ACiA Submission

To

Senate Community Affairs Reference Committee

Re

Inquiry into planning options and services for people aging with a disability

28 May 2010

Contents

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About ACiA

Attendant care refers to any paid care or support services delivered at a person's home or in their community to assist them to remain living in the community. It targets people of all ages, with ill health or a disability. Attendant care aims to maintain or improve a person's independence and reduce his/her risk of admission to a facility or hospital. This is achieved by providing assistance based on each person's individual needs. It may include nursing care and assistance with all activities of daily living including personal assistance, domestic services, community access, vocational support, educational support, child care services, gardening/home maintenance, respite care, palliative care, social support, therapy program support**.**

Attendant care therefore supports the Commonwealth and State policies of allowing people to actively participate in society, remain in their own homes and avoid unnecessary residential care.

The Attendant Care Industry Association of NSW Inc. (ACiA) is the peak body representing private and charitable Attendant Care service providers. While it is based in NSW, its focus is National. ACiA's vision is that the Attendant Care industry is known and respected as a provider of quality services. To achieve this vision, ACiA provides education, resources and support to the industry and has now also developed a management systems standard (endorsed by JAS-ANZ) that addresses specific attendant care quality requirements.

Context

As ACiA's membership is concerned with the delivering of community based care, ACiA's comments relate to the provision of community based services. They are a broad assessment of the issues facing the industry as funding bodies and service providers struggle to meet the needs of a wide range of service users. While the comments are relevant to service users aging with a disability and their Carers, they are generally relevant to the provision of any attendant care service to any service user group.

Issue 1: The Lack of a Clear Policy on What Level of Paid Care and Support Should be Provided

While it is completely understandable from a political level, our society and the major funding bodies do not have clearly articulated policies about the types and levels of support that **will or should** be provided. This means that policy

makers/service funders do not really have a clear idea of the current need and the current shortfall. The level of support provided is determined by **each** funding program. This assessment does not appear to be based on a clear set of parameters on what we, as a society, should be able to provide.

Recommendation 1

The National Disability Standards are currently being reviewed and revised. This is an ideal opportunity to consider the minimum standards of support to which every person with a disability should have access, whether this is paid or unpaid support.

Issue 2: The Lack of an Accepted Method of Assessing Care and Support Needs

Currently there is no consistent or integrated National approach or method of assessing the need for community based care and support. As Professor Kathy Eagar (Centre for Health Service Development, University of Wollongong) succinctly puts it, "Without valid and consistent tools to measure the 'need' for community care, it is impossible to measure 'need' independent of supply, impossible to target services to those with most 'need' and impossible to measure the cost effectiveness or the outcomes of community care interventions. Instead, the only policy option is to assume that need equals demand. … The Centre for Health Service Development database alone holds 352 different assessment forms that were in use in Victoria in 2000. Our estimate is that there are probably 1200 forms being used across the country. The cost is staggering. Each has been designed by a 'working party' or 'committee' that met multiple times, there are significant training and retraining costs and there is a high cost to consumers in re-telling their stories multiple times."

This lack of ability to accurately assess need, in a timely manner, for any of the target groups in the community (for example persons with a disability or a mental health condition or a temporary debilitating illness or the frail aged), means we have been unable to assess real need and hence understand the current and potential service gaps.

This is made even more complicated by the lack of consistent agreement on when service needs should be assessed and/or reassessed. That is, what are reasonable assessment trigger points that may alert the need for services in a timely method so that there can be greater prediction of service demand. This in turn may prevent

the current support networks from collapsing and triggering admission to institutions.

Recommendation 2

Establish a working party to develop a consistent or integrated National approach or method of assessing the need for community based care and support.

Issue 3: The Initial Lack of Recognition of (unpaid) Carer Support Provided

As an adjunct to the lack of consistency in assessing needs (Issue 2), assessments do not generally accurately document the current hours of unpaid support and care being offered by family and friends. Hence, when these unpaid supports are withdrawn (for example once the Carers are too aged to continue as active carers), either there is no method for determining what services are required to maintain the person in their home, or the whole assessment process needs to be repeated.

Recommendation 3

Ensure the National approach or method to assessment of community based care and support needs (referred to in Recommendation 2 above) includes assessment of unpaid or informal support and care. The University of Sydney, with a research grant from the NSW Lifetime Care and Support Authority, is already conducting some research in to this area with regards to 24 hour care, and it would be useful for this work to be built on.

Issue 4: Lack of Funding/Services

There is a genuine shortage of available services. For example, the Home and Community Care (HACC) program clearly states it is "an ELIGIBILITY-based program, not an entitlement program; HACC eligibility does not guarantee provision of service". Therefore, even if a service user meets the requirements to obtain a service, they may never receive it.

While it is acknowledged that it is a complex cause and effect, there appears to have been little attempt to develop a model for assessing the impact of these service gaps on sustainability of people in their own homes.

Recommendation 4

Ensure the National approach or method to assessment of community based care and support needs (referred to in Recommendation 2 above) includes a model for assessing the potential and actual impact of lack of service provision in both individual cases and in order to build situational risks and profiles. This could then be used to help direct policy making and perhaps address service gaps through a clearer cost/benefit analysis.

Issue 5: Lack of Integration of Services/Support/Funding Packages

It can seem to those outside the system (and even for those inside the system) that there is a lack of integration of many services and support options for the service user and the Carer. Some of these potential integration gaps come from the federal/state funding mix and others come from the different streams of funding that are based on the type of problem/condition/disability that a client/service user may experience. This may mean that support to ageing parents/Carers (whilst they remain the primary carers for a person with a disability) may not be able to be provided to the person with a disability in the same time frames. This may mean that unintentionally, families may not be sufficiently supported to remain together as they both age and this may then lead to dissolution of the family unit.

Also, current funding 'streams' may mean some service needs can fall 'between the gaps'. For example, a person with a disability, or their Carer, may develop a new service need due to growing older. If they currently only have funding through the disability type services, they may not be able to access aged care services, or, if they can, they may then lose their disability funding.

This also makes it difficult to integrate packaged support services/hours to achieve efficiency or economies of scale.

This can particularly be a problem in regional and remote communities when the number of funding packages are limited and/or where services are restricted to a small number of providers.

Recommendation 5

By considering more closely the issue of 'need', as discussed in previous recommendations, it may be easier to identify how services could and/or should integrate. This could lead to a more integrated framework of services that clarified

when it was unreasonable for funding to be removed simply because a new area of support, whether temporary or permanent, was required.

Issue 6: Lack of Flexibility

Dealing with a crisis is often such a critical time for any family unit, but particularly so when high levels of care are being required with the family. Any crisis within the life of a person with a disability or their Carer can tend to put the delicate balance that helps sustain a person in their home. Short-term illness of the person with the disability or their carer (or even any part of this delicate balanced world such as a neighbour), death or chronic illness of a Carer or even a financial crisis (such as the need for additional medicine, a new refrigerator) can have a major impact. However, in these circumstances, being able to use available services in a more flexible way, or the provision of even a small amount of additional service (eg increased domestic assistance, shopping, respite) or financial assistance could help the family unit through a crisis.

However, due to the generally rigid eligibility criteria for the majority of funding programs, services cannot be reallocated and/or additional services or resources are generally difficult to access.

These issues can be compounded in regional and remote communities, when the number of support services, particularly respite services, are often very limited.

Recommendation 6

 ACiA understands the need for allocated funding to be used for the purpose in which it was intended. However, similarly to recommendation 5 above, identifying clear situations where it was possible for either additional resources to be allocated, or the funding to be used, even temporarily, for a new/different area of support would be useful to service users, their families and those managing funding programs.

Issue 7: Lack of Locally Available Services

It has now been understood and acknowledged that decreased access to 'mainstream' health services in regional and rural communities has lead to poorer health outcomes for those within these communities. To address these gaps,

significant steps are now being made to either provide additional services on site or through such methods as e-health.

Similarly, lack of access to services within the geographical boundaries of where service users live, can have a significant impact on whether families can continue to maintain the family unit. Of particular impact is the availability of high quality respite care. While this is a major issue in regional and remote areas, it is also significant even in metropolitan areas.

An elderly Carer may place the person they support into respite for periods of time to rest or to have some of their own care needs attended. However, they will generally not wish to sever all ties during that time and will often visit the person in the respite situation. If the respite is not local, the Carer may often decide to not look after his./her own needs and 'struggle through'. In turn, this may have an impact on the longer term positive functioning of the family unit.

Recommendation 7

(Note: This recommendation is also relevant to Issues 4, 5 and 6)
The provision of locally available supports, especially respite care, which promotes family ties, has to be a key component of all planning service options.

Issue 8: Inability to Find Out What Services Are Available

For many people, even being able to find out what services are available to access is a major stumbling block for them being able to support themselves and those they care for. This is particularly an issue when Carers may have spent all their lives dealing with one funding stream such as disability services and not be aware that other services exist to assist with new problems/issues. It is acknowledged that attempts have been made in recent years to address this, but the ability to easily find out what services are available to whom, is generally not easy.

Recommendation 8

Further explore ways of informing the community and disability service providers about the breadth of services available. The development of frameworks alluded to in recommendations 5 and 6 may assist with all community based services being able to more readily identify this.

Issue 9: Confidence That High Quality Services Are Available

Finally, service users need to be able to receive high quality services that focus on their individual care needs. Currently the community/attendant care industry has been fast-growing and its services are in demand. However, the sector is still largely unregulated, resulting in a lack of consistency in service delivery. For example, in the recent 'Shut-Out' Report we were disturbed, but not necessarily surprised, to see the disability service system being characterised as "broken and broke". While attempts have been made to introduce quality systems, these are either state-based, program-based or 'generic'. As each state or program-based service has some quality requirements, this means that service providers are currently 'drowning' in quality/performance reporting requirements. Some of our members have to address up to 13 different funding body requirements. In addition, any generic programs that are Australia wide are not focused on the specific requirements of the industry.

In order to address this clearly unsustainable effort with questionable outcomes, ACiA has developed a National Quality Certification System specifically for the attendant care industry that will meet most funding body quality requirements. The system utilises the Attendant Care Industry Management System Standard (ACIMSS). This Standard has been developed by key stakeholders and endorsed by the Joint Accreditation System for Australia and New Zealand (JAS-ANZ). It focuses on many of the issues raised in the Shut-Out report with a focus on individualised care and respect for the human rights of the service users.

Our experience to date has been that the ACiA quality system has a very positive impact on quality of care and service delivered.

Recommendation 9

We strongly recommend the adoption of National, external quality programs that are specific to the industry so that high quality of care and services can be considered the norm. Any funding program will then just have to 'map' their requirements against the available systems and address any specific program gaps, rather than commencing from' scratch'.