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(Inq into better support for carers)

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Carers
AUSTRALIA

Placing Carers First

House Standing Committee on Family, Community, Housing and Youth

Inquiry into Better Support for Carers

Carers Queensland

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Executive Summary

Care is an inevitable part of life for most people – as is the receipt of care. This care is often embedded in a deep sense of familial mutuality and reciprocity.

Caring, of course, is not a new phenomena. Families have long provided assistance to its members.

The nature and extent of this care is, however, shaped by the policy context in which it occurs. Currently, the responsibility for the overwhelming majority of care is vested in the family with little support from the government or community.

An Integrated System of Carer Support would provide caring families with assistance that responds to their situation and their preferences. Caring is diverse and each caring situation has its own unique support requirements. There are, however, common approaches that support the caring role.

Better support for carers means more than the 'preservation' of the caring role. It means the exercise of genuine choice and control for caring families. The objective of such support is to enhance the capacity of caring families and to facilitate their participation in the community and the economy.

Ultimately, though, the social and economic inclusion of caring families can only be achieved through a more equitable sharing of care among all of the stakeholders who benefit from this care.

Care is central to the well-being and prosperity of all. It is of considerable value to the whole of society: government, community, business, families and individuals. The more equitable distribution of care among all stakeholders who benefit is therefore warranted.

Currently there are serious inequities in the way in which responsibilities are shared. It is all too common for individuals and families to bear these responsibilities while the community benefits. Due to inadequate support, caring exacts a high price for families. In most cases, these costs are clearly unsustainable and so a new mix of caring responsibilities is important – not just for the well-being of caring families but for the whole community.

A truly shared approach to care is the only way to facilitate choice and opportunity for caring families.

Introduction

Carers Queensland welcomes the Parliamentary Inquiry into Better Support for Carers with some reservations. We believe that the inquiry could provide the opportunity to address the situation of those, mainly families, who provide care. However, the true value of the opportunity will only be measured by the extent to which it produces practical and tangible support to caring families.

In recent times we are aware of, and indeed have been involved in, a number of parliamentary inquiries and departmental reviews of relevance to carers in the areas of health, mental health, disability, older people, income support, employment participation etc. These activities have failed to produce substantial improvements for caring families. What is required to move these issues forward is political will and leadership.

It is our profound desire that, as a result of this inquiry, important improvements are introduced that make a real difference in the lives of caring families. In this spirit, we look forward to the recommendations of the Committee that will, we hope, truly value care and thereby offer those caring and those they support with much needed assistance.

Carers Queensland

Carers Queensland is dedicated to supporting Queensland's 535 800 unpaid carers providing assistance to a family member, friend or neighbour who requires support because of a disability, physical or mental illness or frailty associated with age.

Carers Queensland was formed by carers in 1989 as the voice for carers in Queensland.

The purpose of Carers Queensland is to enhance the quality of life of those Queenslanders in a caring role, promote their rights and needs and provide information and support services.

Carers Queensland provides carers with:

- information to assist them in their caring role including carer-specific publications and resources
- advice about the full range of services available for carers
- the opportunity to link together with other carers – for companionship and support
- professional telephone and face-to-face counselling
- training and education to support them in their caring role
- advocacy support to promote the rights and needs of carers with government, service providers and others, and
- assistance to address issues of concern to carers.

Carers Queensland has 11 offices located throughout the state – Far North Queensland (Cairns), North Queensland (Townsville), Mackay, Central (Rockhampton), Wide Bay (Hervey Bay), Sunshine Coast (Maroochydore), Darling Downs (Toowoomba), Gold Coast (Elanora), Moreton (Ipswich) and 2 Brisbane offices.

Our submission

This submission is not intended to canvass the full range of issues identified in the terms of reference for the inquiry. For a comprehensive examination of these issues, the reader is directed to Carers Australia's submission which Carers Queensland has contributed and which we endorse. Rather, this submission examines some of the major issues and developments within the Queensland context.

1. Caring

Care is central to our humanity.

Care is an inevitable part of life for most people – as is the receipt of care.

This care is provided, in the main, within the context of the family and also by trusted friends.

Mutuality, reciprocity and exchange naturally occur within families. They are paramount to family life and functioning.

Care is often embedded in this deep sense of familial reciprocity.

In the case of disability or illness it is generally expected but also accepted that families will support its member.

Families generally have a deep and abiding concern for its members. Families support and protect its members and keep them safe and well. This is true of all people including those with disability, illness or condition that necessitates care.

Families, better than anyone else, have intimate knowledge of their family member, know their history and their aspirations, have the capacity to recognise what they prefer and what is best for them, and can understand how to achieve these aspirations. They are also more likely to stay true and committed to their family member.

As a result, the ideas and responses that they develop for a meaningful life with and for their family member are usually much better than those devised by people who do not know the family well.

On this basis, families have a natural authority in relation to their members and their own circumstances. Families have an unassailable integrity in this regard.

Recommendation: Australian Government policies and services recognise and respect the natural authority and integrity of families in the lives of people who require assistance.

1.a. The Caring Role

Caring, of course, is not a new phenomena. Families have long provided assistance to its members with routine as well as complex tasks.

However the caring role is shaped by the policy setting in which these caring relationships are located. Public policy frameworks influence the nature and extent of these caring relationships. The state, in this respect, has a significant role in the shaping of care.

Most critical to the current discussion, the deinstitutionalisation of people who require support (whether due to disability, health, mental health issues or older people) has served to rapidly relocate care back into the home. While support within the home is the preference of most people requiring or providing support, the implications of this for family life are significant.

With the relocation of this support back into the family home, responsibility on the part of the state in the provision of direct support for people who require assistance has diminished. Responsibility for this support has clearly and deliberately shifted from the state towards the family.

As care within the home has become the main avenue for support for people who require assistance, accompanying policy initiatives increasingly govern the care provided within the home. Because of this, norms and standards are clearly expected in the provision of care provided within the home, including that provided by family and friends. Policy therefore fashions the expected conduct of the carer: setting out that which is proscribed and that which is forbidden. This serves to shape conduct at the most personal level in order to meet broader policy objectives[i]. A range of policies and initiatives are involved e.g. Hospital in the home, Guardianship Legislation, etc. In this way, the moral and ethical character of carers is prescribed.

Associated with this development, carers are monitored and heavily scrutinised in a variety of ways concerning the way and degree to which they provide this support. Others outside of the family judge them and their capacities.

Whilst expectations related to care have clearly developed, the support available to the family has not increased accordingly. Often families receive little or, in many cases, no support.

It is important to recognise the difficulties that can arise for the family in creating a good life for their family when they have a member who requires support. Clearly, providing support can sometimes be a complex activity that requires a high level of understanding, specialist skills and available time and resources. However, many people who assume the role receive little information or support.

If families do not meet the expectations set for them, they are faced with punitive responses e.g. removal of choices typically centred within the family through to allegations of neglect or abuse (e.g. under the Queensland Criminal Code, Domestic and Family Violence Legislation etc). The responses to complex issues facing families are sought mainly through punitive measures, rather than exploring underlying social issues and addressing these with supportive and facilitative approaches.

Recommendation: Australian Government policy and service responses focus on the person who requires assistance within the family support structure. This involves protection and assistance that focus on the needs of the person and that of the family.

Furthermore, the unintended consequence of some government interventions that seek to assist the individual who requires support has been to further disenfranchise the, often struggling, carer. This is exhibited across a variety of domains, for example, in mental health treatment, elder abuse, guardianship tribunals and child safety. These interventions often not only leave the carer more vulnerable but also leave the person who requires support worse off.

Care must be understood within the context of the relationship in which it takes place. Clearly appropriate support and the realisation of the rights of either party (person caring and person who requires support) can not be realised independently of one another. Ideally, support for the rights and needs of one person involved in the relationship would work to enhance the support and rights of the other.

Recommendation: The development of new Australian Government programs, interventions or supports for people who require assistance includes a comprehensive analysis to ensure that the objective of appropriate protection and assistance for the person and their family, as described above, is achieved.

1.b. The Contribution of Caring

Care is central to the well-being and prosperity of all of society. It sustains our community.

It has profound value or worth to both the private and public sphere: to the person requiring assistance, the family, community and to the economy.

The dollar worth of this care is remarkable with its replacement value estimated to be in excess of $30.5 billion a year nationally[ii]. But more than that, it has a value to which dollars can not be ascribed. Care has an intrinsic worth that can not be completely commodified[iii].

The most valuable of these profound contributions is to the wellbeing of the person requiring support. Through the carer's commitment, their family members is able to live a more meaningful life then would likely otherwise be possible.

While care, undoubtedly, has very substantial value this is coupled with responsibilities. These responsibilities, however, are not shared amongst those who benefit. Government and the community have abrogated much of their responsibility and so care is concentrated within the family. This results in those who are caring being unable to undertake other activities like education, training, training, employment and social activities. This produces financial, social and health costs for the family.

Recommendation: Australian Government policies and services aim to value the care provided by families and share responsibility for such care through the provision of appropriate support to caring families.

1.c. Recognition of Caring

While the community in general and government in particular profess to value care, this does not translate into adequate recognition or support.

Unpaid care continues to be viewed by most as a private matter – the broader economic and social benefits are generally taken for granted.

Sharing the care would ensure that direct and indirect costs associated with care were shared more equitably amongst those who benefit.

For this to occur, adequate recognition from the government needs to be understood within a comprehensive policy encompassing social policy, employment practices and conditions, income support, education and training, housing, aged care, disability services, health services etc.

The Queensland Government has developed a Carer Recognition Policy as a first step towards a policy framework in Queensland.

True recognition of the value of caring however would come not just from government but from services, employers, businesses, schools, educational institutions, other family members, friends and the community.

Currently, a disproportionate spread of responsibility is vested in the family. A better balance is required.

Recommendation: Broader policy goals of the Australian Government work towards and encourage the sharing of care among all stakeholders who benefit from care – government, business, community and families.

2. Social and Economic Participation and Inclusion

The impacts currently associated with care are well documented with many carers experiencing strains on financial resources; diminution of recreational time, natural networks, social and cultural activities; constraints on participation in employment and education and deleterious effects on health and wellbeing. These impacts are likely to be felt across the life-course, influencing long-term opportunities in almost every aspect of life.

These barriers to social and economic participation do not necessarily arise from the intrinsic activities involved in the provision of care, but rather result from the relative dearth of supports and resources available to people involved in caring.

It is this lack of appropriate support that results in considerable consequences as a result of care and therefore constrains social and economic participation.

2.a. Helping Carers find Employment

Many Carers currently out of employment wish to return to work on a part-time or full-time basis[iv]. However existing employment programs tend to lack the appropriate sensitivity and understanding of the caring role and its implications in assisting carers. This is one area in which Carers Queensland has devoted some attention, becoming both an Employment Service Provider and developing a resource for other Employment Service Providers to assist carers into employment.

MOMENTUM PROGRAM

Carers Queensland's Momentum Program is a carer-specific Employment Service. It provides carers with employment preparation assistance to overcome barriers associated with participation in employment along with customised support to facilitate entry into the workforce. Participants are also offered the opportunity to undertake accredited training in a range of areas.

A carer who gained employment through the program talks about the benefits of employment:

> *"Personally I feel less stressed as I now have 'time out' from my caring role. It is a chance to be 'ME'!"*

Momentum understands the challenges carers face in their attempt to combine their caring role with paid work (see below). The Program has reinforced that, while carers face barriers to employment shared with other disadvantaged job seekers, many of these barriers are likely to be felt even more acutely by carers. Carers also have significant additional barriers that are not experienced by other jobseekers. Carers too have some specific strengths that enable them to better respond to some barriers.

Employment barriers associated with caring[v]

Individual barriers
- limited time and energy available due to caring responsibilities
- lack of skills and confidence often associated with time out of workforce
- social isolation and limited social and job networks
- poor health
- debilitating emotional states associated with caring such as depression and grief
- lack of knowledge to market themselves to employers
- costs involved in seeking work
- poor career motivation

Systems barriers
- lack of assistance for people with disabilities, illness, mental illness and older people i.e. alternative care for the person they support so that carers can participate in work and/or training
- perceived and real financial disincentives in the social support (including income support) systems and tax systems to combine care with work and/or training e.g. loss of Health Care Card
- poor recognition from Employment Service Providers to identify carers and address their needs
- the design of Employment Programs are not responsive to carers i.e. short timeframe, limited incentive to participate in education, no capacity for discretionary funding e.g. emergency care fund etc.

Labour market barriers
- Limited understanding from employers about the caring role
- Limited understanding from colleagues and co-workers
- Inflexible working arrangements
- Few accommodations for carers in the workforce
- Lack of recognition of carers' transferable skills.

The Momentum Program has devised specific strategies to overcome barriers associated with caring. Carers Queensland has also developed a resource or 'Toolbox' for Employment Service Providers to assist them to work effectively with carers in their return to paid work.

While Momentum and other services can obviously work with carer jobseekers in relation to certain barriers, there are systemic barriers with which they can do little: few alternative support options for the person that they assist; a lack of carer-friendly workplaces to accommodate their caring responsibilities and disincentives within the social support, income support and tax systems. These, however, are often the most significant barriers that carers face.

These barriers effectively exclude many carers from the workforce. Often these factors can conspire so that people feel that they essentially do not have a genuine choice. Many feel that there is no other option but to forego employment in order to provide care. Presently, the government and business accept little responsibility for mitigating these barriers. This results in carers' exclusion from the workforce and society.

Recommendation: Employment Service Providers demonstrate an understanding of caring situations in the provision of support to carers to return to employment.

Recommendation: The Australian Government works in conjunction with business, where appropriate, to offer caring families genuine choice in their ability to combine employment and care, by providing:

- *affordable alternative support options*
- *carer-friendly workplace practices*
- *the removal of disincentives in the social support, income support and taxation*
- *coverage under Anti-Discrimination/Equal Opportunity Legislation*
- *support under Industrial Relations Legislation*
- *employment programs that are responsive to caring situations.*

2.b. Carers and Income Support

A range of prevailing factors dominate the landscape within which people's preferences and decisions about employment and care are determined. Carers decisions about employment are influenced by public policy – particularly in relation to income support, workplace practice, service availability and community attitudes. Often these factors can conspire so that people feel that they essentially have no other option but to provide care and forego employment.

'CARERS' AND WORKERS

The current income support system views care as largely incompatible with work i.e. people are seen as either 'workers' or 'carers'. This division needs to be removed. Among the most obvious examples to illustrate the division between workers and carers in income support policy is that the eligibility criteria for Carer Payment only allows carers to engage in activities outside of caring for up to 25 hours per week. This discourages the sharing of care with either natural networks (such as spouses) or through the formal care system and, as such, limits the involvement of carers in the paid workforce. The removal of this eligibility criterion would facilitate carers' entry into the workforce by encouraging the sharing of care more equally in families and the community. The retention of the means-test and the assessment of the care recipient would still ensure that the payment is focused on people who are unable to participate in the workforce full-time as a result of their caring responsibilities. However, it would provide carers with the opportunity to enter employment (e.g. through study) and engage with the workforce.

Without a rethink some carers, mostly women, will continue to perform the bulk of caring and, as a consequence, be consigned to a life of economic dependency and poverty. These long-term positions of disadvantage are untenable – both for families and the economy.

Recommendation: Australian Government income support policies assist people to combine their caring responsibilities with employment.

3. Practical Measures to Better Support Carers

A comprehensive framework for carer support is currently not well developed.

Supports for carers have evolved in a fragmented fashion with relatively little co-ordination or co-operation – either between government departments or across jurisdictions. Initially, practical supports for carers were guided by policies that focused on the 'preservation' of the carer – primarily through respite. More recently, supports have focused on 'capacity building' related to caring. And now supports are developing that are focused on providing genuine choice and control for families: supporting families to make decisions that respond to their situation and preferences.

Currently there are:

- significant gaps in services
- issues with service quality and effectiveness
- no equity of access for carers (i.e. carers of people with disability, older people, people with mental health issues etc)
- considerable variability in geographic coverage and
- limited availability or access to important enablers that facilitate support (e.g. alternative support for the person they assist when the carer attends education and training).

Access to the most appropriate option at the most appropriate time in their caring journey, requires an integrated system of carer support: a strategic and multi-faceted range of supports. The types of services would likely vary by phase of the caring journey, relationship to the person being supported, the families place in the life course, the condition of the person requiring support and the preferences of those involved.

3.a. Integrated Carer Support

Recommendation: The Australian Government develop an Integrated Carer Support Framework that includes the following components:

- *Specialist Information and Advice*
- *Peer Activities and Support: Group and Individual*
- *Education and Training*
- *Counselling: Individual and Group*
- *Family Support*
- *Family Mediation and Conciliation*
- *Family Advocacy*
- *Carer Employment Programs*
- *Carer Health Programs*
- *Financial Support*
- *Respite.*

Along with enablers such as:

- *Alternative Support Options*
- *Education and Training for other stakeholders re: Carers*
- *Carer Participation and Representation*
- *Awareness Raising.*

This Integrated Carer Support framework would:

- provide emotional and practical assistance to caring families
- enhance the capacity of the family
- facilitate the families' ability to participate in the community
- enhance the quality of life of carers and those that they support
- share the care across the community.

Many of the supports that would form part of this integrated support system currently exist but need to be expanded and extended in a co-ordinated way. Discussion in this section highlights some of the major service developments in Queensland. The development of these services has primarily been driven by carers. The following discussion is an attempt to signpost key components of a more comprehensive support model of integrated carer support.

FAMILY SUPPORT

Family Support provides families with the opportunity to devise their own informed solutions for the future. Few avenues exist for families to consider their, often previously unstated, expectations and assumptions regarding the future of their family including the provision and receipt of future care for their family member. Ideally, family support would provide an opportunity for planning in both the short and long-term and in the case of emergencies.

In their discussion and planning, families may wish to utilise the existing service systems, draw on the experience of other families with a similar experience or various professions (such as lawyers, financial advisors etc) who have relevant expertise along with experience and understanding of the situation of caring families.

> *Carers Queensland opened up our lives, they put us in the right direction.*
>
> *The most significant benefit identified by the carer was the practical and emotional support provided 'when I didn't know where to turn'.*[vi]

MEDIATION AND CONCILLIATION

Family discord is a reality for many families at some time. Within our families it is not uncommon to experience disagreement – sometimes all the stronger because we are family.

Given that caring often takes places against a highly emotive backdrop, it is not surprising that conflict and tension commonly occurs in families who have a member who requires support. Often this conflict is directly related to caring with one in five carers having disagreements with others specifically about caring[vii].

Of course, not all of these disagreements require any intervention, however, in some cases the facilitated resolution of this conflict is necessary for the family to survive and to thrive.

Conflict within the family, appropriately resolved, reconciles diverse opinions and perspectives. Mediation can be part of a robust process to reach more informed decisions that will ultimately better serve the family.

FAMILY ADVOCACY

Because of their often consuming role, carers can lack the time, energy and skills to be effective self-advocates when confronted with complex or difficult issues such as guardianship hearings, cases of inequity or discrimination, and issues associated with eligibility or access to services.

Carers currently seek advocates to work for, and with, them in a range of situations including dealings with employers, the Guardianship and Administration Tribunal, Centrelink, government departments, community care providers, health funds and more.

> *It made a big difference to know that someone was on your side*
>
> *The organisation has played a significant and vital role in supporting myself and my mother and gave us confidence that we are not alone*[viii]*.*

A failure to provide advocacy for carers can result in a breakdown of the caring arrangement – leaving the person requiring support more vulnerable and/or the carer worse off.

The Family Support and Advocacy Program in Queensland currently provides vital assistance to families who contact the Queensland Guardianship instrumentalities. The service is in extraordinary demand. Performance targets were exceeded by 50% in its first year of operation. It has also secured considerable credibility and acceptance from the Guardianship jurisdiction for its valuable contribution in assisting the jurisdiction to function as it should: in the best interests of the individual. This program has only received time limited funding. Ongoing recurrent funding is required to consolidate and expand the service – both in the services that it is able to provide and its target group.

PEER ACTIVITIES AND SUPPORT

Peer activities provide those who are caring with the opportunity to meet and share experiences on a regular basis. These activities typically offer information, practical advice and emotional support as well as an opportunity to socialise.

Carer Groups

Traditionally peer support has been provided in the context of Carer Groups. Carers Queensland supports over 100 carer groups throughout the state with more than 1000 members.

These groups meet for a number of different purposes including:
- social opportunities
- information, advice and support

- to act together on issues relevant to their experience ('collective advocacy')
- activities focused on maintaining the carers' own health and well-being[ix].

Carer-Connect

Not all carers are interested in a group experience for peer support. Some prefer the dynamic of peer support on an individual basis. Carers Queensland responded to this preference through the Carer-Connect program.

The purpose of Carer-Connect is to links carers for companionship and support to:

- reduce social isolation
- enhance capacity to care
- improve health and well-being, and
- recognise the valuable experience and knowledge of carers.

Carers are linked via two partnerships:

- Buddy Partnerships, and
- Carer Mentoring Partnerships.

The Buddy Program links carers with similar experiences who are willing and able to support each other on an ongoing basis without extensive support from Carers Queensland.

Carer Mentoring matches more experienced carers with less experienced carers to provide additional support. Carers Queensland in turn provides additional training and support for carers in the mentoring role.

Both partnerships are founded on the simple principle that no-one understands the caring role better than another carer.

> *I have no friends. I really need this contact.*
>
> *For the first time, in a long time, I feel part of the world again.*
>
> *When I talk about my situation she knows what I am going through.*
>
> *Because she's a carer, she understands what it is like.*
>
> *It was great as we didn't need to go out and meet them in the first place. Someone did that for me. It is difficult for me to get out and meet people. Partly because of my caring role. Partly because of my health and mainly because it is too expensive for us.*[x]

The Carer Connect program, currently funded through HACC, is limited in its geographic coverage and availability. Additional funding is required to extend it throughout our regional networks.

CAREER EMPLOYMENT PROGRAMS

Essentially, Momentum is a carer-specific Employment Service. It provides carers with employment preparation assistance and the opportunity to undertake accredited training in a range of areas. Most importantly though it provides carers with customised support to overcome barriers associated with participation in employment and to facilitate their entry into the workforce.

For a full discussion of the Momentum Program see the previous section.

NO INTEREST LOANS

To respond to the dire financial situation that caring families can find themselves in due to a lack of sufficient support, Carers Queensland has established a No Interest Loans Scheme (NILS) for carers through funding from the National Australia Bank.

Carers Queensland's NILS program is designed to help low income carers buy essential items. Many low income carer households get by week to week, but are completely stuck when they need to buy essential household items such as a fridge or air conditioner, get the car fixed or purchase equipment or aids.

Often credit is necessary but with high interest charges it is beyond the means of some carers. The NILS process provides credit on fair and reasonable terms.

Clearly this program is responding to the symptom of insufficient financial support for carers rather than addressing the cause of financial disadvantage. This program will unfortunately be necessary to provide caring families with limited assistance until adequate financial support is introduced.

FINANCIAL SUPPORT

A specific discussion of financial support is warranted given how critical it is.

It is important that caring doesn't consign families to poverty.

A major deficiency in the current social support system is that if fails to address the costs associated with disability/illness and the costs of care. Very few families receive assistance to purchase the aids, interventions, therapies or support that they require. For those families that do, the current scope of coverage is quite arbitrary e.g. the Child Disability Assistance Payment and Carer Adjustment Payment. Payments related to cost need to provide equity for all caring families regardless of the age of the person who requires assistance or the cause of disability.

Recommendation: The Australian Government introduce payments for all caring families that recognise and contribute towards the cost of care and costs associated with disability/ illness.

RESPITE

Respite is, similarly, an essential service for carers. Whilst many carers have a positive experience of respite, there continue to be significant issues associated with it including difficulty with accessing, inconsistency, unreliability, a lack of carer focus, inflexibility and the deterioration in the condition of the person being supported[xi].

In addition, traditional respite programs can fail to address the capacity-building and choice that many carers are seeking. All too often, respite provides a small reprieve with people returning to situations within which they continue to struggle. More recent National Respite for Carers (NRCP) programs (i.e. the young carers program, the ageing carers program, employed carers) have moved toward the provision of a meaningful experience for both people. Carers are able to engage in meaningful activities such as education and employment while the person they support is also engaged in meaningful activities. In this respect, respite is shifting its focus for carers. Rather than 'a break' carers are provided with opportunities to participate in life experiences of their choosing.

Recommendation: The further development of programs by the Australian Government that offer the carer and the person they support opportunities to participate in life experiences according to their own choices and preferences.

Integrated Carer Support: In action

These stories give a sense of how an integrated system of Carer Support might work to assist families.

Mother with a child with disability

Suzanne first makes contact with the Carer Advisory Service because her car broke down almost 2 weeks ago and she 'has tried everywhere' for assistance to get it fixed but no-one has been able to help her. The car is vital to the family as it has been modified to transport Jackson, Suzanne's son, who was born with spina bifida, has limited mobility and uses a wheelchair. Without the family car, Jackson is not able to easily get around. For 2 weeks Suzanne has paid for a taxi to get Jackson to and from school and this has cost her close to $250. This is money she would have otherwise used to get the car fixed. Suzanne says that she is 'going backward' and is at her 'wit's end'.

The Carer Advisory Service identifies a potential funding source that Suzanne does not think she has tried but Suzanne has to attend several appointments that day with Jackson and does not have time to follow it up. Instead, Suzanne gives her consent for the Carer Advisory Service to make enquiries on her behalf. Unfortunately, this avenue does not prove fruitful. When calling to advise of this, the Carer Advisory Service staff is however able to tell Suzanne about the No Interest Loans Scheme that Carers Queensland operates for carers. Suzanne sees this as her only chance. In completing the application form that afternoon, and discussing her income, it becomes apparent that Suzanne is having difficulty with Centrelink.

Suzanne has recently separated from Stephen, Jackson's father. At that time she applied for the Carer Payment (child) but was not deemed eligible. Instead, she is on the Parenting Payment. She is finding this very stressful as Centrelink is continually asking her to look for work but she feels this is not feasible given her and Jackson's circumstances. The Carer Advisory staff inform her of the possibility of a temporary exemption from her participation requirements on the basis of her caring responsibilities. Suzanne had never heard of this. Nor was she aware of the Carer Allowance. She has an appointment with Centrelink in two days time and expresses how uncomfortable she feels in raising these issues with Centrelink as she feels that they do not understand her situation. The Carer Advisory staff offers for a person to accompany her to her appointment and she accepts this offer. She is pleased with the outcome of the meeting with results in an application for an Activity Test exemption along with an application for Carer Allowance.

Several weeks later, Suzanne calls back. She noticed in the information she received from Carers Queensland that the organisation provides counselling. She feels that she has not dealt with her separation and, especially, her feelings over what she perceives as Stephen 'abandoning' Jackson. She feels that this is hampering Stephen's relationship with his sons. In subsequent sessions, she admits, she sometimes blames Jackson's disability for her separation from Stephen as she feels this contributed to the conflict in their relationship. Suzanne attends several useful sessions with the counsellor. At the conclusion of these sessions, the counsellor proposes to Suzanne that she and Stephen might like to meet with the Family Support Worker to talk more about the family's plans for the future. They agree that this would be a good idea. Stephen explains that while he wants to stay involved with his boys, he isn't able to have Jackson at his place yet as his new flat isn't set up to accommodate Jackson. They are able to come to a short-term arrangement while Stephen looks for new accommodation that allows him to spend more time with his sons at the family home. This also gives Suzanne the opportunity to get away every now and again.

Suzanne also explains to the Family Support Worker that she is worried about her son, Darren, who is 3 years younger than Jackson. She thinks he seems quite withdrawn lately. The Worker informs the family of an activity group for young people who have siblings with disability and Darren decides to join. At first Darren is quiet but after a while he likes to talk with other kids who know how he feels. Here he can talk about how he sometimes gets a bit jealous of the attention that Jackson receives and how bad he feels about that. He also mentions how he would really love to play soccer but believes that his Mum doesn't have the time so he hasn't told her. The group facilitator encourages Darren to talk with his Mum and she agrees to enroll Darren in the local soccer club. Although it's sometimes difficult for Suzanne to get Darren to practice, the coach lives nearby and he often offers to give Darren a lift. Suzanne and Jackson both enjoy watching Darren play on the weekends and attending the BBQ that the club holds afterwards.

Adult children whose father has had a stroke

Lorna's father, Albert, has had a stroke and is recovering in hospital. He is still not able to communicate and the doctors think he will most likely never recover this capacity. The doctors have advised that the stroke has caused significant damage to his brain that is likely to be permanent. He is likely to require a high level of support for the remainder of his life. They are suggesting to Lorna that the best option for her father is a nursing home.

Lorna however wants to bring her father home. Some years ago, after her mother's death, Lorna had promised her father that she would never consider putting him in a 'home' and she wants to keep that promise. She thinks that with the sale of her parent's house, they could use some of the money to build in the space under her Queenslander home and create an independent living space for her father. She has talked with her brother Brian about this idea. He agrees with the doctors and thinks that Albert should move into a nursing home. He has been to look at a few Aged Care Facilities and has found one close to him in Northern NSW where he thinks that Albert will be well looked after. Brian holds Albert's Enduring Power of Attorney and is refusing to co-operate with Lorna.

Albert is due to leave the hospital in a month. Lorna and Brian are in total disagreement about how to proceed and are so upset with one another that they are no longer talking. Realising this, the Social Worker at the hospital talks with the family and arranges a Family Mediation appointment for Brian and Lorna to discuss their views on Albert's future care and living arrangements. Through this process Brian realizes that if Albert were to live with Lorna he would stay close to his family and friends and the Italian community that he has long been part of. It arises that Brian's resistance to the idea of Albert living with Lorna emanates from his concern that his inheritance will be used to increase the value of Lorna's home. Brian eventually comes to understand though that this is really Albert's wishes. From this process, Lorna also comes to appreciate the significant impacts that bringing her father to live with her will have not just on her life but that of her family. Lorna is particularly worried about the impact that this decision will have on her employment.

Lorna works with an Advocate to put together a case for flexible working arrangements that is ultimately accepted by her employer. This will enable her to work from home 3 days per week. For the other 2 days of the week, an old friend of Albert's has agreed to spend time with him – taking him to the Italian club and out to their old haunts. Albert will holiday regularly with Brian as he had frequently done prior to his stroke.

To assist with Brian's understanding of his role as Enduring Power of Attorney, Brian attends Education and Training on his roles and responsibilities in this regard.

Eventually everyone in the family is able to agree that it is in Albert's best interest to live with Lorna and that this is also a workable arrangement for Lorna and her family.

At first, the doctor's do not consider it a good idea but Brian and Lorna are firm and Albert returns home to live with Lorna on his release from hospital.

Mother of adult daughter with mental illness

Late one night Rhonda calls the Carer Advisory Service. She was given this number some years ago and didn't know where else to turn. She is terribly worried about her daughter.

Rhonda lives in Bundaberg with her partner, James. Their youngest daughter, Jessica, moved to Brisbane at the start of the year to attend University. Rhonda explains how in year 10 Jessica had had some mental health issues for which she had been hospitalised for a short time. Since that time, Jessica has been on medication that had stabilized her condition and she appeared to have recovered well. She settled into her studies and was excited at being offered a place at University.

Since moving to Brisbane, Jessica had been to see a new psychiatrist rather than make the 8 hour round-trip home for the appointment. Rhonda describes how this new doctor had changed Jessica's medication. Rhonda thought that this had not agreed with her daughter because the last time that Jessica was home she was quite withdrawn and 'things did not appear right'. Rhonda had tried to talk with the new Psychiatrist about this but he had refused simply saying that he did not discuss patient’s details due to 'privacy' reasons.

Rhonda is becoming increasingly worried. In the last few phone calls she has had with Jessica she feels that Jessica has not been making a lot of sense and has been quite erratic. Several times Jessica has talked about doing injury to herself. She worries that her daughter will hurt herself if she doesn’t get the help she needs.

The Carer Advisory service provides Rhonda with information about initiating an Involuntary Assessment under the Mental Health Act to determine if Jessica needs treatment.

As agreed with Rhonda, the Carer Advisory Service staff calls back some days later to find out whether Rhonda would like any further support. They find that Rhonda has just returned home from visiting her daughter who was admitted to hospital in Brisbane. Rhonda is very upset that it has come to this. She knows that Jessica blames her for the fact that she is in hospital and she is finding this very difficult. Rhonda is put in touch with the Carer Counsellor in her area and through this is assisted to overcome her feelings of guilt and blame accepting that, although difficult, her actions were necessary for Jessica’s safety.

Jessica is expected to be in hospital for at least 6 weeks. Rhonda makes several trips to Brisbane to spend time with her daughter over this time. She finds it difficult to fit this in around her work commitments but it is terribly important to her that Jessica knows she is there for her. The Carer Advisory service tells Rhonda about the availability of Carers Leave. Rhonda was not previously aware of this leave and it makes her feel a bit better about taking time off.

After a month in hospital, Jessica is given a diagnosis. Rhonda is determined to learn everything she can about the illness and its symptoms and enrolls in the next Carer Education and Training Program on mental illness. In learning about the illness she realizes that she is not responsible for Jessica’s condition. She had thought that it might somehow have been her fault.

Meanwhile, in the hospital, the staff are considering putting Jessica on a particular medication. Rhonda knows that Jessica does not want to take this medication again as the last time it had had significant side effects. At the training Rhonda had heard about the role of ‘Allied Person’. She talks with Jessica about this role and Jessica appoints her mother to represent her views and interests. The formalisation of her role emboldens Rhonda to discuss Jessica's experience and views on medication. The staff take this advice on board and revise Jessica’s medication regime. As a result, a noticeable improvement is observed in Jessica’s condition.

At the training, Rhonda also heard about the Carer Connect Program. She feels she doesn’t have the time and isn’t interested in joining a Carer Group but likes the idea of connecting with another person who has been through a similar experience and to whom she can talk regularly. Rhonda is matched with Carol, whom Rhonda calls her ‘saviour’. Carol's husband has a mental illness and she understands Rhonda's experience. Especially those issues associated with living with mental illness in a small community.

Rural/Remote Caring

Queensland is the second largest State in Australia. It covers almost one quarter of the total area of Australia. In addition, Queensland is heavily decentralised.

Carers Queensland attempts to provide a state-wide network of support to carers with

11 service locations across the State. Effective support for carers in Queensland depends on an understanding of, and acceptance within, the local community.

Rural and remote communities face particular challenges but also posses certain strengths. Distance and decentralisation are the most significant barriers in providing equity of access to people in Queensland regardless of where they live.

The provision of services to rural and remote communities requires:

- innovative service delivery systems
- funding which reflects distance, isolation and travel costs
- communication and information technology opportunities
- addressing workforce issues and strategies
- the building of social capacity.

Recommendation: Australian Government service options provide equity of access for caring families in rural and remote areas.

3.b. Disability, Mental Health, Health and Aged Care Systems

Quite often, carers main concern is direct support for their family member or friend whom they assist. Addressing the lack of sufficient investment and appropriate service delivery in the disability, health, mental health and aged care sectors is a high priority for most carers.

Currently, families are experiencing undue responsibilities and pressures in their caring roles due to significant gaps or inadequate service delivery in these sectors.

Recommendation: Increased investment in the disability, mental health, health and aged care systems.

In many cases, there is often a benefit to carers derived from quality support services. And, whilst ideally the case, it would be a mistake to consider that the support systems for people with disability, health, mental health conditions or older people automatically assist or support the family. These systems and services impact on the person's life and also, by their close association, on that of their carers.

Often services have developed with an exclusive focus on the individual. They view the individual in isolation without taking into account the integrity and authority of the family and natural support networks surrounding the person.

This not only limits the effectiveness of the support provided to the person it can actually have detrimental effects for the family.

As mentioned previously in Section 1, the unintended consequence of some government interventions that seek to assist the individual has been to further disenfranchise the, often struggling, carer. This is exhibited across a variety of domains in mental health, elder abuse, guardianship tribunals, child safety, aged care complaints systems etc.

Guardianship

Monica* has three children, two of whom were born with multiple disabilities, including decision-making disabilities. Both of these children are now young adults. Monica has been their primary carer since they were born and their sole carer for the past decade. Despite their high needs, the children receive limited funding or support apart from that provided by their mother. The eldest of these two children, Fiona, does attend an employment program run through a large community organisation. One of the workers from this service reported to the Adult Guardian suspicions that Fiona had been abused by her mother. Monica was completely unaware that such a complaint had been made or that associated investigations had occurred until her daughter mentioned the complaint to her ten days later. At no stage had Monica been informed of the investigation or with the opportunity to reply to the allegation against her. Only after Monica approached the Adult Guardian about the matter was she informed that an allegation had been made against her that had subsequently been dismissed as trivial.

At this time, Monica was also experiencing considerable stress associated with her caring role which had been exacerbated by the behaviour of her older son with an acquired dual diagnosis disability. With the assistance of a friend she was able to secure respite for her children to enable her to take a short break from her caring responsibilities. Whilst her children were in respite Monica came to the decision that due to her current physical and emotional state she was not able to take her children back into her care unless she received support to assist her in caring for them. She also felt very vulnerable to further allegations, and actioning of those allegations, by the service provider in view of the fact that there was apparently no obligation to inform her of any allegation made against her or to provide her with the opportunity to respond to any such claim.

In response to Monica's concerns, some attempt was made by disability services to provide her with support that would enable her to continue caring. However, these negotiations failed to reach a solution that Monica felt would safely or appropriately support the family unit. Ultimately, when a solution could not be agreed on, Monica was notified that an application would be made to the Guardianship and Administration Tribunal (GAAT) for both children to go under Guardianship order.

During this time, despite Monica's objections, her children had been placed with a service a considerable distance from their home. Monica was not informed of their whereabouts or their welfare and as a result was unable to visit with them. Eventually, after much persistence, her ex-husband was allowed to visit with the children. Monica, however, remained separated from her children for 12 weeks. This separation, understandably, placed additional strain on her. Faced with the prospect of losing contact with her children for whom she had cared for, for over 27 years, Monica lodged her own application for Guardianship of her children.

Ultimately, the result of the hearing was that Monica was granted Guardianship and the Public Trustee appointed as Administrator. Her children have since returned home to live with her. The episode, however, has left an ongoing legacy of uncertainty and fear. Her son, especially, has been quite affected by the experience. He is apprehensive and agitated when separated from his mother, even for short periods. The carer also continues to feel vulnerable.

* The details of those involved have been altered to some extent to protect their identity.

Mental Health Treatment and Privacy

In the mental health area, for example, an unexpected outcome of the complex interaction of the Privacy Act 1988, the Freedom of Information Act 1988 and Mental Health Acts is that carers are denied information about a consumer are still "expected" to care for and support the consumer upon discharge.

This issue has been highlighted in a number of forums from Coroner's Reports to newspaper articles. The following is from an article in The Age:

"The parents say that hospitals are refusing to disclose information about their children's whereabouts or treatment, despite requests for information.

One woman told The Age she found her unstable, psychotic son at the Melbourne Remand Centre because she "guessed" he would be there. He was later moved to Port Phillip Prison, and again she was not informed.

"Now parents can't find their own children, and if they have a mental illness that can potentially be a fatal problem," she said.

Another mother told The Age her son was released from a psychiatric hospital after five days and the family was not even notified. He simply showed up at the family home. Nor could she speak to the doctor who was treating her son. …

A third mother said the hospital would not provide details of her son's treatment because of privacy legislation, even though her son had allergies and she was concerned the treatment would produce harmful side effects. She was later sent a letter from the hospital stating: "Under the current Victorian Privacy Legislation we are unable to disclose information regarding (her son's) current treatment."[xii]

People who require support are more vulnerable when they are not supported to belong to families and other natural networks. For this reason, support for families and carers which ensures the integrity of the family unit and encourages resilience is essential. One option to achieve this is to vest choice and control back in the family through family-governed services such as Family Support Collectives.

FAMILY SUPPORT COLLECTIVES

Carers Queensland has attempted to address the lack of support for the person within the context of the family through the Family Support Collective Project. As explained earlier, families have the natural authority to act with and for the person that they assist. The Family Support Collective Project aims to strengthen the resilience of families who have a member with disability by providing families, individually and as a collective, with the opportunity to share issues and work on practical solutions together. The focus is on relationship building and development of solutions through the wisdom of the collective.

The collectives have available a relatively small amount of funding to provide families with meaningful and timely responses to meet their needs – as identified by them.

Carers Queensland acts as a funds holder but decisions about allocation of resources are the decision of the Collective.

Carers Queensland has established four of these Family Support Collectives and following their evaluation will look to extend them, as appropriate.

Recommendation: The Australian Government develop service options that vest control over support within the family.

4. Choice and Opportunity

Access to the same range of opportunities and choices while caring can only occur through a more equitable sharing of the care.

Because of an ineffective mix in the way in which care is shared between the private (family) and public sphere there is, currently, no real choice for caring families. Families must provide the overwhelming majority of support.

Families, currently, have little choice over the extent to which they share responsibility for care with the community or, indeed, whether they want to be involved in caring.

There has never been an acceptable form of resistance to the caring role[xiii]. In any case, carers do not resist because they know that if they are not there for their family member then they will be more vulnerable. They care too much to allow that to happen. The government knows this and takes advantage of it.

Government and community abrogate their responsibility for this care so it is concentrated almost solely within the family – particularly among women. When this occurs it exacts a price. The caring role becomes a dominating force for the family – socially and economically. The costs remain contained within the family while the public benefits.

Instead, we need to recognise that the worth of this care transcends public and private boundaries and ensure an effective policy mix so that those who benefit from this care accordingly share the responsibilities associated with it – government, business, community (through public policies) and families.

This will facilitate choices for families that best meet their needs and preferences. These choices will ensure that caring families do not incur undue penalty.

Conclusion

All stakeholders share the benefits of care and so should share the responsibilities too. Currently there are serious inequities in the way in which responsibilities are shared. It is all too common for individuals and families to bear these responsibilities while the community benefits. Due to inadequate support, caring exacts a high price. In most cases, these costs are clearly unsustainable and so a new mix of caring responsibilities is important. Not just for the well-being of caring families but for the whole community.

Recommendation: The Australian Government commits to a truly shared approach to care in order to facilitate real choices and opportunities for caring families.

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[iii] For a discussion of this issue see Cass, B (2007) Caring Lives, In: Carers NSW Conference Proceedings: Partnerships for Better Health Outcomes.

[iv] See, most recently, Gray, M., Edwards, B., & Zmijewski, N. (2008) Caring and women's labour market participation. Family Matters 2008 No. 78. Australian Institute of Family Studies: Melbourne.

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