



Response to Parliamentary Inquiry into Accommodation and Intensive Family Support Funding for People with Disability

Carers WA



For inquiries please contact

Dr Donna Turner 9228 7431 donna.turner@carerswa.asn.au

With our thanks to the families who shared their stories with us for this submission.

1. Introduction

Carers WA is the peak body representing people who provide ongoing care to a family member or friend with ongoing care needs due to disability or chronic illness, including age-related disability, drug and alcohol issues and mental illness.

The Carers Recognition Act 2004¹ is Western Australian legislation that requires health, mental health and disability service providers to identify and recognise family members who provide ongoing, unpaid care for a person with care needs.

The Australian Bureau of Statistics² has recently estimated that there are more than 250,000 people in a caring role in Western Australia although academic researchers have argued that this is an undercount and there is more likely to be upwards of 307,000 people in Western Australia in a caring role.³

Information gathered for this submission has been provided to Carers WA by family members in a caring role in response to a call for input to the Parliamentary Inquiry. We thank those families for their contributions. In addition, information has been collected and collated as a result of requests for support and advice by the many carers who have contacted our organisation over the past years.

Please note that as Carers WA is the peak body advocating on behalf of family members in a caring role, and in the awareness that disability advocacy bodies are making submissions on behalf of people with disability, this submission focuses on the needs of family members in a caring role.

Carers WA would be pleased speak to this submission in future hearings relating to this inquiry and would be pleased to assist carers to speak to the committee members.

January 2014

¹ Available from the State Law Publisher at [http://www.slp.wa.gov.au/pco/prod/FileStore.nsf/Documents/MRDocument:21015P/\\$FILE/CarersRecognitionAct2004-01-a0-01.pdf?OpenElement](http://www.slp.wa.gov.au/pco/prod/FileStore.nsf/Documents/MRDocument:21015P/$FILE/CarersRecognitionAct2004-01-a0-01.pdf?OpenElement)

² ABS. 2012. *Survey of Disability, Ageing and Carers*. Canberra.

³ Edwards, B., Gray, M.C., Baxter, J. and Hunter, B.H. 2009. *The Tyranny of Distance? Carers in Regional and Remote Areas of Australia*. Commonwealth of Australia and Carers Australia, Canberra.

2. The policy environment for carer identification, recognition and inclusion in Western Australia in the field of disability

Under the terms of the Carers Recognition Act 2004, the Disability Services Commission and the service providers it funds must comply with the Carers Charter.⁴

WA Carers Charter

1. Carers must be treated with respect and dignity.
2. The role of carers must be recognised by including carers in the assessment, planning, delivery and review of services that impact on them and the role of carers.
3. The views and needs of carers must be taken into account along with the views, needs and best interests of people receiving care when decisions are made that impact on carers and the role of carers.
4. Complaints made by carers in relation to services that impact on them and the role of carers must be given due attention and consideration.

In order to comply, it is necessary that these agencies have in place measures to recognise and include carers.

The Disability Services Amendment Act 2012⁵ further strengthened carer recognition and inclusion in the disability sector, requiring that programs and services be designed and implemented such that they:

- (a) acknowledge, recognise, respect and respond to the role of families, carers and significant others in supporting people with disability; and
- (b) respond to the views and needs of families, carers and significant others; and
- (c) strengthen and build the capacity of families, carers and significant others in supporting people with disability.

The Health and Disability Services Complaints Office (HADSCO) is the agency to which carers can make complaints about a disability service provider with regard to compliance with the Carers Recognition Act.

3. Response to the terms of reference

The Community Development and Justice Standing Committee resolved on 13 November 2013 to inquire into the provision of funding for accommodation and

⁴ Government of Western Australia. 2004. *Carers Recognition Act*.
http://www.austlii.edu.au/au/legis/wa/consol_act/cra2004197/

⁵ Disability Services Amendment Act 2012.
http://www.austlii.edu.au/au/legis/wa/num_act/dsaa201240o2012339/

intensive family support services by the Disability Services Commission and will examine:

- 1. The adequacy of current processes for determining funding support for people with disabilities who live with their families;*
- 2. The level of unmet need; and*
- 3. The nature and extent of planning required to meet increasing demand for these support services in Western Australia in the future.*

Please find below comments addressing each of the terms.

1. The adequacy of current processes for determining funding support for people with disabilities who live with their families

Data from the Survey of Disability, Ageing and Carers⁶ indicates that approximately 75 per cent of people in a primary caring role live in the same household as the person with disability. This means that their lives, needs and levels of wellbeing are intertwined in multiple ways. Besides providing the majority of personal care needs, in some cases, the person in the caring role may be a substitute decision maker and may be the person who communicates best with the individual, taking responsibility for communicating information about options and choices in service provision and in ensuring these services are available to the individual in a coordinated way. The resilience and the wellbeing of the family members in a caring role will therefore impact on the wellbeing of the person with disability. This leads to several concerns about the adequacy of the current processes for determining funding support.

A current concern in the processes for determining funding support is the assessment of the ability of the family to sustain their caring role. The method of conveying information to individuals and their families about the likely success of an application for funding or an unsuccessful funding application has a big impact on the family's resilience and their ability to continue in the caring role.

Family members have reported that LACs tell them they are unlikely to be successful in a bid for IFS funding. In response, people state that they feel they need to 'drop the bundle' in order to demonstrate the actual level of support required for the individual, that is, they have to demonstrate 'crisis' in order to obtain the support they need. This undermines family relationships and family resilience.

The process of supporting individuals and families to make applications, impacts on the information families are able to supply as part of the application process. Carers are commonly under significant stress and are time poor. As a result many are not conscious of the extent to which they perform caring duties and often downplay their role in order to cope with the reality of their lives. They may also see some of

⁶ Australian Bureau of Statistics. 2012. Survey of Disability Ageing and Carers.
<http://www.abs.gov.au/AUSSTATS/abs@.nsf/DetailsPage/4430.0.55.0092012?OpenDocument>

the tasks that they undertake as part of their parental or familial role despite that they are undertaking caring tasks not required of most parents. This can lead to a tendency for many carers to provide insufficient evidence to obtain funding. There is a need for support to be provided to carers in the form of counselling and guidance through the application process with regard to demonstrating need.

Some people report feeling that others who are less needy are getting more than them. The lack of transparency in the decision making process regarding funding applications adds to people's sense of feeling unfairly treated. More easily available information and guidance in the application process could assist to overcome this.

Being advised of an unsuccessful funding bid represents a serious transition and decision-making point for families. For example, it is at this is a point that decisions are made about ceasing employment in order to provide care by family members in the absence of being eligible for funded services. Processes must be in place to ensure family members are supported to make contact with services providing carer counselling and support. They may require information about Centrelink payments (Carer Payment and Carer Allowance), carer advisory services, Financial Information Services, and respite options through the Commonwealth Respite and Carelink Centres.

Recommendations

Training of LACs in communication and conflict resolution skills so they can confidently manage the situation when providing guidance to individuals and families about the likelihood of their success in receiving funding.

Training of LACs and the development of clear processes in how best to provide guidance and support to individuals and families through the application process, acknowledging the diversity of families and recognising that this is a potentially stressful period.

Training of LACs regarding the services, supports and referral processes to guide and enable carers and other family members to access available services such as counselling, education and advisory services for carers.

Greater transparency about the entire application and decision making process so that families are better able to make realistic decisions about the likelihood of success.

Where a family receives a package that is not adequate to their needs, a number of issues can arise. For example, service providers may decide a package is inadequate to a family's needs and refuse service. One family reported that they applied for Intensive Family Support but were unsuccessful. They received another, much lesser funding package. In their view, their existing service provider realised that the family's needs are greater than can be met under that lesser funding and so

has refused to continue to provide services. This means the family will need to change service providers resulting in a loss of continuity of service, along with the need to establish new relationships with service providers and a further administrative burden. A change in service provider can also result in significant distress for the individual with disability which in turn causes distress for the family.

In the absence of adequate supports, families are not always able to sustain their caring role leaving them and the person they support, vulnerable to chronic disease, long term unemployment, restricted housing and education options and social isolation. Unfortunately carers experience depression and low levels of wellbeing at a rate significantly higher than the general population.^{7 8}

Recommendation

The assessment process for determining levels of funding and eligibility for funding must take into account the ability of the family to continue to provide care and be flexible enough to support the person with disability at the level they require when the family is unable to provide care, for example, when the carer needs to participate in paid employment, study or requires medical care.

2. The level of unmet need

The Survey of Disability Ageing and Carers⁹ measures levels of satisfaction and the need for further assistance experienced by people with disability and primary carers, that is, family members taking on the majority of the caring role for an individual.

In 2012, across Australia, 48 per cent of people with disability reported being satisfied with the range of organised and formal supports available. In WA, the comparable figure was 43.6 per cent.

From the perspective of family members in a caring role, 32.6 per cent of carers were satisfied with the range of formal services to help them with their caring role. Around 30 per cent of primary carers in WA reported a need for further assistance with this figure being over 40 per cent for primary carers outside of the metropolitan area. This was the highest level of unmet need recorded across Australia.

⁷ beyond blue. 2012. *beyond blue Guide for Carers*. Available at www.beyondblue.org.au

⁸ Cumins, R., J. Hughes, A. Tomy, A. Gibson, J. Woerner and L. Lai. 2007. *The Wellbeing of Australians – Carer Health and Wellbeing*. Report 17.1. Deakin University, Melbourne.

⁹ Australian Bureau of Statistics. 2012. Survey of Disability Ageing and Carers. Tables available from <http://www.abs.gov.au/AUSSTATS/abs@.nsf/DetailsPage/4430.02012?OpenDocument>

Hidden need

Three issues arose in the responses we received from families which contribute to the likelihood that the number of unsuccessful applications is not an accurate measure of unmet need.

Firstly, some families are reluctant to use formal services as they are not confident that formal service providers will deliver the type of engagement they believe is appropriate to meet the needs of the person with disability.

Specific reasons for not using formal services include a lack of confidence that service providers will adhere to values that are consistent with those of the family. For example, values relating to particular cultural practices; judgements about allowing sexual activity by younger teenagers; and, the need for same sex care workers to provide intimate personal care. The changing of sanitary pads and showering of young women with physical and intellectual disability by male support workers is not acceptable to some individuals and family members and yet occurs in disability accommodation settings.

Individuals and families with concerns about the appropriateness of formal services are less likely to apply and hence will not be captured in measures of unmet need.

Secondly, families report that their LAC advised them that they were unlikely to be successful in their application. It is quite possible that this discourages people from applying. This needs to be taken into account in deciding whether the number of unsuccessful applications is a reliable measure of unmet need or whether there are much larger numbers of families in need who have not applied for various reasons.

Thirdly, the fear of making a complaint was mentioned by some families who expressed concern about maintaining positive relationships with DSC staff on whom they feel reliant for continued funding and access to information. This fear could also disguise unmet need.

3. The nature and extent of planning required to meet increasing demand for these support services in Western Australia in the future

We respond to this question in two ways as there is a need for improvement in planning to be implemented at the systemic level and at the individual level.

At the systemic level, planning for future needs should take into account the ageing of Australia's carers, the increased labour force participation of women, and the fact that carers themselves experience high rates of disability. In Western Australia, approximately 40 per cent of primary carers experience disability.¹⁰ To properly

¹⁰ ABS 2012. Survey of Disability Ageing and Carers.

plan for the care needs of people with disability requires a population wide assessment of the availability of family carers to provide care within the family. It is likely that some of the care currently provided by family members will need to be replaced or supplemented with formal service provision.

The planning process for an individual with support needs should identify the needs of family members who are formal and informal substitute decision makers either as Guardians (Guardianship and Administration Act), carers (Carers Recognition Act 2004) and/or nominees (National Disability Insurance Scheme) of a person with decision making disability. The capacity of family members to help plan and manage funding and service coordination will have a big impact on the wellbeing of the person with disability. Family members would value education and training so they can carry out these roles in the way that best meets the needs of the person with disability but which also helps the family to balance other needs.

Specifically, families should be eligible to receive training in the management of funds, employing staff, taxation arrangements, service planning and coordination, and supported decision making so they feel more confident that decisions made reflect the wishes of the person with disability.

Thus far, information from the NDIS launch sites indicates that the time taken to develop plans that truly reflect the needs of an individual and their family is likely to be longer than previously allowed for in funding models. This reality needs to be factored into future planning at a system wide level as well as at the individual level.

Sustaining the levels of care provided by family members

Family members continue to provide the majority of care received by people with disability who have long term care needs. The provision of this care underpins our existing disability support system. It is logical and necessary that disability support providers be able to refer the family members in a caring role to carer supports and services that assist in sustaining the caring role.

Service providers working with individuals who have a family member acting as a substitute decision maker and who wish to move towards supported decision making need to have access to relevant training to ensure that the needs of the person with disability and the family carer are addressed. In the absence of such training, the potential exists for self-direction to lead to increased family tensions.

Recommendations

Demographic data regarding family carers should be included in assessing the future need of service provision.

Planning processes for a person with disability should identify and address the needs of family members in a caring role in order to support the changing needs of the person with disability and the changing needs of the family members.

To support greater self-direction for people with disability, service providers must be able to access training in supported decision making techniques that contribute to the sustainability of family relationships.

4. Comments on the process of participating in this inquiry

a. The timing of the inquiry, being over the Christmas/New Year break, has potentially limited the ability of families to participate. Carers WA appreciates the extension of the due date for providing a written submission as this provided us with more opportunity to consult with families and disability service providers. Carers WA would suggest that in order to support greater participation by family members in a caring role, informal hearings within and outside of the metropolitan area could be conducted in February and/or March. Carers WA has also participated in the development of a survey to assist individuals and family members to provide feedback to this inquiry. We request an opportunity to present the survey findings at a later date.

b. Some families who contacted Carers WA with information requested confidentiality which we have guaranteed. It was reported to us by some family members that, on contacting the Committee, this was not allowed as an option when providing a submission directly to the Inquiry. This may have reduced the amount of feedback provided directly to the inquiry.

c. In order to ensure the participation of people with intellectual disability in this inquiry, plain language documents and other engagement supports should be available. Informal hearings would be a useful opportunity to engage more people with intellectual disability to participate in the inquiry.