# Support for families and carers

Independent Advisory Council to the NDIS  
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## Executive Summary

Families[[1]](#footnote-2), carers[[2]](#footnote-3) and other informal supporters[[3]](#footnote-4) 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 people with disability to access and engage in a range of service systems. The intersection of families and carers is a strong one, with 90% of carers being family members of the person with care needs.[1](#Reference_1)

Australian data on the impacts of caring shows that carers and their families experience higher rates of mental and physical health problems than the general population. Caring has also shown to have an impact on the carer’s ability to participate in employment, in family functioning, and their quality of life.

Support for families and carers of people with disability is critical for positive participant outcomes and for the sustainability of the NDIS. However, since the introduction of the Scheme, carer resources have been significantly depleted. NDIA data shows that the NDIS has not had a significant beneficial impact for many families and carers. In fact, since the onset of COVID-19, the wellbeing of families and carers has further deteriorated.

For people with disability to have a good life, they need twofoundations from their families. They need a family that has capacity to care (that has time and emotional energy to care); and the ability to provide developmental support to visualise an ordinary life. 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.

Investment in families is a strategy that mitigates the risk of participants requiring paid support in all areas of their lives. Well-supported families are more likely to assist their family member with disability to thrive, bringing long term benefits for participants, their families and the Scheme.

To fulfil this vision, the Council recommends the NDIA:

1. Develops, operationalises and implements practice guidance in relation to support for families and carers, consistent with the Practice Guidance included in the paper. This guidance should place particular emphasis on family judgement to inform what is necessary to sustain family care, to 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. Makes representations to Department of Social Services (DSS) in relation to commissioning services in the Information, Linkages and Capacity Building (ILC) that strengthen families’ vision of an ordinary life and develop their skills to guide their family member to get there.

## Introduction

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.[2](#Reference_2) 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.[3](#Reference_3)

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

The NDIS recognises the importance of families and carers. 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.[4](#Reference_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, so the extent 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 advice aims to provide guidance to the NDIA about the most effective way the Agency can support families to facilitate the best possible lives for people with disability.

This paper will:

* scope the size of the issue with data on 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; and
* make recommendations about NDIS support for families.

## Disability and Caring

### Overview of Australian data

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 Australians (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).[5](#Reference_5) 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.[6](#Reference_6) Families provide 96% of the unpaid care and 55% of primary carers provide 20 hours or more care per week.[6](#Reference_6),[7](#Reference_7)

Further analysis[[4]](#footnote-5) of this survey is presented in Figure 1.[5](#Reference_5) 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.

Figure : Disability and carer status by age

An bar graph showing the percentages of people with a disability who are also primary carers in each age group.

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.[7](#Reference_8)

People with disability and carers are among the most disadvantaged population groups worldwide.[6](#Reference_6),[8-10](#Reference_8). Australian work has shown that Australians with disability have low levels of social and economic participation and experience poverty, housing stress and homelessness at much higher levels than the general population.[11-17](#Reference_11) They also have poorer health outcomes even for conditions unrelated to their impairment, mostly related to their socio-economic disadvantage.[18-21](#Reference_18) This situation is mirrored world-wide, although Australia rates poorly relative to other OECD countries on employment and poverty.[9](#Reference_9) Carers are also more disadvantaged and have poorer health than the rest of the population; again, a situation reflected internationally.[10](#Reference_10),[22-24](#Reference_22)

### Impact of caring on families

Understanding the impact of caring on families provides some guidance 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, found that carers and their families experience higher rates of mental and physical health problems than the general population.[25](#Reference_25) Factors found to be associated with poor mental and physical health included caring for a person who has high care needs,[[5]](#footnote-6) 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.[25](#Reference_25) 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.

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 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.[26](#Reference_26) 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 compared the mental health and vitality of people caring for a family member with disability with that of the general population.[27](#Reference_27) This study found increased risk of mental health problems and lower levels of vitality, even after adjusting other factors that may be related with becoming a carer that might explain the association. These differences are consistent with evidence from overseas studies and major large-scale Australian studies on this issue.[16](#Reference_16),[28-30](#Reference_28)

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.

### 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.[31](#Reference_31) 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 siblings without disability, perhaps because of a reduction in the attention they receive.[32](#Reference_32)

Llewellyn conducted research to identify factors most likely to sever the caring relationship.[33](#Reference_33) 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.

### NDIS Outcomes data

The success of the NDIS should be judged based on the progress of participants since they entered the Scheme, noting their differing starting points. Regular NDIA reports analyse change in outcomes over time, providing insights into the impact of the nature of disability, level of function, gender, Indigenous and culturally and linguistically diverse (CALD) status and geography.

The impact of the NDIS for families and carers has been mixed.

#### Families of children aged birth to 14

After three years in the Scheme, families of children aged birth to 14 have reported significant and material overall improvement, with reports of improvement in 15 domains of life and deterioration in 10 domains. Actuarial data indicates an increase in the percentage of families and/or carers who:

* are working in a paid job, with a stronger increase for mothers (+8.4% from 43.8% to 52.2%) than fathers (+4.3% from 61.2% to 65.5%). These percentages are still considerably lower compared to Australian population figures of 73.2% for females and 84.6% for men;
* know what specialist services are needed to promote their child’s learning and development (+11.9% from 41.4% to 53.3%); and
* have people they can talk to for emotional support (+1.7% from 60.8% to 62.5%).

However, there has been a decrease in the percentage of families who:

* have friends and family they see as often as they like (-6.4% from 45.0% to 38.6%);
* have people they can ask for practical help as often as they like (-6.7% from 41.6% to 34.9%); and
* have people they can ask for childcare as often as they need (-5.6% from 29.5% to 23.9%).

For most families of this cohort, indicators of support would include having access to practical and childcare assistance, and being able to see friends and family (for social and emotional support). Unfortunately:

* More than 60% do not see their family and friends as often as they’d like
* More than 65% do not have access to practical assistance as often as they’d like
* More than 75% do not have access to childcare as often as they’d like.

Not surprisingly, there has been a deterioration in the percentage of families and/or carers who rate their health as excellent, very good or good (-9.8% from 74.5% to 64.7%), compared to 85.7% in the general population[[6]](#footnote-7).[50](#Reference_50) There has also been a decrease in the percentage of families who are able to engage in social interactions and community life as much as they want (-4.5% from 27.6% to 23.1%), with the child’s disability increasingly identified as the major barrier to their participation (+4.2% from 92.0% to 96.2%).

The NDIS is one factor that is expected to impact on family and/or carer experience. It is not however the only factor. Families and carers are asked to rate whether the NDIS has helped in relation to each domain, for example, whether the NDIS helped them to be in a paid job, to know about specialist services or to feel supported.

Families and/or carers indicated that the NDIS helped them to help their child develop (+2.5% from 73.6% to 76.1%), to access services (+2.1% from 69.6% to 72.1%) and to feel supported (+2.7% from 66.8% to 69.5%). The NDIS did not however have an impact on families’ ability to know their rights and to advocate for their family member with disability.

#### Families and carers of participants aged 15 to 24

After three years in the Scheme, families of young people aged 15 to 25 have reported significant and material overall improvement, with reports of improvement in 14 domains of life and deterioration in 4 domains. Actuarial data indicates an increase in the percentage of families and/or carers who:

* are working in a paid job (+4.9% from 49.4% to 54.4%);
* are working more than 15 hours per week (+5.1% from 85.1% to 90.2%);
* feel that services listen to them (+8.0% from 64.0% to 72.0%);
* say that services meet their needs (+18.6% from 17.7% to 36.3%);
* agree or strongly agree that their family member with disability gets the support they need (+29.6% from 40.9% to 70.5%); and
* report they have people to talk to for emotional support (+2% from 52.2% to 54.2%).

However, 63.7% of families and/or carers continue to think that the family member with disability does not get the support they need. They also report a decline in health with a decrease in the percentage who rate their health as excellent, very good or good (-8.3% from 64.9% to 56.6%). This is considerably lower compared to the 82.3% of Australians aged 40 to 69 who rate their health as excellent, very good or good and continues the downward trajectory of younger cohorts.[50](#Reference_50)

Opinions on whether the NDIS has helped tend to be slightly less positive compared to the cohort aged birth to 14. The greatest improvement was observed in the domains of families feel supported (+7% from 60.9% to 67.9%) and access to services (+7% from 58.4% to 65.4%).

#### Families and carers of resident participants aged 25+

After three years in the Scheme, families of resident participants aged 25 and over have reported significant and material overall improvement, with reports of improvement in 12 domains of life and deterioration in 6 domains. Actuarial data indicates an increase in the percentage of families and/or carers who:

* strongly agree or agree that services and supports have helped them to better care for their family member with disability (+40.9% from 36.4% to 77.3%);
* feel that the services their family member with disability use, listen to them (+8.1% from 67.6% to 75.7%);
* feel that services their family member with disability and their family receive help them to plan for the future (+31.8% from 40.9% to 72.7%); and
* rate their health as excellent, very good or good (+4% from 49.3% to 53.3%).

Opinions on whether the NDIS has helped vary by domain. The percentage responding positively was lowest for health and wellbeing (+1.2% from 41.2% to 42.4%) and highest for families feeling supported (+6% from 68.8% to 74.8%).

#### General

Families and/or carers of participants with low level of function do more poorly for the majority of indicators in all domains for all cohorts, compared to families and/or carers of participants with higher level of function.

Mapping health and wellbeing for families and carers across the lifespan of their family member with disability shows decreases in health and wellbeing from birth, through childhood and adolescence and into adulthood, demonstrating little change since the major work by the Australian Institute of Family Studies in 2008.[25](#Reference_25)

The NDIS data shows a picture of families and carers of children having a difficult time, reporting they do not get the amount of support they feel they need. The significant majority struggle to get assistance with childcare and practical challenges of life and are unable to see family and friends as often as they would like. Life gets a little easier for many families and carers of young adults but significantly, more than 60% do not think their family member with disability gets the support they need. Their health and wellbeing continue to fall.

NDIS data shows a somewhat different picture for families and/or carers whose family member with disability aged 25+ who lives with them. Spouses or partners start to become a higher proportion of respondents for this cohort (hence similar age to the participant) and they report that services and supports help them to better care for their family member with disability and help them to plan for the future. Their health and wellbeing have improved 3 years into the Scheme, but it is still below the health and wellbeing of younger cohorts of NDIS participants and well below the health and wellbeing of their peers.

### Learnings from research

#### Physical and mental health

There is no simple way to improve the physical and mental health of families providing care. The observation that poorer health is associated with providing support to a person with a significant disability and 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.

#### Informal support

Increases in informal support (having people to call upon for practical and emotional support) improve family health and wellbeing and 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 focussing to address 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 more effective when tailored to the specific needs and priorities of the family and under their control so 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 in relation to carers and personalisation, reported that for the personalisation agenda to have a positive impact on carers there needs to be.[34](#Reference_34)

* 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 & 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 siblings without a disability 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.

#### Crisis support

The knowledge that support is available in the event of a crisis is an important element of peace of mind for families 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 support needs 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 Scheme sustainability. Llewellyn’s research indicates 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 means not only is the family supported, but they feel they are supported in ways that address their specific needs and 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.[8](#Reference_8) Data from the June 2018 NDIS Quarterly Report demonstrates that a large number of non-employed carers of working age want to be in paid employment.[18](#Reference_18) 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.

## Government supports for families and carers

### Carer resources depleted

Carer resources have been significantly depleted with the introduction of the NDIS. In announcing new carer initiatives in 2019, the Department of Social Services (DSS) 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*’.[35](#Reference_35)

Data from the NDIA June 2020 Quarterly Report demonstrates the NDIS hasn’t had a significant impact for many families and carers.[36(p115)](#Reference_36) 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, with more than 80% of those who report being unable to work as much as they want, citing the situation of their family member with disability as a barrier to greater workforce participation.

This reflects the findings of the 2018 Carers Australia Report that argued respite is not an acknowledged service in the NDIS on the assumption that participant packages 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 negative term and must not be used.[37](#Reference_37) The Carers Australia 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.

The wellbeing of families and carers has in fact deteriorated with COVID19 with Carers Australia reporting evidence of:

* adverse impacts on the mental health and stress levels of carers and the people they cared for, and the increased isolation in lockdown
* reduced service access to respite opportunities including the use of formal services and informal opportunities to take a break from the caring role
* considerable challenges maintaining employment responsibilities while caring for someone at home including children with additional needs who were unable to attend school and were not well catered for in a digital environment.

Significant action is urgently required with Deloitte Access Economics analysis of future demand and supply of informal carers, suggesting a widening gap between demand and supply that will have significant implications for the NDIS and all governments.[38](#Reference_38) Deloitte Access Economics recommends to reduce the deficit in caring include greater flexibility in working arrangements, strategies to alleviate the impact of caring including carer respite services and improving the flexibility of care options.

### Recognising the needs of families and carers in their own right

In the UK, the policy shift to individual budgets for people with disability saw 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 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.[8](#Reference_8)

The parallel policies that recognise the needs of carers in their own right were not evident in the policy framework of the NDIS. It was not until March 2019 that the Australian Government announced the roll-out of a new model of carer support services (Integrated Carer Support Services (ICSS)) to replace those it currently funds.[39](#Reference_39) However funding for ICSS does not restore the funding for planned respite that was transferred to the NDIS, with planned respite only available through a limited number of $3,000 ICSS packages.

The Council recognised the need for additional support for carers in their own right and used its submission on the National Disability Strategy to recommend that DSS use the National Disability Strategy to develop and resource a new National Carer Strategy that would increase resources to family and carer support to at least pre NDIS days and provide a clear seamless pathway to support for carers in their own right. The submission also urged State and Territory governments to increase resources to family and carer support programs.

### Respite support

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.[40](#Reference_40) 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.
* 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, families and carers. Ultimately, the quality of experience for the person with disability relates to the extent 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 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.”*[41](#Reference_41)

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.

## What families need and what the NDIS provides

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 their 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.

There is a need for an integrated approach that aligns what the families need in their caring role, and what the NDIS provides to support them to continue on this role.

### 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 the life of a participant to enrich their life and as a safeguard such as through Circles of Support
* 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

There is no comprehensive register and analysis of Information, Linkages and Capacity Building (ILC) funded projects, so it is difficult to determine the extent capacity building identified above is available for families. An analysis of the 2018-19 Disabled Peoples and Families Organisations ILC grant round identified at least ten organisations nationwide providing capacity building for families, with three in Victoria, three in NSW, one each in Queensland, NT, ACT and one nationally. Seven of the organisations offer capacity building support to families of people of all disability types, one related to intellectual disability, one hearing impairment and one to people with autism spectrum disorder.

With the increase in virtual access in response to COVID-19, the resources identified above may have greater reach to families. This must be balanced however by the increased pressure on families as a result of COVID-19, who may have less clear-headed time to link in to virtual capacity building sessions and resources. It is therefore difficult to comment on the extent capacity building resources developed through ILC investment are adequate.

### Reasonable and necessary support for families across the lifespan

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. The NDIA information about supports for families and carers is reproduced in **Appendix 1**.

#### Current practice

##### Often unrealistic NDIA expectations of families

Appendices 2 to 6 are drawn from the Council’s 2014 paper ‘[Reasonable and necessary support *across the lifespan:* an ordinary life *for people with disability’*](https://static1.squarespace.com/static/5898f042a5790ab2e0e2056c/t/5b1a003a562fa72ab72fbc07/1598505538299/Reasonable+and+necessary+support+across+the+lifespan%3A+An+ordinary+life+for+people+with+disability+%28October+2014%29+Advice.pdf). They use a lifespan approach to identify the assistance families and carers need to enable participants to lead an ordinary life and the NDIA support provided.

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.

Table : Challenges for participants and suggested approach for building reasonable and necessary supports

| Cohort | Challenges not always reflected in R&N decisions | Suggested approach |
| --- | --- | --- |
| 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 |
| 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 Council 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.

##### Need for increased flexibility

Support for families was a strong theme in Practical Design Fund[[7]](#footnote-8) 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 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.

Council is pleased to see moves to increased flexibility in packages. The flexibility needs 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 fulfil the participant goal of increased independence and inclusion, while simultaneously providing an opportunity to reduce the impact of caring on other family members.

##### 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.[42](#Reference_42) 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 were 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 describing them under a goal of community participation.

#### Practice guidance that is inclusive of families and carers needs

The NDIA provides practice guidance to frontline staff to promote nationally consistent practice across all regions, whilst having regard to the individual circumstances of participants.

All NDIA practice guidance should consider the role of families and carers’ roles and the principles for support for all families and carers. This involves support that is highly flexible, enabling the family to determine its changing priorities so support can be used in ways the family perceives as priority in enabling all family members to thrive.

Council’s recommendations for NDIA Practice Guidance are included in **Appendix 7**. These recommendations are designed to inform operational policy, planning processes, communication with participants and training for NDIA and partner staff in considering the needs of families and carers.

## Recommendations

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.

### Example of 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.[[8]](#footnote-9)

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 adults with disability while simultaneously providing the opportunity for family members to have their own lives, include Shared Lives (also showcased in the Council paper *Contemporary options of housing and support)* and supporting participants to go on holidays and community camps.

#### Shared Lives

Shared Lives is a model of support where 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.[43](#Reference_43)

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 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 having a learning (intellectual) disability and 5% having a physical impairment. Shared Lives provides a vital service for regular planned time allowing participants and families to be apart in socially valued ways. Many Shared Lives relationships provide support when unplanned events happen in family life.

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 a 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 Australia Taxation Office (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 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.

### Council Recommendations

The Council recommends the NDIA:

1. Develops, operationalises and implements practice guidance in relation to support for families and carers consistent with the Practice Guidance included in this 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. Makes representations to DSS in relation to commissioning services in the ILC that strengthen families’ vision of an ordinary life and develop their skills to guide their family member to get there.

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## Appendices

### 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.

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

1. for a participant who is a **child**:
2. that it is normal for parents to provide substantial care and support for children; and
3. 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
4. the extent of any risks to the wellbeing of the participant’s family members or carer or carers; and
5. 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;
6. for other participants:
7. 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
8. the suitability of family members, carers, informal networks and the community to provide the supports that the participant requires, including such factors as:
9. 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
10. 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
11. 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
12. the extent to which informal supports contribute to or reduce a participant’s level of independence and other outcomes;
13. for all participants—the desirability of supporting and developing the potential contributions of informal supports and networks within their communities.

**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 *“while the NDIS plan focuses on the person you care for, the types of supports in the NDIS plan may also have direct or indirect benefits for you as a carer. This may include*[44](#Reference_44)*:*

* *family support and counselling due to a family member’s disability*
* *building the skills and capacity of other family members to help manage how disability affects family life*
* *supports that increase the participant’s independence, and ability for the participant to enjoy social and community activities independent of their carers*
* *supports to help with the role of caring, such as personal care and domestic help related to the person’s disability*
* *a support worker to be include in family outings to help the person with disability, especially if the family has other children*
* *access to respite care to give carers a break from their caring responsibilities.”*

### Appendix 2: Support for families of children from birth to 5 years of age[[9]](#footnote-10)

| 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  Reasonable & Necessary 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  To work in partnership with service providers to meet the needs of their child. | 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  Reasonable & Necessary Support |
| 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  Reasonable & Necessary Support |

#### Challenges to current practice

Support for families of children from birth to 5 years of age 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

It is hoped that strengthening practice in early childhood intervention to recognise the value of intervention in natural settings will contribute to family confidence to use grandparents and extended family to look after the child with disability.

### Appendix 3: Support for families of children aged 6 to 15[[10]](#footnote-11)

| 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/ Support Coordinator  Reasonable & Necessary Support |
| 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/NDIA planner  LAC/ Support Coordinator  ILC |

#### Challenges to current practice

Supports for families of children aged 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 and to develop informal support at school and in community

### Appendix 4: Support for families of young people aged 16 to 25[[11]](#footnote-12)

| 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  Reasonable & Necessary Support  LAC |
| 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 |
| 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  Support to maintain life roles other than as carer  Support to maintain relationships and belonging | Reasonable & Necessary Support |
| 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 | Reasonable & Necessary Support  ILC |
| 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  LAC |

#### Challenges to current practice

Supports for families of young people aged 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 aged 26 to 55[[12]](#footnote-13)

| Goals | Outcome | Supports | System |
| --- | --- | --- | --- |
| 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 have the support they need to care  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  Support to maintain life roles other than as carer  Support to maintain relationships and belonging | Reasonable & Necessary Support |
| 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 |
| 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 | Reasonable & Necessary Support  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 | Reasonable & Necessary Support  ILC |
| 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 | Reasonable & Necessary Support  ILC |

#### Challenges to current practice

Supports for families of adults aged 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 aged 55 +[[13]](#footnote-14)

The supports for people aged 55+ are the same as those outlined for people aged 26 to 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 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  Support to maintain life roles other than as carer  Support to maintain relationships and belonging | Reasonable & Necessary Support |
| 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 | 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 | Reasonable & Necessary Support  ILC |
| 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 | Succession planning seminars  Support to strengthen informal support  Positive opportunities for people with disability away from family including overnight | Reasonable & Necessary Support  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 |
| 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 | Reasonable & Necessary Support  ILC |
| 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 | “Whatever it takes’ supports to facilitate a healthy well-functioning family  Information, support & vision building  Practical support | Reasonable & Necessary Support  ILC |

#### Challenges to current practice

Supports for families of adults aged 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 7: Practice Guidance Recommendations for Families and Carers

The Practice Guidance below is designed to inform operational policy, planning processes, communication with participants and training for NDIA and partner staff in considering the needs of families and carers.

#### NDIS processes

* take 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
  + 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 / Support Coordinator role should extend to supporting families and carers to negotiate workplace adjustments enabling them to balance employment and carer roles.

##### In determining the level of support for families

* 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 families of children and young people

* to 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.

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). [↑](#footnote-ref-2)
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. [↑](#footnote-ref-3)
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. [↑](#footnote-ref-4)
4. By Professor Anne Kavanagh, Chair in Disability and Health, Melbourne School of Population and Global Health [↑](#footnote-ref-5)
5. including behaviours of concern [↑](#footnote-ref-6)
6. Families/carers of 0 to 14-year-olds are likely to be towards the younger end of the 25-69 age range. [↑](#footnote-ref-7)
7. 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. [↑](#footnote-ref-8)
8. In NSW there are centre based facilities providing respite for babies and very young children, some of whom are NDIS participants. [↑](#footnote-ref-9)
9. Extract from the Council’s 2014 advice ‘[*Reasonable and necessary support across the lifespan: an ordinary life for people with disability*’](https://static1.squarespace.com/static/5898f042a5790ab2e0e2056c/t/5b1a003a562fa72ab72fbc07/1598505538299/Reasonable+and+necessary+support+across+the+lifespan%3A+An+ordinary+life+for+people+with+disability+%28October+2014%29+Advice.pdf). [↑](#footnote-ref-10)
10. Extract from the Council’s 2014 advice ‘[*Reasonable and necessary support across the lifespan: an ordinary life for people with disability*’](https://static1.squarespace.com/static/5898f042a5790ab2e0e2056c/t/5b1a003a562fa72ab72fbc07/1598505538299/Reasonable+and+necessary+support+across+the+lifespan%3A+An+ordinary+life+for+people+with+disability+%28October+2014%29+Advice.pdf). [↑](#footnote-ref-11)
11. Extract from the Council’s 2014 advice ‘[*Reasonable and necessary support across the lifespan: an ordinary life for people with disability*’](https://static1.squarespace.com/static/5898f042a5790ab2e0e2056c/t/5b1a003a562fa72ab72fbc07/1598505538299/Reasonable+and+necessary+support+across+the+lifespan%3A+An+ordinary+life+for+people+with+disability+%28October+2014%29+Advice.pdf). [↑](#footnote-ref-12)
12. Extract from the Council’s 2014 advice ‘[*Reasonable and necessary support across the lifespan: an ordinary life for people with disability’*](https://static1.squarespace.com/static/5898f042a5790ab2e0e2056c/t/5b1a003a562fa72ab72fbc07/1598505538299/Reasonable+and+necessary+support+across+the+lifespan%3A+An+ordinary+life+for+people+with+disability+%28October+2014%29+Advice.pdf). [↑](#footnote-ref-13)
13. Extract from the Council’s 2014 advice ‘[*Reasonable and necessary support across the lifespan: an ordinary life for people with disability*’](https://static1.squarespace.com/static/5898f042a5790ab2e0e2056c/t/5b1a003a562fa72ab72fbc07/1598505538299/Reasonable+and+necessary+support+across+the+lifespan%3A+An+ordinary+life+for+people+with+disability+%28October+2014%29+Advice.pdf). [↑](#footnote-ref-14)