

# Carers: Doing it Tough, Doing it Well

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## About Anglicare Sydney

**Anglicare** is an aged care and community services organisation of the Anglican Diocese of Sydney. Anglicare has been making Christ's love real to people in need for over 150 years. Each year, Anglicare reaches out to thousands of people, bringing Christian care and support to those living with disadvantage or vulnerability.

Anglicare's services include support programs for carers; emergency relief for people in crisis; services for children and youth, including foster care and adoption services; aged care services through nursing homes and in the community; independent living for people aged over 55; counselling services; mental health services; migrant and refugee services; opportunity shops providing low cost clothing; recovery services in times of disaster and chaplains in hospitals, prisons, mental health facilities and juvenile justice institutions.



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## Executive Summary

Almost 2.7 million Australians identify as carers and of these 850,000 are primary carers (ABS 2016). Caring, especially over the longer term, can have significant negative impacts on a range of life domains – physical health, stress and anxiety, personal wellbeing, family relationships, employment, income and disconnection from community life often leading to isolation and social exclusion.

The recently introduced *National Disability Insurance Scheme* (NDIS) will radically alter the way that care will be funded for people with disabilities. Under the Scheme, Government funding for disability services and support will be directed to the person with the disability to choose their funded supports, rather than as block funding to service providers. Consequently this traditional form of carer support will be withdrawn as Government funding ceases.

Carers' needs and supports are not formally recognised as part of NDIS packages. There is no formal assessment of the needs of the carer, no funding package for the carer and no guarantee of involvement in the assessment of the care recipient's needs. Until recently it was unclear what supports would be available for carers under the new system, given the closure of many block-funded services. Provision of federally funded carer supports will be directed through the Integrated Carer Support Service ("ICSS"), which is currently being designed by the Department of Social Services (DSS, 2016a). However with the imminent closure of carer-specific support services, Anglicare is concerned that carers will no longer receive even the same levels, let alone improved levels, of support under the new system.

This report presents the results of evaluation of two block-funded carer support programs run by Anglicare Sydney – Support Coordination (SCP) and Respite Options (ROP). Evaluation data was collected over a number of years using entry and evaluation surveys, which incorporated several outcomes measures including the Personal Wellbeing Index (PWI) and part of the Depression, Anxiety and Stress Scale (DASS) to determine if, over the life of carers' participation in the program, there had been significant improvements across a range of domains.

This report aims to:

- Outline the impacts of the caring role on care givers;
- Identify the positive impacts of current block-funded programs in the lives of carers;
- Identify likely areas of shortfall in proposed approaches to carer support;
- Make recommendations to Federal and State Governments.





## Support Coordination Program (SCP) Findings

The Support Coordination Program is a case-managed service designed to provide support over a period of 12 months, improve service access and support, and develop transition planning for parent carers over the age of 60 years who are caring for an adult son or daughter with a disability. Evaluation of Anglicare's program took place over a 6 year period and findings include:

1. There were substantial increases in carer access to case management (+60%), transition planning (+51%), assistance to increase carer's social contacts (+46%) and assistance for the care recipient to pursue their goals and interests (+32%).

2. There was an increase in average Personal Wellbeing Index scores from a low of 58.1 out of 100 to 63.9 (compared with 75 for the average population), as well as improvements in particular domains of wellbeing. The areas of greatest improvement were in the carer's life as a whole, their sense of future security, their health, their personal relationships and feeling part of the community.

3. Carers evidenced much higher levels of stress (45 out of 100) than the general population (19) and this did not markedly decrease over the life of the program – a reflection that while support and increased access to services may improve overall wellbeing, caring remains a stressful and tiring commitment.

4. The vast majority of carers entering the SCP (80%) were concerned about what would happen to their disabled son or daughter if they were unable to continue providing care. After at least 12 months in the program, fewer carers were anxious about this issue (65%).

5. There was a significant improvement in the proportion of carers who were aware of sources of assistance (from 50% to 79%) and a significant reduction in the proportion of carers who agreed that they needed time out from their caring role.

6. The majority of carers who received help from Anglicare to increase their social contacts reported an improvement in this regard (59%). Among care recipients who received assistance from Anglicare to increase their social contacts, almost half (48%) experienced an improvement in social support, as reported by their caregiver.

7. After at least 12 months in the program, SCP carers on average became more satisfied with their financial situation and the suitability of their home for meeting the needs of their relative with a disability.

The central plank of this service model has been case management, involving proactive planning of care to assist carers to access the resources to attain their identified goals. Using a person-centred approach, priority is given to meeting the greatest needs, with the carer being supported in decision-making. The outcomes identified in this report indicate that case-managed service models are associated with positive outcomes for carers and care recipients.

## Respite Options Program (ROP) Findings

The ROP, open to carers under the age of 65 years, provides in-home and day centre respite with a range of activities tailored to meet the needs of the care recipient. Respite choices are often based on the changing needs and circumstances of both the person with a disability and their family/carer. Evaluation of the ROP was conducted over a 6 year period using the same survey tools implemented in the SCP.

Key findings include:

1. There were significant improvements in average Personal Wellbeing Index scores from 59.7 out of 100 to 66.3. The areas of greatest improvement among carers across specific domains of wellbeing were: feeling part of the community; their current achievements in life; their life as a whole and their personal relationships.
2. As with the SCP, carers in the ROP evidenced much higher levels of stress (50.4 out of 100) than the general population (19). Only a slight decrease in stress was detected that was not statistically significant, indicating prolonged stress as a result of the caring role was not ameliorated by service supports.
3. There have been measurable improvements in carers having better service access for social contact (from 49% upon entry to 63% after at least 12 months).
4. Almost two-thirds of carers who received help from Anglicare to increase their social contacts reported an improvement in this regard (64%). Among care recipients who received assistance from Anglicare to increase their social contacts, most (81%) experienced an improvement in social support, as reported by their caregiver.
5. Nine out of ten (92%) carers continued to be concerned about what would happen to their son/daughter if they were unable to continue caring for them and three quarters (78%) maintained they needed regular breaks or 'time out' from their caring role.
6. There was no improvement in the carers' perception of either their financial or housing situation.

Provision of respite is the key element in this program and is associated with positive, measurable outcomes for carers. This finding is supported by the literature which indicates that respite improves wellbeing, satisfaction with life, the quality of family relationships and social connectedness and can strengthen marriages and partnerships. Internationally, countries have already implemented policies which include the provision of respite care. The findings from this Anglicare study challenges an emerging view within government that there is little evidence of the beneficial effects of respite.

It is clearly evident that while positive outcomes have been achieved by both programs, a wider range of benefits accrued to carers in the SCP – a reflection of the role that case management can play in making a difference in the lives of both carers and care recipients.







## Conclusion

It is concluded that:

- There is clear evidence that case management and respite yield positive outcomes for carers; and
- In the new world of the NDIS, carer support is intrinsic to maintaining their capacity to care. Funding for social supports and emergency planning needs to be provided to ensure sustainability of the caring role. Just as importantly, carer involvement in planning and ongoing access to respite are critical if carers are to be adequately supported into the future.

## Policy Recommendations

1. Anglicare recommends that carers have access to and an option to appoint an **Independent Carer Support Coordinator** as part of the services available through the Integrated Carer Support Service. Carers should be informed of this option when accessing the Carer Gateway and other supports in the Integrated Carer Support Service.

2. Anglicare recommends that carers have access to and options to take up **flexible respite services** as part of the services available through the Integrated Carer Support Service.

Respite services should be:

- Available as a stand-alone service as well as part of a multi-component service;
- Responsive and easily adaptable to individual and changing circumstances;
- Available in the home and for extended periods out-of-home;
- Available at planned and regular occasions as well as in emergency situations;
- Promoted to carers when they access the Carer Gateway and other supports in the Integrated Carer Support Service, such as the education and information streams; and

- Promoted as beneficial for carers' wellbeing and capacity to sustain the caregiving role.

3. Anglicare recommends that the Integrated Carer Support Service provides funding for appropriately qualified and experienced organisations to run **Social Support Programs** specifically designed to support carers in their caregiving role.

4. Anglicare recommends that the Integrated Carer Support Service provides supports for **emergency planning**, registration of a plan and reasonable and necessary services required to implement the emergency plan.

5. Anglicare recommends that the education, information and awareness components of the Integrated Plan for Carer Support Services and the Local Area Coordinators in the National Disability Insurance Scheme include accessible information for carers regarding their **involvement in the participant's planning** and their opportunity to provide a **Carer's Statement**.

## 1. Introduction

Large numbers of Australians live with a disability or care for someone with a disability. It has been estimated that in 2015 nearly one in five Australians or 4.3 million people had a disability. Of these, 1.4 million people (5.8% of Australians) had a profound or severe disability (ABS, 2016). The primary caregiver for these Australians is often a parent, spouse or relative.

It has long been recognised that carers make a huge contribution to sustaining the health system financially. Indeed, recent estimates suggest that the replacement value of unpaid care in 2015 was \$60.3 billion, providing more than 1.9 billion hours of unpaid care (Carers Australia, 2016). Such caring includes caring for a person with a disability, for a frail aged person or for a person with a chronic illness.

***“1.4 million people (5.8% of Australians) had a profound or severe disability.”***

The recently introduced *National Disability Insurance Scheme* (NDIS) represents a seismic shift in the way that care will be funded for people with disabilities. Under the Scheme, Government funding for disability services and support will be directed to the person with the disability to choose their funded supports, rather than as block funding to service providers. The NDIS is a landmark reform in supporting people with a disability to exercise choice and control in their life decisions. NSW was the first state to sign up to the Commonwealth NDIS, with full implementation of the Scheme across the state planned by 2018.

***“The NDIS is a landmark reform in supporting people with a disability to exercise choice and control in their life decisions.”***

However carer needs and supports are not formally recognised as part of NDIS packages. There is no formal assessment of the needs of the carer, no funding package for the carer and no guarantee of involvement in the assessment of the care recipient's needs. Until recently it was unclear what supports would be available for carers under the new system, given the closure of many block-funded services. Provision for federally funded carer supports will be directed through the Integrated Carer Support Service (“ICSS”), which is currently being designed by the Department of Social Services (DSS, 2016a).

Along with other charities and not-for-profit organisations, Anglicare has, for many years, been a provider of block-funded services for carers of people with disabilities. These services will eventually be closed as funds for carer support services are subsumed into state contributions towards the NDIS.

Two such services include:

- Support Coordination Program (SCP) for carers aged 60 years and over, who provide care for an adult child with a disability; and
- Respite Options Program (ROP), which provides respite for carers of people with a disability.

With the closure of carer-specific support services, Anglicare is concerned that carers will no longer receive the same amount of support, let alone improved levels of support, under the new system.

## 1.1 Aim of this Report

This report seeks to:

1. **Outline the impacts of the caring role on care givers.** Some carers may have been caring for their child for five or six decades. Their care-giving is virtually a lifelong 'career' and affects them in significant ways – financially, emotionally, socially and in their life choices. Most carers live with the person for whom they care, which requires a 24 hour, 7 day a week, all year round commitment, that is only relieved by occasional respite.
2. **Identify the positive impacts of current block-funded programs in the lives of carers.** These impacts are identified through evaluation of Anglicare's SCP and ROP services, using pre and post survey data collected from clients over several years. The evidence presented here demonstrates the tangible benefits to carers of the current block-funded services.
3. **Identify likely areas of shortfall in proposed approaches to carer support.** While the current role of some carers may well diminish under the new system, there is no doubt that informal, long-term care provided by carers will continue to be a major pillar of the care system for people with disabilities. The challenge in the new system will be to ensure that sufficient supports and consequent benefits will continue to flow to carers, to support them in their ongoing role.
4. **Make recommendations to Federal and State Governments** designed to address likely shortcomings in carer supports as the NDIS is rolled out and block-funded carer services begin to be withdrawn.

***“Carer needs and supports are not formally recognised as part of NDIS packages.”***

## 2. Impact of Caring

### 2.1 The Caring Role: A Statistical Picture

Perhaps one of the most comprehensive surveys of carers and their contribution was carried out by the Australian Bureau of Statistics (ABS) in 2015, involving a large sample of over 75,000 people. Based on that survey it has been estimated there are almost 2.7 million Australians caring for people with a disability, frail aged or people with chronic illnesses. Around 850,000 (32%) of these were identified as primary carers.

For many carers their caring role is a 7 day a week, 24 hour role. The majority of primary carers (58%) spent at least 20 hours per week caring for a person with a disability and 40% of primary carers spent at least 40 hours per week on caring tasks. Most primary carers (79%) resided in the same household as the person for whom they provided the most care. Of those primary carers not living in, two-thirds were caring for a parent (67%). Almost three-quarters (71%) of primary carers lived with at least one person with a profound core activity limitation (ie. someone who always needs help with a mobility, self-care or communication task).

***“For many carers their caring role is a 7 day a week, 24 hour role.”***

Females made up the majority of carers (68% of primary carers). Carers also tended to be older than the general population. The proportion of Australians who were carers generally increased with age, from 1.3% of those aged less than 15 years to 20% of those aged 55 to 64 years; the proportion then diminished among those older than 65 years.

Of concern was the proportion of primary carers who themselves have a disability – around a third of primary carers had a disability (38%), compared with

16% of people living in households who were not in a caring role. Around 23,900 male and 41,600 female primary carers themselves had a profound or severe core activity limitation (ABS, 2016).

For two out of three carers the most common motivation for caring (67%) was a sense of family responsibility, followed by a feeling that they could provide care better than anybody else (50%) and feeling an emotional obligation to do so (44%) (ABS, 2016).

### 2.2 The Impact of Caring

A previous report by Anglicare Sydney (Bellamy et al, 2014) provided detailed information about the deleterious effects of long-term caregiving on those supplying the care. It showed that carers' physical, mental, emotional, social and economic wellbeing are often compromised by their caring role. A recent review of the literature conducted for this report indicates that the situation has not changed. There are a number of life domains which are impacted by long term intensive caring.

#### 2.2.1 General Wellbeing

Subjective wellbeing scores are lower amongst carers than in the rest of the general population. Hammond, Weinberg & Cummins (2014) surveyed over 4000 informal carers and reported that while the normative range for the Personal Wellbeing Index (PWI) in the general population is 73.6-76.6 points, a value of 58.5 was measured amongst the carers. They remarked that the carers' average PWI score, *“represents the lowest level of well-being found within demographic population sub-groups ... in the 13 years of the Australian Unity Wellbeing Index”* (Hammond, Weinberg & Cummins, 2014:1539-1540).

Furthermore, the 2014 survey of carers in New South Wales (Carers NSW, 2014) found that mean PWI scores for carers decreased as the hours of care given each week increased, showing that intensive caregiving reduces levels of personal wellbeing.



## ***“Carers have the lowest level of well-being found within population sub-groups.”***

In another Australian study using quality of life measures, Remedios and colleagues (2015) found that caregivers registered clinical levels of distress, moderate levels of fatigue and mental health scores which were below the average for the general population. Carers using the services of Wesley Mission (2014) also reported that their general wellbeing was adversely by their involvement in caring.

### **2.2.2 Physical Health**

Caregivers' physical health scores on quality of life measures were shown to be below average levels when compared with standardised population data from both the United States and Australia (Remedios et al, 2015). Other recent studies have reinforced the findings of this study: carers suffer from a variety of physical ailments as a direct result of providing care (Coleet et al, 2016; De Oliveira & Hlebec, 2016; Link, 2015; Neville et al, 2015; Nunez, 2016; Willemse et al, 2016). Those carers who care for more than twenty hours per week were particularly impacted in terms of worsening physical health status. Furthermore, physical health declined over time with ongoing care-giving, especially for those carers who were also attempting to maintain employment as well as providing care (Kenny, King & Hall, 2014).

### **2.2.3 Mental and Emotional Health**

According to research, mental and emotional health is most adversely affected when a person is required to provide intensive care to someone else over a prolonged period of time. The research of Remedios and colleagues (2015) revealed disturbing results for

carers in the area of mental health. Similar results were found by Hayes and colleagues (2016); over 40% of their sample of sixty Australian carers met the criteria for a possible psychiatric disorder. Following analysis of a survey of more than 5000 carers in Canada, Glavin & Peters (2015) found that the effects of caring were complex: women may experience greater detrimental effects on their mental health, whilst men were more likely to experience stress as a result of work-family conflict. Caregiving of over twenty hours per week was found to be particularly onerous for carers' mental health status, as was the cumulative effects of caregiving over many years (Kenny, King & Hall, 2014).

## ***“Caregiving of over twenty hours per week is particularly onerous for carers' mental health status.”***

### **2.2.4 Family Life**

Another domain which can be significantly impacted by the caring role is that of family life and the quality of family relationships. In particular, marriages and partnerships can be placed under tremendous strain. A survey of 101 couples with a child with an autism spectrum disorder revealed high levels of marital stress, a finding which aligns with previous research in this area (Harper et al, 2013). The family as a whole, including typically-developing children, can be adversely affected due to the presence of a person with care needs in the household (Link, 2015). Consequently, matters such as regular household tasks and the needs of other family members may be either postponed or ignored due to the pressing requirements of the care recipient (Welsh, Dyer, Evans & Fereday, 2014).

### 2.2.5 Employment and Income

Work and financial matters may be neglected when a person is struggling to cope with the care recipient's needs as well as meeting the obligations of employment (Glavin & Peters, 2015). Carers have lower labour force participation than non-carers – 57.2% compared with 80.3% - for those of workforce age (ABS, 2016). Carers may have a lower socio-economic position as a result of the combined effects of loss of employment and financial expenses associated with caring (Williamson & Perkins, 2014). Financial stress is particularly high when caregivers co-reside with care recipients and provide high hours of caregiving (NAC and AARP Public Policy Institute, 2015). Recent ABS (2016) data show that the main impact of the caring role for parents of a child with a disability was either decreased income or increased expenditure due to the needs of the care recipient.

***“Carers have lower labour force participation than non-carers.”***

### 2.2.6 Exclusion and Disconnection

Social isolation of carers is acknowledged widely in extant literature. Hayes and colleagues (2015) surveyed sixty Australian carers and found that they were ten times more likely to be socially isolated than people in the general population. Similar findings concerning the isolating effects of prolonged caring were made by Rodger, O'Neill & Nugent (2015). For example, a person caring for a spouse may no longer self-identify as the person's spouse but as the person's carer, thus shifting the basis of the relationship. Carers NSW (2014) found decreased levels of social support among carers with higher hours of care duties per week.

***“Carers were ten times more likely to be socially isolated than people in the general population.”***

Carers NSW (2014) found a number of factors which may increase the negative impacts of caring. These include a commitment of over 70 hours per week to care duties, the carer's age being between 45 and 54 years, the carer belonging to the CALD sector of the population, the carer having been in the caring role for more than 15 years and carers who have experienced an illness or disability within the previous twelve months.

### 2.2.7 High Risk Groups

Parent carers who are sole parents face particularly difficult circumstances. The majority in this category are women, many of whom are forced to rely on family and friends for assistance and informal respite care, and who struggle with inflexible workplaces where they are unable to negotiate conditions which would optimise their ability to provide care. As well as assistance with workplace relations, these carers often need support with other aspects of their caring roles as they struggle to fulfil this role on their own (Cole, Crettenden, Roberts & Wright, 2016).

Carers living in regional and remote areas also need special consideration. Often these carers are faced with fewer choices about services and may be required to travel longer distances in order to access services. The particular stresses of caring in a situation where options are limited should not be forgotten in policy development and program planning (Broady, 2014).

The multiple combinations of life situations, care situations and coping strategies that can be found among carers demonstrates the need for personalised and tailored service provision in order to assist individual carers in their unique set of circumstances. For instance, children with autism spectrum disorders require more health services than the general population (Bears et al, 2015), while carers of adults suffering from schizophrenia may spend six to nine hours each day providing care (Yesufu-Udechuku et al, 2015).

### 2.2.8 Summary

Many caregivers' lives are compromised in multiple ways as a direct result of the caring role. This is the case across both a variety of care recipient diagnoses and different caregiver profiles in terms of age, gender and socio-economic status. Caring usually exacts a toll on those who are required to provide it. The problems that flow from the caring role can be severe, including loss of physical health, a range of mental illnesses from severe stress to anxiety disorders to depression, poor levels of general wellbeing, fractured personal and family relationships, loss of employment and social exclusion and disconnection. There is a clear need for both Government and community support for carers in their role.

***“Many caregivers’ lives are compromised in multiple ways as a direct result of the caring role.”***

# SCP at a Glance

## Description of Program

The SCP provides community-based programs for ageing parent carers aged 60 years and over, as well as Aboriginal and Torres Strait Islander carers aged 45 years and over. The program aims to support ageing parent carers to maintain their caring role for as long as possible by providing case management and respite opportunities, and to plan for a transition from parental care. The program provides flexible support with links to appropriate services; development of informal networks and peer support; assistance with planning for the future; and opportunities for social and community participation.

## Carer Demographics



Upon entry to the program, around **nine in ten carers were aged over 65 years (93%)**.



The majority of carers in the matched sample were **female (81%)**.

## The Caring Role

The majority of carers (**93%**) provided care for a **son or daughter**.



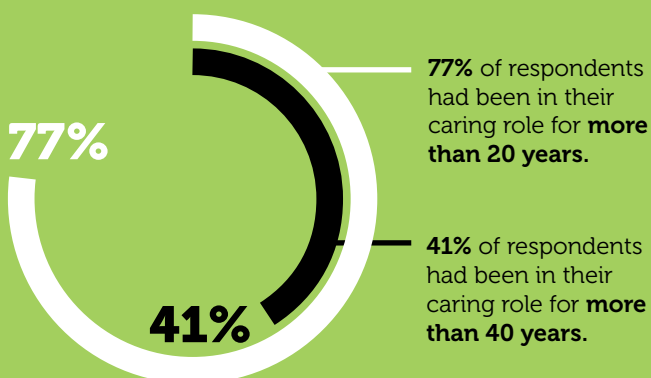
Carers sometimes have a dual caring role - caring for parent, parent-in-law or spouse, as well as caring for their son or daughter with a disability.



**8%** of the matched SCP sample cared for **more than one person**.



**Most carers in the matched sample had been caring for a person with a disability for many years:**



## Program Activities



**Intensive case management**



**Transition planning**



**Social assistance**  
(carer and care recipient)



**Respite**



**Help to pursue goals/interests**  
(care recipient)



**Community and personal care**



**Life skills training**  
(care recipient)



**Counselling**  
(carer)



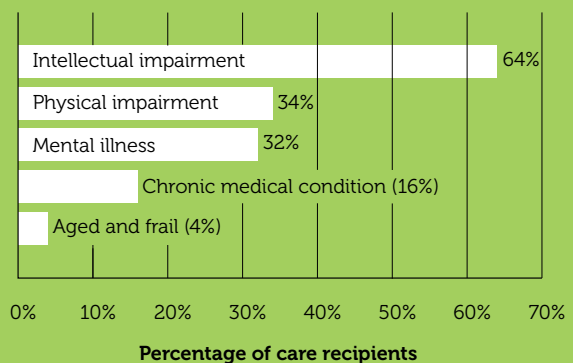
**Education and training**  
(carer)

## Nature of Disability

When asked about the nature of the care recipient's disability, 64% of carers cited an intellectual disability (see Figure 1). About one in three carers raised a physical impairment (34%) or mental illness (32%) as an issue for their care recipient.

More than one in four carers in the matched sample (28%) identified two kinds of disability. Around one in ten (9%) identified three or more kinds of disability.

**Figure 1: Nature of Care Recipient's Disability**



## 3. Anglicare Support Coordination Program (SCP)

### 3.1 Description of the Support Coordination Program

#### 3.1.1 Overview

The SCP supports older parent carers of an adult son or daughter with a disability to maintain their caring role for as long as possible by providing support and respite opportunities, and to plan for a transition from parental care. The program seeks to:

- Work with mainstream services to identify and engage with older parent carers, particularly those who are not currently accessing disability or family support services;
- Establish local older parent support groups and peer support groups;
- Engage with families to develop a comprehensive respite and skills development plan for the person with a disability paying particular attention to a continuum of support, the availability of informal supports and community participation;
- Assist older parent carers to address the issues of emergency care and planning for transition from parental care, through a comprehensive plan;
- Utilise Carer Assistance Packages (up to \$5000 per family over a two year period) to build skills, establish social contacts and procure flexible respite if not otherwise available.

The program has a particular focus on assisting older parent carers, who for a range of reasons are not currently accessing disability or family support services. The program is focused on the provision of services for:

- Parents over 60 years who are caring for a son or daughter with a disability;
- Aboriginal and Torres Strait Islander parent carers aged 45 or over are eligible in recognition of their shorter life expectancies, higher mortality rates at all ages and earlier ageing experiences.

*“A key aspect of the SCP service model is strengths-based needs assessment, case management and planning.”*

#### 3.1.2 Service Model

A key aspect of the SCP service model is strengths-based needs assessment, case management and planning. Upon entry to the program, families are supported to develop a plan which outlines their needs, goals and interests and details funded and unfunded supports/services to be provided. The plan is driven by the needs of both the parent carers and person with a disability. It provides developmental opportunities and the flexibility people are seeking to respond to their individual circumstances and needs. The care plan also includes contingencies for emergencies, to enable a less crisis driven approach to care problems.

Parent carers and the person with a disability are supported throughout their time in the program by holistic case management. A designated case manager works with each family and has the flexibility to vary the frequency of visits depending upon client needs. Maintaining ongoing contact with carers is considered important in building trusting relationships and reducing the need for unplanned crisis interventions. The case manager assists families by organising supports, either using referrals or by directly organising arrangements where needed. The service also manages the payment of services and supports that are brokered on behalf of carers and people with a disability. Where services are sub-contracted, the SCP monitors the quality, cost and amount of service purchased on behalf of the family and ensures that all the responsibilities are fulfilled through the sub-contracting arrangements.



### 3.1.3 Program Activities

The activities conducted as part of the SCP are flexible and customised, based on the particular needs of the carer and the person with a disability. As such, there is no uniform set of activities conducted with all clients. Some of the core elements of the program include:

- **Case management:** Involves identifying and managing the client's support needs and, over time, developing a client's capacity to self-manage their own access to supports they need (Gronda, 2009);
- **Goal setting:** Goal setting flows out of the initial needs assessment which establishes the needs and wants of carers and their son or daughter with a disability (e.g. supported accommodation, respite, skills development). Once these needs and wants are determined, the case manager assists by recording the steps required to achieve the desired outcome and the timelines for each step;
- **Transition planning:** The development and/or review of a plan to address matters such as the future needs of the care recipient, contingencies in case of emergency, housing, legal and guardianship arrangements, and financial arrangements;
- **Community care services:** Involves organising brokered services such as garden maintenance, meal delivery, community transport, personal care, cleaning, arranging equipment etc;
- **Carer counselling:** Is offered through the program on the basis of need – some clients may be referred internally to Anglicare counselling services;
- **Carer education and training sessions:** Sometimes education or training is arranged by case workers when multiple carers require information about the same topic (e.g. wills, guardianship and navigating the service environment);
- **Life skills training:** Training in skills such as shopping, banking, phone use, using public transport and housekeeping can be an important intervention for care recipients, especially those with an intellectual disability;
- **Access to respite:** Case managers broker respite services for carers including episodic and ongoing flexible respite as well as day programs. The SCP may also refer clients to the Commonwealth Respite and Carelink Centres (CRCC) for additional respite; and
- **Enhancing social networks:** The service assists carers and people with a disability to build their own informal networks of support and to maintain their significant friendships over time.

*“The activities conducted as part of the SCP are flexible and customised, based on the needs of the carer.”*

### 3.1.4 Program Evaluation

**Program Logic Modelling:** A common starting point for evaluation is to develop a program logic model, which identifies and maps client needs, program activities and outcomes. A Program Logic Model for the SCP was developed both through a review of the ADHC Service Delivery Schedule and through consultation with local SCP workers.

**Client surveys:** In order to obtain data for the evaluation, clients were asked to complete two different surveys:

- **Entry survey:** This survey sought to identify needs upon entry to the service and to create baseline results for aspects such as subjective wellbeing, stress levels and self-assessed health; and
- **Evaluation survey:** This second survey was offered to the carer upon leaving the program or after some experience of the service. The survey sought to identify ways in which the program had been of assistance to the carer and to repeat results for wellbeing measures obtained in the Entry Survey.

Nearly all questions in the surveys were close-ended, allowing selection of a response from a list of possible responses. Some questions in the survey appear in other population surveys, allowing comparisons with national benchmarks. These questions include the Personal Wellbeing Index (PWI), which is a widely-used measure of subjective wellbeing, and the stress sub-scale from the Depression, Anxiety and Stress Scale (DASS). The statistical data provided in this report is complemented by comments made by carers as part of the surveys.

The Entry and Evaluation surveys were matched manually on the basis of client number, respondent name and/or birth date. This process was limited where respondent identifiers were missing or incomplete, meaning that some survey forms could not be matched, or where carers had not attempted

both surveys. Unless otherwise stated, analysis in this report has been limited to the fully-responding sample of carers, hereafter referred to as the 'matched sample'.

Between January 2008 and March 2013, a total of 158 carers in the SCP completed both an entry and an evaluation survey (47% of all entry survey respondents).

The characteristics of carers in the matched sample were generally similar to those of who completed an entry survey only. In the SCP, carers who had only completed an entry survey were more likely to be aged under 65 years, married, providing care to a grandchild or living in a separate residence from the person they care for. In the ROP, carers who had only completed an entry survey were more likely to be aged under 45 years.

Comparison of results between Entry and Evaluation surveys enabled any improvement in wellbeing scores to be detected during the period of involvement with the program as well as any increase in the type of services being used by carers.

Carers provided consent when undertaking Entry or Evaluation surveys. Carer names and other identifiers have been used only for the purpose of matching Entry and Evaluation survey forms. Every effort has been made to protect the confidentiality of carers and no carers are named in this report or any other reporting study.

## 3.2 Carer Outcomes Associated with the Program

### 3.2.1 Service Access

Anglicare survey data reveals that the SCP enabled carers to access a wider range of support services than they had accessed in the past.

In order to better define carers' patterns of contact with support services, carers were asked which services they had received in the 12 months prior to entry to the SCP as well as the services they had received during the program. In the 12 months prior to making contact with Anglicare, carers had accessed an average of two services. This doubled to an average of four services accessed through Anglicare. The vast majority of clients (89%) received at least one new service through Anglicare that they had not received in the 12 months before entry. Critically, about one in five carers (21%) had not accessed any services in the 12 months prior to entering the program. This indicates that some carers had been out of contact with service providers before coming to Anglicare, or in fact never accessed any service supports. Reaching these 'hidden carers' is one of the aims of the SCP.

Figure 2 shows the specific support services that carers had accessed in the 12 months prior to, and during the SCP. The improvement in service access may be calculated as the difference between the proportion of carers who accessed a service prior to entry and the proportion who received the service from Anglicare. The largest improvement in service access was in case management (60% improvement – from 33% to 93%). Other large improvements in service access were in the areas of transition planning (51% improvement), assistance to increase carer's social contacts (46% improvement) and assistance for the care recipient to pursue their goals and interests (32% improvement). Respite was the most commonly accessed service in the 12 months

prior to program entry (42% of carers), however there was only a small improvement in access to respite during the program (6% improvement). This may reflect the relatively high demand for this service in the community. According to practitioners it may also reflect the addition of extra supports may have meant the demand for respite did not continue to increase over the period of service.

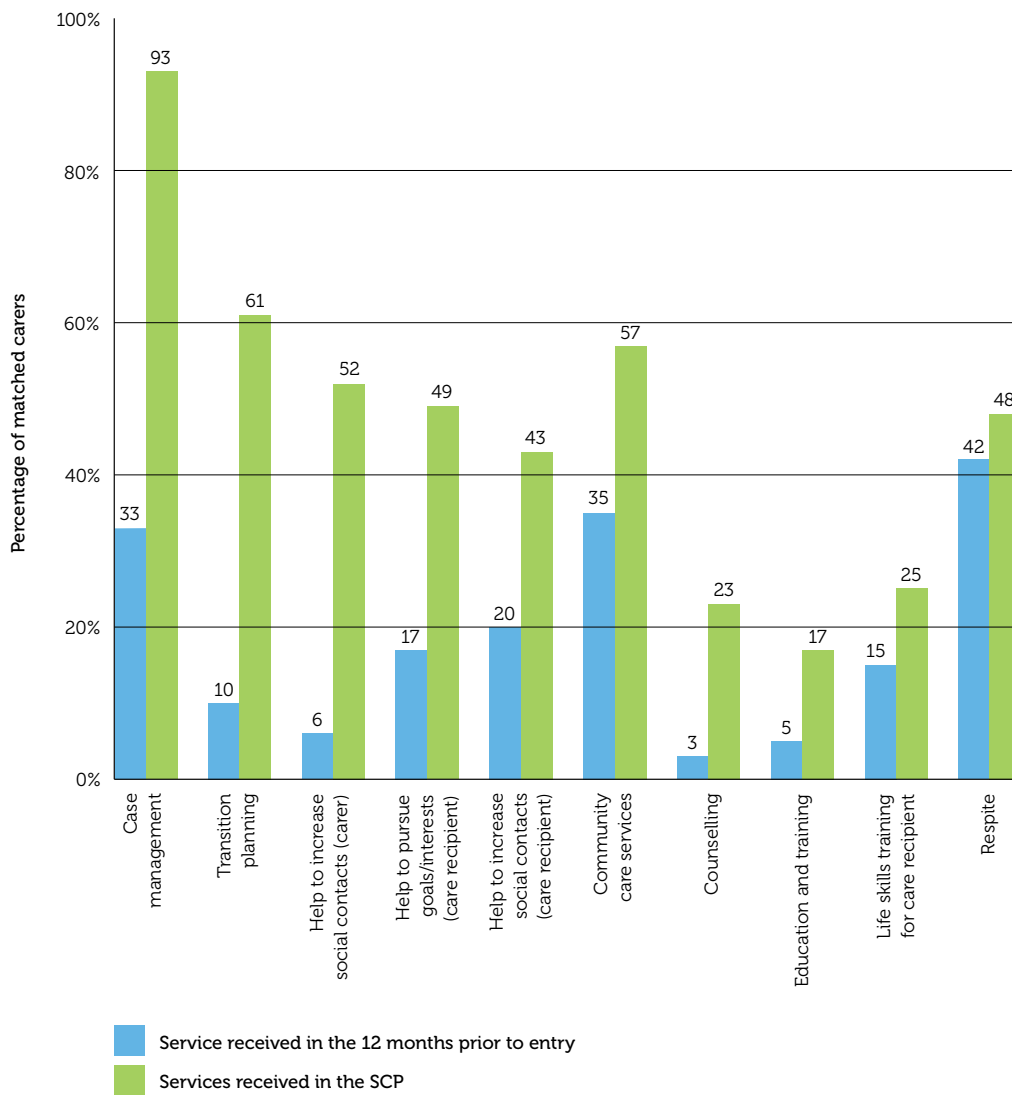
### 3.2.2 Length of Participation and Other Outcomes

The average length of participation in the SCP among carers in Anglicare's matched sample was 1 year and 6 months, although the average figure masks a wide distribution in participation from a few weeks to several years. Correlational analysis of Anglicare's data found that the length of participation in the program was related to carers' initial assistance needs. For instance, the greater the reported need upon entry for respite care, the longer the carer tended to spend in the program. Carers who considered respite to be 'very important' or 'quite important' spent an average of 1 year and 9 months in the program, more than twice the length of time spent by carers who did not feel the same need for respite services ( $r=0.35$ ).

Length of time spent in the program was also positively correlated with a greater need for carer education and training ( $r=0.25$ ), assistance for the care recipient to pursue their goals and interests ( $r=0.24$ ), community care services ( $r=0.22$ ) and life skills training for the care recipient ( $r=0.21$ ).

Given that carers with the greater needs tended to stay longer with the program, is there any evidence that the program makes a difference to carer outcomes? By comparing the survey responses for the same carers upon entry to the program and again after a long period of participation in the program, changes in average carer responses were identified.

Figure 2: Carers' access to various support services in the 12 months prior to entry and during the Support Coordination Program



Source: Anglicare matched sample of carers in the Anglicare Support Coordination Program

### 3.2.3 Carer Wellbeing

The Australian Unity Personal Wellbeing Index (PWI) has been used to establish the subjective wellbeing of carers in Anglicare's SCP, both upon entry to the program and during the program. Carers were asked to rate their levels of satisfaction from 0 to 10 across seven life domains comprising the PWI. The combined score for all seven items was then converted to a score out of 100. The national average score for this index is around 75 out of 100 for the population, while a national study of carers showed a lower average score of 58 (Cummins and Hughes, 2007). As shown in Table 1, Anglicare has identified a similarly low wellbeing score of 58.1 among carers entering the SCP. When the scale was re-administered in the evaluation survey, the average score had increased significantly ( $p < 0.01$ ) to 63.9.

Individual items in the PWI as well as other items in the survey reveal carer satisfaction for different life domains at the time of program entry and evaluation. Table 2 shows that among carers in the matched Support Coordination sample, health (average score = 4.8 out of 10), satisfaction with life (5.2) and achievement in life (5.4) were the areas of least satisfaction for ageing parent carers whilst the carer's sense of safety (6.8) was the area of greatest satisfaction. After at least 12 months in the program, carers were significantly more positive about their lives across most of the domains measured in the survey. The areas of greatest improvement among carers in the SC program were the person's life as a whole (+1.0), their future security (+0.7), their health (+0.6), their personal relationships (+0.7) and feeling part of the community (+0.6).

### 3.2.4 Carer Stress

The level of stress being experienced by carers was measured using the stress subscale of the Depression, Anxiety and Stress Scales (DASS) instrument. When converted to a score out of 100, the national

average stress score for the general population is 19 (Crawford et al, 2011). The average stress score for carers entering the SCP was considerably higher at 45 out of 100. This score had reduced marginally at the time of the evaluation survey, although the reduction was not statistically significant (see Table 3).

These consistently high stress scores may seem incongruent with the significantly improved wellbeing scores among both samples of carers. However, feedback from Anglicare case managers suggests that carers are still subject to the ongoing stresses and demands associated with caring for a family member with a disability, despite feeling better about some aspects of their lives.

***“After 12 months in the program, carers were more positive about their lives across most domains in the survey.”***

Despite the ongoing stress experienced by carers in the SCP, there were some significant improvements in selected areas of concern (see Table 4). The vast majority of carers who were entering the SCP (80%) were concerned about what would happen to their disabled son or daughter if they were unable to provide care. After at least 12 months in the program, fewer carers were anxious about this issue (65%) ( $p < 0.01$ ). There was also a significant improvement in the proportion of carers who were aware of sources of assistance (from 50% to 79%) ( $p < 0.01$ ) and a significant reduction in the proportion of carers who agreed that they needed time out from their caring role (59% to 51%) ( $p < 0.05$ ).



**Table 1. SCP trends between entry and evaluation surveys – Personal Wellbeing Index (average scores out of 100)**

Indicator	Entry	Evaluation
Personal Wellbeing Index	58.1	63.9

**Table 2: SCP trend between entry and evaluation surveys – Personal Wellbeing Index subscales (average scores out of 10)**

Indicator	Entry	Evaluation
Satisfaction with life as a whole	5.2	6.2
Satisfaction with standard of living	6.4	6.6
Satisfaction with health	4.8	5.4
Satisfaction with current achievements in life	5.4	5.8
Satisfaction with personal relationships	6.0	6.7
Satisfaction with personal safety	6.8	7.3
Satisfaction with feeling part of community	5.9	6.5
Satisfaction with future security	5.7	6.4

● No significant difference between entry and evaluation

● Statistically significant improvement between entry and evaluation ( $p < 0.05$ )

Statistical significance based on the result of paired-sample t-tests



**Table 3. SCP trends between entry and evaluation surveys – DASS stress subscale (average scores out of 100)**

Indicator	Entry	Evaluation
DASS stress subscale	45.1	42.1

Statistical significance based on the result of paired-sample t-tests

**Table 4: SCP trends between entry and evaluation surveys – selected aspects of caring role (proportion of carers in agreement with statement\*)**

Indicator	Entry	Evaluation
I worry a lot about what would happen to my <i>son/daughter/relative</i> with a disability if I was unable to provide care	80%	65%
I find I need 'time out' from my <i>son/daughter/relative</i> who has a disability	59%	51%
I often have disputes with my <i>son/daughter/relative</i> who has a disability	36%	31%
I know where I can get help if I need it in my role as carer	50%	79%

-  No significant difference between entry and evaluation
-  Statistically significant improvement between entry and evaluation (p<0.05)

\*Agreement includes the categories 'tend to agree' and 'strongly agree'.

Statistical significance based on the result of McNemar's test on paired nominal data

### 3.2.5 Social Support

Social support is very important to carer wellbeing. For instance, an Australian study of older parents of adults with intellectual disabilities found that carers in better health also enjoyed both the close support of a network of family, friends and neighbours and a lower care-load (Llewellyn et al, 2010: 1176).

Retrospective questions were used in the SCP evaluation survey to determine whether the social connections of the carer and the care recipient had changed during their time in the program. Figure 3 shows that the majority of carers who received help from Anglicare to increase their social contacts reported an improvement in this regard (59%).

***“59% of carers reported an increase in their social contacts.”***

Among care recipients who received assistance from Anglicare to increase their social contacts, almost half (48%) experienced an improvement in social support as reported by their caregiver. Care recipients were more likely to experience ‘no real change’ in social support during the program (38%) compared with carers (30%). This may be related to challenges in building social contacts associated with the nature of the care recipient’s disability. Care recipients (who received social assistance from Anglicare) were also more than twice as likely as carers to have received social assistance prior to entry (18% compared with 8%).

The social events that were conducted as part of the program were mentioned in the open-ended responses of a number of carers. Most carers who mentioned these events commented that they promoted relaxation and the reduction of stress. One carer alluded to the benefits of meeting with other carers who are experiencing similar challenges:

*“All carers feel some stress, that’s why I enjoyed some of the outings you provided.”*

### 3.2.6 Other Changes

Carers in the SCP were asked to rate their satisfaction with their housing for their needs and those of the care recipient, as well as their satisfaction with their financial situation. After at least 12 months in the program, SCP carers became more satisfied with their financial situation ( $p < 0.01$ ) and the suitability of their home for the needs of their relative with a disability ( $p < 0.05$ ) as shown in Table 5. This may be related to the nature of the SCP as a holistic case-managed service. As part of the SCP approach, some carers would have been made aware of their eligibility for additional sources of financial support. Additionally, case managers would have referred carers to necessary services (such as occupational therapists) to improve the suitability and safety of the home environment for caring duties.

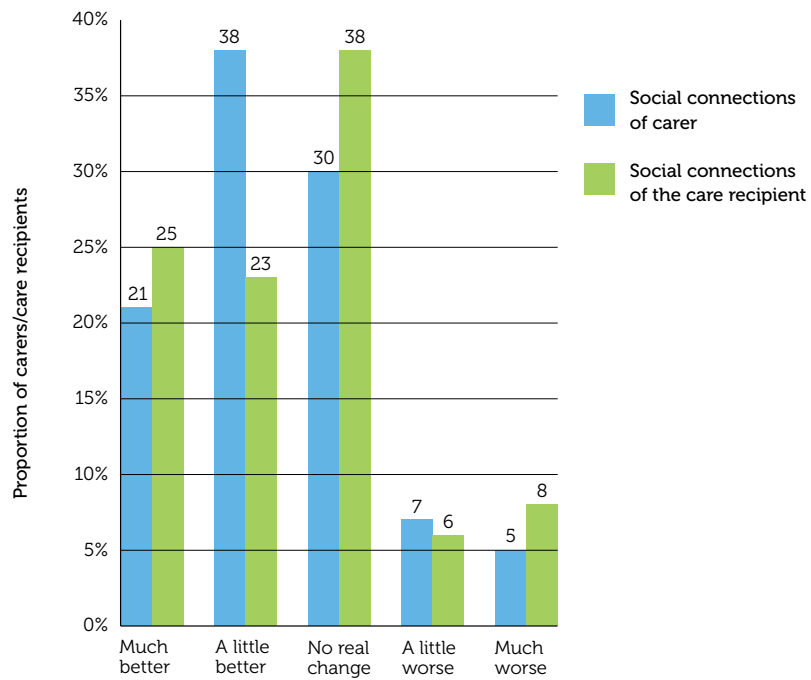
## 3.3 Discussion

### 3.3.1 Case Management

The central plank of this service model is case management, involving proactive planning of care to assist carers to access the resources to attain their identified goals. Using a person-centred approach, priority is given to meeting the greatest needs, with the carer being supported in decision-making. Indeed good case management is predicated on striving to empower clients through enabling them to make their own choices (Taylor et al, 2016). The outcomes identified in this report would indicate that case managed service models can create positive outcomes for carers and care recipients.

***“The critical element in the SCP service model is case management.”***

Figure 3: SCP carers' retrospective assessment of social support changes since entering program (carers who received social assistance only)



Source: Anglicare matched sample of carers in the Anglicare Support Coordination Program

Table 5: SCP trend between entry and evaluation surveys – satisfaction with finances and housing (average scores out of 10)

Indicator	Entry	Evaluation
Satisfaction with financial situation	5.1	5.8
Housing suitability for own needs	7.1	7.5
Housing suitability for care recipient's needs	6.4	7.1

No significant difference between entry and evaluation
  Statistically significant improvement between entry and evaluation (p<0.05)

Statistical significance based on the result of paired-sample t-tests

The benefits of case management are supported by the literature. Improvements in physical and psychological wellbeing have been observed (World Health Organization, 2016; You et al, 2012) along with positive effects on health outcomes for case managed clients (Taylor et al, 2016). Having one's wishes noted and a personalised program developed is satisfying for clients (Gowing et al, 2016). Just knowing that there is someone who is readily contactable, familiar with a given situation and available for consultation may provide considerable relief for overburdened carers (Randall et al, 2014). In a review of thirty-nine scholarly articles concerning various modes of investment in social services, Taylor and colleagues (2016) found that 88% of the care coordination and community outreach programs had statistically significant, positive effects on health outcomes and health care expenditure in the relevant population cohorts.

Case management is even more likely to produce beneficial outcomes when it has been developed from a process of collaboration with caregivers as well as care recipients (Goeman et al, 2016; You et al, 2012). When services are offered in a model characterised by integration and collaboration, the carer burden is reduced (Valentini et al, 2016). Inclusion of the carer's wishes and opinions, especially where carer-focussed interventions are part of the management package, has been shown across multiple research studies to be helpful to carers in their care roles (Yesufu-Udechuku et al, 2015). The end result is a care environment which has been developed with input from all of the relevant stakeholders and which is likely to have considered a much wider variety of influences and opinions (Cree et al, 2015).

Case management is particularly helpful for carers endeavoring to navigate the complex world of service delivery and the new world of the NDIS. Within a group of forty-two parent carers in

South Australia, half of them required assistance to complete the NDIS registration process. Issues encountered include complex application forms, lack of information on the website, lack of computer skills amongst parents, low levels of awareness of available services and lower socio-economic and education status amongst parent carers. Whilst simplified application processes would be beneficial, dedicated support coordination workers would be able to answer questions, assist with administrative tasks and direct parents to appropriate service providers, so making the whole process less onerous (Ranasinghe et al, 2016).

### 3.3.2 Conclusion

The outcomes identified in this report indicate that case-managed service models such as the SCP are associated with positive outcomes for carers and care recipients. During their time with the program, carers had wider access to services and other supports, improved overall wellbeing and enhanced social supports both for the carer and the care recipient. Levels of stress were largely unchanged, reflecting the ongoing nature of the caring role.

***“There is clear evidence of positive outcomes for both carers and care recipients involved with the SCP.”***

These findings suggest that case management meets many important needs among carers and may well be critical for them to be able to maintain their caring role into the future.

# ROP at a Glance

## Description of Program

The ROP provides respite support for people caring for a family member aged 0-64 years with a disability. The purpose of the program is to provide respite support to promote the independence and inclusion of the person with a disability and to build the resilience and capacity of the carer and their family. The program provides regular, planned, flexible respite care either in the home or the community, arranged in consultation with the participant and their carer.

## Carer Demographics



Upon entry to the program, **just over half of carers were in the 40-59 year age group** (53%).



The majority of carers in the matched sample were **female** (84%).

## The Caring Role

The majority of carers (**91%**) provided care for a **son or daughter**.



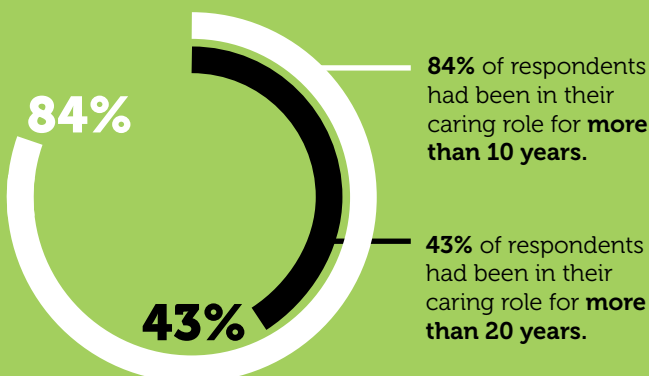
Carers sometimes have a dual caring role - caring for parent, parent-in-law or spouse, as well as caring for their son or daughter with a disability.



**9%** of the matched ROP sample cared for **more than one person**.



**Most carers in the matched sample had been caring for a person with a disability for many years:**



## Program Activities



**In-home respite**



**Visit to a specialised recreation day centre**



**Camps or weekends away**



**Help to pursue goals/interests (care recipient)**



**Outings and recreational activities in the community**



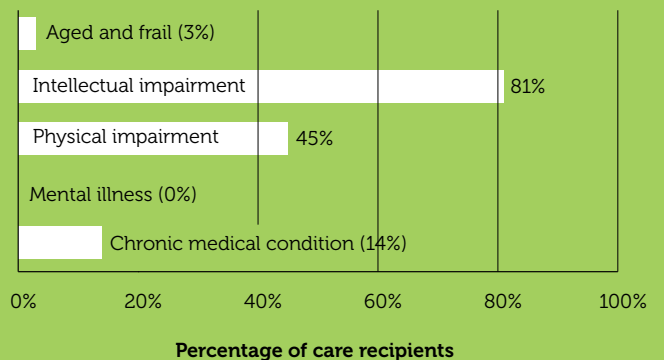
**Social assistance arising from outings or functions (carer and care recipient)**

## Nature of Disability

When asked about the nature of the care recipient's disability, 81% of carers cited an intellectual disability (see Figure 4). Almost half of carers mentioned a physical impairment (45%) as an issue for their care recipient.

Around one in four carers in the matched sample (25%) provided care to a person with more than one diagnosed condition.

**Figure 4: Nature of the Care Recipient's Disability**





## 4. Anglicare Respite Options Program (ROP)

### 4.1 Description of the Respite Options Program

#### 4.1.1 Overview

The ROP provides flexible respite to meet carers' individual needs and circumstances. The primary outcome of the program is to maintain the primary care-giving relationship and to support the care giver or givers in order to keep the family unit as cohesive as possible.

***"The ROP provides flexible respite to meet carers' needs and circumstances."***

Respite gives carers time to take a break from their caring duties, to tend to the needs of other family members, to catch up on the myriad of tasks that their caring responsibilities preclude or simply to take it easy and catch up on sleep. Other objectives of the program include:

- Enhancing the coping strategies of carers supporting family members with disabilities and improving their capacity to sustain a positive experience;
- Empowering families by fully involving them in decision making about the planning and delivery of services;
- Creating opportunities for a positive experience for the family and the person with disability;
- Assisting families to identify formal and informal family centred supports, and sustain access to such services from the community;
- Developing culturally and linguistically appropriate respite for individuals and families;
- Providing appropriately trained, skilled and understanding staff to provide respite support.

The main eligibility criteria for the program is the provision of care for a family member aged 0-64 years with one or more physical, intellectual or functional disabilities with moderate to high support needs. Particular priority is given to carers whose ability to continue long term caregiving is at risk due to the complexity and demands of the care situation, living alone or having limited access to other support services.

A number of Anglicare programs fell under the general umbrella of the Respite Options Program. In some instances these programs delivered the same service under other names ('Flexible Respite' or 'Flexible Respite Options'). In a very small number of cases (max. n=8), participants in the SCP received the respite component of their service from the ROP.

#### 4.1.2 Characteristics of the Program

The ROP seeks to provide flexibility for the family and the person with a disability to choose the type of respite they receive. Families are offered a range of choices in respite where the person being cared for is safe and secure, and is participating in meaningful activities which seek to enhance their experience of life. Respite choices are often based on the varying and changing needs and circumstances of both the person with a disability and their family/carer.

***"The ROP focusses on the delivery of respite which may lead to other benefits such as increased social support."***

An assessment process is conducted during intake to determine the needs of the person with a disability and his or her carer(s). This process is typically conducted via a home visit which provides the opportunity to explore available services to address

the particular concerns and stressors of the family and person with a disability. The assessment process leads to the development of a Person-Centred Respite Plan to determine the nature of the respite service to be delivered and the expected outcomes. The agreed respite package is then reviewed quarterly to determine whether respite needs are being met or have changed, and to update the package if required.

The ROP service model shares some similarities with that of the SCP, particularly the importance of ongoing consultation and flexibility to tailor services to meet individual circumstances. However it should be noted that the ROP has a more limited scope which focusses on the delivery of respite which may lead to other benefits such as increased social support. Other elements of the SCP such as intensive case management, transition planning, community care services, counselling and seminars for carers are not included within the scope of the ROP.

#### 4.1.3 Program Activities

The ROP provides a range of respite activities that are tailored to the individual circumstances of the person with a disability and their family. Some of the most common activities conducted as part of the program are outlined below.

- **In-home respite:** Respite is provided in a person's home either through a brokered direct care worker, a Nursing Agency or an alternative family carer employed by Anglicare;
- **Visit to a specialised recreation day centre / outings / camps / weekends away:** Provides an opportunity for the person with a disability to engage in meaningful recreation while providing respite for the carer. Specific activities in the community are based on the preferences and interests of the person with a disability (may include movies, attending football games, bowling, Riding for the Disabled, etc);

- **Assistance to pursue goals/ interests (care recipient):** This is achieved by tailoring respite activities to suit the interests and wants of the person with a disability; and
- **Social assistance arising from outings or functions (carer and care recipient):** Outings provide the opportunity for the person with a disability to interact with others and build friendships. Family members also sometimes take part in outings which provides them with the opportunity to build their own informal networks of support.

#### 4.1.4 Program Evaluation

**Client surveys:** Clients were asked to complete two different surveys:

- **Entry survey:** This survey sought to identify needs upon entry to the service and to create baseline results for aspects such as subjective wellbeing, stress levels and self-assessed health; and
  - **Evaluation survey:** This second survey was offered to the carer upon leaving the program or after some experience of the service. The survey sought to identify ways in which the program had been of assistance to the carer and to repeat results for wellbeing measures obtained in the Entry Survey.
- As with the SCP evaluation, nearly all questions in the surveys were close-ended, allowing selection of a response from a list of possible responses. Some questions in the survey appear in other population surveys, allowing comparisons with national benchmarks. These questions include the Personal Wellbeing Index (PWI), which is a widely-used measure of subjective wellbeing, and the stress sub-scale from the Depression, Anxiety and Stress Scale (DASS). The statistical data provided in this report is complemented by comments made by carers as part of the surveys.

The Entry and Evaluation surveys were matched manually on the basis of client number, respondent name and/or birth date. This process was limited where respondent identifiers were missing or incomplete, meaning that some survey forms could not be matched, or where carers had not attempted both surveys. Unless otherwise stated, analysis in this report has been limited to the fully-responding sample of carers, hereafter referred to as the 'matched sample'.

Between July 2009 and June 2015, a total of 78 carers in the ROP completed both an entry and an evaluation survey (48% of all entry survey respondents).

## 4.2 Carer Outcomes Associated with the Program

### 4.2.1 Access to Services

Survey data reveals that carers generally accessed a similar range of respite services from Anglicare compared with the services they received from previous providers. In order to better define carers' patterns of contact with support services, carers were asked which services they had received in the 12 months prior to entry to the ROP as well as the services they had received during the program. In the 12 months prior to making contact with Anglicare, carers had accessed an average of three services. Carers also accessed an average of three services from Anglicare. However, these average figures mask a wider variation in the specific types of services that carers accessed. Indeed, the majority of carers (56%) received at least one new service through Anglicare that they had not received in the 12 months before entry. In addition, almost one in ten carers (7%) had not accessed any services in the 12 months prior to entering the program.

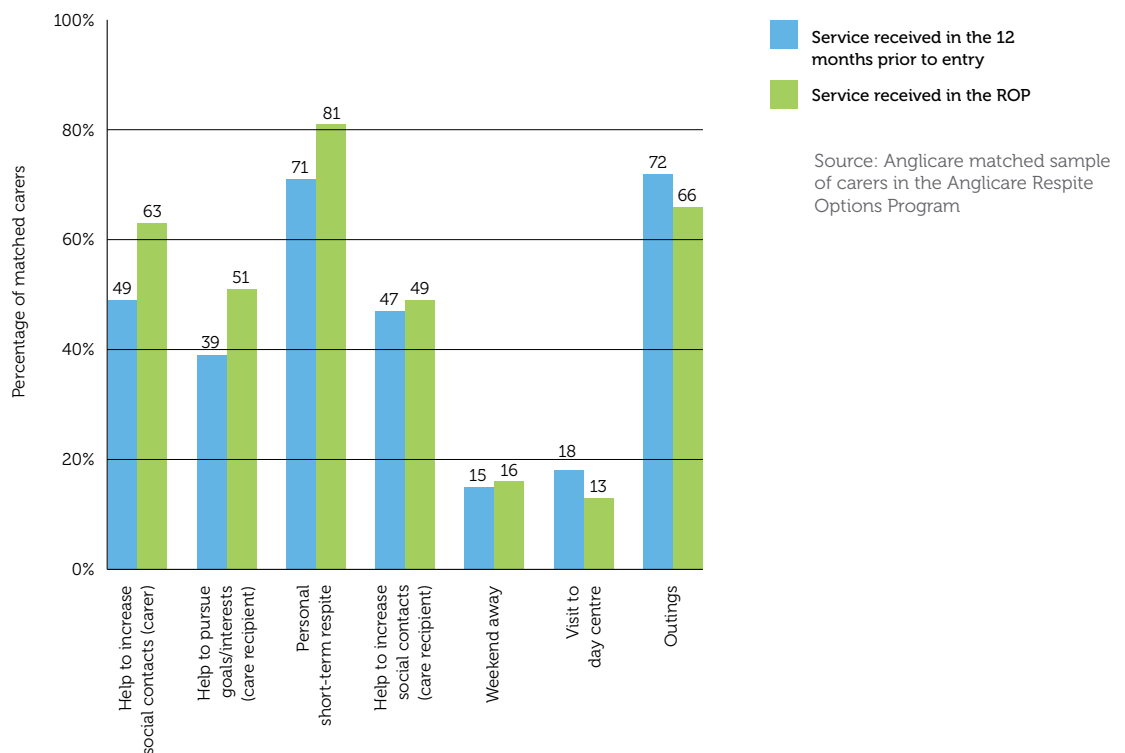
Figure 5 shows the specific support services that carers had accessed in the last 12 months prior to, and during the ROP. The improvement in service access may be calculated as the difference between the proportion of carers who accessed a service prior to entry and the proportion who received the service from Anglicare. The largest improvement in assistance related to the social contacts of the carer (14% improvement – from 49% to 63%). Access to personal short-term respite increased modestly (10% improvement), which was offset by a decline in access to day centres and outings (5% decline each).

### 4.2.2 Length of Participation and Other Outcomes

The average length of participation in the ROP among carers in Anglicare's matched sample was 1 year and 7 months. The length of participation was relatively uniform, with the majority of carers remaining in the program for either exactly one year (40%) or two years (15%). Correlational analysis of Anglicare's data found that the length of participation in the program was not related to any of the carers' initial needs, including the need for various forms of respite (outings for the care recipient, centre-based care, home-based care or weekend care). This may reflect the more 'transactional' nature of the ROP – periodic access to respite is an ongoing need for many carers which does not cease after one occurrence of service provision. When carers leave a respite-focused service, this may indicate a change in providers rather than the cessation of need.

By comparing the survey responses for the same carers upon entry to the program and again after a period of participation in the program, changes in average carer responses were identified.

**Figure 5: Carers’ access to various support services in the 12 months prior to entry and during the Respite Options Program**



### 4.2.3 Subjective Wellbeing

As was the case for carers in the SCP, the Australian Unity Personal Wellbeing Index (PWI) has been used to establish the subjective wellbeing of carers in Anglicare’s ROP. As shown in Table 6, the average wellbeing score of carers entering the ROP was 59.7, well below the national average score for the population of around 75 out of 100 (Cummins and Hughes, 2007). When the PWI scale was re-administered in the evaluation survey, the average score had increased significantly ( $p < 0.01$ ) to 66.3.

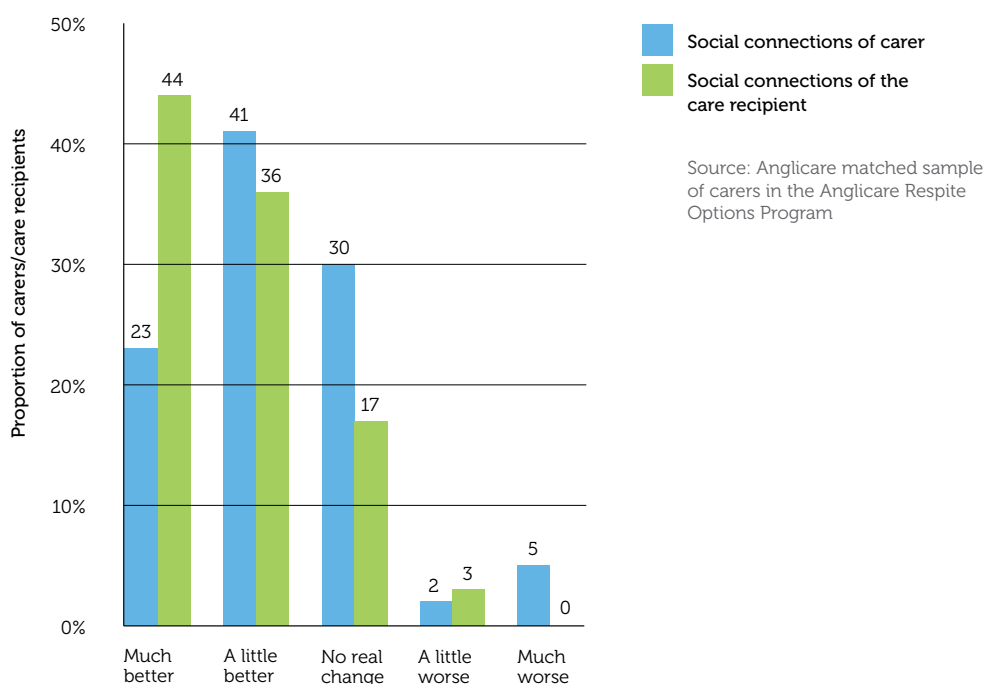
Individual items in the PWI as well as other items in the survey reveal carer satisfaction for different life domains at the time of program entry and evaluation. Table 7 shows that among carers in

the matched ROP sample, the carer’s current achievements in life (average score = 5.2 out of 10) and health (5.4) were the areas of least satisfaction for ROP carers whilst the carer’s sense of safety (7.3) was the area of greatest satisfaction. After at least 12 months in the program, carers were significantly more positive about their lives across most of the domains measured in the survey. The areas of greatest improvement among carers in the ROP were the person’s feelings of being part of the community (+1.0), their current achievements in life (+0.8), their life as a whole (+0.9) and their personal relationships (+0.7).

### 4.2.4 Carer Stress

As with the SCP surveys, the level of stress being

**Figure 6: ROP carers’ retrospective assessment of social support changes since entering program (carers who received social assistance only)**



experienced by ROP carers was measured using the stress subscale of the Depression, Anxiety and Stress Scales (DASS) instrument. The average stress score for carers entering the ROP was 50.4 out of 100, considerably higher than the national average stress score for the general population of around 19 (Crawford et al, 2011). Table 8 shows that this score had reduced marginally at the time of the evaluation survey, although the reduction was not statistically significant. As with the SCP carers, stress does not significantly reduce among ROP carers, despite improvements in other areas of their lives.

According to the Anglicare survey data, carers continued to experience concerns about their caring role even after participating in the ROP (see Table 9). These ongoing concerns may be related to the

narrower focus of the ROP compared with the SCP. For example, carers may have remained concerned about the future care of their family member because transition planning was not included in the ROP. Awareness of sources of assistance also did not improve significantly, which may be related to the lack of intensive case management as part of the program as well as the fact that carers were more likely to be connected with support services upon entry to the ROP.

#### 4.2.5 Social Support

As with the SCP evaluation survey, retrospective questions were used to determine whether the social connections of the carer and the care recipient had changed during their time in the ROP. Figure 6



**Table 6. ROP trends between entry and evaluation surveys – Personal Wellbeing Index (average scores out of 100)**

Indicator	Entry	Evaluation
Personal Wellbeing Index	59.7	66.3

**Table 7: ROP trend between entry and evaluation surveys – Personal Wellbeing Index subscales (average scores out of 10)**

Indicator	Entry	Evaluation
Satisfaction with life as a whole	5.7	6.6
Satisfaction with standard of living	6.6	7.1
Satisfaction with health	5.4	5.9
Satisfaction with current achievements in life	5.2	6.0
Satisfaction with personal relationships	6.1	6.8
Satisfaction with personal safety	7.3	7.7
Satisfaction with feeling part of community	5.7	6.7
Satisfaction with future security	5.7	6.3

No significant difference between entry and evaluation
  Statistically significant improvement between entry and evaluation (p<0.05)

Statistical significance based on the result of paired-sample t-tests


**Table 8. ROP trends between entry and evaluation surveys – DASS stress subscale (average scores out of 100)**

Indicator	Entry	Evaluation
DASS stress subscale	50.4	47.0

Statistical significance based on the result of paired-sample t-tests

**Table 9: ROP trends between entry and evaluation surveys – selected aspects of caring role (proportion of carers in agreement with statement\*)**

Indicator	Respite options	
	Entry	Evaluation
I worry a lot about what would happen to my <i>son/daughter/relative</i> with a disability if I was unable to provide care	93%	92%
I find I need 'time out' from my <i>son/daughter/relative</i> who has a disability	79%	78%
I often have disputes with my <i>son/daughter/relative</i> who has a disability	17%	19%
I know where I can get help if I need it in my role as carer	53%	68%


 No significant difference between entry and evaluation

\*Agreement includes the categories 'tend to agree' and 'strongly agree'.

Statistical significance based on the result of McNemar's test on paired nominal data

**Table 10: ROP trends between entry and evaluation surveys – satisfaction with finances and housing (average scores out of 10)**

Indicator	Entry		Evaluation
Satisfaction with financial situation	5.3	→	5.5
Housing suitability for own needs	7.3	→	7.3
Housing suitability for recipient’s needs	6.9	→	7.2

 No significant difference between entry and evaluation

Statistical significance based on the result of paired-sample t-tests

shows that almost two-thirds of carers who received help from Anglicare to increase their social contacts reported an improvement in this regard (64%). Among care recipients who received assistance from Anglicare to increase their social contacts, the vast majority of care recipients (80%) experienced an improvement in social support as reported by their caregiver. Some of the open-ended responses of carers in the ROP pointed to the benefits of meeting with other carers who are experiencing similar challenges. For example, one carer commented that, *"Having friends with kids with Autism has been a big help."*

#### 4.2.6 Other Aspects

Carers in the ROP were asked to rate their level of satisfaction with their housing for their own needs and the needs of the care recipient, as well as their satisfaction with their financial situation. As shown in Table 10, carers' satisfaction with these aspects of life generally remained unchanged after at least 12 months in the program. This is probably due to the narrower focus of the ROP which, unlike the SCP, did not include holistic case management.

### 4.3 Discussion

#### 4.3.1 Respite and its Benefits

While a range of supports are provided by the ROP, the central support is that of respite. However a recent discussion paper about the Integrated Carer Support Service stated that,

*"There is a lack of quality evidence that respite services effectively reduce carer burden and mental and physical health problems"* (DSS, 2016a:4).

This statement is not supported by either the research carried out by Anglicare or by current research studies reported in the literature. Respite care has been demonstrated to provide tangible assistance to carers across a variety of domains:

physical, mental, social and economic.

Wellbeing has been shown to improve as a result of the provision of respite. A study of 40 English carers found that carer wellbeing was positively impacted by access to respite care (Moule et al, 2014). Carers who accessed Wesley Mission's services reported benefits to their wellbeing through respite service provision (Wesley Mission, 2014). Data from the Third European Quality of Life Survey, in which almost 5000 respondents were surveyed, showed that carers' satisfaction with life improves when they are able to access respite care and so take a break from their caring responsibilities (De Oliveira and Hlebec, 2016). In the USA, the research of Nunez (2016) revealed that carers feel that respite allows them to feel better in themselves; in other words, respite improves their sense of personal wellbeing. In a rare study which measured physiological responses to stress, Zarit and colleagues (2014) found that the days when respite care was provided correlated with elevated levels of dehydroepiandrosterone-sulfate, a biological indicator of positive mood, amongst their sample of 151 caregivers. This finding showed that respite care resulted in better psychological and physiological wellbeing amongst the participant cohort.

***"Respite care has been demonstrated to provide tangible assistance to carers in a variety of ways."***

Carers NSW (2016) conducted a national survey on the issue of respite on behalf of the National Network of Carers Associations. Some 70.8% of 1,803 national respondents were informally caring for a person with a disability, with a third caring for a son or daughter under the age of 18 years and a quarter caring for an adult son or daughter. When asked the main purpose or benefit of respite, respondents cited:

- A break from caring responsibilities (83.8%);
- The opportunity to look after their own health and wellbeing (76%); and
- A propensity to help them sustain their caring role (67.5%).

Of the almost two-thirds of respondents who had accessed respite, support workers at home (38.8%), family members or friends (32.2%), and support workers on outings (26.1%) provided the majority of respite. Almost 90% of carers accessing respite stated that the service helped them maintain their caring role, their health and wellbeing, and almost 80% said that it assisted them with the quality of their family relationships and connecting with friends and the community.

Carers who accessed respite regularly placed higher importance on all these outcomes. The main reasons for not accessing respite were cited as: not knowing where or how to access it; unsuitability to the needs of the care recipient; unaffordability; not wanting to use it; ineligibility and not being available in their local area.

Other studies highlight further aspects of life which are positively impacted through respite from caring. Fatigue levels improve and psychological adjustment levels are normalised when carers are able to take time for their own needs (Remedios et al, 2015). The availability of more time in which carers can catch up on sleep, of which they have been deprived due to their caring responsibilities, has been underlined in several studies (Jack et al, 2014; Ling et al, 2015; Welsh et al, 2014). Respite also allows carers to attend to other personal needs such as household chores and personal appointments (Welsh et al, 2014).

Respite care also provides an opportunity for marriages and partnerships to be strengthened as partners are able to focus more on each other (Harper et al, 2013). The opportunity to have a rest from the duties of caring has been described as

having a restorative effect, in that the carers were able to return to the caring role following the period of respite care (Collins et al, 2013; Neville et al, 2015). Moule and colleagues (2014) described the same phenomenon as having provided an improved ability to care.

***“The provision of respite represents a public declaration that the role of carer is one which is arduous and stressful.”***

Respite has been cited as an important means through which the caring role may be validated. The provision of respite represents a public declaration that the role of carer is one which is arduous and stressful, and deserving of the assistance provided by both governments and service organisations (Harper et al, 2013; Moule et al, 2014).

#### **4.3.2 International Experience**

Rose and colleagues (2015) reported that most of the OECD countries have already implemented policies which include the provision of respite care. Examples include Germany, where carers may be eligible for respite care for a holiday and a further four weeks of respite care per year, and Sweden, where four hours per week of respite is provided free-of-charge.

The Carers Act was implemented in the UK in 2014 and is designed to recognise and legitimise the role of carers (Carers Trust, 2015a). In a review of the effects of the Act, the Carers Trust suggested a number of recommendations, including the introduction of carers' rights in all localities, to ensure that carers receive support and breaks as needed (Carers Trust, 2015b). Moule and colleagues (2014) demonstrated that the provision of Carers



Breaks in the Bristol area proved beneficial to carers. Carers Breaks are a non means-tested payment to carers, allowing them to access whatever respite they choose, whether it be residential care for the care recipient so that the carer can have a holiday, or several short periods of relief. The United States government has also made a commitment to respite care, providing US\$2.35 million per year to fund Lifespan Respite programs which now operate in thirty-three states (Link, 2015).

#### 4.3.3 What is Required for Effective Respite?

The Department of Social Services (2016a) acknowledges that a respite care system, if offered, should be easy to navigate, readily available and able to be accessed when required. The literature has suggested that services should be available within carer's own localities (Ling et al, 2015), inexpensive (Carers NSW, 2014) and provide a positive experience for the care recipient (Welsh et al, 2014). However there is still a lack of available respite services nationally (Hamilton et al, 2016; Judd et al, 2016; Wesley Mission, 2014).

***“Nationally there is an overall lack of respite services.”***

The DSS (2016a) indicates that only 10.7% of primary carers use respite services. This may reflect a lack of availability of such services and also a reluctance among some carers to access respite due to a previous bad service experience (Ling et al, 2015; Neville et al, 2015). This is particularly relevant where the care recipient has multiple co-morbid conditions or exhibits challenging behaviours which are especially difficult to manage.

***“Respite provided significant positive outcomes for carers and care recipients in the Anglicare service.”***

#### 4.3.4 Conclusion

Provision of respite is the key element in the ROP and is associated with positive, measurable outcomes for carers. During their time with Anglicare, carers experienced increased levels of social connection and contact for both carers and the person with a disability. There has been a significant improvement in overall wellbeing, particularly satisfaction with life as whole, current achievements in life and with feeling part of the community.

These findings are supported by the literature which indicates that respite improves wellbeing, satisfaction with life, the quality of family relationships and social connectedness and can strengthen marriages and partnerships. Internationally, countries have already implemented policies which include the provision of respite care. The findings from this Anglicare study challenges the view that there is little evidence of the beneficial effects of respite.

In the absence of a case management service such as the SCP, some 92% of ROP clients were still concerned about the future of their son/daughter if they could not provide care and more than three quarters still felt that they need ongoing breaks from care. While ROP clients obtained benefits through respite, it is clear that SCP clients gained an even greater range of benefits. This suggests that further support through the type of case management provided in the SCP may provide for a wider range of positive outcomes.

## 5. Policy Context

### 5.1 The NDIS

Both the SCP and ROP are funded by the NSW State Government until 2017 or 2018 (depending on geographical region and the roll out of the NDIS), after which all funds for carer and respite support services will be fully subsumed into state contributions towards the National Disability Insurance Scheme. Provision for federally funded carer supports will be directed through the Integrated Carer Support Service which is currently being designed by the Department of Social Services (DSS, 2016a).

The *National Disability Insurance Scheme Act 2013* has instigated a new way of providing community linking and individualised support for people with permanent and significant disabilities, their families and carers. Government funding for disability services and support is directed to the person with the disability to choose their funded supports, rather than the block funding of service providers. The NDIS is a landmark reform in supporting people with a disability to exercise choice and control in their life decisions, a right embodied in the United Nations Convention on the Rights of Persons with Disabilities (United Nations, 2006). NSW was the first state to sign up to the Commonwealth NDIS, with full implementation of the Scheme across the state planned by 2018. The NDIS has already been in operation in the Hunter and Nepean regions in NSW. The *NDIS Act 2013* establishes the National Disability Insurance Agency (NDIA) to deliver and administer the scheme.

#### 5.1.1 Carers in the NDIS

Carers of people with a disability who are accessing a package under the NDIS may or may not be included in the assessment and planning of the supports required, depending on the desire of the participant. Carers NSW workers have pointed out that in the Hunter Valley area of NSW where the

NDIS was initially rolled out, feedback from carers has identified some weaknesses in the current system (Judd, Taylor & Broady, 2016). In particular, carers felt that insufficient information about the mechanisms of the NDIS had been supplied to them. Just over three-quarters of the carers were not aware that a Carer's Statement could be submitted, while almost a quarter were unaware that carer supports could be included in an NDIS plan. Around half of the carers reported that the supports provided by the NDIS had not reduced their caring load in terms of the number of hours of care they needed to provide. More than a third of the carers did not receive any identified carer supports in the plan for their care recipient.

***“Carers felt that insufficient information about the mechanisms of the NDIS had been supplied to them.”***

From interviews with service users, carers and service workers, Foster and colleagues (2016) have noted that the areas of unmet need were diverse, including personal equipment, community access services, respite services and rehabilitation services. With regard to respite services, carers and other family members felt that they had no opportunity to take holidays or pursue leisure activities which would provide them with a short break from their caring duties, and that provision of the chance to enjoy these activities would be beneficial to them. The authors have concluded that the NDIS has been established on the premise of the provision of care which is 'reasonable and necessary', but the participants reported shortcomings in terms of both the scope and depth of available services. It has been suggested that a clearer understanding of 'reasonable and necessary' should be provided to those assessing

potential clients and that the personal context of each case be acknowledged so that 'reasonable and necessary' becomes a term which is nuanced and adaptable according to changing circumstances. Some carers are not aware of what supports will be lost under the NDIS. For example, many day programs include transport (covered by block funding) but not all people will get transport in their NDIS plan.

Laragy, Fisher, Purcal & Jenkinson (2015) found that many people are unaware of the means by which their allocated funding may be used to the best advantage, and have urged the government to provide as much information as possible so that informed decision-making may be facilitated. In a detailed analysis of the governance of the NDIS, Clark (2016) identified the lack of a blueprint as being a major reason that carers are unable to identify the components of the scheme, the way in which each component operates and how the components complement each other to produce a whole structure. She has pointed out that a blueprint would lead to better website design which, in turn, would enable the government to interact with all stakeholders in the most efficient way possible.

The NDIS, by design, assumes a focus on adults with disabilities. Families of very young children with disabilities feel that insufficient information about the NDIS is provided to them, with 50% of those interviewed reporting having no knowledge of the NDIS while another 33% have very limited knowledge. Among this group, there would be parents who are new to the experience caring for a child with a disability and negotiating with disability services. It has been suggested that the provision of information which is clear, concise and ongoing would be of great benefit to this group of parent carers (Howard et al, 2015).

However, Kendrick (2014) has pointed out that possession of theoretical knowledge concerning

the direction of care choices does not guarantee that carers will have the capacity to optimise their use of that knowledge. The NDIS needs to support people with the,

*"many specific administrative, bureaucratic, financial, programmatic, personnel issues which may arise"* (2014: 16).

***"The NDIS needs to support people through the many issues which may arise."***

Kendrick has suggested that processes for familiarisation are needed, so that care recipients and providers will know about all their options and how to achieve the best care service plan, adding that any notion of *pro forma* plans should be avoided, with a focus on individualisation being paramount in future planning processes.

In another review of the NDIS, researchers from the Social Policy Research Centre at the University of NSW have observed that there is no formal process of carer need assessment built into the system (Hamilton, Giuntoli, Johnson & Fisher, 2016). Such a process has been formalised in the United Kingdom through the UK Care Act, and includes the assessment of carers whose care recipients are not receiving services themselves. The disengagement of carer's needs from those of the care recipient validates the caring role and recognises that the carer has needs which are not directly linked to levels of service provision to the person for whom they are caring.

### 5.1.2 Carer Rights

The Federal Government's National Carer Recognition Framework involves legislation that gives recognition to carers, the *Carer Recognition Act 2010* (Commonwealth Government 2016), and a strategy to improve outcomes for carers, the National Carer Strategy. States and territories have developed corresponding carer recognition legislation for their jurisdictions (eg *Carers (Recognition) Act 2010* in NSW, NSW Government 2016). This legislation does not create any legally enforceable rights or duties, however it importantly recognises carers, their rights and role, and establishes the NSW Carers Charter and the NSW Carers Advisory Council. Both the Federal and State frameworks have advanced the efforts to increase the profile of carers, recognise their contribution to the lives of care recipients and the community at large, and highlight their support needs to government agencies, service provision and the private sector. The carer legislation and strategies set out principles regarding carer rights; however there are no legally enforceable rights embodied in those instruments.

In contrast, United Kingdom carer legislation includes the protection of the rights of carers, as well as recognition of their caregiving role through the *Care Act of 2014* (Carers Trust, 2015a; 2015b). In principle, the UK has sought to be inclusive of carers and recognise their needs and rights. While this legislation is new and its full effects may not yet be felt, it has the potential to provide appropriate support and recognition of carers.

### 5.1.3 Integrated Plan for Carer Support Services

The Integrated Plan for Carer Support Services is the Australian Government's platform to recognise, support and sustain the vital work of unpaid carers. The Plan consists of two stages:

1. **The Carer Gateway** "to provide a recognisable source of clear, consistent and reliable information to help carers navigate services and supports"; and
2. **The Integrated Carer Support Service** to "deliver supports that reduce caregiver strain (based on a model of social, psychological, physical and financial outcomes) with the twofold objective of increasing a carer's wellbeing and reducing the risk of the caring role ending" (DSS, 2016a).

The Australian Government released *Designing the New Integrated Carer Support Service* in May 2016 (DSS, 2016a), in which its proposed provisions for carers were outlined. A draft model for the delivery of these services was released in November 2016 (DSS, 2016b).

At present the proposed draft service model includes the following features:

- **Awareness and community linkage:** to raise awareness in the general community about carers, their value to society and their needs;
- **Information and advice:** to provide carers with information and advice, tailored to their needs and circumstances and support to navigate, coordinate and access other services;
- **Education and training:** to help carers to obtain skills in their caring role, building resilience, increasing capacity to access and navigate service systems and attain care related qualifications;
- **Peer support:** to help carers to connect and share their caring experience;
- **Needs and assessment planning:** to help carers to identify their needs and suggest appropriate supports (both informal and formal) to address these areas;
- **Coaching and mentoring:** to help carers to acquire skills and resilience to assist them in managing their caring role, through delivery of a goal orientated support program;

- **Counselling:** to support carers in their caring role, through the provision of therapeutic counselling;
- **Respite:** to provide information and support and assist carers in arranging respite services to meet emergency or short term carer needs;
- **Targeted financial support:** to support carers to remain in the workforce, return to the workforce, and undertake or remain in formal education.

These supports will be delivered at a national, regional and local level. The channels for national support will generally be delivered on-line; regional via telephone and local via face-to-face. Regional hubs and local services will be helpful for carers uncomfortable with accessing on-line services (DSS, 2016b:17-25).

It is envisaged that the integrated support should connect carers with government departments such as My Aged Care, the NDIA and the Department of Veterans Affairs but the nature of this linkage is not clear. This needs to be clearly defined as phone or electronic referral; otherwise the confusion experienced by carers in the South Australian trial mentioned earlier in this report, may recur.

#### 5.1.4 The Role of Carers in Disability Support

Carers are important stakeholders in the care situation, and there are a number of reasons for inclusion of carer opinions and ideas in the formulation of care plans. Carers, especially in a long term role, have had long experience of the person with the disability, their unique characteristics and the particular situation in which that person lives. Thus, carers bring valuable knowledge and understanding which may be utilised to formulate an optimal care plan in collaboration with both the care recipient and professional staff (Berk & Berk, 2015; Cree et al, 2015).

*“Carers are important stakeholders; there are reasons for inclusion of carer opinions and ideas in the formulation of care plans.”*

The inclusion of carers as collaborative partners in the planning process can validate their position as carers (Harper et al, 2013; Moule et al, 2014). This validation may then have dual effects: participation in care planning can have a positive impact on carer outcomes (Jones et al, 2014) and can also result in care plans which are not only more appropriate for the care recipient but also more cost-efficient than those devised without carer input (Berk & Berk, 2015).

Anglicare has previously recommended that carers be afforded a separate carer assessment in addition to the participant’s plan, so as to ensure that their needs are fully considered and appropriate supports provided (Bellamy et al, 2014). This was initially recommended by the Productivity Commission (Productivity Commission, 2011). The Government has not adopted this approach, and will deliver supports to carers as they access the Carer Gateway and ICSS. The DSS acknowledges that there is an increasing demand for informal care, due to the increased level of disability in the community and lower propensity to provide informal care (DSS, 2016a:14). The purpose of the ICSS is to deliver supports that reduce caregiver strain with the twofold purpose of increasing a carer’s wellbeing and reducing the risk of the caring role ending (DSS, 2016a:14).



## 6. Conclusion and Recommendations

Each year carers provide billions of dollars' worth of unpaid care and, for many, this has been a lifelong commitment spanning seven days a week, with few breaks and intermittent support. Many find themselves disconnected and isolated from both the wider community and within their own social and family networks.

There are two major conclusions to be drawn from this report:

### 1. Case management and respite yield positive outcomes for both carers and care recipients.

More than seven years' worth of data collection for the State funded Anglicare programs – SCP and ROP – has provided clear evidence that block funded services targeting carers improve access to services, enhance wellbeing across a range of domains and facilitate greater social connection and participation via the provision of case management and respite. In some respects this challenges the view that such interventions, and in particular respite, yield no strong evidence base for positive outcomes.

### 2. Carers require targeted support in the NDIS.

The advent of the NDIS has fuelled anticipation for carers that long term and adequate supports for the person for whom they are caring will now be realized. However within this new system there is concern on the part of peak bodies, service providers and carers themselves that their own needs will not be adequately addressed. This is critical if they are to sustain their unpaid caring role into the future. Funding for social supports and emergency planning needs to be provided to ensure sustainability of the caring role and just as importantly carer involvement in planning and ongoing access to respite are critical if carers are to be adequately supported into the future.

*“Each year carers provide billions of dollars' worth of unpaid care.”*

Given the stated purpose of the ICSS, and the evidence presented in this report, Anglicare recommends that four key additional components be included in the design and operation of the service and we make a fifth recommendation in relation to carer involvement in planning.

#### 6.1.1 Carer Access to an Independent Carer Support Coordinator

The draft service model for the ICSS helpfully includes access to information, education, peer support and mentoring (amongst other supports), but not to a dedicated coordinator who can assume the role of coordinating the various supports that a carer may need. The information stream includes a regional service to provide carers with short term support to navigate, coordinate and access other services (DSS, 2016b:18). The current proposal for ICSS is built on the premise that the carer will assume the overarching coordination role and understand how and where to access all the required supports after receiving information. That will be possible for some carers accessing the service, but not all those carrying out a primary caring role. In acknowledgement that individual capacities, desires and skills differ, there is provision in the NDIS package for people with a disability to elect to receive coordination support in their suite of supports.



The SCP model utilised support workers to provide one-on-one, holistic assistance to carers. Support workers have helped carers by making them aware of services they may not have considered and by providing assistance to evaluate options and make decisions. The strength of this approach was the development of an ongoing, trusting relationship between the carer and the support worker in which the carer felt safe. Anglicare is concerned that the ICSS places the onus much more on carers to seek and arrange their own support. Carers are often so emotionally and physically impacted by the caring role that they are not able to research or make contact with service providers when they cannot navigate the path easily. Some CALD carers have English as a second language, others may suffer from lower levels of literacy and/or access to internet platforms, some indeed have a disability themselves which makes independent coordination a challenge.

## ***“More onus will be placed on carers to seek and arrange their own support.”***

There is a risk that carers will be left behind unless the new integrated system provides one-on-one, holistic support. A Care Coordinator could:

**1. Assess needs and identify, manage and coordinate supports:** Carers have a tendency to underestimate the time, nature and intensity of their caregiving role. The coordinator is able to provide an objective assessment of the carer’s duties and supports needed to assist them carry out their role. The DSS states that the

*“approach of empowering carers to identify their own needs is consistent with consumer directed care models” (DSS, 2016a:32).*

Some carers would have more insight into their care needs than others, and be adequately assisted by self-identification of needs through a tool such as the Carer Support Needs Assessment Tool (CSNAT).

Practitioner-facilitated assessment is particularly important for the ageing parent carer cohort as historically this group has been less likely to seek access to carer support services, given their self-reliance and longevity in caring. Importantly, only 51% of carers entering the SCP agreed that they knew where to get help if they needed it in their role as a carer. Therefore, Anglicare is concerned that such carers would tend to underestimate their need for support if self-assessment was the sole approach to needs identification.

**2. Build trusting relationships:** Frontline staff in the SCP noted the importance of building trust and relationship with long-term carers who were sometimes reluctant to allow support staff into the caring context after being the primary or one of the main caregivers over decades. In such circumstances, it may be difficult for some carers to connect with and access services that have not been fostered through a support co-ordinator who has built relationship and trust with the caregiver, care recipient and family. Wherever possible, carers should have ongoing access to the same support worker to facilitate the development of an open and trusting relationship.

**3. Provide individualised supports as required:** Supports should include transition planning, crisis and emergency planning, goal setting and life administration (eg will preparation).

***“There is a risk that carers will be left behind unless the new integrated system provides one-on-one, holistic support.”***

The proposed range of supports in the ICSS are not as detailed or specific as those currently included in funded carer supports. It is noted that some of these supports (such as transition planning and accommodation assistance) will most likely be covered by care recipient-funded support through Community Aged Care (CAC) and the NDIS. For people who are not covered by an NDIS package, the Local Area Coordinator stream (or equivalent new carer liaison roles) will be essential for education and advice. Local Area Coordinators need to be well trained with sufficient capacity to handle this additional task on top of their existing workloads. Advisors will require an extensive and up-to-date knowledge of the support services in carers’ local geographic areas.

**Anglicare recommends** that carers have access to and an option to appoint an Independent Carer Support Coordinator as part of the services available through the Integrated Carer Support Service. Carers should be informed of this option when accessing the Carer Gateway and other supports in the Integrated Carer Support Service.

### 6.1.2 Carer Access to Respite Services

The ICSS makes provision for emergency and short term respite services for carers, to enable carers to participate in activities such as education, peer support or coaching, or in response to an unforeseen event (DSS, 2016b:24). As discussed earlier in this report, carers of NDIS participants have varying experiences of respite supports in the package. The NDIS aims to consider the health and wellbeing of the carer in the planning of supports, and views the participant’s plan directly and indirectly benefitting the carer through the provision of services of the person with a disability (NDIS, 2016). While the provision of an NDIS plan for the person with a disability may provide a respite effect for carers it is a significant change since the carer will no longer be able to have a say in when and where the respite takes place, resulting in a loss of choice for the carer.

Anglicare has particular concerns for carers and care recipients in the following cohorts:

- Complex or dual diagnoses requiring specialised support - where carers may have had negative experiences of respite;
- Mental health disorders and high functioning autism - where the participant views the carer’s role differently to that of the carer, resulting in planned supports that do not accurately reflect the caregiving role and necessary respite;
- People with a disability who do not qualify for an NDIS package and the carer does not receive the benefits of any formal supports for the person with a disability; and
- Cases where the carer and care recipient hold different views on the nature and intensity of the caregiving role, resulting in planned supports that do not accurately reflect the caregiving role and necessary respite.

Data obtained from clients accessing respite supports in both ROP and SCP clearly indicates a significant improvement for clients in their wellbeing scores, which is supported by current national and international literature on the benefits of respite. It is acknowledged that there is some earlier conflicting evidence as to improvements that carers experience in their physical and mental health (DSS, 2016a:40) particularly in relation to stress. However the ongoing burden of the caregiving role may mean that carers continue to experience a higher than normal level of stress and anxiety even when other wellbeing and health domains improve through supports. This is acknowledged by the DSS in that “caregiving has all the features of a chronic stress experience” (DSS, 2016a:9). Nevertheless, the carers consistently state that appropriately delivered and timed respite helps them carry on their caregiving role, and clients accessing the ROP experienced significant improvements in their wellbeing.

***“The proposed range of supports in the ICSS are not as detailed or specific as those currently included in funded carer supports.”***

The lower than expected take up of respite services in the SCP may be explained by the chronic shortage of respite services that are available and appropriate at any one point in time for a particular set of circumstances. Anglicare frontline services report a shortage of respite beds for both planned occasions and emergencies, with high demand for long-term and in-home respite. Further, some carers and care recipients may find it difficult to take the step of allowing a third party into the caring context.

This is especially the case in long-term caring relationships and where there has been a negative respite experience in the past. Again, it is essential that carers are given opportunities to build trust and relationship with support staff who are assisting through ICSS services, and not be faced with a new staff worker for each contact with the Carer Gateway or support services.

***“The ICSS does not adequately acknowledge the benefits that respite provides for carers.”***

Anglicare is concerned that the proposed ICSS does not adequately acknowledge the benefits that respite provides for carers in relieving their caring burden and supporting them to continue in their role, thus compromising the effectiveness of the supports that will be available to carers under the scheme. As discussed in this report and evidenced by data obtained from clients in the RO and SC programs, the provision of respite services is an important means of alleviating the burden of care for caregivers. Significant improvements in carer health and wellbeing are evidenced through objective indicators such as the Personal Wellbeing Index and subjective indicators such as the carer’s own assessment of the benefits of respite in their caregiving role.

**Anglicare recommends** that carers have access to and options to take up flexible respite services as part of the services available through the Integrated Carer Support Service.

Respite services should be:

- Available as a stand-alone service as well as part of a multi-component service;
- Responsive and easily adaptable to individual and changing circumstances;
- Available in the home and for extended periods out-of-home;
- Available at planned and regular occasions as well as in emergency situations;
- Promoted to carers when they access the Carer Gateway and other supports in the Integrated Carer Support Service, such as the education and information streams; and
- Promoted as beneficial for carers' wellbeing and capacity to sustain the caregiving role.

### 6.1.3 Access to Funding for Social Support

The proposed ICSS will include peer support to assist carers to connect with other carers of a similar experience and help reduce isolation that carers may experience (DSS, 2016a:30; DSS, 2016b:19).

Social support formed an important part of both the SCP and ROP, providing carers and care recipients opportunities to connect with others in the program through a variety of social activities. About three in

five carers in both programs expressed improvement in their own social connections throughout the program, and half cited improvement for the care recipient in the SCP with four in five in the ROP.

Both programs conducted activities that benefited both the carer and the care recipient, as respite care or activities were often provided for the person with a disability whilst the carer engaged with other carers in a social setting. The programs offered specific activities for carers such as friendship and hobby groups (eg gardening or craft), regular carer support groups (eg meeting for a coffee every fortnight), and weekend retreats. The weekend or short getaways were particularly useful for carers, as they had an opportunity for respite, connecting with other carers and relationship building, relaxation, as well as education and information sessions on issues such as transition planning and financial matters. Frontline staff reported that events such as these provided them with an informal opportunity to help build trust and relationship with carers outside of the more formal context of carer services. Staff also highlighted the importance of these events for 'hidden carers' in building relationships and trust with case managers and other carers, who had been in their caring role for decades prior to being connected with formal support and meeting other carers. The SCP would organise respite for the care recipient if required for these events.

Anglicare is concerned that there will be a significant loss of the social and peer support provided to carers that was integrated into the service when funding for these programs ceases and carers are directed to the Integrated Plan for Carer Support Services. It is anticipated that the ICSS Peer Support service may facilitate some of these activities.

For carers in an intensive caring role with minimal familial and social supports already in place, the social supports provided through SCP and ROP were organised and made possible for carers, at the

very least as an initial event. The logistical burden of organising a retreat like the example mentioned above may be too burdensome for a primary carer to consider undertaking. Similarly, anecdotal reports from staff reveal that carers are interested and willing to meet up regularly with other carers for social support groups, but usually need at least the initial organisation and connections facilitated so as to decrease the emotional and logistical efforts in an already busy caring context. Some of the ageing parent carers had no access to private or public transport and the SCP arranged for transport for them to attend regular social support groups with other ageing parent carers.

***“Carers report that social connections with others in a similar role helps them continue in their own caring role.”***

It is anticipated that carers will be connected with mainstream supports through the Local Area Coordinator, which will be helpful for some. There are many not-for-profit community and faith organisations that coordinate invaluable social support networks and meetings in the community to benefit people from all backgrounds and life circumstances. Nevertheless, carers report that social and peer connections and solidarity with others in a similar role help them continue in their own caring role.

**Anglicare recommends** that the Integrated Carer Support Service provide funding for appropriately qualified and experienced organisations to run Social Support Programs specifically designed to support carers in their caregiving role.

#### 6.1.4 Access to Emergency and Crisis Funding

The proposed ICSS provides for carers to register their emergency plan through an online account (DSS, 2016b:27). This option might be appropriate for some but not all carers. The draft service model also refers to an opportunity for carers to speak to someone about creating an emergency plan (DSS 2016b:27). The kind of assistance that carers require for this planning will vary from carer to carer. Some carers may not have a formal emergency plan at all and would require intensive face-to-face support to put a plan together. Other carers would rely on their extended family in an emergency. The process of planning an emergency or crisis contingency may involve a guided and holistic consideration of several factors which could be facilitated by an Independent Carer Support Coordinator, as recommended above. The draft service model also allows for emergency respite (DSS, 2016b:24).

Some carers may only instigate contact with the Carer Gateway at the time of an emergency, and may have no prior plans or contingencies. Historically, the NSW Government’s Ageing Disability and Home Services (ADHC) provided a last port of call or safety net in such circumstances. With the devolution of ADHC and outsourcing of its services, there is a significant gap in the provision of a safety net for carers and people with a disability when one of them is in crisis and in particular when the carer cannot carry out their caring role for a short period of time or indefinitely.

Providing care to a person with a disability is a demanding role in which crisis situations can occur. While services do seek to avoid crisis points, there are times when unanticipated events occur, such as carer breakdown or illness. For example, some older carers will contact the Gateway because they are no longer able to provide care and they need crisis accommodation. It is vital that appropriate channels and information are provided to ensure that emergency assistance can be accessed when



needed. Furthermore, the procedures for accessing emergency assistance should be communicated well to carers because they may sometimes forget key information in a crisis.

***“There is a lack of a safety net for carers and people with a disability when one of them is in crisis.”***

Anglicare is concerned that carers may not be professionally guided and assisted in the preparation of an emergency plan, understand their need for such a plan, and then encounter difficulties accessing emergency assistance in a crisis situation. The ICSS should cover: the supports required for the understanding and awareness of emergency plans; registration of plans; and the timely co-ordination of and delivery of the supports required to carry out the emergency plan (including respite, accommodation etc).

***Anglicare recommends that the Integrated Carer Support Service provides supports for emergency planning, registration of a plan and reasonable and necessary services required to implement the emergency plan.***

### 6.1.5 Carer Involvement in Planning

It remains essential that the person with the disability be given the choice and control in the planning of their NDIS package. Anglicare has concerns about some carers not having appropriate input to the participant’s planning process (where the participant chooses to have their carer included). Where differences exist between the carer and care recipient in the nature and intensity of the caring role, unintended deficiencies may arise in the

participant’s plan that adversely impact both the care recipient and the carer. For example, a care recipient may include their carer in the planning process, but not raise in the discussions the magnitude of the caring role given their perspective of their needs and the nature of the familial relationship. In such circumstances, the needs of the person with a disability may not be properly assessed and addressed. It is therefore essential that LACs and those advising carers appropriately include the voice and experience of the carer in the process, whilst prioritising the desires of the participant.

***“Anglicare has concerns about some carers not having appropriate input to the participant’s planning process.”***

Carers Australia (2016) have developed a Carer Checklist to assist carers through the planning process and help them identify and speak to the issues that will inform good planning. Carers NSW’s 2016 research on the inclusion of carers in planning and their provision of a Carer’s Statement highlights the importance of continued education and awareness for carers as the people they care for undergo the planning process.

***Anglicare recommends that the education, information and awareness components of the Integrated Plan for Carer Support Services and the Local Area Coordinators in the National Disability Insurance Scheme include accessible information for carers regarding their involvement in the participant’s planning and their opportunity to provide a Carer’s Statement.***





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**Around 1.4 million Australians have a profound or severe disability. The primary caregiver for these Australians is often a parent, spouse or relative, who may provide a lifetime of care.**

The recently introduced *National Disability Insurance Scheme* (NDIS) represents a seismic shift in the way that care will be funded for people with disabilities. Under the NDIS, Government funding for disability services and supports will be directed to the person with the disability rather than to service providers. The NDIS is a landmark reform in supporting people with a disability to exercise choice and control in their life decisions.

However carer needs and supports are not formally recognised as part of NDIS packages. There is no formal assessment of the needs of the carer, no funding package for the carer and no guarantee of involvement in the assessment of the care recipient's needs. There is concern among peak bodies, service providers and carers themselves that their own needs will not be adequately addressed in the new system.

This report presents research findings demonstrating how two Government-funded, Anglicare programs – the Support Coordination and Respite Options Programs – have been effective in meeting the needs of carers over many years. In view of the closure of such programs as a result of the NDIS, this report concludes that a range of targeted carer supports is required in conjunction with the NDIS, beyond what has so far been promised by Government. These supports will be critical if carers are to sustain their vital role into the future.

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