



Submission to Inquiry into Support for Carers

Introduction

A person in a carer's role usually takes care of one or more family members who are unable to look after or provide for themselves. The care recipients range from children to adults with a variety of specific needs, which may include disability, frailty, mental illness and/or chronic medical conditions. Carers range in age from young children right through to those who may be frail aged themselves.

Tandem is an organisation that provides regular respite in the home or community to over 600 families in the ACT with special needs. Tandem supports carers of children or adults with a disability or with complex medical needs, frail aged, and adults with mental health conditions. The support provided to individuals may involve transport to, and assistance with, accessing recreational and community activities and developing living skills. Support may also include assistance with personal care, grocery shopping, administration of medication, and assistance with meals and feeding.

This support assists carers, where possible, to continue employment, keep appointments, and carry out day-to-day tasks such as grocery shopping, cleaning, and paying bills. It also allows carers to spend time with significant others and take time out to rest.

Key Issues

- *The role and contribution of (unpaid) carers in society and how this should be recognised*

Carers are usually family members of a person with special needs, including children and adults with a disability, frail aged, and people with mental illness and/or a chronic medical condition. The carers supported by Tandem include parents, siblings, partners, children and friends, all of whom support our care recipients in an unpaid, informal context. Often these carers take on multiple caring roles with aging parents, siblings with a disability and/or their own children with special needs.

Carers enable care recipients to continue living within the community, thereby reducing the strain on residential respite and accommodation options. Carers are often responsible for organising and coordinating services for care recipients and making day-to-day decisions to support the recipient in ways most suited to their needs.

Carers support the care recipient through personal care and assisting with daily living, as well as financial support, including equipment purchases, medication and general living costs. Carers enable care recipients to continue living within their homes, expand their social networks, and facilitate the lifestyle that the care recipient desires. This places a huge physical, mental and financial burden on carers that in many cases is not sustainable without adequate support options. If carers are not adequately supported, this strain can lead to long-term poverty, family breakdown and reliance on government.

We recommend that the contribution of carers be recognised through more financial assistance, respite and accommodation options, opportunities for growth and development, social support, natural supports and more funding for support groups.

- *The barriers to social and economic participation for carers, with the focus on helping them to find and/or retain employment*

Carers, by virtue of the very nature of their role, have limited opportunities to participate in social and economic life. The caring role is often full-time and means that carers need to be constantly vigilant, and be ready and able to respond when required. For example, when a paid support worker becomes ill, school has suspended their child, or after school and holiday care is not available.

Many of our carers frequently report that they are not able to work within their previous capacity prior to entering the caring role. Amongst other things this can place a significant financial burden and lifestyle change on the carer, which has a consequential impact on the carer's physical and mental well-being. It also impacts heavily on personal and social relationships with a high proportion of family breakdowns and increased isolation because of greater responsibilities to the care recipient.

Carers frequently find employers are not able to be flexible around their daily caring commitments. Many carers have either ceased or changed their work habits to meet the demanding needs of the care recipient. This may lead to health complications, as carers are liable to have minimal rest, physical injuries and no ability to actively address their own health issues.

Whilst there are services available to assist carers, these services are limited and often inflexible and do not meet the specific needs of the family. This is to the point where families sometimes give up using services as they can create a bigger burden on their caring responsibilities. As a service provider, we recognise the difficulty in meeting the needs of families within the parameters of the programs we provide, and the added difficulty in recruiting and retaining support workers in the current employment market.

Other social and economic barriers include carers having to retire from work at an early age to care for their care recipient. This is particularly evident during life transitions such as when their child graduates from school, or when their partner's dependence increases because there is a shortage of services available to support them. Another social and economic barrier is the prohibitive cost of services when available for recommended therapies, such as Applied Behaviour Analysis. We have found many families living in poverty and in some instances, having to sell their family homes to provide the best opportunities for their family, or to simply maintain basic requirements such as food, shelter, clothing and medications.

- *The practical measures required to better support carers, including key priorities*

Carers experience extra financial burden, decreased working ability, social isolation, and decreased mental well being. In general, carers and those they care for could be better supported by increasing opportunities for social inclusion through access to and participation in activities that are available to the wider community. This would encourage the development of natural supports (ie. friends and extended family) for both the carer and the care recipient.

We recommend the following measures to enable carers to have the choice to return to work:

Increasing and Broadening Program Parameters and Funding - to give carers greater choice and opportunity to be more supported in their caring role by enabling access to more services, for example respite, personal care, accommodation, and therapeutic interventions. Service options need to be more relevant to carers requirements, addressing identified areas of unmet need, such as after school and holiday respite, as well as providing carers with choice.

Special Equipment Subsidy - equipment and dietary costs are often of great concern to carers. Increased funding or equipment subsidies would enable carers to access required items at a lower cost. This would also include a home modification subsidy. A program such as this would enable carers to have more choices in the appropriate distribution of funds.

Flexible Service Provision - services are very constrained and often have long waiting lists and strict eligibility criteria. This often means that when the carer and care recipient are in the greatest need they must wait until a place or funding becomes available. Programs are restricted in the type of support, and hours of support, they provide. With greater flexibility, carers would be more able to return to work, or have a break to maintain their own lifestyle and concentrate on their health.

Greater Coordination Between Services - by enabling services to better coordinate with each other instead of competing for funding, care recipients and carers would be the beneficiaries. Services could provide a more efficient case managing role, thus alleviating stress on carers and providing a more relevant service.

Training and Access to Information and Resources - carers need to have training and information to assist them in their caring role. Many carers do not feel that they have the knowledge or full understanding of the care recipients needs. In addition, carers need greater access to resources and services in order to support them in their caring role.

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