Disability Care and Support

CARERS WA
SUBMISSION

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1. About Carers WA

Carers WA is the recognised peak body for carers in Western Australia. Since 1996 Carers WA has provided systemic advocacy and grassroots support to the more than 307 000 family members and friends in WA who provide the overwhelming majority of care and support to those who need assistance to live in the community.

2. Carers in Western Australia

A family carer is someone who provides care and support to a parent, partner, child, relative or friend who has a disability, is frail aged or who has a mental or chronic illness. Carers cut across all aspects of West Australian society: from ages 5 to 95 years of age, they can be from any ethnic group; they live in both urban and rural communities within the state; they care for people who live with the whole spectrum of illness, disability or age-related frailty; they comprise almost 307 000 West Australians. They are your neighbours, friends and relatives, they are unpaid and many are struggling.

Western Australia was the first State in Australia – and only the second Government in the world – to legislate an Act recognising carers. The WA Carers Recognition Act 2004 has been a significant and positive step forward in the recognition of the important role that carers play in our society.

3. Introduction

Carers WA agrees that there are multiple systemic weaknesses in the current systems providing services to people with disabilities. These shortcomings have placed unnecessary pressures on people with disabilities and their family carers. A review of existing arrangements is therefore welcomed and Carers WA appreciates this opportunity to have a submission considered by the Productivity Commission.

Carers WA argues that the overarching goals of a disability care and support scheme should be consistent with Australia's commitment to the United Nations Convention on the Rights of Persons with Disabilities and with the Australian Government's Social Inclusion Agenda. Therefore, the proposed National Disability Insurance Scheme should be inclusive of all people with needs associated with disability, regardless of age, how the disability was acquired, or its severity. The scheme should be holistic, well coordinated, flexible and family centred to reduce the administrative burdens and the gaps in service provision that currently characterise access to disability support and services.

One of the strongest themes emerging from the National Disability Strategy consultations was the desire to end the segregation experienced by people with disabilities and their families. 'Many called for an end to segregated services and options for people with disabilities, and their families, friends and carers, which people believed only reinforced and exacerbated prevailing attitudes' (NPWDCC 2009:4). The experiences of people with disability and their carers provide a strong case for an approach to the coordination and delivery of services to people with disability built around a 'whole of life focus'. Similarly, the Australian Government's *Social Inclusion Agenda* referred to the need to build 'joined up services and whole of government solutions'.

Unpaid family carers currently provide the overwhelming majority of care to people with disability in Australia. This means that most of the care delivered to people with disabilities is unfunded and only a limited proportion of care is funded in the form of paid support staff and services. The long term economic sustainability of a disability care and support scheme is intrinsically linked to the ongoing contribution of family carers. Unsupported carers are less likely to be able to maintain their contribution and may ultimately require high cost health care themselves. Initiatives to more adequately support carers are required. The assessment of need must be holistic and include the family and carer's circumstances and capacity to care over the long term. If assessments purely focus on the disability of the care recipient then the scheme will fail if the unpaid support is not sustained. A person with a more severe disability may actually be better placed than one with a lesser disability if more sustainable family and friend supports are in place.

Support for family carers must therefore be a central platform of the proposed scheme. This will require the implementation of nationally consistent legislation that places a legal obligation on government agencies and service providers to recognise family carers. It requires the implementation of income and other supports that fully acknowledge the loss of earnings and other opportunity costs associated with undertaking the caring role. Recommendations to address these and other issues associated with maintaining and supporting family carers were outlined in *Who Cares* (HRSCFCHY 2009: xxi-xxx).

4. Responses to selected questions

Question 1. Who should be the key focus of a new scheme and how they may be practically and reliably identified?

In July 2010, the Australian Human Rights Commission made the following observation:

> People with disability and their families do not enjoy all human rights in Australia. There are particular concerns regarding adequacy of care for people with mental ill-health, availability of supported accommodation for adults with disabilities, and support for disability carers. The Commission commends the development of a National Disability Strategy that aims to address obligations under the

> Convention on the Rights of Persons with Disabilities. **The Commission recommends that the National Disability Strategy be integrated with the National Action Plan on Human Rights, including with benchmarks, timelines and monitoring processes (Australian Human Rights Commission 2010:6).**

Data from the Survey of Disability, Ageing and Caring (SDAC, ABS 2004, Table 16) demonstrates the extent to which people with disability do not participate in social, educational and community activities. As has emerged recently in Victoria, which has a Charter of Human Rights, people with disability have successfully pursued claims for increased levels of assistance based on their right to participate fully in society (Szoke 2010). This move towards a rights based approach has the potential to impact on the eligibility criteria and the level and nature of services that will need to be available under a national disability care and support scheme.

Recommendations

- The overarching goal of the proposed national disability care and support scheme should be consistent with Australia's obligations towards the United Nations Convention on the Rights of Persons with Disabilities.
- The proposed national disability care and support scheme should be consistent with the goals of the Australian Government's Social Inclusion Agenda.

It is vital that those who are identified as severely or profoundly disabled receive the services and support required. However, in Western Australia, if eligibility for the National Disability Insurance Scheme was restricted to those with profound or severe limitations aged under 65, this would exclude 333 900 out of 405 500 people who reported having a disability in 2003 (ABS 2004, Table 1). That is, approximately 82 per cent of people with disability would not be within scope of the NDIS either because of age or because their level of disability is not considered severe enough. These people and their carers would need to seek assistance through alternative arrangements. This suggests that additional schemes will be required to meet the needs of people with disability assessed as less than profound or severe. This raises the spectre of administrative duplication, multiple assessments and the possibility of people falling through the cracks of eligibility which is essentially a continuation of the current unsatisfactory arrangements.

Recommendations

- The basis of eligibility should be need, regardless of how and when the disability was acquired, nor how significant, profound or otherwise.
- Needs should be identified using a family centred assessment process.

Given the multiple systemic problems identified in *Shut Out* (NPWDCC 2009) and *Who Cares* (HRSCFCHY 2009), a strong social justice and economic argument can be made for a holistic, coordinated, flexible and family centred scheme that provides for the needs of all people with disability and their carers. The complex interactions between the needs of people with disabilities, older Australians and unpaid family carers strongly reinforce the need for a straightforward set of arrangements that do not impose extra costs and administrative burdens simply because the care recipient ages.

For example, consider the additional pressures placed on a family carer trying to organise services for a person over 65 who is otherwise part of the aged care system but who acquires a disability that is not age related and so must seek services within the disability system. Conversely, certain groups of younger people with disability are likely to acquire 'age-related' conditions, such as dementia, before reaching 65. Family carers may again be forced to source services from two different systems.

If it is deemed necessary that separate schemes based on age must exist, at the least there should be a seamless transition from one scheme to another particularly given that the population of people with disabilities is ageing as are their carers. To provide relatively fewer support services for people with age related disability would be discrimination on the basis of age and would be contrary to Australia's Social Inclusion Agenda.

Recommendations

- Research should be conducted into the viability of a disability care and support scheme that does not segregate people with disability on the basis of their age or whether the disability is age related.
- In the interim, the goal should be to create a seamless transition between schemes as the person with disability ages.

Those who experience disability and mental illness currently must seek services from both systems and often fail to satisfy the eligibility criteria for either, thus falling through the gaps and often then accessing emergency intervention, as it is the only option available. This is a false economy.

Recommendations

- Research should be conducted into the viability of a disability care and support scheme that does not segregate people with disability on the basis of whether the disability is a physical or mental health condition.
- In the interim, the goal should be to implement mechanisms for coordination of supports across each scheme.

Question 2. Which groups are most in need of additional support and help?

As stated above, any person with disability identified as having needs should be supported. The focus should be on the individual, their family and circumstances including the level of sustainable support available through family and friends rather than assuming homogeneity of needs across groups. Specific areas of disadvantage were identified in *Shut Out* (NPDCC 2009:56-60).

In Western Australia, the level of funding provided to the Disability Services Commission has imposed rationing on the delivery of services. Only people considered 'worst off' are able to access funding. Many people who require services therefore do not receive them when required. This is a false saving as it may later result in the need for higher cost crisis care. As a result, it is often people with less severe levels of disability who are not having their needs met. The impact of this extends to their caring family members.

As outlined in *Who Cares...?* (HRSCFCHY 2009), the needs of carers have not been well met by the existing arrangements surrounding access to services for people with disability.

Recommendation

- This inquiry should acknowledge the outstanding recommendations from *Who Cares...?* (HRSCFCHY 2009: xxi-xxx).

Question 3. Kinds of services that particularly need to be increased or created?

Specific areas of disadvantage experienced by people with disability were identified in *Shut Out* (NPDCC 2009:56-60).

For carers to best support the care recipient, the carer's role must be acknowledged by relevant staff across multiple government agencies. This need is reflected in the Carers Recognition Act 2004 in Western Australia, in similar legislation in other states and in the national Carer Recognition Bill 2010. The implications for the care recipient of the carer not being adequately recognised have been explained in detail in *Who Cares…?* (HRSCFCHY 2009).

Recommendations

- Funding for the design and delivery of educational programs to health and disability sector to improve their recognition of carers.
- Extending the WA Carers Recognition Act 2004 to cover a wider range of government agencies, for example, education, housing, transport and employment, is required. To ensure a new scheme is viable and sustainable all key agencies within a State/Territory should be legally required to comply with the principles of carers legislation
- Where the Commonwealth has jurisdiction, national carer recognition legislation will be required.

For carers, further services are particularly required at transitional stages in the caring role. For example, in the immediate aftermath of an incident leading to an acquired brain injury, or after the initial diagnosis of a condition, carers are often in urgent need of practical and psychological support. Where a child turns 16, or an adult turns 65, carers must become familiar with a new set of administrative requirements in order to meet the needs of the care recipient. Information and support is required to ensure continuity of services for the person with disability, and to address the higher rates of depression and other mental illness experienced by carers. Research by Edwards et al (2008:68) highlights the particular vulnerability of carers in their first year of caring. Conversely, the death of the care recipient, who is often the spouse or child of the carer, generates complex emotional and psychological needs. Access Economics concluded that 'increased expenditure on carer support programs such as respite care, counselling and carer training to improve the carer's capacity to fulfil their caring role...can produce a net benefit' (Access Economics 2005:40).

Recommendations

- Develop a framework for the assessment of carer needs.
- Identify the needs of carers from the commencement of caring and particularly during transitions in care.
- Fund the design and delivery of practical and psychological support to carers during transitional periods.

A frequent issue for carers is the need for assistance with transport for the care recipient. Ageing carers, and carers with disabilities, may be unable to physically cope with this task on behalf of their partner or child and may not own a vehicle suited to transporting the care recipient. In some states, the costs of taxis are only partially subsidised. In Western Australia, there are approximately 82 fully accessible taxis available. Lacking transport options restricts the ability of the carer and the care recipient to fully participate in the community. This issue is exacerbated for young carers and those living in regional and remote areas where transport options are more limited and costs much higher.

Recommendations

- Provision for transport for the carer/s and care recipient to be funded as part of the proposed National Disability Scheme.
- Transport needs should be determined and allowed for on a rights-based and family-centred basis.
- Extra allowances should be provided to cover the higher transport and accommodation costs experienced by those who must travel from regional, rural and remote areas to access services.

A shortage of appropriate respite continues to create difficulties for both carer and care recipients. If a carer or the recipient is concerned about the quality of the respite, or if the distance away from home is too great, they are less likely to make use of it even though there may be a strong need.
Recommendations

- Ensure respite staff possess skills appropriate to the needs of the care recipient which may include, for example, the ability to provide health related services such as injections.
- Respite services should be located throughout the community.

Young carers (aged under 26) face multiple challenges in their caring role as they attempt to participate in education, training or employment while caring for parents and/or siblings.

Recommendations

- Amend the 25 hour activity rule for young carers who would otherwise be eligible for carer payment.
- Increase funding to the Young Carers Respite and Information, Advice and Referral Services.

Ageing carers caring for adult children with disability face a particular set of challenges that require a coordinated approach to avoid the physical break-up of the family should one or both parents need to enter residential aged care. Older carers would also like more certainty and support in planning for the needs of their adult child with disability. As the adult with intellectual disability ages and retires from their employment, their parents, who are themselves ageing, are faced with a lack of alternative activities for their adult child.

Recommendations

- Funded education and awareness program to promote advance planning or 'futures planning' for carers (ASLARC 2010, 2008; FAHCSIA 2009).
- Investigate models for family-centred accommodation to support the continuity of families with mixed care needs (ageing, mental health and disability).
- Provide age appropriate and locally based social and other activities for older adults with disability who have retired.

Carers with disabilities are often misunderstood in their dealings with service providers who fail to acknowledge that a person with disability can just as easily be a parent, partner or carer.

Recommendations

- Adopt a family centred assessment to identifying needs which includes assessing the needs of the carer/s.

Question 4. Ways of achieving early intervention

The knowledge of carers is crucial in alerting health professionals to the needs of the care recipient. Carers are an invaluable but often ignored source of information. Carers should be viewed as partners in care by health professionals. Failure to include or involve carers can be a duty of care issue, particularly with regard to discharge planning, changes in treatment and therapy or any other service that impacts on the carer or their caring role.

Recommendations

- Implement nationally consistent carer recognition legislation.
- Fund the design and delivery of training for carers to enhance their ability to identify and accurately report in changes in the wellbeing of the care recipient – effectively being recognised as a key care team member.
- Investigate the inclusion of a facility for identifying carers in State and Federal e-health identifiers.

Question 5. How could a new scheme encourage the full participation by people with disability and their carers in the community and work?

People with disability and their families have provided highly relevant information in *Shut Out* (NPWDCC 2009) which will be invaluable to this current inquiry. A family-centred, rights-based assessment process, consistent with Australia's commitments under the United Nations Convention on the Rights of Persons with Disabilities is most likely to identify the services and supports each person and family requires to achieve their fullest possible participation in society.

The costs of caring for people with disability go beyond the funding of services and include the productivity losses experienced by carers and the community if the carer has given up work, has lost skills and is unable to return to the workforce to accrue earnings and superannuation. Investing in the skills of carers will not only assist them to provide better care for care recipients, but will also assist in the carer's return to the paid workforce. Edwards et al (2009:08) identified that 'a large number of non-employed carers of working age expressed a desire to be in paid employment'.

Many carers are prevented from continuing or pursuing paid employment, study and other training opportunities due to their caring role. The provision of suitable respite as well as a range of other activities suited to the needs of the person with disability would make more time available to the carer to pursue their own goals. Additionally, as outlined in *Who Cares…?* (HRSCFCHY 2009), carers should be supported in their caring role in ways that allow them to continue to participate in social, educational and employment related activities.

Recommendations

- Introduce a fully funded awareness campaign targeted at employers so that they gain an understanding of carers' issues and introduce benefits such as flexible working conditions for employees in a caring role.
- Ensure that respite services are flexible and appropriate to the needs of the care recipient and the working carer.
- Amend the Fair Work Act to allow for flexible working conditions for all caring situations.
- Fund and deliver training to assist long term carers back into paid employment.
- Provide educational opportunities for young adults with developmental disabilities who have completed high school but who have been assessed as able to benefit from continuing education.
- Review the 25 hour activity rule within FaHCSIA for payments and pensions, particularly with regard to looking at exclusion of travel given that many people rely on public transport, or live far from their place of work.

As mentioned above at Question 3, young carers are at risk of underachieving in education and the workplace (Social Policy Research Centre 2009). Young carers require additional support to remain in their caring role while also participating in education and other activities associated with preparing for the workforce.

Recommendations

- Amend the 25 hour activity rule for young carers who would otherwise be eligible for carer payment.
- Increase funding to the Young Carers Respite and Information, Referral and Advice Services.

Question 6. How to give people with disabilities and/or their carers more power to make their own decisions?

As was clearly voiced in *Shut Out* (NPWDCC 2009), many people with disability and their carers would like to take a greater role in managing their care arrangements. However, given the diversity of caring situations, it is vital that people with disability and their carers be offered a choice of care management models.

Recommendations

- A choice in the model of care management should be available to the person with disability and/or their carer, depending on their individual circumstances.
- Flexibility should be built into the arrangements to allow the person to opt in and out of self directed control if necessary.

For those who choose to take on a greater role in managing their care, research from the United Kingdom (Leadbetter et al 2008:62) has highlighted the importance of providing support and training to organisational staff, family carers and the care recipient given the cultural shift and other complexities that can be involved in self managing care arrangements. While administrative monitoring must be put in place to ensure that funds are spent to the benefit of the person with disability, it is also important that carers be protected in this decision making role. This may require legislation at the state or national level. Similarly, what a service provider or funder believes may not be an appropriate service or support may be exactly what the family requires. This requires a big shift away from the paternalistic 'we know best' ideology to a more flexible and open-minded approach.

Recommendations

- Organisational staff should be provided with support and training as part of the shift towards self managed funding.
- People with disabilities, their families and carers need to be able to access appropriate training and guidelines in how to self-manage.
- The legal position of carers who take an active role in self managed funding should be clarified and protected.
- The legal position of young carers who are minors and take an active role in self managed funding should be clarified and protected.
- Services that support the carer in their own right need to be made available for purchase under this model also.

In the UK, Corden et al (2010:2) identified a number of benefits accruing from the provision of an extra living allowance to people with disability and family carers. The person in receipt of the allowance was able to spend the funds at their own discretion which resulted in a greater sense of control being experienced.

Recommendation

- Based on the UK experience, explore the social and economic benefits of providing an extra living allowance to people with disability.

Question 7. How to improve service delivery – including coordination, costs, timeliness and innovation?

In many families there are mixed needs (ageing, disability and health, including mental health). Currently, people with disability and their carers have to search for services across departments, agencies, service providers and jurisdictions covering every level of government and requiring multiple eligibility rules and assessment processes.

In Western Australia, the Economic Audit Committee overseeing a major structural review of the delivery of services by the public sector has responded by presenting a 'hub' model (Government of Western Australia 2009). This may provide a useful coordinated and holistic framework for delivering services in a coordinated fashion but further research will be required to understand how this model will impact fully.

Recommendations

- From a carers' perspective, fund research into the factors that have contributed to successful hub service delivery models.
- Research into the hub delivery model must recognise that there is the potential for hubs to work differently depending on geographical location, such as city versus urban areas, and within different cultural communities.

Innovation suggests thinking outside of the box, and taking a preventative approach and yet many funding 'guidelines' and services remain rigid and exclusionary for many. It appears sometimes that there is a thought at a bureaucratic level that citizens will take more than they ought, at risk of 'throwing the baby out with the bath water'. For example, a single mother with an 11 year old son with autism didn't necessarily want her son to go into respite due to his challenging behaviours, but did ask for a Playstation for him. The Playstation would be utilised every day for an hour or so. This would provide the mother with some time to spend with her other child, do housework etc, whilst her son was entertained and happy. At a cost of $300, compared to potentially $1000's in respite care costs, the initial request was declined as it was not within the 'guidelines'. Much distress, time and advocacy later and the request was finally agreed upon.

Whilst the above outcome was a positive one, the process that it required was onerous and exhausting for the carer, who only wanted what would work for her son. The request was simple, cost effective and of benefit to everyone involved.

Recommendation

- Incorporate a preventative approach into funding models.
- Consider relaxation of funding purchasing guidelines in order for increased innovation and needs-based services and supports being purchased.

Question 8. Factors that affect how much support people get and who decides this

A family centred approach is more likely to identify the full range of supports required to support the care recipient and their family carer/s. The level of support people receive should be linked to the goals of the Social Inclusion Agenda and Australia's commitments to the UN Convention on the Rights of Persons with Disabilities.

Carers WA has heard on numerous occasions from families who just want to have the ability to access support that is tailored to their own needs and keeps them together as a family. As an example, The 'Smith' family have a 23 year old son – 'Carl' - who has complex care needs, along with 2 younger daughters aged 13 and 15. The family has never holidayed together due to the amount of care that Carl requires. Mr and Mrs Smith also want to provide as much care as they can themselves, rather than relying on 'the system', however, they are exhausted and would like a break. An opportunity has arisen for the family to go away, however they have been advised by the provider they use that it is less expensive to put Carl into a respite bed for the time than to provide a care worker. The family decide not to go away despite there being a strong need for the family to holiday together as any family might.

The above scenario illustrates a false economy in that the family rarely ask for anything – preferring to support their situation as best as they can. A family holiday where all can be involved for once, without having to provide additional care, will provide time out that can't be measured in $$$, is family-centred and enables the family to continue to live as a family.

Question 9. How to ensure that any good aspects of current approaches are preserved

Accessible and inclusive consultative processes with stakeholders, including people with disability and their carers, should take place at each stage of the redesign process to ensure the retention of existing features within the system that are useful.

Question 10. Rural and Remote Areas – harder to get services

The extra challenges facing people with disability and their carers in rural and remote regions have been well documented in *The Tyranny of Distance?* (Commonwealth Financial Planning 2009) and are relevant to the inquiry. It was found that carers were affected by

- An absence of services
- Too few services
- The extra time required to travel to services
- The cost of services and the costs of accessing services

These factors impacted particularly on Indigenous families who are more likely to live in remote areas and are more likely to experience disability and are more likely be in a caring role (ABS 2006:21).

Recommendations

- That an assessment of the costs to households of caring be undertaken, acknowledging the extra costs imposed by geographical distance from services.

- The services for carers and people with disability in Aboriginal communities should be examined to determine their cultural suitability.
- Investment in communication technologies to allow people to access specialist services via video conferencing.

Question 11. Reducing unfairness, so that people with similar levels of need get similar support?

Relevant suggestions to address this are included in *Shut Out* (NPWDCC 2009) and *Who Cares...?* (HRSCFCHY 2009). An holistic assessment approach that values the input of the person with disability and carers is most likely to accurately assess needs and identify appropriate services.

Question 12. Getting rid of wasteful paper burdens, overlapping assessments (the 'run around') and reduction of duplication in the system

People with disability and carers have stated the need for a more streamlined, coordinated means of assessment of need and in accessing services (NPWDCC 2009).

Duplication of assessments can occur where agencies do not share information efficiently and require people with disability and their carers to complete slightly different forms. Similarly, there can be a lack of faith between organisations that assessment has been carried out to their standards. Duplication can also occur where the person with disability and carers are required to complete the same form on a recurring basis to maintain eligibility. Where a disability is likely to be lifelong, this is wasteful and stressful.

Portability of funding also needs to be taken into consideration. Currently there is a lack of consistency across Australia as to what people are eligible for. If a person with a disability moves from one jurisdiction to another, their disability does not change, however, their eligibility for services may!

Recommendations

- Coordination between agencies should take place to put information sharing arrangements in place.
- Recognition of lifelong conditions should be made at an early stage and information management plans put in place that reflect this lifelong status.
- The e-health indicators should include provision for recognising the family carer.
- Portability of funding and services needs to be incorporated into planning long-term care and support.

Carers WA has worked with relevant health and disability services staff to raise awareness of the Carers Recognition Act 2004 and the Carers Charter. If the creation of a national scheme changes jurisdictions, it is vital that the new legislation adopts consistent definitions and supports existing legislation so as not to negate the educative gains already achieved.

Recommendation

- National consistency in definitions and legislation is required to ensure the recognition of carers across all agencies and jurisdications.

Question 13. How to finance a new scheme so that there is enough money to deliver the services that are needed and provide greater certainty about adequate care in the future

While the funding of the system must be adequate to address the needs of people with disability and to support their carers, these costs can be reduced through better planning and coordination and preventative spending to support unpaid family carers.

The care provided by family carers is delivered at a much lower cost to the tax payer than other care services (Access Economics 2005:29). To replace the care provided by informal carers with other forms of care, such as paid community care or residential care, would vastly increase the costs of providing care to people with disability. Unsupported carers may burn out, they may have to withdraw their caring role and may themselves require health services (Glendinning et al 2009:133). The socio-economic arguments for supporting the health and wellbeing of carers are consistent with those underpinning the Australian Government's preventative health measures (Commonwealth of Australia 2010:21).

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