

The National Disability Insurance Scheme: Effects on the Quality of Life and Personal Well-Being of Australians Caring for Individuals with an Autism Spectrum Disorder

Matthew Snow^{1*} and James Donnelly²

Department of Psychology, Southern Cross University School of Health and Human Science, Hogbin Drive Coffs Harbour, New South Wales, Australia

Abstract

This repeated measures study controlled for levels of positive and negative state affect while measuring the personal wellbeing 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 wellbeing 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 wellbeing however there was a trend for NDIS carers to report increasing 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: Australia; Autism; Carers; National disability insurance scheme; Personal wellbeing; Quality of life

Introduction

The funding model used in the NDIS is focused on providing a customized profile of services for the person with a disability. Early reports from the National Disability Insurance Agency (NDIA) indicate mostly positive satisfaction ratings from those participants who are able to offer feedback. However, very little has been reported about the effect the NDIS is having on the quality of life and personal wellbeing of those caring for an individual with an autism spectrum disorder (ASD). Some anecdotal evidence suggests both positive and negative effects of the NDIS on carers already accessing the scheme for a participant with an ASD but for those carers waiting to get their caree enrolled potential changes in available support, including the elimination of carer respite services, are causing concern.

This research quantified the effects the rollout of the NDIS has had on carers' personal wellbeing and quality of life while controlling for their current state affect. This provides the National Disability Insurance Agency and the Coalition of Australian Governments empirical evidence regarding the overall wellbeing of carers of those with an ASD under the NDIS at the time close to when they first entered the scheme and 12 months later. This will hopefully aid in the identification and implementation of strategies, if needed, to further support this group of carers already identified as being at high risk for mental health concerns.

The National Disability Insurance Scheme: Effects on the quality of life and personal wellbeing of Australians caring for individuals with an autism spectrum disorder. The National Disability Insurance Scheme (NDIS) is described as a lifetime support system for Australians who have a permanent and significant disability that limits their capacity, and their care givers capacity, to participate in the community [1]. 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 [2]. 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 [3]. 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 [4]. Illustrating this is a report about concerns among participants, parents and family's in the Canberra trial site nine months after the NDIS began in that region [5].

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 (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. 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,

***Corresponding author:** Matthew Snow, Department of Psychology, Southern Cross University School of Health and Human Science, Hogbin Drive Coffs Harbour, New South Wales, Australia, Tel: +61266511223; E-mail: Matthew.Snow@scu.edu.au

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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 and another indicates major inconsistencies in packages provided to individuals with similar levels of disability [6,7]. 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 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 [8,9].

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 wellbeing 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. 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). 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" and that the full cost of early intervention would be covered by the scheme [10]. 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 \$35000.00 AU per annum [11]. Reports indicate that families of individuals with an ASD who require early intervention are receiving enough funding for just 6 hours per week (\$16000.00 AU per annum) under the NDIS [12]. 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" [13].

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 [14]. A report by the Productivity Commission supported this by stating, "The scheme would substantially increase the personal wellbeing of many people with disabilities and their carers" [15]. However these predictions are challenged by Bellamy, Paleologos, Kemp, Carter, and King 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" [16]. 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. 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 [17-22]. 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. 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 wellbeing 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 wellbeing 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 wellbeing 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 to 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

to 61 years of age ($M=43.03$, $SD=6.75$) and 4 males (4.3%) aged 40 to 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 to 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 to 62 years of age ($M=45.69$, $SD=6.40$) and 3 males (7.9%) aged 46 to 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 was 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 Wellbeing Index (PWI) [23]. The PWI has been reported to have good convergent validity (0.78) with the Satisfaction with Life Scale [24]. To reduce participant fatigue the stress subscale questions of the 21-question, Depression, Anxiety and Stress Scale (DASS) were not used [25]. Although Antony, Bieling, Cox, Enns, and Swinson report the DASS subscales have good internal consistency (Depression $r=0.94$, Anxiety $r=0.87$, Stress $r=0.91$) it was believed that a high correlation would be found between the DASS Stress subscale and the Caregiver Strain Questionnaire (CGSQ) also included in the current study [26,27]. 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 care giver 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 [28]. Quality of life for informal caregivers was measured using the Carer Quality of Life instrument (CQoL) [29]. The CarerQoL has been shown to be a reliable and valid measure for carers of individuals with an ASD [30]. The reliability of the CQoL is further shown by Brouwer 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 [31,32]. To summarise across items on this measure we computed a new variable that gave positive weight to items that suggested effective functioning and negative weight to items that indicated diminished or problematic areas

of functioning. The following formula was used to create this variable called CQoL_Tot: (Item 2+Item 3+Item 4+Item 5+Item 7) – (Item 1+Item 6). The CQoL_VAS was not included in this computation as it covaried significantly with the other scale items and with our independent and more comprehensive index of state affect or mood.

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 1.

A pair of One-way ANCOVAs was conducted to determine if there was a statistically significant difference between NDIS carers and Non-NDIS carers on their reported levels of subjective wellbeing (SWB) 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 subjective wellbeing after controlling for dysphoric mood, $F(1, 95)=6.07$, $p=0.016$, $\eta^2=0.06$. NDIS carers reported a lower sense of subjective wellbeing ($N=26$, $M=29.21$, $SD=15.62$) compared to Non-NDIS carers ($N=72$, $M=34.56$, $SD=16.85$). No significant effect of carer type on reported care quality of life scores was found after controlling for dysphoric mood, $F(1, 96)=0.653$, $p=0.421$, $\eta^2=0.007$. NDIS carers reported similar quality of life scores ($N=26$, $M=7.38$, $SD=2.06$) as Non-NDIS carers ($N=73$, $M=7.08$, $SD=3.0$).

To analyse the repeated measures data, residualised scores for subjective wellbeing (SWB_Time_1 and SWB_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 SWB and CQoL across 2-time periods (approximately 12 months apart).

There was also no significant main effect of Carer Type, Wilks Lambda=0.89, $F(2, 44)=0.27$, $p=0.07$, partial eta squared=0.11. However, the main effect of Carer Type on residualised SWB was significant, $F(1, 45)=5.02$, $p=0.03$, partial eta squared=0.10. This indicates a large effect of Carer Type on SWB across time. There was no significant effect of Carer type on residualised CQoL, $F(1, 45)=2.57$, $p=0.12$, partial eta squared=0.05. There was no significant main effect of time, Wilks Lambda=.99, $F(2, 44)=0.30$, $p=0.75$, partial eta squared=0.01 and there was no significant interaction between Carer Type and time, Wilks Lambda=0.95, $F(2, 44)=1.24$, $p=0.30$, partial eta squared=0.05.

As shown in Figure 1, post hoc independent samples T tests revealed a significant difference in SWB between NDIS Carers ($M=-0.61, SD=0.99$) and Non-NDIS Carers ($M=0.21, SD=0.91$) at time 2, $t(45)=-2.65, p=0.011$, two-tailed, $d=0.92$, after controlling for dysphoric mood at each point in time. There was no significant difference between NDIS Carers and Non-NDIS Carers on SWB at time 1. There was also no significant difference between NDIS Carers and Non-NDIS Carers reported levels of CQoL at time 1 or 2 after controlling for dysphoric mood.

To further investigate the significant difference between carer types on subjective wellbeing residualised PWI scores were calculated to control for the level of dysphoric mood at both time 1 and time 2. Independent samples T tests, with a Bonferroni corrected alpha level of 0.007, were conducted to compare Carer Types on each item of the PWI at each point in time. As shown in Figure 2 NDIS carers ($M=-0.69, SE=0.30$) reported significantly lower levels of feeling like part

of the community than Non-NDIS carers ($M=0.24, SE=0.14$) at time 1, $t(45)=-3.03, p=0.004$, two tailed. Similarly, at time 2, NDIS carers ($M=-0.70, SE=0.30$) again reported significantly lower levels of feeling like part of the community $t(45)=-3.11, p=0.003$, two tailed than Non-NDIS carers ($M=0.24, SE=0.15$) as shown in Figure 3.

Discussion

The hypothesis that NDIS carers would have similar levels of subjective wellbeing 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 subjective wellbeing 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, while NDIS carers reported lower levels of subjective wellbeing their data indicated slightly more satisfaction with their quality of life than Non-NDIS cares. This counter-intuitive 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 wellbeing 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 subjective wellbeing. The trend in NDIS carers subjective wellbeing data showed that over a 12-month period in the NDIS their sense of subjective wellbeing decreased. Also evident in the data was a trend for NDIS carers to report increasing 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) but benefits to the carers in terms of community connection is also implied [1]. For example, the investigation into this long term care and support scheme by the Productivity Commission predicted a substantial "increase in the personal wellbeing of many people with disabilities and their carers" [15]. While the NDIS may, or may not, be achieving this for participants, it appears to be decreasing the personal wellbeing 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 (Citation removed to maintain anonymity) so state affect was included here as a covariate [32]. However even when controlling for state dysphoria in the current study, NDIS-carers still endorsed lower personal wellbeing 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 wellbeing and quality of life of those providing care for other types of disabilities, health issues, etc. needs to be explored. This

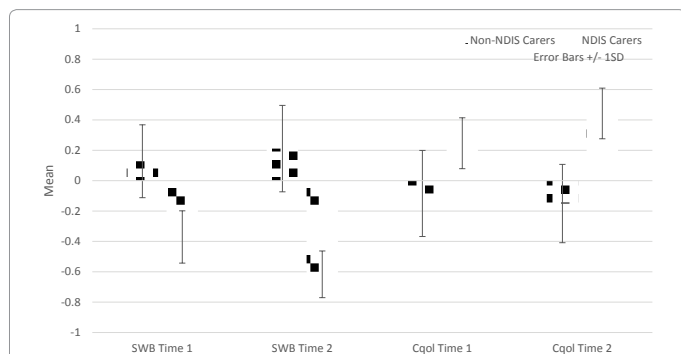


Figure 1: Standardised residual scores for SWB and CQoL controlling for dysphoric mood over time.

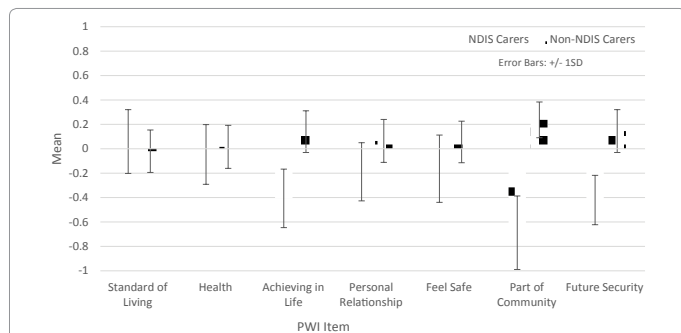


Figure 2: Carers residualised PWI scores at time 1 controlling for dysphoric mood.

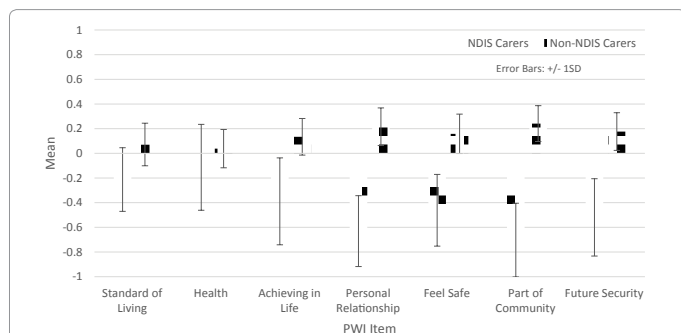


Figure 3: Carers residualised PWI scores at time 2 controlling for dysphoric mood.

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 indicate that the results of this research are far more reflective of the experiences of female carers of those with an ASD.

Conclusion

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. This research implemented robust methods to control for the effect dysphoric mood has on an individual's self-reported levels of personal wellbeing and quality of life. The difference between NDIS and Non-NDIS carer's levels of personal wellbeing 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 wellbeing 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.

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