Medicare to have a politically and socially
functioning framework is of key importance. The 3-year long NDIS trials began on July 1,
2013. The nationwide rollout commenced on July 1, 2016, just 18 months ago at present date. There are still expectations of delays in the roll out process (Conifer, 2017) especially in Western Australia. As such, the focus of the research conducted for this thesis is the effects generated by the ‘roll out’ of the NDIS and not the final form that the scheme will likely transform into at a future date. Those in the trial areas were targeted for data collection relating to the NDIS prior to July 1, 2016.

Rationale for Current Study

There is an overwhelming amount of literature indicating that parents and carers of an individual with an ASD report significantly higher levels of depression, stress and anxiety than the greater population (Allen, Bowles, & Weber, 2013; Baker et al., 2003; Benson & Karlof, 2009; Benson, 2006; Bitsika & Sharpley, 2004; Davis & Carter, 2008; Dunn, Burbine, Bowers, & Tantleff-Dunn, 2001; Estes et al., 2009; Falk, Norris, & Quinn, 2014; Hoffman, Sweeney, Hodge, Lopez-Wagner, & Looney, 2009; Keen, Couzens, Muspratt, & Rodger, 2010; McStay, Dissanayake, Scheeren, Koot, & Begeer, 2014; Pisula, 2007; Rao & Beidel, 2009; Siman-Tov & Kaniel, 2011). Even when compared to those caring for individuals with cystic fibrosis (Bouma and Streiner 1990, as cited in Cummins, 2001) or those caring for an individual with Down Syndrome (DS) (Pisula, 2007) carers of an individual with an ASD report significantly higher levels of stress. Herrema et al. (2017) reported significant, medium to large, negative correlations for the factors of depression ($r = -0.66$), anxiety ($r = -0.47$), and stress ($r = -0.52$) on the Depression Anxiety and Stress Scale 21 (DASS 21) (Lovibond & Lovibond, 1995) and quality of life as measured by the Quality of Life Scale (QoL) (Brouwer, van Exel, van Gorp, & Redekop, 2006) for carers of individuals with an ASD.

Together with the Cummins et al. (2007) findings that Australian carers’ report lower subjective well-being on the Personal Well-Being Index (PWI) than any other group, it is clear
that this population is in desperate need of support. What is not clear is if the findings from international research are representative of an Australian sample. Also, as much of the research regarding Australian carers does not group carers by the type of physical or mental health, illness, or disability of the individual they cared for, it is unknown if carer’s QoL and subjective well-being varies based on carer type.

The NDIS is one thing the majority of all Australian carers have in common. There is no avoiding it if carers want funded support for the person they care for they will have to navigate the application process. For some access will be denied, adding to their burden of care. For those carers who access the scheme respite may be limited. As clearly stated by the NDIA (n.d), “If you are a carer you can’t get a plan or support package for yourself”. There is no funding for direct carer respite of any type under the NDIS despite findings by Harris, Diminic, Marshall, Stockings, and Degenhardt (2015) that four in five Australian carers of an individual with a psychological disability had an unmet need for respite care. Reports from the NDIS trial areas about the lack of help developing plans and flexibility in funding along with inconsistency between clients in the amount of funding given, technology problems, and parliamentary in-house fighting have done little to reduce the levels of dysphoric mood felt by carers waiting for the NDIS (Gibbs, 2014; Morton, 2016; Naufal, 2016; NSW Carers Australia, 2014). The history of the Australian Government’s inability to implement a smooth transition during major policy reform is seemingly being repeated and placing increased burden on an already at-risk population. It is conceivable that the negative impact the NDIS roll out has on the quality of life and subjective well-being of Australians carers, especially those caring for an individual with an ASD, will be significant and requires longitudinal monitoring during the roll out and into the future.
Research Aims of Thesis

This thesis investigated the possible longitudinal effects the Australia-wide roll out of the NDIS had on the quality of life and the personal well-being of those who care for an individual with an ASD. The impact of caring for an individual with an ASD has on several factors related to well-being are highlighted throughout the literature. Sawyer et al (2010) reported that pressure to manage caregiving time can affect caregivers’ capacity to cope. Similarly, Seymour, Wood, Giallo, and Jellett (2013) report that problematic behaviours shown by children on the spectrum significantly increase parental fatigue. These findings are supported by Siman-Tov and Kaniel (2011) who suggest the severity of a child’s autism is positively related to parental stress. Although two of the mentioned studies relate to Australian carers of children with an ASD (ASD carers) many factors specifically concerning this group remained to be explored at the beginning of this project in 2014.

The current program of research included three components. A preliminary investigation was conducted to identify if results from international research regarding ASD carers were supported when using an Australian population of ASD carers (Snow & Donnelly, 2016). This preliminary investigation also aimed to identify if Australian ASD carers reported levels of depression, anxiety and stress that differed from Australians caring for typically developing (TD) children. It also investigated factors that could possibly mediate levels of dysphoric mood and help seeking behaviours among Australian ASD carers.

Identifying a baseline for these factors was necessary to establish an overall well-being profile of Australian ASD carers prior to the NDIS roll out. The preliminary research revealed that dysphoric mood was significantly elevated in ASD carers, therefore its effect on self-report measures of well-being and quality of life were controlled throughout the rest of the research. The second part of the research aimed to identify if the well-being profile of
ASD carers in the NDIS (NDIS carers) varied compared to ASD carers who were still waiting to enter the NDIS (Non-NDIS carers). It also investigated if this well-being profile changed over time in either carer type. Finally, the third part of the project investigated if the well-being profile of ASD carers varied compared to carers of individuals with other types of disabilities. It also investigated if being in the NDIS, or the length of time in the NDIS, had any effect on the carers’ well-being profile.

**Methodology**

This research project was conducted in stages and for clarity, in this section, they will be referred to as stage one, two, and three. This thesis incorporates two published articles generated from stages one and two of this project. Each of the published articles contains its own methods section. To maintain a consistent format throughout the thesis, the data and findings from stage three, are presented in the same format. The following explains the overall methodology used in this project, its inherent strengths, and its limitations according to the available literature. The psychometric measures used, their validity and reliability, statistical analysis methods, the Autism agencies used to target specific populations, and participant demographics are detailed in the each of the following articles. To avoid being repetitious they will not be discussed here.

This internet-based research was conducted with various nomothetic methods. Nomothetic methods use a quantitative approach to gather unbiased data using scientific methods to establish norms across groups (Fisher, Newman, & Molenaar, 2011). Typically, the means, standard deviations and other score distribution features from a clinical or specific subgroup of the population are compared to non-clinical samples or the population as a whole. In stage one, a single point survey was conducted to identify if Australian ASD carers reported a similar distribution of scores on multiple psychometric measures as other
carer types; if any of those factors affected their help seeking behaviour; and if their profile significantly differed from those caring for typically developing children. The populations of interest in this first stage were targeted using probability sampling techniques as described in chapter 3.

In stages two and three, a longitudinal, quantitative repeated measures methodology was used to acquire data from self-report surveys completed by the populations of interest across varying time spans. The longitudinal design was implemented as it held two distinct advantages for this project. First, it enabled the researcher to identify the extent, and direction, of change across individuals and groups. Second, it is the best design for investigating the effects of a change in environment (Shaughnessy, Zechmeister, & Zechmeister, 2008); in the current case, the effects of the changing environment of disability care in Australia. The repeated measures by group design allowed for comparisons between, and within groups, over time. Group design was chosen as it eliminates several threats to validity (Wampold & Poulin, 1992) and variance is reduced as participants act as their own controls (Ellis, 1999).

Ethics Approval

Prior to data collection an expedited ethics application was made to, and approved by Southern Cross University’s Human Research Ethics Committee - Approval Number: ECN-15-192 (Appendices 1)

Internet Based Research

Using the internet to obtain data from carers might be criticized because a narrower range of respondents might be included or that the method may be vulnerable to other sources of sampling bias or artefacts. Internet based research has previously been said to induce sampling bias due to the number of individuals who do not have internet access
(Shaughnessy et al., 2008). However, the point argued by Shaughnessy et al. is being locally eroded by the rapid increase of internet connections in Australia. In 1998 just 16% of Australian households were connected to the internet. At the time of the Shaughnessy et al. (2008) publication this figure had grown to 64% (Australia Bureau of Statistics, 2008). At stage one of this project the Australia Bureau of Statistics (2015) reported that 86% of Australian homes had access to the internet and users averaged 10 hours per week of personal use. Sixty three percent of those who did not have internet access reported they had no need for it. The increasing connectivity rate of Australian households to the internet has reduced the possibility of sampling bias due to the number of individuals not connected.

However, the author concedes it does not completely eliminate the chance of sampling bias. For example, age negatively correlates with internet use among carers. Older carers seemingly access and use the internet less than younger carers (Buchanan, Huang, & Crudden, 2012; Kinnane & Milne, 2010). Blackburn and Hughes (2005) also suggest that female carers are more likely to use the internet than males. This finding came from responses to a mail survey that asked participants about their internet use. The finding is reflective of the higher female response rates (76%) Blackburn and Hughes received to written communication compared to males. Although internet-based research and surveys have some limitations, in multi-cultural Australia they offer the ability to include a diverse range of participants from varying backgrounds, ethnicity and cultures (Shaughnessy et al., 2008). The author implemented other methodologies (see Sampling Method below) to reduce the effect of these limitations.

Other factors that support the use of this methodology are that internet surveys have been successful in accessing hard to reach populations such as ASD carers (Coomber, 1997; Elford, Bolding, & Sherr, 2001; Nicholson, White, & Duncan, 1999). In addition,
internet-based survey respondents report significantly less social anxiety and social
desirability bias compared to participants completing the same test using paper-based
methods (Joinson, 1999). Participants may also report more accurately and honestly than
participants in face to face interviews (Davis, 1999; Joinson, 1999). Based on examination of
IP addresses and demographic data, internet-based sampling methods also do not appear to
be negatively affected by participants responding repeatedly, and results obtained from
internet surveys are found to be consistent with the results obtained using traditional
methods (Gosling, Vazire, Srivastava, & Oliver, 2004).

Sampling Method

Shaughnessy et al. (2008, p. 142) state, “Probability sampling is far superior to
nonprobability sampling in ensuring that selected samples represent the population.” The
type of probability sampling used in the current program of research was stratified random
sampling. This method was utilised due to its reported advantages in including difficult to
access minority populations and obtaining useful results with smaller samples due to its
statistical accuracy (Lund Research, 2012). The target populations identified for this project
were Australian carers. It was believed that targeting specific carer types would result in a
simple random sample of participants (of similar group size) for between and within subject
factors. Within this population participants naturally appeared as being grouped on the
following factors:

a) Type of individual cared for:
   i. Autism Spectrum Disorder (ASD Carer)
   ii. Other Disability (Other Carer)
   iii. Typically Developing (TD Carer)

b) Individual cared for NDIS status:
i. Individual cared for NDIS participant (NDIS Carer)

ii. Individual cared for not an NDIS participant (Non-NDIS Carer)

Length of time caring for an NDIS participant also naturally varied across and within groups consistently.

During stage one and two of this project the NDIS was still being trialled in various sites across Australia. In stage one, factors relating to the NDIS were not of concern and all ASD carers and TD carers were targeted. However, stage two and three of the project required the inclusion of ASD carers and ‘Other Carers’ who were both NDIS and Non-NDIS carers. For stage two, the NDIS trial sites were targeted to gather a probability sample of ASD carers who cared for an individual who was an active participant in the NDIS. Areas outside of the NDIS trial sites were targeted to gather ASD carer participants not caring for an individual participating in the scheme. Probability sampling was used to reduce the risk of sampling error found in internet surveys as proposed by Shaughnessy et al. (2008).

Sampling

At stage one of the project resident Australian parents of children under 18 years of age, with or without an ASD, were contacted via two Autism advocacy groups - Autism Spectrum Australia (ASPECT) and Autism Victoria (AMAZE). Participants for both parent types were also solicited via Facebook, Twitter, and a recruitment email was sent to staff and students of the authors affiliated university. In stage two only resident Australian parents and carers of an individual with an ASD were contacted via major autism and carer service providers. Those caring for an NDIS participant were targeted in the NDIS trial areas, especially in South Australia as NDIS reports indicated it held the highest number of participants with an ASD. In stage three resident Australian ASD carers and carers of individuals with a disability other than ASD, both in and out of the NDIS, were targeted.
Those caring for an NDIS participant were targeted in areas where the NDIS had been rolled out in the previous 6 months. The services providers utilised to contact potential participants in stage two and three included:

- ASPECT Australia
- AMAZE Victoria
- Autism South Australia
- Autism Queensland
- Autism NT
- Carers Australia (All states)
- The Growing Space: Independent Disability Support, Information and Advocacy for Families in South Australia
- The Luke Priddis Foundation
- Macedon Ranges Autism Network Victoria
- Disability Advocacy NSW
- Disability Information and Service Hubs NSW

The author utilised Twitter to contact Nicole Rogerson, founding Director and CEO of Autism Awareness Australia (1637 followers) and Tracey Spicer, double Walkley Award winning journalist (56900 followers) and numerous other ASD support services who in turn shared a tweet with a brief description and link to the study. The author also shared a link to the study via the NDIS Grassroots Facebook page after receiving approval from the page administrators. At the time this Facebook group comprised of 34800 members. The methodology used for sampling restricts the ability to indicate the response rates for each study as it is unknown how many possible participants received the request to participate.

With these key factors in mind and despite undertakings to minimise sampling error the
findings of this research should be considered representative of individuals with access to
the internet who choose to participate in online research. Also, the significantly high number
of female participants in this research compared to males requires consideration when
interpreting the results. Although not definitive confirmation of Blackburn and Hughes
(2005) finding that female carers are more likely to use the internet than male carers, the
number of female participants in this research does reflect that 88% of those caring for a
child in Australia are female (Australian Bureau of Statistics, 2016)

**Measures**

This thesis is formatted to included two published articles. To avoid repetition
readers are directed to the Materials sections in chapters 3, 4 and 5

**Data Analysis**

Across all three stages cleansing of the quantitative data was performed using strict
controls for incomplete surveys. All questions had to be completed for a survey to be
entered into the data sets. This was done as participants were informed at the beginning of
the survey that ‘completion of the survey will imply consent’. Of note here is that qualitative
data responses from participants in all stages of the project were not systematically
analysed. To avoid repetition the reader is advised that more detailed discussion of how the
quantitative data was analysed is reported in the Results sections of chapter 3, 4 and 5.

**Insider Research / Personal Bias**

The author, a parent of a child with a profound level of Autism Spectrum Disorder,
was acutely aware of the issues surrounding personal bias faced by insider researchers from
the very beginning of this research project. Breen (2007, p. 163) defines insider researchers
as “those who choose to study a group to which they belong”. Some literature suggests
being an insider researcher has specific advantages, especially in qualitative research
These advantages also have an equal number of disadvantages, particularly the effect of personal bias. At every stage of this research project the author was aware of these potential issues and consulted supervisors to specifically mitigate these factors. Of note is that the author did not have any personal experience with the NDIS until September 2017 when the scheme became available in his area. At that time stages one and two of the research had been completed and the research articles generated and published. Data for times one and two of stage three had also been collected prior to the author having any personal involvement with the NDIS.

This project assesses quantitative data obtained from a range of carers who accessed support services requested by the author to help assist in gathering participants. At the time of requesting the assistance the author, nor his family, were engaged with, or members of the services contacted. Those who participated in all stages of the research retained complete anonymity. The author also adds that his family’s personal experience with the NDIS is not representative of the findings in this research. While navigating the NDIS has been challenging, and at times extremely frustrating, it has enabled the author to employ a formal carer to assist with caring for his son. This has enabled the author, and his wife, to return to full time work which has improved their quality of life and personal well-being.

**Organisation of this thesis:**

**Chapter 2: Literature Review.** This chapter introduces the definition, history and the complex factors related to Autism Spectrum Disorder, including its aetiology, possible genetic, perinatal, neonatal and environmental factors and diagnostic criteria. Literature that reports the multiple issues faced by carers in Australia is reviewed. Finally, the history of the National Disability Insurance Scheme and the literature that covers the issues the scheme presents to Australian carers, and individuals with an ASD is also reviewed.
Chapter 3: Study One - Factors mediating dysphoric moods and help seeking behaviour among Australian carers of individuals with autism. This published article aimed to identify factors that may have had mediating effects on the dysphoric mood and help seeking behaviours in ASD carers. With the nationwide roll-out of the NDIS set to commence it was considered necessary to identify potential pre-existing, mediating factors as they may act as confounding variables during data collection regarding NDIS participation in the following research. The effects of factors such as location, personality, depression, anxiety and stress as well as help seeking behaviours are investigated in this chapter.

Chapter 4: Study Two - The National Disability Insurance Scheme: Effects on Australian Carers of Individuals with Autism Spectrum Disorder. Continuing from the findings presented in chapter 2 this published research aimed to identify if parents and carers of individuals with an ASD, who are participants in the NDIS (NDIS carers), varied on carer well-being and quality of life when compared to their counterparts who cared for non-NDIS participants (Non-NDIS Carers) when their level of state affect was controlled for. I also followed the participants over a 12-month period to identify if carer reports changed as a function of group membership (NDIS vs Non-NDIS carers). This data was required prior to beginning stage three of the project which aimed to identify if carer reports changed across carer types and/or as a function of group membership (NDIS vs Non-NDIS carers).

Chapter 5: Study Three – The National Disability Insurance Scheme: Comparison of Effects on Australian Carers by Type of Care Given. This chapter introduces “other carers” who are defined as those who care for an individual who has a disability other than an ASD. To identify if ASD carers present a unique mood profile while navigating the NDIS it was important to compare them to other carers also navigating the scheme. The carers quality of life and personal well-being are investigated while controlling for their level of state affect to
identify if participation in the NDIS has a greater effect on either carer type. The results and findings are discussed along with the limitations surround the research.

**Chapter 6: General Discussion, Summary and Conclusion.** In this chapter the overall results are interpreted. Their meaning and importance are explored along with consideration of other possible alternative explanations. Limitations of the project are highlighted and recommendations for future research to increase what is known about carer well-being and quality of life are discussed. These factors are summarised, and the author offers a brief conclusion of the research project findings.
Chapter 2. Literature Review

The current chapter focuses on definitional and conceptual aspects of the research program. It also highlights specific factors that affect the personal well-being of those who care for an individual with an Autism Spectrum Disorder (ASD). The author has found that empirically based research of the NDIS, and this program’s effects on carers or those with a disability is extremely limited. Literature details related to each study are included in the chapters discussing the conduct and results of those projects. There is also a large volume of media based, anecdotal literature about these effects which will be explored toward the end of this chapter. I begin by introducing the biological complexity of ASD, and the early biological myths born from that complexity. The unsubstantiated causal myths of ASD are discussed to indicate the potentially severe impact they may have on the parents, in particular the mothers, of children with an ASD. When monitoring the quality of life and personal well-being of ASD carers during the NDIS rollout it is important to understand the intricate factors that create a range of significant challenges. To assist the reader in understanding these significant challenges the literature indicating how caring for an individual with an ASD can affect the care giver is introduced. Finally, literature that highlights the complexity of the NDIS is discussed while focussing on key factors that ASD carers may find significantly challenging to manage.

Autism Spectrum Disorder

Definition

ASD is a developmental disability defined by significant deficits in social, communication and adaptive behaviour (American Psychiatric Association, 2013; Centre for Disease Control and Prevention, 2016). Some individuals may display stereotypic and repetitive behaviours, poor eye contact and experience significant distress in response to
changes in routine. These symptoms range from subtle to very severe within the autism spectrum (Bauman, 2010).

**Aetiology and Myth**

It is most likely that ASD has several genetic and environmental causes (Autism Society, 2015; Whitehouse, 2016). It is outside the scope of this work to report in detail on the research testing every factor that has been investigated as a possible cause of ASD, which include oddities such as exposure to magnetic fields generated by powerlines, or television signals (Kane, 2004), or the month of conception (Zerbo, Iosif, Delwiche, Walker, & Hertz-Picciotto, 2011). Instead, a summary of the empirical evidence on the main factors is presented along with refutation of the unsubstantiated theories regarding putative causal factors that have been harmful to carers and children.

**Genetics**

Genetic issues seemingly have a role in ASD. An enormous volume of literature reporting on individual genes linked to ASD is available (for example see Lyons-Weiler (2016). A search of the Ebscohost databases using the term ‘Autism gene’ returned 2194 scholarly peer reviewed research articles conducted between 1985 and current date (16/01/2018). For the purposes of this thesis a brief overview of how genes play a role in ASD is given.

The way in which genetic problems occur is twofold; 1) a defective gene, or genes is received by the child from one or both parents or; 2) a gene is altered during embryogenesis (Arndt, Stodgell, & Rodier, 2005; Miller et al., 2005; Rodier, 2004). Evidence to support the role genes have is the increased rates of ASD found in individuals who are born with other genetic disorders including tuberous sclerosis, congenital rubella syndrome and fragile X syndrome (Autism Society, 2015; Miller et al., 2005). However, authors of the California
Autism Twins Study, the largest ever study of twins with an ASD (54 monozygotic and 138 dizygotic pairs), concluded that the heritability of ASD was only moderate (Hallmayer, Cleveland, Torres, & et al., 2011). This suggested that shared prenatal environmental factors may also play some role in accounting for variance in risk for an ASD. Hallmayer et al. (2011) reported a 70% chance of a monozygotic twin developing an ASD when the other twin was diagnosed with an ASD but for dizygotic twins, the chance was still 35%.

An Australian study carried out by Williams, Helmer, Duncan, Peat, and Mellis (2008) supported the Hallmayer et al. (2011) theory that a less than optimal shared prenatal environment is a significant risk factor for any twin pair. Another familial risk factor linked to ASD is advanced maternal age (Guinchat et al., 2012). Bilder, Pinborough-Zimmerman, Miller, and McMahon (2009b) reported that the rate of ASD was significantly increased in children of older mothers and also in mothers who had increased parity (number of previous pregnancies carried to a viable gestational time). Williams et al. (2008) also reported that maternal age over of 35 years significantly increased the risk of an ASD developing. Exactly how maternal age or number of pregnancies influences ASD risk remains unclear. The most significant genetic risk of ASD is being born male (Bilder et al., 2009b; Guinchat et al., 2012; Hallmayer et al., 2011; Williams et al., 2008). Australian data indicates that 81 to 86% of individuals with an ASD are male (MacDermott, Williams, Ridley, Glasson, & Wray, 2006). Again, why males are at greater risk is also unclear.

**Perinatal Factors**

Some individuals born premature (<37 weeks of gestational period) are reported to have increased rates of ASD (Brimacombe, Ming, & Lamendola, 2007; Buchmayer et al., 2009; Durkin et al., 2008; Johnson et al., 2010; Schendel & Bhasin, 2008; Williams et al., 2008; Zhang et al., 2010b). Although there is research that indicates a relationship between
premature birth and ASD, others have found no significant relationship between the two variables (Bilder, Pinborough-Zimmerman, Miller, & McMahon, 2009a; Burstyn, Sithole, & Zwaigenbaum, 2010; Karmel et al., 2010). No other single factor associated with higher rates of ASD has been reliably linked to the perinatal period (Guinchat et al., 2012). However, a small number of candidates require further investigation for example, breeched births (Bilder et al., 2009a; Burstyn et al., 2010; Levy, Zoltak, & Saelens, 1988; Maimburg & Vaeth, 2006), prolonged labor (Brimacombe et al., 2007; Finegan & Quarrington, 1979; Juul-Dam, Townsend, & Courchesne, 2001; Karmel et al., 2010) and low birth weight (Ikejiri, Hosozawa, Mitomo, Tanaka, & Shimizu, 2016; Limperopoulos et al., 2008). In addition, while the evidence indicates a relationship between prenatal status and other perinatal factors with ASD it is far from conclusive (Kinney, Munir, Crowley, & Miller, 2008).

**Neonatal Factors**

The APGAR test (Appearance, Pulse, Grimace, Activity, Respiration) (Apgar, 1953) is performed on newborns 1 and 5 minutes after birth. Initial score (1-minute test) is believed to indicate how well the baby has tolerated the birthing procedure and the secondary score at 5 minutes shows how well the newborn is coping outside of the womb (Mediline Plus Medical Encyclopedia, 2016). The examiner checks the newborn’s breathing effort, heart rate, muscle tone, reflexes and skin colour. A low score on the 1-minute APGAR test is reportedly linked with increased rates of ASD (Finegan & Quarrington, 1979; Glasson et al., 2004; Wang, Geng, Liu, & Zhang, 2017; Williams et al., 2008; Polo-Kantola et al., 2014). Similarly, low scores on the 5-minute APGAR test are also said to have the same link (Bilder et al., 2009a; Buchmayer et al., 2009; Burstyn et al., 2010; Finegan & Quarrington, 1979; Tsai & Stewart, 1983; Polo-Kantola et al., 2014). Again, it is unknown if these are reflective of a range of possible risk factors creating some causal mechanism for ASD or signs of an existing
ASD caused by genetic or prenatal influences. It is difficult to separate perinatal and neonatal risk factors for ASD as APGAR scores vary considerably for newborns born prematurely or with low birth weight (Rüdiger et al., 2009). Also, the positive correlation between premature gestation and low birth weight further complicates identification of the risk indicated by low APGAR scores.

The relationship between APGAR scores and ASD does seem to have merit in relation to delayed crying and birth asphyxia as some studies have shown significant correlations between these two factors and rates of ASD (Hadjkacem et al., 2016; Low, 2004). Checking the newborns skin colour using the APGAR is also valuable as newborns later diagnosed with an ASD had higher rates of neonatal jaundice (Mamidala et al., 2013; Zhang et al., 2010a). There is need for further research here as approximately 60 to 80% of newborns have neonatal jaundice (Riordan et al., 2016) so specificity for ASD is poor. It is also understood that neonatal jaundice is a primary indicator of bilirubin encephalopathy, another genetic disorder that can affect the central nervous system (Riordan et al., 2016).

The various theories about the potential causes of ASD are important to consider as parents may desperately look for answers to why their child is different and what they can do about it. Early accurate, evidence-based information about the range of symptoms that can be addressed, methods for supporting their child based on early assessment, and early access to support for the parents’ psychological reactions and physical stresses associated with caring for a child with an ASD may all reduce risk for carer dysphoria (Roberts & Prior, 2006). In addition, dispelling myths such as immunisations causing ASD postnatally is essential as they may lead parents to ignore other causal factors, blame themselves unnecessarily, and avoid using immunization to protect their child from life threatening
illnesses. A brief discussion of some of these purported or erroneous explanations for ASD are covered below in considering environmental factors that have been linked to ASD.

**Environmental Factors**

Many environmental factors have been found to have a correlational relationship with ASD (Dietert, Dietert, & Dewitt, 2011). While not considered to be causational, they are seen as possible susceptibility factors. Some that relate to the prenatal environment include viral infections (Arndt et al., 2005), exposure to thalidomide and valproic acid (Miyazaki, Narita, & Narita, 2005), and vitamin D deficiency (Grant & Soles, 2009). Postnatal factors include abnormal melatonin synthesis (Grabrucker, 2012) and zinc deficiency (Grabrucker, 2012). There is a vast amount of research being conducted to identify other possible environmental factors that may, or may not relate to ASD (Grabrucker, 2012) however many of these are outside of the scope of this literature review.

**Myths Regarding Environmental Effects**

**Refrigerator Parents Theory**

Incorrectly reported to be a cause of ASD, this theory had and continues to have, harmful effects on the quality of life and personal well-being of ASD carers. It is believed to have originated when Leo Kanner (1943, p. 250) described the parents of the autistic child participants in his misleading article in the following manner:

“One other fact stands out prominently. In the whole group, there are very few really warm-hearted fathers and mothers. For the most part the parents, grand-parents, and collaterals are persons strongly preoccupied with abstractions of a scientific, literary, or artistic nature, and limited in genuine interest in people. Even some of the happiest marriages are rather cold and formal affairs.”
Although Kanner was careful in 1943 not to suggest a lack of parental warmth as a causal factor of ASD, during a later interview with Time Magazine he described parents of children with an ASD as “just happening to defrost enough to produce a child” (Thomas, 1960, p. 78). It is believed that the phrase ‘refrigerator parents’ or ‘refrigerator mothers’ was first used in the 1950’s. The refrigerator parent theory posits that parents who are emotionally frigid and distant elicit autistic behaviour from their children. Even though Kanner is quite often credited with forming the theory it was Bruno Bettelheim who prominently subscribed to, and endorsed the theory (Wolff & Morris, 1971).

In The Empty Fortress Bettelheim, once a prisoner of war in Nazi Germany (Fleck & Müller, 1997), compared parents of children with an ASD to the Nazi SS guards of the Dachau and Buchenwald concentration camps. Bettelheim stated that behaviours shown by children with an ASD were similar to the behaviour shown by ‘Moslems’ in the camps. He described Moslems as prisoners who “deteriorated to near autistic behaviour” and who “had resigned themselves to death” due to the treatment by their captors (Bettelheim, 1972, p. 65). Since both individuals with an ASD and ‘Moslems’ displayed similar behaviour Bettelheim supposed that it must be caused by those responsible for their care. In the end Bettelheim opposed Kanner’s theory that ASD was partly innate by stating, “My own belief...is that autism has essentially to do with everything that happens from birth on...” (1972, p. 393).

This stigmatising of parents of children with an ASD has been shown to have harmful effects on their social confidence and well-being (Altiere & Kluge, 2009; Carter, Martínez-Pedraza, & Gray, 2009; Dunn, Burbine, Bowers, & Tantleff-Dunn, 2001; Firth & Dryer, 2013; Gray, 2002, 2003, 2006; Gray & Holden, 1992; Griffith, Totsika, Nash, Jones, & Hastings, 2012; Hoefman et al., 2014; Lam, Wong, Leung, Ho, & Au-Yeung, 2010) yet this invalid theory
that bad parenting is a cause of ASD still appears in current media. Journalist Angela Shanahan recently employed the theory in an article for The Weekend Australian (2016) which reported on the financial sustainability of the NDIS. In the piece Shanahan states:

“the explosion in autism spectrum disorder means the fledgling National Disability Insurance Scheme is faced with huge numbers of children with various psychosocial disorders, and vocal parents who are doctor-shopping for an autism diagnosis demanding early intervention and increased financial support for an often ill-defined behavioural problem under the cloak of disability...a small but growing number of health professionals and teachers are asking whether many children on the mild end of the spectrum are suffering developmental delay combined with inept parenting, in an age when most parents have hardly seen a baby before having one themselves”

Shanahan’s reporting that parents of an individual with an ASD are vocal, doctor-shopping, demanding and inept was totally lacking in any support from empirical evidence. This inept public reporting forces ASD carers to use valuable energy to refute the refrigerator parent myth. Shanahan’s article brought forth the ire and despair of ASD carers as shown by the self-advocation of former journalist (also from The Australian) and mother of three children with an ASD, Cathy Pryor. In her reply to Shanahan’s article on the Asperger Autism Advocacy Australia (A4) website Pryor (2016) says:

“it beggars belief that years after the notion that autism was caused by uncaring, “refrigerator mothers” was debunked-, parents would again be
blamed for being “inept” because they are seeking help for the challenges their children face”

The unconstrained use of non-factual theory in public and social media can have serious negative effects on parents and carers as shown by Rees (2017, n.p) who reported that one mother “feared being reported to social services daily because people confuse her son’s (ASD) symptoms with neglect”.

**Vaccinations and Thiomersal**

The role of vaccinations in ASD was one of the most damaging and enduring myths to be falsely linked as a causal factor of ASD, especially for parents of a child diagnosed around the time of this myth’s conception. In October 1997 Andrew Wakefield (also known to have unethically taken blood from children at his own son’s birthday party) submitted a self-contradicting article to *The Lancet* journal. In the article, published February 1998, Wakefield identified that ASD behaviour was first detected in 9 out of his 12 child participants within weeks of receiving the Measles Mumps and Rubella (MMR) vaccination. It was believed Thiomersal, the mercury-based preservative in the vaccine, was to blame due to the known harmful effects of mercury poisoning. The article contradicts itself in several places where Wakefield (1998, p. 640) states: “Rubella virus is associated with autism and the combined measles, mumps and rubella vaccine” but then follows with (p. 641) “We did not prove an association between the measles, mumps and rubella vaccine and the syndrome described.”

How the research was funded offers some explanation for the contradictions.

The funding, supplied by The Legal Aid Board, for Wakefield’s research was arranged by solicitor Richard Barr (General Medical Council, 2010). Barr had been working with several clients seeking compensation for alleged harm caused by the MMR vaccine during the 1990’s. In 1996 Wakefield advised Barr on what research would be required to prove
that the MMR vaccination was causing the injuries (General Medical Council, 2010). The General Medical Council’s hearing into Wakefield’s fitness to practice (one of the longest hearings in its history) revealed that Wakefield had intentionally supplied Barr what he needed. This theory was supported by the fact that participants had been screened to ensure they had been vaccinated with the MMR vaccine and that they had also manifested a disintegrative disorder (General Medical Council, 2010, p. 8).

An overabundance of research and commentary that debunks Wakefield’s claims (American Academy of Pediatrics & United States Public Health Service, 1999; Baker, 2008; Fitzpatrick, 2005; Gorski, 2007; Honda, Shimizu, & Rutter, 2005; Lenzer, 2005; Stokstad, 2003) was published in the decade following The Lancet article. Strong evidence against Wakefield’s claims is now found in the constant number of Australian children diagnosed with an ASD despite changes in the vaccines. Thiomersal was removed from all vaccines on the Australia National Immunisation Program for children under 8 years of age in the year 2000 (National Centre for Immunisation, 2009). It was also removed from all immunisation vaccines in the United States in 2001 (Centers for Disease Control Prevention, 2013). If Wakefield’s hypothesis held any merit, why have we not seen a notable reduction in the number of children being diagnosed with an ASD since 2001?

It took 12 years for Wakefield’s article to be retracted (Harris, 2010) but the harm was already done. In those 12 years the number of children being vaccinated plummeted (Rao & Andrade, 2011) and a number of measles outbreaks occurred in the UK, USA and Canada (Eggertson, 2010). Shortly after the publication was released Petrovic, Roberts, and Ramsay (2001) revealed that 13% of GP’s and 27% of nurses believed that the MMR vaccine was very likely to cause ASD which gives evidence to support the claim that Wakefield’s fraudulent act is considered one of the most serious in medical history (Godlee, 2011).
For parents of children with an ASD this potentially elicited more feelings of guilt by making many believe they had poisoned their children. Despite the insurmountable empirical evidence that refutes a link between vaccination and ASD some, such as the Safe Minds Group, still promote this damaging theory. After hearing about Wakefield being struck off the medical register and the article being retracted, Jim Moody, director of Safe Minds said the actions taken “would strengthen Dr. Wakefield’s credibility with many parents” (Harris, 2010, p. np). Moody, desperate not to have his beliefs discredited, exhibited his lack of knowledge regarding the peer review process by stating, “Attacking scientists and attacking doctors is dangerous ... This is about suppressing research, and it will fuel the controversy by bringing it all up again.” The scientific community is obliged to expose false and damaging research and have done so in the above two cases. However, the arguments about Thimerosal, refrigerator parents and their relationships with ASD go on and continue to stigmatise ASD carers and other immediate family members (Neely-Barnes, Hall, Roberts, & Graff, 2011). The continuation of high-quality research into ASD and those who care for those with this spectrum of conditions is therefore essential in combatting the ignorance and misinformation that persists.

**Diagnosis Procedure**

The diagnostic procedure for ASD is long and complex. It is an especially stressful time for parents (Stuart & McGrew, 2009). Early indicators are usually spotted by parents and or early childhood workers (Dereu et al., 2012). During this critical time parents are torn between retaining their child’s ‘normal’ status or to risk an ASD diagnosis (Russell & Norwich, 2012). When the decision is made to identify if the child has an ASD the first appointment is commonly with a General Practitioner (GP) for referral on to a Paediatrician.
Normally from this point there is a team of professionals involved in the process. This team may include clinical psychologists as well as speech, behavioural and occupational therapists.

The paediatrician investigates the child’s developmental history and consults with the parents regarding family health history. The psychologist will normally conduct a battery of psychological assessments to ascertain the child’s abilities across several domains. For children as young as 12 months the Autism Diagnostic Observation Schedule (ADOS) (Lord et al., 2000), which uses observational techniques in a play-based format, may be used. Semi-structured interviews and tools such as the Diagnostic Interview for Social and Communications Disorders (DISCO) (Wing, Leekam, Libby, Gould, & Larcombe, 2002) and the Autism Diagnostic Interview – Revised (ADI-R) (Rutter, Le Couteur, & Lord, 2003) are also commonly used. Accurate assessment for children who are non-verbal requires a trained specialist who is able to use, and accurately interpret, non-verbal measurements during assessment. Speech therapists are required to build a functional communication profile to determine if the child has significantly delayed speech for their age (Neubauer & Fernandes, 2013). Occupational therapists can assist by developing a full sensory profile for the child to determine which of their senses is most effected by external stimuli and if any supports for motor impairments are required.

The information obtained by the team of specialists is combined to give an overall view of the child’s capacity across the several domains. In Australia, the child’s profile is evaluated against the diagnostic criteria in the Diagnostic and Statistics Manual of Mental Disorders 5th Edition (DSM-V) (American Psychiatric Association, 2013). The individual’s ASD severity, or location on the spectrum, is based on the level of social communication impairment and how restrictive and repetitive the patterns of behaviour are. The DSM -V has 5 criteria that need to be met the first two, criteria A and B, contain 3 and 4 sub-criteria
consecutively. Clinicians are also asked to rate the level of support the individual requires based on the severity of the condition (American Psychiatric Association, 2013). The support ratings are:

- Level 1 – Requiring Support
- Level 2 – Requiring Substantial Support

Despite the DSM-V clearly stating, “the descriptive severity categories should not be used to determine eligibility for and provision of services” (American Psychiatric Association, 2013, p. 51) the NDIS legislates those with a Level 1 rating are not eligible for funding (Australian Department of Human Services, 2017). These support ratings have an effect on those previously diagnosed with Asperger’s Syndrome (AS) under the Diagnostic and Statistics Manual of Mental Disorders IV, Text Revised (DSM-IV-TR) (American Psychiatric Association, 2000). As noted in the DSM-V diagnostic criteria (American Psychiatric Association, 2013, p. 51):

“Individuals with a well-established DSM-IV diagnosis of autistic disorder, Asperger’s disorder, or pervasive developmental disorder not otherwise specified should be given the diagnosis of autism spectrum disorder. Individuals who have marked deficits in social communication, but whose symptoms do not otherwise meet criteria for autism spectrum disorder, should be evaluated for social (pragmatic) communication disorder”

For many previously diagnosed with AS, who once received funding for services and supports, the new DSM-V support ratings and the NDIS legislation have left them without the support they require (Autism Asperger’s Advocacy Australia, ND). Those caring for these children are by extension negatively affected in terms of financial support and access to specialist resources.
**Treatment**

There is no known cure for ASD however, an early diagnosis coupled with early intervention and other psychosocial treatment therapies may help reduce the impact of some symptoms, such as anxiety (Sung et al., 2011; Walters, Loades, & Russell, 2016). Early diagnosis and support for parents of children with ASD has also been shown to be helpful in reducing familial stress (Dillenburger, Keenan, Doherty, Byrne, & Gallagher, 2010). A diagnosis enables parents to stop worrying about the unknown and develop a strategy for early intervention. For example, Cognitive Behavioural Therapy (CBT) for older children is reported to be effective in some cases of ASD (Cartwright-Hatton et al, 2004, as cited in Walters et al., 2016) yet there is still much debate about its overall effectiveness in treating those with severe communication impairments (Chalfant, Rapee, & Carroll, 2007). Applied Behavioural Analysis (ABA) therapy, when used as part of an Early Intensive Behavioural Intervention (EIBI) has been found to improve expressive and receptive language and adaptive behaviour in young children with an ASD (Peters-Scheffer, Didden, Korzilius, & Sturmey, 2011). Its efficacy in older individuals is still debated.

**Family and Carers**

Caring for an individual with an ASD effects every aspect of an ASD carer’s life. It has been reported that the more profound the level of ASD an individual has their carer will report increasing levels of dysphoric mood (Bromley, Hare, Davison and Emerson, 2004). What these increased levels of dysphoric mood have on the outcomes for the individual with an ASD is unclear now. I have reviewed below several effects on carers related to the current thesis including dysphoric mood, social dysfunction and isolation, and negative effects on relationships and financial status. I also review the literature on possible predisposing factors
such as personality and most importantly for the current program of research, what the National Disability Insurance Scheme entails and how it might affect carers.

**Depression, Anxiety and Stress**

ASD carers are consistently shown to have significantly increased rates of depression, anxiety and stress when compared to parents and carers of typically developing individuals (Allen, Bowles, & Weber, 2013; Baker et al., 2003; Baker, Seltzer, & Greenberg, 2011; Benson & Karlof, 2009; Bitsika & Sharpley, 2004; Duarte, Bordin, Yazigi, & Mooney, 2005; Dunn et al., 2001; Falk, Norris, & Quinn, 2014; Sanders & Morgan, 1997; Sharpley, Bitsika, & Efremidis, 1997; Weitlauf, Vehorn, Taylor, & Warren, 2014). Sivberg (2002) suggests this difference is driven by the greater level of strain, and its effect on coping, found within families of individuals with an ASD. The level of parental strain is positively correlated with the level of aberrant behaviour displayed by the family member with an ASD (Baker et al., 2003; Lecavalier, Leone, & Wiltz, 2006; McStay, Dissanayake, Scheeren, Koot, & Begeer, 2014; Sanders & Morgan, 1997). This increasing level of strain is thought to diminish parental coping which in turn leads to an increase in dysphoric mood.

These significantly increased rates of dysphoric mood are also found between ASD carers and those who care for individuals with other types of disabilities (Sanders & Morgan, 1997). Pisula (2007) and Sanders and Morgan (1997) reported that mothers of individuals with an ASD have greater levels of stress than mothers of individuals with Down’s Syndrome (DS). An insight into the foundation of this phenomenon is offered by Siklos and Kerns (2006) who investigated what needs were reported as most important by British Columbian parent carers (56 ASD and 32 DS) and which of those needs were being met. They found that ASD carers were significantly less satisfied with the professional support given to their child from the time of diagnosis when compared to DS carers. Siklos and Kerns also revealed that
93% of the ASD carers reported inadequate funding for supports as the most unmet need for their child compared to 63% of DS carers. This finding is considered important to the overall scope of this thesis as individuals with a level one, ASD support rating are not eligible for any funding under the NDIS as previously reported.

Another finding of importance for this project is that mothers of individuals with an ASD have been shown to have increased levels of dysphoric mood compared to fathers (Allen et al., 2013; Davis & Carter, 2008; Little, 2002; Olsson & Hwang, 2001). Personal connection to the individual maybe one reason for this gender effect, as illustrated by Grzadzinski, Luyster, Spencer, and Lord (2014), who indicated that children with an ASD show less pro-social behaviour towards their fathers than their mothers after a brief separation. However, fathers are far less likely to participate in research on autism, parental stress and family functioning (Johnson & Simpson, 2013). The current author found that mothers accounted for 90% of participants in the ASD research he conducted. The differences in scores across gender groups could therefore be a statistical artefact; a larger sample of participants should score closer to the overall population mean score, suggesting that small samples of fathers may more significantly deviate from the mean than scores from mothers. This alone may account for the variation in apparent dysphoric mood levels between parents when assessed at the group level.

**Personal Well-Being**

Personal well-being is defined as the level of satisfaction an individual has with their life as a whole (Cummins et al., 2007). It differs from happiness in that it is relatively stable and does not rapidly change from one moment to the next. Between 2001 and 2007 the Australian Centre on Quality of Life at Deakin University conducted 17 surveys investigating the personal well-being of several groups within the Australian population. The mean
Personal Well-Being Index (PWI) score for the Australian population was 74.9 out of 100. One of the key factors in the conceptualisation of this thesis was the finding by Cummins et al. (2007) that of all the groups surveyed, carers reported the lowest collective well-being. Not only did Australian carers record a mean score on the Personal Well-Being Index (PWI) of just 58.5 they were also the largest group surveyed by Cummins et al. This finding occurred despite means based on larger samples typically being closer to the mean score for the population. Cummins et al. (2007) determined that factors which normally mitigate low PWI (social supports, wealth, relationships, etc.) may not be as effective for carers as they are for the rest of the population.

Prior to his findings about carers’ personal well-being, Cummins (2005, p. 335) stated a carer’s role “is to provide resources and protection against strong threats to homeostasis” to ensure the individual they care for has a normal range of personal well-being. This task can seem insurmountable for ASD carers due to the significant levels of fatigue they report compared to carers of typically developing individuals (Giallo, Wood, Jellett, & Porter, 2013). Fatigue and lack of sleep have been shown to have a negative effect on health and well-being (Institute of Medicine, Research, Colten, & Altevogt, 2006). Despite these stressors, some ASD carers show incredible resilience and coping skills (Bayat, 2007; Cashin, 2004). In a population that has significantly lower levels of personal well-being even small amounts of resilience can be beneficial in buffering its effect (Bitsika, Sharpley, & Bell, 2013) however it is uncertain how long ASD carers can maintain these levels of resilience.

**Felt Stigma**

A stigma is defined as an “attribute or characteristic that conveys a social identity that is devalued” (Crocker et al, 1998 as cited in Link & Phelan, 2001, p. 369). Stigmatisation occurs when components of “labelling, negative stereotyping, separation, status loss, and
discrimination co-occur in a power situation that allows the components of stigma to unfold” (Link & Phelan, 2001, p. 367). The phenomena of ‘felt stigma’ or the stigma felt by carers raising a child with an ASD has been found globally (Austin, Galijot, & Davies, 2018; Daniels et al., 2017; Farrugia, 2009; Kinnear, Link, Ballan, & Fischbach, 2016; Phelan, 2005; Thibodeau & Finley, 2017). Broady, Stoyles, and Morse (2017) suggest that ASD carers in Australia are seen by others as having similar deficits to the individual they care for.

Gray (2002) reports that during a public meltdown by their child with an ASD, carers feel they are judged (stigmatised) as bad parents while Greene (2003) reports parents feel their child is judged as ‘bad’ rather than disabled. When comparing levels of perceived stigma between carers for children with differing types of disorders (ASD, intellectual or physical), ASD carers report significantly higher levels of stigmatisation than the other carer types (Werner & Shulman, 2015). The effect of this perceived and felt stigma is that many ASD carers resort to avoidance type behaviours (Werner & Shulman, 2015). It is easier to avoid social events and public places than to deal with the negative effects that stigmatisation has on their personal well-being and the well-being of the individual they care for (Gray, 2006; Green, 2003).

**Social Isolation**

Informal carers experience higher levels of social isolation than non-carers (Harris, Diminic, Marshall, Stockings, & Degenhardt, 2015). A lack of social, family and financial supports are all factors that contribute to carers becoming socially isolated (Bellamy, Paleologos, Kemp, Carter, & King, 2014; Broady et al., 2017; Buultjens et al., 2014; Harris et al., 2015). Gill and Liamputtong (2013) offered a theory that ASD carers socialize into the label they have been given. This theory posits that society labels someone a parent and, as a parent, should act and behave in a specific way. ASD carers feel socially isolated (again
stigmatised) by this concept as they have to employ very different parenting strategies, some of which do not fit in with societal views.

For individuals with an ASD, social places, such as supermarkets, restaurants and movie theatres can be the antecedents to a ‘meltdown’ (Ryan, 2010). A meltdown is defined by Bedrossian (2015, p. 6) “an involuntary physical and emotional reaction to a situation from which there is no perceived escape... Autism-related meltdowns result from peaking stressors and overload of the nervous system, causing an explosive behavioural release.”

Avoidance in those who are already socially anxious has long been identified as a negative reinforcement loop which serves to increase one’s social isolation and the severity of anxiety disorders (Ekman & Hiltunen, 2015). Due to the unpredictable nature of meltdowns, carers choosing to avoid social situations is reinforced by the immediate reduction in anxiety or frustration associated with past experiences of stigmatisation when their child struggled in a public setting (Gray, 2002). In addition, for many ASD carers who may be willing to go to a restaurant, movie theatre, or to the homes of other family and friends, the lack of respite services to care for the individual while they go (Harris et al., 2015) or a lack of available finances (Fletcher, Markoulakis, & Bryden, 2012) can also be significant social barriers.

Financial Concerns

The time demands of caring for an individual with a disability can impact the family members’ capacity to engage in an occupation (Crowe & Michael, 2011). This finding is supported by Crowe and Florez (2006) who reported that carers of individuals with a disability spend a significantly greater amount of time in giving care than parents of TD children. This burden of care has a limiting effect on the carers’ earning capacity (Sawyer et al., 2010). Compounding this issue is the extra financial cost of raising a child with an ASD. Jarbrink, Fombonne, and Knapp (2003) calculated the extra weekly out of pocket expenses
to be approximately £73.10 (AUD $129.75) to raise a child with an ASD compared to a typically developing child. These extra costs primarily included household damage, specific foods, laundry and transport. They did not include services or items such as health services, medications, early intervention or education.

In Australia, labour force participation rates for primary carers (as defined on page 18) is just 56.3% compared to 80.3% for non-carers (Australian Bureau of Statistics, 2016). Among carers this number varies significantly based on the level of care they provide. Of those caring 20 hours or less per week 69.4% had employment in the labour force compared to only 35.5% of those providing 40 hours or more of care. Jarbrink et al. (2003) reported that ASD carers, on average, provide 43 hours per week of care. Based on these findings it is highly likely that many ASD carers in Australia are at significant risk of underemployment and severe financial burden.

**Marriage and Relationships**

While ASD appears to pose more challenges for parents than other types of disabilities (Seltzer et al., 2003) the effect it has on marriages for ASD parents is unclear. Hartley et al. (2010) report the vulnerability period for divorce in ASD parents is longer than the general population where the risk of divorce peaks in the first several years of marriage and during the time when couples have children. For ASD parents this vulnerability period extends until their children are adults in their early thirties. One factor that may affect the divorce rate of ASD parents is the low levels of marriage satisfaction that mothers report (Rodrigue, Morgan, & Geffken, 1990; Weitlauf et al., 2014).

However, King et al. (2006) report that the challenges faced by ASD parents can cause their relationship to become more cohesive. This theory is supported by Weitlauf et al. (2014) who suggest the unique challenges ASD parents face can bring them closer
together. Although the difference in divorce rates between ASD and TD parents is multifaceted and unclear, Rodrigue et al. (1990) identified that mothers of children with an ASD reported greater family cohesion than mothers of a child with DS. However, ASD mothers reported significantly less family adaptability and sense of parental competence. Whether the seemingly positive reports about greater ‘cohesion’ or ‘closeness’ within the family of children with an ASD is a consequence or side-effect of social isolation has not been investigated.

**Parenting Competency**

ASD carers largely report lower levels of parental competence on the Parenting Sense of Competency Scale (PSOC) (Gibaud-Wallston & Wandersman, 1978) than carers of TD individuals (Keen, Couzens, Muspratt, & Rodger, 2010). Factor analysis of PSOC scores from Canadian and Australian participants revealed 2 constant factors being measured by the instrument: parental satisfaction and parental efficacy (Johnston & Mash, 1989; Ohan, Leung, & Johnston, 2000; Rogers & Matthews, 2004). Parental efficacy is defined as “the feeling of competence in the caretaking role” (Kuhn & Carter, 2006, p. 565). Research has revealed that this sense of parental efficacy negatively correlates with dysphoric mood (Coleman & Karraker, 1998; Cutrona & Troutman, 1986; Jackson & Huang, 2000; Scheel & Rieckmann, 1998; Teti, O’ Connell, & Reiner, 1996). Based on previously reported evidence that ASD carers experience significantly increased levels of dysphoric mood, they may also be at increased risk of having a low sense of parental competence.

Kuhn and Carter (2006) conceptualise parental competence as one who demonstrates a sense of agency. Agentic parents might be seen as those who assume an active role in their child’s development and persist with trying to minimize a child’s aberrant behaviours while increasing their adaptive behaviours. This may appear as a seemingly
doggled determination in seeking services and reflecting on the most effective supports for their child. Knowledge of ASD, therapies and their outcomes can also increase parental agency. Kuhn and Carter (2006) also describe how parental guilt can reduce this sense of agency. Certainly, if a parent notes that their dysphoria or maladaptive behaviour is affecting their child this could further contribute to these feelings of guilt. In stark contrast to the refrigerator parent theory, evidence indicates that carers of children with ASD may be agentic and engaged, even when quite distressed in their roles as they seek to find adequate support. However, the burdensome nature of being an ASD carer, its negative effects on mood, parental competence and agency, as well as the generation of guilt may lead to social withdrawal. This may offer some explanation as to why Kanner (1943, p. 250) described ASD carers as “preoccupied…and limited in genuine interest in people” (Kanner, 1943, p. 250).

**Personality**

Examining what we refer to as personality among carers of those with an ASD can be problematic. One’s personality can affect how coping with stressors of all kinds however our personality does not cause genetic disorders in others. Once the carer starts to face the challenges of the carer role, how they appeared previously may change. Personality’s role in caregiver coping has been investigated however the effect caregiving has on personality has not been investigated. Schofield et al. (2012, p. 256) define personality as “a set of psychological characteristics that lead one to behave in meaningfully consistent ways.” The possible effects that personality has on help seeking behaviour of ASD carers is an important factor investigated in this project. It is primarily investigated to identify if it effects carers help seeking behaviour. The five factors of personality (John, Naumann & Soto, 2008), openness, conscientiousness, extraversion, agreeableness and neuroticism have all been found to affect various factors related to the carers and risk for dysphoria. Early research of
the relationship between personality and parenting by Belsky (1984) discusses the influence a child can have on a parents’ personality.

The theory posed by Belsky (1984) is maintained by Oliver, Guerin, and Coffman (2009) who reported higher levels of conscientiousness positively mediated a carer’s ability to reduce the problematic adolescent behaviour displayed by their children. Prinzie, Stams, Dekovic, Reijntjes, and Belsky (2009) agreed with Oliver et al. (2009) however they reported that effective control over a child’s behaviour was also associated with higher levels of carer openness, agreeableness and extraversion. Bornstein, Hahn, and Haynes (2011) report that higher levels of neuroticism are associated with higher anxiety and lower levels of parental satisfaction and competency in parents of typically developing children. One part of neuroticism is the level of concern held for others (Bornstein et al., 2011) which suggests that ASD carers may score higher on this factor due to the high levels of concern they hold for their child’s future (Todd & Jones, 2005).

Personality has been confirmed as the best predictor of life satisfaction in a longitudinal Australian study that used a large sample \( N = 8625 \) (Boyce, Wood, & Powdthavee, 2013). One dimension of personality that is challenged by Boyce et al. (2013) is the belief that it is relatively consistent or fixed. They showed that personality does change, and that these changes to personality co-occur with changes to personal well-being and quality of life. What still needs to be answered is the direction of this effect. Does increasing levels of personal well-being increase quality of life which in turn elicits more positive aspects of personality or, vice a versa? Overall, the possible effect that personality may have on ASD carers help seeking behaviours needs to be identified.
National Disability Insurance Scheme

The history, legislation, management, variation in WA and the implementation factors of the NDIS have been alluded to in the previous chapter. This section will review factors of the NDIS that directly affect carers. At the time of writing there was minimal empirical evidence regarding NDIS and carers however what is available will be supported by multiple news and media reports.

Reasonable and Necessary Information

Accessing adequate information regarding disability support has been reported as a significant challenge, particularly in terms of what is required for a child to qualify for support (Dew et al., 2013). For example, Simpson and Baldwin (2017) reviewed 140 websites providing NDIS information for carers of individuals with a hearing impairment. They reported that the information available was only of fair quality and only 8% (N = 11) of the sites linked users to the actual NDIS website. They also found that the accessibility of NDIS information for carers was poor. Importantly ASD carers in Australia have been recognised as being more aware of the support services available (Ranasinghe, Jeyaseelan, White, & Russo, 2017). This finding is interpreted cautiously as the sample of ASD carers in Ranasinghe et al. (2017) study of carers’ experience with the NDIS was small.

Ranasinghe et al. (2017) conveyed that carers reported the lack of information on the NDIS website made the application and registration process difficult. This partially relates to the core principle of the NDIS which is “reasonable and necessary supports”. The Australian Department of Human Services (N.D.) defines the terms as:

“Reasonable means something fair and necessary means something you must have. The NDIS funds reasonable and necessary supports relating to a person’s disability to help them live an ordinary life and achieve their goals.”
This appears to be the first point of confusion for many navigating the NDIS due to the contradiction of the two main words (Foster et al., 2016). The Oxford dictionary defines necessary as “Needed to be done, achieved, or present; essential” (Oxford University Press, 2018) and reasonable “As much as is appropriate or fair; moderate” (Oxford University Press, 2018). However, the two terms are not separated under the NDIS and the conjunction ‘and’ indicates that both must occur. The provision of necessary supports is limited by what is considered reasonable (Foster et al., 2016). The wording of this clause enables the NDIA to ‘moderate’ the level of ‘essential’ supports needed by people with a disability (Foster et al., 2016). For example, a Local Area Co-ordinator (LAC) from the NDIA may agree that a front fence is necessary to prevent a person with a disability from absconding onto a highway however, NDIS policy does not consider it reasonable for the fence be funded under the individual’s NDIS package. One term appears to relate to the true needs of the child while the other relates to NDIS funding limitations, or even the knowledge, training or whims of the person making rulings on individual cases and requirements.

Further evidence of the confusion caused by the NDIS literature is found in a report from NSW Carers Australia (2014). After the first year of trials carers were still confused by the terminology being used. NDIA and NDIS were being used interchangeably, there was a vast lack of key term definitions in legislation and guidelines, and most puzzlingly for ASD carers, words such as “respite’ were out of favour but an alternative had not been offered. The report also highlights issues in the quality and consistency of information given by the NDIA and the NDIS website. The first two recommendations given by NSW Carers Australia (2014, pp. 13 - 14) to the NDIA were:
1. “...the NDIA and NSW Government improve the availability, consistency, timeliness and accessibility of information provided to people with disability and their carers in NSW regarding the NDIS”

2. “... the NDIA simplify and define the language used in their communications”

Those recommendations, and many others submitted to the NDIA (which will be discussed shortly) fell on deaf ears. Although the available NDIS and NDIA literature has evolved, the term ‘reasonable and necessary supports’ still causes considerable confusion for ASD carers (AMAZE, 2017).

**ASD Eligibility Debate**

Perhaps the most distressing issue for ASD carers was / is the debate surrounding the eligibility of individuals with an ASD to enter the NDIS (Victorian Parliament, 2017). National newspaper headlines such as “Surging Autism puts a Strain on NDIS” (Morton, 2016b) and “Rethink on NDIS Autism Strategy” (Morton, 2016a) have done little to quell the worries of ASD carers. As previously stated the “descriptive severity categories should not be used to determine eligibility for and provision of services” (American Psychiatric Association, 2013, p. 51). Despite this notice the Australian Department of Human Services (2017, p. N.P.) requires evidence of ASD permanent impairment / functional capacity to qualify for the NDIS as follows:

“Autism diagnosed ... and assessed using the current Diagnostic and Statistical Manual of Mental Disorders (DSM-V) diagnostic criteria as having severity of Level 2 (Requiring substantial support) or Level 3 (Requiring very substantial support)”

Minister for Disability Reform, Jenny Macklin’s pre-NDIS rollout statement that “most people with autism would be covered by the NDIS” (Aubusson, 2013 as cited in Ergas, 2013, p. 340) is apparently far fewer than anticipated. ‘Most people’ was sounding more like ‘the
number affordable’. Backhouse (2017) stated that an acceptable level of care is not possible for Australians with a disability under the current version of the NDIS. The NDIS model using restricted, diagnosis-based criteria (rather than on true needs) will see many young children (<5 years) with an ASD diagnosis and severity rating of one excluded from early intervention programs that could improve their long-term outcomes on several life factors (Badawi, 2012). Autism Asperger’s Advocacy Australia (ND, para 1) summarise the NDIS exclusion of individuals with an ASD by stating “The NDIS fails many people with ASD, denying them the services and supports they need.”

This is a contentious issue for ASD carers and the NDIA that is currently a topic of much debate and fuels heated online debates which further affects ASD carers’ well-being. An example of the damaging comments about kids with autism and their parents who are trying to access NDIS funding is found in the comments responding to a Rick Morton’s (2015) social affairs article in The Australian titled, ‘NDIS role suspected in the rise of autism.’ The article attempts to form a link between the availability of NDIS funding and an increase in ASD rates. Comments about the article strongly illustrate why ASD carers feel socially stigmatised and why the debate about access to NDIS funding for individuals with an ASD may be exacerbating the dysphoric mood of ASD carers.

**Henry (August 2, 2015)** “We know nothing about autism, and why numbers are exploding, the one thing we do know, ‘apparently’, is that the vaccines aint [sic] to blame” Comment liked 15 times.

**David (August 2, 2015)** “...NDIS was designed to mainly deal with the severely disabled & how autistic children have become severely disabled is unclear...Unfortunately whenever large amounts of government money becomes available the line up to get that money gets longer...” Comment liked 15 times.
Raymond N (August 1, 2015) “Don't get between any industry (especially a medical or self diagnosing or self identifying one) and a barrel of other peoples' money.” Comment liked 18 times.

Daniel (August 1, 2015) “autism is a scam, just like add, and adhd. nothing some solid disipline [sic] couldn't resolve. kids need fresh air, vegetables, sunlight, and supervision. if you can't provide this, you shouldn't be a parent.” Comment liked 8 times.

Level of Support

If the individual with an ASD does get into the NDIS, accessing the required level of support / funding becomes the next hurdle for the carer. This hurdle arises specifically for individuals with an ASD and their carers due to the appalling lack of planning that occurred in the South Australia (SA), NDIS trial. The SA state government and the Commonwealth of Australia signed a bilateral agreement (Commonwealth of Australia & State of South Australia, 2013) to fund 5000 individuals based on an SA state government estimation of the number of eligible individuals under the age of 15, within the first three years (Byrt, 2013). The number of eligible individuals, even when the restricted DSM-V diagnostic criteria were applied, turned out to be 8400 (Marcus, 2015). The result was a political dispute over funding for the ‘excess’ individuals.

Attention turned to how the estimate was so wrong and the largest group of any one type of disability, ASD, came under scrutiny. Individuals with an ASD accounted for 48% of SA, NDIS participants (National Disability Insurance Agency, 2016b). The number of children with an ASD in SA became a newsworthy story and some of the media reports blamed those with ASD for delays and cost blowouts in the NDIS (Marcus, 2015; Morton, 2015, 2016a; Morton, 2016b). As a result, the NDIA announced the release of a nationally consistent approach to intervention called the NDIS Early Childhood Early Intervention (ECEI) Approach.
The final product has been met with dismay by the panel of autism experts who were commissioned to produce an advisory report for the NDIA in relation to the best early intervention practices for young children with an ASD (Browne, 2014).

The panel recommended, “Children who have received a diagnosis of autism should receive 20 hours per week of early intervention that involves interaction with them” (Roberts, Williams, Smith, & Campbell, 2013, p. 11). While not indicated in the report the cost for 20 hours per week of early intervention per annum has been estimated to be between $40,000 and $80,000 Australian dollars (AUD) (Browne, 2014). In the final model of ECEI the NDIA did not include a monetary estimation of the cost per child however research since its introduction revealed that the majority of young NDIS participants had annual packages around AUD$12,000 (Marchbank, 2017; Ranasinghe et al., 2017). The issue of children who require 20 hours per week of early intervention getting funded for just 6 hours per week (Browne, 2014; Hughes, 2017) was not addressed by the NDIA’s introduction of the ECEI model. This funding at such low levels for some young children with ASD may suggest variability across children who meet somewhat broad NDIS inclusion criteria, and variability in carer’s ability or knowledge in advocating for their child. It may also demonstrate the remarkable power that rests with the local area coordinators in judging the necessity and reasonableness of support. While the financial sustainability of the NDIS is a key factor to take into consideration, the ECEI model requires proper funding.

**Support Services for Severe or Profound ASD and Age Limitations**

The issue with the NDIS for older individuals with an ASD is not in the amount of funding but the lack of services on which they can spend their allotted funds. Applied Behavioural Analysis has been shown to improve life skills in older individuals with an ASD.
however the NDIS has not recognized the Board Certified Behaviour Analysts (BCBA) in the Australia as NDIS service providers (Autism Asperger’s Advocacy Australia, 2017). In their submission to the Productivity Commissions study into the NDIS costs, Autism Asperger’s Advocacy Australia (2017) assert that older individuals with an ASD are unable to spend all their NDIS funds due to a significant lack of available specialists. They further allege that individuals with a profound or severe level of ASD who exhibit challenging behaviours are being refused support by disability support providers. This is an example of ‘enabled discrimination’ as the NDIA will not supply funds for the purpose of obtaining an independent disability advocate (NDIS Rights, 2018).

The definition of ASD is that it is a developmental disability that causes significant deficits in social, communication and adaptive behaviour (American Psychiatric Association, 2013; Centre for Disease Control and Prevention, 2016). There is a plethora of literature reporting the significant stress experienced by individuals with an ASD in social situations (Beresford, Tozer, Rabiee, & Sloper, 2004; Bishop-Fitzpatrick, Mazefsky, Minshew, & Eack, 2015; Nation & Penny, 2008; Ochs, Kremer-Sadlik, Solomon, & Sirota, 2001; Orsmond, Krauss, & Seltzer, 2004; Singhi, Adam Kadwa, Sahu, Malhi, & Mittal; Tentori, Escobedo, Hernandez, Matic, & Hayes, 2016). Importantly, there is no evidence that exposure even under highly supported circumstances will decrease the level of distress. Individuals with severe or profound ASD have shown no positive changes when interventions aimed at improving social interaction capacity were implemented (Duffy, Baluch, Welland, & Raman, 2017). Maljaars, Noens, Scholte, and van Berckelaer-Onnes (2012, p. 810) report that children with severe ASD are “only able to perceive the world at the level of sensation or presentation, which implies that they do not (completely) understand symbolic or representational means of communication.” In summary, those affected by a profound or
severe level of ASD find social interaction and participation more disabling than enabling. It is highly likely that those with severe or profound ASD will continue to struggle tremendously in social settings even into old age, therefore how their carers are supported in facing this challenge needs to be considered.

The NDIS core support feature referred to as, “supports to assist people with disability to enjoy social and community interaction” (Australian Department of Human Services, 2018b, p. N.P) is at least irrelevant to those with a severe or profound level of ASD. Based on the above information the author argues that this feature funded by the NDIS is actually detrimental to individuals with a severe or profound level of ASD, who are negatively affected by social interaction. The core of an NDIS package is the participant’s individualized plan which “is tailored to their goals, personal circumstances and disability support needs” (Australian Department of Human Services, 2018b, p. np) so funding programs that potentially negatively affect the well-being of an individual and their carer is highly inconsistent with the stated goals of the scheme.

**More Carer Burden and No Respite**

There are two other NDIS factors that could possibly have a detrimental effect on carer well-being and quality of life. The first factor (funded in an individual’s NDIS package) is training to enhance informal carer’s ability to provide care (Australian Department of Human Services, 2018b). Informal ASD carers spend significantly more time providing care than other parent types (Smith et al., 2010), however the NDIA feels ASD carers should be formally trained to provide more ‘enhanced’ care. This enhanced care funding covers such things as an occupational therapist (OT) training the family members how to conduct occupational therapy sessions with the family member who has an ASD. It has been revealed by Carers Australia (2015b) that the majority of NDIS carers report the NDIS had not reduced
their amount of caregiving hours nor had it made it any easier for them to engage in training. In addition, relative to someone with 3 or 4 years of university-based, specialist training, it is absurd to think that a few hours of training would qualify any lay person to supply the same quality of therapy required by an individual with complex needs such as those with profound ASD. As indicated by Leif (2017, n.p.) “at its core, the NDIS wants value for the money when providing funding to families.” It is therefore reasonable to imagine that trying to apply ‘therapy’ without proper qualifications would further deflate the carer’s already low sense of competence and add to the sense of guilt when not meeting the unreasonable expectations posed by the NDIA.

It appears that NDIS plans are designed for short term fiscal benefits rather than the best outcomes for the individual with an ASD or that the contributions of carers are fully being considered. Carers Australia (2015a, p. 15) reported, “The total replacement cost of informal care in 2015 is estimated as AUD$60.3 billion.” At current date an informal Australian carer is entitled to a Carer Payment of AUD$894.40 per fortnight (Australian Department of Human Services, 2018a) which is $11.92 per hour for a 37.5-hour week. These figures strongly relate to the financial stress that ASD carers report. In contrast, formal carers are paid an hourly rate of $44.72 for weekdays between 9am and 5pm, $62.03 for Saturdays and $79.38 for Sundays (National Disability Insurance Agency, 2017). The majority of informal ASD carers also provide significantly more than 37.5 hours per week in the caring role for which they are not compensated (Alexander, 2016; Jarbrink et al., 2003; Sawyer et al., 2010). If their contribution was considered, Australian informal carers save Australian taxpayers AUD$60.3 billion annually, almost double the expected cost of the NDIS per annum (AUD$32 billion). The NDIA is not only expecting informal ASD carers to do more
than they are capable of, they are asking them to do it without the availability of funded carer respite.

Summary

ASD is a multifaceted disorder with an unknown cause for which there is no cure. It has a severe effect on many carers’ personal well-being and quality of life and pervades every domain of a carer’s life. Carers report feeling socially stigmatized and isolated due to the lasting and damaging effects of pseudoscience, and social contact with those who do not understand the disorder or the carer challenges. Many ASD carers struggle financially as the caring role effects their capacity to work. The personal and familial relationships of ASD carers, prior to the NDIS, have been found to be strained. From the reviewed literature pertaining to trial areas it is apparent the burden of the caring role appears to be increasing under the NDIS. Any added burden on ASD carers during the full NDIS rollout needs to be monitored. Early investigation to identify factors that may affect the help seeking behaviour of Australian ASD carers is required prior to the full NDIS rollout in order to control for the variation they may cause in ASD carers’ well-being and quality of life.
Chapter 3. Factors mediating dysphoric moods and help seeking behaviour among Australian 
carers of individuals with autism

Position of published article within the overall argument of this thesis.

The following article was published February 2016 in the Journal of Autism and Developmental Disorders and has been replicated to match the style and format of this thesis. The wording has not been altered.

This preliminary explorative research was conducted using a sample consisting of two carer types: carers of children with an ASD and carers of Typically Developing (TD) children to identify if ASD carers’ dysphoric mood, personal well-being and quality of life profile varied from that of TD carers. It also aimed to identify factors that may have mediating effects on the dysphoric mood-help seeking relationship in ASD carers. With the imminent nationwide roll out of the NDIS it was considered necessary to identify potential pre-existing, mediating factors as they may act as confounding variables during data collection regarding NDIS participation. For example, if this initial research indicated that an ASD carers’ location (remote, rural, regional, metropolitan) significantly affected their dysphoric mood or access to services then the variable location could be controlled for when comparing data between NDIS carers and Non-NDIS carers.
Abstract

This study compared levels of state affect, dysphoric mood, and parenting sense of competence in Australian parents of children with or without autism. The effects of personality and location on the parents’ experience were also examined, while controlling for current affect. Possible relationships among personality, location factors and help-seeking behaviour were also explored in parents of children with autism. Prior findings of higher dysphoric mood levels in parents of children with autism were supported, as was the positive correlation between dysphoric moods and Neuroticism levels. Parenting Sense of Competence did not differ across locations, and there were no parent type by location interactions. Access to services among parents of a child with autism did not moderate dysphoria levels.

Keywords

Autism spectrum disorder, depression, parenting sense of competency, Australian mental health
Autism Spectrum Disorder (ASD) is a neurodevelopmental condition defined by the Diagnostic and Statistics Manual of Mental Disorders-5th Edition (DSM-V) (American Psychiatric Association, 2013) as a dyad of persistent deficits that include: 1) restricted and repetitive behaviour patterns, and 2) social communication and interaction deficits. These deficits are typically pervasive, present in early childhood, and apparent in different settings, however there is great diversity across individuals who receive a diagnosis of an ASD and therefore great diversity in the challenges and social support needs for parents.

Social support is defined as “a network of family, friends, neighbours, and community members that is available in times of need to give psychological, physical, and financial help” (National Cancer Institute, 2015). Under this definition Autism support agencies and help providers are considered community members. The term ASD is used throughout this paper to represent autism and those conditions previously listed as subcategories in the DSM-IV-TR (Asperger’s syndrome, Childhood Disintegrative Disorder, and Pervasive Developmental Disorders-Not Otherwise Specified). The term ‘parents’ is used as a general term to describe those who are the primary care givers of a person with ASD although it is recognized by the authors that this care may be provided by a range of family members. The current work also focuses on the care of a child or teenager with an ASD although this responsibility often extends into parenting or supporting the same person as an adult.

Parents who provide care for a child with an ASD report a range of mental, physical, and health issues that is seemingly as broad and challenging as the child’s autistic behaviours. These parents regularly report clinical levels of depression, anxiety and stress (Bitsika & Sharpley, 2004; Firth & Dryer, 2013). They also report lower relationship satisfaction with their partners (Doron & Sharabany, 2013; Weitlauf, Vehorn, Taylor, & Warren, 2014 & Warren, 2014), lower sense of parenting competence (Hines, Balandin, &
Togher, 2012b 2012; Neely-Barnes, Hall, Roberts, & Graff, 2011 & Graff, 2011; Osborne & Reed, 2010), lower sense of psychological well-being (Serrata, 2012), and have been found to be significantly more at risk of sleep deprivation (Hoffman et al., 2008; Mayes & Calhoun, 2009) and mental health disorders (Bernier, Mao, & Yen, 2010 2010; Hodge, Hoffman, & Sweeney, 2011 2011; Johnson, Frenn, Feetham, & Simpson, 2011 & Simpson, 2011) than parents of typically developing (TD) children.

Another factor that influences the reported well-being of parents of children with an ASD is their country of residence and cultural background (Hussein, Taha, & Almanasef, 2011 2011; Magaña & Smith, 2006). Importantly, it has been identified that a family’s cultural beliefs and values directly influence their decisions about diagnosis, early intervention and ongoing therapies for their child with an ASD (Ennis-Cole, Durodoye, & Harris, 2013 2013). Culture affects diagnosis and early intervention as delayed social and language skills are viewed as something that will be grown out of by some cultural groups (Danesco, 1997, as cited inEnnis-Cole et al., 2013). The delay in diagnosis may impact the effectiveness of early intervention. Trembath, Balandin, and Rossi (2005) indicate that cultural minority groups teach their children to function cooperatively within groups whereas cultural majority groups tend to raise children to be self-directed learners who can be socially interactive yet independently oriented. These values impact the family’s choice of ASD treatment.

Investigation of any effects Australia’s multi-cultural society has on parents of children with an ASD is outside the scope of this investigation, however, the current study did examine some factors that are related to the Australian experience of raising a child with an ASD.

In Australia, carers (including all types, not just those involving ASD) are identified as having the lowest collective well-being compared to any other group of adults, including those who are unemployed and live alone (Cummins et al., 2007). Distance from support
services, lack of time and limited availability of services are factors identified in the Cummins et al report as being contributing negative factors. Individual differences in the carer’s willingness to seek help and connect with others were positively correlated with well-being, suggesting that personality features that lead one to be extraverted versus more socially reticent, for example, might put carers at differential risk.

Although there have been studies of the role of personality among carers for those with dementia (Campbell et al., 2008) and those with developmental disabilities (Jobe & Glidden, 2008) they did not address risk for mood disorders or help-seeking behaviour. Early studies that assessed personality factors in parents of children with autism in particular were considered to be invalid or unrelated to the current study (e.g., fathers of children with autism were more likely to endorse schizotypal traits (Wolff, Narayan, & Moyes, 1988). Of greater interest to the current authors was the link among personality, risk for mood disorders and help-seeking behaviours that may or may not be exhibited by carers of children with autism.

Help-seeking and socialising behaviours, which were shown by Cummins et al. (2007) to increase personal well-being, have been linked to personality traits. Levels of various personality traits in parents of children with an ASD have not yet been investigated but may hold one of the keys to understanding differential risk for dysphoria and social withdrawal in this population. Assessing personality traits within this vulnerable group might be informative (Schmitt, Allik, McCrae, & Benet-Martínez, 2007 & Benet-Martínez, 2007). Neuroticism is defined as the relatively stable trait of responding negatively to a threat, grief or loss with intense and emotional behaviour that is out of proportion to the challenge being faced (Lahey, 2009). It has been shown to negatively correlate with help-seeking and socialising behaviours (Bitsika, Sharpley, & Bell, 2013; Cohen & Wills, 1985) and positively
correlate with depression and anxiety (Flett, Galfi-Pechenkov, Molnar, Hewitt, & Goldstein, 2012; Ode & Robinson, 2009; Rantanen, Pulkkinen, & Kinnunen, 2005; Roberts, Kuncel, Shiner, Caspi, & Goldberg, 2007; Vollrath, Knoch, & Cassano, 1999). In their well-being study, Booth, Murray, Marples, and Batey (2013) identified that levels of perceived social support was negatively correlated with Neuroticism. Almost half of the Australian parents in the Bitsika and Sharpley (2004) study also reported severe levels of anxiety; nearly two thirds of their sample reported clinical levels of depression. If higher levels of depression and anxiety significantly correlate with higher levels of neuroticism, which negatively correlates with social support, one might predict that some Australian parents of children with an ASD may have increased levels of neuroticism that may result in a reduction in help-seeking behaviour. A complex relationship between Extroversion and help-seeking, which may differ across samples based on age, gender, level of dysphoria and how the constructs are measured (see for example, Kakhnovets, 2011; Roness, Mykletun, & Dahl, 2005) also reportedly exists and will be explored as we consider links among mood, personality and behaviour in parents of children with an ASD.

Reportedly at highest risk for dysphoria are those in rural and regional areas of Australia because of a general increased risk of depression and fewer or more distant autism support services (Farmer & Reupert, 2013). This could conceivably place the onus on someone with a mood disorder to be highly proactive and persistent when seeking support for their child while coping with a tendency to withdraw socially, view themselves as incompetent and view the situation as hopeless. Getting this group to engage in and maintain help seeking behaviour is vital (Featherstone & Broadhurst, 2003), however, due to financial difficulties and time constraints (Sawyer et al., 2010) parents of children with an ASD are a hard to reach population. Limited access to services has already been identified as
a major barrier for this group (Clifford & Minnes, 2013b; Krauss, Gulley, Sciegaj, & Wells, 2003; Ruble, Heflinger, Renfrew, & Saunders, 2005). When they do access services, the perceived benefit of, and parental satisfaction with the service may also affect their future help-seeking behaviour.

As with most healthcare services, failure of support services to meet the needs of parents of children with an ASD (Chiri & Warfield, 2012; Siklos & Kerns, 2006) and feelings of dissatisfaction with the quality of the support given (Montes, Halterman, & Magyar, 2009; Spann, Kohler, & Soenksen, 2003) may reduce help-seeking behaviour due to a lack of positive reinforcement or failure to reduce distress. Failed attempts to obtain appropriate support may also be interpreted as parenting incompetence, both by the parents themselves and others in the community, which would maintain a sense of helplessness, negative mood and possible social disconnection. It is therefore critical to investigate any factors that potentially reduce levels of help seeking behaviour in this group as programs and interventions could then be designed to address what might demotivate or isolate parents who are the primary sources of support for children with high needs. Therefore personality, parenting sense of competence and service access among those raising a child with an ASD were investigated in the current study.

The design and implementation of a online support network for parents of children with an ASD might be useful in understanding the barriers, areas of dissatisfaction and potential solutions in terms of service provision (Clifford & Minnes, 2013a). But first we need to better understand the factors linked to dysphoric mood and how parents with and without children with an ASD might differ. Dysphoric mood is used here to define reported symptoms of depression, anxiety and stress along with increased negative affect coupled with low levels of positive affect.
The literature indicates that Australian parents of children with an ASD report significantly increased levels of depression, anxiety and stress (Bitsika & Sharpley, 2004); it also suggests a significantly reduced level of personal well-being for parents and carers of those with a disability (Cummins et al., 2007). What has not been investigated are the effects personality traits and geographic location (rural, regional or metropolitan) have on reported symptoms in carers of those with an ASD. The Rural, Remote and Metropolitan Areas (RRMA) classification was developed in 1994 (Australian Institute of Health and Welfare, 2015) and includes several classifications of location. Inner metropolitan areas are capital cities and outer metropolitan areas are classified as other metropolitan centres (population > 100,000). For the purpose of this study a regional centre is a large rural centre with a population of 25,000-99,999 and rural areas are small rural centres with populations < 24,999.

Given that all parenting can be stressful, the current project aimed to identify differences in reported dysphoric mood and positive and negative state affect between Australian parents of children with or without an ASD. We then, while controlling for level of affect, investigated if the two parent types differed on perceived parenting competence and personality factors, across geographic locations. We further examined if the level of support required by a child with an ASD had an effect on the reported levels of dysphoric mood while controlling for the parents’ reported sense of competence. Finally, we aimed to identify if personality traits reportedly related to help-seeking behaviour by parents of children with an ASD and if these profiles differed across localities within Australia.

In line with the prior findings above, we hypothesized that Australian parents of children with an ASD would report higher levels of depression, anxiety and stress, as well as higher levels of Neuroticism and lower levels of Extroversion relative to parents of typically
developing (TD) children. We proposed that the carers of children with an ASD may be at higher risk for depression and anxiety given prior reports on the psychological effects of serving as a carer. We suggested that this may be due to personality correlates such as high neuroticism or low extraversion which have also been linked to depression risk (Uliaszek et al., 2010). Decreased help-seeking previously linked to depression and anxiety may therefore also be negatively correlated with reported neuroticism in this sample.

The putative differential risk for dysphoria in rural and regional areas and restricted ASD services also suggested that parent group differences would be particularly clear for these locations relative to more urban settings. Reported access to services was expected to be lower in rural and regional areas relative to metropolitan locations and that access would be related to lower levels of dysphoria in parents of children with an ASD in all locations.

**Methods**

**Sampling**

Resident Australian parents of children under 18 years of age, with or without an ASD, were contacted via two Autism advocacy groups - Autism Spectrum Australia (ASPECT) and Autism Victoria (AMAZE). Participants for both parent types were also solicited via Facebook, Twitter, and a recruitment email was sent to staff and students of the authors affiliated university. No incentives were offered to participants.

**Participants**

Initially, 427 individuals (365 females, 61 males, 1 non-specified) began the survey. Removal of incomplete surveys ($n = 101$), non-parents ($n = 8$) and non-Australian residents ($n = 5$) reduced the final number to 313 participants (261 females, 52 male). Thirty-six (11.5%) were born overseas, 168 (53.7%) were parents of a child with an ASD, and 145 (46.3 %) were parents of typically developing (TD) children. Seventy (22.4%) participants
reported living in rural areas, 120 (38.3%) regional centres, 43 (13.7%) outer metropolitan and 80 (25.6%) were from metropolitan locations. The number of locations were collapsed into two groups - Rural/Regional \((n = 190)\) and Metropolitan \((n = 123)\).

**Dependents’ Demographics**

The median number of children was three with the median number of children with an ASD in the parent’s care being one. Parents of children with an ASD \((n = 168)\) were asked to nominate if their child required; minimal support, support, substantial support or very substantial support. The data was collapsed into two groups requiring support \((n = 98)\) and substantial support \((n = 70)\). The data was collapsed into two groups due to a small cell size for the minimal support category \((n= 19)\).

**Materials**

Online questionnaires were used to collect information from parents. A 19-question survey was used to gather personal information. This first section included questions about sex, marital status, number of children and location. Questions about parenting a child with an ASD such as availability of ASD services, number of services used, perceived benefit of services, level of required support and number of children with an ASD, were restricted to those who endorsed an ASD diagnosis for at least one child. The 21-question Depression, Anxiety and Stress Scale (DASS) (Lovibond & Lovibond, 1995) was used to measure participants’ levels of dysphoria. This measure has been found to have adequate internal consistency with Cronbach’s alphas for the subscales reported as .94 for Depression, .87 for Anxiety, and .91 for Stress (Antony, Bieling, Cox, Enns, & Swinson, 1998).

Participants rated each symptom’s frequency relative to how they felt during the past week, using a four-point scale with zero indicating ‘never’ and four indicating ‘almost always’. Participants’ reported levels of current state affect were obtained using the Positive
and Negative Affect Scale (PANAS) (Watson, Clark, & Tellegen, 1988). Each emotion or affective state was rated by respondents using a five-point scale with one indicating ‘very slightly or not at all’ and five indicating ‘extremely’. Ratings on the PANAS indicated how they felt at the present moment to control for mood effects when they completed the questionnaires.

There is longstanding and substantial evidence to suggest that humans do not experience single emotions in the course of responding to stressful experiences but rather “blended emotions” that might be clustered based on variations in attention, pleasantness or even level of anticipated effort (Smith and Kirby, 1988, as cited in Gratch & Marsella, 2013). It is also reasonable to assume that approach-avoidance dynamics might be involved in parenting especially when soliciting social support for example might give rise to anxiety regarding stigmatisation but also hopefulness or excitement regarding the possible delivery of help. Therefore, the current authors also included a composite PANAS score to reflect the possibility of blended emotions related to the experience of both positive, approach-related feelings and negative, withdrawal-related feelings. PANAS positive (PA) and negative (NA) subscales were combined to compute the percent difference between these features of affective state (PANAS-Diff) by using the following formula \((PA-NA/PA+NA)*100\). Higher scores represented greater PA relative to NA for that individual. Prior pilot research by the second author and colleagues into emotional state and response to cognitive and emotional challenges in the laboratory has demonstrated that the composite PANAS score used in the current study, which included the relative balance of PA and NA for each individual, explained more variance in behaviour (e.g., performance on an emotional memory recall task) than either subscale alone. Its utility in the current context was explored directly.
The Parenting Sense of Competence Scale (PSOC) (Gibaud-Wallston & Wandersman, 1978) included items estimating Satisfaction, Efficacy, and Interest in Parenting that were then combined to estimate overall self-ratings of competence. When tested on an Australian population the PSOC was found to have good internal consistency for mothers with alpha coefficients of .77 for the Satisfaction, .78 for Efficacy, and .58 for Interest. For Australian fathers, the alpha values were .80 for Satisfaction, .82 for the Efficacy, and .62 for Interest (Rogers & Matthews, 2004). Participants rated each statement about their parenting experience using a six-point scale with one indicating ‘strongly disagree’ and two indicating ‘strongly agree’. Finally, the 44-item Big Five Personality Inventory (BFI) (Benet-Martínez & John, 1998; John, Naumann, & Soto, 2008) was used to assess the personality factors of Openness, Conscientiousness, Extraversion, Agreeableness and Neuroticism. The excellent validity and reliability of this measure has been reported elsewhere (John et al., 2008). Participants rated each item using a five-point scale with one indicating ‘disagree strongly’ and five indicating ‘agree strongly’.

Procedure

Participants were directed via email or an advertisement to the survey securely hosted on Survey Monkey. Prior to presentation of the survey, participants were informed of the study’s purpose, the university ethical clearance and complaint policy, privacy and confidentiality of their data, and their right to withdraw at any time, and given contact details for clinical support services and the researchers. The online introduction to the survey also stated that completion of the entire survey would imply their consent.

Participants were then asked to complete the demographic/personal information questionnaire and the other survey components. All participants completed the online PANAS, PSOC, DASS-21 and BFI-44, in that order.
Results

After data cleaning, assumption testing and outlier analyses a series of analyses were used to test hypotheses. One multivariate outlier was removed due to extreme scores on the DASS and the PANAS that indicated significant distress. The outlier was detected by using Mahalanobis’ distance computed as greater or less than 97.5% of the Chi-Square distribution with degrees of freedom. Analysis was conducted with and without the outlier and it was found that inclusion of the outlier led to what appeared to be spurious correlations.

Parents of a child with an ASD endorsed items indicating significantly lower levels of positive affect relative to negative affect when using the PANAS-Diff score ($M = 8.00, SE = 2.00$) when compared to parents of TD children ($M = 31.16, SE = 1.68$), $t(311) = -8.73, p = .008, d = .90$ (Figure 2). Follow-up analyses of group effects using independent-samples t-tests on the PANAS data indicated significantly lower levels of reported positive affect by parents of children with an ASD ($M = 26.73, SE = 0.67$) compared to parents of TD children ($M = 29.45, SE = 0.68$), $t(311) = 2.46, p = .015$. Parents of children with an ASD also reported significantly higher levels of negative affect ($M = 23.12, SE = 0.72$) relative to parents of TD children ($M = 15.08, SE = 0.50$), $t(283.83) = 9.32, p = .000$. Parents of children with an ASD also endorsed items that indicated significantly higher levels of overall dysphoric mood on the DASS ($M = 21.45, SE = 1.01$) compared to parents of TD children ($M = 12.52, SE = .76$), $t(311) = 6.87, p = .000, d = 0.63$. This group effect was consistent across all DASS subscales so only DASS Total scores will be included below.
As expected, there was a significant negative correlation between PANAS-Diff and Total DASS $r = -.74$, $p = .000$, indicating that lower levels of PA relative to NA in the moment were related to how parents reported on their dysphoric mood retrospectively for the past week. Given that current affective state was expected to influence personal judgments, the PANAS-Diff, the most proximal estimate of mood, was used in a regression model to partial out the variance which related to how participants felt in the moment when they completed the BFI and PSOC questionnaires. The two parent types were then compared on the saved standardised residual’s for PSOC scores and the five personality factors.

Parent types did not vary on PSOC scores after controlling for their positive and negative affect while answering the questionnaire. Of the five personality factors, parents of children with an ASD reported significantly higher levels of Neuroticism ($M = .13$, $SE = 0.08$) than parents of TD children ($M = -.16$, $SE = 0.07$), $F (1,311) = 6.73$, $p = .01$, $r^2 = .021$. Neuroticism was the only standardized residual personality factor score on which groups
significantly differed after controlling for their positive and negative affect (Figure 3). There was a trend for groups to differ on standardised residual Extraversion scores with parents of children with an ASD ($M = .10, SE = 0.08$) reporting slightly higher levels than parents of TD children ($M = -.11, SE = 0.07$) however they did not differ significantly.

![Figure 3](image.png)

*Figure 3. Residual BFI subscale scores for parents with and without a child with ASD, controlling for state affect.*

The above findings indicated group effects on dysphoric mood and personality, in particular residualised Neuroticism scores, so we then tested links between mood and personality for the entire sample and for each group separately. The links between mood and personality, whether current affect was controlled for or not, did not follow typically reported correlations. In this sample overall, Total DASS and non-residualised Neuroticism scores were negatively correlated, while Extroversion, Conscientiousness and Openness scores were positively correlated with Total DASS (Table 1). These findings did not appear to be due to some unique feature of parents of children with an ASD as the identical
A constellation of correlations between Total DASS score and BFI subscales was found for each parent group. The Neuroticism scores were less negatively correlated with DASS score in the ASD parent group than the TD parent group (Table 2).

**Table 1. Overall Pearson’s correlations between DASS Total score and non-residualised BFI subscale scores.**

<table>
<thead>
<tr>
<th></th>
<th>Extraversion</th>
<th>Agreeableness</th>
<th>Conscientiousness</th>
<th>Neuroticism</th>
<th>Openness</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total DASS</td>
<td>.571**</td>
<td>-.032</td>
<td>.486**</td>
<td>-.214**</td>
<td>.254**</td>
</tr>
</tbody>
</table>

Note - *** p<.001

**Table 2. Correlations between DASS Total score and non-residualised BFI subscale scores by Parent Group**

<table>
<thead>
<tr>
<th>ASD Carer</th>
<th>Extraversion</th>
<th>Agreeableness</th>
<th>Conscientiousness</th>
<th>Neuroticism</th>
<th>Openness</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes - Total DASS</td>
<td>.523***</td>
<td>.002</td>
<td>.473***</td>
<td>-.157*</td>
<td>.262***</td>
</tr>
</tbody>
</table>

| No - Total DASS | .483*** | .005 | .411*** | -.361*** | .224** |

Note - * p<.05  ** p<01  *** p<.001

We also attempted to understand how the multivariate combination of scores on the DASS, PSOC and BFI might vary across Locations. Interpreting Wilks Lambda from a MANOVA did reveal a significant multivariate effect of Location on the parents’ Total DASS and their standardised residuals on the PSOC and BFI (variance due to PANAS Differential removed), Λ = 0.95, F (7, 285) = 2.25, p = .030. However, this effect was due primarily to differences across locations on the DASS. Univariate ANOVA’s revealed that overall those in rural/regional locations (M = 15.46, SE = 0.92) reported significantly less dysphoria on the
Total DASS compared to those in metropolitan locations ($M = 20.11, SE = 1.15$), $F(1, 291) = 10.04, p = .002, \eta^2_p = .033$, primarily due to low scores in the non-ASD parent group.

Univariate ANOVA’s also indicated that parents of children with an ASD reported significantly higher Total DASS scores compared to parents of TD children, $F(1, 289) = 22.91, p = .000, \eta^2_p = .073$, regardless of location as shown in Figure 4. There were no differences within the ASD parent group across rural/regional and metropolitan locations, but within the non-ASD parent group those in rural/regional locations reported significantly lower DASS scores ($M = 11.07, SD = 8.27$) than those in metropolitan areas ($M = 17.87, SD = 10.20$). No differences were found between Locations on the BFI or PSOC using standardised residuals controlling for state affect, and there were no univariate or interaction effects of Location and Parent Group on BFI or PSOC scores.

*Figure 4. Mean Total DASS scores across locations and parent type*
To test the potential effect of symptom severity in the child with an ASD on parent dysphoria we used the reported level of required support as a proxy for the behavioural challenges faced by the parent. Parents of children requiring substantial support reported significantly higher levels of dysphoria (Total DASS) \((M = 24.90, SE = 1.24)\) compared to parents whose children required support \((M = 18.99, SE = 1.64)\), \(T(166) = -2.94, p = .004\). However, as perceived parenting competence (PSOC) was negatively correlated with Total DASS score \((r = -.54)\), an ANCOVA was used to determine if the level of support required by a child with an ASD continued to have an effect on Total DASS when the parent’s sense of competence was included as a covariate. The parents of children requiring significant support \((M = 55.93, SE = 1.38)\) reported significantly lower levels of parenting competence than parents of children requiring support \((M = 60.12, SE = 1.14)\), \(T(154) = 2.36, p = .020\), and after controlling for this variable the ANCOVA revealed no significant differences in dysphoric mood between the groups defined by required level of support for their child, \(F(1,153) = 3.08, p = .081\), \(\eta^2_p = .020\).

A MANOVA was conducted with the residualised BFI factor scores as the dependent variables to assess if Location or use of services by parents of a child with an ASD were related to reported personality. No main or interaction effects of Location or Service Use were found. Finally, an independent t-test indicated no significant differences in levels of dysphoria (Total DASS) between parents who had found services beneficial and those who had not.

**Discussion**

This research compared Australian parents of children with or without an ASD on reported typical mood, perceived parenting competence, personality and state affect. We also examined if residential location or the level of support required by a child with an ASD
had an effect on reported levels of dysphoric mood while controlling for the parents’ reported sense of competence. We further tested if personality traits varied between parents of children with ASD who reported help-seeking behaviour and those who did not, and if these profiles differed across localities. Lastly, we tested if the perceived benefits of a service were related to dysphoric mood in parents of children with an ASD.

The parents of children with an ASD reported significantly higher levels of depression, anxiety and stress symptoms compared to parents of TD children. They also reported significantly lower levels of parenting sense of competence and positive affect, and higher levels of negative state affect. These findings are consistent with those from previous studies (Bitsika & Sharpley, 2000; Cummins et al., 2007; Firth & Dryer, 2013; Hines, Balandin, & Togher, 2012a; Osborne & Reed, 2010).

This appears to be the first attempt to measure personality traits in parents of children with an ASD and the findings suggest that a unique profile may be associated with differential risk for social withdrawal and dysphoria in this population. Expectations formulated from prior findings in personality research (Flett et al., 2012; Rantanen et al., 2005; Roberts et al., 2007; Vollrath et al., 1999), that parents of children with an ASD would report higher levels Neuroticism relative to parents of TD children were supported. However, the data also indicated a trend for ASD parents to describe themselves as more Extroverted than parents of TD children, and the links between BFI personality scores and dysphoria were highly atypical (see further discussion below). Given the higher levels of dysphoria, Neuroticism and Extroversion, Australian parents of a child with an ASD, appear to present with a unique profile related to increased parenting and social demands.

The most parsimonious explanation for higher levels of some personality features in our sample of parents of children with an ASD relative to TD parents is that those who
reported higher levels of Neuroticism and dysphoria, as well as Extroversion, were more likely to respond to our request for participants. Although we attempted to access participants in various ways and our response rate was adequate for online surveys, it may be important to give parents various ways to engage with investigators such as through focus groups or by having researchers go to them at meetings or appointments where they attend. It could also be assumed, however, that parents of TD children may also have been the most distressed or extroverted of that group in the community so our effects, noting our limited sample, may still reflect true differences.

Another possible explanation for the elevated levels of Neuroticism, and to a lesser extent Extraversion, in parents of children with an ASD, may be the necessity that the parent advocate on behalf of their child in social and service provider settings. Responses by parents of children with an ASD to BFI questions such as - I am someone who: is talkative; has an assertive personality; is reserved (reverse scored); tends to be quiet (reverse scored); is sometimes shy and inhibited (reverse scored), may be confounded by the possible requirement to advocate for their child in a wider range of settings more frequently. While a parent of a child with an ASD may be naturally less talkative and assertive in normal social circumstance, when dealing with numerous ASD and government agencies, as well as healthcare and education providers, they may have no choice but to be assertive, unreserved and speak in an uninhibited manner. This possible conflict between natural preferences and the demands of parenting a child with special needs might reasonably lead to greater dysphoric mood. The finding that even those who seek services are still dysphoric, suggests that even being extraverted, may not bring positive results for parents. As noted previously, failure of support services to meet the needs of parents of children with an ASD (Chiri & Warfield, 2012; Siklos & Kerns, 2006) and maybe dissatisfaction with the quality of
the support given (Montes et al., 2009; Spann et al., 2003) may with time reduce help-seeking behaviour due to learned helplessness or a lack of positive reinforcement for one’s efforts (Peterson, Maier, & Seligman, 1993) however these explanations require further investigation. Neuroticism which has been shown to negatively correlate with help-seeking and socializing behaviours (Bitsika et al., 2013; Cohen & Wills, 1985) and perceived social support (Booth et al., 2013) was higher in our ASD parent group, but whether a parent chose to seek support or not was unrelated to their reported Neuroticism. This may suggest that personality does not relate to help-seeking for the parents of a child with an ASD, but we did not examine help-seeking in sufficient detail in this study.

Of note in the current study help-seeking was operationalised by asking about past and current use of services. We did not differentiate perceived support or received support, from an objective index of available support or services. Whether or not true support was available would certainly also have to be considered in future studies. Measuring these factors directly in future research would help clarify how personality and other individual factors influence help-seeking and perceptions regarding the adequacy of services in a more refined manner. Similarly, one might imagine that a recipient of services could passively take advantage of available services without seeking help at all in a highly resourced area where support was proactively delivered. Unfortunately, those low on Extraversion or high on Introversion may apply this passive style even in less resourced areas and therefore not get the help they may need. Recipients of services could also either be satisfied with the services or not, independent of their quality or availability, or the personality style of the recipient. How to best assess quality and availability of services, and intrapersonal or interpersonal variables that influence effective help-seeking requires further investigation in this population across rural, regional and urban sites. A combination of quantitative and
qualitative assessments may elucidate the experiences of those accessing autism-related services so they can be fully understood. This is particularly important as a National Disability Scheme is being rolled out and refined.

Importantly, failed attempts to obtain appropriate support may also be interpreted as parenting incompetence, both by the parents themselves and others in the community, which would maintain a sense of helplessness, negative mood and possible social disconnection. A more thorough investigation of the development of dysphoria and factors that might mitigate against helplessness, such as more refined, early and customised service provision, is required to better understand the differential risks for this parent group. The implementation of the National Disability Insurance Scheme in Australia should reportedly allow for greater control by parents in selecting appropriate services but again access to those services may remain an issue.

The current study also shed light on the relative weight of parental personality factors, level of support required for the child with an ASD, and ASD service access when trying to understand dysphoria. Dysphoria was negatively correlated with parenting sense of competence and Neuroticism, and positively correlated with Extraversion, Conscientiousness and Openness to Experience subscale scores for both parent groups. The associations noted here between mood and personality as measured by the BFI subscales are highly inconsistent with previous reports. Neuroticism, reportedly a risk factor for dysphoric mood and depression (Flett et al., 2012; Ode & Robinson, 2009; Rantanen et al., 2005; Roberts et al., 2007; Vollrath et al., 1999) was associated with lower reported dysphoria on the DASS. Cummins et al. (2007) reported that higher reported personal well-being was linked to Extroversion, while in our sample overall and within parent groups, Extroversion was strongly positively correlated with dysphoria. Conscientiousness did not
differentiate those who accessed support services from those who did not and was also positively correlated with reported dysphoria. This is inconsistent with reports that Conscientiousness on the BFI was related to accessing support services and higher levels of social support in those with symptoms of depression. Although seemingly counterintuitive, the lack of difference on the Openness, BFI subscale between ASD parents who did or did not access services was consistent with prior reports about dysphoric adults who either sought or did not seek help.

To further explore the atypical link between Extraversion and dysphoria we considered whether concurrent individual differences in Neuroticism might account for the findings. Prior research suggests that a profile that includes gender, extroversion and neuroticism may be a better way to account for variance in estimates of PA and NA (McFatter, 1994). Extraversion predicted NA and PA scores but only when individuals were also high on Neuroticism in the McFatter study. Although this prior work was conducted on first year psychology students who did not meet criteria for any mental health disorder, and we did not have sufficient numbers of males, we conducted a regression analysis to determine if the interaction of Neuroticism and Extraversion accounted for significant variance in NA, PA and PANASDiff in our current sample. The results indicated that accounting for variance in neuroticism scores did not change the atypical relation we found between affect (PA, NA or PANASDiff) and extroversion for the sample as a whole or for either parent group. Although our correlations may be atypical further investigation online with Australian carers of children is warranted as standard assumptions about personality-dysphoria links may not apply.

Level of support required by the child was also positively correlated with reported dysphoric mood among parents of children with an ASD, even after controlling for parenting
sense of competence. Level of behavioural or health challenges in the child with an ASD, as indexed here by level of required support, being linked to level of parental dysphoria makes intuitive sense but this appears to be the first report of this finding in Australian parents. These findings suggest that more proximal factors (daily parenting/carer challenges and how the parent views herself in the parent role) may combine with personality factors to account for level of dysphoric mood and the tendency to seek support.

Although Farmer and Reupert (2013) suggest that living in rural Australia increases risk for depression relative to metropolitan residents, that association was not found for parents of a child with ASD in the current study. Those parenting a child with an ASD had equally high levels of dysphoria across locations while parents of TD children living in rural areas reported significantly less dysphoric mood than their counterparts in metropolitan areas. Importantly, personality profiles, a potential mediating factor, did not vary between parents within the ASD group who had or had not engaged support services, nor did they vary across locations. These findings suggest that either access to ASD services does not differ across locations or they are equally unhelpful across locations in terms of decreasing dysphoria. This is an important finding as future research is required to identify the beneficence of the available services to parents and carers of children with an ASD. Whatever benefits are conferred to rural/regional parents with a TD child did not appear to positively affect the ASD parent group.

The results from the PSOC in this study also do not follow the trend of previous research indicating lower parenting sense of competence in parents of children with an ASD relative to parents of TD children (Hines et al., 2012b; Neely-Barnes et al., 2011; Osborne & Reed, 2010). In contrast to previous studies, we found no difference across groups, but we controlled for the respondents' current affective state when judging group differences.
Repeating the analysis did indicate a significant difference between groups if we ignored how current affect might relate to ratings of confidence. However, given that groups differed significantly on state affect and that state affect was highly correlated with one’s reported sense of parenting confidence it seemed inappropriate to ignore how current affect might influence group differences on the PSOC.

Along with the typical sampling issues with online data collection, limitations of this study also included a predominately female sample despite efforts to attract more male participants. Anecdotally, it seemed that resistance among fathers to reflecting on their parenting experience was a barrier to participation that requires further attention. Determining how to make it more convenient for or acceptable to male carers to participate should be a goal of future research efforts. If parents of children with an ASD are at increased risk for depression and males in particular have been found to be at higher risk for suicide, especially in rural settings (Sankaranarayanan, Carter, & Lewin, 2010), determining how to better engage fathers seems like an imperative as we consider how to better support parents. Mothers of children with an ASD were seemingly the primary family contact in support services used to solicit participants, even contact details for both parents were sometimes available. Having separate email addresses for parents may be part of the solution when announcements are circulated via agency email lists so that fathers can respond independently and confidentially.

Another limitation was that we did not ask respondents to report on the child’s age or years of caring for the child with an ASD. These responses may have, for example, allowed us to assess if personality or interpersonal style in parents of a child with an ASD changed as the child aged or as experience as a carer increased. Does spending time as a carer of a child with ASD lead one to develop a characteristic style of relating that leads to success versus
dysphoria, help-seeking behaviour versus social isolation? Does more carer time translate into more fixed styles of relating or greater flexibility or adaptive functioning in the parent? These developmental questions would require a different research focus than the current study but might clarify how parents adapt with or without ASD resources.

Future studies could also expand on how we screened for some moderating factors such as level of required support, and level of access and satisfaction with services. We only coarsely estimated these individual differences in parent experience in an effort to minimise time in completing the survey. The lack of difference between those who accessed services and those that did not in terms of personality factors such as Extraversion or Neuroticism argues against the possible suggestion that there is something inherent in the parent that affects their soliciting support. The fact that accessing services was not related to lower levels of dysphoric mood may indicate that service provision did not address factors that sub-serve the distress or practical issues associated with parenting a child with an ASD. Of note is that services may have been aimed at the child not the parents and the effects on the child were not assessed in the current study. We presumed that access to ASD support services would translate into improved mood in the parents, but we did not ask about the service type accessed (e.g., child-focused versus carer-focused). Although we asked about access and whether services were beneficial, we could not discern why reported benefit was not related to level of dysphoria. If these factors were examined in more detail, we would have had greater explanatory power regarding how help-seeking behaviour across locations was related to dysphoria and personality.

Conclusion

There are many factors associated with caring for a child who has increased support needs including greater financial stress, social isolation, decreased ability to meet work
demands and lack of appropriate support services. The finding that access to support services, even when reportedly beneficial, had no effect on participants’ dysphoric mood requires further investigation. The results suggest that the use of support services did not lower the parent’s level of depression, anxiety or stress. This raises another important question; do services that parents find non-beneficial have a detrimental effect on the parent’s mood and sense of competence? Follow-up studies that examine service access and experiences of parents of children with various levels of ability, and the links to mood and sense of perceived parenting competence are required. Understanding better these dynamic interacting factors may inform interventions that reduce risk of mood disorders.

As has been demonstrated by other investigators and clinicians using online resources to support those with mood disorders such as postnatal depression (Danaher et al., 2012) and anxiety (Mewton, Wong, & Andrews, 2012; Titov, Andrews, Johnston, Robinson, & Spence, 2010), a website that provides links to educational resources as well as peer and professional contacts may be useful for parents of children with an ASD, especially those in rural and regional areas. Some informational resources already exist however they do not allow for interactions between parents who may be aware of local ASD resources on a discussion board and their benefit to parents has not been assessed. Informing the content and functions of an ASD parent support website through focus groups that include a wide range of parents serving as carers of children with an ASD at different stages of development and disability would be essential.
Chapter 4. The National Disability Insurance Scheme: Effects on Australian Carers of Individuals with Autism Spectrum Disorder

*Position of published article within the overall argument of this thesis.*

The following article was published September 18, 2017 in the peer reviewed Journal of Depression and Anxiety. An amendment to the original publication has been submitted to the publishers and the amended version has been replicated here to match the style and format of this thesis. The amendment to the original article made changes to the scoring method used for the Carer-giver Quality of Life (CQoL) scale. The original scoring included a statistical issue in one spreadsheet column that resulted in a minor error in participants CQoL scores. The error did not affect the overall results.

After identifying factors which mediated ASD carers help seeking behaviours in the first stage of this project, this second stage of the research aimed to identify if parents and carers of individuals with an ASD, who are participants in the NDIS (NDIS carers), varied on carer well-being and quality of life when compared to their counterparts who cared for non-NDIS participants (Non-NDIS Carers) when their level of state affect was controlled for. The second aim was to follow the participants over a 12-month period and identify if carer reports changed as a function of group membership (NDIS vs Non-NDIS carers). This data was required prior to beginning stage three of the project which aimed to identify if carer reports changed across carer types and/or as a function of group membership (NDIS vs Non-NDIS carers).

*Survey/Assessment Item Changes*

A core priority of this research was to reduce participant fatigue by minimising the number of survey items used. Participant attrition can have a significant effect on the overall power of longitudinal research and it was believed that reducing the load on participants
would help to reduce attrition rates. Anecdotally, parents and carers of individuals with a disability are time poor, therefore it was decided that survey items from the first stage of this project that revealed no significant difference between TD carers and ASD carers would be removed from future surveys. For example, parent types did not vary on Parenting Sense of Competency (PSOC) scores, even after controlling for their positive and negative affect while answering the questionnaire.

The decision to use the Depression, Anxiety and Stress Scale (DASS) instead of the PANAS to control for dysphoric mood was made for three specific reasons. Firstly, there is an abundance of literature to support the use of the DASS with the population of interest. Second, parents of children with an ASD endorsed items that indicated significantly higher levels of overall dysphoric mood on the DASS compared to parents of TD children and the group effect was consistent across all DASS subscales in the first stage of this research. Finally, there was a significant correlation between PANAS differential scores reflecting current affective state and total DASS scores based on the previous week.

The intention at this point was to design a survey to use in the second and third stages of the project. The key factors of interest, personal well-being and quality of life, were measured with the Personal Well-Being Index (PWI) and the Carer Quality of Life Scale (CQoL). It was also considered necessary at this point to measure caregiver strain and for this purpose the Caregiver Strain Questionnaire (CGSQ) was introduced. The aim of keeping the survey tool the same for stages two and three was to allow comparisons of carers’ data over a two-year period. This would allow investigation of correlations between caregivers’ DASS, PWI, CQoL and CGSQ scores and time in the NDIS.
Abstract

This repeated measure’s study controlled for levels of dysphoric mood while measuring the personal well-being and quality of life of those caring for an individual with an Autism spectrum disorder. It investigated the difference between those caring for an NDIS participant (NDIS carers) and those caring for a Non-NDIS participant (Non-NDIS carers). NDIS Carers reported significantly lower levels of personal well-being compared to Non-NDIS carers after controlling for dysphoric mood. No significant effect of carer type was found on quality of life. Time spent in the NDIS, 12 months, did not increase NDIS carers levels of personal well-being however there was a trend for NDIS carers to report decreasing quality of life. These findings are considered in terms of the need for carer respite under the NDIS. Possible strategies to identify the psychological dynamics and support needs of this high-risk group under the NDIS are discussed.

Keywords

National Disability Insurance Scheme, Carers, Autism spectrum disorder, Personal well-being, Quality of Life.
The National Disability Insurance Scheme (NDIS) is described as a lifetime\(^1\) support system for Australians who have a permanent and significant disability that limits their capacity, and their caregivers’ capacity, to participate in the community (National Disability Insurance Agency, 2015). The aim of the NDIS is to provide financial assistance so participants can obtain the support they require to achieve goals such as independence and community involvement. In July 2012, the Coalition of Australian Governments (COAG) announced the NDIS would be rolled out nationally. Initially trial sites were launched in South Australia, Tasmania, and the Australian Capital Territory (National Disability Insurance Agency, 2016b). For Australian parents and carers of an individual with an Autistic Spectrum Disorder (ASD) this announcement would seemingly be expected to bring feelings of relief regarding their child’s future, however, these emotions are reportedly tempered by a level of apprehension.

The framework, rules and regulations of the NDIS are constantly evolving. Since the beginning of the rollout the National Disability Insurance Agency (NDIA), the body responsible for the NDIS, has been quick to respond to any challenges the key stakeholders have encountered (NSW Carers Australia, 2014). Consequently, there have been numerous changes to the rules and regulations, and these have been implemented to improve the scheme. However, these constant changes have created confusion and anxiety for participants and carers attempting to prepare for the NDIS rollout in their area (Gibbs, 2014). Illustrating this is a report about concerns among participants, parents and families in the Canberra trial site nine months after the NDIS began in that region (Belot, 2015).

\(^1\) The NDIS provides early intervention support for children until age 7 and after age 65 the funding for adults is discontinued.
Conflicting self-reports about the experience of carers already participating in the NDIS have added to the confusion and concern about the future for those still waiting for its arrival. The latest quarterly report (31st of March 2016) from the NDIA to the COAG Disability Reform Council indicates that of the 2011 individuals surveyed, who were either participants, carers or family members, 95% responded that their experience with the agency was either very good or good (National Disability Insurance Agency, 2016a). The remaining participants in the survey had a neutral, bad or very bad experience with the NDIA. The same report indicates that there are currently 29,769 participants in the NDIS. Based on the NDIA statistics, 5% or 1488 participant’s experiences with the transition to the NDIS have not been positive.

These negative experiences resonate with multiple reports from reputable media sources. One indicates that the scheme is failing to deliver the support it promised (Winter, 2014) and another indicates major inconsistencies in packages provided to individuals with similar levels of disability (Kirkwood, 2016). It is not only NDIS participants and their families who have had issues with the NDIS. Most recently, due to a technical issue, some service providers have not been paid for two months (Morton, 2016) and as a result some of them have refused to provide client services until the issue is resolved. While these issues may be eventually resolved as the roll out continues, they have caused great concern for those yet to become a part of the scheme (NSW Carers Australia, 2014).

The current research concentrated on Australian parents and carers of individuals with an ASD and the effects the NDIS has, or will have, on their personal well-being and quality of life as a carer. This is distinct from reports on the “participants” (those with the identified disability). Monitoring this particular group through the NDIS transition is essential for three reasons. First, this group has been shown to have significantly increased levels of
depression, anxiety and stress that are comorbid with significantly lower levels of positive affect relative to negative affect (Snow & Donnelly, 2016). Secondly, individuals with an ASD or a related disorder currently make up the largest group (31% of all participants) within the NDIS. Third, the average funding package currently being offered to individuals with an ASD or a related disorder is 25% ($26,755) less than the national average for all other disabilities ($35,992) (Browne, 2014). These factors may place this subset of carers at particular risk for difficulties in providing the essential specialist care for a child or young adult presenting with what can be a complex constellation of medical, psychological and behavioural needs.

One of the key areas the NDIA monitors is the financial sustainability of the scheme and this has focused attention on ASD. Jenny Macklin, the Minister for Disability Reform announced in May 2013 that the NDIS would support “most people with autism” (Aubusson, 2013 as cited in Ergas, 2013, p. 340) and that the full cost of early intervention would be covered by the scheme. These statements raised concerns about the sustainability of the NDIS due to the large number of individuals with an ASD in Australia. The recommended minimum effective amount of early intervention per week is between 20 and 40 hours at a cost of approximately $35 000.00 AU per annum (Roberts & Prior, 2006). Reports indicate that families of individuals with an ASD who require early intervention are receiving enough funding for just 6 hours per week ($16 000.00 AU per annum) under the NDIS (Browne, 2014). The panel of ASD experts who consulted for 15 months with the NDIA to ensure best practices of early intervention are also concerned. After the consultation period the NDIA released the Early Childhood Early Intervention Approach report which “gives no clear direction on what funding will be provided through the NDIS for children diagnosed with autism” (Every Australian Counts, 2016, n.p.).
The NDIA predicts that carers’ will benefit under the NDIS in two ways. First, representatives of the NDIA believe that supporting the participants to achieve goals it will directly and indirectly have a positive impact on carers, and secondly, this positive impact will occur due to information about, and linkage and referral to other service providers (National Disability Insurance Agency, n.d.). A report by the Productivity Commission (2011, p. 62) supported this by stating, “The scheme would substantially increase the personal well-being of many people with disabilities and their carers.” However, these predictions are challenged by Bellamy, Paleologos, Kemp, Carter, and King (2014, p. 4) who state, “Carers are acknowledged in the NDIS legislation, and although they may be included in the participant’s assessment and planning, there is no guarantee that carers’ needs will be assessed or catered for under any participant plan”. Fulltime carers have a legitimate reason to be anxious. At present, Australian carers receive 27.7% (single rate) of the Australian male total average weekly earnings per week and are permitted to be out of care for only 25 hours per week (National Commission of Audit, 2014). This equates to 143 hours per week of time in care for the individual at a rate of AU$2.89 per hour.

From these reports, it can be seen how parents and carers of an individual with an ASD, yet to participate in the NDIS, may be experiencing increased levels of anxiety and stress which would be reasonably expected to affect their quality of life. Abundant research has shown the negative effects of raising an individual with an ASD and the associated financial strain has on the mental and physical health of their parents and carers (Falk, Norris, & Quinn, 2014; Firth & Dryer, 2013; Hoefman et al., 2014; Hoffman, Sweeney, Hodge, Lopez-Wagner, & Looney, 2009; Khanna et al., 2011; McStay, Dissanayake, Scheeren, Koot, & Begeer, 2014; Sawyer et al., 2010; Seymour, Wood, Giallo, & Jellett, 2013). Although the rollout of the NDIS offers the hope of possible relief from these varying factors, this group of
carers are faced with the task of navigating a confusing new system of support that is still under construction.

This research is part of an ongoing project that has so far identified significant differences in dysphoric mood between Australian parents and carers of individuals with an ASD and those caring for typically developing individuals while controlling for factors including personality and location (Snow & Donnelly, 2016). There were two specific aims of this phase of the research. Our first aim was to identify if parents and carers of individuals with an ASD, who are participants in the NDIS (NDIS carers), varied on carer well-being and quality of life when compared to their counterparts who cared for non-NDIS participants (Non-NDIS Carers) when their level of state affect was controlled for. Based on the NDIA claims, it was hypothesised NDIS-carers would not be worse off than those not yet covered by the scheme, however there is no evidence to support an expectation of significant improvements in their quality of life or sense of personal well-being compared to Non-NDIS Carers. The fact that the program is still in its infancy and in development in trial sites also suggested that potential positive effects might not yet be realised by carers.

Our second aim was to follow the participants over a 12-month period and identify if carer reports changed as a function of group membership (NDIS vs Non-NDIS carers). It was believed, after controlling for state affect, quality of life and personal well-being of carers of individuals with an ASD would improve over time spent in the NDIS as carers covered under the scheme would have worked through the initial challenges related to understanding the program, participant assessment and customised service implementation. No change was expected for Non-NDIS carers.
Methods

Sampling

Resident Australian parents and carers of an individual with an ASD were contacted via major autism and carer service providers. Those caring for an NDIS participant were targeted in the NDIS trial areas, especially in South Australia as NDIS reports indicated it held the highest number of participants with an ASD.

Participants

Originally, 122 individuals began the survey. Removal of incomplete surveys (n = 23) reduced the final number to 99 participants (95 females, 4 male). Twenty-six (26.3%) were NDIS Carers consisting of 24 females aged 28 – 62 years of age (M = 39.77, SD = 7.75) There were 73 (73.7%) Non-NDIS Carers. This group consisted of 69 females (95.7%) aged 28 - 61 years of age (M = 43.03, SD = 6.75) and 4 males (4.3%) aged 40 - 57 years of age (M = 49.00, SD = 7.87). Of these participants 38 (38.4 %, 21 NDIS Carers and 17 Non-NDIS Carers) lived in South Australia, 31 (31.3%, 4 NDIS Carers and 27 Non-NDIS Carers) in NSW, 23 (23.2%, 1 NDIS Carer and 22 Non-NDIS Carers) were from Victoria and 6 (6.1%, all Non-NDIS Carers) lived in Queensland. One participant (Non-NDIS Carer) did not report the state in which they lived.

Of the 99 participants that completed the survey originally 53 (50 females, 3 males) completed the survey approximately 12 months after first completing it. Fifteen (28.3%) were NDIS Carers consisting of all females aged 33 – 63 years of age (M = 44.07, SD = 7.97) There were 38 (71.7%) Non-NDIS Carers. This group consisted of 35 females (92.1%) aged 32 - 62 years of age (M = 45.69, SD = 6.40) and 3 males (7.9%) aged 46 - 58 years of age (M = 55, SD = 6.24). Of these participants 19 (35.9%, 9 NDIS Carers and 10 Non-NDIS Carers) lived in South Australia, 18 (33.9%, 5 NDIS Carers and 13 Non-NDIS Carers) in NSW, 13 (24.5%, 1
NDIS Carer and 12 Non-NDIS Carers) were from Victoria and 3 (5.7%, all Non-NDIS Carers) lived in Queensland.

Materials

A 27-item, online survey was used to collect information from parents and carers. The questions included gender, marital status, location, financial position, and number of both typically developing and individuals with an ASD in the participant’s care. These questions also identified the level of support required by the individuals with an ASD. Level of formal and informal care were identified by questions about ASD service use, perceived benefit of services and level of support received from family and friends.

Other assessment items included the Personal Well-Being Index (PWI) (International Wellbeing Group, 2013). The PWI has been reported to have good convergent validity (.78) (Thomas, 2005 as cited in International Wellbeing Group, 2013) with the Satisfaction with Life Scale (Diener, Emmons, Larsen, & Griffin, 1985). To reduce participant fatigue the stress subscale questions of the 21-question, Depression, Anxiety and Stress Scale (DASS) (Lovibond & Lovibond, 1995) were not used. Although Antony et al. (1998) report the DASS subscales have good internal consistency (Depression $r = .94$, Anxiety $r = .87$, Stress $r = .91$) it was believed that a high correlation would be found between the DASS Stress subscale and the Caregiver Strain Questionnaire (CGSQ) (Brannan & Heflinger, 1997) also included in the current study. With the modified DASS (DA_Tot at times 1 and 2) participants rated frequency of anxiety and depression symptoms during the past week, using a four-point scale with zero indicating ‘never’ and four indicating ‘almost always’. As current dysphoric mood may have influenced participants’ ratings on other measures related to their perceived burden of care or current quality of life, the modified DASS score was included as a potential covariate.
Objective, subjective and total caregiver strain was measured using the CGSQ. This 21 question instrument has an internal consistency reliability (Cronbach’s alpha) of 0.94 and the subscales of objective strain, subjective externalised and internalised strain are 0.93, 0.75, and 0.82 respectively (Khanna et al., 2012). Quality of life for informal caregivers was measured using the Carer Quality of Life instrument (CQoL) (Brouwer, van Exel, van Gorp, & Redekop, 2006 & Redekop, 2006). The CQoL has been shown to be a reliable and valid measure for carers of individuals with an ASD (Hoefman et al., 2014). The reliability of the CQoL is further shown by (Brouwer et al., 2006) who indicate the CQoL VAS (level of happiness) scores are significantly negatively correlated ($r_s = -0.50$) with perceived burden as assessed by the Caregiver Strain Index (Robinson, 1983). The CQoL measures seven dimensions of caregiving. According to Hoefman et al (2011, p 882) the five-negative dimension are: “relational problems with the care recipient, mental health problems, problems with daily activities, financial problems, and physical health problems”. The two-positive dimension included are: fulfillment and support. Participants are asked to respond: (1) no, (2) some, and (3) a lot to the questions. Answers on the positive dimensions are scored: 0 (no), 1 (some), and 2 (a lot) while answers to the five negative dimensions are reverse scored (0 - a lot, 1 -some and 2 - no) (Hoefman et al. 2011).

Finally, participants were asked if they agreed to be contacted again to complete the same survey at a later date. A simple yes or no answer was given. Those who chose to continue participation were directed to leave an email address. Approximately 12 months after first completing the survey participants were emailed a request to complete the survey for a second time.
Procedure

The survey was securely hosted on Survey Monkey and participants were directed via email or an advertisement to the online access point. Participants were informed prior to commencing that completion of the entire survey would imply their consent. Participants were then asked to complete the demographic/personal information questionnaire, the online PWI, Modified DASS-21, CGSQ, CarerQol, and continuation of participation items in that order.

Results

Dysphoric mood scores were calculated by adding Anxiety and Depression total scores from the modified DASS21. CGSQ scores were found to be significantly correlated with dysphoric mood scores so they were excluded as a covariate. After assumption testing a series of analyses of covariance were done on data collected at time one.

A pair of One-way ANCOVA’s was conducted to determine if there was a statistically significant difference between NDIS carers and Non-NDIS carers on their reported levels of personal well-being (PWB) and carer quality of life (CQoL) while controlling for their current level of dysphoric mood (DA_Tot_1). There was a significant effect of carer type on reported levels of personal well-being after controlling for dysphoric mood, $F(1, 95) = 6.07, p = .016$, $\eta^2 = .06$. NDIS carers reported a lower sense of personal well-being ($N = 26, M = 41.76, SD = 22.32$) compared to Non-NDIS carers ($N = 72, M = 49.38, SD = 24.08$). No significant effect of carer type on reported care quality of life scores was found after controlling for dysphoric mood, $F(1, 96) = .653, p = .421$, $\eta^2 = .007$. NDIS carers reported similar quality of life scores ($N = 26, M = 5.62, SD = 2.06$) as Non-NDIS carers ($N = 73, M = 5.92, SD = 2.97$).

To analyse the repeated measures data, studentized residual scores for personal well-being (PWB_Time_1 and PWB_Time_2) and carer quality of life (CQoL_Time_1 and CQoL_
Time_2) were computed by removing the variance associated with the participant’s level of dysphoric mood at each time (DA_ Time_1 and DA_ Time_2). A mixed between-within participant’s ANOVA was conducted to assess if carer type (NDIS Carer and Non-NDIS Carer) had an effect on their PWB and CQoL across 2-time periods (approximately 12 months apart).

There was no interaction effect between carer PWB scores and time in the NDIS. However, the main effect of Carer Type on residualised PWB was significant, $F(1, 45) = 5.02$, $p = .03$, partial eta squared = .10. There was no significant interaction effect between carer CQoL scores and time in the NDIS. There was also no significant main effect of Carer Type on residualised CQoL scores. As shown in figure 5, post hoc independent samples T tests revealed a significant difference in PWB between NDIS Carers ($M = -.62, SD = 1.00$) and Non-NDIS Carers ($M = .22, SD = .93$) at time two, $t(45) = -2.64, p = .011$, two-tailed, $d = .92$, after controlling for dysphoric mood at each point in time.

![Figure 5. Standardised residual scores for PWB and CQoL controlling for Dysphoric mood over time.](image-url)
To further investigate the significant difference between carer types on personal well-being, residualised PWB scores for each item were calculated to control for the level of dysphoric mood at both time one and time two. Independent samples T tests, with a Bonferroni corrected alpha level of .007, were conducted to compare Carer Types on each item of the PWI at each point in time. As shown in figure 6, NDIS carers ($M = -.69, SE = .30$) reported significantly lower levels of feeling like part of the community than Non-NDIS carers ($M = .24, SE = .14$) at time one, $t (45) = -3.03, p = .004$, two tailed. Similarly, at time two, NDIS carers ($M = -.70, SE = .30$) again reported significantly lower levels of feeling like part of the community $t (45) = -3.11, p = .003$, two tailed than Non-NDIS carers ($M = .24, SE = .15$) as shown in figure 7.

Figure 6. Carers residualised PWI scores at time one controlling for dysphoric mood
Figure 7. Carers residualised PWI scores at time two controlling for dysphoric mood

**Discussion**

The hypothesis that NDIS carers would have similar levels of personal well-being as Non-NDIS carers was not supported by the participants’ responses on the PWI. In fact, the data revealed that, while controlling for the effects of dysphoric mood, NDIS carers reported a lower sense of personal well-being than Non-NDIS carers. Although this finding was significant it should be interpreted with caution. Most of the NDIS carers in the sample were from trial areas where issues with the system were being identified. Secondly, NDIS carers reported slightly decreasing satisfaction with their quality of life than Non-NDIS cares. This finding was not significant but a trend in the data was evident.

The second hypothesis that an improvement in the quality of life and personal well-being of carers of individuals with an ASD would improve over time spent in the NDIS was not supported. The repeated measures data, which controlled for dysphoric mood, again revealed NDIS carers reported significantly lower levels of personal well-being. The trend in
NDIS carers personal well-being data showed that over a 12-month period in the NDIS their sense of personal well-being decreased. Also evident in the data was a trend for NDIS carers to report decreasing quality of life compared to Non-NDIS carers.

An important finding from this study is that NDIS carers report significantly lower levels of feeling like they are part of the community. This effect was found after controlling for the carers’ level of dysphoric mood at each point in time. As previously indicated the main aim of the NDIS is to assist participants to become involved in their community (National Disability Insurance Agency, 2015) but benefits to the carers in terms of community connection is also implied. For example, the investigation into this long-term care and support scheme by the Productivity Commission (2011, p. 62) predicted a substantial “increase in the personal well-being of many people with disabilities and their carers”. While the NDIS may, or may not, be achieving this for participants, it appears to be decreasing the personal well-being of those caring for an individual with an ASD. In the long term this could significantly disadvantage those relying on them for care and support. As the individuals with an ASD form the largest single group of NDIS participants, it appears vital the NDIA address the NDIS carers reported diminishing sense of feeling like a part of the community.

With regard to limitations of the current findings the authors did attempt to control for some potential confounds. In a prior study ASD carers reported significantly higher levels of dysphoric mood and significantly lower levels of positive affect relative to negative affect (Snow & Donnelly, 2016) so dysphoric mood was included here as a covariate. However even when controlling for state dysphoria in the current study, NDIS-carers still endorsed lower personal well-being and quality of life. Other limitations with the current study include the relatively small number of NDIS carers who participated at the second time point so a larger
follow-up sample of this group is needed and will therefore be the focus of the continued work by the authors. In addition, all participants in the current study were carers of an individual with an ASD. The effect of the NDIS on the personal well-being and quality of life of those providing care for other types of disabilities, health issues, etc. needs to be explored. This will help determine the common and unique experiences among carers and how carer types differ with respect to their lived experience of the NDIS. Another limitation to these findings is the lack of male carers. Just 3 completed the repeated measures which indicates that the results of this research are far more reflective of the experiences of female carers of those with an ASD.

Preventing carer burnout in those caring for individuals with an ASD is vital to the quality, and duration, of the care they are able to provide (Green & Mears, 2014). This research implemented robust methods to control for the effect dysphoric mood has on an individual’s self-reported levels of personal well-being and quality of life. The difference between NDIS and Non-NDIS carers’ levels of personal well-being was significant and needs to be investigated further, possibly by improving links to community. For example, research into the effect of increased respite for carers on carer and participant well-being and quality of life would inform policy decisions regarding funding package features that might help those who provide the care as well as those who rely on a strong resilient carer. Obviously, any changes would require an examination of the long-term financial viability of the NDIS which is already under pressure. However, in terms of overall cost, carer fatigue and failing mental health have the potential to cost the Australian government significantly more than the funding required for carer respite.
Chapter 5. The National Disability Insurance Scheme: Comparison of Effects on Australian Carers by Type of Care Given

The previous chapter indicated that ASD carers supporting an individual in the NDIS reported significantly lower levels of personal wellbeing as compared to ASD carers supporting an individual not in the NDIS. Importantly, dysphoric mood was considered at the time they were assessed. Also, during the first 12 months an ASD carer was involved with the NDIS their reported low level of personal wellbeing did not improve. Although cautiously interpreted due to the majority of participants being in trial areas, this evidence challenges the NDIA’s claim that supporting participants to achieve goals would ‘directly and indirectly’ have a positive effect on carers, and those positive effects would occur due to information about, and linkage and referral to other service providers (National Disability Insurance Agency, n.d.). What is unknown is if other carer types report similar personal well-being, quality of life, and dysphoric mood profiles. It needs to be clarified if ASD carers have a unique profile of these factors, especially those functioning within the NDIS.

The hypothesis that dysphoric mood profiles would vary between carer types (ASD carers and Other carers) was postulated from items covered in the literature review regarding the NDIS. Specifically, it was thought that a range of factors would put ASD carers at greater risk for dysphoric mood reactions once engaged with the NDIS. For example, the stringent eligibility criteria for individuals with an ASD (Autism Aspergers Advocacy Australia, ND), the low level of funding available under the NDIS Early Childhood Early Intervention (ECEI) component (Marchbank, 2017; Ranasinghe, Jeyaseelan, White, & Russo, 2017) and the negative perceptions portrayed in the national media that ASD would significantly increase the cost of the NDIS (Flynn, 2017; Hughes, 2017; Morton, 2015; Morton, 2016) would differentially affect ASD carers as compared to other carer types.

Note - The methods used in this section of the project are similar, but not identical, to those used in chapter 4, therefore there is some repetition in the following.
To support the theory that carer types may differ on personal well-being and quality of life under the NDIS the following evidence is offered. Holmes and Carr (1991) identified that ASD carers have to deal with significantly more child behavior issues than carers of children with Down Syndrome (DS carers). This is an important factor to consider as the NDIA proposes that carers should be formally trained to provide more ‘enhanced’ care (Australian Department of Human Services, 2018), as opposed to the scheme funding the provision of ongoing specialist support. If ASD carers are already tasked with managing far more or more severe behavioural issues (Brouwer, van Exel, van Gorp, & Redekop, 2006; Cummins, Eckersley, Pallant, van Vugt, & Misajon, 2003; Hoefman et al., 2014), the extra burden of training and the possibly unrealistic expectation of having to provide enhanced care could result in serious negative consequences for those carers. It would be reasonable to expect that they might develop feelings of helplessness, a predisposing factor for depression, if faced with these additional challenges. McConnell, Parakkal, Savage, and Rempel (2015) report that informal carers tasked with providing home-based therapies reduces their employment activities and personal time vital to personal well-being and quality of life. As an indication of the possible negative effects of such an approach, McConnell et al. (2015) found that time providing therapeutic interventions positively correlated with reported level of personal sacrifice and negatively correlated with family well-being.

The significant negative influence ASD behaviours can have on the family unit has been reported by Povee, Roberts, Bourke, and Leonard (2012). These authors found from their research into the family functioning of Down Syndrome carers that concurrent ASD type behaviour problems in individuals with DS was associated with poorer family functioning. Another result of these differences between carers of those with DS alone versus those with concurrent ASD is the lower frequency of divorce and greater family coping and functioning in the former carer group (Urbano & Hodapp, 2007). These, and other factors
have given rise to the unfortunately named phenomenon “Down Syndrome Advantage” for those with a DS diagnosis alone (Cahill & Glidden, 1996, p. 2).

Another factor that contributes to the reported differences between DS and ASD carers is the positive correlation between maternal age and incidence of DS (Fisch et al., 2003). Older mothers of children with DS are reportedly more educated and further into their careers which in turn reduces the financial stress of the caring role. In addition, Hodapp, Ly, Fidler, and Ricci (2001) also report the increased social competence, language use and lower levels of problematic behaviour displayed by DS individuals may have a positive effect on the wellbeing of DS carers. Despite these seemingly positive effects, DS carers still report significantly “higher levels of stress, adjustment difficulties and poorer coping when compared to families of non-disabled children” (Povee et al., 2012, p. 962). Any variance in quality of life and personal wellbeing between ASD and DS carers needs to be quantified as the total number of NDIS participants with an intellectual disability, including DS, now equals the number of individuals with an ASD (National Disability Insurance Agency, 2018).

The experience of carers for children with other developmental disorders also needs to be considered.

One in 500 Australians born are diagnosed with Cerebral Palsy (CP) and there are approximately 34,000 Australians currently living with the condition (Cerebral Palsy Alliance Research Institute, 2013). One quarter of all individuals with CP present with behaviour disorders that have been identified in this thesis as having a significantly negative affect on carer well-being and quality of life. The estimated annual cost of care for each individual with CP in 2013 was $43,400 AUD of which 37% was met by the individual’s immediate family. This cost figure is exponentially increased for one fifth of CP carers who care for an individual that requires gastrostomy tube feeding. Interestingly, despite the extra cost associated with gastrostomy tube feeding, Sullivan et al. (2004, p. 800) report a “significant,
measurable improvement in the quality of life of carers (mothers predominately) after overcoming the feeding problems of children with CP by insertion of gastrostomy feeding tubes”. This phenomenon, and the DS advantage, illustrate the difficulties faced while trying to control for extraneous variables when measuring well-being across carers of individuals with various disorders.

Carers of individuals with a psychosocial disability face significant challenges under the NDIS. A report from the Commonwealth of Australia (2015) indicated 690,000 Australian’s have a severe mental health issue however the Australian Government estimated that just 230,000 of them would require ongoing support (Smith-Merry et al., 2018). The figure’s given by the National Disability Insurance Agency (2017) significantly underestimate the services required relative to the numbers provided by the Commonwealths. The NDIA suggest the total number of NDIS participants will be 460,000 and that only 13.9% (64,000) will be individuals with a psychosocial disability which is a shortfall of funding for 166,000 individuals. The gaps in the system for those with a psychosocial disability are already apparent. Currently just 6.4% of NDIS participants have a psychosocial disability (Smith-Merry et al., 2018). Many who were previously eligible for federal programs such as the Partners in Recovery initiative have found themselves ineligible for the NDIS (Smith-Merry & Hawkins, 2018). This has left them, and their carers, with nowhere to turn as funding for these federal programs, including Partners in Recovery, has been diverted to the NDIS (Commonwealth of Australia, 2016).

Many carers serve as the advocate for an individual who is unable to live in the family home, making housing issues under the NDIS a major concern. Currently only a small number (approx. 6%) of NDIS recipients are eligible under NDIA legislation for specialist disability accommodation funding (Endeavour Foundation, 2017). With a lack of specialist accommodation and the inability to afford what may be available, young persons with a
disability (PWD) now account for 5% of the population in residential aged care. This is despite the Community Affairs Reference Committee (2015) stating that the special support required by PWD cannot be provided by age care workers. This housing-related example illustrates the effect the early roll out the NDIS, without thorough investigation of critical factors, has had on participants and those helping them find appropriate services. The Mental Health Council of Australia (2014, p. n.p) has likened it to ‘designing an airplane as it is taking off the ground’.

Previously, to reduce the number of young people entering residential aged care, the Council of Australian Governments spent 244 million dollars over 5 years (2006 – 2011) on the Young People in Residential Aged Care initiative (Summer Foundation, 2016). Systemically, it was a failure as only 250 individuals benefitted from the scheme by moving out of aged care facilities, while 7183 young people with a disability qualified (Australian Government Productivity Commission, 2015). Only 244 avoided admittance into aged care within 2 years of the program being implemented. However, more research is required to understand the link between housing options and wellbeing. If differences in accommodation settings is linked to poorer carer or NDIS participant outcomes, it would support the argument for funding of more specialist accommodation and changes to the NDIA legislation to support participants currently situated in age care residences to move into more adequately supported housing currently situated in age care residences to move into more adequately supported housing.

It is believed a significant contributor to the low levels of personal well-being and quality of life among ASD carers is the persistent negative portrayal by main stream media regarding the cost of care for those with Autism to the NDIS and by extension to the taxpayers. This topic has caused division, even between carer types, as illustrated by Ms Angela Shanahan. This mother of 9, has 3 children who receive funding through the NDIS for
disabilities other than ASD. She is also a reporter for News Corporation’s, Australian newspaper. Shanahan (2018, n.p.) published an article calling for the NDIA to remove ASD from the list of disabilities that qualify for support. Shanahan was scathing in her attack against ASD carers stating “ASD usually is diagnosed after parents have doctor-shopped to obtain help with their children’s behavioural problems” and “I cannot understand how any claim can be made on the NDIS of parents with children who have relatively mild autism”.

She also notes that her children are more disabled than children with an ASD although the clinical literature indicates that those with an ASD present with far more severe behavioural issues and lower adaptive functioning than those with other disabilities.

In the current author’s view, Ms Shanahan’s nationally distributed comments about ASD and their carers are evidently uninformed and illogical. The claim that parents have gone “doctor-shopping” illustrates a total lack of knowledge regarding the diagnostic process for ASD; a process that requires a team of trained professionals to conduct the assessments, and parents spending thousands of dollars while coping with extreme levels of stress due not only to the challenging behaviours of their child but also the lack of availability of specially trained professionals. Stating that the majority of ASD parents would put themselves through such a stressful process multiple times illustrates Shanahan’s extreme negative bias. A response to Shanahan’s unfounded rhetoric, posted on the Autism Asperger’s Advocacy Alliance web site, summed up the thoughts of many ASD carers by stating “Ms Shanahan’s personal experience of having three children with a disability does not appear to have given her any empathy whatsoever for those with children with less overtly visible disabilities” (Brandis, 2018, n.p.).

The comments section of online newspaper articles about the NDIS, such as Shanahan’s (2018), also illustrate the public’s perception of Autism, ASD carers and the cost
of the NDIS. They include opinions that may contribute to ASD carers’ significantly reduced quality of life. Some examples include:

**Fair Comment** - “The NDIS should target only those who are permanently and totally incapacitated and that means excluding people with high functioning autism, mild learning difficulties and episodic mental health issues who can be managed by mainstream services.” (as cited in Ryan, 2018)

**John** - “Take no responsibility for diet and discipline or that all kids are different. Go doctor shopping. One out of six will eventually diagnose your child with ADHA or autism spectrum even though they can go to school and voila.” (as cited in Bolt, 2017)

**David** - “The many thousands of "bad behaviour" cases now being diagnosed as "autism spectrum " will be included in these rorts.” (as cited in Bolt, 2017)

**ShaneFromMelbourne** - “Put Autism on the NDIS so the entire scheme can be destroyed through bankruptcy sooner rather than latter” (as cited in Wardale, 2017)

**David** - “…NDIS was designed to mainly deal with the severely disabled & how autistic children have become severely disabled is unclear…Unfortunately whenever large amounts of government money becomes available the line up to get that money gets longer…” (as cited in Morton, 2015)

**Raymond N** - “Don’t get between any industry (especially a medical or self-diagnosing or self-identifying one) and a barrel of other peoples’ money.” (as cited in Morton, 2015)

**Daniel** - “autism is a scam, just like add, and adhd. nothing some solid disipline [sic] couldn't resolve. kids need fresh air, vegetables, sunlight, and supervision. if you can't provide this, you shouldn’t be a parent.” (as cited in Morton, 2015)

The large number of comments describing ASD carers as doctor shopping bludgers are reminiscent of reporter’s views (Morton, 2015; Shanahan, 2018) published by one of
Australia’s most read newspapers. It is not hard to understand why Australian ASD carers, whose child is an NDIS participant, feel negatively stigmatised by the Australian media and by some segments of the general public.

During data collection for the current project, several significant incidents occurred that may have affected ASD carers’ overall dysphoric mood. First, in September 2017, the first draft of Australia’s national guideline for ASD diagnosis was released by the Autism CRC for consultation (Autism CRC, 2017). Possibly concerning for ASD carers was the realisation that the development of the new diagnosis guidelines was funded solely by the NDIA. This raises serious ethical questions as the Operational Guidelines of the NDIS state “the total annual funding base required by the NDIS is determined by an actuarial estimate of the reasonable and necessary support needs of the target population” (Australian Department of Human Services, N.D, n.p.). Currently there are 14 400 more NDIS participants with an ASD than predicted by the Productivity Commission (2011). Evidence of the NDIA trying to reduce the cost of ASD comes from the chief research officer of Autism CRC, Professor Andrew Whitehouse who stated the Australian ASD diagnostic guidelines now bring ASD diagnoses “into line with the principles of the NDIS” (Whitehouse, 2018, n.p.). One of the four principles of the NDIS is minimising the support costs over a participant’s lifetime (Australian Department of Human Services, N.D.).

Second, fears that the NDIA would remove more individuals with an ASD from the NDIS arose in May 2018 when a leaked document revealed that only individuals with a level 3, ASD diagnosis would be eligible for NDIS support (Knaus, 2018). Although the NDIA denied the changes claiming a clerical error had occurred, The Australian newspaper reported that the NDIA had “accidentally published part of its plan to restrict access for autism” (Morton, 2018). This claim was supported by an NDIA submission to the
Productivity Commission who were investigating the cost of the National Disability Insurance Scheme (NDIS); as the NDIA conceded it had concerns about autism being included. ASD carers are rightfully feeling like the individuals they care for are in the cross hairs of the Australian government, media and the general public for all the wrong reasons. Data from participants in the current study indicate that the risk of decreased funding for essential care and the unpredictability of NDIA policies seemingly fuels anxiety about how proper care and associated carer burden might be managed in the future.

The research findings discussed in the current chapter is part of an ongoing project that has so far identified significant differences in dysphoric mood between Australian parents and carers of individuals with an ASD participating in the NDIS and those caring for a non NDIS participant (Snow & Donnelly, 2017). There were three specific aims in this final phase of the research program. The first was to identify if parents and carers of individuals with an ASD, (ASD-carers), varied on carer well-being and quality of life when compared to those caring for individuals with other disabilities (Other-carers) when their level of state affect was controlled for. Based on the literature above, it was hypothesised that ASD-carers would report a lower quality of life and sense of personal well-being compared to Other-carers as defined here. It was also hypothesised that ASD carers would report significantly higher levels of caregiver strain than Other carers, in or out of the scheme.

The second aim was to identify if carers caring for an NDIS participant (NDIS-carers), regardless of disability type, varied on personal well-being and quality of life when compared to their counterparts who cared for a non-NDIS participant (Non-NDIS Carers) when their level of state affect was controlled for. Based on previous results it was hypothesised that NDIS-carers would report significantly lower personal well-being and
quality of life compared to Non-NDIS Carers. The fact that the NDIS is still in the roll out phase also suggests that potential positive effects might not yet be realised by some carers.

Our third aim was to follow the participants over a 12-month period and identify if carer reports changed as a function of group membership (ASD-carers vs Other-carers x NDIS Type). It was hypothesised, after controlling for state affect during reporting, the quality of life and personal well-being of carers of individuals with an ASD would improve over time spent in the NDIS as carers covered under the scheme would have worked through the initial challenges related to understanding the program, participant assessment and customised service implementation. No change was expected for Non-NDIS carers. The methods, psychometric tools

Methods

Sampling

Resident Australian parents and carers of an individual with a disability were contacted via major autism and carer service providers and by Facebook and Twitter. Those caring for an NDIS participant were targeted in areas where the NDIS had been rolled out in the previous 6 months. Participants who completed the first survey were contacted 2 more times, at 6 monthly intervals to complete the survey again.

Materials

A 29-item, online survey was used to collect information from parents or other carers. The respondents were asked to provide information about their gender, marital status, location, and the number of persons with a disability (PWD) in their care. They also identified the disability of the person for whom they provided care and the level of support required. Non-NDIS carers were asked about their confidence in the NDIS’ capacity to benefit their own and the PWD’s quality of life and personal wellbeing. NDIS-carers were asked about their satisfaction with the effect of the NDIS on carer and PWD’s quality of life
and personal wellbeing. Ratings of level of perceived support from family and friends were also obtained.

Participants also answered the Personal Wellbeing Index (PWI) (International Wellbeing Group, 2013), the 21-item, Depression, Anxiety and Stress Scale (DASS) (Lovibond & Lovibond, 1995), the Caregiver Strain Questionnaire (CGSQ) (Brannan & Heflinger, 1997) and the Carer Quality of Life instrument (CQoL) (Brouwer, van Exel, van Gorp, & Redekop, 2006 & Redekop, 2006), as used in the previous chapter. Finally, participants answered yes or no when asked if they agreed to be contacted again to complete the same survey at a later date. Those who chose to continue participation were asked to leave contact details. Approximately 6 months after first completing the survey, participants were contacted via their preferred method (email, text message or phone call) and asked to complete the survey for a second time, and then again 6 months later for a third and final time.

Procedure

The survey was securely hosted on Survey Monkey and participants were initially directed via email or an advertisement to the online access point. Participants were informed prior to commencing that completion of the entire survey would imply their consent. Participants were then asked to complete 4 security questions which were used to formulate a secure code. This personal code enabled their response at time 1, 2 and 3 to be linked. This was followed by demographic/personal information questions, the online PWI, DASS-21, CGSQ, CQoL, and continuation of participation items in that order.
Results

Time One

Participants

At time one, 175 individuals originally participated. Removal of incomplete surveys \((n = 12)\) reduced the final number to 163 participants (152 females, 11 males) who formed four natural group based on carer type and the NDIS status as indicated in table 3.

Table 3. Gender and age demographics of participants by carer type and NDIS status

<table>
<thead>
<tr>
<th>Carer Type by NDIS Status Time One</th>
<th>Gender</th>
<th>(N)</th>
<th>Age Min</th>
<th>Age Max</th>
<th>(M)</th>
<th>(SD)</th>
</tr>
</thead>
<tbody>
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<td>33</td>
<td>77</td>
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<td>11.08</td>
</tr>
<tr>
<td></td>
<td>Male</td>
<td>4</td>
<td>36</td>
<td>71</td>
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<td>16.27</td>
</tr>
<tr>
<td>Other Non NDIS</td>
<td>Female</td>
<td>46</td>
<td>28</td>
<td>73</td>
<td>54.11</td>
<td>10.69</td>
</tr>
<tr>
<td></td>
<td>Male</td>
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<td>46</td>
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<td>53.00</td>
<td>7.16</td>
</tr>
<tr>
<td>ASD NDIS</td>
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<td>26</td>
<td>56</td>
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<td>7.56</td>
</tr>
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<td>60</td>
<td>60</td>
<td>60.00</td>
<td>0.00</td>
</tr>
<tr>
<td>ASD Non NDIS</td>
<td>Female</td>
<td>23</td>
<td>32</td>
<td>64</td>
<td>46.83</td>
<td>8.26</td>
</tr>
<tr>
<td></td>
<td>Male</td>
<td>2</td>
<td>49</td>
<td>54</td>
<td>51.50</td>
<td>3.54</td>
</tr>
</tbody>
</table>

In this study we were interested in controlling for dysphoric mood while again analysing group differences on a range of variables. Participants reported levels of depression and anxiety during the past week were used to calculate their dysphoric mood (DA_Tot) at the time of completing the survey. These scores were entered as a covariate to control for any influence they had on participants’ ratings on other measures. The stress subscale from the DASS was removed from the calculation of DA_Tot due a significant correlation with scores on the CGSQ.

After data cleaning, assumption testing and outlier analyses, independent samples \(t\) tests were used to identify difference between ASD and Other Carers, as well as NDIS and Non-NDIS Carers, on their reported levels of Personal Wellbeing (PWB), Carer Quality of Life (CQoL) and Caregiver Strain (CGS) scores after controlling for participants’ dysphoric mood (DA_Tot). The carer groups were then combined, and an ANOVA was used to identify
any significant variance in reported DASS levels across the four carer types. Three ANCOVAs were conducted to test if carer types varied significantly on reported levels of PWB, CQoL and CGS scores after controlling for DA_Tot. A Bonferroni adjusted alpha level of 0.017 was used.

To test the hypothesis that ASD carers would report lower personal well-being and quality of life compared to Other Carers, independent sample T tests were conducted using residualised scores for all measures which removed the variance related to carers’ level of dysphoric mood. As current caregiver strain was thought to possibly contribute to variations across carer types, CGS residualised scores were also analysed.

DA_Tot residualised measures were included in the following analyses. ASD Carers reported significantly lower levels of PWB ($M = -0.25, SD = 0.92$) than Other Carers ($M = 0.17, SD = 1.02$), $t(161) = 2.66, p = .009$. They also reported significantly lower levels of CQoL ($M = -0.25, SD = 0.98$) than Other Carers ($M = 0.16, SD = 0.98$), $t(161) = 2.61, p = .010$. ASD Carers also reported significantly higher levels of CGS ($M = 0.34, SD = 0.96$) than Other Carers ($M = -0.22, SD = 0.96$), $t(161) = -3.64, p = .000$.

To test the hypothesis that NDIS-carers would report lower levels of PWB and CQoL and higher levels of CGS compared to Non-NDIS Carers, independent sample T tests were conducted, again using residualised scores to control for the carers’ level of dysphoric mood. No significant differences between Non-NDIS and NDIS carer types was found across any of the variables.

A one-way ANOVA was used to investigate the difference in self-reported levels of depression, anxiety and stress across carer type and NDIS status using all three subscales of the DASS-21. The four carer types were ASD NDIS, ASD Non-NDIS, Other NDIS and Other Non-NDIS. No significant effect of carer type on self-reported levels of depression-related symptoms was found. There was a significant effect of carer type on self-reported levels of
anxiety $F(3, 159) = 3.20, p = .025, \omega = 0.20$ and stress $F(3, 159) = 4.34, p = .006, \omega = 0.24$. Post hoc analyses using a Bonferroni corrected alpha level revealed ASD NDIS Carers reported significantly higher levels of anxiety ($M = 6.83, SD = 4.46$) and stress ($M = 12.25, SD = 4.52$) compared to Other Non-NDIS Carers (Anxiety $M = 4.24, SD = 3.88$) (Stress $M = 8.94, SD = 4.48$). No other significant differences were found between carer types across scores on the Anxiety and Stress subscales of the DASS-21.

The DA-Tot score was entered as a covariate in ANCOVAs to identify if the combination of carer type and NDIS influenced carers’ PWB, CQoL and CGS scores. All findings are reported after variance related to dysphoric was removed. The first ANCOVA revealed a significant effect of carer type on PWB scores $F(3, 158) = 3.49, p = .017, \eta^2 = 0.062$. Post hoc testing revealed that ASD NDIS carers reported significantly lower PWB scores ($M = 44.89, SE = 2.43$) compared to Other NDIS Carers ($M = 54.92, SE = 2.20$) as illustrated in figure 8. The second ANCOVA revealed similar significant effects of carer type on CQoL scores $F(3, 158) = 2.99, p = .033, \eta^2 = 0.054$. Post hoc testing revealed that ASD NDIS carers reported significantly lower CQoL ($M = 4.72, SE = 0.33$) compared to Other NDIS Carers ($M = 6.02, SE = 0.30$) as illustrated in figure 9.
Figure 8. Carer PWB scores controlling for DA_Tot at time one

Figure 9. Carer CQoL scores controlling for DA_Tot at time one
The third ANCOVA revealed a significant effect of carer type on CGS scores while controlling for dysphoric mood $F(3, 158) = 5.62, p = .001, \eta^2 = 0.096$. Post hoc testing revealed that ASD NDIS carers report significantly higher CGS ($M = 76.62, SE = 1.92$) compared to Other NDIS Carers ($M = 66.66, SE = 1.74$) and Other Non-NDIS Carers ($M = 68.10, SE = 1.72$) as illustrated in figure 10.

![Bar chart showing Carer CGS scores controlling for DA_Tot at Time 1](chart.png)

*Figure 10. Carer CGS scores controlling for DA_Tot at time one*

**Time Two**

**Participants**

The number of participants who completed the survey at time 2 ($N = 87$) reduced by 47% from time 1 ($N = 163$). Also, a number of participants who were originally Non-NDIS carers became NDIS carers ($N = 20$) in the 6-month period between time 1 and 2. These factors resulted in a significantly reduced number of participants in the ASD Non-NDIS group ($N=9$) as shown in Table 4.
Table 4. Gender and age demographics of participants by carer type and NDIS status at time two

<table>
<thead>
<tr>
<th>Carer Type by NDIS Status</th>
<th>Time Two</th>
<th>Gender</th>
<th>N</th>
<th>Age Min</th>
<th>Age Max</th>
<th>M</th>
<th>SD</th>
</tr>
</thead>
<tbody>
<tr>
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<td>33</td>
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<tr>
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</tr>
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<td>3.54</td>
</tr>
</tbody>
</table>

To test the hypotheses that ASD carers would report lower personal well-being and quality of life, and increased care giver strain compared to Other Carers, independent sample T tests were conducted using residualised scores which controlled for carers’ level of dysphoric mood. A Bonferroni adjusted alpha level of 0.017 was used. No significant differences between ASD and Other carers were found on PWB, CQoL and CGS scores reported at time two. Similarly, no difference was found between NDIS and Non-NDIS carers on these factors.

A one-way ANOVA found no significant effect of carer type on self-reported levels of depression, anxiety and stress across the four carer types at time two. The dysphoric mood score at time two was entered as a covariate in the ANCOVA’s to identify if carer type x NDIS status influenced carers’ PWB, CQoL and CGS scores reported at time two. The ANCOVA’s revealed no significant effect of carer type x NDIS status at time two on PWB, CQoL or CGS scores after controlling for dysphoric mood.

**Time Three**

**Participants**

Data from Non-NDIS carers was not analysed at time three due to the small sample \((N = 10)\) left after attrition and the transfer of individuals cared from non-NDIS status into the NDIS. Demographics for the sample at time 3 are shown in table 5 below.
Table 5. Gender and age demographics of participants by carer type and NDIS status at time three

<table>
<thead>
<tr>
<th>Carer Type by NDIS Status Time Three</th>
<th>Gender</th>
<th>N</th>
<th>Age Min</th>
<th>Age Max</th>
<th>M</th>
<th>SD</th>
</tr>
</thead>
<tbody>
<tr>
<td>Other NDIS</td>
<td>Female</td>
<td>29</td>
<td>34</td>
<td>73</td>
<td>54.31</td>
<td>10.69</td>
</tr>
<tr>
<td></td>
<td>Male</td>
<td>2</td>
<td>46</td>
<td>69</td>
<td>57.50</td>
<td>16.26</td>
</tr>
<tr>
<td>Other Non-NDIS</td>
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<td>34</td>
<td>71</td>
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<td>14.71</td>
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</tr>
<tr>
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<td>54.33</td>
<td>5.51</td>
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<td>47</td>
<td>55</td>
<td>51.00</td>
<td>5.66</td>
</tr>
</tbody>
</table>

A series of independent samples t test using a Bonferroni corrected alpha of 0.017 found no significant effect of carer type on self-reported levels of depression, anxiety and stress at time three. The studentized residual values which controlled for participants dysphoric mood at time three when reporting their levels of PWB, CQoL and CGS were then analysed with three independent samples t test, again using a Bonferroni corrected alpha of 0.017. No significant difference was found between ASD carers’ reported levels of PWB at time three compared to Other carers. ASD carers did report significantly less CQoL ($M = -.41, SD = .98$) compared to Other carers ($M = .24, SD = .92$), $t (64) = .2.74, p = .008$. ASD carers also reported significantly higher levels of CGS ($M = .44, SD = .89$) compared to Other carers ($M = -.27, SD = .96$), $t (64) = -3.03, p = .004$.

Repeated Measures

Time One to Time Two

Because the covariate (dysphoric mood) was time affected, mixed design repeated ANOVAS were conducted using studentized residual scores calculated to independently account for dysphoric mood at time one and two when assessing PWI, CQoL and CGSQ over time. Only carers of NDIS participants at time one and two ($N = 41$) were included in the
analysis as the effect of the NDIS was the factor of interest. Also, participant attrition and changing of NDIS carer status had reduced the number of Non-NDIS carer significantly.

There was no significant interaction effect of time in the NDIS across Carer type on PWB, however there was a significant main effect of Carer type on PWB scores, $F(1, 39) = 11.74, p = .001, \eta^2 = 0.231$. Post hoc t tests indicated that ASD NDIS carers reported significantly lower levels of PWB after controlling for dysphoric mood than Other NDIS carers at time one, $t(39) = 2.15, p = .038$, and at time two, $t(39) = 3.670, p = .001$. Figure 11 indicates the trend of increasing PWB scores for Other Carers in the NDIS after controlling for their dysphoric mood. The data also suggests that time spent in the NDIS does not increase ASD carers’ PWB scores.

![Figure 11. Carer PWB scores controlling for DA_Tot at time one and two](image)

There was a significant interaction effect between time and carer type on CQoL residual scores, $F(1, 39) = 8.29, p = .006, \eta^2 = 0.175$. There was no significant main effect for CQoL residualised scores across carer types. Post hoc t tests to investigate the interaction effect between time and carer type indicated that ASD NDIS carers reported significantly
higher levels of CQoL than Other NDIS carers at time one, \( t(39) = -3.27, p = .002 \). At time two the opposite results were found with ASD NDIS carers reporting lower levels of CQoL than Other NDIS carers although the difference was not significant. This suggests that, after controlling for dysphoric mood, time in the NDIS reduces ASD Carer quality of life but increases it for Other Carers as illustrated figure 12.

*Figure 12. Carer CQoL scores controlling for DA_Tot at time one and two*

There was no interaction effect between time and carer type on CGS residual scores. Also, there was no significant main effect of Carer type on CGS residual scores. The trend in the data suggests time in the NDIS may increase care giver strain for ASD Carers but reduce it for Other carers as illustrated figure 13.
Figure 13. Carers CGS scores controlling for DA_Tot at time one and two

Time Two to Time Three

Only carers of NDIS participants at time two and three (N = 32) were included in these repeated measures factorial ANOVA’s to examine the effects of time and carer type on the variables of interest. They consisted of 15 Other NDIS carers (14 female, 1 male) and 17 ASD NDIS carers (16 female, 1 male). No interaction effect of time and carer type on residualised CGS scores was found. There was a significant main effect of carer type, $F(1, 30) = 6.94, p = .013, \eta^2 = 0.188,$ with ASD NDIS carers reporting significantly higher overall CGS compared to Other NDIS carers as indicated in figure 14. No effects were found for PWB or CQoL residualised scores across time or carer type, or for their interaction.
There was no effect of carer type or time on residualised PWB scores. No interaction effect of time and carer type on residualised CQoL scores was found, but there was a significant main effect of carer type, $F(1, 30) = 7.33$, $p = .003$, $\eta^2 = 0.261$. ASD NDIS carers reporting significantly less quality of life overall compared to Other NDIS carers as indicated in figure 15. No interaction effect of time and carer type on residualised CGS scores was found. There was a significant main effect of carer type, $F(1, 30) = 12.88$, $p = .001$, $\eta^2 = 0.30$, with ASD NDIS carers reporting significantly higher CGS when averaged across times 1 and 3 and compared to Other NDIS carers (figure 16).
Figure 15. Carer CQoL scores controlling for DA_Tot at time one and three

Figure 16. Carer CGS scores controlling for DA_Tot at time one and three
Discussion

The following discussion addresses findings regarding the quality of life, personal well-being and levels of caregiver strain of ASD and Other carers. All the following reports on hypothesis testing that removed the variance related to dysphoric mood in the participants’ reporting on the dependent variables of interest. This is a unique contribution to the literature which will be reflected on in Chapter 6.

The hypothesis that ASD carers would report lower quality of life, after controlling for dysphoric mood, compared to Other carers was supported at times one and three. Similarly, the hypothesis that ASD carers would report higher caregiver strain than Other carers was also supported at times one and three. The hypothesis that ASD carers would report lower levels of personal well-being than Other carers was supported at time one only. None of the hypotheses regarding the ASD versus Other carer comparisons were supported at time two.

Importantly, the hypothesis that NDIS-carers would report lower levels of personal well-being and quality of life compared to Non-NDIS Carers, after dysphoric mood was controlled for, was not supported at time one or two. Low numbers of Non-NDIS participants resulted in not enough statistical power to test this hypothesis at time three. Another important finding is that participation in the NDIS did not improve reported quality of life of either ASD or Other carers. Further, 12 months participation in the NDIS did not improve carer-reported personal well-being. Also, NDIS participation had no effect in reducing the significantly higher levels of caregiver strain reported by ASD carers compared to Other carers.

It is vital to understand that being an NDIS-supported carer had zero effect on the carers’ personal well-being, quality of life or caregiver strain at any of the three-time points,
or over the 12 months’ while in the NDIS scheme. This finding directly refutes the NDIA’s claim that participation would ‘directly and indirectly’ have a positive impact on carers (National Disability Insurance Agency, n.d.). Further, it opposes the recent statement by NDIA chief executive, Robert De Luca that “the scheme was having a positive impact” for carers (Knaus, 2018). It is understood that the main goal of the NDIS is to help individuals with a disability to achieve their goals in life and not to assist carers. However, misleading comments made by the NDIA about the scheme positively affecting carers may cause further disillusionment among carers. The argument that the scheme is in its infancy, and will improve in the future, is no longer viable as the scheme had been trialled and operated for four years prior to the current data collection. The author argues this allowed ample time for the NDIA to identify what was established in the current study, that the scheme has not improved the experience for many carers and that very low levels of wellbeing and quality of life persist, especially for those caring for someone with ASD.

The overall significantly higher levels of care giver strain found in ASD carers compared to Other carers supports findings by Holmes and Carr (1991) that ASD carers deal with significantly more adverse child behaviour issues than Other carers. The overall increased levels of caregiver strain that ASD carers deal with is reflected by the finding they also report significantly lower quality of life compared to Other carers overall. While NDIS participation was not meant to rectify this unique factor for ASD carers, the scheme should, at the very minimum, attempt to address this issue. As Green and Mears (2014) indicated, preventing ASD carer burnout is vital to the quality, and duration, of the care they are able to provide.

It appears reasonable to conclude that the longstanding aim of the NDIA to reduce the number of individuals with an ASD in the NDIS may be partially responsible to the
reported diminished quality of life among ASD carers. Although not directly assessed in the current program of research, evidence of threats to reduce funding, coupled with the unpredictable and seemingly arbitrary and variable decision-making regarding funding packages, could clearly foster significant anxiety, lower quality of life and greater levels of care giver strain even relative to other carers. The release of the national guidelines for ASD assessment and diagnosis are concerning. The fact that the NDIA funded the committee for establishing these guidelines, that they now mirror NDIS priorities, and that the NDIA conceded that they under-estimated the number of individuals with an ASD (Morton, 2018), all tend to raise suspicions about their validity.

Another possible driving factor is the media’s portrayal of ASD carers as attempting to defraud the NDIS and tax payers. To what extent these factors have contributed to the results above is currently unknown, however, based on the words of Shanahan (2018), an NDIS carer herself, and other articles cited above, a reasonable person would assume that those already stressed in their caring roles would be significantly disheartened. Further investigation is required to explore more fully the causal mechanisms that subserve the reports of a low sense of wellbeing, quality of life and excessive carer strain. More in depth qualitative studies that explore in detail carer expectations regarding the NDIS and their experiences as they progress through the scheme on behalf of the person for which they provide care would be most illuminating.
Chapter 6. General Discussion, Summary and Conclusion

As this thesis includes discussion of study findings above, this general discussion section will be brief to avoid repetition. A novel approach has been that results were reported after removing variance related to carers’ dysphoric mood when reporting on the dependent variables of interest. This method offers a unique contribution to the current literature about ASD carers’ well-being and quality of life. It appears to be the first attempt to measure these factors while controlling for significantly elevated levels of dysphoric mood characteristic of this population of carers, and the findings suggest that they present a unique profile compared to other carer types.

The finding that ASD carers report significantly higher levels of depression, anxiety and stress compared to other carers and parents of typically developing children supports previous reports (Allen, Bowles, & Weber, 2013; Baker et al., 2003; Baker, Seltzer, & Greenberg, 2011; Benson & Karlof, 2009; Bitsika & Sharpley, 2004; Duarte, Bordin, Yazigi, & Mooney, 2005; Dunn et al., 2001; Falk, Norris, & Quinn, 2014; Sanders & Morgan, 1997; Sharpley, Bitsika, & Efremidis, 1997; Weitlauf, Vehorn, Taylor, & Warren, 2014). The current findings also indicate that the complex nature of caring for an individual with an ASD may not only be a causal factor in carers’ elevated levels of dysphoria but also, the lifetime care required for ASD may act to maintain symptoms of anxiety and depression. The impact of dysphoric mood should be controlled for when using psychometric tests to measure ASD carers. As indicated in chapter 3, when dysphoric mood was not controlled for ASD carers reported significantly lower levels of parenting sense of competency that parents of typically developing children. This indicates that the Parenting Sense of Competency Scale (Gibaud-Wallston & Wandersman, 1978) measures feelings of dysphoria as well as a parents’ sense of competency. These findings also support the concept that parental competency is negatively
affected by the level of dysphoric mood (Coleman & Karraker, 1998; Cutrona & Troutman, 1986; Jackson & Huang, 2000; Scheel & Rieckmann, 1998; Teti, O’Connell, & Reiner, 1996)

The personality of ASD carers was falsely represented as a causal factor of Autism nearly 60 years ago (Bettelheim, 1972; Kanner, N.D, as cited in Thomas, 1960) and this stigmatising inaccuracy is still hinted at in the media (Shanahan, 2016; Morton, 2015; Morton, 2016a; Morton 2016b). The only personality differences found in the current research of parents of a child with an ASD versus those with a typically developed child were higher levels of neuroticism and extroversion. The most parsimonious explanation was given above however, it is also believed that current high levels of neuroticism reported by ASD carers may be a result of the constant negative reports regarding the cost of ASD under the NDIS and, the portrayal of ASD carers as doctor shoppers looking for a free hand out. Research into ASD carers’ perception of their portrayal by the media, specifically regarding the NDIS, is needed. One limitation of this study is that it did not attempt to identify the direction of the effect between caring for an individual with an ASD and levels of neuroticism and extroversion. This requires further investigation as caring for an individual with an ASD may increase an individual’s level of extroversion due to the compulsory disability advocating that is required. Longitudinal research that monitors ASD carers personality from the time of the child’s diagnosis to adolescence, is needed to fully understand any interaction that may occur.

It was initially thought, based on previous literature, that ASD carers in rural and remote areas within Australia would face a greater number of challenges seeking support services for their child (Clifford & Minnes, 2013b; Krauss, Gulley, Sciegaj, & Wells, 2003; Ruble, Heflinger, Renfrew, & Saunders, 2005). This was expected to have a significant bearing on the level of help-seeking behaviour reported by ASD carers living in rural/remote
locations compared to those in more densely populated areas where there is a larger number of available service providers. When aiming to measure the effect of the NDIS within this population it was necessary to identify if location did affect help-seeking behaviour. No difference in ASD carers’ help-seeking behaviour was found across remote/rural and metropolitan locations. This determined help-seeking behaviour shown by Australian ASD carers to access the best possible services for the individual they care for may partly explain why the Productivity Commission (2011) grossly underestimated the number of individuals with an ASD that would be eligible for the NDIS. As the NDIS has rolled out into more rural and remote areas, the issue of travel costs to access disability support has been reduced. This has enabled some ASD carers, previously unable to afford travel to distal support systems, to engage essential support.

One of the unique contributions this research has made to our current knowledge of Australian ASD carers is the identification of factors that have the potential to affect ASD carers’ self-reported levels of personal well-being and quality of life. Identifying that parental sense of competency did not significantly vary across carer types, and that location did not reduce ASD carers’ reported levels of help-seeking behaviour, prior to the NDIS rollout, strengthens the findings of the longitudinal studies conducted. One factor that requires detailed discussion is carers’ sense of personal well-being. There was a negative difference in personal well-being level reported by ASD carers navigating the NDIS compared to those not in the NDIS in the second stage of this research. But, these findings were not found between ASD carers and Other carers in the third stage. Regrettably, it was not possible to compare between NDIS and Non-NDIS carers at stage three due to the significant attrition rate of Non-NDIS carers in the later stages of the study. However, an overall view of how carer personal well-being is changing over time is required. To do this, the mean personal well-
being scores of participants in this research project need to be discussed in comparison to those found by Cummins et al. (2007).

Cummins et al. concluded in 2007 that “Carers have the lowest collective well-being of any group we have yet discovered” (p. 14) based on their Personal Well-Being Index (PWI) scores. Of the 428 completed PWI forms collected between 2016 and 2018 by the current author, 213 were completed by ASD carers and 215 by Other carers. Some carers completed multiple (Max = 3) PWI’s at separate points in time due to the longitudinal nature of the research. The mean PWI score (47.9) of carers in this research is graphically illustrated against the 2017 Australian average score and the average score reported by Cummins et al. (2007) in figure 16 below. The mean PWI score for all carers in this research is 38% lower than the 2017 Australian mean score reported by Australian Unity (2017). This is an 18.1% reduction in carers’ reported levels of personal well-being scores relative to those reported in 2007 by Cummins et al.

Figure 17. Carer Personal Well-being 2007 to 2018
The most consistent difference noted between carer types was the significantly lower quality of life reported by ASD carers. The first time point in stage three of this project indicated that ASD NDIS carers reported the lowest quality of life compared to all other carer types. The current author and others believe this finding is related to the extra burden placed on ASD carers by the NDIS. As Smith et al (2010) reported, prior to the NDIS, informal ASD carers were already spending significantly more time providing care than other parent types. They are faced with the added burden of navigating the NDIS and the requirement that the enhanced care funding provided in an ASD individual’s NDIS package be used to train their care giver to provide specialist care (Australian Department of Human Services, 2018b) normally done by professionals with 3 to 4 years of university training. Support for this theory can be seen in the responses given by ASD carers to the question, ‘What was the most difficult part of transitioning into the NDIS’? One participant responded, “Electronic tools not working. Responsibility of payments being the care coordinator or parent. Language is abysmal with assumptions that all people understand the meaning. Ad infinitum.” These factors may have negatively affected the levels of care giver strain reported by ASD NDIS carers.

We were unable to compare groups at time three as there was an insufficient number of non-NDIS carers who were classified as such at time 1 and again at time 3. More NDIS carers left the research program (51.1%) relative to non-NDIS carers (41.3%), but a significant percentage of non-NDIS carers transitioned to the NDIS during the project (36.4%, N = 24). This left only 10 original members of the non-NDIS group at time 3. Why NDIS carers were more likely to discontinue their involvement remains unclear. Some written comments by NDIS-supported carers indicated that additional administrative responsibilities and hassles in managing the prescribed plan made continued participation prohibitive in terms
of the time required. In attempting to understand differential risk for participant attrition, scores at time one and two for those enrolled in the NDIS who later left the research program were compared to those in the same group but continued to be involved. Those who chose to continue participation reported lower levels of depression, anxiety and stress. More in-depth interviews with those who chose to discontinue their involvement would have been informative and might be considered a limitation of the current research. However, consideration of the carers’ already challenging circumstances was the priority.

It is important to consider the required support rating, as given in the DSM-V diagnostic system (American Psychiatric Association, 2013), and noted by ASD carers when considering their level of care giver strain. The majority of ASD carers reported their child’s diagnostic support rating as level 2; requiring substantial support. As previously reported, levels of carer strain are positively correlated with the level of deviant ASD behaviour (Baker et al., 2003; Lecavalier, Leone, & Wiltz, 2006; McStay, Dissanayake, Scheeren, Koot, & Begeer, 2014; Sanders & Morgan, 1997) which would reasonably be linked to the consistently higher reported levels of care giver strain by ASD carers. However, ASD NDIS carers reported significantly higher levels of care giver strain compared to Other Non-NDIS and Other NDIS carers, and while not significant, they reported a 5% higher strain rating relative to ASD Non-NDIS carers. This indicates that navigation into, and the maintenance of, an NDIS support package puts ASD carers at risk of increased levels of care giver strain.

ASD carers in the NDIS also reported the lowest sense of feeling like a part of their communities. The failure of the NDIS core support that aims to, “assist people with disability to enjoy social and community interaction” (Australian Department of Human Services, 2018b, p. N.P) is potentially a causal factor. As previously indicated, Duffy et al (2017) reported that individuals with severe or profound ASD show no positive changes when
interventions aimed at improving social interaction capacity are implemented and those with ASD may experience exacerbation of extreme negative behaviours when exposed to complex, bombarding social circumstances. This means that those affected by severe ASD are being funded for supports that are more disabling than enabling, while funding of respite for carers that may foster continued connection to their community has been eliminated. Without the availability of supports for individuals with a severe, or profound, level of ASD that do not require participation in disabling social interaction, carers are forced to either deal with the meltdowns triggered by sensory overstimulation in social environments, or to not engage with funded social interaction supports. Not engaging with the currently unsuitable supports means a participant may not use their allocated funding in a year. This increases the risk of their funding amount being cut in the following year. Certainly, this has a negative effect on ASD carers’ sense of feeling like a part of their communities, their level of carer strain, and their quality of life.

As discussed above, during stage two of this project ASD carers were asked if they could briefly tell us what was the most difficult part of transitioning into the NDIS. Although this qualitative data was not systematically analysed, some participants' responses are reported here to illustrate how the NDIS roll out has affected their lives:

“NDIA workers not understanding autism and not listening to me about what my child needs. An underlying belief from some workers in the NDIA that autism can be ‘fixed’ by applying therapies and that it is not a lifelong disability” Female, 44 years of age.
“Planners being completely unsupportive and having no understanding of how having more than one severely autistic child affects our ability to do anything other families do” Female, 34 years of age.

“The wait between accessing assessment (due to lack of specialist availability) and access to funded supports (not available without assessment) and not knowing anything about the diagnosis, or where to go for support” Female, 40 years of age.

One participant’s comment supports the theory that the NDIA is endeavouring to reduce funding for participants who have an ASD

“The first plan was easy, the 2nd plan had to fight for what my son required” Female, 46 years of age.

While it is understood that the NDIA does not have a bottomless barrel of money to distribute, the decision to target a specific disability to reduce expenditure opposes one of the three core functions upon which the scheme was built: “provide individually tailored, taxpayer-funded support, which should be targeted at people with significant disabilities who are assessed as needing such support” (Productivity Commission, 2011, p. 63). This core function has been eroded through the constant disparagement of individuals with an ASD and their carers by the NDIA staff and the Australian media. They have been labelled, and treated, as a group rather than individuals with a disability that require support. Autism is a lifelong disorder for which there is no cure. Despite these facts the NDIA has, and is, purposefully trying to limit financial support for individuals who have been assessed as
requiring substantial support. Efforts being made by the NDIA to reduce the number of individuals with an ASD that qualify for funded supports include their funding of research to create new autism diagnosis guidelines. To which, Professor Andrew Whitehouse stated those guidelines now bring ASD diagnoses, “into line with the principles of the NDIS” (Whitehouse, 2018). The relevant NDIS principle being to minimise the costs of support over a participant’s lifetime (Australian Department of Human Services, N.D.). This represents a significant conflict of interest when the true needs of the disabled persons and their carers are concerned.

Despite the many problems with the NDIS, if the core feature of individualised support planning is applied, the potential long-term benefits can far outweigh them. There are many positive reports about interaction with, and benefits of, the NDIS from carers. For many, especially older carers (some in their 70’s), it’s their last hope their child will be cared for when they are gone. The majority of ASD carers informally spoken with by the author elucidate their desire for the NDIS to be successful in the long term. They hope that by having the NDIS assist them to pay for the therapies their children require now will enable their child to live with less support requirements in the future. In particular, full funding of therapeutic interventions for autism now has the potential to save the NDIA immeasurable amounts of money in the future.

The financial savings to the Australian Government would extend much further than just the jobs created by fully funding proper therapeutic support. As previously indicated Australian carers, receiving a carer’s payment, are permitted to be out of care for just 25 hours per week (National Commission of Audit, 2014). By fully funding the best practice therapeutic interventions for ASD there is significant potential to reduce the number of Australian ASD carers reliant on a carer’s payment by enabling them to work full, or even
part time. Simple economics suggests this would result in more Australian carers paying income tax and being able to purchase more goods and services that include a GST component in the price. Done correctly, the NDIS has the potential to put more money back into the Government’s barrel than can be saved by denying funding to those who require substantial support. Although conducted for making the case for early interventions for child behaviour and mental health Karoly, Kilburn, and Cannon (2005) report a return of between $1.80 and $17.07 for each dollar spent on early intervention programs. There has not been a careful examination of this economic argument for children with a disability and their carers.

With Australian informal carers saving Australian taxpayers almost double the annual cost of the NDIS (Carers Australia, 2015a) it makes financial sense to ensure that informal carers are protected from the carer burn out discussed by Green & Mears (2014). Occasional carer respite is critical for carers to maintain their capacity to cope with the stress that comes with full time care provision (Harris et al., 2015). The NDIA is funding some research projects, specifically those that address information, linkage and referral to mainstream services that aim to assist carers (National Disability Insurance Agency, 2018b). However, the provision of information, linkage and referral to non-funded carer support may not be as effective in improving carer quality of life and reducing caregiver strain as funding occasional carer respite.

In summary, Australian ASD carers displayed high levels of depression, anxiety and stress, caregiver strain and low levels of personal well-being and quality of life prior to the NDIS roll out. The NDIA claimed that supporting the participants to achieve goals would ‘directly and indirectly’ have a positive impact on all carers (National Disability Insurance Agency, n.d.) however the findings from this research strongly refute that suggestion,
especially in the case of ASD carers. Jenny Macklin’s pre-NDIS rollout statement that “most people with autism would be covered by the NDIS” (Aubusson, 2013 as cited in Ergas, 2013, p. 340) has indeed translated the word ‘Most’ as ‘the number affordable’. The findings by Backhouse (2017) that an acceptable level of care is not possible for Australians with a disability under the current version of the NDIS are being felt first by ASD carers.

In conclusion, the restricted, diagnosis-based rather than true needs model legislated by the NDIA will see many with an ASD diagnosis excluded from support services that could improve their long-term outcomes on several life factors. The current goals of the NDIA appear to closely imitate that of other major insurance companies that strive to improve the bottom line for investors by denying as many genuine customers’ claims as possible. Regrettably, in the case of the NDIA, the investors are Australian Government political parties while the claimants are one of the most stigmatised and vulnerable groups among Australians. The statement made by Autism Asperger’s Advocacy Australia (ND, para 1) summarises the current state of the NDIS from the perspective of this advocacy group: “The NDIS fails many people with ASD, denying them the services and supports they need.” For ASD carers, it is a problem they desperately want resolved and until that time, it is predicted that their personal well-being and quality of life will continue to decline.

It is vital ASD carers’ personal well-being be monitored now that this new paradigm of disability support that promised all carers “certainty about the future” and “more respite” (Productivity Commission, 2011, p. 12) has been operationalised. To continue the monitoring and examination of appropriate interventions for ASD carers’ personal well-being requires replication of Cummins et al. 2007 study with a large sample of Australian ASD carers. Without urgent evidence-based support, a significant proportion of ASD carers, may succumb to the carer burnout that Green & Mears (2014) discussed, and remain at high risk
for mental health disorders. The disabled children for whom they care, and Australian taxpayers will also suffer the consequences of the failure to sufficiently support carers.
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NDIS & Carers of Individuals with Autism


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NDIS & Carers of Individuals with Autism

programs/healthreport/gaps-in-ndis-coverage-for-people-with-psychosocial-disability/9370084#transcript.


Appendix 1: Ethics Approval

SCU HUMAN RESEARCH ETHICS COMMITTEE (SCU HREC)

NOTIFICATION

Expeditied Application Approval

To: Dr James Donnelly and Ms Tahlia Sow

From: Professor Bill Boyd
    Chair, Human Research Ethics Committee (HREC)

Project name: Effect of the NDIS on Australian Parents of Children with an Autism Spectrum Disorder

Approval Date: 2nd July 2015

Approval Number: EON-15-192

Nearly Date: 1st October 2018

Dear Annie,

Thank you for the expedited ethics application received 1st July 2015. This was considered by the Chair of the HREC Professor Bill Boyd and it was found to be of merit, low risk and meeting the Statement principles. I am pleased to advise you that ethics approval has been granted for this research project. Please note the ethics approval number above.

Your responsibilities under this approval are as follows:

1. The Coordinating Principal Investigator will immediately report any study that might warrant review of ethical approval of the project on the Adverse Events form.
2. The Coordinating Principal Investigator will immediately notify the SCU HREC, on the appropriate form, of any change in protocol.
3. The Coordinating Principal Investigator will report to the SCU HREC annually in the specified format and notify SCU HREC when the project is completed.
4. The Coordinating Principal Investigator will notify the SCU HREC if the project is discontinued at a participating site before the expected completion date, with reasons provided.
5. The Coordinating Principal Investigator will notify the SCU HREC of any plan to extend the duration of the project past the approval period listed above and will submit any associated required documentation.

Researchers conducting a study in a country other than Australia, need to be aware of any protocols for that country and ensure that they are followed ethically and with appropriate cultural sensitivity.

Should you have any queries about the SCU HREC’s consideration of your project please contact ethics.terms@scu.edu.au. The SCU HREC Terms of Reference, membership and standard forms are available from http://scu.edu.au/research/index.php?ctid=1225&catid=1225.

SCU HREC wishes you every success in your research.

Kind Regards,

Prof. Bill Boyd
Chair, Human Research Ethics Committee
Appendix 2. Survey One

Australian Parenting Experiences

Parenting in Australia: Risks for mood disorders related to Location, Services, and Personality

Previous research from overseas has found that parents, siblings, and carers of a child with Autism Spectrum Disorder (ASD) are at greater risk of depression, anxiety, parental stress, and low levels of parenting confidence when compared to their counterparts caring for, or living with, typically developing children. The aims of this research are to:

1. Describe personality, perceived parenting competence and resource use profiles of Australian parents and carers of children with, and without, an autism spectrum disorder
2. Determine if these profiles differ across localities within Australia
3. Gather essential data to design and trial a web-based support service specifically for Australian parents and carers of autistic children and;
4. Increase our knowledge and understanding of several key factors associated with caring for autistic and non-autistic individuals within Australia

Participant’s requirements

If you choose to participate, you will be asked to complete an online survey that has several components. The first section includes questions about marital status, number of children, location (rural, regional, metropolitan), availability of services, number of services used, etc. You will also be asked to report any previous or current periods of depression, anxiety, and stress with a simple yes or no answer format. The next sections ask about your personality (The Big Five Personality test), current level of emotion (Positive and Negative Affect Scale - PANAS), perceived parenting competence (Perceived Sense of Competence Scale - PSCS), and symptoms sometimes related to depression, anxiety and stress (Depression Anxiety and Stress scale – DAAS).

Privacy and Confidentiality

All data collected from participants will be de-identified to protect your privacy and confidentiality. Your completion of the survey will imply consent.

Withdrawal of participation

Participants can withdraw their consent at any time with no negative consequences and all data obtained up until that point will be deleted. Participants can simply withdraw from participation by closing their web browser to exit the survey or by contacting the investigators.
Researchers Contact Details

Matthew Snow (BPsych Hons)
Doctoral Candidate / Psychology,
School of Health and Human Sciences
Southern Cross University (SCU),
Coffs Harbour, NSW 2450

Dr James Donnelly
Lecturer / Psychology
School of Health and Human Sciences
Southern Cross University (SCU)
Coffs Harbour, NSW 2450

Ethical Clearance

Southern Cross University Human Research Ethics Sub-Committee Approval Number: ECN-14-155

ASPECT Research Approvals Committee Reference Number: 1428

Southern Cross University Ethics Complaints Policy

The Ethics Complaints Policy involves reporting a complaint about the ethical conduct of the research or the researchers. To do this, you can contact the Ethics Complaints Officer via post or email. The details are:

Ethics Complaints Officer
Human research Ethics Committee
Southern Cross University
PO Box 157
Lismore, NSW, 2480.

This the first point of contact. All information is confidential and handled as soon as possible.

Support Services

In the case where participation in this research causes any distress participants should contact their local G.P. or for immediate assistance contact:

Beyond Blue – 1300 22 4636
Lifeline – 131114
# Australian Parenting Experiences

* 1. Are you a permanent Australian resident?
   - [ ] Yes
   - [ ] No

* 2. Were you born in Australia?
   - [ ] Yes
   - [ ] No

* 3. Current residential postcode
   

* 4. Do you consider your residence to be:
   - [ ] Rural
   - [ ] Regional Centre
   - [ ] Outer Metropolitan
   - [ ] Metropolitan

* 5. Gender
   - [ ] Male
   - [ ] Female
   - [ ] Non-specified
6. Current Relationship Status

- Single
- In a Relationship
- De Facto Relationship
- Partnership
- Married
- Divorced
- Separated
- Widowed

Other (please specify)

7. How many dependant children, under the age of 18, live with you?

- 0
- 1
- 2
- 3
- 4
- 5
- 6
- 7
- 8

8. How many dependent children diagnosed with an autism spectrum disorder live with you? (Clinical diagnosis only)

- 0
- 1
- 2
- 3
- 4
- 5
- 6
- 7
- 8
9. How would you describe your autistic child’s needs?

- Requiring minimal support
- Requiring support
- Requiring substantial support
- Requiring very substantial support

10. What autism spectrum disorder support services are available in your area?


11. Are you currently on a waiting list for any of the above listed autism spectrum disorder support services?

- Yes
- No

Name of Service(s) (please specify)


12. If you are currently on a waiting list for any of the above listed autism spectrum disorder support services, how long have you been on the waiting list?

- 1 month or less
- 1 to 6 months
- 6 to 12 months
- 12 months or more
- N/A

13. Have you had access to any of the above listed autism spectrum disorder support services?

- Yes
- No
- N/A
14. Do you currently have access to any of the above listed autism spectrum disorder support services?
   - Yes
   - No
   - N/A

15. Were, or are, any of the above listed autism support services beneficial to you as a parent or carer?
   - Yes
   - No
   - N/A

16. Can you tell us briefly which of the above listed autism support services you have found beneficial.
**Australian Parenting Experiences**

17. *Prior* to becoming a parent or carer were you diagnosed by a medical practitioner with a clinical level of:

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18. *After* becoming a parent or carer were you diagnosed by a medical practitioner with a clinical level of:

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19. Are you currently receiving treatment, based on a diagnosis by a medical practitioner, for a clinical level of:

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Appendix 3: Survey Two, Time One

Monitoring the effect of the NDIS on Australian Parents of Individuals with an Autism Spectrum Disorder

Our research from 2014 found that Australian parents of a child with Autism Spectrum Disorder (ASD) are at significantly greater risk of depression, anxiety and parental stress than those parenting typically developing children. With the Australia-wide roll out of the National Disability Insurance Scheme (NDIS) set to begin, it is important that the effects of this program on personal well-being and quality of life of carers is monitored. This will enable us to inform future policy of the National Disability Insurance Agency (NDIA) as to how the NDIS affects this important group.

The aims of this research are to:

1. Describe the personal well-being of Australian carers of individuals with autism prior to NDIS roll-out and then after the individual for which they care gains access.
2. Describe the personal well-being and NDIS-related experience of Australian carers of individuals with autism who are currently accessing the NDIS and measure carer profile changes over a one year period.
3. Determine if these profiles differ across rural, regional and metropolitan localities within Australia.
4. Gather essential data to inform the NDIA specifically about the experiences of Australian parents and carers of individuals with an ASD and
5. Increase our knowledge and understanding of several key factors associated with caring for individuals with an ASD within Australia.

Participant’s requirements

Participants will be asked to answer an online questionnaire about their age, gender, marital status, number of children, post code, NDIS management strategy, etc. After completion of the questionnaire participants will also complete four online measures. The measures will assess personal well-being (The Personal Well-being Index – PWI), emotional states of depression and anxiety (Modified Depression Anxiety and Stress scale – DASS), level of caregiver stress (Caregiver Strain Questionnaire – CSQ) and the quality of life as a caregiver (Caregiver Quality of Life instrument – CQoL). The space will also be available for respondents to add their comments.

Privacy and Confidentiality

All data collected from participants will be de-identified to protect privacy and confidentiality. Participation is voluntary and completion of the survey will imply consent.

Withdrawal of participation

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Researchers Contact Details

Matthew Snow (BPych Hons) Doctoral Candidate / Psychology, School of Health and Human Sciences Southern Cross University (SCU), Coffs Harbour,

Dr James Donnelly Lecturer / Psychology School of Health and Human Sciences Southern Cross University (SCU) Coffs Harbour, NSW 2450

Counselling Services
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Lifeline - 13 11 14
Men's Line Australia - 1300 78 99 78
Salvo Care Line - 1300 36 36 22

Ethical Clearance

Southern Cross University Human Research Ethics Sub-Committee Approval Number: ECN-15-192

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Ethics Complaints Officer
Human research Ethics Committee Southern Cross University
PO Box 157
Lismore, NSW, 2480.

This the first point of contact. All information is confidential and handled as soon as possible.
About You

1. Are you a permanent Australian resident?
   - Yes
   - No

2. In which state or territory do you live?
   - NSW
   - QLD
   - VIC
   - TAS
   - SA
   - WA
   - NT
   - ACT

3. What is your residential postcode?

4. Gender?
   - Female
   - Male
   - Not Specified

5. Please enter your age

6. Current relationship status?
   - Single
   - In a relationship
   - Married
   - Divorced
   - Separated
   - Widowed
### Financial Information

**7. What is your personal weekly income?**
- [ ] Nil income
- [ ] $1-$199
- [ ] $200-$299
- [ ] $300-$399
- [ ] $400-$499
- [ ] $500-$599
- [ ] $600-$699
- [ ] $700-$799
- [ ] $800-$899
- [ ] $900-$999
- [ ] $1,000-$1,249
- [ ] $1,250-$1,499
- [ ] $1,500-$1,999
- [ ] $2,000 or more

**8. What is the combined weekly income of your household?**
- [ ] Nil income
- [ ] $1-$199
- [ ] $200-$299
- [ ] $300-$399
- [ ] $400-$499
- [ ] $500-$599
- [ ] $600-$699
- [ ] $700-$799
- [ ] $800-$899
- [ ] $900-$999
- [ ] $1,000-$1,249
- [ ] $1,250-$1,499
- [ ] $1,500-$1,999
- [ ] $2,000 or more
**9. Please use the drop down boxes to enter your children's/dependent's gender, age, if they have a clinical diagnosis of an ASD and the level of support your children/dependents with an ASD require? (Please list all children/dependents, regardless of their age, who live with you and whose care you are responsible for)**

<table>
<thead>
<tr>
<th></th>
<th>Gender</th>
<th>Age</th>
<th>Clinical Diagnosis of an Autism Spectrum Disorder</th>
<th>Support Level Required (Children with an ASD only)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Child 1</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Child 2</td>
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<tr>
<td>Child 3</td>
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<td>Child 4</td>
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<td>Child 5</td>
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<td>Child 6</td>
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<td>Child 7</td>
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<td>Child 8</td>
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<tr>
<td>Child 9</td>
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</tr>
<tr>
<td>Child 10</td>
<td></td>
<td></td>
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<td></td>
</tr>
<tr>
<td>National Disability Insurance Scheme (NDIS)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>---------------------------------------------</td>
<td></td>
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</tr>
<tr>
<td>10. Are any of your children/dependents currently participating in the National Disability Insurance Scheme trials?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>○ Yes</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>○ No</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
### National Disability Insurance Scheme

**11. How long did you wait for your planning/assessment appointment?**

<table>
<thead>
<tr>
<th></th>
<th>1 Month</th>
<th>2 Months</th>
<th>3 Months</th>
<th>4 Months</th>
<th>5 Months</th>
<th>6 Months or More</th>
</tr>
</thead>
<tbody>
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<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**12. How long after the appointment did you wait for your plan?**

<table>
<thead>
<tr>
<th></th>
<th>1 Month</th>
<th>2 Months</th>
<th>3 Months</th>
<th>4 Months</th>
<th>5 Months</th>
<th>6 Months or More</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**13. When was your fund made available?**

<table>
<thead>
<tr>
<th></th>
<th>1 Month</th>
<th>2 Months</th>
<th>3 Months</th>
<th>4 Months</th>
<th>5 Months</th>
<th>6 Months or More</th>
</tr>
</thead>
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<tr>
<td></td>
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<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

14. Can you briefly tell us what has been the most difficult part of transitioning into the NDIS?


15. Can you briefly tell us how the NDIS has benefited you as their carer?


16. Are you self managing the NDIS funding package on behalf of your child/dependent?

- Yes
- No
<table>
<thead>
<tr>
<th>Non NDIS Support Systems</th>
</tr>
</thead>
<tbody>
<tr>
<td>* 17. Have you previously had access to any autism spectrum disorder support services?</td>
</tr>
<tr>
<td>○ Yes</td>
</tr>
<tr>
<td>○ No</td>
</tr>
<tr>
<td>* 18. Do you currently have access to any autism spectrum disorder support services</td>
</tr>
<tr>
<td>○ Yes</td>
</tr>
<tr>
<td>○ No</td>
</tr>
<tr>
<td>* 19. Were, or are, any of the autism support services beneficial to you as a parent or care?</td>
</tr>
<tr>
<td>○ Yes</td>
</tr>
<tr>
<td>○ No</td>
</tr>
<tr>
<td>20. Can you tell us briefly which autism support services you have found beneficial to you as a carer:</td>
</tr>
</tbody>
</table>


### Formal Support

* 21.

**How many hours per week of early intervention did/does your child/children with an ASD receive?**

<table>
<thead>
<tr>
<th></th>
<th>None</th>
<th>1 - 5</th>
<th>6 - 10</th>
<th>11 - 15</th>
<th>16 - 20</th>
<th>21 - 25</th>
<th>25 - 30</th>
<th>30+</th>
</tr>
</thead>
<tbody>
<tr>
<td>Child 1</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Child 2</td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Child 3</td>
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<tr>
<td>Child 4</td>
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<td></td>
</tr>
</tbody>
</table>

* 22. Was/is this early intervention part of an NDIS package

- [ ] No
- [x] Yes

* 23.

**Do you feel the amount of hours of early intervention provided was/is adequate for your children?**

<table>
<thead>
<tr>
<th>Strongly Disagree</th>
<th>Disagree</th>
<th>Somewhat Disagree</th>
<th>Neither Disagree or Agree</th>
<th>Somewhat Agree</th>
<th>Agree</th>
<th>Strongly Agree</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
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<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
### Informal Support

* 24.
How much support do you receive from your *spouse/partner* to care for your child/dependent with an ASD?

<table>
<thead>
<tr>
<th>1 - None</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7 - A Lot</th>
<th>N/A</th>
</tr>
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<td></td>
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</tr>
</tbody>
</table>

* 25.
How much support do you receive from your *other children* to care for your child/dependent with an ASD?

<table>
<thead>
<tr>
<th>1 - None</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7 - A Lot</th>
<th>N/A</th>
</tr>
</thead>
<tbody>
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</tbody>
</table>

* 26.
How much support do you receive from *family members* (besides your spouse or your other children) to care for your child/dependent with an ASD?

<table>
<thead>
<tr>
<th>1 - None</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7 - A Lot</th>
</tr>
</thead>
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</tbody>
</table>

* 27.
How much support do you receive from *friends* to care for your child/dependent with an ASD?

<table>
<thead>
<tr>
<th>1 - None</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7 - A Lot</th>
</tr>
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</tbody>
</table>
Continuing Participation

Would you like to help highlight the importance of the personal well being of parents of children with an ASD to the National Disability Insurance Agency? Your continued participation would be greatly appreciated and will assist us to report to the Coalition of Australian Governments how the NDIS affects parents of children with and ASD.

* 33. I agree to be contacted via email for future participation in this research project

   ○ Yes
   ○ No

34. You can contact me via email at

   Email 1

   Email 2

Thank you for participating in this important research.
Appendix 4: Survey Two, Time Two

Monitoring the effect of the NDIS on Australian Parents of Individuals with an Autism Spectrum Disorder

Thank you for your continuing participation in this research project. With the Australia-wide roll out of the National Disability Insurance Scheme (NDIS) moving forward, it is important that we continue to monitor its effects on the personal well-being and quality of life of carers. This will enable us to inform future policy of the National Disability Insurance Agency (NDIA) as to how the NDIS affects this important group.

The aims of this research are to:

1. Describe the personal well-being of Australian carers of individuals with autism prior to NDIS roll-out and then after the individual for which they care gains access.
2. Describe the personal well-being and NDIS-related experience of Australian carers of individuals with autism who are currently accessing the NDIS and measure carer profile changes over a one year period.
3. Determine if these profiles differ across rural, regional and metropolitan localities within Australia.
4. Gather essential data to inform the NDIA specifically about the experiences of Australian parents and carers of individuals with an ASD and
5. Increase our knowledge and understanding of several key factors associated with caring for individuals with an ASD within Australia.

Participant’s requirements

You will be asked to answer an online questionnaire about your age, gender, marital status, number of children, post code, NDIS management strategy, etc. After completion of the questionnaire there are also four online measures. The measures will assess personal well-being (The Personal Well-being Index - PWI), emotional state (Modified Depression Anxiety and Stress scale – DASS), level of care giver stress (Caregiver Strain Questionnaire – CGSQ) and the quality of life as a care giver (Caregiver Quality of Life instrument – CGQoL). Space will also be available for you to add comments.

Privacy and Confidentiality

Your data will be de-identified to protect your privacy and confidentiality. Participation is voluntary and completion of the survey will imply consent.

Withdrawal of participation

You can withdraw your consent at any time with no negative consequences and all data obtained up until that point will be deleted. You can simply withdraw from participation by closing your web browser to exit the survey or by contacting the investigators.
Researcher Contact Details

Matthew Snow (BPsych Hons)
Doctoral Candidate / Psychology,
School of Health and Human Sciences
Southern Cross University (SCU),
Coffs Harbour,

Dr James Donnelly
Lecturer / Psychology
School of Health and Human Sciences
Southern Cross University (SCU)
Coffs Harbour, NSW 2450

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Lismore. NSW. 2480.

This the first point of contact. All information is confidential and handled as soon as possible.
<table>
<thead>
<tr>
<th>Security Question</th>
</tr>
</thead>
</table>

1. Please enter the participant code sent to you via email

2. Please enter the email address used to contact you with your participant code
About You

* 3. In which state or territory do you live?

<table>
<thead>
<tr>
<th>NSW</th>
<th>QLD</th>
<th>VIC</th>
<th>TAS</th>
<th>SA</th>
<th>WA</th>
<th>NT</th>
<th>ACT</th>
</tr>
</thead>
<tbody>
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<td></td>
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<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

* 4. What is your residential postcode?


* 5. Gender?

- Female
- Male
- Not Specified

* 6. Please enter your age


* 7. Current relationship status?

- Single
- In a relationship
- Married
- Divorced
- Separated
- Widowed
## Financial Information

* 8. What is your personal weekly income?

  - Nil income
  - $1-$199
  - $200-$299
  - $300-$399
  - $400-$599
  - $600-$799
  - $800-$999
  - $1,000-$1,249
  - $1,250-$1,499
  - $1,500-$1,999
  - $2,000 or more

* 9. What is the combined weekly income of your household?

  - Nil income
  - $1-$199
  - $200-$299
  - $300-$399
  - $400-$599
  - $600-$799
  - $800-$999
  - $1,000-$1,249
  - $1,250-$1,499
  - $1,500-$1,999
  - $2,000 or more
**Your Children**

*10. Please use the drop down boxes to enter your children's/dependent's gender, age, if they have a clinical diagnosis of an ASD and the level of support your children/dependents with an ASD require? (Please list all children/dependents, regardless of their age, who live with you and whose care you are responsible for)*

<table>
<thead>
<tr>
<th>Gender</th>
<th>Age</th>
<th>Clinical Diagnosis of an Autism Spectrum Disorder</th>
<th>Support Level Required (Children with an ASD only)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Child 1</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Child 2</td>
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<td>Child 3</td>
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<td>Child 4</td>
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<td>Child 5</td>
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<td>Child 6</td>
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<td>Child 7</td>
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<td>Child 8</td>
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<td>Child 9</td>
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<td></td>
<td></td>
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<tr>
<td>Child 10</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
**National Disability Insurance Scheme (NDIS)**

11. Are any of your children/dependents currently participating in the National Disability Insurance Scheme trials?

- [ ] Yes
- [ ] No
National Disability Insurance Scheme

* 12. How long did you wait for your planning/assessment appointment?

<table>
<thead>
<tr>
<th>1 Month</th>
<th>2 Months</th>
<th>3 Months</th>
<th>4 Months</th>
<th>5 Months</th>
<th>6 Months or More</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

* 13. How long after the appointment did you wait for your plan?

<table>
<thead>
<tr>
<th>1 Month</th>
<th>2 Months</th>
<th>3 Months</th>
<th>4 Months</th>
<th>5 Months</th>
<th>6 Months or More</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

* 14. When was your fund made available?

<table>
<thead>
<tr>
<th>1 Month</th>
<th>2 Months</th>
<th>3 Months</th>
<th>4 Months</th>
<th>5 Months</th>
<th>6 Months or More</th>
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<td></td>
<td></td>
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</tr>
</tbody>
</table>

15. Can you briefly tell us what has been the most difficult part of transitioning into the NDIS?

16. Can you briefly tell us how the NDIS has benefited you as their carer?

17. Are you self managing the NDIS funding package on behalf of your child/dependent?

○ Yes
○ No
<table>
<thead>
<tr>
<th>Non NDIS Support Systems</th>
</tr>
</thead>
</table>

* 18. Have you **previously** had access to any autism spectrum disorder support services?
  - Yes
  - No

* 19. Do you **currently** have access to any autism spectrum disorder support services
  - Yes
  - No

* 20. Were, or are, any of the autism support services **beneficial** to you as a parent or care?
  - Yes
  - No

21. Can you tell us briefly which autism support services you have found **beneficial** to you as a carer: 

[Blank space for answer]
## Formal Support

### * 22.

How many *hours per week* of early intervention did/does your child/children with an ASD receive?

<table>
<thead>
<tr>
<th></th>
<th>None</th>
<th>1 - 5</th>
<th>6 - 10</th>
<th>11 - 15</th>
<th>16 - 20</th>
<th>21 - 25</th>
<th>25 - 30</th>
<th>30+</th>
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<tbody>
<tr>
<td>Child 1</td>
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<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
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<td>Child 2</td>
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<tr>
<td>Child 3</td>
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<td>0</td>
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<td>0</td>
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</tr>
<tr>
<td>Child 4</td>
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<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
</tbody>
</table>

### * 23. Was/is this early intervention part of an NDIS package

- [ ] No
- [ ] Yes

### * 24.

Do you feel the amount of hours of early intervention provided was/is adequate for your children?

<table>
<thead>
<tr>
<th>Strongly Disagree</th>
<th>Disagree</th>
<th>Somewhat Disagree</th>
<th>Neither Disagree or Agree</th>
<th>Somewhat Agree</th>
<th>Agree</th>
<th>Strongly Agree</th>
</tr>
</thead>
</table>
## Informal Support

* 25.

How much support do you receive from your **spouse/partner** to care for your child/dependent with an ASD?

<table>
<thead>
<tr>
<th>1 - None</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7 - A Lot</th>
<th>N/A</th>
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<td></td>
<td></td>
<td></td>
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</tr>
</tbody>
</table>

* 26.

How much support do you receive from your **other children** to care for your child/dependent with an ASD?

<table>
<thead>
<tr>
<th>1 - None</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7 - A Lot</th>
<th>N/A</th>
</tr>
</thead>
<tbody>
<tr>
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<td></td>
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</tr>
</tbody>
</table>

* 27.

How much support do you receive from **family members** (besides your spouse or your other children) to care for your child/dependent with an ASD?

<table>
<thead>
<tr>
<th>1 - None</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7 - A Lot</th>
</tr>
</thead>
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<tr>
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<td></td>
<td></td>
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<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

* 28.

How much support do you receive from **friends** to care for your child/dependent with an ASD?

<table>
<thead>
<tr>
<th>1 - None</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7 - A Lot</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
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</tr>
</tbody>
</table>
Thank you for helping to highlight the importance of the personal well being of parents of children with an ASD to the National Disability Insurance Agency. Your participation is greatly appreciated and will assist us to report to the Coalition of Australian Governments how the NDIS affects parents of children with and ASD.

* 34. Would you like to be informed about the results from this research?
   - [ ] Yes
   - [ ] No

35. Please forward me information about this research results to:

   Email 1

   Thank you for participating in this important research.
Appendix 5: Survey Three, Time One

Participant Information

**Monitoring the effect of the NDIS on Australian Carers of Individuals with a Disability**

Thank you for your participation in this research project. With the Australia-wide roll out of the National Disability Insurance Scheme (NDIS) moving forward, it is important that we continue to monitor its effects on the personal well-being and quality of life of carers. This will enable us to inform future policy of the National Disability Insurance Agency (NDIA) as to how the NDIS effects this important group.

**The aims of this research are to**

1. Describe the personal well-being of Australian carers of individuals with a disability prior to, during, and after the NDIS roll-out.
2. Describe the personal well-being and NDIS-related experience of Australian carers of individuals with a disability and measure carer profile changes over a one year period.
3. Determine if these profiles differ depending on the type of disability.
4. Gather essential data to inform the NDIA specifically about the experiences of Australian parents and carers of individuals with a disability.

**Participant’s requirements**

You will be asked to answer an online questionnaire about your age, gender, marital status, number of individuals you care for, the NDIS, etc. After completion of the questionnaire there are also 4 online measures. The measures will assess personal well-being (The Personal Well-being Index - PWI), emotional state (Depression Anxiety and Stress scale – DASS), care giver strain (the Care Giver Strain Questionnaire - CGSQ) and the quality of life as a care giver (Caregiver Quality of Life instrument – CGQoL). You will also be asked about continuing your participation in this vital research.

**Privacy and Confidentiality**

Your data will be de-identified to protect your privacy and confidentiality. Participation is voluntary and completion of the survey will imply consent.

**Withdrawal of participation**

You can withdraw your consent at any time and all data obtained up until that point will be deleted. You can simply withdraw from participation by closing your web browser to exit the survey or by contacting the investigators.
Researchers Contact Details

Matthew Snow (BPsych Hons)
Doctoral Candidate / Psychology,
School of Health and Human Sciences
Southern Cross University (SCU),
Coffs Harbour,

Dr. James Donnelly
Lecturer / Psychology
School of Health and Human Sciences
Southern Cross University (SCU)
Coffs Harbour, NSW 2450

Ethical Clearance

Southern Cross University Human Research Ethics Sub-Committee Approval Number: **ECN-15-192**

Southern Cross University Ethics Complaints Policy

To report a complaint about the ethical conduct of the research or the researchers to the Ethics Complaints Officer the details are:
Ethics Complaints Officer
Human research Ethics Committee
Southern Cross University
PO Box 157, Lismore, NSW, 2480.
**Data Security Questions**

To enable us to track your data without identifying you we need to ask you some questions. If you do not know the answer to the following questions please type “Don't know” in the answer box.

1. What is your mother's middle name?

2. What year did you leave high school?

3. What is your shoe size?

4. What was the name of the street you first lived in?
### About You

* 5. In which state or territory do you live?

<table>
<thead>
<tr>
<th>NSW</th>
<th>QLD</th>
<th>VIC</th>
<th>TAS</th>
<th>SA</th>
<th>WA</th>
<th>NT</th>
<th>ACT</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

* 6. What is your residential postcode?


* 7. Gender?

- Female
- Male
- Not Specified

* 8. Please enter your age


* 9. Current relationship status?

- Single
- In a relationship
- Married
- Divorced
- Separated
- Widowed
### Person/s cared for with a disability

* 10. In regards to the person/s with a disability that you care for what is/are their-

<table>
<thead>
<tr>
<th>Individual</th>
<th>Gender</th>
<th>Age</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2</td>
<td></td>
<td></td>
</tr>
<tr>
<td>3</td>
<td></td>
<td></td>
</tr>
<tr>
<td>4</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

* 11. Does the person/s cared for live with you?

<table>
<thead>
<tr>
<th>Individual</th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2</td>
<td></td>
<td></td>
</tr>
<tr>
<td>3</td>
<td></td>
<td></td>
</tr>
<tr>
<td>4</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

* 12. If the person/s does not live with you do they reside in a care facility?

- [ ] Yes
- [ ] No
- [ ] Not Applicable
- [ ] Other (please specify)

<input type="text" placeholder="Please specify."/>
Person/s cared for with a disability

* 13. Please state the **primary disability** that the person/s you care for has been **diagnosed** with. (e.g. Autism Spectrum Disorder, Cerebral Palsy, Spina bifida, Down Syndrome, Mental health issue, etc. Please note you will be asked to list any co-morbid or other disorders the person has in the next question)

| Individual 1 |  |
| Individual 2 |  |
| Individual 3 |  |
| Individual 4 |  |

14. Please list any comorbid or other disorders the person/s you care for is affected by in the spaces below

| Individual 1 |  |
| Individual 2 |  |
| Individual 3 |  |
| Individual 4 |  |

* 15. Please indicate on the scale below the level of support the person/s you care for require for day to day living.

<table>
<thead>
<tr>
<th></th>
<th>No Support</th>
<th>Complete Support</th>
</tr>
</thead>
<tbody>
<tr>
<td>Individual 1</td>
<td>☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐</td>
<td></td>
</tr>
<tr>
<td>Individual 2</td>
<td>☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐</td>
<td></td>
</tr>
<tr>
<td>Individual 3</td>
<td>☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐</td>
<td></td>
</tr>
<tr>
<td>Individual 4</td>
<td>☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐</td>
<td></td>
</tr>
<tr>
<td>National Disability Insurance Scheme (NDIS)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>---------------------------------------------</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

* 16. Please select which of the following statements applies to you

- [ ] I am currently caring for an individual who is an NDIS participant.
- [ ] I am currently caring for an individual waiting for the NDIS to roll out in our area.
### Expectations of the NDIS

**17. When will the NDIS be available to the person/s you care for**

- [ ] 1 Month
- [ ] 2 Months
- [ ] 3 Months
- [ ] 4 Months
- [ ] 5 Months
- [ ] 6 Months
- [ ] 12 Months
- [ ] More than a year
- [ ] Not Sure

**18. Please indicate on the scales below**

- **Not at all**
- **Very**

<table>
<thead>
<tr>
<th>Question</th>
<th>Scale</th>
</tr>
</thead>
<tbody>
<tr>
<td>How confident are you that the NDIS will have a positive effect on your</td>
<td></td>
</tr>
<tr>
<td>quality of life as a carer?</td>
<td></td>
</tr>
<tr>
<td>How confident are you that the NDIS will have a positive effect on your</td>
<td></td>
</tr>
<tr>
<td>personal well-being as a carer?</td>
<td></td>
</tr>
<tr>
<td>How confident are you that the NDIS will have a positive effect on the</td>
<td></td>
</tr>
<tr>
<td>quality of life of the person/s you care for?</td>
<td></td>
</tr>
<tr>
<td>How confident are you that the NDIS will have a positive effect on the</td>
<td></td>
</tr>
<tr>
<td>personal well-being of the person/s you care for?</td>
<td></td>
</tr>
<tr>
<td>How prepared for the NDIS do you feel?</td>
<td></td>
</tr>
<tr>
<td>How anxious are you about the NDIS rollout?</td>
<td></td>
</tr>
</tbody>
</table>
* 19. Do you intend to self manage the person/s that you care for NDIS funding package?

☐ Yes

☐ No

☐ Other (please specify)

[boxed text area]
Experience with the NDIS

* 20. How long has the person/s you care for been an NDIS participant

- 1 Month
- 2 Months
- 3 Months
- 4 Months
- 5 Months
- 6 Months
- 12 Months
- More than a year
- Not Sure

* 21. Please indicate on the scales below how -

<table>
<thead>
<tr>
<th>Not at all</th>
<th>Very</th>
</tr>
</thead>
<tbody>
<tr>
<td>much of a positive effect has the NDIS had on your quality of life as a carer?</td>
<td></td>
</tr>
<tr>
<td>much of a positive effect has the NDIS had on your personal well-being as a carer?</td>
<td></td>
</tr>
<tr>
<td>much of a positive effect has the NDIS had on the quality of life of the person/s you care for?</td>
<td></td>
</tr>
<tr>
<td>much of a positive effect has the NDIS had on the personal well-being of the person/s you care for?</td>
<td></td>
</tr>
<tr>
<td>prepared for the NDIS were you?</td>
<td></td>
</tr>
<tr>
<td>anxious about the NDIS roll out were you?</td>
<td></td>
</tr>
</tbody>
</table>
22. Do you help the person/s that you care for to self manage their NDIS funding package?

- [ ] Yes
- [ ] No
- [ ] Other (please specify)


### Informal Support

**23.**

How much support do you receive from your **spouse/partner** in caring for the person/s with a disability?

<table>
<thead>
<tr>
<th>1 - None</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7 - A Lot</th>
<th>N/A</th>
</tr>
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<tbody>
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</tbody>
</table>

**24.**

How much support do you receive from your **children** in caring for the person/s with a disability?

<table>
<thead>
<tr>
<th>1 - None</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7 - A Lot</th>
<th>N/A</th>
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</tr>
</tbody>
</table>

**25.**

How much support do you receive from **family members** (besides your spouse or your other children) in caring for the person/s with a disability?

<table>
<thead>
<tr>
<th>1 - None</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7 - A Lot</th>
<th>N/A</th>
</tr>
</thead>
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</tr>
</tbody>
</table>

**26.**

How much support do you receive from **friends** in caring for the person/s with a disability?

<table>
<thead>
<tr>
<th>1 - None</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7 - A Lot</th>
<th>N/A</th>
</tr>
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</tr>
</tbody>
</table>
Continuing participation and Thankyou

Your continued participation in this project would be *extremely valuable* in assisting us to identify any effects the NDIS has on Australian carers. It would also be *greatly appreciated*. Continued participation would require completion of the survey again in August/September 2017 and again in January/February 2018.

* 33. Would you like to be contacted in future to continue participating in this research?
   
   ☐ Yes
   
   ☐ No

34. How would you like to be contacted? (Please enter the contact details. These details will be stored securely and separate from your data)

<table>
<thead>
<tr>
<th>Contact Method</th>
<th>Details</th>
</tr>
</thead>
<tbody>
<tr>
<td>Email (address)</td>
<td></td>
</tr>
<tr>
<td>Text (Mobile Number)</td>
<td></td>
</tr>
<tr>
<td>Phone Call (Phone Number)</td>
<td></td>
</tr>
<tr>
<td>Twitter (# twitter name)</td>
<td></td>
</tr>
</tbody>
</table>

Thank you for helping to highlight the importance of the personal well being of those who care for individuals with a disability. Your participation is greatly appreciated and will assist us to report to the Coalition of Australian Governments how the NDIS affects Australian carers.
Appendix 6: Survey Three, Time Two

Participant Information

Monitoring the effect of the NDIS on Australian Carers of Individuals with a Disability

Thank you for your participation in this research project. With the Australia-wide roll out of the National Disability Insurance Scheme (NDIS) moving forward, it is important that we continue to monitor its effects on the personal well-being and quality of life of carers. This will enable us to inform future policy of the National Disability Insurance Agency (NDIA) as to how the NDIS effects this important group.

The aims of this research are to

1. Describe the personal well-being of Australian carers of individuals with a disability prior to, during, and after the NDIS roll-out.
2. Describe the personal well-being and NDIS-related experience of Australian carers of individuals with a disability and measure carer profile changes over a one year period.
3. Determine if these profiles differ depending on the type of disability.
4. Gather essential data to inform the NDIA specifically about the experiences of Australian parents and carers of individuals with a disability.

Participant’s requirements

You will be asked to answer an online questionnaire about your age, gender, marital status, number of individuals you care for, the NDIS, etc. After completion of the questionnaire there are also 4 online measures. The measures will assess personal well-being (The Personal Well-being Index - PWI), emotional state (Depression Anxiety Stress scale – DASS), care giver strain (the Care Giver Strain Questionnaire - CGSQ) and the quality of life as a care giver (Caregiver Quality of Life Instrument – CGQoL). You will also be asked about continuing your participation in this vital research.

Privacy and Confidentiality

Your data will be de-identified to protect your privacy and confidentiality. Participation is voluntary and completion of the survey will imply consent.

Withdrawal of participation

You can withdraw your consent at any time and all data obtained up until that point will be deleted. You can simply withdraw from participation by closing your web browser to exit the survey or by contacting the investigators.
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Lecturer / Psychology
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PO Box 157, Lismore, NSW, 2480.
<table>
<thead>
<tr>
<th>Data Security Questions</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>To enable us to track your data without identifying you we need you to enter the information you received in our request for you to participate again in this research study</strong></td>
</tr>
<tr>
<td>* 1. Please enter the participant code you received</td>
</tr>
<tr>
<td>[ ]</td>
</tr>
<tr>
<td>* 2. Please enter the coded sentence you received</td>
</tr>
<tr>
<td>[ ]</td>
</tr>
</tbody>
</table>
### National Disability Insurance Scheme (NDIS)

3. Please select which of the following statements applies to you

- [ ] I am currently caring for an individual who is an NDIS participant.
- [ ] I am currently caring for an individual waiting for the NDIS to roll out in our area.
**Expectations of the NDIS**

4. When will the NDIS be available to the person/s you care for

- 1 Month
- 2 Months
- 3 Months
- 4 Months
- 5 Months
- 6 Months
- 12 Months
- More than a year
- Not Sure

5. Please indicate on the scales below how:

<table>
<thead>
<tr>
<th>Not at all</th>
<th>Very</th>
</tr>
</thead>
<tbody>
<tr>
<td>confident are you that the NDIS will have a positive effect on your quality of life as a carer?</td>
<td></td>
</tr>
<tr>
<td>confident are you that the NDIS will have a positive effect on your personal well-being as a carer?</td>
<td></td>
</tr>
<tr>
<td>confident are you that the NDIS will have a positive effect on the quality of life of the person/s you care for?</td>
<td></td>
</tr>
<tr>
<td>confident are you that the NDIS will have a positive effect on the personal well-being of the person/s you care for?</td>
<td></td>
</tr>
<tr>
<td>prepared for the NDIS do you feel?</td>
<td></td>
</tr>
<tr>
<td>anxious are you about the NDIS rollout?</td>
<td></td>
</tr>
</tbody>
</table>
* 6. Do you intend to self manage the person/s that you care for NDIS funding package?

- [ ] Yes
- [ ] No
- [ ] Other (please specify):
  
  [ ]
**Experience with the NDIS**

* 7. How long has the person/s you care for been an NDIS participant

- 1 Month
- 2 Months
- 3 Months
- 4 Months
- 5 Months
- 6 Months
- 12 Months
- More than a year
- Not Sure

* 8. Please indicate on the scales below how much of a positive effect has the NDIS had on your quality of life as a carer?

<table>
<thead>
<tr>
<th>Not at all</th>
<th>Very</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
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</table>

much of a positive effect has the NDIS had on your personal well-being as a carer?

<table>
<thead>
<tr>
<th>Not at all</th>
<th>Very</th>
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<tbody>
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</table>

much of a positive effect has the NDIS had on the quality of life of the person/s you care for?

<table>
<thead>
<tr>
<th>Not at all</th>
<th>Very</th>
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<tbody>
<tr>
<td>0</td>
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</table>

much of a positive effect has the NDIS had on the personal well-being of the person/s you care for?

<table>
<thead>
<tr>
<th>Not at all</th>
<th>Very</th>
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</table>

prepared for the NDIS roll out were you?

<table>
<thead>
<tr>
<th>Not at all</th>
<th>Very</th>
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<tbody>
<tr>
<td>0</td>
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<td>0</td>
</tr>
</tbody>
</table>

anxious about the NDIS roll out were you?
9. Do you help the person/s that you care for to self manage their NDIS funding package?

- Yes
- No
- Other (please specify)
**Informal Support**

* 10.

**How much support do you receive from your spouse/partner in caring for the person/s with a disability?**

<table>
<thead>
<tr>
<th>1 - None</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7 - A Lot</th>
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</table>

* 11.

**How much support do you receive from your children in caring for the person/s with a disability?**

<table>
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</tbody>
</table>

* 12.

**How much support do you receive from family members (besides your spouse or your other children) in caring for the person/s with a disability?**

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</tbody>
</table>

* 13.

**How much support do you receive from friends in caring for the person/s with a disability?**

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<th>3</th>
<th>4</th>
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</tbody>
</table>
Your continued participation in this project is *extremely valuable* in assisting us to identify any effects the NDIS has on Australian carers. It would also be *greatly appreciated*. Continued participation would require completion of the survey again in January/February 2018.

19. Would you like to be contacted in future to continue participating in this research?
   - [ ] Yes
   - [ ] No

20. How would you like to be contacted? (Please enter the contact details. These details will be stored securely and separate from your data)

   - Email (address)
   - Text (Mobile Number)
   - Phone Call (Phone Number)
   - Twitter (if twitter name)

Thank you for helping to highlight the importance of the personal well being of those who care for individuals with a disability. Your participation is greatly appreciated and will assist us to report to the Council of Australian Governments how the NDIS effects Australian carers. Southern Cross University is currently undertaking further research to identify several factors believed to be critical to the well-being of Australian carers. We understand that carers are very busy however, if you are a parent of a child with a disability and would like to contribute further to the current research being undertaken please [Click Here]

Once again, Thank You for your continuing participation in this vital research that aims to improve the quality of life and personal well being of Australian carers.
Appendix 7: Survey Three, Time Three

Participant Information

Monitoring the effect of the NDIS on Australian Carers of Individuals with a Disability

Thank you for your participation in this research project. With the Australia-wide roll out of the National Disability Insurance Scheme (NDIS) moving forward, it is important that we continue to monitor its effects on the personal well-being and quality of life of carers. This will enable us to inform future policy of the National Disability Insurance Agency (NDIA) as to how the NDIS affects this important group.

The aims of this research are to

1. Describe the personal well-being of Australian carers of individuals with a disability prior to, during, and after the NDIS roll-out.
2. Describe the personal well-being and NDIS-related experience of Australian carers of individuals with a disability and measure carer profile changes over a one year period.
3. Determine if these profiles differ depending on the type of disability.
4. Gather essential data to inform the NDIA specifically about the experiences of Australian parents and carers of individuals with a disability.

Participant’s requirements

You will be asked to answer an online questionnaire about your age, gender, marital status, number of individuals you care for, the NDIS, etc. After completion of the questionnaire there are also 4 online measures. The measures will assess personal well-being (The Personal Well-being Index - PWI), emotional state (Depression Anxiety and Stress scale – DASS), care giver strain (the Care Giver Strain Questionnaire - CGSQ) and the quality of life as a care giver (Caregiver Quality of Life instrument – CGQoL). You will also be asked about continuing your participation in this vital research.

Privacy and Confidentiality

Your data will be de-identified to protect your privacy and confidentiality. Participation is voluntary and completion of the survey will imply consent.

Withdrawal of participation

You can withdraw your consent at any time and all data obtained up until that point will be deleted. You can simply withdraw from participation by closing your web browser to exit the survey or by contacting the investigators.
Researchers Contact Details

Matthew Snow (BPsych Hons)
Doctoral Candidate / Psychology,
School of Health and Human Sciences
Southern Cross University (SCU),
Coffs Harbour,

Dr. James Donnelly
Lecturer / Psychology
School of Health and Human Sciences
Southern Cross University (SCU)
Coffs Harbour, NSW 2450

Ethical Clearance

Southern Cross University Human Research Ethics Sub-Committee Approval Number: ECN-15-192

Southern Cross University Ethics Complaints Policy

To report a complaint about the ethical conduct of the research or the researchers to the Ethics Complaints Officer the details are:

Ethics Complaints Officer
Human research Ethics Committee
Southern Cross University
PO Box 157, Lismore, NSW, 2480.
**Data Security Questions**

To enable us to track your data without identifying you we need you to enter the information you received in our request for you to participate again in this research study.

1. Please enter the participant code you recived

2. Please enter the coded sentence you received
### National Disability Insurance Scheme (NDIS)

1. Please select which of the following statements applies to you

- [ ] I am currently caring for an individual who is an NDIS participant.
- [ ] I am currently caring for an individual waiting for the NDIS to roll out in our area.
### Expectations of the NDIS

* 4. When will the NDIS be available to the person/s you care for

- 1 Month
- 2 Months
- 3 Months
- 4 Months
- 5 Months
- 6 Months
- 12 Months
- More than a year
- Not Sure

* 5. Please indicate on the scales below how -

<table>
<thead>
<tr>
<th>Rating</th>
<th>Not at all</th>
<th>Very</th>
</tr>
</thead>
<tbody>
<tr>
<td>confident are you that the NDIS will have a positive effect on your quality of life as a carer?</td>
<td>☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐</td>
<td>☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐</td>
</tr>
<tr>
<td>confident are you that the NDIS will have a positive effect on your personal well-being as a carer?</td>
<td>☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐</td>
<td>☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐</td>
</tr>
<tr>
<td>confident are you that the NDIS will have a positive effect on the quality of life of the person/s you care for?</td>
<td>☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐</td>
<td>☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐</td>
</tr>
<tr>
<td>confident are you that the NDIS will have a positive effect on the personal well-being of the person/s you care for?</td>
<td>☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐</td>
<td>☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐</td>
</tr>
<tr>
<td>prepared for the NDIS do you feel?</td>
<td>☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐</td>
<td>☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐</td>
</tr>
<tr>
<td>anxious are you about the NDIS rollout?</td>
<td>☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐</td>
<td>☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐</td>
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</tbody>
</table>
6. Do you intend to self manage the person/s that you care for NDIS funding package?

- Yes
- No
- Other (please specify)

[Blank space for other]
**Experience with the NDIS**

* 7. How long has the person/s you care for been an NDIS participant

- 1 Month
- 2 Months
- 3 Months
- 4 Months
- 5 Months
- 6 Months
- 12 Months
- More than a year
- Not Sure

* 8. Please indicate on the scales below *how* -

<table>
<thead>
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<th>Not at all</th>
<th>Very</th>
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</thead>
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<td>much of a positive effect has the NDIS had on your quality of life as a carer?</td>
<td>[ ] [ ] [ ] [ ] [ ] [ ] [ ] [ ] [ ] [ ]</td>
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<tr>
<td>much of a positive effect has the NDIS had on your personal well-being as a carer?</td>
<td>[ ] [ ] [ ] [ ] [ ] [ ] [ ] [ ] [ ] [ ]</td>
</tr>
<tr>
<td>much of a positive effect has the NDIS had on the quality of life of the persons you care for?</td>
<td>[ ] [ ] [ ] [ ] [ ] [ ] [ ] [ ] [ ] [ ]</td>
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<td>much of a positive effect has the NDIS had on the personal well-being of the persons you care for?</td>
<td>[ ] [ ] [ ] [ ] [ ] [ ] [ ] [ ] [ ] [ ]</td>
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<tr>
<td>prepared for the NDIS were you?</td>
<td>[ ] [ ] [ ] [ ] [ ] [ ] [ ] [ ] [ ] [ ]</td>
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<tr>
<td>anxious about the NDIS roll out were you?</td>
<td>[ ] [ ] [ ] [ ] [ ] [ ] [ ] [ ] [ ] [ ]</td>
</tr>
</tbody>
</table>
* 9. Do you help the person/s that you care for to self manage their NDIS funding package?

- [ ] Yes
- [ ] No
- [ ] Other (please specify)


Informal Support

* 10.
How much support do you receive from your **spouse/partner** in caring for the person/s with a disability?

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* 11.
How much support do you receive from your **children** in caring for the person/s with a disability?

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* 12.
How much support do you receive from **family members** (besides your spouse or your other children) in caring for the person/s with a disability?

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</table>
Thankyou

We would like to thank you for completing the 3 stages of this vital research. The results will be written up as soon as possible and prepared for publication.

19. Would you like to receive a copy of the results from this research
   □ Yes
   □ No

20. If yes, can you please inform us of the email address you would like the results to be sent to?
   Email (address) ____________________________________________________________

Once again, Thank You for your participation in this vital research that aims to improve the quality of life and personal well being of Australian carers.
Appendix 8: Statement of Co authorship

The following people and institutions contributed to the publication of work undertaken as part of this thesis:

1. Matthew Snow (Candidate) – School of Human Health and Science, Southern Cross University

2. James Donnelly - School of Human Health and Science, Southern Cross University

Authorship details:


Located in Chapter 3

Candidate contribution: Matthew Snow was the primary author responsible for the conception and design of the research project. Matthew Snow collected the data, conducted the data analysis with guidance from James Donnelly and prepared the first draft of the manuscript. Overall, the Candidate contributed approximately 80% to the planning, execution and preparation of the work for the paper.

Dr James Donnelly contributed to the project by assisting in the design, supervising the development of the methods and their implementation and reading and editing all drafts of written work. This accounted for approximately 20% of the production of this article co-authored with Mr Snow.

Authorship details:


Located in Chapter 4

Candidate contribution: Matthew Snow was the primary author responsible for the conception and design of the research project. Matthew Snow collected the data, conducted the data analysis with guidance from James Donnelly and prepared the first draft of the manuscript. Overall, the Candidate contributed approximately 80% to the planning, execution and preparation of the work for the paper.

Dr James Donnelly contributed to the project by assisting in the design, supervising the development of the methods and their implementation and reading and editing all drafts of written work. This accounted for approximately 20% of the production of this article co-authored with Mr Snow.

We the undersigned agree with the above stated “proportion of work undertaken” for each of the above published (or submitted) peer-reviewed manuscripts contributing to this thesis:

Signed:
Candidate, Author 1

Signed:
Supervisor, Author 2