



**Response to
Inquiry into the Early Intervention and Care of
Vulnerable Children in the ACT**

**for the Standing Committee on Health and Disability
Karin MacDonald (Chair) Legislative Assembly for the
Australian Capital Territory**

April 2008

Enquiries on this submission may be directed to:

Dee McGrath
Chief Executive Officer
Carers ACT

Telephone: (02) 6296 9901
Fax: (02) 6296 9999
Email: deem@carersact.asn.au

This document was prepared by:
Annemarie Ashton, Policy Advisor

A number of people are gratefully acknowledged for their time and assistance, which has contributed to the creation of this document, including Dee McGrath, the Board of Carers ACT, Natalie Tolley and the many Carers who have been so generous with their time in responding to our requests for information on Carer needs.

Carers ACT

Suite 5 Ground Floor
Churches Centre
54 Benjamin Way
Belconnen ACT 2617

telephone: (02) 6296 9900
fax: (02) 6296 9999
email: carers@carersact.asn.au
website: www.carersact.asn.au

This work is subject to copyright and may not be reproduced, either in whole or in part, without the prior written approval of Carers ACT.

Carers ACT acknowledges that modern day Canberra has been built on the traditional lands of the Ngunnawal people. We pay our respects to their elders and recognize the displacement and disadvantage they have suffered since European settlement. Carers ACT celebrates the Ngunnawal's living culture and valuable contribution to the ACT community.

Contents:

1.	Introduction	1
2.	Supporting the Care of an Infant or Child with Special Needs	3
3.	Early Identification of a Child at Risk	6
4.	Conclusion	8
5.	References	9

1. Introduction

In response to the Legislative Assembly Standing Committee on Health and Disability's inquiry into the early intervention and care of vulnerable children in the community, Carers ACT wishes to draw attention to two less well recognized sections of the community at risk that would benefit from early intervention. Firstly, parents of children and infants who are diagnosed with a disability need comprehensive long-term support to help them cope with the impact of diagnosis and their ongoing needs in caring for their child. Secondly, Young Carers in the community, who are children providing care for members of their family due to disability, mental illness, chronic conditions or illnesses, and drug and alcohol problems. While Carers ACT understands that this review is primarily focusing on unborn children and those aged 0-2, it is critical that babies born to a parent with complex needs are recognised as being at risk of becoming a Young Carer in the relatively near future. It is also relevant that families in the above groups may have other children who are already providing care.

Carers ACT is a non-profit, community based, incorporated association and registered charity dedicated to improving the lives of the estimated 43,000 family Carers living in the Australian Capital Territory. We represent unpaid family Carers who are providing care for people with disabilities, mental illness, chronic conditions, palliative care, or who are aged and frail.

It takes a flexible and responsive organization to effectively support such a diverse population. Carers ACT provides a service focused specifically on the needs of the family Carer, from the crisis of diagnosis through to the adjustment in coping if the caring role has ceased. The organization is much more than just a safety net, as it has an active role in service provision, future planning and representation across the community services sector within the ACT. Carers ACT holds a vital role as the conduit between government and community. It ensures the continued sustainability of community-based care, and manages substantial levels of Government funding in the ACT.

Carers ACT believes that all Carers are entitled to the same rights, choices and opportunities as other Australians in order to enjoy optimum health, social and economic wellbeing and to participate in family, social and community life, employment and education. This aspiration falls far short of the reality for many Carers, who have the lowest wellbeing scores for any group in Australia, being far more likely to suffer chronic health conditions and depression (Cummins, 2007). This research also provided support to the perception that Carers as a group are significantly more highly stressed and extremely time poor in comparison to other population groups. It found evidence that "consistent, daily immediate caring responsibility is sufficient to severely damage wellbeing" (Cummins, 2007 p. 37). While caring is a normal part of life, the role does go beyond that of usual family relationships and creates additional stress and strain beyond common expectations.

Research has consistently shown that Carers are already a group more vulnerable to the pressure of external social and economic factors than the majority of non-Carers in the population. Yet anyone can become a Carer, at any time, as we all have family, friends or neighbours who may need our care at some time in their lifespan, due to accidents, chronic illness or simply from the increasing frailty of old age. Decisions on future supports for Carers, therefore, have a much wider reach than the current Carer population already resident in the ACT.

The changing pattern of social life and family structures means that fewer people now have access to the support provided by an extended family or a neighbourhood network. Current economic pressures are also placing many families under enormous strain to keep providing the basics of food, housing and access to essential services. Add to this picture the pressure of having a child diagnosed with a disability or a parent struggling with mental illness, and it is clear that vulnerability leads to crisis, which becomes total breakdown if left unsupported in the long term.

Care needs are not homogenous across the population. Support needs vary with the complexity of issues for the care-recipient, the availability of other forms of informal support, the skills level of the Carer and their individual health factors. However, all Carers have an essential role in maintaining the health and social welfare system, which relies upon a model of community care. The work of Carers is of substantial economic benefit to the ACT Government, saving a conservatively estimated \$524.6 million per annum in replacement formal care services.

Caring in the ACT: An Essential Part of the Community			
Number of Carers in ACT:	43,000 ¹	Number of Primary Carers (<i>percentage of total ACT Carer population</i>):	8,600 ¹ (20%)
Estimated annual cost of replacing unpaid care with formal care in the ACT:	\$524.6 million pa ²	Estimated annual opportunity cost to ACT economy from Carers' reduced participation in workforce	\$88.9 million pa ²
Sources: ¹ Data extrapolated from ABS (2003) Survey of Disability, Ageing and Carers ² Carers ACT, using model developed by Access Economics (2005) applied to SDAC data.			

It is clear that if Carers did not provide this care, government or other care services would be unable to provide an equivalent quality or level of care. Successive governments have recognized that supporting Carers through funding organizations such as Carers ACT provides a very cost effective way of achieving health and wellbeing benchmarks. Failure to adequately support Carers will have an immediate and dire impact on the economy, as replacement of informal care with formal care has been conservatively calculated at 3.5% of GDP (Access Economics, 2005). It is clear that a systematic breakdown of community-based care would be a health-care disaster for the ACT population.

Carers ACT applauds the ACT Government's ongoing commitment to improving the health and welfare of children and families in the Australian Capital Territory. The development and implementation of strategic support plans for vulnerable sections of the community are a proven means of preventing costly demand for additional services to treat the complex problems which arise from the systemic neglect of wellbeing. This submission is not intended to be a comprehensive treatise on all issues relating to the early intervention and care of vulnerable children, but examines two issues of direct concern to Carers ACT, specifically, the provision of support to families when an infant or child is diagnosed with special needs; and the early identification of children who are at risk of becoming Young Carers in the future.

2. Supporting the Care of an Infant or Child with Special Needs

Raising a child is a unique experience which requires parents to develop specialist skills, acquire new knowledge and interact with a range of previously unfamiliar places, such as child health clinics and day care centres. Parenthood fundamentally changes social perspective, as individuals suddenly have total responsibility for another person. Every choice they make must now include consideration of the impact on their child, and everything that happens to their child will also have an impact on them.

A significant number of Australian parents face a learning curve beyond all usual imagining when they discover that their child has a disability. The catastrophic impact of such news is largely unrecognized and unsupported in our society. It is a sad fact that many parents in such circumstances still get offered little more support than being told to “go home and try to get on with your lives as best as you can”.

The reality is that parents must quickly acquire the highly specialized knowledge and skills they need to adequately care for their child's special needs. They may have to learn to conduct medical procedures, such as tube feeding or giving injections. Some parents will have to take their child for painful, distressing, or invasive medical procedures. Sleep deprivation is commonplace, as many children with disability have complex needs which require parents to get up many times in a night.

It can often take time to obtain a precise diagnosis, and this can be very distressing for families. Many parents know something is wrong with their child, but it may take months of investigation, with endless tests and appointments with different specialists to obtain any kind of an answer. Some parents' lives may be so altered that they feel like they are living in clinics and waiting rooms, and talking to no-one other than medical personnel.

Many parents describe an overwhelming sense of grief and loss following diagnosis, as they start to understand that their child may not do all the things they had previously taken for granted, such as riding a bike, going to university or even having kids of their own one day. There is also a huge adjustment in personal expectations, as parents begin to realize the amount of extra care needed, and how they must adjust their lives to cope. It is not uncommon for parents to feel confused and overwhelmed, as they struggle to gain knowledge on their child's needs, while also having to explain the situation to family and friends.

A Parent's View

The worst part has to be helping to hold him down when they attach all the tubes and wires. He screams and cries and struggles to get away.

I always feel like such a traitor. It goes against every instinct as a mother to be a part of something that hurts your child, but I won't wait outside and let him go through it alone either.

The nurses are great; they always try to do it as quickly as they can. I know it's for the best, that it has to be done.

In the beginning, I used to wait until he was asleep, and then go outside to cry. Now, I just feel too tired for crying.

This adjustment time may also be a time of high financial stress, as typically household income drops and expenses increase. For example, one or both parents may have to alter their paid employment to meet the needs of their child. Many children need specialized equipment, which is expensive and quickly outgrown over the years, some need costly private therapies or medicines which may be completely or partially unsubsidized.

For parents of children with severe or obvious disabilities, learning to cope with public misunderstanding can be traumatic, from the well-meaning but horribly misguided comments which can cause intense personal distress, to the stares and the fear of those who just don't understand. Regretfully, our society is yet to achieve real inclusion, as ignorance, avoidance, discrimination, hostility and rejection are still common responses to those who are different. It is, therefore, highly understandable that social isolation is one of the biggest factors for people with disabilities and their Carers, as they struggle to overcome the multiplicity of physical, economic and social barriers preventing equitable participation and full citizenship.

Parents and Carers of children with a disability don't need pity or charity or short-term band-aid approaches for dealing with complex and life-long challenges. Continual feedback to Carers ACT from parents proves that they need recognition, they need appropriate and individualized support, and most of all they need to develop options for a meaningful future for their child.

Parents need to know that support is available from the first point of diagnosis. However, part of the adjustment process involves a point of self-recognition; a realization of having additional needs due to demands beyond the usual expectations of a parenting role. Due to the overwhelming stress of the diagnosis transition point, many parents may not realize that they qualify for assistance in their own right. Some parents may also need follow-up contact to ensure that messages about support services have not been lost or missed due to 'information overload' or shock at the time of diagnosis.

Long-term strategies are needed to educate service providers to give a direct referral to Carers ACT when parents are attending hospitals or medical centres. Carers ACT has a comprehensive Service Provider Education Program already developed and implemented in 2006-07 under the ACT Government's Carers Recognition Grant program. The program was a one-off grant, and Carers ACT has no other funding available to support the staff hours needed to continue delivery.

A Carer's Feedback

I wish someone had told me about the services at Carers ACT in the beginning. It's great to have someone to talk to who can offer practical help.

After years of trying to manage by myself, I was really depressed and not coping at all well with things.

I am in and out of hospitals all the time with my daughter, but nobody had told me that extra help was available, I guess they are always too busy trying to cope with all the patients.

Carers ACT helped me to get some respite and now I even go to a support group that has other parents of kids with disabilities. It's good to know that I am not alone in dealing with this.

Due to the high staff turnover rates in health and social work professions, any such education program needs to be comprehensive and ongoing. It also needs to be supported by appropriate resources and media campaigns to better inform the whole of the ACT about disability issues, increase Carer self-recognition rates, and improve general awareness of Carers needs and their essential contribution to the community.

According to the last ABS Survey of Disability, Ageing and Carers, in 2003, 8.3% of all Australian children had a disability, with 4.3% of all children having a severe or profound limitation (ABS, 2003). Australian Institute of Health and Welfare (2007) notes that while the chance of disability does increase with ageing, the age-specific rate of disability “also peaks during early childhood and the school years”. Disability in childhood may be congenital or acquired from injury.

Injury and poisoning is the leading cause of death and a major cause of disability among children in Australia ... Injuries can have lasting effects, such as disability or disfigurement, which can impair a child's development and future wellbeing. In addition, disability or death from injury significantly affects on a child's family. (AIHW, 2005)

There were 4,210 births registered to mothers usually resident in the ACT during 2005 (ABS, 2007). Of these 4,210 babies, around 349 can expect to be born with a disability or acquire a disability, while still a child, as a result of accident or chronic illness. As the following table illustrates, the ACT has an estimated 6,640 children with a disability, of which 3,437 will be expected to have a severe or profound limitation.

Children with a Disability in the ACT¹			
<i>Age (in years)</i>	<i>Number of children</i>	<i>Estimated number with disability</i>	<i>Estimated number with a severe or profound limitation</i>
0-4	20,067	1,665	862
5-9	20,369	1,690	875
10-14	21,336	1,770	917
15-18	18,255	1,515	783
Total	80,027	6,640	3,437

Service planning and the development of effective early intervention programs in the ACT would be greatly assisted by obtaining comprehensive information on the exact number of children with disability and indication of their current needs. At present there is no single figure for each age group in the ACT, beyond the standardized data above obtained through the ABS Household Survey process. While this data is certainly valuable, better sector availability and use of existing data collection done by the Departments of Education and of Health, and/or the development of a voluntary register containing information on specific needs, would be of premium assistance in developing effective resources. Such data would also enable the establishment of a more efficient, cross-portfolio, cohort planning scheme for health, education and disability services in the ACT, and would also facilitate new research opportunities within the region.

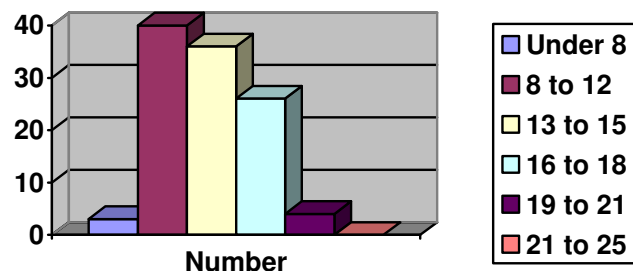
¹ Based on ABS SDAC 2003 national rates of disability applied to ABS Census 2006 population for ACT.

3. Early Identification of a Child at Risk

Early identification of children at risk is a vital part of designing and implementing appropriate support strategies for the whole community. Preventing the development of complex issues of poverty and ill-health depends upon provision of access to equitable resources and sustained health promotion strategies from the earliest possible age. Regrettably, many programs aimed at reducing the negative impacts of vulnerable children in the community often neglect to consider the needs and existence of Young Carers.

Young Carers are those people aged 25 and under who provide care to family members with a disability, chronic condition, mental illness or who have a drug or alcohol problem. Carers ACT currently provides support to over 130 Young Carers but estimates that many thousands more remain hidden in the wider ACT community. Most referrals to the Young Carers program are for children aged between 12-15 years old, but currently the youngest client is 7 years old. The majority of Young Carers in the Carers ACT Young Carer program care for a parent with a chronic illness (28%), a mental illness (27%), a chronic condition (19%) or a physical disability (15%). Currently, 74% of Carers ACT's Young Carer program clients provide care for a parent or guardian and 25% provide care for a sibling.

Profile of Carers ACT's Young Carers Program by Age Groups as at 30/12/07



While Carers ACT understands that this review is primarily focusing on unborn children and those aged 0-2, it is critical that babies born to a parent who already has a mental illness, a disability, a chronic condition or a drug or alcohol problem are recognised as being at risk of becoming a Young Carer in the relatively near future. It is also relevant that families in the above groups may already have other children who are providing care to the parent or looking after younger siblings.

As the Australian Institute of Health and Welfare (2005) contends:

There is increasing recognition that the health and wellbeing of young children cannot be addressed in isolation from the family, community, and broader socioeconomic, political and cultural environments in which children live. A child's experience in life is largely influenced by the care they receive, or fail to receive, from their families and from the wider

community. These experiences have a lasting effect on all aspects of a child's immediate and future wellbeing: physical and mental health, learning and education, employment, and social interaction.

It is therefore vital that all programs looking at early intervention for vulnerable children consider the wider context, seek to identify Young Carers and refer them to those programs which are specifically designed to meet their needs.

While caring affects every level of society, research conducted by Carers Australia (2002) indicates that Young Carers are more likely to come from low income families and care for a parent, who often is someone with a mental illness. This is usually because a majority of Young Carers come from sole parent families, and they often provide care because they are the only ones at home available to fulfill this role. Yet, most are willing to take on this role and want to continue to provide care as long as they and their families receive adequate support and services (Carers Australia, 2002). It is essential that government and service providers understand that a lack of self-identification as a Young Carer may limit access and referral to Carer support services. It is critical that all health professionals, educators and service providers, learn ways to assist in identifying Young Carers and become aware of the specialist programs and supports available to help them in the ACT through Carers ACT Young Carers Program, COPMI (Children of Parents with Mental Illness) and Cyclops ACT.

It is vital that young people providing care are identified and supported at the earliest possible stage. Early intervention greatly assists in reducing the negative impacts on Young Carers which may arise from their caring role and lower socioeconomic status. Carers Australia (2002) research discovered that Young Carers:

are often at risk of experiencing poor physical or mental health, impaired psychosocial development, low participation rates in education, training and employment, difficulty and delay in gaining independence and a general lack of choice and opportunity which significantly increases their chances of being economically and socially marginalised.

Things like not having a healthy diet, not getting enough sleep, and having high levels of anxiety about leaving the person you care for to attend school, can all have very negative impacts on health and wellbeing in the long term. Helping Young Carers stay at school is a core aim of the Carers ACT Young Carers Program. The program also offers practical supports, respite assistance, and provides Young Carers with opportunities to learn new coping skills and strategies. Building social links with other Young Carers also greatly helps to improve wellbeing, as a peer group that understands the complexity of being a Young Carer is vital for optimum psychosocial development, especially in teenage years. Safeguarding the mental health of all Young Carers is also proven to improve their chances of positive life outcomes.

Community- population based research has reported between 14-18% of children and young people (under 18 years) experience mental health problems of clinical significance. The burden of mental health problems in young people is far greater if at risk groups are considered including infants, children and adolescents with developmental disabilities, learning problems, those who have experienced some form of abuse, are in foster care, who have comorbid substance abuse or who live with parents themselves challenged by mental health symptoms, disability or substance abuse. (AICAFMHA, 2006)

Clearly there is a demonstrated risk for those Young Carers in the ACT who continue to 'fall through the gaps' and remain unrecognised and unsupported. A risk that can be greatly reduced by increasing the awareness of Young Carer issues with all health and community service provider personnel by educating them about ways to identify Young Carers and improving their knowledge of specialist services already existing in the ACT which provide much needed support. The ACT Government also needs to commit to immediately increasing the funding of existing programs, which are already underfunded in comparison to identified need, to ensure long-term sustainability of a vital and proven early intervention program for a very vulnerable section of the community. This request was detailed in the 2008-09 ACT Budget Submission, and would benefit from the additional support of the Standing Committee on Health and Disability.

4. Conclusion

The provision of support to families when an infant or child is diagnosed with special needs; and the early identification of children who are at risk of becoming Young Carers in the future are two critical areas requiring early intervention services in the ACT. Carers ACT already offers a range of programs in support of parents of children diagnosed with a disability. It is critical that early referral to these programs be obtained from health services staff interacting with parents during the process of diagnosis. Similarly Young Carers in the community also benefit from early referral to the existing Carers ACT Young Carers Program.

Carers ACT needs funding from the ACT Government to enable additional staff time to re-implement the existing Service Provider Education Program and also to promote greater awareness of Young Carers in the community. Carers ACT urgently needs additional funding to enable the Young Carers Program to sustainably meet the identified additional need already evident in the ACT, as detailed in the 2008-09 ACT Budget Submission. Early intervention programs for vulnerable sections of the community are a proven means of preventing costly demand for additional services to treat the complex problems which arise from the systemic neglect of wellbeing. Carers ACT offers the ACT Government the opportunity to continue to develop a strategic approach to promoting and maintaining an effective system of early intervention which assists Carers in maintaining their vital unpaid work which provides significant benefit to the wider community.

5. References

- Access Economics (2005) *The economic value of informal care*. Canberra: Carers Australia
- Australian Infant, Child, Adolescent and Family Mental Health Association (2006) AICAFMHA Position Paper. Stepney, SA: AICAFMHA Ltd. Downloaded from AICAFMHA website on 29th April 2008 at http://www.aicafmha.net.au/resources/files/Position_Paper_AICAFMHA_071106.pdf.
- Australian Bureau of Statistics (2003) *Disability, ageing and carers, Australia: Summary of findings*. (ABS Catalogue No. 4430.0)
- Australian Bureau of Statistics (2007) *Australian Capital Territory in focus*. (ABS Catalogue No. 1307.8)
- Australian Institute of Health and Welfare (2005). *A picture of Australia's children*. Canberra: AIHW.
- Australian Institute of Health and Welfare (2007) *Australia's welfare 2007*. Canberra: AIHW.
- Carers Australia (2002). *Young Carers Research Report: Final Report*. Canberra: Department of Family and Community Services.
- Cummins, R., Hughes, J., Tomy, A., Gibson, A., Woerner, J., Lai, L. (2007) *The wellbeing of Australians – Carer health and wellbeing*. Melbourne: Australian Centre on Quality of Life, Deakin University.