Independent Advisory Council to the NDIS

Support for families and carers

March 2019

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Introduction

Families[1], carers[2] and other informal supporters[3] play a central role in supporting people with disability in Australia. Whilst their roles may change over the lifespan, a significant proportion of families and carers provide enormous social and economic support, assisting their family members to access and engage in a range of service systems. Not surprisingly, research demonstrates the significant positive relationship between family support and the health and wellbeing of young people.[4]

One of the factors that influences family capacity to care is family functioning. This relates to a family's ability to interact, communicate, make decisions, solve problems and maintain relationships. Models of strong families usually describe those that are cohesive, flexible and communicate well.[5] The level of functioning within a family can be affected by changes in family circumstances, relationships between individual family members, the balance between parental employment and family life, and other stressors that may affect the home environment. [6]

Having a family member with disability is one such factor that can affect family functioning.

The NDIS recognizes the importance of families and carers.[7] In deciding the nature and level of support for participants, the NDIS is required to consider what it is reasonable to expect families, carers and informal networks to provide.[8]

For people with disability to have a good life, they need two foundations from the family. They need a family that has capacity to care – that has time and emotional energy to do what it takes. And for the long-term benefit of the person with disability, that support needs to happen in ways that allow all members of the family to thrive including enabling siblings to develop as strong capable adults with a willingness and capacity to remain connected and parents to be socially and economically engaged and maintain contact with their own families and informal supports. Secondly people with disability need family guides, people who have a vision of an ordinary life and the knowledge and skills to break down barriers and facilitate opportunities on their behalf. Translated into support for families, this requires two forms of support – practical assistance that shares the tasks of caring and other responsibilities and vision and skill-building support to enhance the capacity of families as advocates.

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[1] For the purpose of this paper, a contemporary notion of family is used, i.e. family is an interdependent group of people who are bound together over time by ties of mutual consent, birth and/or adoption or placement (including alternate families for children with disability in out of home care).

[2] People who provide unpaid care and support to family members and friends who have a disability, mental illness, chronic condition, terminal illness, an alcohol or other drug issue or who are frail aged.

[3] People who are part of the person's social network (e.g. family, neighbour, colleague at work, member of faith based community) who provide ad hoc assistance and friendship to the person

[4] Australian Institute of Health and Welfare, 2011, Young Australians: their health and wellbeing, Cat. No. PHE 140

[5] Olson, D.H. & Gorall, D.M. (2003) Circumplex model of marital and family systems, in Walsh, F (ed) "Normal family processes: growing diversity and complexity, 3rd edition, New York, Guilford, p514-547

[6] Silberg, S., (2001) Searching for family resilience. Family Matters 58:52-57

[7] The intersection of families and carers is a strong one with the 2015 Australian Bureau of Statistics Survey of Disability, Ageing and Carers reporting that 90% of carers are family members of the person with care needs.(Reported in Carers Australia, All about Carers Fact sheet about carers (external) Accessed 27 April 2018

[8] NDIS Rules, Supports for Participants s3.4

Family support represents an important strategy to mitigate risks related to Scheme sustainability. Families tend to be there for the long run around people with disability and so the extent to which the NDIA can strengthen families' capacity to care, the better the outcomes of the participant and the lower the lifetime costs of care and support.

This paper aims to provide guidance to the NDIA about the most effective way in which the Agency can support families in order to facilitate the best possible lives for people with disability. The paper will:

- scope the size of the issue with data on the people with disability and carers
- report evidence about the impact of caring on families and explore its implication for the nature of support
- examine the availability of support for families and carers
- discuss the concept of respite
- report on what families and carers need and what the NDIS provides
- provide guidance to underpin practice
- outline examples of contemporary service responses
- make recommendations about NDIS support for families.

Disability and Caring in 2015

Based on the 2015 ABS Survey of Disability, Ageing and Carers of over 70,000 Australians, an estimated 18% of the Australian population have a disability (4.3 million people) and 12% of the population (2.7 million) provide informal (unpaid) care to someone with a disability for one or more of the core activities (mobility, communication and self-care). In Australia there are nearly 900,000 primary carers (defined as the carer who provides most of the informal care), two thirds of these are women.[9] Families provide 96% of the unpaid care and 55% of primary carers provide 20 hours or more care per week.[10]

Further analysis [11] of this survey is presented in Figure 1. One in four Australians have a disability, are carers or both, ranging from 9% in the 0-14 year-old age-group to 57% in those aged over 65 years. Importantly, 340,000 Australians have a disability *and* are primary carers.

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[9] Productivity Commission: National Disability Insurance Scheme (NDIS) costs: Productivity Commission Study Report. Canberra; 2017.

[10] Productivity Commission: National Disability Insurance Scheme (NDIS) costs: Productivity Commission Study Report. Canberra; 2017.
Commonwealth Government. National Disability Strategy 2010-2020. Canberra 2011

[11] By Professor Ann Kavanagh, chair in Disability and Health, Melbourne School of Population and Global Health

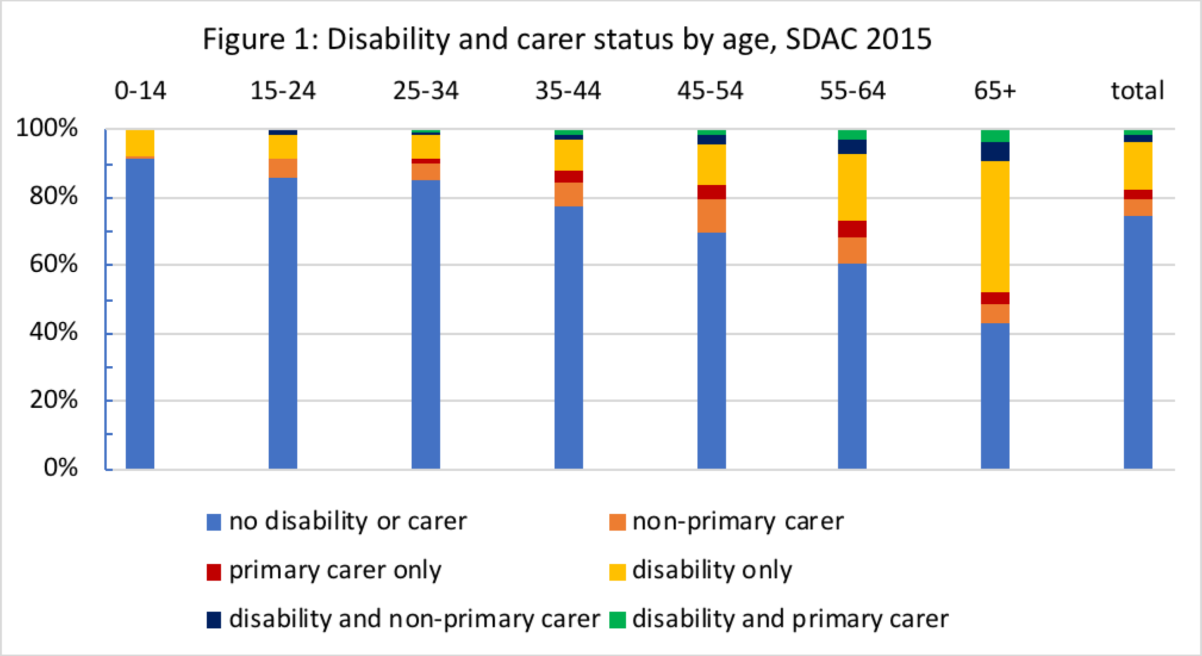
Figure 1: Disability and carer status by age, SDAC 2015

The financial implications of disability and caring are significant with an estimated 1.9 billion hours of unpaid care provided per year. If all hours of informal care were replaced by paid services, the replacement value would be over 60 billion dollars per year, nearly 4% of Australia's gross domestic product.[12]

People with disability and carers are among the most disadvantaged population groups worldwide.[13] Australian work has shown that disabled Australians have low levels of social and economic participation and experience poverty, housing stress and homelessness at much higher levels than the general population.[14] They also have much worse health outcomes even for conditions unrelated to their impairment[15] much of which is related to their socio-economic disadvantage.[16] This situation is mirrored

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[12] Commonwealth Government. National Disability Strategy 2010-2020. Canberra 2011

[13] Productivity Commission: Disability care and support. Productivity commission inquiry report. No. 54. Canberra; 2011.
Productivity Commission: National Disability Insurance Scheme (NDIS) costs: Productivity Commission Study Report. Canberra; 2017. Parliament of Australia: Budget Review 2014-15. *Research Paper Series, 2013-14.* Canberra; 2014.
Parliament of Australia: Disability Support Pension: Historical and Projected Trends. Canberra: Commonwealth of Australia; 2018.

[14] Deloitte Access Economics: The economic value of informal care in Australia in 2015. Canberra: Carers Australia; 2015.
Commonwealth Government of Australia: Budget Paper No. 1: Budget Strategy and Outlook 2018-19. Canberra; 2018.
Emerson E et al. Measuring Australia's progress in reducing the disadvantage for adults with disabilities 2001-2016. CRE-DH; 2018.
Kavanagh A et al. Trends in socio-economic inequalities for women and men with disabilities in Australia. *Int J Equity Hlth* 2013, 12:73.
Kavanagh A et al. The health of people with disability. In: *Oxford Texbook of Global Public Health.* OUP; accepted Sept 2018.
Cummins R et al. Wellbeing of Australians: carer health and wellbeing. *Australian Unity wellbeing index, report 171.* Deakin Uni 2007.
van den Berg B, Fiebig DG, Hall J: Well-being losses due to care-giving. *J Health Econ* 2014, 35:123-131.

[15] 16. National Disability Insurance Agency: COAG Disability Reform Council, Quarterly Report, June 2018. 2018.

[16] Mavromaras K, Moskos M, Mahuteau S, Isherwood L: Evaluation of the NDIS: Final Report. In. Adelaide: Flinders University; 2018.
Craig P, Katikireddi S, Leyland A, Popham F: Natural Experiments: An Overview of Methods, Approaches, and Contributions to Public Health Intervention Research. *Ann Rev Public Health* 2017, 38:39-56.
Dunning T: Natural Experiments in the Social Sciences. Cambridge: Cambridge University Press; 2012.

world-wide, although Australia rates poorly relative to other OECD countries on employment and poverty.[17] Carers are also more disadvantaged and have poorer health than the rest of the population; again, a situation reflected internationally.[18]

Impact of caring on families

Understanding the impact of caring on families provides some guidance as to the most effective support.

The Australian Institute of Family Studies report into the nature and impact of caring for family members with disability in Australia[19] found that carers and their families experience higher rates of mental and physical health problems than the general population. Factors found to be associated with poor mental and physical health included caring for a person with has high care needs,[20] caring for more than one person with disability, having another care role (e.g. looking after children), having one or more problems in dimensions of family functioning and needing more support than they were currently receiving. Carers aged 18 to 50, the age when they would most likely be caring for children, had the worst mental health and vitality and the highest rates of depression.

The study found that a significant proportion of carers had a change in labour force participation since taking on a caring role with a large number of non-employed carers of working age expressing a desire to be in paid employment. With the reduction in employment, it was not surprising that compared to the general population, a higher proportion of families of carers suffered from greater financial hardship.

The study reported on carers' support networks, carers' relationships, relationship breakdown and family functioning. Although most carers had supportive people around them, there was a substantial minority of carers (one in five) who had no assistance from other people, in caring for the person or people with disability.

Conflict is the aspect of family functioning that carers most frequently saw as problematic (one in three identified this aspect as a problem). Carers of someone with a psychiatric disability were most likely to report two or more problems in family functioning, with carers of someone with a physical disability the least likely. Poor family functioning was associated with greater care needs of the person with disability, suggesting that the level of impairment is a good proxy measure of the likely impact of caring on broader family relationships.[21] Almost one in three female carers aged 50 or under had separated or divorced since they started caring, while one in seven over the age of 50 had separated or divorced since they started caring.

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[17] Parliament of Australia: Budget Review 2014-15. *Research Paper Series, 2013-14.* Canberra; 2014.

[18] Parliament of Australia: Disability Support Pension: Historical and Projected Trends. Canberra: Commonwealth of Australia; 2018.
World Health Organisation: Towards a Common Language for Functioning, Disability and Health (ICF). Geneva;2002.
Eikemo TA, Bambra C: The welfare state: a glossary for public health. *J Epidemiol Community Health* 2008, 62(1):3-
Esping-Andersen G: The Three Worlds of Welfare Capitalism. London: Polity; 1990.

[19] Australian Institute of Family Studies, (2008) *Nature and impact of caring for family members with a disability in Australia,* Research Report No 16

[20] including behaviours of concern

[21] Australian Institute of Family Studies, op cit, pxv

At the individual level, research focusing on the impact of caring for an adult with disability shows caring can have both positive and negative impacts on parents' quality of life (QOL). A qualitative study[22] of 12 parents who were full time carers of an adult with intellectual disability reported they experienced positive impacts on their QOL by enabling participants to develop relationships and receive support, participate in leisure activities, achieve a sense of personal satisfaction and enable a more positive appraisal of their lives. Caring had a negative impact on participants' QOL by restricting their relationships, leisure activities and employment opportunities. Caring was also associated with financial insecurity, frustrations at the service system and fear of what the future held for their offspring.

An Australian study by Edwards and Higgins[23] compared the mental health and vitality of people caring for a family member with disability with that of the general population and found increased risk of mental health problems and lower levels of vitality, even after adjusting other factors that may be associated with becoming a carer that might explain the association. These differences are consistent with evidence from overseas studies[24] and major large-scale Australian studies[25] on this issue.

The study confirmed factors that place carers at risk of poor mental health and low vitality are similar to that of other large-scale studies and include family functioning, the level of informal support by friends or relatives and the level of care needs of the person with disability. Financial factors are also significant with financial hardship more prevalent where there is someone in the household who has a disability.

The NDIS evaluation,[26]commissioned by the Australian Government to assess the impacts of the NDIS in trial sites on people with disability, their carers and a range of other stakeholders, found overall that the NDIS has led to modest improvements in the wellbeing of people with disability with evidence of increased improvement over time. Better wellbeing was found to be associated with increased levels of support and independence. Opportunities for greater social participation, improved skills and developmental progress also contributed to enhanced wellbeing under the NDIS.

The evaluation did not however find evidence that the NDIS had improved the wellbeing of the families and carers of people with disability. A negative impact of the NDIS on wellbeing was reported by those caring for children with disability. Furthermore, levels of carer wellbeing fell slightly over the duration of the evaluation. The wellbeing of families and carers was strongly related to the amount of perceived control over how the carers themselves spend their time. Carers of NDIS participants

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[22] Yoong, A., Koritsas, S., (2012) The impact of caring for adults with intellectual disability on the quality of life of parents, *Journal of Intellectual Disability Research,* v56, no 6 p609-619

[23] Edwards, B & Higgins, D., (2009) Is caring a health hazard? The mental health and vitality of carers of a person with disability in Australia, *Medical Journal of Australia,* 190 (7 Suppl): S6, Accessed at Journal article on caring for people with a disability (external) 24 July 2018

[24] Cochrane, J, Goering PN, Rogers, JM. The mental health of informal caregivers in Ontario: an epidemiological survey. *Am J Public Health* 1997: 2002-2007
Hirst, M. Carer distress: a prospective, population-based study. *Soc Sci Med 2005;* 61: 697-708

[25] Cummins RA, Hughes J, Tomyn, et al. Australian Unity Wellbeing Index Survey 17.1. The wellbeing of Australians – carer health and wellbeing. Melbourne: Deakin University, Carers Australia and Australia Unity.
Schofield, H, Bloch S, Herrman H, et al editors. Family caregivers: disability, illness and ageing, Melbourne: Allen and Unwin, 1998.

[26] National Institute of Labour Studies (2018), Evaluation of the NDIS, Final Report, Flinders University, South Australia

with mental/psychosocial disability had lower levels of wellbeing than those caring for people with other types of disability. Anxiety about the long-term sustainability of the NDIS and the administrative burden associated with NDIS processes were found to have a negative impact on carer wellbeing.

Specific impacts of caring for a young child with disability

Research that focused on children under seven with behaviours of concern or high medical support needs found that families with strong social support networks that offered practical as well as emotional support made less use of respite care.[27] For the majority of carers who did have support, the support provided was not without issues with one in five carers having disagreements with others about caring.

Importantly, the provision of care was not associated with dissatisfaction with carer’s relationships, but it did seem to affect carer’s satisfaction with how their children got along with one another. This is consistent with research showing the negative impact of caring for a person with disability on non-disabled siblings, perhaps because of a reduction in the attention they receive.[28]

Llewellyn[29] conducted research to identify factors most likely to sever the caring relationship. She investigated families’ decision to seek out-of-home care for children with disability with high support needs. Her findings provide important guidance for preventive support and are discussed in the section on implications. Llewellyn found that families most likely to seek alternate care are those experiencing:

- a lack of congruence in their everyday lives between the needs of their child with disability and the needs of other family members;
- a lack of integration of the child with disability into their everyday family life and the community more generally; and
- concerns about the effect of the child with disability on their siblings both now and in the future.

Implication of carer research

Physical and mental health

There is no simple way to improve the physical and mental health of families providing care. The observation however that poorer health is associated with providing support to a person with a significant disability and with the perception that the amount of support provided is insufficient must be taken seriously. Wellbeing research suggests that families feel supported when they have people to call upon for practical and emotional support.

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[27] Centre for Developmental Disability Studies, 2004, *Appropriate and effective models of respite care for children under 7 years and children with disability and challenging behaviour or high medical support needs*.

[28] Higgins, D. J., Bailey, S. R., & Pearce, J. C. (2005). Factors associated with functioning style and coping strategies of families with a child with an autism spectrum disorder. Autism, 9(2),125–137.

[29] Llewellyn,G., Dunn, P., Fante, M., 1996, *Families of young children with disability and high support needs*, Report to Ageing and Disability

Informal support

Increases in informal support (having people to call upon for practical and emotional support) improve family health and wellbeing as well as reduce the call on formal support. Support for families should include proactive assistance to strengthen and sustain their informal support.

Relationship breakdown

Strategies to reduce family conflict would lead to better outcomes for all family members. The Australian Institute of Family Studies data suggest that support services that focus on addressing relationship conflict in the first year of caring and target carers under the age of 50 may reduce separations and arguments between spouses.

Individualising support

Support is much more effective when it is tailored to the specific needs and priorities of the family and when it is under their control so that it can be adjusted in response to changing circumstances. Given the critical importance of children growing up in families for the wellbeing of the child and sustainability of the Scheme, planning must take a child-centred family-focused approach.

UK research [30] in relation to carers and personalisation reported that for the personalisation agenda to have a positive impact on carers there needs to be:

- a genuine partnership with carers at all levels of service design and delivery
- opportunities for carers to design and direct their own support, have access to direct payments and be engaged in the support plan of the person they care for
- whole of family approaches to ensure there is integrated support planning that benefits everyone
- recognition of the differing social and emotional impacts of providing support to another person and that these do not necessarily correlate to the number of hours spent or the tasks undertaken in providing care
- a range of support options and opportunities to match the diverse needs of carers and the diverse outcomes they want to achieve.

Impact on siblings

The research demonstrating the negative impact of caring for a person with disability on non-disabled siblings is of concern. For all people with disability but especially for those with cognitive impairment, the presence of siblings can provide an important long-term safeguard. Family support must seek to strengthen not weaken sibling relationships.

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[30] Social Care Policy, Department of Health (2010) *Carers and Personalisation: Improving Outcomes,* Best Practice Guidance, London Accessed at Department of Health UK website (external) 24 July 2018

Crisis support

The knowledge that support is available in the event of a crisis is an important element of peace of mind for family and safety for the person with disability. NDIA planning processes should assist families and carers to plan for unexpected events to prevent them escalating into crisis. In addition, the NDIA requires an effective process for very rapid plan review when increased need for support arise from unplanned events.

Prevention of out-of-home care for children

The breakdown of family care, especially for children, has significant negative impacts on the child and on Scheme sustainability. Llewellyn's research indicates that intense effort must be directed to build congruence in everyday lives between the needs of the child with disability and other family members and to integrate the child with disability into the everyday life of the family. This requires that not only is the family supported, the family needs to feel it is supported in ways that address their specific needs in their unique circumstances.

Where children are already in statutory out-of-home-care arrangements, such as alternate family, foster carers, kinship carers, residential care and/or family group homes, they should be eligible for the support outlined in this paper and the reasonable and necessary support for the child should assist the child to remain engaged with his/her birth family where this reflects the child's will and preferences and is in the child's best interests.

Labour force participation

The 2011 Productivity Commission Report, *Disability Care and Support* showed that the economic benefits of the NDIS relied on a significant number of carers being able to return to work.[31] Data from the June 2018 NDIS Quarterly Report [32] demonstrates that a large number of non-employed carers of working age want to be in paid employment. Employment laws provide minimum requirements, Carer Recognition Acts in some States and Territories provide other assistance but their impact on changing workplace practices is slow.

Carers returning to work following long term caring responsibilities often move to entry level jobs that are insecure and lowly paid. They need access to rapid plan review to be able to access additional support when work becomes available.

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[31] Productivity Commission 2011, *Disability Care and Support,* Report No. 54, Canberra, p966

[32] at p37

Support for families and carers in the NDIS

Carer resources depleted

A recent Carers Australia Report (the Report)[33] argues that respite is not an acknowledged service in the NDIS on the assumption that participant packages will provide so much support that carers will not need access to formal respite; that carers can get access to planned respite in their own right through the Commonwealth Respite and Carelink Services and that respite is a pejorative term and must not be used.

The Report uses the NDIA June 2018 Quarterly Report[34] to demonstrate that the NDIS has not yet had a significant impact for many families and carers. Reports of the health of families and carers 'not being good, very good or excellent' and reports of families and carers being unable to work as much as they want, provide a picture that at least one third of families and carers are not well supported. The issue comes into sharp focus with the Quarterly Report data that more than 80% of those who report being unable to work as much as they want cite the situation of their family member with disability as a barrier to greater workforce participation.

The Report goes on to demonstrate that families and carers are frequently unable to access carer support, often because the funding of such programs was rolled into the NDIS by Commonwealth, State and Territory Governments.

Rethinking respite

Over the past 20 years, the concept of respite has been reframed from a discourse that established an unhelpful tension between the person with disability and their family and carers, to a policy that considered dual objectives of the carer and the person with disability with desired outcomes in relation to health, wellbeing and participation for both groups.[35] Carers Australia argue however that with the further move to individualised support under the NDIS, the needs of families and carers may have been lost.

In the UK, there has been a change of language from respite to 'short breaks' to reflect the fact that short breaks encompass a much wider range of supports than out-of-home placement in specialist residential facilities. In the UK, as well as Australia, services used to facilitate short breaks are extremely diverse and vary in:

- location, which could include the person's own home, the home of a contracted short break carer, centre based facility, or any number of community settings.
- duration, which could include anything from a few hours, to an overnight stay, to overnight stays of several days or even longer.

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[33] Carers Australia (2018) Position paper: Reasonable and necessary supports: the case for respite Accessed Paper on Respite webpage (external) 20 October 2018

[34] at p37

[35] Hamilton, M., Giuntoli, G., Johnson, K., Kayess, R., & Fisher, K. R. (2016). Transitioning Australian Respite (SPRC Report 04/16). Sydney: Social Policy Research Centre, UNSW Australia. p18

- timing, which could include weekdays, weekends, evenings and overnight.

The change of language to describe diverse practice has helped to diffuse the tension with short breaks focusing on positive impacts for participants with disability as well as their families and carers. Ultimately, the quality of experience for the person with disability relates to the extent to which the short break is age appropriate, fun, provides a range of experiences, is local to forge real relationships and when overnight, uses family based or holidays and camps in a similar way to persons without disability.

An international literature review [36] on the impacts of short break provision on disabled children and families in the UK concluded that:

"……short breaks appear to have the potential to positively impact on not only the well-being of carers, but also the children receiving short breaks and their families as a whole. However, short breaks are not a panacea. In many cases, short breaks are simply allowing carers to engage in the basics required for human functioning such as sleep and social contact. To suggest that short breaks will somehow enable carers to build an informal support network or solve all the problems inherent in caring for their child is not warranted by the evidence."

The NDIS aims to provide effective, life-enhancing and age-appropriate support for the person with disability that simultaneously has a 'respite effect' for the family. Planner and LAC refusal to talk about the need for 'respite', the need for short breaks, caused angst to many families and carers who are happy for the improved opportunities for their family member with disability but feel exhausted and overlooked by the NDIS.

While the NDIA and its partners have been reluctant to directly address the needs of families and carers, organisations continue to promote their existing respite services. Demand for respite services still exists and the service system is set up to provide these services. The best of these are flexible and individualised while congregated centre based services are also available. Experience, at least in NSW, shows large providers using blog posts to advertise centre-based overnight respite services with families, including families of very young children.

Recognising the needs of families and carers in their own right

In the UK, the policy shift to individual budgets for people with disability has seen the concurrent introduction of a policy framework for assessing carers' needs independently of the needs of the persons for whom they care. Sweden and the Netherlands have a form of carer assessment or brokerage resembling that of the UK. In the US, research points to the proliferation of consumer-directed family support programs that assess the needs of all members of the family at once, suggesting positive outcomes for both participants and carers. [37]

The parallel policies that recognise the needs of carers in their own right had not been evident in the policy framework of the NDIS. In March 2018 the Australian Government

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[36] Robertson, Janet and Hatton, Chris and Emerson, Eric and Wells, Emma and Collins, Michelle and Langer, Susanne and Welch, Victoria (2010) The impacts of short break provision on disabled children and families: an international literature review. [Report]. Accessed at Strath prints website (external) 28 January 2019

[37] PC 2011 reported in SPRC p30

announced the roll-out of a new model of carer support services (Integrated Carer Support Services (ICSS)) to replace those it currently funds.[38] In announcing the initiative, the Department of Social Services acknowledged, that '*direct funding for support services to assist carers with their own needs has been declining over a number of years with the introduction of the NDIS and national aged care reform which have seen the transfer of some funds and programs from carer support to the support of those they care for*'.[39]

The new ICSS will provide digital resources through the Government's Carer Gateway and targeted services delivered by a network of regional delivery partners that provide needs assessment and planning, targeted financial packages (capped at $3,000) with a focus on supporting employment, education, respite access and transport, coaching, counselling and peer support, access to emergency crisis support and assistance in system navigation.

Funding for ICSS does not however restore the funding for planned respite which is slowly being transferred to the NDIS. Planned respite is only available through a limited number of ICSS packages. $3,000 does not buy much respite.

Whilst it is important to recognise and plan for carers in their own rights, the lack of integration in planning around the person with disability and the family may lead to models that do not promote innovation. Models originating from carer frameworks are often not life enhancing for the person with disability and current NDIS models are not necessarily working for families.

What families need and what the NDIS provides

Vision building and advocacy skills

The introduction to this paper proposed that people with disability need two anchor points from family: one stemming from time and emotional energy to care and the other from an ability to act as a guide that breaks down barriers and enhances opportunities for an ordinary life. This second role is a capacity building role of providing the developmental support to visualise an ordinary life and move toward it. To fulfil this role families must be exposed to people to assist with:

- visions of a life included in the community
- plans to move toward the vision
- intentional strategies to bring others into one's life as a safeguard such as through Circles of Support

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[38] Integrated plan for carer support services webpage (external) Accessed 7 May 2018
[39] Q&A regarding announcement of the National Approach to Carer Support Services, March 2018

- skill building to manage a budget of support resources or recruit, train, supervise and support one's own staff.

Most families have significant experience of the capped crisis-driven State service system and have not been encouraged to be more empowered, more self-sufficient or more active agents in their own lives.

Current practice

In its 2014 paper *Reasonable and necessary support for an ordinary life*, the IAC outlined NDIA support for families across the lifespan. This is reproduced in Appendices 2 to 6 and identifies the IAC vision of assistance families and carers need across the lifespan to enable participants to lead an ordinary life.

An analysis of 2018 ILC national and jurisdictional grants in NSW indicates however that none of the support sourced from the ILC is available for participants and their families in NSW. Support for families sourced to the ILC that is not available includes support to: build a positive vision and pathway; develop parent advocacy skills; develop / strengthen informal support; build skills to enhance social and relationship skills of their family member with disability; connect with parent peer networks; assist their family member to make decisions and plan for the future (including succession planning).

It is hoped that the new ILC round for Disabled Persons Organisations and Family Organisations will strengthen the ability of families and carers to be guides to the family member with disability.

Reasonable and necessary support for families across the lifespan

NDIA discourse

NDIA Participant Rules, the outcomes framework and public information for families and carers give encouragement that the issues and needs of families and carers are considered. The support is targeted at improved outcomes for participants with guidelines to assist NDIA decision makers to weigh up what is reasonable to expect the family to provide against the extent to which the wellbeing of family members is at risk. These are reproduced in Appendix 1.

Current practice

NDIA expectations of families often unrealistic

Many participants report frustration that support in the plan bears little resemblance to NDIA discourse and that NDIA expectations place their relationships / marriages at risk.

Across the lifespan, families and carers experience additional challenges that many participants argue are not sufficiently considered when the NDIA determines what is reasonable for families to provide. The table below identifies challenges for each cohort that do not appear to be reflected in reasonable and necessary decisions. The table also suggests responses that may address the challenges.

Cohort	**Challenges not always reflected in R&N decisions**	**Response**
Children birth to 6	Informal child care from grandparents, friends and neighbours not always readily available	May need core supports for in home childcare and/or support to build capacity of informal carers
Children 6-15	Informal supports available to other families often less available when child has a disability e.g. harder to share car pools, less invitations with friends More parental planning and energy required for children to participate in mainstream activities May have to be available to provide personal care support during mainstream activities No age appropriate after school and vacation care for secondary students	May need increased core supports to support mainstream participation Requires deeper LAC / Support Coordination time to negotiate inclusive opportunities and build belonging
Young people 16-25	Additional requirements in relation to personal care, transport and facilitation of opportunities take capacity, energy, resilience and time that families may not always have. NDIA expectations of family support that exceed family expectations of their capacity, strains relationships in ways that are detrimental to the participant	May need increased core supports to support mainstream participation Requires deeper LAC / Support Coordination time to negotiate inclusive opportunities and build belonging Respect for family judgment on what is reasonable for family to provide Support to develop and strengthen informal support in family, neighbourhood, workplace and leisure activities

Cohort	Challenges not always reflected in R&N decisions	Response
Adults 26+	Additional requirements in relation to personal care, transport and facilitation of opportunities take energy, resilience and time that families may not always have. NDIA expectations of family support that exceed family expectations of their capacity, strains relationships in ways that are detrimental to the participant	May need increased core supports to support mainstream participation Requires deeper LAC / Support Coordination time to negotiate inclusive opportunities and build belonging Respect for family judgment on what is reasonable for family to provide Support to develop and strengthen informal support in family, neighbourhood, workplace and leisure activities Support for succession planning
All	• Challenge that bottom up planning facilitates a shopping list approach to support. Participant and family criticism where NDIA prioritizes options • Support provided by LACs and Support Coordinators not always as active and extensive as NDIA suggests	• In a budget determined by a reference package, participants and families set their own priorities within a predetermined budget • Requires deeper LAC / Support Coordination time to negotiate inclusive opportunities and build belonging

Uncertainty of crisis support

Planning for unexpected events is a critical safeguard for vulnerable people, reducing the risk that unexpected events become crises. The NDIS does not yet have robust mechanisms that give confidence to families and carers that help will be available. In addition, processes do not encourage families to make appropriate plans.

Superficial attention to 'sustaining informal support'

Sustaining informal support is an important strategy to mitigate against the risk of families placing their child in out-of-home care and their adult family member in supported accommodation. Carer groups and the NDIA however have different views about what is required to 'sustain' informal support. The NDIA identifies personal care and domestic assistance related to the person's disability. Carers Australia acknowledge that while some assistance with caring can provide families and carers with a little extra time for themselves, it does not replace the opportunity for the sort of break that allows them to recharge their batteries.

The IAC has written frequently about the efforts required to build and strengthen informal support arguing that requirements in role statements of LACs and Support Coordinators pay lip service to a function that is critical for Scheme sustainability. Alternate strategies are required.

Since participants with more informal support use less reasonable and necessary support it can be argued that sustaining family support represents value for money for the NDIA, mitigating risks to Scheme sustainability.

Importance of flexibility

Support for families was a strong theme in Practical Design Fund[40] projects that focused on people in rural and remote areas. The strongest message related to the critical importance of flexibility, pragmatism and common sense to respond to the unrelenting pressure that can arise from the lack of formal services. Families argued strongly that the rigidity in services made life so much more difficult than it needed to be, that families know what will make a difference and their views should be respected and supported, enabling the use of local capacity in innovative and impromptu ways.

Families in rural and remote areas argued that restrictions on flexibility inhibit the nimble response to day-to-day contingencies. This is especially evident for young families and families of participants with acquired disability who are not aware of their needs at the time of a planning conversation. A recent example of a single parent with three young children, one of whom has a complex disability provides insights into the impacts of restrictions. The parent was prevented from attending a school event for her two children without disability because her NDIS plan focused exclusively on therapy leaving no place to use her package for in-home support for the evening event.

NDIA packages should be flexible enough to enable the participant and his/her family to decide the best ways to enable all family members to thrive; flexible enough to create short breaks that fulfill the participant goal of increased independence and inclusion, while simultaneously providing an opportunity to reduce the impact of caring on other family members.

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[40] Practical Design Fund: $10M fund used to fund 73 projects that contributed to the development of an NDIS and help to prepare people with disability, their families and carers, the disability services workforce and disability service organisations for significant change.

A respite effect may not represent respite

Some families and carers argue that the NDIS focus of supporting participants is beneficial for the participant but they sorely want and need a break at a time and under circumstances that suit them.[41] They argue the need for respite, not just the respite effect of having their family member with disability actively engaged.

Many families continue to feel unsupported or under-supported and this has negative impacts for participants and the Scheme. Negative impacts include increased behaviours of concern of participants living in stressed families, increased social isolation of participants arising from the alienation of siblings and families seeking out -of-home care for their family member with disability at an earlier age, all of which increase the cost of care and support, increasing pressures on Scheme sustainability.

Variable NDIA response depending on whether family ‘knows the NDIA script’

The NDIS focus on participants has changed the language used to describe services families previously used for respite. Many participants and their families however do not understand the changed paradigm and language. At transition, there have been numerous reports of families having their request for the continuation of the respite service rejected where more informed families were able to continue with those services by including community participation as a goal for their family member.

Practice guidance

The challenges identified above are summarised into Practice Guidance to inform operational policy, planning processes, communication with participants and training for NDIA and partner staff.

<u>NDIS processes should</u>:

- takes account of family circumstances in determining reasonable and necessary support in the Typical Support Package
- ask about sustainability of the family and respect family judgement about ‘what it takes’ to sustain family care
- introduce the term ‘short breaks’ to refer to age appropriate ways in which a participant and their family/carer have time apart
- register the family/ carer need for support, irrespective of whether the family frames the request for themselves or for the participant
- assist families to plan for unexpected events to mitigate the risk that unexpected events become crises
- be responsive to family stress and
    - have effective processes for rapid plan review

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[41] Arksey et al , 2004, p34 SPRC

    - allocate a Support Coordinator skilled in working with this target group to support the sustainability of family relationships
    - adjust the quantum of support as required.
- The LAC role should extend to supporting families and carers to negotiate workplace adjustments that enable them to balance employment and carer roles.

In determining the level of support for families, the NDIA should

- take account of the specific circumstances of the family and of the person for whom they care
- be responsive to and respect the judgement of families as to what it is reasonable to provide and what is necessary in order to continue to care
- recognise what it takes to develop and sustain informal support and provide proactive assistance including reasonable and necessary support and ILC services to help families develop and sustain informal support
- recognise that informal supports that people without disability may rely on (e.g. extended family support, car-pooling, invitations to friends) are often not available when a person has a disability
- recognise that inclusion requires planning and often individual support (including facilitation of opportunities, personal care and transport) by family and carers. Whilst positive participant outcomes bring satisfaction and joy, the effort will take the family away from other responsibilities and may be exhausting.

Support for all families should:

- be highly flexible, enabling the family to determine its changing priorities so that support can be used in ways that family perceives as priority in enabling all family members to thrive.

In addition, support for families of children and young people should:

- be child-centred and family-focused
- build congruence between the needs of their child with disability and other family members and integrate the child with disability into their everyday life
- strengthen, not weaken sibling relationships
- be responsive to changing family stress with a proactive ‘do whatever it takes’ approach to enable the child to remain in the family

Where a child is in out-of-home care:

- the alternate family should be eligible for support
- the child should be supported to maintain relationships with their birth family.

Contemporary service responses

Support for families of young children should build congruence between the needs of the child and the needs of the family and integrate the child into the life of the family. This is critical for the best interests of the child and the sustainability of the family. A family that feels supported by the removal of a very young child, is on a path to seeking permanent out-of-home care. Hence facility style short term accommodation for very young children should be avoided.[42]

Where it is desirable for children to be out of their parent's home overnight, preference should be given to:

- support to increase the capacity of extended family and friends to host the child
- host family programs
- camps and other age appropriate community based overnight options
- use of regular services that provide opportunities for children to achieve their goals

Services that provide life building opportunities for young people and adult with disability while simultaneously providing the opportunity for family members to have their own lives include Shared Lives (also showcased in the IAC paper *Contemporary options of housing and support)* and supporting participants to go on holidays and community camps.

Shared Lives

Shared Lives[43] is model of support in which the person with disability have short breaks, day support or moves in to live in the home of a compatible Shared Lives carer and their family.

Local Shared Lives schemes, which are regulated by the Care Quality Commission, individually match trained and approved Shared Lives carers with people who need their support. The goal of Shared Lives is an ordinary family life, where everyone gets to contribute, have meaningful relationships and is be active, valued citizens.

In England 2014/15, over 3,260 people with disability enjoyed short breaks and respite through Shared Lives with 76% of the participants have a learning (intellectual) disability and 5% have a physical impairment. Shared Lives provides a vital service for regular planned time that allows participants and families to be apart in socially valued ways. Many Shared Lives relationships provide support when unplanned events happen in family life.

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[42] At least in NSW there are centre based facilities that provide respite for babies and very young children, some of whom are NDIS participants.

[43] Shared Lives Plus: The UK network for shared lives and homeshare, and The State of Shared Lives in England, Report 2016

My Place WA offers a Shared Lives type program supporting people with disability to live in the homes of people without disability. My Place has found that it is significantly easier to recruit appropriate Shared Lives carers who open their homes to a person with disability than to find suitable homesharers who go to live in the home of person with disability.

Shared Lives carers are not employees of My Place but are engaged in a similar way to foster carers. Using a number of the private rulings from the ATO, My Place pays a tax-free reimbursement to homesharers making it financially viable for the Shared Lives householder to cease other employment to dedicate time and effort for the best possible family situation.

My Place recruits, matches, trains, supports and monitors the Shared Lives carers and sustains many long-term links.

Holiday support and camps

Most people spend time away from their families by going on holidays. There are many NDIS registered providers that provide individual and group holidays for people with disability. Often people caught up in the sustaining day to day living have not had time to consider a holiday option that can provide a planned and enriching break for all concerned.

Camps also provide an enriching and inclusive opportunity for young people and often include links to volunteers that can develop into more lasting relationships.

Conclusion

Support for families is critical for positive participant outcomes and for Scheme sustainability. Well supported families are more likely to assist their family member with disability to thrive and defer the need for increased reasonable and necessary support. Investment in families is a strategy that mitigates the risk of participants seeking paid support in all areas of their lives.

Recommendations

The IAC recommends that the NDIA:

1. Develops, operationalises and implements practice guidance in relation to support for families and carers consistent with the Practice Guidance described in the paper, with particular emphasis on family judgement as to what is necessary to sustain family care, remain in or return to work and build informal support.
2. Maximises support when there is a heightened risk of out-of-home placement for children and young people with disability.
3. Introduces the term ‘short breaks’ to replace the term respite and assists participants and their families and carers to plan for mutually rewarding time apart.
4. Explores options for more integrated planning for NDIS participants and their

co-resident families and carers.

5. Commissions services in the ILC that strengthen families’ vision of an ordinary life and develop their skills to guide their family member to get there.

Appendix 1: NDIA information about support for families and carers

Supports for Participants Rules: NDIA expectations of families as determined by the Supports for Participants Rules, identify factors to be considered including whether, because of the child's disability, the child's care needs are substantially greater than those of other children of a similar age. Expectations of family and carer support for adults is required to take account of the type and intensity of support required, whether it is age and gender appropriate for a particular family member or carer to provide that support as well as risks to the long-term wellbeing of people who provide informal care.

Outcomes Framework: The NDIA measures its success in supporting families through the achievement of outcomes. Families that live with an NDIS participant should be able to expect to:

- know their rights and advocate effectively for their family member
- feel supported
- gain access to desired services, programs, and activities in their community
- enjoy health and wellbeing

In addition,

- families of children and young people should be able to expect to:
    - understand their children's strengths, abilities and special needs
    - help their young person to become independent
- families of adults can expect to have the support they need to care and have succession plans.

NDIS information for families and carers: indicates that "*the NDIS funds supports that families need as a result of a family member's disability, as well as supports that enable sustainable caring by family members. This includes* [44]*:*

- *family support and counselling due to a family member's disability*
- *building the skills and capacity of other family members to manage the impact of the participant's disability in family life*
- *supports that increase the participant's independence, as well as supports that enable the participant to enjoy social and community activities independent of their informal carers*
- *supports aimed at increasing the sustainability of family caring arrangements, including personal care and domestic assistance related to the person's disability*

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[44] https://www.ndis.gov.au/families-carers/family-supports

- *where a child's caring or living arrangements changes due to a child protection order, the Scheme can continue to fund the child's disability related supports such as aids and equipment, therapies, transport and community access.*

Appendix 2: Support for families of children birth to 5

Goals	Outcome	Supports	System
To support children to be ready for school	Children are ready to enter school and thrive	Capacity building	ECEI ILC mainstream
To understand their child's development To understands how their child is progressing To have positive views of their child's developmental progress and future To support the child to participates in the traditions of the culture	Families understand their children's strengths, abilities and special needs.	Information Support to build a positive vision and pathway Parent advocacy understandings and skills Contact with families with children with similar needs Early intervention Encouragement to attend playgroups Childcare	ILC ECEI All systems Mainstream
To advocate for services and supports for their child To be able to identify their needs and know how to access available services and supports To understand their rights and the rights of their child	Families know their rights and advocate effectively for their children	Parent advocacy and capacity building Practical support to assist to participate in capacity building	ILC
To understand the interventions needed to support the child To knows what they can do to support their child's development To feel capable in parenting their child	Families help their children develop and learn.	Early intervention Capacity building Childcare and other practical support to assist to participate in capacity building	ECEI ILC R&N support
To feel confident to access services and community activities To see themselves as partners with professionals To feel in control in selecting services and supports that meet the needs of their child and family To see themselves as equal and integral members of the team	Families are able to gain access to desired services, programs, and activities in their community.	Capacity building Early intervention Childcare and other practical support to assist to participate in capacity building	ECEI ILC R&N support

Goals	Outcome	Supports	System
To work in partnership with service providers to meet the needs of their child.			
To have people to call on for practical assistance as often as they need To have people to call on for child care as often as they need To have people to call on for emotional support as often as they need	Families feel supported	Address family issues that might hinder development of relationships Encourage and assist to establish use of informal care of grandparents, friends, babysitters Practical support Support to build congruence in everyday family life between needs of child with disability and needs of other family members	ECEI ILC R&N support

Challenges to current practice

Supports for families of children birth to 5 that exceed current NDIA practice relate to

- child care support to look after children at home
- support to develop and strengthen informal support e.g. to assist grandparents, neighbours and other informal carers to feel confident to ‘babysit’ for the child with disability

Appendix 3: Support for families of children 6-15

Goals	Outcome	Supports	System
To support the development of peer relationships	Families support their child to develop and strengthen peer relationships	Capacity building Skill building to enhance social and relationship skills of children Skill building to facilitate connections	ILC
To understand their child's development and how child is progressing To have positive views of their child's developmental progress and future To include their child in age appropriate traditions of the culture	Families understand their children's strengths, abilities and special needs. Families include child in extended family, culture and community	Information Support to build a positive vision and pathway Parent advocacy understandings and skills Contact with families with children with similar needs	ILC
To advocate for services and supports for their child To identify their needs and how to access available services and supports to meet their needs To understand their rights and the rights of their child with disability	Families know their rights and advocate effectively for their children.	Information Vision building Family advocacy training and support Connection to empowering disability networks	ILC
To make informed decisions about their child To feel confident in their parenting	Families help their children develop and learn.	Information Capacity building	ILC
To have people to call upon for practical support To have people to call upon for emotional support To have people to call upon to look after their child	Families feel supported.	Support use of informal care of grandparents, friends, babysitters "Whatever it takes' supports to facilitate a healthy well-functioning family Support to maintain life roles other than carer Support to maintain relationships and belonging	LAC or Support Co-ordinator R&N support

Goals	Outcome	Supports	System
To feel confident to access services and community activities To see themselves in partnership with professionals and services To feel themselves in control in selecting services and supports that meet the needs of their child and family To view themselves as equal and integral members of the team	Families are able to gain access to desired services, programs and activities in their community	Planning process Support to negotiate with service providers and support workers Capacity building Professionals and services that assume capacity and work in person centred ways	LAC or NDIA planner LAC or Support Co-ordinator ILC ILC

Challenges to current practice

Supports for families of children 6 to 15 that exceed current NDIA practice relate to:

- support to facilitate mainstream inclusion. This is seen as the responsibility of the LAC or Support Coordinator but underestimates what is often required to support inclusion and belonging leaving significant physical and emotional stresses on parents
- child care support to look after children and young people at home
- support to develop and strengthen informal support e.g. to assist grandparents, neighbours and other informal carers to feel confident to look after the child with disability

Appendix 4: Support for families of young people 16 - 25

Goals	Outcome	Supports	System
To plan for adult life including post school education and training, work, valued roles, included in community	Families assist their family member to transition into adulthood	Information, capacity building Support to build a vision, a plan, maximise potential and make decisions “Whatever it takes’ supports to facilitate a healthy well-functioning family Practical support Support the use of informal care Succession planning	ILC R&N support R&N support LAC R&N support ILC R&N support ILC
To support the development of peer relationships	Families support their family member to develop and strengthen peer relationships	Capacity building Skill building to enhance social and relationship skills of children Skill building to facilitate connections	ILC
To advocate for services and supports for their family member and their family To be able to identify their needs and know how to access available services and supports to meet their needs To understand their rights and the rights of their family member with disability	Families know their rights and advocate effectively for their family member with disability	Information Parent advocacy training Family advocacy support Connection to empowering disability networks	ILC ILC ILC ILC
To have people to call on for practical assistance To have people to call on to care for their family member with disability To have people to call on for emotional support	Families feel supported	Flexible individualised support for the person with disability in regular reliable ways and for emergencies Practical assistance with caring roles Practical assistance that makes a difference to the family	R&N support

Goals	Outcome	Supports	System
		Support to maintain life roles other than as carer Support to maintain relationships and belonging	
To feel confident in their ability to access services and work with professional To feel in control in selecting services and supports that meet the needs of their child and family To work in partnership with service providers to meet the needs of their family member with disability	Families are able to gain access to desired services, programs and activities in their community	Planning process Support to negotiate with service providers and support workers Capacity building Professionals and services that assume capacity and work in person centred ways	R&N support R&N support ILC R&N support
To feel confident for the future of their family member with disability with the NDIS To be able to work as much as they want	Families enjoy health and wellbeing	“Whatever it takes’ supports to facilitate a healthy well functioning family Information, support & vision building Practical support Support to develop and use informal care	R&N support ILC R&N support LACs ILC R&N support

Challenges to current practice

Supports for families of young people 16 to 25 that exceed current NDIA practice relate to:

- respect for family judgment on what is reasonable for family to provide
- support to develop and strengthen informal support in school, workplace, leisure activities
- support for succession planning

Appendix 5: Support for families who live with an adult 26 to 55

Goals	Outcome	Supports	System
To have people to call on for practical assistance	Families have the support they need to care	Flexible individualised support for the person with disability in regular reliable ways and for emergencies	R&N support

Goals	Outcome	Supports	System
To have people to call on to care for their family member with disability To have people to call on for emotional support	Families feel supported	Practical assistance with caring roles Practical assistance that makes a difference to the family Support to maintain life roles other than as carer Support to maintain relationships and belonging	
To be able to advocate for services and supports for their family member and their family To be able to identify their needs and know how to access available services and supports to meet their need To understand their rights and the rights of their family member with disability	Families know their rights and advocate effectively for their family member with disability.	Information Parent advocacy training Family advocacy support Connection to empowering disability networks	ILC ILC ILC ILC
To feel confident in their ability to access services and work with professional To feel themselves in control in selecting services and supports that meet the needs of their child and family To view themselves as equal and integral members of the team To work in partnership with service providers to meet the needs of their family member with disability	Families are able to gain access to desired services, programs, and activities in their community.	Planning process Support to negotiate with service providers and support workers Support to negotiate with service providers and support workers Capacity building Professionals and services that assume capacity and work in person centred ways	R&N support R&N support ILC ILC
To plan with family and friends about the future for their family member with disability when they are no longer the primary care givers To support their family member with disability to spend days and overnight away from the immediate family	Families have succession plans	Succession planning seminars Support to strengthen informal support Positive opportunities for people with disability away from family including overnight	R&N support ILC R&N support

Goals	Outcome	Supports	System
To feel more confident for the future of their family member with disability To be able to work as much as they want	Families experience health and wellbeing	“Whatever it takes’ supports to facilitate a healthy well-functioning family Information, support & vision building Practical support	R&N support ILC R&N support

Supports for families of adults 26 to 55 that exceed current NDIA practice relate to:

- respect for family judgment on what is reasonable for family to provide
- support to develop and strengthen informal support in family, neighbourhood, workplace and leisure activities
- support for succession planning

Appendix 6: Support for families who live with an adult 55 +

The supports outlined for people 25-55 are the same as for people 55+. The difference is that the goals and outcomes have progressed.

Goals	Outcome	Supports	System
To have people to call on for practical assistance To have people to call on to support their family member with disability To have people to call on for emotional support	Families have the support they need to care Families fee supported		
Where caring role is held by parents: To implement succession plans To support individual with disability to establish a sustainable home	People with disability are assisted to transition into their own home		
Where family is NOT parents: To plan with family and friends about the future for their family member with disability when they are no longer the primary care givers	Families have succession plans		
To advocate for services and supports for their family member and their family To be able to identify their needs and know how to access available services and supports to meet their needs To understand their rights and the rights of their family member with disability	Families know their rights and advocate effectively for their family member with disability.		
To feel confident in their ability to access services and work with professional To feel themselves in control in selecting services and supports that meet the needs of their child and family To view themselves as equal and integral members of the team	Families are able to gain access to desired services, programs, and activities in their community.		

Goals	Outcome	Supports	System
To work in partnership with service providers to meet the needs of their family member with disability			
To feel confident for the future of their family member with disability To be able to work as much as they want	Families experience health and wellbeing		

Supports for families of adults 55 + that exceed current NDIA practice relate to:

- respect for family judgment on what is reasonable for family to provide
- support to develop and strengthen informal support in family, neighbourhood, workplace and leisure activities
- support for succession planning

Appendix 6: NDIA Rules in relation to support for families

In deciding whether funding or the provision of support takes account of what it is reasonable to expect families, carers, informal networks and the community to provide, the CEO is required to take into account:

(a) for a participant who is a **child**:

(i) that it is normal for parents to provide substantial care and support for children; and

(ii) whether, because of the child's disability, the child's care needs are substantially greater than those of other children of a similar age; and

(iii) the extent of any risks to the wellbeing of the participant's family members or carer or carers; and

(iv) whether the funding or provision of the support for a family would improve the child's capacity or future capacity, or would reduce any risk to the child's wellbeing;

(b) for other participants:

(i) the extent of any risks to the wellbeing of the participant arising from the participant's reliance on the support of family members, carers, informal networks and the community; and

(ii) the suitability of family members, carers, informal networks and the community to provide the supports that the participant requires, including such factors as:

(A) the age and capacity of the participant's family members and carers, including the extent to which family and community supports are available to sustain them in their caring role; and

(B) the intensity and type of support that is required and whether it is age and gender appropriate for a particular family member or carer to be providing that care; and

(C) the extent of any risks to the long-term wellbeing of any of the family members or carers (for example, a child should not be expected to provide care for their parents, siblings or other relatives or be required to limit their educational opportunities); and

(iii) the extent to which informal supports contribute to or reduce a participant's level of independence and other outcomes;

(c) for all participants—the desirability of supporting and developing the potential contributions of informal supports and networks within their communities.

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