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Submission No. 724
(Inq into better support for carers)

Submission to the House of Representatives Standing Committee on Family, Community, Housing and Youth, Inquiry into better Support for Carers.

ANGLICARE
CANBERRA & GOULBURN

Table of Contents

Introduction

Anglicare Canberra Goulburn (CG) appreciates the opportunity to provide a submission to the House of Representatives Standing Committee on Family, Community, Housing and Youth, Inquiry into better support for carers.

Overview of Anglicare Canberra Goulburn

Anglicare CG has been delivering community services in the ACT, NSW South Coast, Goulburn and South Western NSW for over 100 years. The range of services include youth and family services, out of home care, child care, disability respite, specialist youth health services, mental health services and programs to support carers include respite care and a specialised service (CYCLOPS program) focussed on the needs of young carers.

Anglicare is the social service arm of the Anglican Church. We are a values based organisation and we believe in the worth of every individual. Every individual has a right to be treated with dignity and respect and to be given the opportunity to participate in society both socially and economically.

Our policy and program responses are informed by our service practice and input our clients and community stakeholders. This submission is based on the experience gained by our program managers and includes input from people who are carers. Anglicare Canberra-Goulburn has a commitment to having representation with peak body organisations, advisory panels and committees to inform our service practice and to advocate on behalf of the people whose lives circumstances we seek to improve.

CYCLOPSACT Program

Anglicare CG has been operating the Cyclops program in the ACT since 2001. CYCLOPSACT stands for Connecting Young Carers to Life Opportunities and Personalised Supports. The service aims to provide flexible, innovative responses for young carers within the ACT that reconnects young people to mainstream life opportunities that reduce the negative impacts of the caring role. These supports include education, social interaction, recreational activities and respite options and community supports Over the years, CYCLOPS has worked with significant numbers of young people and developed individually tailored supports to meet the specific needs of the young person and their family.

One of our primary goals is to raise the awareness of young carers within the community so that they may be identified and their needs acknowledged. There are 22,000 young carers throughout Australia and they range in age from as young as 5 years old to 25 years. The majority of young carers, we work with are between the ages of 12 and 18 years, however we have worked with children as young as 8 years old.

Flexibility Plus Program

Anglicare CG also provides a range of case management services and respite options through our Flexibility Plus service which has been operating since 1989. The five programs under this service include

- Respite Options for Children (ROC) - provides respite for children with moderate to severe disabilities aged 0-18 years.
- Goulburn Respite Options (GRO) - provides respite for adults with moderate to severe disabilities aged 18-65 years.
- Goulburn Family Interchange (GFI) - provides respite for children and adults with disabilities from birth throughout the whole of life.
- Ageing Carers Program (ACP) - provides respite for ageing parent carers that care for their adult children with disabilities.
- Specialised Case Management and Brokerage Services.

Flexibility Plus has a diverse range of clients with many different complex needs and we provide individual holistic planning and care to cater for the needs of the individual and for the family unit as a whole. Clients may have single parent or dual families, some carers are older parents, some are siblings and some are other relatives or friends of the individual with the disability or health issue.

Prevalence of Carers

In 2003 the Australian Bureau of Statistics survey of Disability, Ageing and Carers, stated that, one in five people in Australia had a reported disability, this represented 20% of the Australian population. In 2003, there were 2.6 million carers providing assistance to someone with a disability or someone who is frail, has physical or mental health needs requiring constant care and/or someone who is aged. 19% of the carers were primary carers and 54% of individuals providing care were women. In October 2005, the Australian Bureau of Statistics conducted a Managing Care and Work survey throughout New South Wales, the topics in this survey included:

- Frequency of care and selected characteristics of the care recipient
- Sector of employment
- Type of work arrangements used to care for someone
- Type of work arrangements wanted to use to care for someone
- Reasons could not use desired work arrangements
- Changes made to work arrangements in order to care for someone
- Whether main reason for self employment was due to caring; and
- Main reason of income if not looking for paid work due to caring responsibilities

The summary of the findings of this survey were that there was an estimated 2,416,500 or 48% of persons aged 18 years and over in NSW that provided care for another adult or child, compared to 42% in October 2000. A higher proportion of females provided care (53%) than males (42%). Of those that provided care, 1,909,500 persons (79%) provided care on an ongoing or continual basis. The main recipients of care were carers own children aged 14 years and (43%), and persons aged 65 years or over (17%).

The role and contribution of carers in society and how this should be recognised;

Caring is a culturally defined response to a need arising in the family or community for assistance and support to its members. In its broadest sense, caring encompasses many of the daily interactions that maintain and enhance human relationships. People can provide care to others in any role they play, whether it is as a mother, son, neighbour or care professional. The different faces of caring all demonstrate the reciprocal nature of human relationships, reinforce norms of trust and mutual obligation and in this way contribute to the cohesion of families, communities and society in general. The shape of the Australian population is changing with the older age groups making up an increasing proportion of the population. As our population ages and we experience increasing life expectancy there is likely to be more people with disabilities and an associated increased demand for carers to look after them.

Our experience in working with carers suggests that carers in general feel very undervalued in the community, often they feel socially isolated and most struggle financially. The work that carers do is not only one which provides significant social value to the community, it also provides an economic benefit which has been estimated at $ 30.5 billion according to a report by Access Economics.

Our extensive work with carers has given us an appreciation of the role and contribution of carers.

Young Carers

Over the last 15 years a hidden group of young people have come to the attention of service providers and researchers. This particular group of young people were labeled as Young Carers due to the fact that they had assumed caring responsibilities for a family member who has a chronic illness, physical / intellectual disability or frail aged.

As a result of extensive research and the commitment of organisations to advocate for the recognition of these young people in our communities, young carers voices began to be heard and over the last 4 years much has been done to provide supports to meet their specific needs. Testimony to this is the Federal governments injection of $ 7 million, to provide a respite program to support young carers to achieve their secondary education.

Yet for all that has been done which includes,

- the creation and implementation of respite programs that provide home care,
- the delivery of holiday programs that allow the young carers time out from there caring role,
- services that deliver intensive support, and
- case management and counseling.

It could be said that these are only secondary supports and do not address the primary need of young carers or allow them a real choice as to whether they assume caring responsibilities within their families. The young carers we work with have articulated that what they want is;

- Better supports for their ill family member.
- Flexibility in the delivery of respite.
- Respite packages that meet the need of the whole family,
- To be kept fully informed about their parent's medical condition
- To have realistic options in the community that allow them a choice as to whether they provide care.
- Access to support after hours and on weekends.

A young carer is generally classified as someone under the age of 25 years who has the primary responsibility of caring for a parent, sibling or partner with a disability, physical or mental illness or who is frail aged. The research literature recognizes that there is a lack of support for young carers both within the family unit and the broader community. There is also a lack of recognition of young carers, notwithstanding the fact that there are a growing number of young carers, particularly as the number of single parent families increases.

Children often do not have a choice, they are the only available person to care for a parent with a physical or mental disability. There is a general lack of awareness in the community of the needs of young carers and one of the primary goals of our CYCLOPS program is to raise awareness of within the general community of the prevalence of young carers so that they may be identified and their needs acknowledged.

Case Study – IS THERE A CHOICE?

Young carers often feel trapped in that they don't feel they have a choice. For them to stop caring from their mum or dad often means they have to leave home, so they feel the only choice they have is to become the primary carer or to remove themselves from the family home.

One young woman we worked with was caring for her mother who suffered from severe emphysema as well as tongue cancer and depression. This young woman was the youngest of 4 children and the caring role had been handed down as the older children left home. She also wanted to leave the family home, obtain a job and create opportunities for herself, but she knew she would be leaving her mum. She also felt a great deal of pressure from her siblings to remain at home to care for their mother.

The psychological impact of this situation, caused this young woman enormous stress. She was beginning to feel resentment towards her mother and felt that the only way she could get out was for her mum to die and then she felt guilty about wanting her mum to die. Eventually the anxiety and stress led her to attempt suicide, she tried to take her own life through a staged car accident.

This story highlights the need for more research around the psychological impact on people in a primary caring role.

Experience of Carers

In our Flexibility Plus program we work with a significant number of people who care for a sick or elderly person, especially a relative at home. The formal definition of a carer is someone who is 'providing unpaid support for others with ongoing needs due to a long-term medical condition, a mental illness, a disability or frailty'. However we feel that the definition really does not describe the relentless demands that most carers have on them 24 hours a day, seven days a week. These are individuals that work harder than in any type of employment, and these individuals are not even paid for the work that they put their heart and soul into everyday. The community needs to acknowledge the social and economic benefit that carers contribute.

The following gives a glimpse into the reality of life for most carers.

Carer's Reality

Imagine for a moment that you are employed to care for someone 24 hours a day, 7 days a week, 365 days a year; with no superannuation, no breaks accept for four hours once a month, no OH&S workplace management, no sick leave, you may have a client who verbally or physically abuses you, you may have a client who needs support to attend to all activities of daily living, such as showering, toileting, dressing and feeding, you have to care for this person when they are sick or recovering/suffering a medical condition, no offer of personal development training to assist your workplace skills, no workplace cover in case of injury.

You have the skills to use medical and therapeutic aids, to clean and fix them; you have the skills to provide therapy to the person on a daily basis, you have the ability to know this person's medical history off the top of your head as well as any medication that the person may have to take, ones that have an adverse a effect, you know all the challenging behaviours that this person displays, you transfer them to bed/car/chair.

You have a lot of the skills that trained medical staff have that is specific to this person. You are deprived of sleep as you have to monitor and/or assist this person during the night and you get paid 20 cents an hour to provide this care, did I mention that is 24 hours a day, 7 days a week! 20 cents an hour is based on the carers allowance per fortnight.

Toni's Story (In my own words)

Hi, my name is Toni; I am a mother and carer of a five year old boy that has Autism, a Coarctation of the Aorta, Bicuspid Aorta valve, chronic ears, nose and throat problems, asthma, low immune system, and reservoir syndrome. I am also mother to an 8 year old "normal" boy, daughter to a 69 year old mother with Alzheimer's disease, sister to a 43 year old sister who has long lasting physical and psychological issues from a work place accident 10 years ago and who is also my mother's live- in carer. Ironically I also work fulltime as a caseworker for disability program for Anglicare Canberra-Goulburn, providing support and advice to other carers. There is much need for Better Support for Carers and the list is ENDLESS due to the fact that not one solution is going to work for everyone. At Anglicare Canberra-Goulburn we pride ourselves on holistic assessment and care for the families and individuals we work with, to provide an individualised service delivery to suit the individual situation. This is sometimes constrained by funding guidelines and the complexity of most situations. I sometimes feel disheartened by the failing system which I also promote.

In looking at how we can provide Better Support for Carers we need to conduct a comprehensive review to understand the specific needs of carers. To start carers come in all shapes and sizes, they are mothers, fathers, siblings, sons, daughters, single carers, partners, wives, husbands, friends, relatives etc. They come from a wide range of socio economic group, some are, working, some not working, some in part-time employment, fulltime employment, casual employment, volunteering.

I do have to first congratulate the Australian society for having better systems then some of the other countries in the world currently have, however we have to be realistic on which way our society is heading, our population is ageing and there is a greater prevalence and emphasis on disabilities and debilitating health conditions. The contribution of carers is significant in terms of social cohesion and improving the life circumstances for people in need of care.

There is plenty of reading material and information about carers roles, it is becoming a significant area of interest for policy makers. Carers are also writing about their experiences, mainly so that people who become carers have some insight to the world that they are to become accustomed. The research into what the government can do to better support carers would be a large undertaking but I believe it can be done. Barriers that carers face are vast, however to name a few that are similar in case scenarios is the "Catch 22" Syndrome, this syndrome as I call it, is for a majority of the carers population, it is the one where a carer cannot live on Carers Allowance or Carers Payment and/or other government pensions or benefits, so the carer goes to work only to turn around and pay someone else to come and do their caring role for them whilst they work. Where is the logic in that? If however you where in the position to work fulltime the extra that you receive in an allowance to assist carers really doesn't reflect the caring role, once you take into account the rising cost of living which included fuel prices, especially to medical appointments that are a generous distance in rural areas and medication expenses that the person that you care for is reliant on and the medication isn't on PBS.

The use of support services or should I say lack of support services, especially respites services and home help services for the prevention of admission into permanent care and family breakdown or crisis.

In this era we want people to remain in their own homes as long as possible and fortunately gone are the days of institutionalisation (thank god), so assistance provided in the home by support services are becoming a fact of life. We don't have to reinvent the wheel, just the way it turns; resources can be shared, discussions held, we need to go back to basics, before it gets to confusing and unusable for carers and the services providing the assistance.

For carers their situations are not confusing, they are reality and pretty black and white; a lot of carers find it very difficult to negotiate the ever increasing minefield that is our community service system, which leads to carers giving up on trying to access these services to alleviate the common stressors of the caring role.

Raising Awareness of the Role of Carers

Whilst much has been done in relation to developing programs and supports for carers, particularly carers, more needs to be done to raise awareness within the general community about the important role of carers and their specific needs. The Australian community, in general has demonstrated a great generosity of spirit towards people who experience misfortune and those who are disadvantaged. Specific education campaigns to help raise awareness of the circumstances carers find themselves in, will be likely to mobilise members of the community to show their support in practical ways.

Recommendations

- Promote the role of carers and young carers and their positive contribution to society through a National Community Awareness campaign, using electronic and print media, Billboards and community events.
- Develop a specific campaign to target schools/higher education, focussing on creating carer and disability friendly environments and highlighting the positive aspects of diversity.
- Focus on promoting 'young carer' friendly schools which provide access to more flexible curricula, on line education and better support and understanding for the young person to complete their education.
- Recognise the contributions of Young Carers through an annual young carers award, ideally this should include a monetary award or a special family holiday etc.

The barriers to social and economic participation for carers, with a particular focus on helping carers to find and/or retain employment;

For carers in general, there are many barriers to social and economic participation by carers, some of which are:

- Financial hardship – many carers have limited income and this makes it difficult for carers to fund skills training, transport and even business clothing they require to equip them to even go to job interviews.
- Social disconnection – the demands of carer often means that carers don't have the time to develop networks.
- Poor Health – because of the demands on their time carers often neglect their own health care needs and consequently minor ailments can escalate into serious illness.
- Wellbeing of carer – the challenge of caring for loved one and the sheer physical and emotional exhaustion they experience can have a significant detrimental impact on the carer's own health and psychological well being emotional and exhaustion.

- Limited time and resources makes it difficult for carers to upgrade their education or vocational skills to improve their career options.

- Being out the workforce for a long period of time means they lack recency of work experience and current

- Lack of Flexibility in Work Places – Even when carers find employment, often they are unable to maintain a job because of the lack of flexibility in work arrangements and lack of understanding amongst employers in general of the importance and needs of carers in our community.

- Weighing up paid employment options – Often carers find themselves caught in a difficult dilemma, where staying at home and providing full time care, even with government financial assistance does not provide sufficient income for the family to become self sufficient and the option of returning to work, means they have to pay someone else to provide care, thereby depleting the family resources.

- Receiving Support from Employment Agencies/Centrelink – Carers often feel that their circumstances are not well understood by agencies established to provide support in the area of income management and job search training and referral.

- Balancing the needs of the whole family – Carers can experience a great deal of stress and sometimes feel a sense of guilt because they are unable to spend quality time with family members and meet the needs of the whole family. This is particularly the case for parents who feel pulled because of the time and place constraints of providing the care for the care recipient.

Case study
One family we worked with involved a mother who had two daughters and her third child was a boy who was severely autistic. The mum felt enormous stress because she found it difficult to spend time which her two older children, since their brother came along. All she wanted was to find some time to spend watching a video with her girls, or to take them shopping for a few hours uninterrupted. A flexible respite and community support program compromising trained volunteers would meet her specific needs.

Recommendations

- Educational approaches to industry to highlight the issues of mental health and how to support workers experiencing mental health issues, are proving to be successful in raising awareness amongst employers. Similar approaches need to be developed to raise awareness amongst employers about the needs and rights of carers and how these can be accommodated within the workplace.

- Appropriate resources, including brochures, DVD's, posters, booklets and web sites need to be developed targeted towards employers and providing them with referrals and links to community based agencies who can provide advice and support them in developing appropriate workforce strategies.

- Recognize those employers who demonstrate a desire to create 'carer friendly' workplaces, similar to Diversity Awards and acknowledgements.

- Employment Agencies also need to be educated about the challenges and demands on carers and how they can better support them in their job search endeavours.

- Specific skills training places need to be provided to help carers upgrade their skills. Courses need to be designed with sufficient flexibility to accommodate caring responsibility. Individually tailored training plans will help carers complete accredited training courses and thereby increase their employability.

Young Carers

Because of the overwhelming responsibility of caring, it is our experience that young carers can become socially isolated. We also find that caring responsibilities can have a deleterious impact on a young person's schooling, not only impacting on their ability to physically attend school but also interrupting home work and recreational and sporting activities associated with the curriculum.

The literature states that approximately 60% of young primary carers aged between 15-25 years are unemployed or not in the labour force (compared to 38% for the general population in this age group) and only 4% of young primary carers aged 15-25yrs are still at school (compared to 23% of the general population in this age group).[1]

Case Study Julie

Julie is 15 years old. She lives with her mother who is a single parent and has no siblings or extended family. Julie has been caring for her mother for more than 3 years. Her mother, Sue has been diagnosed with Multiple Sclerosis and though currently in remission Julie still provides significant care in the form of cooking meals, cleaning the home, shopping for food and organising transport, as they do not own a car. Last year Sue's condition deteriorated resulting in Julie staying at home from school to cope with the increase in care that Sue required. Julie was assisting her mother to bathe, go to the toilet, administer her medication and manage the house and finances as well as providing emotional support and companionship.

Julie is just one example of the many young people we work with who develop a range of high level and transferable skills – we need to ensure that the vocational education system recognises these well developed and finely honed skills.

The role and responsibilities carried by young carers, means that they develop skills in a wide range of areas, including administering medication, applying bandages, household budgeting, risk management, dealing with

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[1] Carer's Australia Young Carer's Research Report

correspondence and a range of government authorities. Many of these skills are transferable and fit into specific occupational types such as personal care attendant in Aged Care, Enrolled Nurse, general management and administrative type roles. The educational system needs to be adaptable in recognized the significant extra curricula learning and knowledge gained by young carers and assess their roles and responsibilities against standard learning requirements within training modules to allow for recognition of prior learning, which in turn should contribute towards their educational attainment.

Furthermore, we need to be open to the notion of more flexible learning approaches for young carers and be proactive in using technology which develops home based curriculum to enable the young carer to complete education tasks when they are required to be at home attending to the care recipient.

Recommendations

- Develop models of Recognition of Prior learning to recognise the significant skills and knowledge young carers develop through their caring responsibilities.

- Develop flexible schooling models which will accommodate periods of physical absence from school and enable young carers to complete education tasks in their home.

The practical measures required to better support carers, including key priorities for action;

There are a range of practical measures which can be developed to support carers and some of these are not costly, but they do require commitment and a co-ordinated approach from governments, community and business.

Community Education Package

To increase the knowledge and support from the broader community for young carers we need a community education package which should include

- A module on the experience and needs of Young Carers be developed and included in core training for teaching students, social workers, youth workers, child protection officers, youth justice etc. This module would include information about how young carers experience their caring, the challenges, barriers and impact to their social, emotional and physical state and how this affects their physical, emotional and psychological being.

- Training provided to professionals in the medical, community services, child protection. Youth justice and educational stream on how to identify young carers and assess their needs and provide appropriate support and referral.

- Developing toolkits and web sites targeted towards schools and community organisation to inform them about how they might better support carers.

Flexible respite options
Although there are an increasing number of services which can provide respite options for carers, however often these services are bound by contractual rules and funding constraints which can often compromise the level of support offered. The way access to respite is currently structured, means that assistance is often quite limited, it may only be available for a certain number of hours on specific days and therefore if a young person or family need assistance in transport to sporting or recreational events, or unexpected visits to hospital, this support may not be available. The feedback that we have received from carers and young carers suggests a need for -

- Provide alternative options for respite that allows the young carer to execute their right to a choice as to whether they provide care.

- Provide flexible options for respite that is determined by and structured to the needs of carers and young carers.

- Provide additional support services for carers, including home support services.

- Extend the Commonwealth Governments Respite Program for Young Carers to include children still in primary school, thereby enabling them to complete their primary schooling.

- Allocate funding to develop volunteer programs designed to support young carer families, particularly those isolated families who have no extended family support and have become disconnected to their local community.

- Provide respite options which will enable the whole family to holiday together.

- Provide higher levels of school supports for young carers, including an acknowledgment that young carers needs are different from the needs of other students. For example they may need access to mobile phones whilst at school.

Case Study – Billy
Billy is an 11 year old boy, who lives in a single parent family. His mother has severe mental illness and has suicidal tendencies and frequently acts on these suicidal tendances. There were no respite options to provide for someone to be in the family home and be on suicide watch. This young boy understood his mothers condition very well and he carried a mobile phone to school, in case his mother needed him desperately. The school has a 'no mobile phone' policy and his phone was confiscated. This resulted in him not going to school so that he could stay home to supervise his mum. He was providing the total care to his mum, cooking family meals, washing, ironing and completing other household tasks, as well as distributing and monitoring her anti depressant medication.

This young boy managed to complete his whole primary schooling and yet was unable to read. The whole system failed this young boy and his issues were not understood or picked up in the education system.

If respite care had been available to do a suicide watch in the home, he would have been able to attend school or alternatively if there had been an option for him to undertake his education 'on line' he could have continued with his schooling whilst looking after his mum.

After Hours and Weekend assistance
Currently there is no service provider of respite within the ACT that Young Carers can access on weekends. Young people who wish to attend a sport, social activity find they are unable to do this, because of the caring demands.

- There is a need to ensure that support is available when it is needed, this would include evenings and weekends.

Alternative Educational Approaches for Young Carers
To ensure that young carers receive equity of access to education in keeping with their basic human rights, we need to ensure that the education system is responsive to their needs. This should include –

- Develop on-line and distance education models for young carers in mainstream and alternative education programs to reduce the number of hours they are required to be at school. This will enable them to balance the caring role around the educational requirements.

- Make brokerage funds available for young carers to purchase a computer and educational resources that supports them to engage in their education at home.

Family Centred Approaches & Joined up services
It is critical that any support provided should take into consideration the needs of the family and be provided in the context of the whole family. Anglicare has recently received funding to run such a program. The program, known as Litmus operates from a family focused model to provide supports to young carers and their families affected by Mental health issues. The Litmus Program recognises that mental health impacts on all members of a family

and that each member of the family has distinct separate needs as well as the common need to remain connected.

- Conduct a research project to identify best practice family-centered support models that address the needs of individual members and the family as a whole.

- Develop a more coordinated and comprehensive assistance system which will enable carers to access services without having to tell their story over and over again.

Access to Grief and Loss Counsellors

This is particularly important for young carers. Within the caring role the child knows that they have lost their childhood and whilst they are happy to care for their loved ones, they are aware of their loss and often don't know how to deal with this.

- Increase access to specific grief and loss counselling for young carers to help them to better deal with some of the grief and loss issues unique to the experience of young carers.

Skills Training for Carers (Particularly young carers)

Some work has been done on skills development for carers however to make this more effective we need to conduct a training needs analysis of carers across different groups.

- Colleges, vocational training providers and higher education institutions should be encouraged to develop formal pathways and tools to assess the needs of carers undertaking study and provide greater flexibility, access to support and prior learning where appropriate.

Financial Supports

Most of the carers we work with experience significant financial hardship and the ancillary costs of caring are not recognised.

- Develop financial support that better reflects the caring role e.g. carers payments from Centrelink.

- Extending the PBS to reduce the costs of prescribed drugs and medication.

- Review medical/therapy intervention fees and/or specialist fees particularly for in those cases where clients have complex medical requirements and the costs of medical interventions creates financial hardship.

Employment and Skill Development Support

We need to increase awareness amongst employers and employment and training providers of the employment aspirations and circumstances of carers and develop initiatives which will enable carers to enter or re-enter the workforces.

- Provide financial assistance to allow carers opportunities to gain skills.

- Explore Job redesign to enable carers to job share and provide incentives to employers to employ carers through flexible employment packages.

Carers Forums

Carers feel that they are denied access to opportunities and choices that other individuals in the wider community take for granted. Carers are not asking for the re-invention of the wheel but they are seeking to have their voice heard. They would also like to see innovative strategies and resource sharing, to make things a little easier for their very diverse role and situation. Some of the ways in which this could be realised include -

- Develop a carer forum's to seek feedback from carers directly, ensure that these are held across Australia, and accessible to all carers especially in regional areas

- Ensure better support services in rural and regional Australia.

- Provide additional funding for services including case management and support services

- Develop programs that are flexible and cater for the holistic family needs

- Create programs that provide stress and family management workshops for carers.

Strategies to assist carers to access the same range of opportunities and choices as the wider community, including strategies to increase the capacity for carers to make choices within their caring roles, transition into and out of caring, and effectively plan for the future.

We need to develop strategies which address the primary issues confronting cares. These have been outlined in this submission and in summary are -

- Limited access to crisis support , respite options and transport on weekends or evenings.
- Limited or no access of supports for young carers in isolated or rural areas.
- Provision of respite is dictated by the requirements of the service.
- Inflexibility within schools.
- Stigma attached to mental illness, drug and alcohol, disability
- Issue of child protection.
- Limited opportunity to gain flexible and meaningful employment, because of the time constraints and at times the unpredictability of the caring role.

Some strategies that would assist carers in their role would be:

- Address the financial burden of the caring responsibility
- Develop initiatives to attract medical and therapy specialists to practice in rural and remote areas.
- Undertake comprehensive research into carers needs and the difficulties they face.
- Facilitate a closer working relationship between health services (e.g. hospitals, doctors) and with non medical services such as a community organisations providing respite services and case management support.
- Create opportunities for carers, health professionals, support services employees to train together.

The financial hardship resulting from limited income and increasing costs of essential health and medication interventions, means that many carers find themselves in a downward spiral, economically, socially and emotionally. We need to address the financial injustice experienced by many carers.

Financial Realities

Carers Payment
Single $546.80*
Couple $456.80* each
Since July 2000, has included a supplement. It is currently: single $18.50, couple $15.50 each

Carers Allowance
$100.60 per fortnight.
$1000 to be paid annually to a person receiving Carer Allowance on 1 July for each child being cared for under 16 years of age.

Single Hourly rate based on 38hr week = $7.20hr
Hourly rate based on 40 hrs of care a week = $6.84 an hour

Amount Paid for the Equivalent in the Paid Workforce
A care services employee (level 2) undertaking tasks such as assisting with showering, dressing the client, general assistance, general cleaning of kitchen, dining room, bathroom and distribute medication if and when required would receive an hourly rate of $17.23.

Compare this to the carer who would engage in similar tasks.

The difference being $10.03 an hour.

As identified by Carers Australia -
"The income for a single carer receiving carer payment is '$200 a week less than the federal minimum wage' Carers provide the equivalent of 1.2 billion hours of care each year. To replace this unpaid family care with subsidised, high cost, formal residential care within health care facilities would cost $30.5 billion, which is equal to each Australian taxpayer paying an extra $3,000 tax a year "" (Carers Australia, Federal budget 07-08 analysis)

This situation needs to be acknowledged within the broader community. We thank the House of Representatives Standing Committee on Family, Community, Housing and Youth, Inquiry into better Support for Carers, for giving us the opportunity to raise the issues we have articulated in this document and would welcome the opportunity for further dialogue on this matter of critical importance to the well being and effective social functioning and health of families, communities and the economy.

Summary of Recommendations

1. Promote the role of carers and young carers and their positive contribution to society through a National Community Awareness campaign, using electronic and print media, Billboards and community events.

2. Develop a specific campaign to target schools/higher education, focussing on creating carer and disability friendly environments and highlighting the positive aspects of diversity.

3. Focus on promoting 'young carer' friendly schools which provide access to more flexible curricula, on line education and better support and understanding for the young person to complete their education.

4. Recognise the contributions of Young Carers through an annual young carers award, ideally this should include a monetary award or a special family holiday etc.

5. Educational approaches to industry to highlight the issues of mental health and how to support workers experiencing mental health issues, are proving to be successful in raising awareness amongst employers. Similar approaches need to be developed to raise awareness amongst employers about the needs and rights of carers and how these can be accommodated within the workplace.

6. Appropriate resources, including brochures, DVD's, posters, booklets and web sites need to be developed targeted towards employers and providing them with referrals and links to community based agencies who can provide advice and support them in developing appropriate workforce strategies.

7. Recognize those employers who demonstrate a desire to create 'carer friendly' workplaces, similar to Diversity Awards and acknowledgements.

8. Employment Agencies also need to be educated about the challenges and demands on carers and how they can better support them in their job search endeavours.

9. Specific skills training places need to be provided to help carers upgrade their skills. Courses need to be designed with sufficient flexibility to accommodate caring responsibility. Individually tailored training plans will help carers complete accredited training courses and thereby increase their employability.

10. Develop models of Recognition of Prior learning to recognise the significant skills and knowledge young carers develop through their caring responsibilities.

11. Develop flexible schooling models which will accommodate periods of physical absence from school and enable young carers to complete education tasks in their home.

12. A module on the experience and needs of Young Carers be developed and included in core training for teaching students, social workers, youth workers, child protection officers, youth justice etc. This module would include information about how young carers experience their caring, the challenges, barriers and impact to their social, emotional and physical state and how this affects their physical, emotional and psychological being.

13. Training provided to professionals in the medical, community services, child protection. Youth justice and educational stream on how to identify young carers and assess their needs and provide appropriate support and referral.

14. Developing toolkits and web sites targeted towards schools and community organisation to inform them about how they might better support carers.

15. Provide alternative options for respite that allows the young carer to execute their right to a choice as to whether they provide care.

16. Provide flexible options for respite that is determined by and structured to the needs of carers and young carers.

17. Provide additional support services for carers, including home support services.

18. Extend the Commonwealth Governments Respite Program for Young Carers to include children still in primary school, thereby enabling them to complete their primary schooling.

19. Allocate funding to develop volunteer programs designed to support young carer families, particularly those isolated families who have extended family support and have become disconnected to their local community.

20. Provide respite options which will enable the whole family to holiday together.

21. Provide higher levels of school supports for young carers, including an acknowledgment that young carers needs are different from the needs of other students. For example they may need access to mobile phones whilst at school.

22. Develop on-line and distance education models for young carers in mainstream and alternative education programs to reduce the

number of hours they are required to be at school. This will enable them to balance the caring role around the educational requirements.

23. Make brokerage funds available for young carers to purchase a computer and educational resources that supports them to engage in their education at home.

24. Conduct a research project to identify best practice family-centered support models that address the needs of individual members and t the family as a whole.

25. Develop a more coordinated and comprehensive assistance system which will enable carers to access services without having to tell their story over and over again.

26. Increase access to specific grief and loss counselling for young carers to help them to better deal with some of the grief and loss issues unique to the experience of young carers.

27. Develop financial support that better reflects the caring role e.g. carers payments from Centrelink.

28. Extending the PBS to reduce the costs of prescribed drugs and medication.

29. Review medical/therapy intervention fees and/or specialist fees particularly for in those cases where clients have complex medical requirements and the costs of medical interventions creates financial hardship.

30. Provide financial assistance to allow carers opportunities to gain skills.

31. Explore Job redesign to enable carers to job share and provide incentives to employers to employ carers through flexible employment packages.

32. Develop a carer forum's to seek feedback from carers directly, ensure that these are held across Australia, and accessible to all carers especially in regional areas

33. Ensure better support services in rural and regional Australia.

34. Provide additional funding for services including case management and support services

35. Develop programs that are flexible and cater for the holistic family needs
36. Create Programs that provide stress and family management workshops for carers.