Evaluation of the Adult Disability Assessment Tool and Child Disability Assessment Tool

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1. Introduction

Carers Australia is the peak body for the 2.6 million family carers in Australia. Its members are the state and territory Carers Associations (the Network) that deliver specialist information and advisory and counselling services to carers in 52 sites around Australia. Carers Australia is informed about carer issues through its member Carers Associations and its participation in national and international forums.

Carers Australia receives secretariat, specialist information advice and National Carer Counselling Program funding from the Australian Government Department of Health and Ageing (DoHA) and funding for the Young Carer Program from the Australian Government Department of Families, Housing, Community Services and Indigenous Affairs (FaHCSIA).

Carers Australia is encouraged that the Federal Government has indicated that it needs to develop a new social inclusion agenda that can bring social and economic policy together to complement each other. Carers Australia believes 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. Unfortunately, research clearly indicates that many carers are disadvantaged socially, physically and economically.

Of the 2.6 million family carers, nearly 500,000 are primary carers – the people who provide the most care. However, comparatively few carers receive Federal Government support through the Carer Allowance or Carer Payment. In 2005-06, 366,960 carers received the Carer Allowance, and 105,058 carers received the Carer Payment. (Source: Australian Institute of Health and Welfare (2007). Australia’s welfare 2007, Canberra.)

2. The current situation

2.1 General comment concerning the current tools

Currently there is little consistency in structure and measurement mechanisms of the Child Disability Assessment Tool (CDAT) and the Adult Disability Assessment Tool (ADAT), and as a consequence, there may be a lack of equity of access to Carer Allowance and Carer Payment between carers of people with different types of disability. We acknowledge the difficulty of developing tools which attempt to make standardised comparisons across a range of types of disability and chronic illnesses.

It is our impression that there is inconsistency in how the CDAT and ADAT are interpreted by carers, medical practitioners and health professionals.

2.1.1 The Child Disability Assessment Tool

The CDAT includes the use of the LORD, or List of Recognised Disabilities. This valuable mechanism guarantees eligibility for Carer Allowance or Carer Payment (within income and asset test obligations) for families with a child with a specific disability or illness where the course and impact of the condition is ‘predictable’. This is a valuable eligibility mechanism for particular diagnostic groups, streamlines the access process and reduces the need for complex review processes.

However, in our view, the CDAT:

- Does not measure the care provided. It appears to measure a child’s functional ability and compares this with age appropriate developmental milestones. As such it does not provide the
capacity to distinguish between, or compare the care load for different disabling or chronic illness conditions.

- It does not appear to be based on any standard functional assessment tools. As such, it allows only one item to be selected in each functional category.
- It is difficult to make a judgement concerning equity of access to Carer Allowance and Carer Payment, when the scoring and weighting systems used with either tool are unclear.
- An objective measure of the care load may be a more effective means of determining eligibility for Carer Allowance and Carer Payment. This should include a greater capacity for family carers to outline the specific nature of the care they provide. It should not be restricted to carers having the opportunity to complete a form to identify the level of care they provide when their score is a little below eligibility. Whilst this may be a well-intentioned attempt to prevent carers completing the form where there may be limited likelihood of success, it effectively denies them a voice.
- For the CDAT, only a qualified medical practitioner is recognised as a treating health professional and able to complete the Health Professional Assessment. Whilst in some cases the treating doctor will be knowledgeable about the child’s condition this is most certainly not the case for all people. This is particularly true for some types of disability. Disability discourse has changed considerably in the recent past, moving from a medical model to a social model of disability. As such, the assessment process should recognise this by allowing other health professionals to complete the CDAT as they will more likely have a better understanding of the disability and its associated consequences for the person and their family or carer.

2.1.2 The Adult Disability Assessment Tool

In comparison, some questions in the ADAT have the capacity to allow a greater differentiation of responses (the four point scale from ‘always to never’). However, the way the completed form is scored remains unclear.

A range of professionals can complete the professional assessment. This allows for the Health Professional Assessment to be completed by people who may be more informed about the functional capacity of the person needing care than the treating medical practitioner. This recognises that medical practitioners are not experts on all conditions, especially disability. It affords carers the opportunity to detail and qualify aspects of the extent of care they provide.

Consideration is required to replace the term ‘health professional’ with ‘service professional’ or similar, i.e professionals that may be used to provide a functional assessment may not necessarily be a health professional, but could be a manager of a day program or similar that has qualification and experience in providing such assessments but in the ‘disability/social services’ field rather than specifically the health field. This amendment would assist carers access appropriate professionals to assist with the professional assessment.

We note the lack of consistency in approach between the CDAT and the ADAT.

2.1.3 Consistency between CDAT and ADAT

Given this lack of consistency there is not always a seamless transition for the carer when the person they support turns 16 years. Reassessments sometimes mean that people considered eligible with CDAT are no longer considered eligible when assessed using the ADAT.
2.1.4 Sensitivity of the tools to the needs of families from Aboriginal and Islander and Culturally Diverse backgrounds

The application forms for Carer Allowance and Carer Payment can be complex and difficult for Australian families. They are particularly difficult for Aboriginal and Islander families, as well as families with culturally and linguistically diverse (CALD) backgrounds. Many of whom may not identify with the construct of carer and, or, may be language disadvantaged. In addition, different cultural attitudes (eg towards disability and mental illness) may also present additional barriers for people from CALD backgrounds, especially in the use of deficit based assessment approaches.

For some families, particularly Aboriginal and Islander, it is difficult or impossible to provide appropriate documentation. Isolated carers and communities also have difficulty accessing Centrelink advisors or health professionals with sufficient knowledge of the application process to assist them complete applications for Carer Allowance and Carer Payment. There is also limited knowledge in these communities about the existence of these support payments, and their own eligibility.

Application forms may also be complex and difficult for people of different ages and educational background. Young carers who may have limited experience with completing forms may have difficulty. This may also apply to older carers that may have limited use of support services, and so have had little experience of the system and completing application forms. Simplification and, or assistance with understanding and completion of forms would be beneficial.

2.1.5 Measuring disability levels and care load

The current tools lack validity as a means of identifying and rating the level of disability of the person needing care, although two recognised assessments are incorporated in the ADAT. The tools are inconsistent one with the other, and neither tool is an adequately differentiated way of measuring care load.

3. CDAT

The CDAT tool is unlikely to be able to measure the degree of disability of people needing care in relation to child development stages.

It is difficult to design a tool which can objectively recognise the variations in the severity of a disability or chronic illness and the differences in care demands. The tool focuses on measuring functional ability and comparing this with age appropriate functioning. It cannot readily distinguish level of disability or care load.

4. Specific groups

4.1 Disadvantaged groups of carers

4.1.1 Related to the nature of disability

The CDAT and the ADAT appear to disadvantage some particular groups of carer and people needing care.

*Carers of people with episodic conditions*

Both tools are weak in determining the care load of episodic conditions such as a mental illness although several psychotic conditions are listed in LORD. The ADAT (Health Professional Assessment)
includes four categories of Psychiatric Disability and a list of behavioural functions in day to day needs. These may be the only items relevant to an adult with mental illness. The tools do not consider the frequency of episodes, nor the care load that may fall on family carers as a result of the need for constant vigilance, encouragement, observation, advice, emotional support, monitoring medication compliance and ‘trouble shooting’. It is noted that this group of carers are often found to be ineligible for Carer Allowance or Carer Payment. Some appeal many times.

In addition, carers of adults with a mental illness may be shut out of having a voice in health professional assessments on the grounds of confidentiality.

The obligation (page 9) when the child has an episodic condition, to rate their behaviour when they are ‘well’, without qualification, seems unfair. For some families episodes of the disability or condition may be widely spaced; for others they may be very frequent.

_Carers of people with mental health, cognitive, behavioural and motivational issues_

There is no absolute consistency between the functional assessment undertaken by carers and those undertaken by treating professionals for people with a mental illness. Different criteria are used. The categories in the carer assessment of care needs may not allow a clear understanding of care load. In our experience carers often underrate their care load, in an effort to present the person with a mental illness as positively as possible, and to protect the person’s self concept.

Both tools seem limited in providing equity of access for carers of people with very challenging behaviours. At times it appears decisions may rest on the eloquence of the carer or health professional (eg ADHD).

Both tools may be weak in differentiating the care load on family carers where the major and demanding care tasks include consistent and considerable prompting, encouragement and reminders of desirable tasks or actions.

Children with conditions such as ADHD who may, for example, have normal levels of communication, mobility, personal care and grooming, and gross motor skills, are likely to score below eligibility. The CDAT has only one question rating challenging behaviour. However, some children with ADHD are likely to make extreme demands on their families in relation to supervision, guidance, intervention, protection and support.

The scoring of the ADAT is more heavily weighted towards assistance with physical functioning. The maximum possible ADAT score is 209 points. Within this score 124 points relate to care needs arising from physical functions and 85 points to mental functions. (Source: Social Security Guide 3.6.9.10.) The CDAT is slightly more multi-faceted in that it weights more heavily deficits of functioning in receptive communication, special care needs, hygiene, grooming, body movement. However, behavioural and cognitive difficulties are overlooked.

The tools, especially the ADAT, are primarily based on Activities of Daily Living (see Social Security Guide 1.1.A.78). They place little emphasis on Instrumental Activities of Daily Living or other care tasks such as assistance with supervising, managing behaviour, encouraging, prompting etc. However, recent empirical evidence suggests that these tasks are the greatest predictor of carer wellbeing. Carer distress is strongly predicted by the time spent on ‘psychosocial care’ i.e. supervising, managing, encouraging, supporting etc. (Source: Pakenham K, Stebbins P, Cannon T and Samios C (2005). Carers in Contemporary Australia: Relations among Carer Illness/Disability Groups, Biographics, Caring
Context, Coping and Distress. See [http://eprint.uq.edu.au/archive/00003236/](http://eprint.uq.edu.au/archive/00003236/) As such, the care load associated with them and their impact on the carer appear to be higher than other tasks.

**Other disadvantaged conditions**

Within the range of children with an intellectual disability, the CDAT has little capacity to distinguish between children with a high degree of functional independence and those where the care demands on their families are more complex and much greater.

The CDAT is poor at differentiating the increased care load for young children with a disability or chronic illness. In addition, there is no inclusion of the demands on families of frequent medical and allied health treatments or interventions, or of the care management tasks that are often performed primarily by families.

Some carer applicants may be disadvantaged as a consequence of the complexity and understanding of the language of the application form. There are many areas of lack of definitional precision which means carers respond with different levels of understanding of the meaning of what is being asked.

The process is intimidating. Many carers report that they give up trying. We note that when applications for Carer Allowance or Carer Payment are perceived by carers as being unfairly rejected:
- Some carers are very reluctant to appeal or reapply
- Some carers have a distrust of such a complicated system
- Some carers think ‘Why bother... it’s too hard’.

There appears to be no apparent reason why the ADAT should not also include a LORD. This may assist to reduce the stress carers experience concerning filling out review forms for people with a lifelong and permanent disability. There is already some precedence for when the care receiver is automatically considered to have attained the ADAT score necessary, eg where a care receiver has been certified by a medical practitioner to be in the final stage of a terminal illness and is not expected to live more than three months.

**Young carers**

The following issues have been identified for young carers in completing the ADAT form:
- Q 10, whilst young carers can tick the ‘single’ box, it would be more appropriate to adequately identify young carers in this question, eg a box of ‘dependent’ or similar
- Q 13, could provide opportunity for a parent’s bank account to be used
- Q 30, fails to address the possibility that the ‘dependent’ child of the care recipient could be the young carer themselves
- Q 31, limitation of 20 hours per week allowed in determining eligibility is prohibitive for young carers who are completing primary, secondary or tertiary education
- Q 32, the income and assets that a young carer identifies may actually be that of their parents
- Q 33, whilst young carers may not legally have dependent children, they may also care for a sibling as well as the care recipient they have identified on the application form
- Q’s 35 and 40, there is no specific answer to state that a young carer may live in their parents home (whether is owned, private rental, public housing etc).

### 4.2 Caring arrangements

There appears to be both poor community and carer awareness of:
- Shared care eligibility for Carer Allowance
- Non co-resident eligibility
• Eligibility of non parent carers

In our experience family carers may not discover their eligibility for Carer Allowance or Carer Payment until they engage with informed direct services providers.

### 4.3 Physical location

Rural and more isolated locations appear to impact on access to Carer Allowance or Carer Payment both in terms of:

- Information about the payments
- Capacity to meet the timelines from intention to claim, when the carer needs to rely on a visiting specialist medical practitioner.

Relevant local expertise is not always available or accessible in order to accurately and fully complete the necessary form.

### 4.4 Extenuating care factors

The largest survey of carers health and wellbeing was released in October during Carers Week 2007. The survey of nearly 4,000 carers was undertaken by Deakin University as a special report for the Australian Unity Wellbeing Index (AUWI). The index used a scale of 0-100 to indicate the wellbeing of the Australian population various and sub-groups.

Three major outcome measures were used to calculate the AUWI. The first is the Personal Wellbeing Index, which is Deakin University’s standard measure of wellbeing. The personal wellbeing index score is the average level of satisfaction across seven aspects of personal life—health, personal relationships, safety, standard of living, achieving in life, community connectedness, and future security. The other two outcome measures are sub-scales taken from the Depression, Anxiety, and Stress Scale, which is a well regarded scale.

Across the previous AUWI surveys conducted by Deakin University over the past six years the value of the means has ranged from 73.4 to 76.4, a fluctuation of three percentage points. Distressingly, the research indicated that carers have the lowest wellbeing (58.5) of any group surveyed over the past six years of the AUWI. It is nearly 20 percentage points lower than normal range. Other groups with low wellbeing index figures include “unemployed” people 66.6 and people “alone and unemployed” 60.0.

The survey also found:

- Sole parent carers had the lowest wellbeing of any carer (50.2), which is 16-19 points below the normative range of other divorced or separated people, and 23.2-26.2 points below the normative range of other population groups. This means they are more likely to suffer from severe to extremely severe depression and other risk factors, including social and financial disadvantages.
- The wellbeing of carers decreases linearly as the number of hours spent caring increases.
- Having primary care responsibilities for less than one hour each day allows normal range satisfaction with the wellbeing domains of living standard, safety and community connection.
- Once primary care responsibilities reach one to two hours a day all domains are well below normal.
- Caring for disabled children imposes greater burden than caring for adults.
- The wellbeing of carers is more vulnerable to physical pain than is normal.
- Carers are more likely than is normal to be experiencing chronic pain.
- Carers are highly likely to be carrying an injury and this is associated with reduced wellbeing.
• Carers have an average rating on the depression scale that is classified as moderate depression, and over one-third have severe, or extremely severe depression.

(Source: Deakin University and Carers Australia (2007). Australian Unity Wellbeing Index, Survey 17.1, Report 17.1, October 2007, Melbourne.)

Carers Australia believes that a measure for extenuating circumstances should be added to the CDAT and ADAT that reflect the carer load. Sole parent carers and their families are among the most disadvantaged groups in our country, and their extenuating circumstances should allow them special access to the Carer Allowance and Carer Payment.

5. Health professionals

5.1 General

We question whether the appraisals of the treating medical practitioner (for children outside the LORD and for adults) are always the most informed, as many carers consider medical practitioners do not complete the forms with care and consideration. Many families quote that their GP seems reluctant to complete the assessment, feeling remuneration is inadequate for the time taken. However, the streamlined access via LORD seems to work well if all diagnoses are included.

Accessing assessments from medical practitioners can be difficult for:
• Caring families who attend a bulk billing medical practice rather than a constant GP
• Country families who may have to wait many months for an appointment with a visiting medical specialist, such as a psychiatrist, or a specialist clinic at a Children’s Hospital
• Aboriginal and Islander carers who have limited access to health professionals. Also, language barriers are increased by carers limited literacy and the poor English of some overseas trained doctors employed in rural and remote areas.

Frequently the treating medical practitioner has limited awareness of the extent of care required.

Carers Australia advocates for:
• Empowering instructions to applicant carers concerning:
  o The need for double appointments with the medical practitioner
  o The need for carers to consider in advance desirable responses from treating medical practitioners (TMR) or health professionals
  o The need for carers to participate in the completion of the responses of the TMR or health professional.

Carers report that health professionals often rely on assumptions regarding the person’s ability rather than on results obtained from direct testing. This approach is reinforced by the instructions that state that direct testing is not required. However, if the doctor has no direct knowledge on a particular question and does not accept the carer’s assessment of the situation, they should be able to support their claims with evidence obtained from a direct assessment.

Whilst health professionals are encouraged to discuss the questions with the carer or family, this does not always occur due to professional prejudices and a denial of the expertise and knowledge of families and carers.
Where there is a choice as to which a Treating Health Professional can complete the forms, carers can be uncertain as to who they should approach to complete the form. In some cases, no one health professional will possess all of the necessary information to accurately complete the form. There is merit in a case conference to allow treating professionals to collaboratively complete the form given that different workers may have different perspectives to contribute.

Inappropriate questions or questions requiring modification for the treating health professionals include:

On the CDAT:
- TDR form should note that the treating doctor should involve carers in completion of the diagnostic categories (Q’s 1-4). Frequently a number of medical specialists may be involved.
- Q 6, CDAT requires clearer definition.
- Q’s 8-18 should be completed in collaboration with the carer.
- Q 16 should be modified to be less deficit focused/extreme.

On the ADAT:
- Inclusion of a process for recording medical diagnoses may be an important addition if a LORD was to be developed.

5.2 The future

5.2.1 Involvement of health professionals

The involvement of a wider variety of health professionals is desirable, in particular carer support workers who are likely to have a clear understanding of the care load; and educationalists or day program support staff who will have a clear concept of the care required.

It would be useful if the process necessitated that the health professional provided the carer with a copy of the completed assessment rather than the provision to carers be optional. This would allow the carer the opportunity to discuss any perceived errors with the doctor.

As discussed above, a role for health professionals aside from medical practitioners in completing the CDAT and ADAT would be appropriate.

5.2.2 How can care load be measured

While we have no ready response to this difficult question, it is our view that future CDAT and ADAT tools should be based on the following principles:
- Based on an ideology of helping and supporting caring families.
- Able to measure care load across different types of disabilities.
- Inclusive of a systemic approach which places the person with a disability or chronic illness within the context of the impact of caring on the caring family.
- Extenuating circumstances related to the caring role, including the care hours required.

See 3.4 Extenuating care factors above.

5.2.3 Recommended changes to tools and processes

- Include a List of Recognised Disabilities within the Adult Disability Assessment Tool and streamline the process for those with an ongoing ‘permanent’ disability.
• Differential weightings according to the condition, e.g., more weight on behavioural and social criteria rather than mobility or physical function for a person with a mental illness
• Differential weightings to allow for extenuating care factors.

Currently the process is reduced to a mechanical one that relies solely on computer calculations. Some humanity needs to be re-introduced to the process. This would be welcomed by carers and, perhaps, staff who indicate that they are unable to affect the process even though there are legitimate claims being made. At a minimum, the validating step of the CDAT should be expanded to both tools. This will allow for the resolution of discrepancies between carers and health professionals particularly in the area of behavioural and special care needs discrepancies. These issues may be particularly difficult for health professionals to identify during a consultation. A process should also be introduced to allow for an examination of extenuating circumstances.