

Submission No. 1088

(Inq into better support for carers)

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**SUBMISSION TO THE HOUSE OF
REPRESENTATIVES
STANDING COMMITTEE ON FAMILY,
COMMUNITY, HOUSING AND YOUTH
INQUIRY INTO BETTER SUPPORT FOR
CARERS**

FAMILIES AUSTRALIA

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Families Australia is the national, independent, peak not-for-profit organisation dedicated to promoting the needs and interests of families.

For further information, contact Families Australia

Telephone: 02 6273 4885

Email: admin@familiesaustralia.org.au

Web: www.familiesaustralia.org.au

Address: 7 National Circuit, Barton ACT 2600

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1. Overview

Carers play a vital and usually hidden role in supporting families and individuals. Their work provides a major underpinning of Australia's prosperity, but they need greater acknowledgement and support. There are many aspects to the issue of better supporting carers, but on the basis of first-hand consultations with a large number of carers over the past 1-2 years, Families Australia wishes to focus attention on two aspects: (i) grandparents who act as primary care givers for children and those who act in child care roles, and (ii) barriers to workforce participation by carers of children with disability and/or ageing family members. We make 16 recommendations to better support these people.

2. Introduction

Families Australia is Australia's national peak, independent, not-for-profit organisation which promotes the interests of families. Families Australia undertakes research and consults families and family and community service organisations on current family-related issues. The outcomes are disseminated to a wide range of stakeholders.

Families Australia welcomes the House of Representatives' Inquiry into Better Support for Carers. We believe that carers need to be better acknowledged and supported for the vitally important, and often hidden, work they do.

While recognising that the topic of caring is vast, this submission discusses the main areas of the Committee's inquiry in terms of:

- (i) grandparents who act as primary care givers for children and those who act in child care roles, and

- (ii) overcoming barriers to workforce participation by carers of children with disability and/or ageing family members.

Families Australia conducted intensive first-hand research into these areas in the past 1-2 years in the form of focus groups for carers, as well as consultations with academics and NGO/community sector experts and practitioners. We wish to acknowledge the contribution of Anne McLeish, Grandparents Australia, in the preparation of the section on the role of grandparents.

3. Better supporting grandparents raising grandchildren and those providing child care

In 2006, Families Australia convened an Expert Forum on 'Grandparenting: present and future' and a focus group with grandparents at Marymead Family and Children's Centre, Canberra, to discuss current national issues relating to the roles of grandparents, draw together the main points of discussion and develop specific recommendations. These consultations and other research indicated that urgent policy attention was required in the areas of grandparents as primary carers and grandparents providing child care while the parents were at work. The following section is structured around these topics.

3.1 Dimensions of the issue

Primary care-giving. Grandparents become carers often because of a parent's drug or alcohol abuse, relationship breakdown, mental or physical illness, incarceration or death. They often face difficulties in taking on parenting at an older age and in accessing assistance. This situation, combined with their own ageing, can result in unexpected social, financial and health problems.

According to the Australian Bureau of Statistics, in 2006-07, there were 14,000 grandparent families in which the grandparents were guardians or main carers of co-resident children aged 0 to 17 years¹. Almost half (47%) of grandparent

¹ Australian Bureau of Statistics, 4442.0 Family Characteristics, Australia, 2006-07.

families were lone grandparent families (compared with 21% of other families with children aged 0-17 years being lone parent families)². Eighty-nine percent of grandparent families had one or two children in their care, and 11% had three or more children³.

In about one-third (34%) of grandparent families, at least one grandparent was employed, and 62% received a government pension, benefit or allowance as their main source of income. Most of this income was received from the Federal Government, with only a quarter of children living with grandparents receiving State/Territory financial support for the costs of care. Children living in grandparent-headed families were about four times more likely than children in any other family type to live with an unemployed parent/guardian⁴.

The support for children in out-of-home care and their carers, including grandparent care, is the responsibility of State and Territory governments. Each State and Territory government determines the level of support that carers, including grandparent carers, receive. Two of the key determinants of whether, and to what extent, a grandparent carer receives financial and other support are the pathway by which the child enters their care and the State/Territory in which they live. The amount of financial and other support varies across jurisdictions and, within jurisdictions, depends on whether the child came into the grandparent's care informally or through a Children's Court or the Family Court.

Grandparents and other relative carers are increasingly called upon by State/Territory child protection agencies to take in children as the numbers of foster carers continues to diminish, yet grandparents are not always recognised as foster carers and so do not receive the same level of financial and other support. In addition to the issue of financial support, training and casework support provided to foster carers is often not extended to relative carers and may

² Australian Government, Australian Bureau of Statistics, *Family Functioning: Grandparents Raising Their Grandchildren*, Australian Social Trends, 2005, 2.

³ *Ibid.*, 1.

⁴ Australian Government, Australian Bureau of Statistics, *Family Characteristics Australia*, June 2003.

depend upon whether or not a child has been legally ordered into the care of a grandparent. If there are no court orders in place, it is less likely that the grandparent/s will receive assistance.

The Federal Government provides family assistance to all grandparent families on the same basis as other Australian families. Federal Government initiatives for grandparents include the opportunity for grandparents to access Family Relationship Centres (FRCs), additional funding for legal aid commissions to involve grandparents in family group conferencing and the introduction of the Grandparent Child Care Benefit (GCCB). These grandparents are also exempted from the need under Federal Government rules to "return to work" or fulfil requirements demonstrating they are actively seeking work.

Cases where a child is placed in the care of a relative under the guidance, or with the knowledge, of a State or Territory government, but outside of the care and protection system, are referred to as 'semi-formal' care arrangements. These carers are normally not given 'registered and active' status. However, there are provisions in the Guide to Social Security Law where a carer is not considered 'registered and active' by a State or Territory, but a 'semi-formal' arrangement is in place. In these situations, a carer may be eligible for a temporary exemption from participation requirements where the State or Territory government provides a letter explaining the situation.

In some cases, the child is placed in the care of a grandparent through the Family Court. These cases involve a judgement that the grandparent is the most appropriate person to provide care for the child. As the current guidelines rely on documentation by the States or Territories, these carers are not considered to be in a similar situation to those grandparents that the States/Territories recognise.

In cases where a child comes into grandparent care through a private arrangement with the child's parent/s or with the involvement of a non-

government organisation, these grandparents do not meet the criteria for being a 'registered and active' carer. It may be possible for these grandparents to formalise their care arrangements through State/Territory authorities or the Family Court.

Good networks are critical for grandparent carers, enabling them to combat isolation, share knowledge and access support services. The Moonee Valley Carers Network (MVCN) is one example of a local model whose findings may inform other such initiatives. Families Australia, through Grandparents Victoria, is acting as critical friend to this project, which is sponsored by Moonee Valley City Council in Melbourne. This project is examining the feasibility of establishing a network of carers based on local government boundaries. The network will bring all carers together, irrespective of whether they are caring for older people or young people and no matter what may be the needs of the person being cared for. This includes foster carers and grandparents raising grandchildren. The network will work with local government to decide on appropriate services that meet the needs of all carers as one group as well as the specific needs of groups of carers and individuals. The outcome will be cost effective ways of delivering these services through collaboration between the local government and the community at a local government level.

Child care. Grandparents are Australia's largest providers of informal child care, and one of the main reasons parents use this and other forms of informal care is to participate in the workforce⁵. According to the Australian Bureau of Statistics, in 2002, almost one in five children aged 0-11 years (19% or 592,000) had been looked after by grandparents in the survey week (equivalent to the proportion who had been in formal care, 597,000). Grandparents provided 31% of the total

⁵ Australian Government, Australian Bureau of Statistics, *Family Functioning: Informal Child Care Provided by Grandparents*, Australian Social Trends, July 2006, 1, 5.

hours of care provided in the survey week⁶. Most children who had been in grandparent care (98%) had been looked after at no cost to parents⁷.

In 2002, of the 591,600 children in grandparent care in the week prior to the interview, just over half (51%) had been in care because their parents were either working, seeking work, or attending work related training or study⁸. The Australian Bureau of Statistics states that “while grandparents may enjoy this caring role, it has the potential to affect aspects of their lives such as their income, health, or access to free time, particularly if they provide large amounts of care.”⁹

3.2 Key concerns

Families Australia’s consultations revealed the following points in relation to the role of grandparents as primary carers:

- Some participants acknowledged that the Family Relationship Centres (FRCs) have the potential to assist grandparents in the context of family breakdown or in other dispute resolution issues relating to their grandchildren. While some grandparents cannot access Legal Aid due to means testing requirements, the three hours of counselling offered on a non-fee basis at the FRCs was seen to be potentially helpful to grandparents. It was also noted that recent amendments to the Federal Family Law Act to include grandparents as “significant others” had usefully recognised the important role grandparents play in the lives of their grandchildren.
- A Centrelink initiative in Western Australia where a Grandparent Liaison Officer is based in a Centrelink Office was widely viewed as being successful.
- Options apart from grandparents taking over full-time care of grandchildren were discussed by some participants, including the use of ‘open adoption’ (where grandparents had ongoing access and contact with their grandchildren), and increased use of high quality foster care.

⁶ *Ibid.*, 1.

⁷ *Ibid.*, 2.

⁸ *Ibid.*, 5.

⁹ *Ibid.*, 1.

- Some grandparents stated that they have found it difficult to access information about matters such as financial and legal entitlements and support services for themselves or their grandchildren.
- Support groups for grandparents providing primary care for their grandchildren were widely viewed as being beneficial to grandparents.
- Some participants considered that income support payments which are assessed against assets, which may include home ownership depending on individual circumstances, disadvantaged retired grandparents with little disposable income who unexpectedly found themselves caring for grandchild/ren.
- While the Family Tax Benefit was available to all grandparent carers, it was noted that not all eligible grandparents were applying. Possible reasons for this include fear that the child would be taken back by the natural parent/s, lack of awareness of their eligibility, and inability to provide evidence that the child was in their care.
- It was stated that grandparents who have no care and protection orders for grandchildren in their care do not receive State or Territory financial support, whereas support is available in cases where orders exist. Thus, even where equal amounts of care are provided by those operating under orders and those without orders, grandparents are unequally treated by the system.
- Some grandparents stated that they had missed out on financial support either as a result of not knowing about the availability of support or as a result of the child's parent/s not being prepared to "sign the child over" as they (the parent/s) would lose their Centrelink payments. This can place grandparents in a difficult position, as some believed that to seek financial support could bring their situation to the attention of government, resulting in the child being returned to the parent/s.

The main points raised about the role of grandparents providing child care were:

- Grandparents often filled gaps by providing child care, including in situations where the parent/s undertook shift or evening work or when the parent/s could not afford, or were dissatisfied with the quality of, available care.
- There was an assumption that grandparents were available and willing to provide child care, which was not always the case.
- Many participants commented on the financial impact on retired grandparents with limited disposable income who provide significant hours of child care.
- Some participants considered that there was a broad lack of acknowledgement of the gap that grandparents filled by providing child care, and that financial support to grandparents who provided long term child care should be considered under the Child Care Rebate Scheme.

Comments on these themes included:

We are not important enough but we're saving them [governments] millions of dollars.

I'd hate to think that if all the children being raised by grandparents at the moment [were sent away from grandparent care], where would the system go? It would go into overload. It's time someone stood up and said these people are doing a job.

We are treated as foster parents but that's not so – we are parents.

All of us have a story of how inept the system has been.

We found out by accident what facilities were available to us.

I didn't know about this child allowance, this kinship allowance, non-parental care allowance – in eight and a half years I never received a thing even though they gave me [the grandchild] and said 'take this baby or we'll put it in foster care'. I couldn't see her going into foster care.

We are a lot older aren't we? and I don't think we are capable, like we took our kids to the football and netball, and soccer and hockey – we could do all these things – I'd love our (grand)kids to do all these things if someone could take them too...We're just not capable.

It cost me \$18,000 [in legal costs], but she [the grandchild's mother] got hers [legal aid] for nothing – how?

The assets accrued over a lifetime disqualify us from such things as legal aid, family allowance, carer's pension, health care cards etc etc, yet we are saving the welfare system millions of dollars by giving children care and safe haven.

3.3 Recommendations

To better assist grandparents in their various roles as carers, Families Australia recommends that:

1. A national grandparent information service (such as a 24-hour telephone line and/or a website) be established, which provides information about financial assistance, family law and other legal matters and referral to local services and supports. This 'one-stop-shop' would assist grandparents who, for example, unexpectedly find themselves in primary caring roles.
2. Grandparent liaison officers be placed within child protection and other support agencies to act as a contact point for grandparents; this would benefit grandparents, in particular those from culturally and linguistically diverse and Indigenous backgrounds, as well as other vulnerable grandparents who may be unfamiliar with, or who experience difficulty in navigating, government systems. This model could be extended to include all Centrelink Offices, as in the Western Australian model.
3. Emergency or discretionary payments from Centrelink or other State/Territory government agencies be provided to assist particularly necessitous grandparents in cases where children are placed in grandparents' care at short notice.
4. To ensure that grandparents who provide primary care receive the appropriate income support payments, strategies could be developed to address cases where Centrelink recipients claim child-related income supports when they are not caring for the child (in other words, where "the money does not follow the child").
5. A review of Legal Aid income assessment processes for grandparents providing primary care of grandchildren be undertaken, so it is based on disposable income as opposed to assets; this could lessen the disadvantage that some grandparents face in accessing legal assistance.
6. Innovative ways be examined to provide information about grandparent carer eligibility for the Family Tax Benefit, to help grandparents access this benefit in greater numbers.

7. Options be explored, such as the use of 'open adoption' and increased use of high quality foster care, to reduce pressures felt by some grandparents that they are obliged to take their grandchildren into their care.
8. A program, within the National Family Relationship Services Program, be developed which specifically targets the needs of grandparents to enhance the usefulness of the FRCs for grandparents and their grandchildren. FRCs could also play a role in the prior assessment of grandparents' capacities to cope with the caring role before children are placed with them. Dispute resolution services should be encouraged to include grandparents in parenting plans, as this may help to ensure that grandchildren have contact with both sets of grandparents after a family separation.
9. In the context of the current review of the requirements placed on people to demonstrate that they are actively seeking work in return for receipt of public unemployment benefits, that grandparents who are primary carers and foster carers continue to be exempt and that foster carers who are between placements for short periods are also exempted.
10. Further research be undertaken into the differing needs of Indigenous and culturally and linguistically diverse grandparents to fill a gap in current understanding; this may lead to the development of specific interventions to assist these groups.
11. Improving the Internet website interconnectivity between the Department of Families, Housing, Community Services and Indigenous Affairs, Centrelink and Family Assistance Office to help to improve grandparents' understanding of and access to services and supports.
12. The provision by local councils and other community organisations of information materials about free, local activities grandparents can do with their grandchildren to assist grandparents when they are providing child care.

4. Overcoming barriers to carer workforce participation

Families Australia conducted consultations with carers in late 2007 in order to better understand their needs and as a contribution to the Taskforce on Care

Costs (TOCC) report, *The hidden face of care: Combining work and caring responsibilities for the aged and people with a disability*. Families Australia ran five focus groups of carers in Sydney, Melbourne and Wollongong and co-convened with Carers Australia an expert roundtable meeting of CEOs of non-government service providers working in ageing, disability and related fields (Alzheimers Australia, Anglicare Australia, Arthritis Australia, Australian Nursing Federation, Carers Australia, Deafness Forum Limited, Families Australia, Family Relationship Services Australia and Palliative Care Australia). The focus groups brought together people who are in, or are likely to be in, caring roles. People might have been caring for an ageing parent with diabetes, or a child with autism, or a young adult with an intellectual disability; many different situations were represented, and some people had more than one caring role. In total, the focus groups involved 58 carers.

4.1 Dimensions of the issue

A large number of Australians care for children with a disability and/or an ageing family member or members. In 2003, it was estimated that 2.56 million people, or 12.9% of the population, provided informal care to a person who is aged and/or has a disability, including 474,600 people who were primary carers (providing the majority of care to another person). The majority of all carers are female (54.1%), with 59.9% of female carers and 52% of male carers aged between 35 and 64 years¹⁰.

Access Economics, in a report for Carers Australia, *The Economic Value of Informal Care*, stated that the labour force participation rates for all carers (in 2005) was 56.1% compared to 67.9% for people without caring responsibilities. However, when considering primary carers, the labour force participation rate is only 39%, with participation in full-time employment only "19.2%, less than half that of the general population"¹¹.

¹⁰ Access Economics, *The Economic Value of Informal Care*, August 2005, p. 1.

¹¹ *Ibid.*, p.12.

4.2 Key concerns

Families Australia's focus group participants highlighted the multiple barriers to workforce, and broader social, participation faced by such carers. The major themes were:

- Some workplaces, particularly large national firms, have employment policies and practices which seek to provide greater work flexibility for those who have caring responsibilities.
- There appears to be a wide degree of variability, however, in policies and practices between employers.
- There can also be wide variations in practices at the level of the work unit within an organisation, with some managers being more supportive than others.
- Sometimes, the level of an individual manager's support or understanding of employee caring responsibilities is not clearly informed by broader organisational policies.
- Several participants cited a lack of information they could easily and comprehensively access to support them in their caring roles, for example, in finding where to obtain in-home and out-of-home care tailored to specific requirements or conditions.
- Many participants wished for more flexible working hours, including employment on a genuine part-time basis (that is, without it becoming a de facto full time job) and greater opportunities to work from home with greater utilisation of the internet. Some participants felt that employers did not trust employees to work distant from the office.
- Many participants perceived that the demands placed on them as a result of their caring roles were often or sometimes not well understood by their work colleagues. This can breed resentments.
- There was concern that caring roles frequently resulted in a person being forced to leave the workforce, undertaking part-time work, refusing to take promotion or having to take extended unpaid leave.

- Many noted that a significant disincentive to leave the workforce to provide care was the adverse effect on the person's superannuation and so on levels of satisfaction and wellbeing in later life.
- There was strong and widespread concern about the lack of adequate paid or unpaid leave for caring roles beyond carer leave entitlements that exist for some employees.
- Several participants referred to the difficulty they faced in accessing before-school, after-school and vacation care, especially for children with a disability.
- Concern was also expressed about the lack of respite for carers, particularly in rural areas. There is a serious lack of respite care for young people, who most often end up (if they get a place at all) in aged care facilities.
- There was broad concern about the difficulty carers faced in understanding how to access assistance, especially from governments. The task of knowing what assistance might be available appeared to have been made particularly complex by the division of caring support between various levels of Australian governments and between various non-government agencies.
- Participants generally felt that there was a far higher caring load in caring for family members with a disability compared with the care required for ageing family members; this related mainly to the unpredictability and need for constant supervision of many persons with a serious disabilities.
- Many participants considered that they needed to stay in the workforce in order to pay the high costs associated with care, yet this meant that getting a satisfactory work-life balance was difficult, and stress levels were often unsustainably high. There was also concern about the unequal burden placed on non-working partners.
- Several noted that the relationship breakdown rate within families where a family member had high care requirements was far higher than for other types of families.

Comments on this theme included:

Managers think you're a hypochondriac unless they've had similar problems. It's the same with caring – employers can't relate to it, especially younger people, as they don't know the pressure people are under.

Co-workers don't understand. You should be able to take them home with you; then they'll stop thinking you're scamming. Perhaps produce some films or ads, showing the real life stuff of caring.

Most people want support – not to be carried – to stay in the work force. I felt I was being penalised for having a daughter with a disability. I was forced out of the workforce into poverty. There is no child care for children with autism; the boss doesn't understand that. You need income, superannuation, investment for the future. The relationship break-up rate is huge.

I keep seeing women forced out of the workforce, living in poverty. Explaining to others is hard. It's limiting for the kids – they don't get into sports teams and have no birthday parties. It's hard work caring and enriching kid's lives. You have to source your own information. It's like a second job which is huge and hidden.

My son has autism and a mental disability. I became a sole parent. I had to make a career choice: less pay, less responsibility in order to cope with the demands. I can't now handle a high pressure job managing lots of staff. It's a full time job trying to access opportunities for my child. In terms of GDP, the cost of having carers unemployed and not contributing financially is creating burdens later on [for society and the individuals concerned].

When my [non-English speaking background] father's neighbours died, my father became very isolated. We found a [language specific] support group where someone drops in on him and takes him shopping, and a centre, where he goes once a week. As he's also deaf, he needs that [communication and stimulus]. It's a load off my mind.

Sometimes you're doubly disadvantaged – even triply. You're caring for someone with a disability or frail and aged, you're not working which means you're in that poverty cycle, and often, especially with kids with disabilities, the rate of marriage breakdown is about 90 percent.

I need to work. My daughter's wheelchair cost \$10,000, and the van we need, with the hoist, cost \$80,000. I want to leave the workforce to help her, but I can't afford to. If I were given the things she needs, I would leave tomorrow.

Participants made a wide range of suggestions for improving the situation for carers of people with a disability or the aged. The main themes were:

In the workplace

- Many participants felt that employers should offer a greater range of flexible workplace arrangements, such as part-time work, leave and the conversion of sick leave entitlements to a carer's entitlement.

- Information about various types of care assistance should be made clearer and more accessible to current and prospective carers and their employers.
- There should be greater education for the co-workers of persons who are in caring roles.
- Employers should be assisted by governments in finding out about available, accessible and quality services in order to make information available to employees about support services.
- There is a need for enhanced consistency in employer care policies and practices both within and across organisations.

Government and service providers

- Participants uniformly called for far greater government financial and other resources to be provided to carers. There were strong calls for more accessible and higher quality services in areas of need.
- Many participants expressed concern and even anger at the current fragmented system of support for carers and wished for a 'joined-up', one-stop-shop approach instead of the current piecemeal approach. This would entail, for example, a designated central point of contact for carers instead of carers' often having to contact numerous organisations for help.
- A suggestion was made for a Federal Government Act which would highlight the needs of carers and establish principles and guidance for government, employers, employees and community organisations.
- Participants from rural and remote areas highlighted the disadvantages they faced compared with metropolitan areas in accessing adequate services and called for a greater range of services to be provided in those areas.
- Workers in care-providing organisations, such as aged care facilities, should be paid more competitive wages, and greater encouragement should be given to people to enter this type of work.
- Finding suitable child care for children and young people with disabilities can be very difficult. Many carers of children with disability called for pre-school,

after-school and vacation care for a variety of reasons, including that such services would encourage workforce participation.

Comments on this theme included:

In the workplace

Internal [workplace] websites can make information more accessible. If it's clear upfront, it's easier for lower level managers. List the [care] options and make it clear.

Employer support works better if services are there in the first place. I had to use Amazon and search the web. You feel isolated. Government has failed on disability services as the system has become privatised which means that you [the carer] become a full time case worker.

Education of employers, not necessarily just of a particular condition, whether it be dementia or whether it be arthritis, the problems of those that need to care and the benefits of supporting those carers in the workplace is where we need to focus.

Government and service providers

There's a need for more education of health professionals. No-one can answer questions. It's hard to make informed choices.

We need a one-stop shop, pulling together the links in the chain. You need to know the right question to ask to find the next link. Every parent reinvents the wheel.

We need a joined-up approach in workplace policy and service provision. Caring needs to be recognised as a social duty.

They [governments] need to advertise stuff – put it out there so people could get help earlier – in newspapers, emergency rooms, GPs. People need to know about getting a Power of Attorney and all that stuff. We need a 'Tool Kit for Caring'.

Government - Federal and Local – should invest extra funding in care. We've got more and more children who have been given to their parents to bring home who've got severe disabilities, and the responsibility falls on the family. Give the family a break with respite.

There are just not enough services. In [my] Local Government area they just said, there will be no growth in family disability funding as it was all going into frail and aged. But at the same time you've got a huge growth in people with disabilities staying home longer because there's no place for them to go.

There is a difference about what happens in rural and in metro areas. The stats show that it's better to die in a small rural community in Australia than in an outer metro area.

Participants also highlighted several priorities for change. The top priorities were:

- Carers should be recognised in the workplace to a far greater extent than at present, for example, through awareness raising programs which are promoted, championed and modelled by senior managers.

- Workplace policies and practices should become increasingly flexible in finding ways to accommodate the varying requirements of carers. Greater effort is needed, for example, to ensure that workplace practices in relation to caring are applied equitably across organisations, and managers are supported to implement those policies.
- Employers are encouraged to institute services which assist their employees to locate and access caring support services, for example, through information and resource services, connected intranet databases and designated human resource support in the area of caring.
- Careful regard is needed to framing flexible workplace policies and practices which take into account the differing operating constraints for large, medium and small businesses and for organisations operating in metropolitan, regional and remote areas. It is suggested that governments, employers' groups and community organisations develop models and ideas designed to support workplaces with varying conditions in support of carers.
- The Federal government is strongly urged to play a greater leadership role by providing greater public recognition of, and financial and other assistance for, carers of the aged and people with disabilities. This should be based, *inter alia*, on a more comprehensive and finer understanding of local and regional caring requirements and capacities than is the case at present.
- Whole-of-government approaches are urgently needed which integrate responses in areas such as the provision of adequate housing, community and workforce awareness raising and greater availability of respite care for carers.
- A Federal Carers Responsibility Act should be adopted, and new and innovative funding arrangements, such as a taxpayer-funded Carers Fund, should be carefully examined in consultation with carers themselves, employers and other interested stakeholders.

Comments on this theme included:

You need to have after school care and vacation care. You need funding to run them and to find and pay the staff

There are a lot of great programs and initiatives out there but joining them is needed.

What would help my company help me is for a service to exist. It's about joining up the government efforts.

Government should be forced to legislate for [people with] disabilities - they should be treated as a minority in the same way as we have special services for Aborigines - people with disabilities should have very special things set aside for them.

What we need is more low cost housing. We need more supported accommodation, beds and spaces.

Centrelink should play a more active part. People should be able to go to them and ask about benefits and services. I found a social worker to look at my case. A hotline would be good for carers.

We need someone local who knows about local services, for example, the community bus, as well as what payments you can get from government, and who knows about services for people from non-English speaking backgrounds.

We need some sort of community care living fund – something that we all contribute to in the very early parts of our work life, because we're all going to require some sort of care at some stage.

We're calling on the Federal Government to look at a family carer's responsibility Act. It's important to remind the Government that the work's been done [Human Rights and Equal Opportunity Commission's report on balancing work and family], and there's been a lot of community and expert consultation. It's just such a shame that it's died.

4.3 Recommendations

To help overcome participation barriers, Families Australia recommends that:

13. Service provision: The Federal Government should develop strategies to enhance access to, and the quality of, aged and disability services. These strategies should ensure the greater integration and resourcing of services.
14. Workplace flexibility: The Federal Government should encourage employers to ensure greater access to the full range of flexible work practices (that is, beyond part-time work) for all carers (that is, beyond the current focus on child care). In addition, employers should be encouraged to work towards greater consistency of implementation by managers across their organisations.

15. Financial supports: The Federal Government should commit to increasing the level of financial supports for employees who are concurrently caring for an aged dependent and/or a person with a disability to enable real choices to be made about work and care.
16. Legislation: The Federal Government should commit to introducing a Family Responsibilities and Carers' Rights Act, as recommended by the Human Rights and Equal Opportunity Commission.

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