Carers

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Overview

Carers are people who provide unpaid care and support to family members and friends who have a disability, mental illness, chronic condition or complex needs, terminal illness, an alcohol or other drug issue or who are elderly or recovering from an illness or accident. Carers may be spouses, parents, grandparents, sons or daughters, siblings, friends, nieces or nephews or neighbours. The caring role can happen gradually, for example helping a person more and more as their health and independence become worse over time or it may happen suddenly, such as after a health crisis or an accident.

Some carers provide 24 hour care to a friend or family member with high care needs. This can involve helping with daily needs and activities like feeding, bathing, dressing, toileting, lifting and moving and administering medications. Others care for people who are fairly independent but may need someone to keep an eye on them or help with them with tasks like banking, transport, shopping and housework.

The importance and demand for carers in Australia is increasing as a result of:

- an ageing population which is increasing demand for health and community services, including caring
- changing societal preferences with people wanting to remain living in their own home for longer
- reforms such as the National Disability Insurance Scheme (NDIS) and Living Longer Living Better aged care reforms.

In 2015, there were approximately 44,800 ACT residents (11.7% of the ACT population) who provided unpaid care to family members or friends who needed support because of a disability, chronic illness, mental illness, drug or alcohol issues, dementia or frailty due to ageing. Approximately 10,900 ACT residents were primary carers (the person who provides the most informal assistance to the person with a disability, specifically related to one or more of the core activities of mobility, self-care and communication) (Australian Bureau of Statistics, 2016).

In 2015, there were approximately 2.7 million Australians that were identified as carers, of which 856,100 (31.7%) were primary carers (Australian Bureau of Statistics, 2016). The average age of primary carers was 55 years compared to 48 years for other carers, both nationally and in the ACT. Females made up the majority of carers, 55.5% of all carers and 68.1% of primary carers in 2015 (Australian Bureau of Statistics, 2016).

Carers are an essential part of our health care system. Our aged and disability community care systems rely on the support of family and friend carers, and 74% of all community care is provided by carers (Carers ACT, 2016). Each carer spends an average of 13 hours a week caring, or 673 hours a year, with some carers providing care for over 40 hours a week and some for only a few hours (Deloitte Access Economics, 2015). If this care was provided by formal care services the estimated cost to replace the 1.9 billion hours of unpaid care in 2015 would be $60.3 billion (Deloitte Access Economics, 2015). The ACT equivalent estimated replacement care in 2015 would be around $1 billion.

Future demand for carers in the ACT will continue to grow because of population ageing, longer life expectancy and the increasing rate of disability in our community. Anyone can become a carer at any time, as everyone has family or friends who may need extended care at some time in their life, due to accidents, chronic illness or frailty of old age.

Unpaid caring is rewarding for many carers but it has a personal cost – poor health and wellbeing, reduced opportunities for employment and education, and social and financial disadvantage (Carers ACT, 2016). Carers need support in their own right and support needs to vary with the complexity of issues the carer faces.

Profile of carers

Employment

Caregiving has a significant impact on a person’s capacity to work. In 2015, for those aged 15 to 64 years, the labour force participation rates for primary carers (56.3%) and other carers (77.2%) was lower than that for non-carers (80.3%) (Australian Bureau of Statistics, 2016). In 2012, of the males who were identified as primary carers, 27.1% worked on a full time basis and a further 11.0% were employed on a part-time basis. For female primary carers, only 14.6% were employed full-time and around a quarter employed part time (23.9%) (Australian Bureau of Statistics, 2013).

Carers are more likely to work in the health care and social assistance industry; and the education and training industry. This is particularly the case for primary carers (ACIL Allen Consulting, 2014). Carers are also more likely to choose workplaces which are conveniently located and provide flexible working conditions to fit within their caring roles (ACIL Allen Consulting, 2014).

Financial impact

Caring can lead to poverty if a person has to give up work to care for somebody or if they are managing on government income support. Carers were more likely than non-carers to have household incomes in the lowest quintile for equivalised gross household income in 2015 (Australian Bureau of Statistics, 2016). Half (50.0%) of primary carers lived in a household in the lowest two quintiles for equivalised gross household income, compared with 26.3% of non-carers.

Many primary carers reported that their financial wellbeing was impacted due to their caring responsibilities, with 17.4% of primary carers reported having extra expenses and difficulty meeting everyday living costs, while 16.6% reported decreased income and difficulty meeting everyday living costs as the main financial impact (Australian Bureau of Statistics, 2016).

Education

For all Australian's aged 15 years and over, those who were carers were less likely to have completed a bachelor degree or above than non-carers across all age groups (17.8% and 23.2%, respectively) (Australian Bureau of Statistics, 2014). The proportion of primary carers who completed a bachelor degree or above was 15.4%. Carers were more likely to have completed a certificate or diploma as their highest level of educational attainment than non-carers (30.2%, compared to 26.6%) (Australian Bureau of Statistics, 2014).

There are a range of barriers to education and training for carers, including:

- The incompatibility of caring responsibilities, which are sometimes unpredictable, and the time and commitment required to participate in education and training
- Costs of education and training
- Poor access to support with their caring responsibilities (ACIL Allen Consulting, 2014).

It is important that carers are provided with support to enable them to participate or maintain education and training or employment. This includes various income supports as well as respite, day care, home visiting and access to support groups.

Time spent caring

In 2012, almost two out of five primary carers (38.9%) reported spending, on average, 40 hours or more per week caring for their main recipient of care, 19.5% reported spending between 20 and 40 hours and 38.5% reported spending less than 20 hours caring in an average week (Australian Bureau of Statistics, 2014). While the carer may not always be directly caring, even being on call has implications for the lives of the carer and their family. Carers may not feel that they can leave the person in their care by themselves, which has implications for engaging in a social life outside of the house and also in employment (Edwards et al., 2008).

Household and family

In 2015, most primary carers (79.3%) resided in the same household as the person for whom they provided the most care (Australian Bureau of Statistics, 2016). Of those primary carers whose main recipient of care did not live with them, most were caring for a parent (67.0%).

While carers have significantly worse mental health and vitality and higher rates of depression than the general population, other family members also experience high levels of depression (Edwards et al., 2008).

Carers' health and wellbeing

Carers have been described as an under-appreciated group who provide unpaid social care for family and friends (The Lancet, 2017). The most important thing to a carer are the needs of the person they care for, and meeting these needs often comes at the cost of the carer's own health and wellbeing. Being a carer can impact people both physically and psychologically. Families are often thrown into the role of day-to-day care. Unfortunately this can happen with little or no training or support, sometimes at the detriment of the carer's own mental health and wellbeing.

Carers have been found to have the lowest personal wellbeing of any large population group, measured by the Australian Unity Wellbeing Index (Australian Unity, 2015, Cummins et al., 2007). Female carers were found to have lower wellbeing than male carers. The study also found carers were more likely than non-carers to be experiencing chronic pain and carers were highly likely to be carrying an injury. It was highlighted that many carers weren't receiving treatment for a significant medical or psychological condition and the major reason for carers not receiving treatment for themselves is that they have no time or can't afford the treatment (Cummins et al., 2007). Wellbeing was seen to decrease linearly as the number of hours spent caring increased.

Primary carers are more likely to have a disability themselves, with over one third of primary carers having a disability (37.8%), compared to 15.7% of non-carers (Australian Bureau of Statistics, 2016). Male carers were more likely to report living with a disability than female carers (42.3% compared to 35.6%) (Australian Bureau of Statistics, 2016). Around 11.3% of primary carers reported having a profound or severe core activity limitation.

Caring can have a major influence on a person's emotional health. About half of all primary carers reported having experienced a negative impact such as feeling weary, often feeling angry, resentful, worried, depressed, or having a stress-related illness (Australian Bureau of Statistics, 2014). Mental illness often has a flow on effect on families, creating tension, uncertainty and big changes in how people live their lives.

Caring can also affect social contact, with 18.3% of carers having face-to-face social contact with friends or relatives outside of the household only once or twice every 3 months, or less often than this, compared to 10.2% in the general population (Edwards et al., 2007). Differences were also seen between carers amount of social contact, with carers who experience two or more events of financial hardship being 2.5 times more likely to have low face-to-face social contact than carers who do not experience any financial hardship. Male carers were 1.45 times more likely than female carers to have low face-to-face social contact, older carers were more likely to have less face-to-face social contact than younger carers and carers caring for a person with a disability with high care needs were 1.9 times more likely to have low face-to-face social contact than carers of a person with low care needs (Edwards et al., 2007). In the same study, almost half (47.9%) of the carers wanted more face-to-face social contact.

Where carers interact with the health system, their burden may be invisible, even to their regular GP. Even when carers are suffering from their own health problems, they may not want to admit they need help. Carers are likely to feel better supported if they can access flexible services and various supports, including respite, carer support groups, carer counselling, and health professionals who ask about and help them manage their own health needs (Carers ACT, 2016).

When a carer’s health suffers, or a caring relationship is no longer sustainable, the cost to the health and/or disability sector can be significant.

It is worth noting that carers also go through a substantial change when they are no longer carers. This can affect them in many ways, particularly going through grief and a sense of loss of purpose, as well as affecting them financially, with a loss of the Carer Payment (higher than the Newstart Allowance) if they were receiving this income support.

Young carers

Young carers are children and young people under 25 years of age who help provide care in families where someone has a chronic illness, a disability or a mental illness or is frail aged or has an alcohol or other drug problem. While the proportion of Australians who are carers generally increases with age until 65 years, in 2015, approximately one in ten carers were aged under 25 years (272,000 carers nationally), with 2.2% of all carers aged under 15 years and a further 7.9% aged 15-24 years (Australian Bureau of Statistics, 2016). In the ACT in 2015, there were approximately 1,000 carers aged less than 15 years and 3,000 carers aged 15-25 years (Australian Bureau of Statistics, 2016).

In 2012, carers aged 15 to 24 years were almost twice as likely to be unemployed than other 15 to 24 year olds who did not have a caring role (20.0% and 11.6%, respectively) (Australian Bureau of Statistics, 2014). Young carers are more likely than other young people to experience socio-economic disadvantage and to achieve lower levels of education, inhibiting their ability to obtain adequate employment and potentially reducing their lifetime earning capacity (Bray, 2012).

Children and young people who help care for a relative or a friend can find caring to be a very positive experience. It can make them feel closer to their families, develop new skills and experiences and feel good about caring for someone they care about (Carers Australia, 2009). However, sometimes families aren't well supported and young carers can miss out on opportunities to go to school, do homework, spend time with friends, have a job or further their studies. They also experience high levels of stress and worry and they can feel confused and uninformed (Carers Australia, 2009). Often young carers need some assistance.

For young carers, taking on caring responsibilities can have negative effects on their mental health, which can affect their ability to remain engaged with education or employment in the critical development period.

Many young carers may not ask for help because they feel that what they're doing is 'normal' or they're afraid of being seen as different from their peers (Carers Australia, 2009). Additionally, many young carers may not ask for help because they're afraid that someone will think they're not coping and that they should be removed from the family. Sharing information about their home life can sometimes be difficult for young carers.

Young carers can also find it difficult, that because of their age, health professionals do not include them in the design and management of care plans for the person they care for. They may feel that they have extensive knowledge of the care needs of the person they care for but their voice is ignored. This can be because of privacy issues, but it is important that young carers be acknowledged as often they do a lot of the care in the community.

Consultation with young carers has identified some of the issues that impact on them in their caring role, including caring for an adult who has a disability and is unable to drive, resulting in a young carer having to rely on walking, public transport when available and help from friends. They can therefore miss out on many of the activities that their peers are undertaking. Another issue was the impact on young carers when the person they are caring for needs to go interstate for treatment or management.

Older carers

An older carer can be defined as a person aged 65 years and over (or aged 50 years and over for an older Aboriginal and Torres Strait Islander person) who provides any informal assistance, in terms of help or supervision, to people with a disability, long-term condition or people who are elderly (60 years and over). This assistance has to be ongoing, or likely to be ongoing, for at least six months (Australian Bureau of Statistics, 2012). Older carers is a group that is often invisible, with many older carers providing long hours of vital care and support while their own health and wellbeing deteriorates, resulting in poor physical and mental health, financial strain, and breakdown in their ability to carry on caring.

Older carers are often very resilient, but at the same time may feel isolated or experience social or financial exclusion as a result of their caring role. As a community we need to have a fuller understanding of the responsibilities that older carers take on for their husband, wife, partner, friend or neighbour and an acknowledgement of the difficulties, physical, mental and social, carers take upon themselves to provide loved ones with dignity and independence.

Stress and anxiety is prevalent among ageing parent carers. One of the most significant causes of stress for ageing parent carers is the future care and accommodation arrangements for their family member with a disability. Most care recipients and their carers wish to stay in the family home together for as long as possible, however it is crucial that there is a plan in place for a time when that living and care arrangement is no longer sustainable.

Factors that impact older carer stress levels include caring for an adult family member with an intellectual disability or dual diagnosis, conflict with the care recipient, needing time out from the caring role, anxiety about the future care of their family member, and lack of awareness about supports for their role. A report undertaken by Anglicare revealed that older carers of people with a disability indicated that case management, transition planning, respite and increased social contacts for the care recipient are the most important support services to them (Bellamy et al., 2014).

Health, finances and future security are particular areas of concern for ageing carers (Bellamy et al., 2014). With an ageing population and increasing demand on health and social care services, supporting older carers better is a key way of keeping people at home, independent and healthy. It can also help to reduce unplanned hospital admissions and avoid premature admission to residential care.

Consultation with carers identified the added difficulties for older carers, with a hard-to-navigate My Aged Care service, particularly when older carers are busy caring and feel burnt out. Finding specific information on the My Aged Care and other websites, for people who may have low internet literacy, can be extremely difficult and frustrating.

Older carers of adult children can also find it hard to engage with the National Disability Insurance Agency and using the NDIS portal.

Culturally and linguistically diverse (CALD) carers

Carers are as diverse as the rest of the community and cultural factors impact on caring. People from culturally and linguistically diverse (CALD) backgrounds may have different expectations about how and who will provide care (NSW Government, 2014). In 2012, 8.9% of carers aged 15 years and over reported that the main language they spoke at home was a language other than English. Approximately 30% of these carers reported that they spoke English 'not well' or 'not at all' (Australian Bureau of Statistics, 2014).

Carers Australia (2016) identifies many key issues faced by CALD carers, these include:

- Different interpretation or lack of awareness of the term 'carer' and available carer supports;
- lack of identification as a carer by professionals, and subsequent lack of referrals;
- lesser uptake of Centrelink carer payments, benefits and concessions;
- problems with the cultural appropriateness of assessment processes and eligibility criteria;
- lack of choice between mainstream and culturally-specific carer services, such as respite, carer counselling, and support groups;
- concerns about the cultural appropriateness and competency of services;
- lack of individual and systemic advocacy;
- lack of involvement in service planning, implementation and evaluation;
- lack of availability of bilingual and culturally and linguistically diverse staff;
- lack of carer information and resources translated into different languages; and
- issues relating to the quality of interpretation services.

Care of younger children by older siblings, and care of elderly and frail relatives by younger family members is common for many cultural groups and these young people don't think of themselves or identify as young carers. CALD carers may not wish to access home and community care services, or there may be no local services who are culturally appropriate or speak their language. Young carers will often need to take on the task of dealing with English speaking health services and government agencies.

Aboriginal and Torres Strait Islander carers

Caring is an important cultural value for Aboriginal and Torres Strait Islander people. Their concepts of care are based on the notion of family obligations, so Aboriginal and Torres Strait Islander carers often take on a large caring role (NSW Government, 2014). Extended family relationships may be broad and complex, so identifying a single carer to receive support services is often inappropriate. It is unusual for young Aboriginal and Torres Strait islander people to identify as a ‘young carer’.

In 2006, 12.4% of the Aboriginal and Torres Strait Islander population identified as carers, compared to 10.5% of the non-Indigenous Australian population (Australian Bureau of Statistics and Australian Institute of Health and Welfare, 2008). Aboriginal and Torres Strait Islander carers are more likely to be younger than non-Indigenous Australian carers, with the average age of Aboriginal and Torres Strait Islander carers being 37 years; 12 years less than the average age of non-Indigenous Australian carers (Australian Bureau of Statistics and Australian Institute of Health and Welfare, 2008). This may reflect higher birth rates at younger ages and earlier onset of many chronic diseases for Aboriginal and Torres Strait Islander Australians. Like non-Indigenous carers, Aboriginal and Torres Strait Islander carers are more likely to be women than men.

Aboriginal and Torres Strait Islander carers were between one-and-a half and three times as likely as non-Indigenous carers to need assistance with self-care, mobility and/or communication (Australian Bureau of Statistics and Australian Institute of Health and Welfare, 2008).

Aboriginal and Torres Strait Islander carers have a lower weekly income than that of non-Indigenous Australian carers and non-Indigenous Australian carers were around one-and-a-half times more likely to be employed than Aboriginal and Torres Strait Islander carers (Australian Bureau of Statistics and Australian Institute of Health and Welfare, 2008).

Carers at risk of abuse or perpetrators of abuse towards their care recipients

Caring relationships can bring about added complexities when abuse occurs and add significant barriers to seeking help. This abuse could be perpetrated by the carer, the care recipient or by someone else in the household (e.g. partner of the carer). There are dependencies in these relationships that can make it hard to seek help, e.g. the carer may be abused by their child, but believe it is their duty to look after their child and they see no alternatives for care. The care recipient may be abused by their carer, who they rely heavily on for assistance. A carer or care recipient may be abused by another member of the household, who they may rely on for financial support because the caring role doesn’t allow the carer time to work.

There are many different types of abuse, these include:

- Physical (hitting, pushing, slapping)
- Psychological (verbal harassment, humiliation, threats)
- Financial (misuse of money, property or resources)
- Social (restricting or stopping activities or contact)
- Sexual (non-consensual sexual contact)
- Neglect (failure to meet basic needs or provide necessities)

The abuse of carers and care recipients crosses gender, religious, cultural and socioeconomic boundaries. Health professionals and supporting organisations can help reduce the risk of abuse by carers by referring them to appropriate services such as Carers ACT for respite, carer counselling and other assistance.

Supporting carers

In order to look after their own health and wellbeing, carers need information, support and time away from their caring role. Carers NSW found that in 32.2% of cases carers reported that there was no one that could help them if they were ill or needed a break, while 42.6% believed they would have difficulty finding someone and only 20.9% indicated they could find someone easily (Carers NSW, 2014a).

Carer-focused support has a positive impact on carers' wellbeing, however, person-centred care in the aged and disability community sectors means carers own needs can be ignored or forgotten. As the national reforms in aged care occur and the majority of current disability funding transitions into the NDIS it is more important that carers needs are not overlooked.

Consultation found that carers feel they need more support. They want to know what services are available for them to utilise in the ACT and feel it is often hard to gather information about a range of things that impact the person they are caring for and themselves. Carers experience frustrations with long waiting lists, lack of bulk billing, changes to continuity of care, access to specialist care in the ACT, and the GP not including them in the management of the person they care for.

ACT Carers Strategy

Unlike other Australian states and the NT the ACT does not have a carers strategy, a carer framework, or a specific Carer Recognition Act. Carers ACT launched an election campaign in August 2016 calling for an ACT Carers Strategy (Carers ACT, 2016). Suggested priority areas include; increased identification, community awareness and information; inclusion as partners in care;

increased employment and education participation; improved health and wellbeing; and improved evidence base. All three major political parties committed to developing a Carers Strategy, if elected in the 2016 ACT Legislative Assembly election. In June 2017, the ACT Government allocated funds in the 2017-18 budget for an ACT Government Carers Strategy, Carers ACT and democracyCo will work in partnership to develop an ACT Carers Strategy. The Government stated that the ACT Carers Strategy will help guide policy development and delivery of Government and community-led programs and activities, and acknowledged the valuable contribution carers make to the community (ACT Government, 2017). There will be an extensive deliberative consultation process to develop vision, outcomes and priorities for the Strategy, which will reflect the views of a broad range of carers who are consulted, with the priority areas suggested by Carers ACT (listed above) not necessarily being reproduced as the priorities in the final Strategy.

The Integrated Plan for Carer Support Services

The Integrated Plan for Carer Support Services (the Plan) is being developed by the Federal Government, and will reflect their priorities for all carers, and outline actions to recognise, support and sustain the vital work of unpaid carers.

Stage one of the Plan, Carer Gateway, was launched in December 2015, in response to the need for a more streamlined, coordinated and consistent approach to carer support and services. Prior to the launch of this, carers were accessing information and services via different pathways across disability, mental health and aged care sectors which were not designed to support their individual circumstances. Carer Gateway is a national online and phone service that provides practical information and resources to support carers. The interactive service finder helps carers connect to local support services, although carers report the ability to use the system and contact these support services is difficult and time consuming as they have no or limited knowledge about these services.

Stage two of the Plan includes the design and development of a proposed new integrated carer support service system through a co-design process. This included the development of a draft Service Concept for the delivery of interventions to improve outcomes for carers. This then informed a draft Service Delivery Model, which outlines the way support is proposed to be delivered to carers in the future, with the aim to reach carers earlier in their caring journey in order to sustain them by providing supports that build their capacity, reduce strain, enable increased participation and ultimately improve their wellbeing. The model is anticipated to commence in July 2018 and includes GPs as a key local provider of referrals to the Carer Support Services Regional Hubs. This would also be a two way referral pathway, that Regional Hubs refer carers to their local GP or health service.

Priority Issues

Identification of carer needs in primary health care

As previously stated, approximately 44,800 ACT residents provide unpaid care for a family member or friend (Australian Bureau of Statistics, 2016). Carers are known to often ignore their own health and are 40% more likely to suffer from a chronic health condition. Some health problems are a direct result of their caring role e.g. back problems, anxiety and depression. It has been found that carers in Australia report the lowest personal wellbeing of any large population group, with four in five carers reporting below average wellbeing (Cummins et al., 2007). Caring over long periods, being a young carer, caring for a person with dementia or a mental health or behavioural condition can further lower carers' personal wellbeing. Many carers are chronically tired and desperately need to refresh with just one night of unbroken sleep, a day off or an extended period with no caring responsibilities.

As a population group, carers generally have a lower income and a lower standard of living than other population groups in Australia. This means that carers are at-risk of poor health and wellbeing due to the social and socioeconomic determinants of health.

Carers report that they feel their caring role is not understood by others, and health care providers do not always ask carers if they are coping or refer them to organisations to assist them.

Providing carers with the opportunity for their own health assessment (e.g. blood pressure, stress levels, physical injuries related to caring, and management of chronic health conditions) could positively assist carers own health and wellbeing. Carers are likely to feel better supported if they can access health professionals who ask about and help them manage their own health needs.

During consultation carers expressed a need for GPs to identify appropriate support available for them, for example, in regards to the NDIS, obtaining their own GP Mental Health Plan or advice in relation to carer support and other services available in the community.

Carers ACT are exploring the development and trial of a carer identification and care plan tool for GPs and health professionals.

Inclusion as partners in care

Carers report they feel excluded by service providers who do not acknowledge their expertise and knowledge and are not considered as partners in the care planning for the person or people they care for. There is also an issue around carers not receiving training to support their caring role, such as safe lifting or medication management. This is particularly evident for young carers, who are not recognised as partners in care.

Strategy

Support and educate GPs and other primary health care providers to identify carers and provide them with the opportunity for their own health assessment e.g. blood pressure, stress levels, physical injuries related to caring, mental health and management of chronic health conditions.

Provide educational opportunities for primary care professionals on issues specific to carers (e.g. including issues in relation to carer and elder abuse in events focusing on domestic and family violence) and encourage awareness of the Statement for Australia's Carers (https://www.legislation.gov.au/Details/C2010A00123) which states that:

- The relationship between carers and the persons for whom they care should be recognised and respected
- Carers should be considered as partners with other care providers in the provision of care, acknowledging the unique knowledge and experience of carers

Training for carers to support their caring role so that they feel more confident in their role and more knowledgeable about the service system.

NDIS and carers

The National Disability Insurance Scheme (NDIS) presents an unprecedented opportunity for Australians with permanent and significant disability to receive the lifelong support they need to pursue their goals and participate in their communities. The NDIS significantly alters the way care is funded for people with disabilities, with funding given directly to the NDIS participant (rather than disability block funding to the service provider), offering greater choice and control. Consequently, some forms of traditional carer support is being transitioned into the NDIS (e.g. some young carer and mental health respite funding).

While the NDIS relies heavily on carers, through the NDIS there is no formal assessment of carers needs, no funding package for carers and no guarantee of involvement in the assessment of the care recipient's needs (Anglicare, 2016). Under the NDIS carers can participate in the planning process (with the participant's agreement), provide a carer statement, support the participant to access the NDIS and implement their plan and benefit indirectly from funded supports in the participants plan. However, carers cannot receive an NDIS plan or funded supports in their own right. Although, NDIS planners can refer carers to services to support their needs – though carer referrals by NDIS planners are not routine.

The types of supports that the NDIS can fund the participant that may have benefits for carers include: personal care to support an individual in their home or community; supports to assist people with disability to enjoy social and community interaction without relying solely on their carer; assistance with tasks of daily living, including help to improve a person's ability to do things; supported employment services and help for people with disability for work; and training related to the caring role that may enhance a carer's ability to provide care. Also, the NDIS Information, Linkages and Capacity Building Program commences in the ACT in July 2017 and provides carer referrals to services that will support them.

A survey conducted by Carers Australia (2015) found that of the carers who participated, only one quarter of them felt prepared when the person they cared for first applied for the NDIS and even after the person they cared for had received an NDIS plan, 23% of carers still had little or no understanding of the NDIS. They also found close to a quarter of carers were unaware that carer supports can be included in an NDIS plan, and another quarter of carers only had some awareness, with the majority of carers (76%) wanting more information about the supports they can receive through the NDIS. Only 23% of carers thought their caring role was taken into consideration by the planner and 78% were unaware they could provide a carer statement (Carers Australia, 2015). Of those who were unaware about the carer statement, 69% would have liked to have had the opportunity to submit a statement. Over half of the carers (56%) were unaware they could ask for a separate conversation with the planner, and of those that were aware, 86% did have a separate conversation with the planner (Carers Australia, 2015).

While carers' needs and supports are not formally recognised as part of the NDIS packages, Carers NSW identified some benefits experienced by carers following the roll out of NDIS. These include (Carers NSW, 2014b):

- Improvements in the amount, quality, value and flexibility of support received by the NDIS participant since entering the scheme;
- Flow on benefit for carers, including the ability to return to work, reduced stress and less financial pressure;
- Some funded supports directly supporting the caring role, including domestic assistance, respite and family therapy; and
- Positive working relationships with NDIS planners.

However, there have also been many challenges faced by carers with the NDIS. These include a struggle to understand and therefore embrace the NDIS. For example, unclear language, limited and inconsistent information, uncertainty about the scheme rollout nationally and inadequate communication with carers about what to expect (Carers NSW, 2014b, Productivity Commission, 2017).

A recent survey conducted by Carers ACT, which looked at the impact of the NDIS on the caring role, found that the NDIS had not improved outcomes for many carers in the ACT (Sheen et al., 2017). While 49% of carers who responded felt the level of support for the NDIS participant had increased, 57% didn't feel an individual's NDIS support provided them with a break from caring. The majority (63%) found that their time spent managing the support needs of the person they cared for increased. And many of those who were self-managing their participants NDIS plan found it difficult (55%) or couldn't cope (5%). The majority (77%) of respondents found it challenging sourcing services provided for in the NDIS. Only 18% of the respondents felt they had more time for themselves, while the majority (47%) felt it's about the same and 35% felt they had less time for themselves (Sheen et al., 2017).

While carers of NDIS participants are likely to benefit from the funded supports provided to the participant and potentially some supports to be funded especially to sustain informal care arrangements, they are also likely to lose supports that were previously available to them (Carers NSW, 2014b). This includes the large number of people with a disability, including psychosocial disability, that aren't eligible for the NDIS and therefore carer access to indirect support can be more difficult due to some funding transitioning into the NDIS. This places a large amount of stress on carers who support these people.

Strategy

GP support and education in relation to the NDIS and awareness of supports available for those not eligible for the NDIS and their carers. This **should** include information such as what the NDIS can and cannot fund (e.g. the NDIS cannot fund a support that is the responsibility of another system to provide, even if they do not provide it). GPs can be informed about the services of Local Area Coordinators (LACs), who can assist NDIS participants to make contact and discuss their needs with appropriate providers.

GPs can also be informed about referring carers to Carers ACT for carer services to manage their caring role, help them reduce stress and to have a break from caring. **1800 052 222** (Carer respite and assistance) or **1800 242 636** (Carer information and advice).

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