Reasonable and Necessary Support for Families

Introduction

Families play a central role providing young people with social and economic support. The degree to which families are capable of providing this support is one of the most important influences on a young person's health, development and wellbeing.[1].

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]. 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].

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

Evidence suggests that families, with all their flaws, tend to be around in the long run for people with disability and so the extent to which we can strengthen families' capacity to care, the better will be the life opportunities of their family member with disability.

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, placement etc. This includes the alternate family where children are in family based out of home care. Evidence of being a family comes not from legal status alone but from a shared sense of history, from shared emotional ties and from the existence of strategies for meeting the needs of individual family members and the group as a whole. In the context of people with disability and the NDIS, families will be diverse but their commonality will come from their mutual efforts that include a person with disability.

The NDIS recognises the importance of families and carers. In deciding the nature and level of support for people with disability, the NDIS is required to take into account what it is reasonable to expect families to provide. In addition, the NDIS supports families through the provision of a range of assistance to reduce the impact of the disability on family functioning.

For people with disability to have a good life, they need two things 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 a way that does not overly disadvantage other family members so that they too develop as strong capable adults with a willingness and capacity to remain connected. 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

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

[2] 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

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

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.

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:

- report evidence about the impact of caring on families and explore its implication for the nature of support
- document the voice of families talking about support
- examine the concept of respite and reframe it to be more productive for both the person with disability and the family
- link support for families to the framework of reasonable and necessary support for people with disability across the lifespan, and
- make recommendations about reasonable and necessary support for families.

Evidence about families and the impact of caring

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 (2008) provides a depressing picture of caring. One of the key issues to emerge from the research was 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 high care needs, 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.

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. Other research[4] demonstrated the impact of informal care, finding that families with strong social support networks that offered practical as well as emotional support made less use of respite care. For the majority of carers who did have support, the support provided was not without some issues attached with one in five carers having disagreements with

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

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.[5].

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 for someone with a disability on broader family relationships[6]. Almost one in three female carers aged 50 or less 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.

Llewellyn[7] 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. 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 in relation to the nature of support

    1. <u>In relation to issues of physical and mental health</u>

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. Further evidence from Llewellyn suggests that families in which there is congruence between the needs of their family member with disability and other family members and where their family member with disability is well integrated into their everyday life at

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[5] Higgins, D. J., Bailey, S. R., & Pxearce, 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.

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

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

least feel able to continue to care. The quantum of reasonable and necessary support and the activities it permits should meet both these outcomes.

2.   In relation to labour force participation of carers

The fact that a large number of non-employed carers of working age expressed a desire to be in paid employment reinforces the importance of policies that support carers who want to work. 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. Advocacy for greater flexibility in the workplace would assist both people with disability and carers to secure and maintain employment.

3.   In relation to concern about the impact on siblings

The research demonstrating the negative impact of caring for a person with disability on non-disabled siblings is of enormous 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. Family support 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.

4.   In relation to informal support

Increases in informal support, having people to call upon for practical and emotional support, improves family health and wellbeing as well as reduces the call on formal support. Support for families should include proactive assistance to help families strengthen their informal support.

5.   In relation to 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.

6.   In relation to prevention of out of home placement

The breakdown of family care, especially for children, has significant negative impacts on the child. Llewellyn's research indicates that intense effort must be directed to supports 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.

Where children are already in out of home care, the alternate family 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 is in the child's best interests.

Observations of support from families

> *".... When you get respite or you get support from a disability service, it is for that one child. So if you have got two kids at school, the kid with disability can be picked up and the other one can't, so that doesn't support a family at all."*

"It's not only about the person with disability in rural and remote areas; its also about their families, the effects on siblings for example, on relationships and single parent families."

Practical Design Fund projects that focused on issues for people in rural and remote areas had significant commentary around support for families. The strongest message related to the critical importance of flexibility and pragmatism in the application of rules; that common sense must trump rules and bureaucracy every time. Additional flexibility was perceived to be required because the lack of formal services can result in the unrelenting pressures on families in caring for a person with disability. People reported that a simple lack of flexibility had made life so much more difficult for people than what it needed to be. Families argued strongly that they know what will make a difference and their views should be respected and supported, utilizing local capacity in innovative and impromptu ways.

Examples of the flexibility required included:

Minding the siblings

"A family may need to take their child with disability to a major city for a medical consultation, minding the child's siblings becomes an issue that can be solved by a flexible package that enables a local person to be paid to perform this role."

Somebody to cook a meal

".... We have had access to allied health services and we have had access to health but that is not actually what we need. When my daughter wakes at 2 a.m. and screams for five hours and then spends many hours screaming during the day, I have no capacity to do my housework, no capacity to do what my son needs; so sometimes what I need is housework. Maybe somebody will cook a meal for me. Respite, God help us, yes, absolutely, we need that………..Sometimes we need really simple stuff. Child-care, for example, we were accessing, three different child-care services for my daughter because the child-care services weren't able to cope with her area of disability."

Money to spend as they chose to support their family

"In Queensland we had what was called the flexible family support until the government took the "flexible" out of it and it became "family support". It provided just a basic amount of money for families to spend as they chose to support their family; not just the child with a disability, but siblings as well, so you could spend on house cleaning, whatever it took to keep the families together. And Queensland has defunded that now."

Implications for 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 the changing life of a family. It is important for families to feel supported in order to build a trust that the NDIS will provide reasonable and necessary support when required.

Rethinking respite

Family support has traditionally been synonymous with respite, 'a short period of relief from something difficult or unpleasant'[8]. This paradigm sets up a most unhelpful dynamic seeing people with disability as 'burdens of care'.

Respite usually has two policy goals: providing support to carers and preventing or delaying admission to residential care. It is based on the assumption that a break will deliver much needed rest and refreshment and that families will have been strengthened and ready to take on the challenges of the returning family member. Evidence suggests however that rather than strengthen families, respite may actually reinforce the necessity for such periods of respite at increasing intervals and durations. McNally, Ben-Shlomo and Newman reported 29 studies from which there was little evidence that respite interventions had either a consistent or enduring benefit on carer well being.[9]

Armstrong and Shevellar[10] argue that respite confuses need with the strategies used to meet that need. For example, no-one 'needs' respite – not even parents. What they may need is rest, recovery, re-energising and inspiration. They may also need a way of hanging on to their own roles in domains of life other than caring for their family member with disability, e.g. caring for other family members, remaining in work or seeing friends. The definition of these needs as a service type, i.e. 'respite', closes off the possibility of exploring the multitude of ways that would really have met those needs.

The respite paradigm is fundamentally flawed. It meets the needs of one party at the expense of the other. The primary purpose of respite has been met by the removal of the person or by the exchange of the caregiver. However, if respite means that the person with disability is forced to be in places or doing activities that are not relevant or life enhancing, the respite may exacerbate the person's need or be damaging for the person, especially because the respite arrangement may be repeated regularly over many years. Significantly, the respite does not address the fundamental problem.

Armstrong argues that respite care changes the nature of the parent child relationship in ways that are not helpful. A broken disability service system encouraged families to present themselves as pathetic as possible in order to be 'eligible' for a particular respite service or payment. This arrangement can foster and promote an unhelpful role dynamic. In the absence of informal supports, families seek increasing amounts of formalised care arrangements to rescue them from difficulty. The parent sees himself or herself as the victim (of a broken disability service system) and the son or daughter is identified as the 'cause of the difficulty' and becomes the burden from which the victim must be rescued.

The need for respite is based on the faulty question of how to assist families to have a break. Where the question is reframed to "what would it take to enable the family and the person with disability to get a life?" one can use socially valued ways of doing things to guide the response.

The response can be based on the assumptions that:

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[8] Oxford dictionary definition
[9] Armstrong, J., & Shevallar, L., *Rethinking respite* at
http://www.socialrolevalorization.com/articles/armstrong/rethinking-respite.pdf
[10] Ibid

- All relationships are enhanced by time together as well as time apart.

- When children, young people and adults with disability are engaged in real life roles, families feel more supported.

- Increased informal networks are supportive for family.

Implications for support

For people with disability to thrive, it is important that all members of their family experience health and wellbeing. This will increase their capacity to care and remain connected. Family support that pits one family member against another; that meets the needs of one at the expense of another is counterproductive. Family support must be framed as life building opportunities for a person with disability while simultaneously providing the opportunity for family members to have their own lives.

Family support as capacity building

Capacity building refers to the developmental support that helps people to think about their lives and their supports in different ways. It exposes people to:

- 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, and
- 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 service system and have not been encouraged to be more empowered, more self sufficient or more active agents in their own lives. Reasonable and necessary support must encourage and support **capacity building to build** on the generic capacity building seminars and material that should be provided in Tier 2.

The impact of capacity building on people with disability and families

Current situation	NDIS without capacity building	NDIS with capacity building
People **maximise their deficits** in an effort to get maximise resources allocated to them	People continue to maximise their deficits in order to maximise their resources	People know that positive lives are built on high expectations. An overstatement of deficit and need is incompatible with high expectations
People **are frightened to use their initiative** lest it reduces their eligibility or priority for govt funded services and supports	People lack examples of the type of initiative that can lead to positive outcomes People do not know how to help people with disability to develop informal support (relationships with people who are not paid to be there)	People have ideas and develop confidence. They understand that paid support contributes to positive lives but understand the need to balance paid support with freely given relationships that are central to a meaningful life.
People **defer to others as the experts** on their lives	People create plans that continue to defer to service providers as the centre of expertise	People have confidence to negotiate what they want and how they want it. They exercise choice and take the level of control they feel comfortable with
People have **service plans**	NDIS planners encourage people to identify goals and then choose service providers to implement their goals. There is little focus on building an ordinary life and few plans include strategies to build informal support. A key focus for families is to get as much as you can from NDIA	People develop goals for the life they want to live and for most this translates into the use NDIS resources to compliment the support and provided by family and friends.
Funding is allocated to services that provide assistance to the most needy	Funding is used to purchase services from traditional disability service providers	People are actively choosing from a range of services and supports including mainstream and informal supports. The NDIS package assists people to build informal support
People are dependent users of service	People are consumers of service who have some choice but limited opportunity to avail	People are active citizens, exercising choice and control, engaging in social, economic

Current situation	NDIS without capacity building	NDIS with capacity building
	themselves of the choice and control anticipated in the NDIS	and political life.

Implications for support

It is critical that support include opportunities for capacity building to enable families to have a vision of an ordinary life and to have the knowledge and skills required to remove barriers and enhance opportunities so that the ordinary life becomes a reality. Capacity building should be available through access to Tier 2 seminars and resources as well as provision for specific individualised strategies funded in the participant's plan.

Reasonable and necessary support for families across the lifespan

Reasonable and necessary for families is related to the age and circumstances of their family member with disability. The two issues have been linked in the Council paper *Reasonable and Necessary Support Across the Lifespan* that guides the provision of support to achieve the following outcomes:

Domain 1:   Families understand the strengths, abilities and special needs of their family member.

Domain 2:   Families know their rights and advocate effectively for their family member.

Domain 3:   Families help their family member to develop and learn.

Domain 4:   Families feel supported.

Domain 5:   Families are able to gain access to desired services, programs, and activities in their community.

Domain 6:   Families enjoy health and wellbeing.

Recommendations

Support for families is a critical element of building ordinary lives for people with disability. Research affirms that the degree to which families are capable of providing this support is one of the most important influences on a person's health, development and wellbeing.[11] Within the context of the NDIS, support for families is always in the context of their family member with disability. Within this frame, the Council recommends that support for families should:

1. Be considered very flexibly: Families feel supported when they have people to call on for practical and emotional support and when their family member with disability is well integrated into their everyday life. Decisions about reasonable and necessary family

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

support should assist families to achieve both these outcomes while simultaneously taking into account the need of all family members to thrive. Once allocated, the family should be given the authority to use the supports flexibly in accordance with the changing priorities of the family.

2. Provide 'whatever it takes' where there is heightened risk of out of home placement.

3. Provide support and facilitation to enable families to build informal support.

4. Include support to enable key family members to remain in or return to work including

    a. stimulating life building support for the family member with disability at those times

    b. if desired, assistance by the LAC in negotiating increased flexibility with a workplace.

5. Phase out any use of the term respite but ensure that it is replaced by a response that allows both the person with disability and their family to have a life. It is critically important that in removing a term that can be perceived as demeaning, we do not overlook the essence of what we are trying to achieve, i.e. supporting family resilience in families that are the primary source of support for the person with disability.

6. Undertake additional work on respite care to understand the nature of current provision and the work that is necessary to reframe the support to enable both the person with disability and the family to thrive.

7. Include capacity building both in Tier 2 seminars and in targeted strategies in support packages.

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