



**Disability Care and Support
Response to the Productivity Commission
Draft Report**

**CARERS WA
SUBMISSION**

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1. Introduction

Carers WA has contributed to and supports the responses to this inquiry submitted by Carers Australia. These additional comments are offered to capture the situation facing carers and the people they care for in Western Australia. Carers WA seeks to strengthen the focus of the reforms to better reflect the needs and situations of family and friends who contribute to the care of people with a disability.

The impact on carers of the draft recommendations into disability care must be considered in the context of concurrent and significant reforms to mental health, disability and health care. Carers WA seeks to ensure that the recommendations will result in a straightforward pathway for carers to be identified, assessed and be eligible for services, independently of the person with disability. This is a clear intention of the federal government's draft National Carer Strategy. A holistic approach is required to provide support to carers whose caring roles overlap ageing, disability, health and mental health and whose individual needs as a person must also be acknowledged and provided for.

Carers WA remains concerned that the resources required to introduce and sustain the wide range of reforms in the disability sector, concurrent with other sectors, risks a deflection of financial and human resources (within government, the NGO sector and commercial service providers) away from front line services to carers and toward the processes required to implement reform. The changes therefore need to be sufficiently resourced, piloted and tested before wholesale change is introduced. Carers WA therefore welcomes the recommendation that changes be introduced on a trial or pilot basis. However, given that the impact on carers crosses all sectors, those trials need to be evaluated in a holistic manner, focusing on outcomes on carers as well as consumers. Without a holistic focus, there is a real danger that established and successful services, such as those provided by Carer Associations, are swept away or at best de-stabilised if the changes are driven by short term budgetary concerns alone.

The expectation and fear of adverse change can increase the turnover of staff in sectors which are already struggling to recruit and retain people with experience and skills. As the Commissioners would be aware, employees within the not for profit sector work at lower rates of pay and conditions than their commercial counterparts but are driven by the social motive. However, the fear of job security can in many cases, provide the final push to leave the sector. Structural change, therefore, has to be introduced over a manageable time period. If this is not done then all the workforce issues identified by the Productivity Commission will be exacerbated.

Finally, the *Carer Recognition Act 2010* requires public service care agencies to adopt policies and practices that are consistent with The Statement for Australia's Carers. Recommendations from the Productivity Commission that impact on public service care agencies therefore need to be consistent with this requirement or the recommendations will not be able to be adopted by public sector care agencies or their associated providers. In Western Australia, recommendations from this inquiry

should also work to support the advances made since the introduction of the *Carers Recognition Act 2004* rather than work against them.

2. Defining the term 'carer' – why consistent use of the term matters

The term carer is defined in both Western Australian (*Carers Recognition Act 2004*) and Commonwealth legislation (*Carer Recognition Act 2010*). A carer is a person who provides care on an unpaid basis to a family member or friend with a disability, a medical condition, chronic illness, mental illness or age related frailty. Paid and volunteer support staff are explicitly excluded from this definition for good reason.

Carers WA argues that the consistent and exclusive use of the term carer to refer to family and friend carers is an essential element in carer identification and carer self identification. When family and friends do not identify as a carer, they do not access the carer services and supports they need to sustain them in the caring role. When service providers do not recognise family and friends as carers, they fail to inform carers of their eligibility for services and fail to meet their own obligations under state and Commonwealth legislation.

Carers WA therefore encourages all agencies, including the Productivity Commission, to define and use the term 'carer' in a manner consistent with the legislation and exclusively in reference to family and friend carers. This is an important contribution to the effort to increase carer identification/self identification, to increase the rates of referral to carer services, to sustain carers, and to assist service providers in meeting their compliance obligations.

3. The diversity and contribution of carers in WA

Based on research by Edwards et al (2009):

- There are an estimated 310,000 carers in Western Australia – 1 in 8 Western Australians;
- Almost 50,000 carers live in outer regional, remote and very remote areas of WA;
- Almost 45 per cent of carers in very remote areas are Indigenous.

According to the Australian Bureau of Statistics (2006):

- over 73 per cent of primary carers are women;
- More than 20,000 carers in Western Australia are under 18 years of age;
- More than 40,000 carers in Western Australia are over 65 years of age.

Based on analysis of research conducted by Access Economics (2010), Carers WA estimates that the cost of replacing the care provided by family and friends in Western Australia would be an annual figure of \$4.1billion.

4. Pathways to carer services for carers of a person with disability in WA

Carers WA would like to draw attention to the following points because of their importance to carers of people with disability.

The Disability Services Commission is required to comply with the Carers Recognition Act 2004 and the Carers Charter. This means the Commission must consider the needs of carers when designing and implementing policies and services and provides an annual report to the Carers Advisory Council on its compliance with the Act. Further, under the Carers Recognition Act 2004, carers are able to make complaints about disability service providers funded by the Disability Services Commission. The complaints can be lodged by a carer either on behalf of the person with disability, or as a carer regarding the treatment of the carer.

When a person with disability applies for services from the Disability Services Commission, the application process identifies whether the person has a carer and identifies restrictions the carer may have in carrying out the caring role. If the assessment indicates that the carer requires assistance in the caring role, this should trigger increased supports to the person with disability. The Disability Services Commission also provides case management to eligible people with disability through Local Area Coordinators (LAC). Carers have reported to Carers WA that effective LACs are an immensely valuable support mechanism, helping them to identify and access services for the person they care for. In rare cases, such as where there are strong cultural and geographic reasons to do so, family members can be paid for a limited time to provide services that would usually be delivered by a disability service provider.

The *Commonwealth Respite and Carelink Centres (CRCCs)* deliver the National Respite for Carers Program and coordinate access to Home and Community Care (HACC) services. If a carer contacts a CRCC, they will be assessed and advised over the phone and referred to appropriate providers, including Carers WA, using an information sharing protocol. This means the carer does not need to repeat basic information to each service provider. Staff at the CRCC will assess the carers' eligibility for emergency and short term respite services under the National Respite for Carers Program. The carer will also be referred to Carers WA. This occurs regardless of whether the person with disability is eligible for or assessed for services.¹

¹ Of course, if the care recipient, for whatever reason, does not accept the respite arrangements, then the carer will be unlikely to utilise this service.

5. The pathway to Carers WA services for carers of a person with disability

Carers can make direct contact with Carers WA to receive services. Many carers make first contact through the Carer Advisory Service and the National Carers Counselling Program currently provided through Carers WA. (The National Respite for Carers Program funds the face to face Carer Counselling and the Carer Advisory Service).

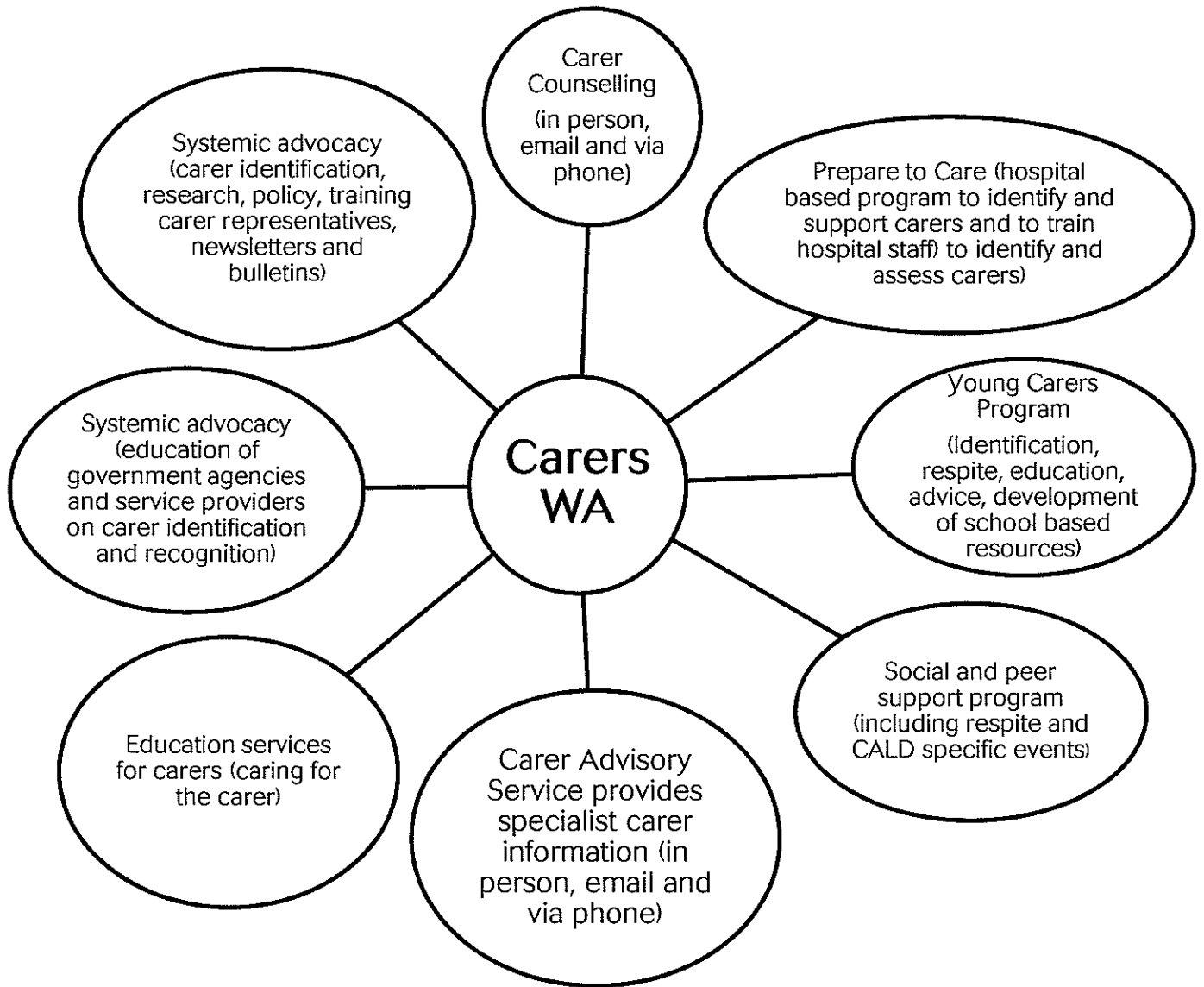
The Carer Advisory Service provided by Carers WA provides a 'one stop shop' service for carers who would otherwise have to seek information from numerous agencies. For example, in one phone call, a carer may seek information about advance health planning, Enduring Power of Guardianship, Enduring Power of Attorney, funding for incontinence products, access to disabled parking, public transport and concessional rebates for power and water bills. Carers WA can facilitate access to a broad range of information to support the carer in their information gathering and decision making role. Carers WA can then refer the carer to appropriate agencies to either seek further information or access services.

Importantly, Carers WA can provide this information, and other services, to a carer, regardless of whether the person with disability is eligible for and receiving services.

Carers WA also provides planned respite, awareness raising and peer support services for young carers of people with a disability through funding provided by the Disability Services Commission in WA. Carers can access these services directly through Carers WA. They do not require assessment by the Disability Services Commission. The Disability Services Commission in WA has also funded Carers WA to prepare training resources for the management and staff of disability sector providers that will assist them to meet their obligations under the Carers Recognition Act 2004.

The diagram below outlines the activities undertaken and services offered by Carers WA. Currently, the CRCCs and Carers WA through its Carer Advisory Service, play an important role in supporting carers to coordinate their access to supports. Carers are also identified by and referred to Carers WA by other service providers.

Figure 1. Services currently offered by Carers WA



What existing carer services provided by Carers WA would survive without block funding?

The services offered by Carers WA are currently block funded and so are able to be provided to carers for free or at a nominal charge. With the introduction of self directed budgets, which is a strong recommendation in the Disability Care and Support inquiry, block funding for many services may cease.

This puts at risk the following services and activities offered by Carers WA:

- Carer advisory service
- Carer representation program which trains carers to be representatives on committees
- Systemic advocacy, research and policy work
- Carer education program
- Social and peer support program
- Young carers program
- Prepare to Care Program (hospital based program to train staff to identify carers).

One of the biggest concerns about the loss of these services is the impact on carer identification and recognition which is the main goal of our systemic advocacy.

Carers need an independent pathway to access services

Carers WA argues strongly that the pathway to access carer services should be clear to the carer, and the carer's eligibility should be independent of that of the care recipient. This is necessary in order to prevent instances of the carer being ineligible for services where the care recipient chooses not to be assessed or access services or is ineligible for services. There will also be occasions where the carer needs to access services confidentially from the care recipient.

If access to carer services is obscured, by for example, creating gateways that focus only on the needs and eligibility of the care recipient, the likelihood of the carer being identified and referred to services will be minimised even further than it is currently.

As an example, many people with disability will not be eligible for funded services provided by the proposed NDIS and will continue to rely on their family for care. If the family carer is then not eligible for services, this will compound the situation facing the carer who will have a heavier caring load and yet not be eligible for carer supports.

If the care recipient chooses not to access services or does not qualify due to strict assessment criteria, the contribution of the family carer becomes more hidden. If a person with disability is not in receipt of service supports then it is highly unlikely that service providers who are focused on the person with disability will provide supports

for the family carers. Therefore the needs of the carer must be recognised in their own right and clearly identified as separate from those of the care recipient. Without such supports many family carers will lose resilience and inevitably the impact will flow on to the care recipient. This can then result in engagement with or increased demand on health and other services. At this point the needs of the carer may be recognised (once the care recipient engages with services) but it may be too late and the resultant impact and demand on services will be much greater than if carer supports were provided earlier.

To prevent a crisis driven model, carers should have direct access to the proposed Carer Support Centres. Where carers do make first contact with the NDIS, staff must be aware of the need to separately assess the needs of the carer, and be aware of the separate eligibility of carers to access their own services, independently of the person with disability. Information sharing protocols between the NDIS, the Seniors Gateway and the Carer Support Centres will facilitate the streamlining of access to carer services.

Under the Carer Recognition Act 2010, the NDIS, if it is to be defined as a 'public service care agency', will be obliged to comply with The Statement for Australia's Carers within the Act. This includes a role in ensuring that carers are recognised and supported.

The identification of carers must not be dependent on the identification of the care recipient

A major hurdle to the access of carer services is the lack of identification of the caring role by service providers and by carers themselves. Carers WA plays a vital role in publicising the role of carers and in training government agencies and service providers to identify and include carers. The *Carers Recognition Act 2004* and the *Carer Recognition Act 2010* require government agencies to implement strategies to ensure carers are identified and their needs taken into account in the design and planning of care services. *The promotion of carer identification and the pursuit of systemic advocacy must constitute a central role of the proposed Carer Support Centres.*

An example of systemic advocacy - identifying carers when the person they care for is admitted to hospital

Many carers become carers when a family member is injured and hospitalised. And actively involves the care in discharge arrangements, the patient may be discharged without the carer being informed of how to provide care and how to access services, both for themselves and the person they are caring for.

Carers WA delivers training to hospital based staff on carer identification and support. Through the provision of this training and other written materials that hospital staff can

provide to carers, carers are now able to be identified, involved in discharge planning and supported in the transition from hospital or rehabilitation facility to home.

Complaints and quality improvements – need to include feedback from carers

Currently in Western Australia, complaints under the Carers Recognition Act 2004 are handled by the Health and Disability Services Complaints Office (HADSCO). As the name suggests, HADSCO is able to receive complaints about a variety of services including health, disability, and mental health. This broad approach is useful because of the frequency with which mental health/health and disability overlap.

6. The proposed Carer Support Centres need to cater for all carers

Carer Support Centres need to offer services to carers regardless of whether they are caring for an older person, a person with a disability, a mental illness or other illness. Many carers care for more than one person, or they care for a person with dual diagnosis and multiple needs. Carers WA argues that Carer Support Centres should be funded and resourced such that they support the goal of the National Carer Strategy to enhance the ability of carers to access services required by them as carers.

'We need to make sure different parts and different levels of government work effectively with each other to achieve these goals, rather than at cross-purposes – simplifying access to support for carers...' (Commonwealth of Australia 2010:6).

Carers need to be able to access support from a clearly identified location rather than needing to call a number of carer support services and to be assessed multiple times for eligibility for different programs that then may not be able to be delivered in a coordinated fashion.

Existing effective carer services could be put at risk by splitting up and duplicating services. For example, if a number of carer counselling services are created, by splitting up carers services into disability, ageing, mental health, health etc, this will impact on the unit costs of providing the service. Currently, staff who provide carer counselling and advice are able to assist carers in all areas of caring, including disability, ageing, mental health and health. This pooled expertise means that carers who care for more than one person, or who care for a person with multiple needs, can have their needs met through one provider. *A scenario where a carer must seek counselling from different agencies dependent on the type of person they care for is not an improvement on the current situation.*

7. Should family carers be considered as part of the workforce and as 'natural supports'?

While family and friend carers provide the bulk of services to people with disability, and their contribution is essential to the sustainability of the paid workforce, family carers do not carry out their role as part of the workforce. A paid employee enters into a contract with an employer and receives wages and other conditions for carrying out these services during set hours. A paid employee is able to retire and receive superannuation. In contrast, a family member or friend becomes a carer through a completely different set of circumstances, some of which are life long, traumatising and represent a significant and unwelcome life transition. There may be no choice but to take on the caring role. Further, there are no employee benefits, little training and no wages or superannuation. In fact, there may be a significant reduction in income if the carer is required to leave paid employment to carry out the caring role. It is disappointing that the circumstances and the role of family carers have been conflated with those of the paid workforce.

Secondly, it is disappointing that family members are presumed to be 'natural supports' when, for most families, there is no 'natural' expectation of a life-long caring role that necessitates the giving up of other 'natural' pursuits in life such as a social life, the ability to earn an income and to participate in education and community activities.

Carers WA therefore argues strongly that the supports required by family carers need to be considered in terms of the needs of the whole person, the family and the caring context which involves an assessment of more than the carer's ability to continue in the caring role. The assessment needs to examine the extent to which the carer wishes to continue in the caring role. *The Statement for Australia's Carers makes it clear that carers have an equal right to other Australians to participate in activities other than caring, such as paid employment, education and social/cultural activities.*

Interactions between aged care and disability

Carers WA is unsure as to the pathways open to a carer if the person with disability transfers from the NDIS to the aged care system. The Productivity Commission report should address whether the carer also makes this transition in terms of supports they may be eligible for.

Interactions between disability and mental illness

Carers WA supports the inclusion of mental illness in the NDIS where the mental illness creates disability. To exclude mental illness risks perpetuating the current situation where people with intellectual disability and mental illness are not assisted in either sector.

The decision to pay family members to provide care

Research from the UK provides examples where the flexibility to use self directed funding to pay a family member to provide care has achieved positive outcomes for both the carer and the person with disability (Newbronner et al 2011).

In the case of people living in remote and rural areas, there may be no other service provider available. If both the person with disability and the family carer are willing, the best solution may be to pay the family member to take on the formal caring role. This may also be a useful consideration in particular cultural settings including Aboriginal families.

8. A's story

A is a 59 year old grandmother who has cared for her daughter, S, for 39 years. S has cerebral palsy and an intellectual disability. She requires constant care from A, who is supported by several of her adult children, and, more recently, by her 15 year old granddaughter. Until 12 years ago, A struggled to provide this care with little financial assistance apart from assistance provided to S by the Cerebral Palsy Centre. A chance interaction with a staff member who had met the family in a previous capacity and commenced employment at the Disability Services Commission led to the family receiving financial assistance to purchase transport that allows S some freedom to participate in outside activities. S also has a Local Area Coordinator who A describes as really good but busy and sometimes hard to catch. Support staff visit the house to assist with personal care for S, and a hoist and other equipment has been installed in the universal access home that the family has rented for about 10 years. S also spends time at the Cerebral Palsy Centre, to participate in activities there and to give both S and A a break. A disability support agency holds the funds that the Disability Services Commission has allocated to S and helps A employ staff and make other spending decisions to support S. If this situation was assessed by the proposed NDIS based on the needs of S alone, then it might appear that A now has all the support she needs.

However, A has her own health issues, with complications from asthma and diabetes. She is herself hospitalised, on average, twice a year, including spending 15 days one year in intensive care. Fortunately, A's adult children have been able to take over the care of S. But this situation is now more complicated by the fact that A has full time care of her five grand children who range in age from 5-15.

The current draft report does not clarify certain practical issues which arise pertinent to this case. The Productivity Commission report should expand its detail to ensure that the principles arising from the above case are addressed in the new system proposed. The principles should address the following questions arising from this case:

- What would happen if A did not have her own adult children available to step in at short notice?
- What would have happened to S and the grand children if A had not been identified as a carer when she was admitted to hospital?
- Will the proposed NDIS identify the full caring load that A is carrying?
- Will it be capable of ensuring that A gets the support she needs as a carer?
- Will it be capable of ensuring that A's 15 year old granddaughter, who is also caring for S, will get the support she needs?
- Will the NDIS support this family into the future?

9. F's story

F is a 65 year old grandmother who gave up full time paid employment three years ago to take on the full time care of her 10 year old grandson L. L has Down Syndrome and autism which has caused him to experience an intellectual disability, incontinence, respiratory issues and severe communication challenges. L's respiratory problems mean that their home must be kept within a limited temperature range, meaning higher than usual gas and electricity bills. L is linked in to the Disability Services Commission through a Local Area Coordinator (LAC). F states that the current LAC is proactive and supportive; this was not her experience with two previous LACs. L attends school daily and, once a month, stays away for a weekend with a disability service provider. F pays a subsidised amount for this respite.

F receives Carer Payment and Carer Allowance. This means she has provided extensive details about her caring load and L's condition to her GP and to Centrelink. As she would like to access some respite, F will also need to repeat her situation to staff at the Commonwealth Respite and Carelink Centre who will assess both F and L for eligibility under the National Respite for Carers Program and for HACC services, such as some light housework, such as the cleaning of L's room. L's incontinence means that F undertakes extra laundering and must purchase additional clothes, including school uniforms. The current continence scheme covers about 4 months supply of continence products for L.

F is also eligible for the Grandparent Child Care Rebate which would pay the full amount of before and after school child care if there was a suitable child care centre available. There isn't. F would like to use this funding to pay for occasional child care in the evenings so that she can go to a film or go out for dinner with friends. The scheme does not allow for this. F has been able to utilise this funding during school vacations when a child care centre she can access provides activities and care that suit her grand-son's needs.

The Productivity Commission report should expand its detail to ensure that the principles arising from the above case are addressed in the new system proposed. The principles should address the following questions arising from this case:

- Will the NDIS advocate for increased flexibility in the Grandparent Child Care Rebate so that it can be used to provide more disability appropriate care?
- Should F be considered a 'natural support'?
- Is the care she provides considered 'substantial' given that her grandson attends school and has monthly weekend stays away?
- Will F need to pay an upfront amount in order for her grandson to receive funded support under the NDIS?
- Will L or F be able to gain some concessions on their higher than usual gas and power bills through the NDIS?
- Will continence products be supplied under the NDIS?
- Will there be an allowance to cover the additional clothing L requires or will F need to continue to purchase this and to pay for respite out of her Centrelink allowance?

Pensioner concessions exist to account for the fact that pensioners are low income earners. They do not exist to offset high energy use by people whose disability requires it. It is important to remember that Carer Payment is not a payment for caring.

It is an income support payment to people whose caring load is so heavy that they are unable to pursue paid employment. That is, carers in receipt of Carers Payment have already foregone a wage.

10. Response to select recommendations

3. Who is the NDIS for?

3.1 Main functions of the NDIS

The main functions of the NDIs are to minimise the impacts of disability in a cost effective manner, maximise the social and economic participation of people with a disability *and their carers*, and create community awareness of the issues that affect people with disabilities.

3.2 Who is eligible to receive funded supports

Estimates of the number of people to receive funded supports have excluded family carers. Estimates of the funding required to deliver funded supports have excluded the funding currently provided to carers of people with disability.

The Productivity Commission report should make it clear whether carers will be considered as clients of the NDIS or if not where appropriate supports will be funded from.

3.3 NDIS exclusions from funded support

The Productivity Commission report needs to make it clear whether a carer of a person with a disability will be eligible for funding from the NDIS if the person with the disability is not.

3.4 Interactions between disability, health, mental health, aged and palliative care sectors

Carers often need to navigate across one or more sectors to receive assistance for the person they care for and for themselves. The report should indicate that a memorandum of understanding should be prepared and to employ information sharing and referral protocols for carers.

3.5 Migration from the disability sector to the aged care sector

The Productivity Commission needs to state whether transfer arrangements apply to carers as well.

3.6 The NDIS will fund all eligible people who have a disability, not just those who acquire a disability after the NDIS is implemented

The Productivity Commission report should address whether this applies to carers and whether an assessment will be made to ensure that no carer is worse off under the new arrangements.

3.7 Supports required will be assessed using an independent assessment process?

The Productivity Commission report should address whether carers will be assessed too and whether this assessment will focus on the needs of the carer. This is important because the needs of the person with disability are not in themselves an indication of the load this places on an individual carer. The carer must be separately assessed.

4. What individualised supports will the NDIS fund?

4.1 The NDIS should cover the current full range of disability supports.

The Productivity Commission Reports needs to address whether the NDIS will fund supports for carers of people with disability.

4.2 No income or asset tests for obtaining funded NDIS services

4.3 An upfront contribution may be required, but to be waived where families have already contributed significantly through unpaid care.

Many carers underestimate the time they contribute to care. Carers in receipt of Carers Payment and Carers Allowance have already provided estimates of the number of hours of care they contribute.

The Productivity Commission report needs to outline how this will be assessed and whether the existing information can be used to reduce the amount of paperwork required.

4.5 Services that meet the needs of people with disability who are not eligible for NDIS funding will lie outside the scheme.

Carers are likely to need to access these services for themselves and for the people they care. It is essential that NDIS staff are able to accurately, and in a timely manner, refer carers to these non-NDIS services, including carer specific services.

Discussion - Carer Payment and Carer Allowance

These are payments that support carers regardless of the type of caring situation, ie, whether they care for a person with disability, someone with mental or chronic illness, or with age-related disabilities. A carer may become eligible for a Centrelink payment due to a combination of caring loads, or as a result of their own level of disability. The carer has their own relationship with Centrelink and the Australian Tax office to determine their eligibility for these payments. To attach these payments to the person with disability is to overlook the rights of the carer.

5. Assessing care and support needs

5.1 The assessment process should identify the supports required to address an individual's reasonable and necessary care and support needs across a broad range of life activities, and should take account of an individual's aspirations and the outcomes they want to achieve.

This statement should also apply to carers of people with a disability. This would be consistent with the Statement for Australia's Carers within the Carer Recognition Act 2010.

5.2 The assessment process

Carers need to be independently assessed. Where carers choose to provide care, they will require support to do so. The extent to which a carer can provide care will shift over time in response to life transitions and their own wellbeing and aspirations beyond the caring role.

5.5 Reassessment to focus on key transition points.

This should include transitions that are particular to the carer as well as to the person with disability.

5.6 Where an 'informal' carer provides a substantial share of the care package, they should receive their own assessment.

Carers should be assessed in a holistic way to determine the extent to which they are caring, keeping in mind that they may have caring loads additional to the care provided to a person with disability, and that for some carers, caring for a person with a moderate disability may still be impacting significantly on the carer. Unless the carer is assessed, it will be impossible to determine what the impact of the caring role is.

5.7 The NDIS should develop a tool box of assessments including assessments that effectively and holistically identify the needs of carers and caring families.

5.8 Assessment tools to be monitored.

Feedback from carers to be included in the monitoring and quality assurance mechanisms.

6. Who has the decision-making power?

6.1 People should have choices in managing and spending their funding

The Productivity Commission report should expand its detail to ensure the following questions are addressed in the new system proposed by the productivity commission:

Will this apply to funding received by the carer to access carer services? What will the impact of this be on carer support centres? Will self directed funding lead to the end of block funding of carer support services?

6.2 Self directed funding

Carers need to be included in the decision making process. Carers should have the choice to opt in or opt out as circumstances change. If carers are expected to make decisions about the use of funding, training and support should be available.

The Productivity Commission report should expand its detail to ensure the following questions are addressed in the new system proposed by the productivity commission:

If a carer makes decisions about expenditure that later generates a complaint, what will the process be for dealing with the complaint? What protections will a carer have if accused of misspending the funds?

6.4 Close family members not to be employed

Research exists that supports the employment of close family members in particular circumstances (Newbronner et al 2011). There are currently provisions in WA for this to occur in geographically isolated areas and in particular cultural settings. Carers WA supports the recommendations for trialled employment of family members.

6.6 Supporting self directed funding

Training needs to include measures that are consistent with carer recognition.

6.9 Monitoring of self directed funding

The input of carers should be included in the evaluation.

6.10 The taxability of funding from the NDIA

Any advice to the ATO must include an assessment of the impact on carers given the interactions between NDIA, ATO, Centrelink and, potentially, Special Disability Trusts. Carers must receive clear and transparent information that allows them to fully understand and make informed decisions about their financial well being.

7. Governance of the NDIA

The NDIA should be considered a public service care agency and therefore be subject to the Carer Recognition Act 2010.

Specialist service providers and disability support organisations receiving funding from the NDIA would then also be subject to the provisions of the Carer Recognition Act 2010.

7.12 Internal complaints office

Carers to be able to complaints on their own behalf as well as on behalf of the person with disability if required.

8. Delivering disability services

8.1 Supporting 'consumer' decision making through the provision of information

Carers should be considered clients of the NDIA/S.

The database of information available must include carer and other family supports and services.

8.2 Shared electronic records

Information sharing protocols should apply to carers and should allow for the supported referral of carers to carer services.

8.3 Quality framework for disability service providers

This should include compliance with the Carer Recognition Act 2010. Carers should have a clear pathway for making complaints about the performance of providers.

9. Disability within the Indigenous community (sic)

As carers, Aboriginal people and Torres Strait Islanders are frequently at a relatively greater disadvantage. The people they care for may experience multiple disabilities while the carer themselves is also at greater than average risk from chronic health issues. Geographical location can also exacerbate these issues.

A carer of a person with a disability may also be caring for a person with a mental illness and chronic ill health, or all of these conditions may overlap in one person or one family. To separate carer services so that a carer of a person with disability must seek other carer services elsewhere adds to the carer burden. It creates another barrier to accessing and receiving carer support. It would make more sense, particular in rural and remote locations, for carer and other services to be hubbed, not divided

up. This would mean that a caring family can access many services either in one trip to a larger regional centre, or through every visit by service providers to the community.

The importance of encouraging Indigenous people to participate in the health, ageing and disability sector workforce is reinforced through comments made to Carers WA by Aboriginal carers who, for cultural and historical reasons, remain cautious about interacting with overwhelmingly non-Aboriginal service provider organisations.

10. Collecting and using data under the NDIS

The experience of carers and their feedback should be sought and included in evaluations and research.

11. Early intervention

Research into early intervention should evaluate and incorporate the impact on the caring family as well as the individual with disability. The benefits of well designed and well implemented early intervention could include significant and cost saving preventative benefits and this should be included in assessing the effectiveness of funds directed to early intervention (Eager et al 2007).

13. Workforce Issues

13.3 Recommendations relevant to family carers have been included in the draft report under 'workforce issues'. It would be more appropriate to include carer issues throughout the report and to consider family carers as clients of the NDIA/S rather than as members of the 'workforce'.

The Productivity Commission report should expand its detail to ensure the following questions are addressed in the new system proposed by the productivity commission:

- Carer Support Centres – will they receive NDIA/S funding?
- Can carers access Carer Support Centres directly?
- Will NDIA staff be able to facilitate supported referrals of carers to the Carer Support Centres?
- Will the Carer Support Centre have eligibility restrictions or will all carers eligible for services?
- Will NDIA staff conduct initial carer assessments over the phone?
- Will carers remain with the NDIA if the person they care for is eligible for funded supports or will the carer receive their supports from the Carer Support Centre regardless of the eligibility of the person with disability?
- 13.4 Amendments to Fair Work Act

- Carers WA supports amendments to the Fair Work Act to allow carers of people over 18 to request leave in order to provide care. However, this amendment should not apply only to people caring for a person with disability covered by the NDIS. It should be a provision available to all carers including those caring for a person with a mental illness or chronic health problem. Is the NDIS the most appropriate body to provide the assessment? It would create a scenario where a family member caring for a person with disability and an ageing parent who needed to apply for leave would firstly need to seek NDIS approval as well as seeking approval from the aged care system or perhaps a GP or whoever else has authority. This creates a series of administrative burdens for carers who are already short of time. Approval needs to be centralised, possibly through a GP or perhaps based on information previously provided to Centrelink, and based on the needs of the carer, not simply based on the specificities of the person they are caring for. As mentioned previously, the level of carer burden cannot be determined by the type of disability of the person they are caring for.

16. National Injury Insurance Scheme

The Productivity Commission report should expand its detail to ensure the following questions are addressed in the new system proposed by the productivity commission:

Questions relating to the needs, rights and pathways to services carers apply to the NIIS as to the NDIS. Will the carer be considered a client of the NIIS? Will carer needs be funded through the NIIS?

17. Implementation

Clear pathways for carers to access services for themselves and services for the person they care for must be in place to ensure no one is denied services during the implementation phase.

17.4 In 2020, there should be an independent public inquiry into the operations of the NDIS and its effectiveness in meeting the needs of people with disabilities *and their carers*.

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