Response to

Evaluation of the Adult Disability Assessment Tool (ADAT) and the Child Disability Assessment Tool (CDAT)

for the Australian Government Department of Families, Community Services and Indigenous Affairs

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Carers ACT acknowledges that modern day Canberra has been built on the traditional lands of the Ngunnawal people. We pay our respects to their elders and recognize the displacement and disadvantage they have suffered since European settlement. Carers ACT celebrates the Ngunnawal's living culture and valuable contribution to the ACT community.

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1. Introduction

Carers ACT is a non-profit, community based, incorporated association and registered charity dedicated to improving the lives of the estimated 43,000 family Carers living in the Australian Capital Territory. We represent unpaid family Carers who are providing care for people with disabilities, mental illness, chronic conditions, palliative care, or who are aged and frail.

Our role is to work in active partnership with Carers, people with care and support needs, health professionals, service providers, government and the wider community to achieve better understanding and an improved quality of life for Carers.

Carers ACT believes that all carers are entitled to the same rights, choices and opportunities as other Australians in order to enjoy optimum health, social and economic wellbeing and to participate in family, social and community life, employment and education.

Carers ACT welcomes FaCSIA's recognition of the many challenges faced by Carers in the community and the people they care for. The evaluation of the Adult Disability Assessment Tool and the Child Disability Assessment Tool demonstrates FaCSIA's commitment to the continuous improvement of services provided to some of the most vulnerable groups within our society.

2. About the Claim for Carers Allowance Forms

Recent research published in the Australian Unity Wellbeing Index 17.1 (Cummins, 2007) has shown that Carers are already a group at risk, more vulnerable to the pressure of social and economic factors than the majority of non-carers in the population. This research also provided support to the perception that Carers as a group are significantly more highly stressed and extremely time poor in comparison to other population groups. It found evidence that "consistent, daily immediate caring responsibility is sufficient to severely damage wellbeing" (Cummins, 2007 p. 37). The research also recommended that "additional support when commencing a caring role may be beneficial to the wellbeing of people new to caring" (Cummins, 2007 p. 39). A sizeable proportion of Carers apply for financial support when they are in this period of transition and adjustment to the caring role. Therefore, it is critical that the process of application be made as stress-free as possible.

There is a relatively low uptake rate of Carer Allowance in comparison to the number of Carers (particularly Primary Carers) as identified through research by the Australian Bureau of Statistics, such as the Survey of Disability, Ageing and Carers (2003). A number of reasons may be contributing to this phenomenon. There is a widely acknowledged problem in identifying and creating pathways of support to assist the many tens of thousands of hidden Carers throughout Australia, who do not self-identify as such. There is also a general lack of awareness that the Carers Allowance is not subject to means testing. It is also apparent that the complexity of the assessment process and

the significant investment of time required to make a claim, leading to a fairly nominal payment, may also be considered as a potential deterrent to some Carers.

Many Carers may also have submitted a claim which was disallowed. Carers ACT is developing productive and cooperative liaison relationships with the Carers Customer Service Support Centre in Wagga Wagga and the Centrelink offices within the ACT. Feedback obtained through advocacy work to date has revealed that the most common cause of rejection of claim (when there exists cause for an otherwise valid entitlement) is usually the incorrect or inaccurate completion of the claim forms. Reports completed inaccurately or with insufficient detail by health professionals have also been grounds for the rejection of claims. Carers commonly describe the forms as complex and confusing. They often find it difficult to comprehend exactly what information they are being asked to provide. It has also been noted that the extremely small print on the forms is difficult to read.

Carers ACT regularly receives requests from Carers to provide assistance and support to complete Centrelink forms, especially claims for Carer Payment. However, it is more usual that Carers make contact for advocacy assistance if their claim is rejected. The receipt of a rejection of claim can be a cause of serious, additional stress to Carers. It is an issue of great concern to Carers ACT as to how many Carers have their claim rejected and give up on the process of claim without making any contact, either to Centrelink or to Carers ACT, for additional assistance with re-submission and/or appeal processes.

Confidential discussions with Carers who have recently completed the Carer Allowance has highlighted a number of areas of concern regarding the process of claim and also identified some specific problems with the assessment tools which are detailed below. An additional area of concern reported, but not covered by the terms of reference for this evaluation, included difficulties encountered when all needed forms were not supplied by Centrelink, even after request for such forms (e.g. claim for mobility allowance, claim for educational supplement) requiring multiple contacts to be made with the service which is highly inconvenient for Carers due to the nature of their caring responsibilities.

3. About the Adult Disability Assessment Tool (ADAT)

The need to balance information provision while retaining simplicity of the forms is a recognizable challenge, a challenge which is partially met by providing a separate information booklet on how to complete the claim forms. However, some Carers find it difficult to cross-reference to the information booklet while also trying to complete the form. The most critical need therefore is a large and easily read invitation giving support options for people who require additional help to complete the form. It is important that these pathways provide choice, as some Carers like to call a phone number because of mobility/transport challenges, while others may need a face to face appointment to feel confident with the process.

There is no definition of carer or caring on the front cover of the forms. Provision of a definition or a brief explanation enables Carers to feel more confident that they are completing the correct form, especially if they do not self-identify with the term 'carer'. There is particular need for a definition of the term 'Primary Carer' on the front of the forms. Carers, especially those who have difficulties with English due to literacy or linguistic challenges, may not understand this term or how it may apply to their situation. The concept of Primary Carer is also problematic for situations where complex networks of family and community care exist, particularly for Indigenous Carers.

Additional resources are also required for Carers from Culturally and Linguistically Diverse backgrounds. A tiny note in English providing a phone number to call to *'speak to Centrelink in languages other than English'* is easily missed and insufficient. Resources need to be culturally appropriate and recognise different concepts of care, for example, a culture may not recognise 'care' in the same way that Western society does, a person either has a kin-ship obligation or not, therefore the provision of financial or other support for kin-ship obligations is quite incomprehensible. Carers from Culturally and Linguistically Diverse backgrounds have also provided general feedback to us indicating the best pathways for support include options for own language materials and resources, with face to face interpreter services where needed, rather than just to have telephone interpretation.

The most critical issue with the ADAT section of the form lies in its failure to provide an accurate and fair assessment of people with episodic conditions, particularly those with mental health conditions. Question 24 on Part C of the form 'About the care you give' contains a note in the second dot point that reads:

> *Where the person's disability or condition is episodic or is only apparent at certain times, the question should be answered for when the person **is not** experiencing an episode or flare-up of the disability/condition.*

The effect of this direction is to provide a blanket disqualification of all people with episodic conditions, no matter how complex their care needs, and how much these needs impact upon their Carers when they are undergoing an episode or flare-up. A more equitable assessment would include a separate page for people with episodic conditions. This assessment could include the use of a matrix tool to measure frequency of occurrence against severity of symptoms/behaviours/care needs, and include an assessment of the level of impact such episodes have on the Carer. The Carer may then adequately answer the questions in the day to day care, behaviour and cognitive sections in relation to episodic conditions with confidence that they are adequately and accurately describing their care situation.

Other important Carer feedback on the ADAT includes concerns that there is not enough focus on assessing the cognitive, intellectual or emotional supports provided through the caring role. Indeed the ADAT seems to imply a bias towards physical disabilities and provision of medical care for chronic symptoms or conditions. Carers felt that this bias did not allow them to fully

quantify the care needs for other types of conditions, such as chronic anxiety conditions (which is not adequately addressed at Question 26.6), or for other elements of the provision of care, such as the constant supervision required to ensure the care-recipient's safety (which is not qualitatively the same as physically harming another as in Question 26.3, or deliberately self-harming as in Question 26.7). This issue is particularly relevant for people who care for someone with delayed development and other cognitive-processing disorders.

The cognitive function section also fails to assess the importance of functionality of communication within a social context, for example, the Carer may find that the person they care for can understand speech but may not be able to apply it effectively within a social context without additional direction. Indeed social skills are a highly complex, but essential part of daily functioning, and any impairment to developing effective social skills becomes a condition of high need for Carer support, and can have significant impact on well-being if left unsupported.

4. About the Child Disability Assessment Tool (CDAT)

The issues identified above for the ADAT in regard to information provision, support options, cultural appropriateness and complexity of measuring care provision also applies to the CDAT. As the Carer of a child with a disability recently noted after contacting Carers ACT for advocacy and support when making a claim for Carer Allowance:

> *"The application forms have been extremely hard to complete and one needs to be very competent with language skills and knowledge of English to be able to complete the form. They are very difficult and complex."*

Again, the episodic or flare-up assessment renders the functional assessment as inequitable, as described previously for the ADAT. Similarly it is recommended that additional use of matrix assessment be developed based on frequency and severity of episodes, and level of impact on the Carer.

The last category of each question uses an 'age-appropriate' assessment criteria, which is only of use to the health professional if they have been provided with a comprehensive guide as to what functions and behaviours are considered to be 'age-appropriate' for each particular age. It is an error to assume that this knowledge is implicit in their training or day to day practice. This information would also be of critical assistance to the Carer in helping them to understand the correct information they need to inform the health professional about.

Many parents have little understanding of age-appropriate development, especially when the child is a first-born or only child, as the Carer may have no other reference point for comparison. It is also not uncommon for Carers of children with special needs to be highly isolated from the wider community due to the demands of their caring role, and have difficulty in accessing many

mainstream services or community groups. Therefore the Carer may not have exposure to other examples of age-appropriate behaviour from attending activities such as playgroups or toddler-gyms. Even a 'pre-consultation checklist' based on different developmental age groups would be a useful aid for parents to complete and discuss with the health professional at time of consultation.

The Behaviour section at Question 16 does not adequately address the issue of the constant supervision required to prevent accidental injury to self or other. It also fails to address issues of chronic anxiety and/or phobias, and it does not suitably assess issues such as depression, psychological withdrawal or sleep disturbances, all of which can create a significant demand for care. The Special Care Needs at Question 17 once again displays a strong bias towards physical and medical issues, as additional cognitive impairments are limited to memory, concentration, planning and organisation.

5. About the Report from Health Professionals

As discussed above, Carers have less time and greater stress levels than non-Carers, however they also face higher costs and lower incomes as a result of their caring role (Access Economics, 2005). Carers may face additional barriers in obtaining a health professional's report, as effective completion of the report usually requires a face to face consultation. This consultation incurs a financial cost and requires additional time to attend. This issue is particularly relevant for Carers of children with disabilities, as a paediatrician's report is usually the most appropriate to obtain regarding issues of diagnosis and levels of functionality. Yet, due to limited consultation times with specialists, Carer's may find it hard to adequately convey all information required for the specialist to fairly ascertain the level of day to day needs of the care-recipient.

It may also be undesirable or inappropriate to discuss many issues in front of the care-recipient, yet they must attend the consultation for the Carer to be able to claim a partial reimbursement of costs from Medicare. In-home assessment is usually the most beneficial aid to a fair and equitable report, but few specialists conduct in-home visits and the costs of such a service would be highly prohibitive for many Carers.

Carers often find that they come away from consultations with a form that is insufficiently completed, and they are often hesitant to return on multiple occasions due to the time and cost issues inherent in the process. As one Carer recently reported:

> *"The paediatrician completed the form upon request but still left areas of the form blank – this is likely due to his inability to answer all the questions relating to [the care recipient's] emotional support care needs."*

This comment also raises the fact that health professionals may not necessarily be the only appropriate source of information for completion of

the claim forms. Appropriate supplementary assessment on social/emotional support and daily functioning needs may also be obtained from other professional sources, including child care centres, schools or respite services. The form makes no provision for multiple sources of input, yet few care situations are easily viewed from a single perspective.

6. Recommendations

a) Inclusion of an invitation on the front of the form detailing Carer support options for completion of the claim, including face to face and telephone contacts.

b) Provision of a brief explanation or definition of the term Carer and/or what it means to provide care to another person on the front of each form.

c) Provide a definition of the term 'Primary Carer' on the front of each form.

d) Improve the note about other language translation telephone services, with a page of messages in all major languages inviting people from other cultural backgrounds to make contact for additional support to complete their claim. Develop additional culturally-sensitive resources about the caring role.

e) Develop an appropriate matrix tool to equitably assess episodic disabilities or conditions. The tool should measure frequency of occurrence against severity of symptoms/behaviours/care needs, and also include an assessment of the level of impact such episodes have on the Carer.

f) Reduce the bias towards physical and medical care in the form by increasing the number of questions which assess cognitive, intellectual and emotional supports required by the cared for person.

g) Include an assessment of functional communication within social contexts.

h) Develop appropriate supports to assist health professionals and Carers to understand and appropriately respond to assessments based on age-appropriate levels.

i) Achieve greater recognition of Carer's role in supervising safety and preventing accidents, especially in CDAT.

j) Include questions regarding psychological conditions/symptoms, such as anxiety, phobia, depression and sleep disturbance into CDAT.

k) Consider the impact of barriers such as financial impact and time constraints for obtaining health professional reports.

l) Consider the use of supplementary reporting from other sources to add depth to the limited perception of a single health report.

7. References

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