



**Submission to Inquiry into Better Support
(Care) for Families Living with Disability
(Carers¹)**

**House of Representatives Standing Committee
on Family, Community, Housing and Youth**

July 2008

¹ Carer is not a term that the majority of families consulted by NCID identified with, they find the term demeaning as it reduces their relationship with their son or daughter (usually) to only one aspect of their many roles. All parents NCID consulted firmly stated that they wanted to be identified with the love they had for their sons and daughters and this was best expressed in the words mum or dad.

The National Council on Intellectual Disability (NCID) was established over 30 years ago by parents and friends in an endeavour to improve the quality of life of people with intellectual disability and to fill the need for national unity and information.

The Council is the recognised national peak body with the single focus on intellectual disability, ie, our actions and priorities centre on issues that affect the lives of people with intellectual disability and their families. Our mission is to work to make the Australian community one in which people with intellectual disability are involved and accepted as equal participating members.

NCID has over 5,000 members representing all 8 States and Territories. In addition to having people with intellectual disability on its Board, NCID receives policy advice from Our Voice. Our Voice is a committee the membership of which is exclusively people with intellectual disability representing all States and Territories.

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Introduction

The National Council on Intellectual Disability (NCID) welcomes the opportunity to provide input to the House of Representatives Standing Committee on Family, Community, Housing and Youth – *Inquiry into Better Support for Carers*.

NCID would like it noted that the constituency represented in this Submission do not in the main refer to themselves as “Carers”. Our constituency are first and foremost the parents and family members of a person with an intellectual disability. In undertaking a “caring” role for their sons and daughters or family members with an intellectual disability, they do so as all parents and families do. **The fact that this role of being a parent or family member is frequently extended into undertaking a role of providing “care and support” outside the norm is due solely and wholly to the inadequacy of appropriate funded supports.**

It is the contention of NCID that if all people with an intellectual disability received adequate and appropriate support and services to enable them to live a fulfilling and meaningful life in society, as would be recognised for any citizen, then this Inquiry and debate would not be taking place. The majority of families living with a person with a disability say that if the community and governments met the needs of the family member with a disability then they would meet the majority of the associated needs of the family.

1. How role & contribution of Carers should be recognised

Carers are only defined as such because they are perceived to be taking on a role in relation to supporting a family member above & beyond what would commonly be accepted as the normal family relationship.

The term “Carer” colloquially applies to someone providing a supported worker role, usually in a paid context. An unpaid “Carer” is usually a family member for whom there is often little or no choice in taking on such a role. All parents have a role caring for their children, however the degree or extent to which they undertake that role is usually a matter of choice. For example I can choose what extracurricular activities I will take my child to but I have no choice over attending multiple medical appointments or my son or daughter having to spend periods of time in hospital.

For many (mostly women, but increasingly not exclusively) stay-at-home parents, the role of caring for and being the major support for their children is generally not valued by society and is seen as a temporary “stop-gap” before going back to “real” work. This is a position continually reinforced by governments as the rhetoric & policy is focused on supporting and encouraging all adults into the paid workforce – the only “legitimate” occupation. Conversely however, there is also a significant social and political position, which expects and encourages families to provide the

requisite care and support for ageing parents or child with a disability as the “right” thing to do.

Because “caring” is generally seen as a “labour of love” (particularly for children) it is assumed the additional recognition and value for the role is not required. This can be compounded by, particularly, parents’ own feelings of guilt, fear, inadequacy and reluctance to allow others in. However, if the society norm is to value the role of caring generally and it is seen within the normal context of a range of supports a person receives/accesses during the span of their lives then many of the negative associations with caring start to fall away.

Families living with a family member with an intellectual disability in the main do not wish to be paid for the care they provide as they wish to preserve the integrity of the family relationship they have. This relationship can become very muddled and the all-important role of advocating for that family member diminished if the relationship becomes a professional one. However, this is not to negate the significant and additional cost there may be to the family in providing support and care. This frequently revolves around the amount of time required to coordinate and manage the level and range of care required by their family member. This also includes considerable time required to source appropriate services and support. Families frequently talk about the amount of time it takes trying to find out what services are available and how to access them. This coordination and advocacy role again is frequently not recognised or valued.

The essential and complex roles that families living with disability provide could be better recognised and valued through government implementing policy and planning that recognises the range of caring models that exist, and supports greater choice for families in the degree to which they to provide care for their child.

Choice in caring is critical; caring for your children is not an option. Whether or not you can access the range of appropriate additional supports/services for your child will determine the level / degree of caring you undertake ,ie, full-time stay-at-home parent through to full-time paid employment outside the home & all variations in-between.

The role of the Carer becomes valued when the “care” is centred absolutely on the needs & requirements of the person with a disability. This means every aspect of the person’s life is supported by the most appropriate service which enables that person to live their life in a way that any “normal” person would expect and this would not usually mean having a family member doing everything for you and supporting you in every aspect of your life.

2. Barriers to social & economic participation (particularly access to employment).

As previously stated, the degree and extent to which parents or family members undertake the role of carer is inextricably linked to the degree and level of other support and services the person requiring the support is able to access. In addition, the role of carer is partially determined by the degree to which the carer *wishes* to take on that role, and this is likely to change over the lifespan of the person requiring additional support.

It is essential that the approach to supporting families living with disability to return to paid employment or to engage in the community is flexible, not model-specific and enables the family to make the choices and decisions. **It is vitally important that policy and planning do not continue to pursue a position in which the expectation is that families will re-enter the paid workforce as well as continuing to provide a majority role in caring for or coordinating the care for the person with a disability.**

The multiple roles that a parent of a child with a disability will continue to undertake need to be fully recognised and appreciated. The extended role of many of these parents (as with many other parents who, for a variety of reasons, remain out of or only partially in the paid workforce) is invaluable in the community. To quote Anne Mann in her essay “Love and Money: The Family and the Free Market” *“They are stalwart volunteers: the fundraisers and lynchpins of local community life. They run everything that matters in the world of the child: playgroups, fundraising for kindergarten committees, school canteens, local sporting clubs and cultural activities.”* In addition to these generally recognised community roles, parents and families of children with disabilities also frequently provide significant amounts of time undertaking a range of other activities such as: supporting organisations which provide information and assistance to families of people with disabilities eg Down Syndrome Association; providing education and information to schools and other organisations; organising support groups, lobbying and advocating for local services and support.

The majority of parents wish to spend some time with their children in their early years. The degree to which they return to the paid workforce is dependent on economic circumstances, access to affordable childcare and the health and wellbeing of their child. There is no single model of what parents wish to do: what is clear is that parents want flexibility and an opportunity to choose what is in the best interests of their family.

For the parents of a child with an intellectual disability this adds a layer of complexity which frequently narrows the range of choice and opportunity: this is particularly compounded where the child has a range of health or physical needs. Opportunities

to undertake paid employment or other community activities is dependent on being able to access appropriate childcare support. Frequently this is provided by other extended family members and not through paid services.

Accessing appropriate support services for a child with complex or profound disabilities often becomes harder as the child ages, prior to admission to school. This frequently means not only do parents not have the choice of returning to the paid workforce, but they can also be isolated from other community and social engagement.

In the early years of life with a child with a disability, opportunities to meet with other parents to discuss issues and obtain information on available supports and services can be critically important. The availability of local early childcare centres, which can be focal points for parents to make contact with other parents or obtain information about access or referral to professional services, could address many issues of isolation. **Talking to other parents and ease of access to relevant information has been identified frequently by parents as having a significant impact on their and their families' stress levels and capacity to cope with the role of caring for a person with a disability.**

As children age, the role of parents changes from that of primary carer of virtually all their child's needs to that of advocate and coordinator of their child's needs. The more complex the needs of the child, the more complex and time consuming this role is. Some parents will take on this role exclusively and some will engage other supports to assist enabling them to undertake other activities such as paid employment. Being able to access after-school care may be critical for some parents to enable them to work, being able to take time off to attend meetings with school or having appropriate transport to and from school may be issues. What is critical is that parents should be able to determine what is most needed for their child and that they are able to access the required support and services.

For most parents, the expectation is that their children will become independent from them at some stage and that they will then be free to undertake other opportunities for themselves. Many parents do however, continue to support their children in a variety of ways this can include through tertiary education, opportunities to travel or obtain somewhere to live independent from the family home or supporting and caring for grandchildren. **For parents of children with a disability, the opportunity for their child to live independently can become dependent on the opportunity to access external support services. This can be a critical juncture when external support services can diminish significantly and parents are left with few options or choices in how they live their lives, as there are few options and choices available to the person with a disability outside the family home.**

3. *Practical measurers required to better support carers.*

It is not possible to better support parents who are caring for a person with an intellectual disability unless the person with an intellectual disability has access to the full range of appropriate services and support that enables them to live a full and productive life in the community. Anything other than this will by default continually leave parents filling roles that could and should be provided by paid supports.

The role of parents is to continue to care for, advocate for and coordinate the relevant support and services their child needs in order to lead a fulfilling and productive life.

Parents still frequently identify the need for better information on where and how to access relevant services and support. This information needs to be available locally through a local service that is already a well-known existing structure within the community, eg local councils. A local single source of information and assistance needs to be made known to parents from birth or time of diagnosis and should continue to be available to parents right through the life span of their child. The segmentation of services and support dependent on the child's life stage only adds to parents' confusion and stresses as each time the time-consuming process of seeking out relevant information starts again.

Parents need to be able to determine what services and support are required for their child and funding for such is attached to the person with the disability throughout their lifespan and is managed by the parent. In this way, parents would be able to determine what is required to enable them to return to the paid workforce if they wish or to support them in a greater "caring" role. In this way, funding would be applied flexibly at differing stages of the person with a disability's life and may be applied to range of differing kinds of support and services.

4. *Recommendations to assist carers to access the same range of opportunities & choices as the wider community (including making choices within the caring role, transition into & out of caring & planning for the future).*

a. *Supporting people with disability is the major way to support their families*

Whatever strategies are finally agreed upon by the Committee and the Government, unless the first one is a major injection of funding into supporting people with disability then this will be just another inquiry in a long line which will continue to stretch beyond the life of this Committee's members.

Recommendation:

That the Government, with the support of all parliamentarians, must commit sufficient funds to meet support needs of all people with disability within the life of this parliament.

b. Families living with disability

As has been stated in this submission, calling families and parents ‘carers’ is highly (if unintentionally) disrespectful and misleading - another expression must be found and NCID’s suggestion is ‘families living with disability’.

Families living with disability are different to families providing support and care to elderly relatives. This situation must be recognised and different consideration be given to the two different groups. A failure to do this will mean that families living with disability will always be disadvantaged and their needs not truly met.

The role of caring is closely associated with the carer being in the same building as the person being cared for. This leads to the misconception that when the person with disability moves away from the family home that the caring role ceases. This is not the case for families living with disability. (This close association is another reason why the ‘carer’ term is insensitive in describing the relationships within a family). In most instances the family will remain the principle support for the individual with a disability and this must be recognised and supported; eg, within guardianship legislation.

Recommendation:

That the Government, with the support of all parliamentarians, stop calling family members ‘carers’ and acknowledge the complexity of a relationship based on love.

Further, that the Government with the support of all parliamentarians use the term, ‘families living with disability’ in the place of ‘carers’ in the context of disability.

c. Flexible supports

The most important consideration for families living with disability, after adequate support funding, is that the support they receive is flexible. In considering the need for flexible supports, two questions are important:

- who best knows the support needs of the family and the person with a disability, and,
- who will bear the consequences of the decisions made.

In both instances, it is obvious that the family and the person with a disability are in the best position to make the decision about their needs and also to change arrangement if their circumstances change, or the original decision needs to be amended. The reliance on bureaucrats to make decisions and to respond to changing needs or amend decisions has led to a situation where support is inflexible and totally non-responsive.

In considering the proper role of bureaucrats we must be mindful of the appropriate role of governments and the appropriate level of decision making; the principle of subsidiarity. Governments have a responsibility to 'spend' taxpayers funds in an equitable and accountable manner; in this context governments have a role in:

- establishing outcomes,
- setting criteria for eligibility,
- developing assessment procedures,
- allocating resources based on the eligibility criteria and assessment and the auditing of funds expended.

Decisions about how the outcomes are achieved must be left to those who have the best understanding of the situation of the family and those who will bear the consequences for the decisions made. Only then will the support be truly flexible and responsive to the needs of the family.

The question of evidence-based policy making and decision-making is one that is never applied to support for people with disability and their families, though it is the first question that is asked when matters of health or education are raised within governments. This situation must change if people with disability are to get their needs met. Two prior questions become essential; "what outcomes do we want from this funding?" And, "what is the best way to achieve these outcomes for individuals?"

See attachment A for NCID principles on Self-Directed Support.

Recommendation:

That the Government with the support of all parliamentarians immediately introduce self directed support for all Australian Government employment and 'respite care' funding.

Further, that the Government in the first instance use the processes and practice of 'in Control UK' as its guiding implementation principle.

d. Change the name of ‘respite care’

There is an old argument that typifies the serious conflict situations that families living with disability find themselves in, because they are seen as ‘carers’. Is respite care for the family, the parents or the individual with disability? To outsiders, ie, non-bureaucrats, it seems like a semantic issue that would ‘obviously have no bearing on whether someone gets support or not’, surely?

But as the decision does not lie with families but with bureaucrats, there are families who miss out on support. For example, a family in NSW wanted in-home ‘respite care’; they were told that the support worker the service would provide could only look after their child with a disability; the ‘non-disabled’ child would have to have a child minder all of their own; respite care was only for the child with a disability, not for the family! The parents pointed out that this would mean they would have two ‘carers’ in the house (which was ‘over the top’) and that if they were going to have to pay for a carer anyway, why would they need one from the respite service! Further, the reason they were asking in the first place was because they could not afford a carer and go out, so the end result was (and remains) no in-home respite care, no break for the parents! When asked why a respite carer could not look after a child without a disability, the parents were told that that was the ‘rule’! So much for meeting the needs of the parents, so much for meeting the needs of the individual with disability, so much for flexibility. We have rules that stop families from receiving support made by people who do not have to bear the consequences, that is, it is the family that has to struggle on without a break, not the bureaucrats.

Recommendation:

That the Government with the support of all parliamentarians no longer use the term ‘respite care’ and instead view the funding as flexible family support.

e. Links to other government initiatives

It is important that any recommendations that the Committee makes, and the Government in its response, are framed within the context of current Australian Government initiatives, ie,

- Ratification of the UN Convention on the Right of Persons with Disability
- National Disability Strategy

- Re-negotiation of the Commonwealth, State and Territory Disability Agreement
- Deliberations of the Disability Investment Group.

One of the great failings of the current system of providing support to people with disability and their families is the disjunction between Government programmes; both within the Australian Government (eg, respite support is funded by both the Department of Health and Ageing and the Department of Family, Housing, Community Services and Indigenous Affairs) and between the Australian Government and State and Territory Governments. People with disability and their families expect support to be funded in a manner that meets their needs (including as their needs change) in a coordinated way with little bureaucracy and not being told to 'go elsewhere'.

Recommendation:

That the Government with the support of all parliamentarians ensure that all support is provide in a efficient and effective manner which does not place additional administrative burden on families living with disability.

f. Autism Package provides three good examples

Aspects of the recently announced \$190 million 'autism package' are commended to the Committee. The initial package set a particular number of families that would benefit from the intensive intervention elements of the package. The Parliamentary Secretary consulted with many families (and professionals) and as a result this element of the package is now available to all families within the qualifying group; this is the first time the Australian Government has implemented a universal entitlement programme for people with disability.

The second aspect of the package that is commended is that it gives the parents the decision making power as to which organisation will provide the intensive support. This is the first instance of the Australian Government explicitly enabling families to self-direct their support to achieve stated outcomes². The provision of specialist autism advisors to assist families to make decisions is welcome.

² Some might want to contest these two statements and use the Australian Government's employment programme as instances of both an entitlement programme and one where participants can choose their provider. NCID's response is that for people needing intensive employment support the Australian Government's employment programme is capped; and the numbers of people with on-going maintenance needs has been decreasing over the past ten years. Participants do not have a choice of employment provider the recent of the allocation of 250 places to business services is an

The third notable aspect is that for the first time the Australian Government is making evidence based decisions based on research. As has been stated this is unknown in the disability area though it is usual in health and education.

Recommendation:

That the Australian Government with the support of all parliamentarians continue to make decisions based on research evidence, that all programmes are entitlement programmes (within the set criteria) and that self-directed support principles are used for all funding for people with disability and their families.

example of this; instead of making a decision on the criteria for access to the 250 places and then letting the successful applicants decide where they would best get their employment outcomes politicians and bureaucrats made this decision for them! And, despite the promises made when case-based funding was introduced recent examples have demonstrated that people are unable to change providers if they are not getting the outcomes they expected from their current provider.
