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Submission No. 1219
(Inq into better support for carers)

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Committee Secretary
Standing Committee on Family, Community, Housing and Youth

SUBMISSION TO PARLIAMENTARY INQUIRY INTO

BETTER SUPPORT FOR CARERS

Attached is my submission to the above inquiry.

Kindest Regards

Deirdre
07 July 2008

Personal Experience of Caring and Carer Issues

At 55 years of age, I have been a carer for much of my adult life.

- Since 1980, I have provided care for my 27 year old son who has a severe intellectual disability due to birth trauma. He is mobile but otherwise totally dependent for all his care and support needs. My son is non-verbal, vision impaired, has epilepsy and autistic tendencies. In his adolescent and now adult years, his father, my ex-husband, has been his "primary" carer.
- From 1991-1996, I supported my mother in the care of my invalid father after he became ill in 1991 until his death five years later. Towards the end of his life my father also suffered from severe depression.
- From 1998-2002, I provided in-home care for my mother (including management of her financial affairs) after she suffered a stroke which resulted in right side paralysis and a speech impairment. While my mother had a physical disability, her cognitive capacity was intact until the last month of her life.

In addition:

- Since the early 1990s, I have been actively involved in disability advocacy aimed at securing better services and support for people with disability and their families.
- I am currently a PhD candidate at Curtin University conducting research into the supply of and demand for accommodation support services for Western Australians with intellectual disability since the 1950s. As part of my research I conducted in-depth interviews with 23 parent carers who were currently applying for, or planned soon to apply for, long term out of home care for their son of daughter with intellectual disability.

The Caring Experience

Based on my personal experience, disability advocacy and current studies, I believe that the experience of providing care is qualitatively different depending on:

- **the cognitive capacity of the person in need of care and support** (e.g. when I was caring for my mentally competent, physically handicapped, mother whilst also caring for my intellectually handicapped son, she understood that meeting my son's needs had to come first. My mother was aware that I also had other demands in my life and was consistently concerned for my wellbeing. My son, on the other hand, has no comprehension of the possibility that he may have to wait in line to have his needs met, nor that I may have needs and responsibilities that are unrelated to him). Based on my personal experience, I believe that caring for a person with a severe intellectual disability is considerably more demanding than caring for a person with a severe physical disability – probably by a function of ten!

- **the nature and quality of the relationship between the person providing care and the person receiving it** (e.g. my experience as a daughter providing care for my mother was influenced by the pre-existing dynamics of our relationship as well as the relationship between me and my siblings. Whereas, as a mother providing care for my son, I have greater authority and responsibility in the caring relationship – although there is no way in the world that I could impose my own will on my man-sized son if he was determined to resist – as he often does). I would imagine that providing care to a partner in what is potentially a more equal, "chosen" relationship is different again.

- **whether the disability is lifelong or acquired** (e.g. my son has always been and will always be dependent on the care and support of others. My mother had an independent lifestyle before she acquired a disability which meant that, as well as her physical support needs she also required support with the management of her financial and domestic affairs associated with her previous lifestyle. She was also aware of what she had been able to do previously, compared to what she was un-able to do after acquiring her disability. My son has no basis upon which to make such a before and after comparison, nor does he have to meet the requirements of a previously independent lifestyle. Indeed, he will never have the opportunity to lead a more independent lifestyle i.e. away from the family home, without substantial service support).

- **the lifestage of the person with disability** (e.g. I have observed in my own son and heard from other parent carers that as the child moves into adulthood they are more determined to assert their own will, forcibly if need be. When this is coupled with impaired cognitive capacity and/or behaviour problems and also considering the adult size of the person with disability, it can be very difficult to elicit compliance or cooperation in the performance of necessary daily tasks or routines. There is also a social expectation that a younger person with disability should have a certain degree of social and economic participation consistent with the norms considered appropriate at this lifestage. As my mother was elderly and nearing the end of her own life, she appeared to be content with a more retiring lifestyle which reduced the demands on me to support a more extensive social engagement).

- **the lifestage of the carer** (e.g. in my younger years I had more stamina to meet the needs of both my son and my mother but I also had greater external demands on my life in terms of building a career, earning a living and maintaining social networks. As such, during my earlier caring years, my caring responsibilities significantly eroded the time available to devote to my other commitments and lifestyle goals. In my latter years, while my stamina is diminished, I am happier to lead a more socially reclusive life such that my caring responsibilities have less of an impact on, and require less of a personal sacrifice in terms of, the other dimensions and demands on my life).

- **the intensity and nature of care required and provided** (e.g. my very slightly-built mother required intense physical care whereas my equally solidly-built adult son also requires physical care but, just as importantly, he requires behavioural management, oversight, guidance and supervision. To my mind the needing to watch over, supervise, organise etc is much more draining and time consuming on the caring responsibility than simply providing for the physical care needs of the other. Also, in his younger years my son was very physically aggressive and had severe, life-threatening epilepsy requiring frequent hospitalisation, both of which added greatly to the demands of caring. Thankfully, these issues are now less prevalent since he has attained adulthood).

- **the period of time over which care is required and provided** (e.g. I provided care for my mother over a five year period from the time she acquired a disability until she died. My caring commitment to my son has extended over the past 27 years and will probably continue, in one way or another, for the rest of my own life). On the same basis, I would suggest that parent carers are likely to have provided care over a much longer period of time than is required or expected of partner carers, or adult sons/daughters who are meeting the needs of elderly parents.

Note: This submission applies most directly to the experiences of parent carers and especially those providing care to an adult son or daughter with a lifelong intellectual disability.

Dimensions of Caring

On the basis of my observations above, I believe that it is not possible to generalise caring as if all carers go through the same experience and can therefore be supported in the same way (i.e. a "one size fits all" strategy).

I also believe it is important to acknowledge that there are different dimensions associated with the caring role and responsibility.

- **Physical dimensions of caring** (e.g. lifting, bathing, feeding, managing medication, hygiene requirements, behavioural management etc).
- **Practical dimensions of caring** (e.g. financial and administrative requirements, providing transport, assistance with shopping, domestic maintenance etc).
- **Emotional dimensions of caring** (e.g. based on a personal relationship, concern for, and commitment to, the wellbeing of the person with disability, advocating for and representing their needs etc).
- **Moral/ethical dimensions of caring** (e.g. as a way of living life compassionately with concern and practical consideration for the needs and vulnerabilities of others).

Some commentators have described these different dimensions of caring as: ***to care for*** (the physical labour of care); ***to care about*** (the emotional relationship of caring); ***to take care of*** (the practical responsibilities of caring) within a moral and social framework of ***an ethic of care***.

Caring Impacts

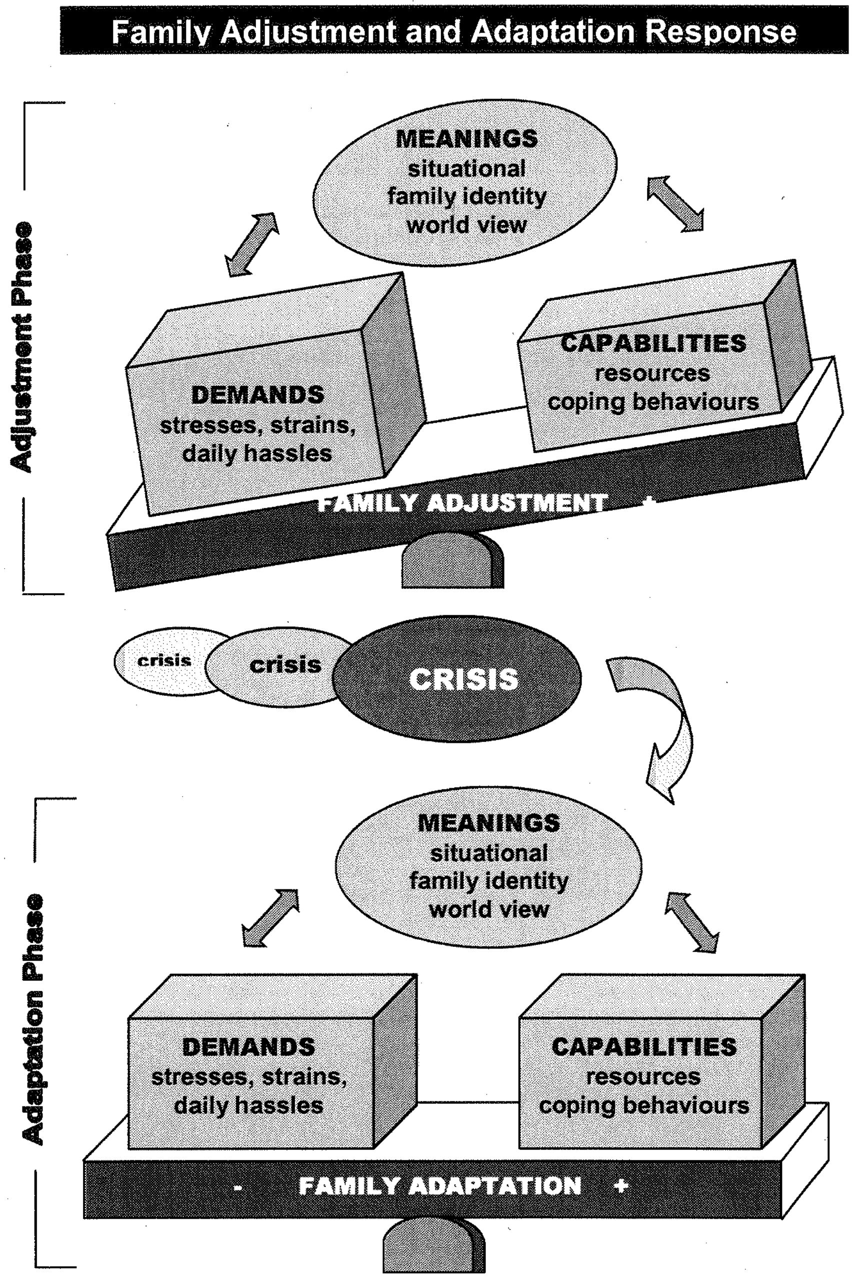
I believe that the quality and dynamics of the relationship between the person providing care and the person receiving it is integral to both the demands of caring and the capacity to deliver the care that is required. These dynamics are likely to be influenced by many factors including whether the relationship is determined by choice, biology or circumstance.

The impact of caring on the person providing it is a function of the extent and nature of the support required by the person in need of care balanced against the capacity of, and resources available to, the person/s providing care.

For example, the provision of care may exact a greater toll if the person with disability has very high support needs (including intense health care needs, behavioural issues, psychological/mental health problems, sleep disorder etc, etc) and/or the capacity of the carer is diminished due to ageing, ill health or multiple other demands and responsibilities, OR, indeed, if both apply i.e. high support needs and diminished carer capacity. It is not in the interests of either party if caring demands exceed carer capacity.

The balance between caring demands and caring capacity is also influenced by the resources/services/supports available to reduce the caring demands and/or increase caring capacity.

In studies on family coping and family resilience, Patterson (2002) has conceptualised this process graphically as below[1].



Adapted from Patterson (1988)

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[1] Patterson, J.M. (2002). Integrating Family Resilience and Family Stress Theory. *Journal of Marriage and Family,* 64(2): 349-360

As can be seen from this diagram, family adaptation occurs when demands balance capabilities. However, the single support upon which the plane of family adaptation is balanced makes the situation very precarious and vulnerable to any increase in demand or diminution of capacity. A more stable situation would exist if there were a series of supports underpinning the plane of adaptation that could better withstand pressures from either end.

That so many carers are reporting adverse health and psychological outcomes as a result of their caring role, would suggest that there is a significant and consistent imbalance between caring demands and caring capacity.

The extent and implications of this imbalance has been a feature of my own personal experience of caring and my current PhD research based on interviews conducted with parent carers. For example in my personal experience:

- My father (who was an only child) provided care to both his ageing parents. When they died, within a year he became ill himself and died five years later.

- My mother provided care for my father during his illness. When he died, she became ill herself (from which she recovered) and then within two years suffered a major stroke and died five years later.

- I provided care for my mother over a five year period and, shortly before she died, was diagnosed with breast cancer requiring six months treatment. (In this instance, I am pleased to report that six years later I am cancer free and still alive!!!).

In my PhD research, many of the parent carers I interviewed reported both physical and mental health problems that were directly attributable to their intense caring responsibilities (including muscular skeletal problems, low energy, anxiety and depression).

The Role and Contribution of Carers

By definition, the role of carer exists as a function of their personal caring relationship with a person needing support due to disability. In other words, it is the need for support of the person with disability that is the paramount consideration in determining the role, identity and label of "carer".

As in all relationships, both parties should, ideally, have equal status and be afforded equal dignity and respect with whatever rights and responsibilities (within capacity) ensue from such a relationship.

I would argue that a policy focus on the role and contribution of carers should derive from a social commitment to supporting <u>both</u> parties in the caring relationship. As such, a policy commitment to supporting carers should <u>not</u> detract from the social need to also provide high quality formal services to meet the needs of people with disability, nor should it be framed as a cost-saving measure in which informal caring is "propped up" as a supposedly cheaper alternative to quality social service provision for people with disability.

Caring requires resources (time and effort) whether these are provided formally or informally. A failure to provide formal services to meet the needs of people with disability does not "save" resources but simply represents a transfer of responsibility for providing them from the public to the private domain.

The "contribution" of carers is both personal and social.

The **personal contribution of carers** derives from the carer's concern for the wellbeing of the person for whom they provide care and their commitment to ensuring these needs are met. This contribution cannot readily be quantified nor costed in monetary terms.

The **social contribution of carers** derives from the contribution of caring towards Australian society and more particularly the creation of a more caring, compassionate society. As such, caring contributes to the nation's social capital. Too often this contribution is quantified and costed as to how much taxpayer's money is saved when caring is provided informally rather than through formal service provision. I do not believe that this should be the criterion for assessing the contribution of carers.

Supporting Caring and Carers

The primary concern of most carers is the wellbeing of the person for whom they provide care. Were this not so, carers would not be prepared to sacrifice their own health and wellbeing, and potentially the wellbeing of others, (as they do) to meet the needs of the person with disability.

Therefore, a major consideration in ensuring better support for carers is ensuring better support for people with disability.

Principles of Supporting Caring and Carers

In developing a policy framework for providing better support to carers, I would like to see the development of some core principles against which specific initiatives are tested and measured[2]. I would imagine that development of such principles would require an extensive development and consultation process. However, they might encompass something along the following lines:

Rights

In Australian society:

- All people with disability have the right to support that will enable them to maintain their health and wellbeing, to develop their capacities to achieve the maximum possible level of independence, and to participate in their community consistent with accepted social norms.

- All adults with disability have the right to live independently (with appropriate support) if that is their wish.[3]

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[2] As part of the first Commonwealth and States Disability Agreement, all jurisdictions agreed to adopt a series of legislative principles based on the Commonwealth Disability Services Act (1986). These principles conferred certain rights on people with disability but provided no mechanism for legal enforcement. I would assert that any statement of the rights of people with disability and their carers must also include a process by which these rights can be legally enforced.

[3] In December 2007, the UK Government published a document *Putting People First: A shared vision and commitment to the transformation of Adult Social Care* which noted "the Government's commitment to independent living for all adults." The document is available via this link

- All people with disability have the right to choose who will meet their need for support and the circumstances under which such support is provided[4]. (In cases of significant cognitive impairment this right may be conferred onto a legal representative of the person with disability).

- The choice to provide informal care and support to a person with disability and the manner and time frame over which such care and support is provided must be freely given rather than obligated due to a shortfall in formal service provision.

- People who provide informal care and support to a person with a disability have a right to access services and supports that will enable them to maintain their own health and wellbeing, to pursue their own lifestyle goals and to meet their responsibilities to others who may depend on them.

- The provision of informal care to a person with disability should not result in any significant diminution in the quality of life of the carer or the quality of life of significant others in that person's life.

Responsibilities

- The community (through Government funding and provision of services) shares in the responsibility of meeting the needs of people with disability.

- Families have a natural responsibility to provide needed support to their own members acknowledging that there is no net value to be gained if the requirements of providing care results in a reduction in the health and wellbeing of the person providing it or the health and wellbeing of other family members who may also be dependent on the carer.

Barriers to Social and Economic Participation

As noted above, caring requires time and effort. The amount of time required to meet the needs of a person with a disability (particular a person with high support needs) inevitably detracts from the time available that might otherwise be spent on other pursuits including social and economic participation.

According to the Australian Bureau of Statistics (2003) close to 600,000 Australians have a disability that is so severe they "always" require assistance with the core activities of self-care, mobility and/or communication while more than 650,000 Australians "sometimes" require assistance with these activities. To meet the needs of people with disability, the ABS reports that in 2003, 175,000 carers spent an average of 40 hours or more a week in caring activities, while a further 87,300 spent between 20 and 39 hours a week[5].

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[4] Galvin, R. (2004). Challenging the need for gratitude: Comparisons between paid and unpaid care for disabled people, *Journal of Sociology*, 40 (2): 137-155 reported on a study of the experiences of people with disability in Australia, New Zealand, the United Kingdom and the United States which indicated that "People who had access to paid personal assistants… tended to feel more comfortable and in control of their lives, while those who relied on the goodwill of others commonly experienced a great deal of shame and frustration in relation to their ongoing needs." (p. 137)

[5] Australian Bureau of Statistics. (2003). Disability, Ageing and Carers: Summary of Findings, 4430.0 available: via this link

A recent survey of 1,000 carers which was conducted by the Australian Institute of Family Studies indicated that the caring time commitment of 60 per cent of those surveyed was in excess of 100 hours a week.[6]

Social and economic participation also requires time and effort. It follows that time spent caring is time that is not available for other activities. Carers providing intense levels of support to a person with disability will not have the time or the energy to participate in the workforce unless the person for whom they provide care receives additional support from elsewhere.

Economic Participation

Carers are already engaged in work which, were it performed by others, would be paid for. The work of unpaid carers has value in its own right and should be valued as a worthy contribution to Australian society even if it is not remunerated.

I would be concerned if this inquiry's focus on increasing the workforce participation of carers was motivated by monetary considerations rather a primary concern for the personal and financial wellbeing of the carer. As such, the decision to pursue paid employment should rest with the carer rather than be imposed or expected under a policy framework of supposedly reducing welfare dependency or the requirements of so-called "mutual obligation". Most carers have more than met their obligations both to the person for whom they provide care and to society.

Acknowledging that caring responsibilities of more than 40 hours a week could be considered the equivalent of a full time job, one possibility for improving the financial position of carers in such cases would be to offer a government funded "salary" equivalent to the weekly award rate for care work.

In my own case, apart from three years after the birth of my son, I have been in paid employment since 1974. Despite my caring responsibilities (and given that my son's father has been his primary carer since 1994), it has been possible for me to engage in paid work and for my ex-husband to engage in paid work because, during the day, our son has had his care and support needs met by others (firstly through attendance at a special school and subsequently in a five day a week post school option).

In this respect, I am aware of many other parents of children with intellectual disability in Western Australia who have not been so fortunate in the post school years (where the hours of daytime support have been reduced from at least 30 hours a week while their son or daughter was attending full-time school to 10-15 hours a week in day activities once they left school). Again, during the school years, transport was normally provided as part of the service, while in the post school years the onus is more likely to be on parents to provide transport to and from whatever day activity the person may be participating in. This reduction in support inevitably diminishes the primary carer's capacity to engage in employment.

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[6] Australian Institute of Family Studies (2008). *The nature and impact of caring for family members with a disability in Australia* available via this link

Many parent carers also report that, in the absence of a structured daily routine and appropriate stimulation, their child's behaviours and skills have deteriorated in the post school years The adult size of their child makes management of challenging behaviour all the more difficult, again increasing the caring demands. At the same time, there are fewer respite services for adults than there are for children which means that parent carers have even less time for themselves than they did when their child was younger and potentially easier to manage.

In my own PhD research, many of the parents I interviewed cited the shortfall in adult services as a factor in precipitating their application for long term out-of-home care for their son or daughter.

In my other caring role, I was able to provide care for my mother only because the nature of my work (as a Communications Officer) enabled me to work flexibly from home on a contract basis. However, in the five years I cared for my mother, her high level support needs meant that I often commenced work when she went to bed at about 10.30 pm. This work schedule was very gruelling and impacted on my own health.

Social Participation

Time spent caring is also a factor in the capacity of carers to engage socially.

However, I would suggest that the presence of challenging behaviour in the person with disability is another major inhibitor to the carer's social participation. I know in my own case, I rarely take my son with me to any social activities or public facilities because of his challenging and socially inappropriate behaviours (including loud screaming and a tendency to become aggressive in unfamiliar environments). Hence when he is with me, apart from taking walks round the block together, we rarely leave the house. As a corollary, the only time that I am able to participate socially is when he is not with me. Again this requires that his care and support needs are being met by others.

Practical Measures to Support Carers

As a general principle, I believe that "unpaid" carers should be afforded the same working conditions as are provided to paid carers under Occupational Health and Safety requirements and regulations. For example, paid carers and family foster carers of people with disability have certain assurances that their health and safety will not be compromised in the course of their work. Typically, there are safety precautions built into caring tasks that require physical exertion such as transferring and lifting etc with equipment supplied if considered necessary. Paid carers are also more likely to receive training on how to provide care including dealing with problem behaviours. Paid carers are assured of regular breaks from their caring responsibilities and can retire from their caring role if and when they choose to.

One practical measure for supporting carers might be to offer carers an occupational health and safety assessment which would enable the identification of additional supports that may be required to safeguard carer health and safety.

This suggestion would help to give effect to the principle I articulated on pages 7-8 i.e.

- The provision of informal care to a person with disability should not result in any significant diminution in the quality of life of the carer or the quality of life of significant others in that person's life.

Services for People with Disability

Consistent with my assertion that the primary concern of most carers is the wellbeing of the person for whom they provide care, a major practical measure to support carers would be to ensure that people with disability are able to access the services they need, when they need them.

This would meet another one of the proposed Principles for Supporting Carers as documented on pages 7-8 above i.e.:

- All people with disability have the right to support that will enable them to maintain their health and wellbeing, to develop their capacities to achieve the maximum possible level of independence, and to participate in their community consistent with accepted social norms.

Reducing Caring Demands

Caring demands are a function of the level of support required by the person with disability and the associated time, effort and skill required to meet these demands.

Obviously the more the person is able to meet their own needs independently, the fewer demands on the carer to meet these needs for them. Inasmuch as services such as physiotherapy, occupational therapy and speech therapy may all increase personal independence they will also decrease caring demands. For people with cognitive impairment, training in independent living skills would have the same effect.

In sum, the provision of services and supports that increase the independence of the person with disability not only enhance that person's independence, autonomy and quality of life, but also reduce the demands on carers.

In the interviews I conducted with parent carers for my PhD research, challenging behaviour was one of the major factors contributing to the demands of caring and associated carer stress. And yet the parents reported that they had received little or no service advice or support on behavioural management techniques. One mother of a 22 year old son who had severe intellectual disability and major behaviour problems informed me that when she approached a government disability agency for assistance in managing her son's behaviour, she was told there was a six month waiting list. In the meantime, her son continued to wreak havoc until an agency psychologist finally visited six months later.

The provision of behavioural management services that can be accessed in a timely fashion would have a major impact on reducing caring demands.

The provision of appropriate equipment and technological aids to assist in the care of people with disability would also reduce the demands on carers.

Increasing Carer Capacity

Carers need time both to meet their own needs and their responsibilities to others who may depend on them. When care is being provided to a person with very high support needs the only time that is available to meet these other responsibilities is when the needs of the person with disability are being met by others i.e. at a day placement, a respite service or in a long term out-of-home care arrangement. If carers are to be able to replenish their reserves and continue to provide care, there must be a guarantee of regular breaks from the caring responsibility.

This is consistent with the proposed principle that:

- People who provide informal care and support to a person with a disability have a right to access services and supports that will enable them to maintain their own health and wellbeing, to pursue their own lifestyle goals and to meet their responsibilities to others who may depend on them.

As with paid carers, informal carers would benefit from training on how best to meet their caring responsibilities in such a way as to limit any adverse impacts on their own health and wellbeing.

Access to Opportunities and Choices

Choices within the Caring Role

In Australian society, it is expected that parents are responsible for providing care for their younger children whether or not they have a disability. Similarly it is expected that when a child becomes an adult, they assume responsibility for their own lives at which time they are legally entitled to make their own lifestyle choices. In other words, parents are no longer financially or practically responsible for their adult children (although many parents may choose to continue to provide some level of support during the early adult years, it nevertheless remains their choice rather than obligation to do so).

For people with severe lifelong disability (and particularly adults with cognitive impairment) who are still living in the family home, the opportunity to move to a more independent adult lifestyle is dependent on the availability of appropriate alternative caring arrangements (or accommodation support services). A major shortfall in the availability of accommodation support services in Australia means that the parents of these adult children have no choice but to continue to provide care.

These issues are reflected in the proposed principles of supporting carers as outlined on pages 7-8 above i.e.:

- All adults with disability have the right to live independently (with appropriate support) if that is their wish.

- All people with disability (or their legal representative) have the right to choose who will meet their need for support and the circumstances under which such support is provided.

- The choice to provide informal care and support to a person with disability and the manner and time frame over which such care and support is provided must be freely given rather than obligated due to a shortfall in formal service provision.

It should be noted that most parent carers who are seeking for their adult children to move into appropriate supported accommodation wish to maintain a close and continuing involvement in their children's lives - albeit to a less intense extent. In line with the distinction between different dimensions of caring, such a move may diminish the physical requirements of "caring for" but not the emotional requirements of "caring about".

As one mother in my current PhD research put it "I don't want to be a carer anymore I want to be a parent".

Transitioning In and Out of Caring

As stated above, in mainstream Australian society it is a normative expectation that adult children will leave the parental home and create a more independent lifestyle for themselves. However, the policy expectation increasingly seems to be that parents will continue to provide care for a son or daughter with disability whether or not they wish to until they (the parents) become incapacitated or die. If the same expectation were applied to the rest of the community, I suspect there would be a dramatic decline in the birth rate.

For people with disability whose care needs are being met within the parental home, the incapacity or death of the parent carer will inevitably require alternative arrangements to be made. Parent carers are particularly concerned that this transition to alternative care takes place in a timely and orderly way well before a crisis precipitates it.

Parent carers in my PhD research reported that they wanted to be in a position where they were still capable of supporting their son or daughter in making a graduated transition from full-time parental care to out-of-home care.

A well planned and orderly transition process is particularly important for people with intellectual disability who, by definition, are limited in their adaptive capacity. Parents are concerned that relocation at a time of family crisis would be especially traumatic, substantially increasing the adjustment difficulties experienced by their son or daughter with intellectual disability.

The illness or death of a parent is usually upsetting for even the most intellectually competent of people, especially if that parent has been the primary source of support in the person's life. One can only imagine how much more disturbing it would be for a person with intellectual disability if, upon the loss of their parent, they were required to simultaneously move out of the stability of their home into the care of strangers.

Planning for the Future

Effective planning requires some measure of predictability. Crises are not predictable. A disability service system based on responding only in crisis situations or in cases of critical need cannot therefore be properly planned.

Parent carers who participated in my PhD research consistently reported that any plans for their lives and that of other family members revolved around the needs of their family member with disability. In applying for long term out-of-home care for their family member all future planning was contingent upon if and when such alternative care might be made available. Some parents had been applying every four months for the past six years describing their lives as being "on hold" as they waited on the outcome of each application. In the meantime, other older parents reported that their adult family member was becoming increasingly emotionally dependent as time went on such that relocation would be even more difficult when the time finally arrived.

The requirement and expectation on parent carers to care indefinitely (until crisis precipitates a breakdown in the caring arrangement) is antithetical to a well constructed planning process. Given that alternative care arrangements will most likely be required eventually, parent carers are seeking the certainty of a timeframe within which a planned and orderly transition to long term out-of-home care can occur. An expected parental caring commitment of between 20-25 years would seem more than reasonable as it would be considered normal and appropriate for a young person of this age to begin the process of creating a more independent lifestyle beyond the parental home.