Submission No. 769
(Inq into better support for carers)

Aoc 15/7/08

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To the Inquiry Chairperson,

ANGLICARE Diocese of Sydney (ANGLICARE Sydney) thanks the Federal Parliament House Standing Committee on Family, Community, Housing and Youth for the opportunity to make a submission to the Inquiry into better support for carers in Australia. ANGLICARE Sydney supports efforts to better recognise the role of carers in society and to arrive at practical measures and strategies to remove barriers to social and economic participation for carers and to better support carers in their valuable role.

We look forward to the deliberations of this Inquiry and sincerely hope that this may lead to positive outcomes for carers – across the continuum of their care.

Ian Jackson

Acting Chief Executive Officer
ANGLICARE Diocese of Sydney
8 July 2008

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Submission to the Federal Parliament House Standing Committee on Family, Community, Housing and Youth

INQUIRY INTO BETTER SUPPORT FOR CARERS

ANGLICARE Diocese of Sydney

July 2008

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1. SUMMARY OF ANGLICARE SYDNEY•S SUBMISSION

1.1. MAIN ISSUES RAISED IN THE SUBMISSION

The submission deals in turn with each of the four terms of reference for the Inquiry:

- The role and contribution of carers in society and how this should be recognised;
- The barriers to social and economic participation for carers, with a particular focus on helping carers to find and/or retain employment;
- The practical measures required to better support carers, including key priorities for action; and
- Strategies to assist carers to access the same range of opportunities and choices as the wider community, including strategies to increase the capacity of carers to make choices within their caring roles, transition into and out of caring, and effectively plan for the future.

1.1.1. The role and contribution of carers

There is a need to better recognise carers: ANGLICARE Sydney holds the view that the value of what carers do is not properly reflected in Australian society. Carers of people with disability, illness or frailty take the majority share of the caring responsibility and receive inadequate financial and practical support. They thus have fewer opportunities for community participation and improved wellbeing. Furthermore carers make a large financial contribution in terms of providing significant savings in Government expenditure through their work. There is much that needs to be done to improve the situation of carers.

1.1.2. Barriers to social and economic participation

Health and Wellbeing issues: Recent national research among carers found lower-than-average levels of life satisfaction, higher levels of depression and poorer health among Australia's carers. ANGLICARE's own research and the experience of ANGLICARE workers shows significant health and well being issues among carers which resonate and add to these national findings.

Social isolation and social support: Carers often suffer from isolation and disconnection from their local communities and sometimes from their family and friends as their caring role can be often physically exhausting, time consuming, stressful and unrewarding. ANGLICARE's research among ageing carers indicates most have no or minimal support from family and friends. Younger carers too miss out on social interaction with their peers as they become housebound and do not get to enjoy sporting and recreational activities enjoyed by others of their age.

Insecurity about the future: There is evidence to support the view that carers – especially ageing carers – have considerable concerns about the future – their own and that of the person for whom they are caring.

Need for better access to services: Many carers appear to be unaware of the services available to them or are reluctant to access these services. While respite seems to be a well accepted service alternative for carers even within this service there is some reluctance to use these services on the part of some carers. For younger carers looking after people under the age of 65 with dementia it is not just a lack of access but a lack services specific for this particular group. There are insufficient social support services for people diagnosed with dementia and less than 65 years of age.

Access to employment: Adults who are caring for their parent or a child with a disability require regular respite to enable them to work or study. There are also specific issues for carers when endeavouring to access suitable employment and training. Their work week may be limited in hours due to their caring responsibilities and they are often not considered suitable by employers because of concern that their caring role will make them unreliable in terms of work commitment. There are similar issues for carer in terms of flexibility of hours when endeavouring to access training. For young carers there is a desperate need for ongo0ing case management to assist them in finding education and employment pathways while in their caring role and once their care is no longer required.

1.1.3. Practical measures to better support carers

Case coordination and management: This is an important component in assisting carers. However to be effective, it needs to reflect best practice, needs to be well resourced and needs to be strongly client focussed. This submission outlines several key principles that should be incorporated into case management among carers.

Respite care: A major need for carers is the availability of respite services. This applies across the spectrum of carers taking care of people with disabilities, chronic illness and at the end of life. Issues in relation to respite can vary considerably depending on whether the care recipient has a disability, has mental health issues, is frail aged or at the end of life. In ANGLICARE Sydney's view there are many issues that need to be addressed in relation to respite, including:

- Increasing the availability of out-of-home respite for people with disabilities:
- Guarantee of booked respite care in DADHC facilities
- The provision of out-of-home respite for people with challenging behaviours
- Allowing greater flexibility in service guidelines to enable services to provide respite for non-disabled siblings
- Restoring funding for respite for palliative carers
- Better regulation of respite beds in nursing homes and hospitals
- Greater access to in home respite for ageing carers

Non-respite care: ANGLICARE Sydney's submission identifies the need for greater flexibility in the CCRC funding guidelines to better respond to the actual support needs of carers in their individual circumstances. For instance the guidelines overly restrict the services in providing short term domestic assistance for carers of people with disabilities, assistance for carers of people with mental illness and transporting children with disabilities

Young carers: There is a great need for case management of young carers, despite the program guidelines limiting workers to take a case management approach only in limited cases. Young carers typically receive little mentoring from the parents they care for. With caring responsibilities, they can grow up too fast, and need to teach themselves to be an adult. The needs of young carers are largely for social time with people their own age and the need for helpful mentoring relationships.

Ageing carers: The growth in the population of people aged over 65 years indicates a need for long term service planning provision in this area. Research indicates that many ageing carers are hidden and have never engaged with formal services. For ageing carers in particular, their role has been a long term one, they have confidence in what needs to be done and there is sometimes reluctance to hand over the care of their adult child to others. For ageing carers there are a number of specific issues that need to be addressed including:

- Assistance with services particularly in relation to respite, home care, residential placement and financial and legal support.
- Access to programs which develop independent living skills and social contact for the adult child with a disability
- Provision of support with planning for the future regarding financial, residential or guardianship arrangements
- Provision of intensive support for first time respite users
- Ensuring the carer's own needs are addressed including caring for their own health and well being and future life planning.

Culturally and Linguistically Diverse carers: The CALD population is seriously underrepresented in Government funded disability services. This community accounts for one quarter nationally of all those identified as having a disability but less than 15% access services. Research indicates that the CALD community experiences serious systemic disadvantage in accessing appropriate services

Information needs to be disseminated in language specific brochures reflecting the larger cultural groups in an area. Best practice models internationally highlight the need for respite programs to be responsive and culturally sensitive. Government needs to provide more workers who are either from a similar CALD background, speak the relevant language or who have received cultural competency training.

1.1.4. Strategies to improve opportunities and choices for carers

Flexibility is the key component in ensuring more choice and opportunities for carers, underpinned by more respite options, carer support, education and counselling and intensive case management. For some groups in the population choices are limited – particularly for indigenous and CALD carers and choice is predicated on access to information and services which are culturally sensitive and competent.

1.2. SUMMARY OF RECOMMENDATIONS

The following recommendations in this submission are made to the Federal Parliament House Standing Committee on Family, Community, Housing and Youth:

1.2.1. How the role of carers should be recognised

Better recognition of carers:

i) The financial support made available to carers be reviewed. Financial support should not be viewed as social security but income in recognition of the responsibility carers accept in caring for society's most vulnerable people.

1.2.2. Removing barriers to social and economic participation

Improving carer health and well-being:

ii) Funding support for programs be increased which have the physical, emotional and psychological health and well being of carers as the measurable outcome.

iii) The number of respite, case management, carer education and carer counselling services be increased.

Improving social support:

iv) Carer Peer Support programs be funded to encourage networking, social interaction and further support for advocacy. Carer Support programs also need to run in the evenings and weekends to ensure that working carers can access them.

v) At the same time, access be increased to flexible respite on-site with the carer support program, so carers and their care recipients can attend together.

vi) Develop funded Social Support programs for carers which enable the joint participation of the carer and the care recipient in shared activities.

vii) Expand young carer programs to provide them with respite, access to peer programs and social support networks and ensure uninterrupted schooling.

Improve carer security:

viii) Improve planning for carers through extended case management and support programs.

Enhance service access:

ix) More intensive marketing be carried out of services available to carers through media, the social workers at local hospitals and local community service providers such as GP's

x) Review all current programs which are provided to carers and care recipients to ensure that they have an education component on the service network and how to access services

Improve employment services for carers

xi) Provide for ongoing long day care to enable carers of children and adults with disabilities to work office hours.

xii) Establish an employment service specifically for carers, or provide for positions within employment centres for employment consultants who work specifically with carers. The service would provide upskilling programs and liaise with and educate employers, advocating for the needs of carers, especially the need for flexibility.

xiii) Provide greater income support for carers to meet the costs of caring and to establish the importance of their caring role within the community. This should include access to financial counselling.

1.2.3. Practical measures to better support carers

Expand and enhance case management for carers

xiv) Key principles set out in this submission for case management practice for carers be adopted. In this respect, the need for greater support for those in dual caring roles is highlighted.

xv) Funding for CRCs to provide case coordination for both the carer and care recipient is needed, and also to provide longer term case management for both carer and care recipient as needed. Alternatively, this funding could be provided to Community Options in order to decrease the waiting list – CRCs should be given some case management funds to look after those carers who "fall through the gaps" or to assist them in the short term in accessing other case managements services that may have waiting lists.

Increase the availability of out-of-home respite for people with disabilities

xvi) More short term respite accommodation for adults with disabilities be provided, both planned and emergency accommodation. There needs to be dedicated emergency respite beds. Intake needs to be managed by Government-subsidised, community run respite homes.

Guarantee of booked respite care

xvii) Advance bookings in DADHC or FaCSIA subsidised respite houses need to be guaranteed. Funding for more community-managed respite houses is needed for both emergency and planned respite.

Enhance out-of-home respite for people with challenging behaviours

xviii) Behaviour management services be given additional funding to reduce the waiting list, and guidelines to improve the ideal and maximum waiting periods. CCRC funding guidelines should also be more flexible to include brokering behaviour management services where there is an urgent, immediate need for respite.

Allow Respite for non-disabled siblings

xix) There be more flexibility in funding guidelines to allow services to use their discretion in providing respite to both the disabled and non-disabled children. This could be in the form of a pool with more flexibility for non-straightforward respite needs, or subsidies for childcare for non-disabled siblings.

Reinstate funding for respite for palliative carers

xx) The Government reinstate palliative care funding for regular respite to prevent palliative carers' possible exhaustion, break down or illness. The level of funding needs to also take into account the increase in the ageing population over the last 2 years. Funding needs to be flexible to provide regular care for as long as the carer requires it. Some clients may be in the program for up to 3 months.

Better access to respite beds in nursing homes and hospitals

xxi) Tighter regulations be put into place to ensure that respite beds in nursing homes are planned and managed as exclusive respite beds

xxii) A simplified care plan summary is needed, containing Activities of Daily Living (ADLs) and mobility assessments for all respite residents no matter how long they stay. The report could be a one page, "tick box" form requiring minimal free text.

xxiii) A system be put into place where carer post-hospital respite needs are flagged upon their admission to hospital.

xxiv) More funds for post- hospital respite be provided.

xxv) An additional respite component to ComPacks be provided for carers for up to 6 weeks after their leaving hospital.

In home respite for ageing carers

xxvi) Increase funding for in home respite for staff who are familiar with the needs of the client, and who can maintain daily routines for the care recipient

Enhancement of non-respite assistance for carers

xxvii) That there be greater flexibility in the CCRC funding guidelines to better respond to the actual support needs of carers in their individual circumstances.

Better support for young carers

xxviii) That the Department of Family, Housing, Community Services and Indigenous Affairs (FAHCSIA) fund the development of information packs for schools on young carers, their issues and needs.

xxix) That funding guidelines for the CCRC Young Carers Program allow the purchase, leasing or borrowing of computers with internet connection for young carers who are studying. Alternatively, funding could also be provided for the service to pay the discounted Centrelink price of a new computer for the young carer, with their family paying only a minimal contribution.

xxx) That a case management service for young carers be established, either within or outside the CCRC Young Carer Program. At the same time funds should not be redirected away from the Young Carer Program's provision of respite

xxxi) Additional funding be provided for CCRC Young Carers programs to run "respite and family strengthening holidays"

Better support for ageing carers

xxxii) Older frail carers need to be offered a respite component in addition to the hours provided in CACP, EACH and EACH Dementia packages.

Better support for carers from CALD backgrounds

xxxiii) Government provide CALD respite services that conform to best practice.

Better support for Indigenous carers

xxxiv) Indigenous communities be consulted in developing specific strategies based on Indigenous needs and culture

Staffing

xxxv) That funding for carer services take into account the need to increase levels of remuneration for staff working in the carer sector to ensure attraction of appropriately skilled and qualified staff.

1.2.4. Strategies to improve opportunities and choices for carers

Indigenous access issues

xxxvi) Indigenous cultural training for service providers be developed in consultation with Indigenous specific services to assist service providers to improve access and service delivery to Indigenous communities.

xxxvii) Indigenous people be offered training on respite care and carer services to enable them to develop their own services.

CALD access issues

xxxviii) Information regarding respite services be disseminated in CALD communities in language specific brochures.

Increasing the capacity for carers to make choices within their caring roles

xxxix) A quarterly review process in undertaken across relevant care programs in consultation with the carer and care recipient. This should be a monitoring process which enables modifications and amendments to be made over time and as need determines.

Increasing the capacity for carers to transition into and out of caring

xl) For young carers, if the parent for whom they are caring dies, case management should be extended to a two year period form the current three months follow up support to ensure that effective pathways into employment, education and social and emotional wellbeing are established

Increasing the capacity for carers to effectively plan for the future

xli) Carer programs should be specifically funded to incorporate transition planning as part of their core service delivery.

2. INTRODUCTION

ANGLICARE Diocese of Sydney (ANGLICARE Sydney) thanks the Federal Parliament House Standing Committee on Family, Community, Housing and Youth for the opportunity to make a submission to the Inquiry into better support for carers in Australia. ANGLICARE Sydney supports efforts to better recognise the role of carers in society and to arrive at practical measures and strategies to remove barriers to social and economic participation for carers and to better support carers in their valuable role.

ANGLICARE Sydney operates a number of services and programs involving carers in the Sydney metropolitan and the Illawarra regions of New South Wales. Therefore comments regarding our experience are limited to this region.

ANGLICARE Sydney's submission is written from the viewpoint of a service organisation seeking to assist carers in their lives. We recognise that our observations will be particularly focussed upon issues where we have the greatest involvement with carers. In this respect we are able to make observations about areas where service delivery could be improved by both service providers and government, which can complement more holistic observations from carer groups and carers themselves.

This submission uses the same definition of carers as that outlined by the Committee, namely: 'individuals providing unpaid support for others with ongoing needs due to a long-term medical condition, a mental illness, a disability or a frailty'. Over the years ANGLICARE Sydney has provided assistance to carers of people in each of these situations.

The submission deals in turn with each of the four terms of reference for the Inquiry:

- The role and contribution of carers in society and how this should be recognised;
- The barriers to social and economic participation for carers, with a particular focus on helping carers to find and/or retain employment;
- The practical measures required to better support carers, including key priorities for action; and
- Strategies to assist carers to access the same range of opportunities and choices as the wider community, including strategies to increase the capacity of carers to make choices within their caring roles, transition into and out of caring, and effectively plan for the future.

2.1. OVERVIEW OF ANGLICARE SYDNEY

ANGLICARE Sydney is one of the largest Christian community organisations in Australia; it embodies the Christian commitment to care for all people in need. ANGLICARE Sydney has been providing a wide range of professional services to the community since 1856 and serves many thousands of people every year. Its services include: counselling; community education for families; family support services; youth services; emergency relief for people in crisis; foster care and adoption for children including those with special needs; migrant services including humanitarian entrants and new emerging communities; English as a second language classes; aged care both through nursing homes and community services; opportunity shops providing low-cost clothing; emergency management services in times of disaster; disability case management and respite and chaplains in hospitals, prisons, mental health facilities and juvenile justice institutions.

2.1.1. How Anglicare assists carers

ANGLICARE Sydney's service delivery aims to be responsive to local and regional needs, with an emphasis on service provision that reaches the most vulnerable and marginalised in our society. Specifically in relation to carers, ANGLICARE Sydney provides the following services:

- **Commonwealth Carelink and Carer Respite Centres (CCRC's):** During the past seven years ANGLICARE has operated both the Commonwealth Carer Respite Centre and the Commonwealth Carelink Centre in the Nepean and South West Sydney regions.
- **Community Options** This is a case management and brokerage service to assist people of all ages with a functional disability, who are at risk of premature admission to residential care, to remain living in their own home. This program covers the Blacktown, Hawkesbury, Holroyd and Penrith LGA's.
- **Support Co-ordination for Older Parent Carers** provides case management for carers over the age of 65 still supporting a son or daughter with a disability at home.
- **Respite Options** provides flexible respite packages to carers who have a child with a disability.
- **ComPacks** - provides short-term case management and brokerage for people being discharged from hospital who have complex needs.
- **Westlink Host Family Program** operating since 1980 this service offers family based respite care provided by volunteer families of individuals in the community, and operates in the LGA's of Auburn, Holroyd, Parramatta, Baulkham Hills, Blacktown, Hawkesbury, Penrith and Blue Mountains.
- **Peer Support** catering for adolescents aged 14-18 years who participate in activities totally within the general community. - Holroyd, Parramatta, Baulkham Hills and Blacktown.
- **Vacation Care** - This offers day care during school holidays to 0-6 year olds and 7-10 year olds. Holiday camps are offered to 10-18 year olds, from the same areas as the Host Family Program.
- **W.H.I.R.L.S. -** Head Injury and Recreational and Leisure Service- this is an out of hours respite service for consumers aged 18 years and over with an acquired brain injury and the carers/families, living in the Blacktown LGA.
- **Complex Care Support** is funded by the National Respite for Carers Program.
- **Dementia Home Support** provides in-home respite to people with dementia and/or their carers. This program is designed to support the person with dementia to maintain their living skills and to assist in prolonging their time in the community. The carer is also supported with information, education and 'time out' in dementia care. DHS operates in the Blacktown LGA and the Nepean Region.
- **Chesalon Care at Home** (Community Aged Care Packages – dementia priority). This allows for frail aged people and people with early dementia to remain in their own home longer.
- **Richmond and Winmalee Day Centres.** Which provides programmes for care recipients and respite for carers

The experience in serving the community with this range of programs means that ANGLICARE Sydney is well placed to provide comments to the Government's Inquiry into better support for carers. Our approach to carers is based on consultation, collaboration and flexibility in relation to differing needs – physical, familial, emotional and cultural. It is client centred endeavouring to be responsive to changing needs and circumstances and it affirms the significant role of the primary carer, often operating under challenging circumstances.

3. RECOGNISING THE CONTRIBUTION OF CARERS TO OUR SOCIETY

3.1. THE CONTRIBUTION THAT CARERS MAKE

ANGLICARE Sydney believes that society has a responsibility to care for its least powerful members - those with disability, illness or frailty. Their care is not only the responsibility of their families and close friends, but also of the rest of society.

In this framework, carers and non-carers alike should have the same opportunities to participate in family, social and community life, employment and education and enjoy health and social and economic wellbeing.

However, this value is not properly recognised in Australian society. Carers of people with disability, illness or frailty take the larger share of the caring responsibility and receive inadequate financial and practical support. They thus have fewer opportunities for community participation and improving their wellbeing.

A 2005 Access Economics report for Carers Australia found that an estimated 1.2 billion hours of informal care were provided in 2005. The replacement value of these hours is estimated to be over 60% of other formal health care – totalling $30.5 billion. This saving to society comes at an estimated opportunity cost of at least $4.9 billion in lost income for carers.[1]

Informal care combined with some community-based care costs society far less than institutionalised care. It is the informal care component that reduces the cost of care, however this is the form of care that is least subsidised. Government benefits to informal carers were estimated at 35% of the opportunity cost to carers in 2005.[2]

3.2. HOW TO BETTER RECOGNISE CARERS

The role of carer involves a sacrifice to one's own life. It is their care that contributes to a society where the least powerful members are valued and their needs considered. Carers however often feel that their sacrifices are not sufficiently acknowledged or supported. Providing support to carers, particularly in the form of respite, is one of the strongest ways to value their contribution to society via their care recipient.[3]

Similarly, supporting carers financially and supporting their employment recognises the extra difficulties carers face in achieving financial security.[4] The carer's role is a 24 hour job, which carers believe is grossly underpaid. Carers use terms like "modern day slaves", "cheap labour" and "second class citizens" to describe the way in which they feel undervalued.[5]

Furthermore, the lack of practical and financial support for carers and the resultant sense of 'going it alone' compounds mental health problems, exhaustion and stress levels that many

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[1] Access Economics (2005) *The Economic Value of Informal Care*, report for Carers Australia, <http://www.carersaustralia.com.au/images/stories/Access%20Economics%20study%20full.pdf

[2] Ibid.

[3] Holland KE and Blood RW (2008) Carer's perspectives on Caring: A Qualitative Analysis of Open-Ended Responses to the Carer Health and Wellbeing Index Survey 2007, Carers Australia, Deakin ACT, <www.carersaustralia.com.au>, p 7.

[4] Ibid, p 7-8.

[5] Ibid, p10.

carers face.[6] In contrast, society through the redistribution of taxes should reflect a commitment to *together* caring for *our* vulnerable members. The recommendations throughout this submission pertain to how carers can be better supported. Simply put, caring for the carers is the best way to recognise their contribution.

Direct care workers who provide support to carers are paid anywhere between $18 (unqualified) and $40 (nursing) an hour to provide respite or home care assistance to carers. It should be noted that care workers who work a few hours earn more than carers who are providing round-the-clock care, 7 days a week. This fact highlights the financial burden carried by carers and the savings carers make to government through their role.

Recommendation:

i) The Department of Families, Housing, Community Services and Indigenous Affairs (FaHCSIA) review the financial support available to carers. Financial support should not be viewed as social security but income in recognition of the responsibility carers accept in caring for society's most vulnerable people.

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[6] Holland and Blood (2008) op.cit.

4. BARRIERS TO CARERS' SOCIAL AND ECONOMIC PARTICIPATION

ANGLICARE Sydney through its extensive service delivery and research has identified a number of barriers to social and economic participation.

4.1. SOCIAL BARRIERS

4.1.1. Health and Well being

International research identifies that for carers there are feelings of overload (having more to do than they can manage), strain (performing tasks that are emotionally difficult) or a sense of role 'captivity' (feeling trapped by the demands of care).[7] These primary stressors often spill over into other areas of life, what Leonard Pearlin refers to as 'secondary stressors' which may include financial strain, loss of self esteem and loss of identity which in combination harm family and individual well being.[8]

ANGLICARE research is also indicating significant health and well being issues for carers. In the recent Support Coordination evaluation carried out by ANGLICARE, 29 ageing carers were asked to provide some indication of their overall health and well being. Two thirds of those surveyed considered that they needed time out and 10 carers indicated that they have conflicts with the person for whom they are caring. Respondents were asked to rank their life satisfaction as a whole from 1-10. More than half considered this aspect of their life was 6 or less and more than two thirds rated their health the same way. Respondents were also asked to describe in more detail how they coped with life in general. One third found it hard to wind down and felt like they often over reacted, would get agitated and found it difficult to relax. Three quarters ranked their health as poor or only fair.

These results are supported by ANGLICARE workers who have observed that ageing carer's often have specific issues which need addressing such as dealing with a cancer diagnosis, managing their own panic attacks brought on by stress and the energy required to be an advocate on behalf of the care recipient. In other carer programs, workers have observed that there is little attention paid to the emotional needs of carers – their stress, anxiety and depression – which is often compounded by grief – related to what is happening to the person for whom they are caring.

Worker Observation: "What word could you use most often to describe a carer other than **GUILT**. It is the most frequently used word across the board. 'I promised mum I would never put her in a nursing home'; 'When I married I promised to care for in sickness and health'; 'Mum knows me and feels relaxed with me, how could I put her into a nursing home?'; 'I feel so guilty when I go out to the doctor, even though I keep having diabetic hypos.'"

For older carers looking after spouses, marital conflict and resentment is not uncommon – especially where there is role reversal and the care recipient, previously dominant in the relationship, has become dependent. ANGLICARE counsellors sometimes see old and frail carers who suffer from injuries and emotional and physical exhaustion in caring for their own frail aged partner.

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[7] Zarit, Steven (n.d.) *Respite Services for Caregivers*, sighted on the 8th April, 2007 at www.nfcsp.org., p6

[8] Ibid

For young carers there is long term grief and loss – of childhood and adult responsibilities at an early age and guilt over whether they are doing enough for their parent or sibling.

Recommendations:

ii) The Government increase funding support for programs which have the physical, emotional and psychological health and well being of carers as the measurable outcome.

iii) The Government increase the number of respite, case management, carer education and carer counselling services.

Worker Observation: "In our day centres on the northern beaches, we find our carers are increasingly frail, many in their 80s +. They have huge health needs of their own. Some of our carers should be in residential care themselves. Often the people they care for have high needs and advanced dementia. The people they care for are often co-dependent and suffer paranoia in the absence of their carer.

Many of our carers see themselves as living a life of sacrifice for their loved ones and put their own lives on hold. They fail to see the need to look after themselves. Often their children are unaware of the high needs of the person being cared for because they are not told and may often live quite remotely from their parents. It is often a shock, when the carer can no longer care and the children have to take over the caring role."

4.1.2. Social Isolation and Social Support

ANGLICARE services have identified that carers suffer from isolation and disconnection from their local communities and sometimes from their family and friends as their caring role can be often physically exhausting, time consuming, stressful and unrewarding.

ANGLICARE Research, using entry surveys for the Support Coordination program for Ageing Carers, identified that there were a number of primary stressors in the lives of carers which reduced their well being and their capacity for community participation and social interaction outside the home. One in five indicated that they did not feel as if they had connection to their local communities and two thirds ranked this aspect of their life as 6 or less.

Levels of disconnection and isolation are determined by the support networks in place for carers from partners, family, friends and the wider community. In the ANGLICARE ageing carer survey just under half of those surveyed no longer had a partner but for those who did a significant proportion considered that they had wonderful support from them. For 3 of the 29 carers there was nil support from their partner – reflecting the caring needs of dependent spouses who also had health issues. For many this area of questioning revealed a significant lack of support and understanding from others of their situation. Over two thirds (68%) of carers indicated either no or minimal support from family and almost 75% had the same result for friends. Only one in three considered that they had very good support from counsellors or professionals.

For other carers, particularly those caring for ageing frail spouses or adult children with a disability there can be resentment that they no longer have the time or energy to spend with their children and grandchildren. This can lead to a sense of disconnection from their own family. One solution to the issue of social disconnection is to provide joint experiences for the carer and the care recipient.

Worker Observation: "Very often carers feel most secure if they can participate in events with their loved one. This is hugely successful in a social situation. We have experienced this frequently on funded activities such as luncheon ferry rides, pampering days, retreat weekends, etc. However, funding for this sort of thing is sporadic."

Younger carers miss out on social interaction with their peers as they become housebound and do not get to enjoy sporting and recreational activities enjoyed by others of their age. This can also lead sometimes to developmental issues especially if their caring leads to interruption of their education on a regular basis.

Recommendations:

iv) The Government fund Carer Peer Support programs to encourage networking, social interaction and further support for advocacy. Carer Support programs also need to run in the evenings and weekends to ensure that working carers can access them.

v) At the same time, the Government increase access to flexible respite on-site with the carer support program, so carers and their care recipients can attend together.

vi) Develop funded Social Support programs for carers which enable the joint participation of the carer and the care recipient in shared activities.

vii) Expand young carer programs to provide them with respite, access to peer programs and social support networks and ensure uninterrupted schooling.

Worker observation: One of the issues facing the carers in attending a carer support group, is being unable to leave the person for whom they are caring, so they can attend the meetings. We have always encouraged them to use the Commonwealth Carer Respite Centre in these situations. They are universally reluctant to do so, as they feel they are the only ones who provide satisfactory care for their loved ones. They are reluctant to leave their relative in the care of a stranger. We have asked the CCRC to come to the centre to provide the respite there so the meetings can go on. They refuse to do this as they only provide emergency respite. They cannot provide regular respite. Most of the carers we deal with are elderly themselves and would not consider coming out at night, when a working family member might provide assistance.

4.1.3. Insecurity

There is evidence to support the view that carers – especially ageing carers – have considerable concerns about the future – their own and that of the person for whom they are caring. Very few carers in the ANGLICARE ageing carer survey for example considered that there was a good transition plan for their son/daughter and as a consequence 24 out of 29 claimed that they worried about the future. ANGLICARE workers halve also identified in their interactions with carers in Day centres that there is often a fear of becoming ill, incapacitated or dying – and the consequences this would have for the person for whom they are caring.

Recommendation:

viii) Improve planning for carers through extended case management and support programs.

4.1.4. Service Access issues

ANGLICARE workers have observed that many carers appear to be unaware of the services available to them or are reluctant to access these services. In the case of ageing carers, a duty of care which has often encompassed 40 years, has made them doubtful that support services will be adequate or appropriate for their adult child with a disability. But there are also information issues which became very apparent in the ANGLICARE ageing carer evaluation. In terms of services accessed in the last 12 months the three most significant in terms of response rate were respite (17), Community care services (11) and case management (10). There was little access to carer counselling or carer education and training. Only 4 had been assisted in the development of a transition plan for their son/daughter and fewer still had been given support in the widening of wither their own or their child's social contact.

However this lack of access did not necessarily reflect a lack of priority. When asked the importance of each of these services to them the contrast between what was being accessed and what was needed was stark. For example although only 10 had accessed case management 24 of the 29 carers thought that it was important or very important. While only 4 had been able to develop a transition plan it is clear from this survey that it is an important component of any care plan as 23 carers rated this highly in terms of importance. While only 3 had been given assistance in helping to widen the social contacts for their son/daughter 23 considered this was an important part of the well being for their children. For many carers access to appropriate services is what makes the difference in sustainability.

Carer Observation: "I will also never forget the huge pressures on me as the 'sandwich' generation of looking after both my father in law and my own children. Luckily we have a close family and we attracted an EACH package which helped us with my father in law over the last month of his life. It was perfect for us. We were lucky but still stressed. I cried at my carers support group at North Manly during that time and was supported by other carers."

ANGLICARE workers have also noted that for carers without internet access there are issues in accessing information on services relevant for their needs.

They have also observed that while respite seems to be a well accepted service alternative for carers even within this service there are some problems. Some carers feel that the care recipient can return from residential respite with deterioration making it more difficult to care for them over the longer term. Others feel that it is a sign of failure when they have to admit someone to residential respite and still others are concerned about the lack of secure lock up respite beds for those with escalating dementia issues.

There is also a range of respite service types, in home, community access, residential, peer support, social support, which have different selection criteria and a range of service providers. This adds to the confusion for carers in trying to access a service.

For younger carers looking after people under the age of 65 with dementia it is not just a lack of access but a lack services specific for this particular group. There are insufficient Social support services for people diagnosed with Dementia less than 65 years of age. Currently the Government funds Commonwealth Aged Care Packages and EACH package for people over 65 years of age. Attendant Care packages of service for people under 65 are self managed packages otherwise there are only stand alone HACC services such as domestic assistance, Personal Care assistance and Respite care which may be provided by multiple service providers.

Recommendations:

xix) More intensive marketing of services available to carers through media, the social workers at local hospitals and local community service providers such as GP's

x) Review all current programs which are provided to carers and care recipients to ensure that they have an education component on the service network and how to access services.

4.2. ECONOMIC BARRIERS: EMPLOYMENT AND INCOME

4.2.1 Employment

Insufficient respite: Adults who are caring for their parent or child with a disability need long term regular respite to enable them to work or study. In the case of children with disabilities their parent carers have great difficulty in accessing before and after school care. The ANGLICARE Kingsdene program is a school for children with profound disabilities and it is supported by a Monday to Friday residential facility. This enables parents to work during the work and care for their child on the weekend. However, once their child leaves Kingsdene then one parent will generally have to forfeit full time work to ensure full time care for their child. For both adults with disabilities and older frail people, activity centres often only operate from 9am – 3pm, and there is a lack of funding for extended operating hours. People with disabilities may only be able to attend a day centre 2-3 days per week. This reduces the opportunities for their carer to find adequate employment.

Carers of people with challenging behaviour have even fewer opportunities as their care recipients may not be eligible for day programs. There is some funding for long day centres for older people with dementia, enabling their carers to work office hours, however this is not available for younger people with disabilities.

Flexible Employment Options: Carers also have specific concerns when looking for work. Whilst carers may only be available to work limited hours a week, or need work that is flexible to their caring responsibilities, employers sometimes have the attitude that carers won't be reliable as they will have to field phone calls or leave early to support their care recipient. Carers should not have to advocate their needs to employment agencies with little understanding of their situation. They need assistance from a service which already understands their needs and not only helps them re-enter the workforce but also advocates their needs to employers.

Flexible Training Options: For carers seeking part time or flexible work arrangements there is often a need to undergo retraining. However carers are often time limted in terms of the commitment they can make for such training and need to be able to access it in a way which is flexible and takes into account their caring responsibilities.

I run a social support service in the Pittwater area. It is for people under 65 years of age with a diagnosis of dementia. The carers of these people are a different service user entirely. Either they are the young spouses/ siblings of these clients or their children. The carer is often still in the workforce, or has been at home caring for teenage children. Very often our client was the main breadwinner. The client is no longer able to cope in the workforce. Sometimes their spouse has not pursued a paid career but has rather stayed at home or been in PPT work. They are now faced with how to maintain their lifestyle/ make ends meet. They often still have a mortgage. These carers are actually in desperate times. We have tried to support them by taking their loved one into our day centres on hours that extend our actual funding etc. Band aid situations are happening all over the place. Where can they go? This is so distressing for all involved.

For some carers, particularly those who are ageing and post retirement age, there is little possibility of a return to the workforce – either because of age, their own infirmity or the 24 hour role of the carer. However this does not mean that they should not have the opportunity for further study – to enhance their connectedness to the community and their own intellectual stimulation and well being. This can only be achieved with the provision of regular respite. This is also true for dual carers – there is little possibility of working when looking after two people with a disability, physical and mental health issues.

4.2.2 Income

For many carers who have not had access to superannuation in their working life or who have not been able to work because of their caring responsibilities, there is heavy reliance on government benefits as the main source of income. Additionally the cost of medications, multiple services, physical aids, mobility aids, household renovations for disability access and continence products, impacts significantly on income. Carers require greater income support to meet the costs of caring and to recognise the valuable role they play in reducing the costs on the health system if caring was no longer done in the home.

Recommendations:

xi) Provide for ongoing long day care to enable carers of children and adults with disabilities to work office hours.

xii) Establish an employment service specifically for carers, or provide for positions within employment centres for employment consultants who work specifically with carers. The service would provide upskilling programs and liaise with and educate employers, advocating for the needs of carers, especially the need for flexibility.

xiii) Carers require greater income support to meet the costs of caring and to establish the importance of their caring role within the community. This should inclu8de access to financial counselling.

5. PRACTICAL MEASURES TO BETTER SUPPORT CARERS

5.1. CASE COORDINATION AND MANAGEMENT

Case coordination and management is an important component in assisting carers. However to be effective, it needs to reflect best practice, be well resourced and be strongly client focussed.

Building resilience

ANGLICARE Sydney's experience indicates that case coordination and case management must recognise the importance of involving family members in planning for the family. The aim should be to build the resilience of all the family including the individual with the disabilities. Such resilience is often a reflection of a complex interplay of variables including the socio economic background of the family, family problem solving abilities, the quality of the family relationships, the family's access to other disability support services and the degree of severity of the disability. [9]

A suite of service options

ANGLICARE recognises that what is needed for carers is access to substantial care packages, information and education, accessible respite and accommodation and other support options – emotional and financial. For each carer the circumstances may vary as to whether they are sole or dual carers and whether they have other family support or experience cultural barriers in terms of service access. In a recent evaluation of the Support Coordination program by ANGLICARE one in six carers was looking after an adult child with a disability as well as an ageing parent or partner with multiple issues. Dual caring is an exhausting and difficult commitment and such carers need additional support structures in order to build their resilience, well being and coping mechanisms.

Context

Case management plans should take into account the age and physical capacity of the carer and person/s for whom they are caring, the ability of the family to solve problems and the relationship context within the household and local community in terms of other formal and informal support networks. Each of these represents different scenarios which will require different care options and support mechanisms. Case management needs take into account age, culture, religion and language,

Customising Programs

Programs need to be customised to address the various needs identified through the assessment process. The emphasis should be on working with the family in the natural setting of their home and building a personal relationship. This approach is supported by the research which indicates that an important factor in effective outcomes is trust between the service and the family and care recipient[10].Thus central to this capacity to respond is the understanding of the needs presented via a careful assessment process and the choice or range of options provided. In a 2001 literature review on effective outcomes for respite

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[9] Ibid

[10] Pollock, Nancy, Law Mary, King S. and Rosenbaum Peter (2001) *Respite Services – A Critical Review of the Literature*, sighted on 8th April 2007 at www.canchild.ca, p2

services it emerged that parent preferences for respite were centred on choice - "access to a wide variety of options... and the need for a positive, enriched and supportive environment". [11]

Client focused

ANGLICARE operates its current services on outcomes which are based on the principle that best practice reflects two clients in the person centred delivery of disability services – the carer and the care recipient. ACSA (2005) notes in their research the need for an integrated, coordinated model which practises flexibility, is genuinely inclusive and responsive and equitably maximises the effective options for both the carer and the care recipient of a culturally appropriate service. Canadian and Australian research also supports family focus, single entry point and responsiveness to need. Carer support needs to be planned and organised so as to be preventative in focus to enable family/carers to maintain a healthy relationship with the care recipient. For ANGLICARE the outcomes for case management need to be person centred – that of a positive experience for the carer and care recipient, greater opportunities for access to and participation in the community and a more positive view of the care recipient from the perspective of the family for whom, it is hoped, there will be less stress and improved coping strategies as a result of the service.

Evaluation

Evaluation on entry and exit from services should be an important component of all case management when working with carers. It is important to understand the stressors experienced by carers and whether or not being part of particular programs such as flexible respite and support coordination are effective in reducing levels of stress, increasing capacity to cope as well as enhancing well being. Evaluation should deal with service satisfaction, ways to improve the service delivery model through client feedback and assessing the meeting of outcomes for the care recipient.

Outcomes based

Government policy for carers needs to be focused on service provision which is outcomes based, including:

- Reduction of primary stress as a result of emotional support, financial and long term planning and access to mainstream services
- Widening of the informal family and support networks particularly within their own cultural, ethnic and religious community contexts
- Increasing access to services and other networks appropriate for care
- Allowing the carer to acknowledge their needs and consider the priority of their own health and well being.
- Long term planning - for the satisfaction of both the carer and the care recipient.
- The opportunity to build healthy relationships outside everyday family life
- The experience of self determination through carer decision making and choice
- Peer and external support networks will have been expanded and enriched through participation in activities.
- The opportunity to widen participation especially within the carer's own ethnic and cultural community contexts
- A service experience which is positive so that the family builds trust in the service and considers it as a quality of life option for all concerned.
- The delivery of care has been consistent and has built a strong relationship between the case manager and the individual/care/family.

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[11] Ibid

- An action research and evaluation process that enables the family to participate in the development of innovative service delivery options.
- The development of further understanding of the role that the service can play in reducing primary stressors in the carer's life and the contribution this can make to the wider service network.
- The building of service capacity in the area that will reduce the current stress on existing services and enhance accessibility by community groups that currently are underrepresented across all such services in the region.

Recommendation:

xiv) Key principles set out here for case management practice for carers be adopted. In this respect, the need for greater support for those in dual caring roles is highlighted.

Case management for many disability programs are centred on outcomes for the person with a disability, not the carer. For those services which consider case management for both there are long waiting lists. The Carer Respite Centres are not designed to provide regular respite or ongoing case coordination and management outside the mental health service.

Recommendation:

xv) Funding for Carer Respite Centres (CRC) to provide case coordination for both the carer and care recipient is needed, and also to provide longer term case management for both carer and care recipient as needed. Alternatively, this funding could be provided to Community Options in order to decrease the waiting list – CRCs should be given some case management funds to look after those carers who "fall through the gaps" or to assist them in the short term in accessing other case managements services that may have waiting lists.

5.2. RESPITE CARE

A major need for carers is the availability of respite services. This applies across the spectrum of carers taking care of people with disabilities, chronic illness and at the end of life.

Practical measures in relation to providing respite care need to take into account the isolation of many carers, as outlined previously in this submission. Issues that need to be taken into account and planned for include:

- The different emotional responses of carers, from resistance to the idea of sharing responsibility with others, through to freely taking a break
- Lack of knowledge about the support services that are available, especially among older carers
- Issues of identity among carers: the parents of a person with a disability might not see themselves as a carer but simply as a parent
- Commonwealth and State governments have different definitions of disability and respite which can be confusing for carers.

Several practical measures are outlined in this section regarding the provision of respite care.

5.2.1. Increasing the availability of out of home respite for people with disabilities

In ANGLICARE Sydney's view, there is a chronic shortage of both emergency and planned respite beds. For example, in the Nepean district of Sydney, there is limited provision for overnight respite to allow carers have an extended break. People with physical disabilities have limited out of home respite options and may stay in respite houses with people with intellectual disabilities or in aged care facilities. Whilst older frail people can enter aged care facilities for respite, there are few subsidised respite houses for younger people with disabilities. On the other hand, the demand for longer term respite in South West Sydney means that emergency respite is often not available. Furthermore, in some respite houses, unused respite that is previously booked will not be returned.

In South West Sydney there is limited subsidised respite for people with disabilities such as vacation respite care, overnight respite or weekend day programs. Respite options for children under 16 years with disabilities are particularly limited. This is especially true around major holidays. When subsidised respite is unavailable, ANGLICARE's Commonwealth Carer Respite Centre (CCRC) pays a care worker to provide respite on an hourly basis. However it needs to be recognised that this is not a cost effective solution.

Recommendation:

xvi) More short term respite accommodation for adults with disabilities be provided, both planned and emergency accommodation. There needs to be dedicated emergency respite beds. Intake needs to be managed by Government-subsidised, community run respite homes.

5.2.2. Guarantee of booked respite care

With high demand for respite and limited subsidised respite houses, ANGLICARE's CCRC often resorts to brokering emergency respite in the more expensive private houses and longer, planned respite in subsidised houses. However, planned respite cannot be guaranteed in those subsidised respite houses that are managed by Government departments (DADHC or FaCSIA). Emergency respite requests are often prioritised over previously booked places. This is less the case in houses that are funded by DADHC or FaCSIA but managed by non-profit organisations; however in the Nepean district of Sydney such respite houses are very few.

Case Study: A carer booked a holiday to Queensland and organised in advance for their care recipient to go to a respite house near their home. While they were away, the respite house was faced with an emergency respite request and prioritised this over the care recipient who was booked in advance. The carer had to return early from their holiday and take their care recipient out of respite to allow the emergency respite to take place.

Recommendation:

xvii) Advance bookings in DADHC or FaCSIA subsidised respite houses need to be guaranteed. Funding for more community-managed respite houses is needed for both emergency and planned respite.

5.2.3. Out-of-home respite for people with challenging behaviours

There is a lack of residential respite for people with disabilities who also have behavioural problems. For instance in Sydney's Nepean district there is a lack of respite for people with challenging behaviours, and if a place is found it is very costly. Respite lasting 3 to 4 days can cost around $3,000. Yet this is a hugely recurring need especially for care recipients who are young people with disabilities.

The waiting list for a DADHC-funded behaviour intervention service for a young person with a disability can be one year or more. (Note that the behaviour management program is conducted by a psychologist.) But respite is difficult to find until the behaviour can be managed. Therefore there is a need to reduce this waiting list. The CCRC can use its discretion to broker a behaviour management service for the care recipient, however not on a regular basis as this is not a priority in the guidelines. CCRC services can also apply to roll over previous year's funds into specific things, and perhaps this might include brokering emergency respite, however it is better to plan the year's service provision so that there are not funds left over.

Recommendation:

xviii) Behaviour management services receive a funding boost to reduce the waiting list, and guidelines to improve the ideal and maximum waiting periods. CCRC funding guidelines should also be more flexible to include brokering behaviour management services where there is an urgent, immediate need for respite.

5.2.4. Respite for non-disabled siblings

Carers of both children with disabilities and children without disabilities may be unable to access respite services. When emergency respite is required (for example if a carer needs to be admitted to hospital) carers of both disabled and non-disabled children are only able to receive respite for their disabled child. In most cases family members can be called on to care for other siblings. However, there are low income families in the community without supportive or nearby relatives who find themselves with few options for the care of their non-disabled child. Carers may be reluctant to take up respite in the situation where there are disabled and non-disabled siblings in a family. An intellectually disabled children can feel anxiety over being separated from their non-disabled sibling, leading to the carer being unable to use the respite service.

One possible solution would be to change the respite guidelines to enable the non-disabled sibling to also be taken into care in special circumstances. These special circumstances may include when the carer is unwell, where there are other family issues that need attention by the carer, or where a traumatic incident has occurred to the family. Yet mainstream services generally do not help with the care of non-disabled siblings. In one instance where ANGLICARE Sydney was asked to assist the father of a disabled child had been in a car accident; the mother was then in a situation of needing respite care for her child with Asbergers Syndrome, but also had a non-disabled child.

Recommendation:

xix) There be more flexibility in funding guidelines to allow services to use their discretion in providing respite to both the disabled and non-disabled siblings in a family. This could be in the form of a pool with more flexibility for non-straightforward respite needs, or subsidies for childcare for non-disabled siblings.

5.2.5. Respite for palliative carers

Carers of people who are reaching the end of life often need overnight respite so they can sleep. Specific palliative care funding was provided to CCRCs for 12 months only but it was discontinued in 2006. The Government promised that palliative respite care funding would be redistributed to other services but this has not occurred. In the meantime, ANGLICARE Sydney's Nepean service has received an influx of such requests in the past few months. Carers may only need respite for 2 weeks but have to wait for 2 weeks for an assessment. There is a risk that the carer themselves could become distressed, exhausted or ill while waiting. These carers generally don't ask for too much – if anything they are reluctant to ask for help. They often seek assistance from the CCRC at the recipient's end stage of life, so care is usually provided for only a short time. This type of respite, however, requires a registered nurse, which costs more.

Recommendation:

xx) The Government reinstate palliative care funding for regular respite to prevent palliative carers' possible exhaustion, break down or illness. The level of funding needs to also take into account the increase in the ageing population over the last 2 years. Funding needs to be flexible to provide regular care for as long as the carer requires it. Some clients may be in the program for up to 3 months.

5.2.6. Respite beds in nursing homes and hospitals

At present emergency respite for older care recipients can be obtained through nursing homes. However many of these beds are disappearing. Nursing homes should have dedicated respite beds if they have respite funding – not only when a bed is available on their terms. In ANGLICARE Sydney's experience, some nursing homes manage their respite beds well but others don't. In some cases, if the respite bed is vacant for up to 2 weeks, the CCRC will pay the facility to keep it open as a respite bed.

One solution may be for nursing homes to negotiate an arrangement where the CCRC manages respite beds on their behalf. This, however, should not be a requirement for CCRCs. If the CCRC has to manage a respite bed in a facility with bad reputation then the CCRC should not pay for vacant bed days. Furthermore, the facility's bad reputation may also reflect on the CCRC.

Recommendation:

xxi) Tighter regulations be put into place to ensure that respite beds in nursing homes are planned and managed as exclusive respite beds.

For short stay respite in a hospital or nursing home, a detailed nursing care plan (a minimum 30 page document) must be completed, even in cases where only two weeks care is being provided.

Recommendation:

xxii) A simplified care plan summary is needed, containing Activities of Daily Living (ADLs) and mobility assessments for all respite residents no matter how long they stay. The report could be a one page, "tick box" form requiring minimal free text.

In the event of a carer needing unplanned hospital treatment, the care recipient needs care during this time, as well as during the carer's recovery at home. In the ComPacks model-of-care system, six weeks of post-hospital care is provided where a patient is discharged from a public hospital. It allows for 5 hours care per week – much of this is used for the patient's post hospital personal care. There is little time left to meet respite needs if the patient is a carer. ComPacks was really designed to meet the personal care needs of discharged patients – as a result it is inadequate for carers. CCRC funding precludes the provision of 24 hour care for 6 weeks for carers discharged from hospital.

Furthermore, it is often a case of knowing how to ask for post-hospital support. The discharge planner may refer the carer to Home Care, however the waiting list may be quite long.

Recommendations:

xxiii) A system be put into place where carer post-hospital respite needs are flagged upon their admission to hospital.

xxiv) More funds for post- hospital respite be provided.

xxv) An additional respite component to ComPacks be provided for carers for up to 6 weeks after their leaving hospital.

5.2.7. In home respite for ageing carers

Many carers are uncomfortable with out of home respite. The care recipient is taken into unfamiliar surroundings and, as was discussed earlier in this submission, some carers feel that the care recipient can return from respite care in a more deteriorated state. Care givers can feel guilty or see it as a sign of failure that they are making use of out-of-home respite care.

Worker Observation: "Many carers have experienced the negative results of using both in-home and residential respite. They know that the person they care for will 'make them pay' for putting them into respite, when they return home. They also know that often the caree's abilities decline whilst in residential respite and will thus have higher needs when they return home. They are understandably reluctant to use respite."

In view of these issues, there is a case for increasing the funding available for in-home respite care. In an home respite situation, staff become familiar to the care recipient, whom the care recipient learns to trust. The care giver too becomes more confident in the respite care as they observe the staff person giving care such as personal care/ showering, activities around the house, going for drives etc. It is more likely they will be willing to leave their loved ones in respite situations in order to look after themselves.

Worker Observation: Some day centres have received funding to provide overnight respite. This is a good solution to the respite situation for attendees of day centres. They can have their respite in a familiar setting, with familiar staff.

Often due to their frailty, carers cannot have their loved one up and dressed, ready for the day centre bus to pick them up in the morning. It would be good to have funding for extra staff to go into homes 1:1 to assist with this and even to drive the person to the day centre if they are reluctant to leave the carer and go on the bus.

If we can't think of ways to ensure the carer trusts us, they will not generally use respite.

Recommendation:

xxvi) Increase funding for in home respite for staff who are familiar with the needs of the client , and who can maintain daily routines for the care recipient

5.3. NON-RESPITE ASSISTANCE FOR CARERS

ANGLICARE Sydney's Carer Respite Centres experience a lack of flexibility in the funding guidelines regarding how carers can and cannot be supported. This often results in the carer's actual needs not being met, despite the existence of a service to support carers. There needs to be more flexibility in the funding guidelines to enable the service to operate most effectively with an understanding of the carer's actual needs.

For instance, when carers are unwell, they may seek short term domestic assistance; however this assistance is outside the CCRC's guidelines to provide. If a mother who has a child with disability becomes ill, she cannot receive assistance with housework during the day while her child is at school, as the assistance is not considered a form of respite.

The Mental Health Program funding guidelines within the CCRCs require more flexibility to better respond to carers' needs. Carers of people with mental illness are not always required to provide constant care. Mental illness is episodic in nature; the person with a mental illness may otherwise be quite independent. Carers' requests for short breaks, social activities or transport may not be provided as these are generally outside the funding guidelines.

Another identified service gap is assisting parents with transporting children with disabilities to and from their school, when parents also need to transport non-disabled siblings to and from school. Assistance in the home is also required to help the child with disability get ready for school so that the parent can help their other children also get ready and take them to school.

Recommendation:

xxvii) That there be greater flexibility in the CCRC funding guidelines to better respond to the actual support needs of carers in their individual circumstances.

5.4. PRACTICAL MEASURES FOR DIFFERENT CARER GROUPS

The needs and kinds of practical help that carers require will vary substantially depending upon the demographics of the carer and the type of disability experienced by the care recipient. This section outlines practical suggestions in relation to four groups of carers taking into account their diverse situations:
- Young carers
- Ageing carers
- Culturally and Linguistically Diverse (CALD) carers
- Aboriginal & Torres Strait Islander (ATSI) carers

5.4.1. Young carers

Young carers typically receive little mentoring from the parents they care for. They can also lack life experience and specific skills needed to provide care. With caring responsibilities, they can grow up too fast, and need to teach themselves to be an adult. The needs of young carers are largely for:

- social time with people their own age and
- the need for helpful mentoring relationships.

Whilst the CCRC Young Carers Program can organise young carer support groups, the young carers may not attend on an ongoing basis if they cannot arrange respite care for those times. Regular respite is not provided under the service's guidelines; however not all young people can make arrangements for other family members or friends to care for their parent.

Along with the lack of mentors, it is ANGLICARE Sydney's view that more could be done by schools to assist young carers to better manage their situation. A starting point would be the provision of information for local school authorities. There needs to be more understanding from schools about the caring situation of young carers.

Recommendation:

xxviii) That the Department of Family, Housing, Community Services and Indigenous Affairs (FAHCSIA) fund the development of information packs for schools on young carers, their issues and needs.

Young carers need computers with internet connection for their schooling as their families often lack money to purchase one and the young carer does not have the time to use computers in libraries. Some families cannot even afford the heavily discounted computers available through Centrelink. Funding guidelines for the Young Carers Program allow the purchase of computers only after alternative sourcing avenues are exhausted. This however is a common need which should be recognised within the program funding.

Recommendation:

xxix) That funding guidelines for the CCRC Young Carers Program allow the purchase, leasing or borrowing of computers with internet connection for young carers who are studying. Alternatively, funding could also be provided for the service to pay the discounted Centrelink price of a new computer for the young carer, with their family paying only a minimal contribution.

There is a great need for case management of young carers, despite the program guidelines limiting workers to take a case management approach only in limited cases. Case management over a longer time period could assist carers to participate in their schooling and plan for employment training; the service could also develop an emergency care plan and a future care plan to enable the young person to plan further study or employment.

If the young carer has ongoing family issues, the CCRC Young Carers Program can refer to a Family Support service; this service provides simple case work and focuses on the family as a whole, not specifically on the issues of the young carer. Whilst some support is provided to the young person, this service may engage with the parents more than the young person. A case management service for young carers could interact with both carer and parents, for example to encourage the parent to allow their son or daughter to attend recreational activities. There is limited time to allow this to occur under the current CCRC Young Carers Program guidelines; usually contact with the parent is only made in the initial visit.

Case Study: In a sole parent family from CALD background, the child cares for his parent. A lack of trust by the parent prevents the child attending recreational activities organised through ANGLICARE's CCRC Young Carers Program in South West Sydney. Provision of case management would enable the caseworker to build rapport with this parent and allow much needed respite for the young carer.

A case management service for young people should either be separate to the CCRC Young Carers Program or incorporated into it. However, it should not divert funds away from the provision of respite for young carers. This will allow the Young Carers Program within the CCRC to focus on providing respite to young carers.

Recommendation:

xxx) That a case management service for young carers be established, either within or outside the CCRC Young Carer Program. At the same time funds should not be redirected away from the Young Carer Program's provision of respite.

ANGLICARE Sydney has found that when children and young people are carers for their parents, the role reversal limits the opportunities for real family connection. The dynamic of children holding responsibility and parents retaining the authority whilst being the subject of care needs to be rebalanced.

One possible solution would be a live-in workshop on family dynamics. The ideal setting would be 3 to 5 families with children of similar age, with care workers and family therapists. There would be recreational time where the young people could interact, while the parents are cared for through respite. Then the families could come together for family strengthening sessions.

Recommendation:

xxxi) Additional funding be provided for CCRC Young Carers programs to run "respite and family strengthening holidays"

5.4.2. Ageing carers

The ABS data recognises that there are 6,400 parent carers aged over 65 years, with a rising cohort in the 45-64 years age group of 27,700 carers. This indicates a need for long term service planning provision in this area. Research indicates that many ageing carers are hidden and have never engaged with formal services[12]. For ageing carers in particular, their role has been a long term one, they have confidence in what needs to be done and there is sometimes reluctance to hand over the care of their adult child to others. Many ageing carers have found services not suitable for their offspring or have had negative experiences which has made them reluctant to pursue further service access [13] For ageing carers there may also be issues with social isolation and a sense of self reliance which has inhibited their access to services.

For ageing carers there are a number of specific issues that need to be addressed:

- Assistance with services[14] particularly in relation to respite, home care, residential placement and financial and legal support.
- Access to age appropriate social activities for the adult with a disability
- Access to programs which develop independent living skills in the adult child with a disability

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[12] Carers Australia, (2005) *Ageing Carers: Succession planning and long term needs: A response to the federal Government's Budget Initiative 2005-9*, sighted on 16th April 2007 at http://www.survivingthemaze.org.au/Assets/pdfs/PolicyDocs/AgeingCarersSucessionPlanning.pdf p3

[13] Ibid

[14] Cameron, Jill (2005), *Who will look after her when I die?* Report for the Commonwealth Carer Respite Centre/Carer Links West sighted on 16th April 2007 at http://www.carersvic.org.au/Assets/pdfs/Publications/WhoWillLookAfterHer.pdf

- Education for the family on the service system as it currently operates and the services which are available should they choose to access them
- Provision of support with planning for the future regarding financial, residential or guardianship arrangements
- Development of trust between the ageing carers and service providers
- Provision of intensive support for first time respite users
- Appropriate linkages with the aged care system where appropriate for the carers' own aged care needs
- Ensuring transitional arrangements for respite occur such as short visits to a respite service increasing the length of time of the respite so parents can have longer breaks without undue anxiety.
- Collaboration with the disability service system, ethno-specific and ATSI agencies; the aged care system and the mental health system.
- Ensuring the carer's own needs are addressed including caring for their own health and well being and future life planning.
- Developing an Information pack designed to provide information to carers as they plan services that are available to assist them to make decisions about their future

When an older frail carer is receiving a Community Aged Care Package (CACP) or Extended Aged Care in the Home (EACH and EACH Dementia) they are not eligible for other respite services. Although the hours of care provided in these packages may be allocated to respite, there are inadequate hours for both respite and other needs such as the carer's own personal care, transport, shopping assistance and other daily care needs.
For some ageing carers there are also access information issues in relation to the person for whom they are caring. Services will not release information to carers because the care recipient is an adult. Some services will not even listen to what the carer has to say.

Recommendation:

xxxii) Older frail carers need to be offered a respite component in addition to the hours provided in CACP, EACH and EACH Dementia packages.

5.4.3. Carers from CALD backgrounds

ANGLICARE Sydney maintains that carers from culturally and linguistically diverse backgrounds (CALD) have a right to:

- Participate in the resolution of issues affecting their communities
- access to all relevant government funded programs
- Be informed of government services and programs and how to obtain them
- Expect a sensitive response to their needs and requirements
- Expect government and non-government agencies to adopt a coordinated approach to planning and delivery of services
- To have their diversity recognised and valued, and
- To expect equality of outcomes and not just equal use of services.

Culturally Competent services:

It is foundational to a CALD respite service that care recipients and carers be linked to services and programs which reflect similar values, beliefs and understandings. There are several things that can be learned from international experience and research regarding access issues for CALD communities:

- Most people from CALD backgrounds only access services in a crisis
- A lack of cultural competency among the services acts as a barrier, which is reinforced by the lack of information being disseminated to these communities and in their own languages
- Sometimes the service being provided does not take into account cultural, linguistic and religious factors
- There can also be multiple disadvantages for some CALD families including poverty, the disruption caused by migration and insufficient support networks.
- For some communities there is stigma and shame attached to disability and therefore reluctance to access services which highlight this issue for their family [15]
- Sometimes asking for support can be viewed as failure – this can add to reluctance to access services for support.

Respite:

Best practice models internationally highlight the need for respite programs to be responsive and culturally sensitive. One such project in Canada focuses on the Tamil population, aiming to facilitate understanding and access of respite as a quality of life option. It does this through education and information dissemination in the local communities, strategically partnering with local leaders and agencies and providing opportunities for out-of-town retreats.

ANGLICARE maintains the importance of providing workers who are either from a similar CALD background, speak the relevant language or who have received cultural competency training to ensure that the person with a disability receives a service which is respectful and conforming to their commonly held values and belief system. It is also important to initiate, sustain or further enhance the cultural connections with the wider community and other mainstream providers.

Counselling:

There is a particular need for more bilingual counsellors. An element of the therapeutic relationship is lost when an interpreter is involved. In such situations, there may also be reluctance by the client to disclose more information because of confidentiality concerns. Furthermore, cultural issues may not be understood by an Anglo counsellor.

One solution is to train bilingual support workers in counselling skills. Incentives should be provided by Government for bilingual people to train as counsellors. DADHC should employ more bilingual counsellors, located at migrant resource centre and women's health or community health centres. The CCRC can help to link people in with other support services, especially new migrants.

Recommendation:

xxxiii) That Government provide CALD respite services that conform to best practice including the provision of bilingual staff.

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[15] Roberto, Karen (2000) *Respite Care – Adult, Child,* sighted on the 10th April 2007 at http://family.jrank.org/pages/1402/Respite-Care.html

5.4.4. Carers from Indigenous backgrounds

ANGLICARE Sydney believes that Indigenous carers have a right to:

- A service system which supports the social structure of Aboriginal communities
- Be equal partners in the planning, provision and review of services
- Have their unique cultural characteristics recognised and valued, and
- Have increased access to all services and in this way broaden choices of services and programs beyond those that are Aboriginal specific.

Services to Indigenous carers need to:

- recognise that quality of life, health and wellbeing are essential to promoting community development and maximising the ability of people to function independently in society
- be culturally specific and recognise the differing family/carer structure with Indigenous communites
- coordinate across the non-government sector to support Aboriginal families to achieve a better quality of life for their children
- be flexible and focused on meeting their identified needs
- be accountable and participate in ongoing evaluation and monitoring of all government funded Early Intervention service
- support and develop Aboriginal staff
- provide specific training to staff working in and with Aboriginal communities.

Recommendation:

xxxiv) Indigenous communities be consulted in developing specific strategies based on Indigenous needs and culture.

STAFFING

ANGLICARE Sydney has found it difficult to staff services with sufficient remuneration in recognition of the difficulty and skill involved in working with people with a disability and supporting their carers. Increased funding is required in order to raise the base wage rate in order to attract the appropriate people with skills into the sector.

Recommendation:

xxxv) That funding for carer services take into account the need to increase levels of remuneration for staff working in the carer sector to ensure attraction of appropriately skilled and qualified staff.

6. STRATEGIES TO IMPROVE OPPORTUNITIES AND CHOICES FOR CARERS

6.1. INDIGENOUS ACCESS ISSUES

ANGLICARE Sydney workers have noted that for many indigenous people access issues have also related to problems with culturally competent and sensitive services. There needs to be ongoing consultations with the relevant agencies and networks to ensure that there is continuous feedback on the provision of services. Key features of service plans for Indigenous carers are a range of choice in their care plan, their involvement and that of their family in planning and implementation and flexibility, in order to ensure that fair access to services is provided.

Increasing accessibility through information provision: ANGLICARE Sydney workers consider that the keys to improving access within the Aboriginal community are:

- Dissemination of information on the services in a way that is culturally acceptable and understood
- Working collaboratively and closely with the indigenous community through various community connections
- Utilising existing networks and services to promote access for the community.

There is significant work being done in the area of communication of disability services by the Aboriginal Disability Network which has arisen (2002) because of a perceived lack of culturally appropriate services for Aboriginal people with a disability and the mainstream services which do not consider cultural needs or competency. They publish regular newsletters on their website outlining services and service information.

ANGLICARE understands, based on previous service experience and working within an existing Indigenous network that the identification of elders in the community can be a key point of access in terms of communication. This in turn needs to be two-way process of information exchange, one which takes time and awareness. It is also important to understand that the indigenous community is far from homogenous – there are considerable variations in customs and protocols.

Recommendations:

xxxvi) Indigenous cultural training for service providers be developed in consultation with Indigenous specific services to assist service providers to improve access and service delivery to Indigenous communities.

xxxvii) Indigenous people be offered training on respite care and carer services to enable them to develop their own services.

6.2. CALD ACCESS ISSUES

The CALD population is seriously underrepresented in government funded disability funded services. This community accounts for one quarter nationally of all those identified as having a disability but less than 15% access services.[16] Research indicates that the CALD community experiences serious systemic disadvantage in accessing appropriate services. There is a stereotype which operates and considers that this lack of access is self imposed

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[16] Sedger, Robyn and Diane Boyd (2007) *Proposal to Implement a Study into the Needs of CALD Communities in the Nepean Area,*

as CALD communities are more self reliant on their own family support networks. However, new studies emerging indicate that the access issue is related more to lack of appropriate information and lack of CALD specific services.[17] Thus information is the key to promoting the service, educating the families and widening the access for the CALD community.

ANGLICARE experience and that identified in the social plans of various councils indicates that the Arabic community more readily accesses respite and disability services than other CALD groups. However there is an emerging Sudanese community with serious issues relating to refugee and asylum seeking status with other health related issues.

Information needs to be disseminated in language specific brochures reflecting the larger cultural groups in the area. This should not be underestimated. 2005 qualitative research among CALD people with a disability highlighted that families did not know of services, how to access them or even the word to use – for some there was no equivalent to the word 'respite' in their language.[18] Many families also indicated that the only options they understood were available were group homes or nursing homes – both of which they rejected, sometimes reflecting a personal experience of trauma in the home country where institutionalisation was seen as unacceptable and to be avoided at all costs. Therefore they did not inquire as to other potential options.[19]

Recommendation:

xxxviii) That information regarding respite services be disseminated in CALD communities in language specific brochures.

6.3. INCREASINGTHE CAPACITY FOR CARERS TO MAKE CHOICES WITHIN THEIR CARING ROLES

It is important to understand that with carers what works and is a positive in one family may well be a constraint for another which explains why families in similar circumstances develop different coping strategies[20]. Thus programs need to be flexible, person centred and innovative in approach. The case manager needs to work with the families own priorities and empower them to deal effectively with both the service systems and stressors in the family.

Flexibility should occur at the beginning of the care support process where carers should be offered a range of options which can be tailored to meet their circumstances and requirements and which will optimise outcomes for both carer and recipient. It is important that such flexibility is ongoing throughout the period of service which means that if and when circumstances change so too can care options and arrangements. For some carers opportunities should be provided for advocacy training so they may act as as care advocates across the service system.

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[17] *Ethnic Disability Advocacy Centre (2003) Supporting CALD carers: the service needs of CALD carers of people with disabilities, EDAC, Perth.*

[18] Ibid p13

[19] Ibid P14

[20] Llewellyn ,G., Thompson K., Whybrow S., and Mc Connell D (2003) cited in " *Supporting Families : Family Well-being and Children with Disabilities-* March P 9

Recommendation:

xxxix) A quarterly review process in undertaken across relevant care programs in consultation with the carer and care recipient. This should be a monitoring process which enables modifications and amendments to be made over time and as need determines.

6.4. INCREASINGTHE CAPACITY FOR CARERS TO TRANSITION INTO AND OUT OF CARING

Capacity of carers to transition into and out of caring is dependent on resilience and capacity building which is holistic – across economic, social and health domains. It rests on a number of factors:

a) Collaboration, consultation and emotional support with ongoing and regular contact between case managers and carers

b) Consistency and reliability in the delivery of care services with planning to ensure appropriate access.

c) Provision of support and assistance with access to services at times of family crisis

d) Development of strong interpersonal support by the case manager with an understanding of the specific and different needs of each family in their care.

e) The provision of options and choices which indicates to the family an understanding of their current position and a willingness to adapt to meet their needs now and into the future.

f) The use of carer and care recipient advocates are also an important part of this trust building to demonstrate effective service provision through the words and experiences of other carers and care recipients. ANGLICARE has found that carers are more open to the experiences of others in similar circumstances to themselves and these advocates – either through individual or group activity – can be key in overcoming barriers and apprehensions in accessing services.

g) link carers to programs specifically designed for them such as the National Carer Counselling Program.

h) conduct regular information sessions which gives carers the opportunities to meet others in similar circumstances, access relevant information and feedback what has worked well for them.

i) Opportunity to reconnect with their own peers and friendship groups provided this is regular and consistent.

For young carers in particular what is required is case management

In the current CCRC Young Carers Program, once the parent dies workers can only stay with the young person for 3 months. This is not enough time to set up adequate support mechanisms in order for the young person to move forward positively. The establishment of a case management service for young carers would allow the young person to be supported for longer. Increasing the capacity for carers to effectively plan for the future'

Recommendation:

xl) For young carers, if the parent for whom they are caring dies, case management should be extended to a two year period form the current three months follow up support to ensure that effective pathways into employment, education and social and emotional wellbeing are established.

6.4.1. Responsiveness over time

ANGLICARE recognises that just as needs differ between families at any point in time so too do these same needs vary over time and with changing circumstances. Case management and coordination requires responsiveness to changing circumstances over time such as carer health deterioration, family crises, relationship breakdown, changing health of the person with a disability etc. The critical component in this responsiveness is ongoing and regular review, close contact with the case manager and other ancillary services and planning which can prepare the carer for a range of eventualities and mitigate, at least to some extent the anxiety attached to unforeseen events occurring.

6.4.2. Planning for future contingencies

ANGLICARE thus recognises that this is not just an issue in relation to provision of suitable services, but informing ageing carers of the range of options suitable for their particular circumstance and assisting in the development of long term care plans with ultimate relinquishment of care when the time is appropriate. Transitioning to accommodation options should also be explored so that carers can plan for their own changing circumstances without anxiety or fear reducing the need for crisis intervention.

Recommendation:

xli) Carer programs should be specifically funded to incorporate transition planning as part of their core service delivery.

7. CLOSING COMMENTS

ANGLICARE Sydney greatly appreciates the opportunity of being able to make this submission. ANGLICARE Sydney looks forward to the deliberations of this Inquiry and anticipates that this may lead to positive outcomes for carers – across the continuum of their care. These outcomes need to incorporate flexible support strategies including appropriate respite, financial resourcing, and education and counselling.

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