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ACiA Submission

To

Productivity Commission Inquiry

Into

National Disability Long-term Care and Support Scheme

13 August 2010

Contents

1. 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, allow them to participate in their community 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. The organisations that we represent employ more than 15,000 workers.

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.

2. Context

While ACiA members are vitally interested in all components of this enquiry, as ACiA's membership is concerned with the actual delivery of attendant (community) based care and support, ACiA's comments relate only to the issues that may impact on the effective delivery of such care and support. Our comments are also shaped by ACiA and its member's recent experiences of working with a scheme with a similar focus, the Lifetime Care and Support Scheme.

3. Overall Comment

ACiA strongly supports the implementation of a National Disability Care and Support Scheme (the Scheme). ACiA members daily encounter situations where people with disabilities are in need of additional and/or more flexible care and support services to enable them to remain at home **and** to participate in their community.

It is hoped that this Scheme would go a significant way towards addressing these gaps.

4. Rationale for Scheme and Target Group

Rationale

ACiA endorses the rationales outlined in the Productivity Commission's Issues Report (May 2010) for the need for a National Disability Care and Support Scheme. We are particularly pleased to see acknowledged the:

- Lack of resources in general and for specific types of services
- Inequity in service access
- Lack of flexibility in service selection
- Often poor coordination and duplication in service delivery
- Need for any Scheme to adhere to the United Nations Convention on the Rights of Persons with Disabilities

If, in the design of the new Scheme, these current gaps are clearly addressed, some current shortfalls should be overcome. Some specific design requirements are discussed later in our submission.

Eligibility and Assessment

ACiA acknowledges that determining eligibility for the Scheme is a complex area. It is clear that no matter which criteria are chosen, there will be some groups who will be disappointed at their exclusion.

While it is outside ACiA's expertise to comment extensively on this issue, ACiA believes that including 'need' as a key criterion for eligibility (as suggested in the Issues Report), will considerably strengthen the Scheme and alleviate stress in many households. It will also likely mean that the Scheme will have a greater chance of meeting the principles of the United Nations Convention on the Rights of Persons with Disabilities.

However, as outlined in the Issues Paper, there is currently 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 all persons 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 way 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.

As an adjunct to the lack of consistency in assessing needs, assessments do not generally accurately document the current hours of unpaid support and care being offered by close family and friends, nor by the informal networks of neighbours and community. Hence, when these unpaid supports are withdrawn, 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.

Therefore, the National approach to, or method of, assessment of community based care and support needs should include 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 care needs, and it would be useful for this work to be built on.

However, whichever eligibility criteria and assessment pathways are chosen, the processes used must be consistent, fair and transparent. This will require, as a minimum, the use of standardised tools and skilled and well-trained independent assessors who are regularly 'evaluated' to ensure they remain consistent and that there is 'inter-rater reliability'.

Additionally, while ACiA has no particular opinion on whether there should be an asset test or not, perhaps, if one was to be introduced, exclusion of wages for the person with the disability may overcome the risk of discouraging work participation.

5. Individualised Funding Model

Defining the Model

Any reading of the literature on 'individualised' funding will highlight the confusion and conflict re definitions in this area. It is important to not mix and confuse two distinct concepts of 'Individualised' and 'Self-directed' when describing funding models (see section 7 of Issues Paper, p 22). Individualised funding should describe funding that is dedicated for a specific service user, and based upon an assessment of that service user needs. In-Control Australia[1] outlines the principles as: independent living; individual budget; self-determination; accessibility; flexible funding; accountability and capacity. ACiA believes most funding should be individualised. As such, individualised funding can always be linked to a provider, whose responsibility is to deliver care in accordance with the assessed needs.

[1] *About Self-Directed Funding* In-Control Australia, http://www.in-control.org.au/about_sdfunding.asp

Self-directed funding perhaps most widely refers to funding that is forwarded to the service user, to source care as considered appropriate. Self directed funding may be individualised, however it is possible that the funding is not based upon an assessment of the service user's specific needs.

Model and Possible Risks

ACiA strongly believes that the services delivered to service users should be:

- **Tailored** to the individual person's **needs** with the **active involvement** of service users and/or their Carers
- Organised so they can be delivered **when** the service user needs them
- Able to be readily **varied** to suit changes in circumstances of the service user (both over the short and long term)
- Adequately funded to offer the quantity and type of services required
- Evaluated, with the service user and his/her Carers central to this process

Therefore, ACiA strongly supports individualised funding models that encourage service delivery targeted to individual needs.

However, it is acknowledged that many current services do not yet meet these core requirements. Key contributors to these deficiencies are:

- Most service funding is linked to a specific type of program and so can often only be used in a fairly limited way. In addition, if a service user wants to move to another program that better suits their needs in the short-term, they may be locked out of their previous program
- While there have been many attempts to encourage service providers to follow the principles of empowerment/involvement of services users, attempts at assessing whether these principles have been systematically implemented and have been erratic or not sufficiently rigorous

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

ACiA is conscious, that in an attempt to address these deficiencies, there is a move towards "individualised funding" as defined in the Issues Paper (p23) that is, where the person with a disability receives their own funding entitlement and spends it on services they believe will best meet their need. At face value this appears to be a positive move and there is some evidence supporting the value of this model (for example, NSW DADHC recently conducted a project[2] into self-directed funding that appeared to have positive outcomes). However, ACiA contends that these principles can be upheld in service delivery without necessarily having to utilise the model expressed in the Issues Paper with its associated risks. The individualised funding model established by the NSW Lifetime Care and Support Scheme is an example of this.

[2] NSW ADHC Attendant Care Program: Direct Funding Project Evaluation, Social Policy Research Centre, Disability Studies and Research Institute, August 2008

ACiA agrees that the risks identified in the Issues Paper (p23) are relevant to consider. For example, despite the positive outcomes described in the evaluation report of the NSW DADHC project[3], these outcomes were achieved with:

- Participants who were clearly performing better on most of the social[4] and personal well-being indicators[5] than both the 'control group' and the general Australian population
- Mostly retaining the same workers who had been recruited and trained by the previous employer and by paying workers more and paying incentives[6]
- No evaluation of objective measures of health and with only a short period of follow-up

In addition, ACiA has considered some additional issues that we believe may arise if funds are to be provided directly to the service user. These issues are particularly relevant to consider for a Scheme that is likely to be assisting persons with more complex care and support needs.

All these issues and potential risks need to be addressed in any new Scheme. ACiA has considered a selection of them below.

Capacity and Support

The NSW ADHC project stated that funding bodies would need to ensure that participants in self-directed funding have *"... the capacity to develop skills and knowledge in the following areas or have the support of people with this capacity:*

- *understanding the way the Scheme works, its guidelines, limitations and obligations*
- *financial and HR management, such as employment responsibilities, support and training for employees, OHS requirements and contract management*
- *sophisticated understanding of managing attendant carer relationships, such as negotiation and communication skills, how to resolve problems and seek advice, and conflict resolution*
- *information technology management for recording and reporting, managing attendant carers and rostering"*[7]

Based on the above requirements, it is likely that this model of funding will not be suitable for all service users and that many service users will require access to administrative assistance to deal with the mandatory infrastructure requirements (such as finances, legal obligations, contracting, technology management) as well as the complex issues around effective staff management. As a result, there is a need for a mixture of funding models, to ensure an appropriate match with service user capacity.

[3] NSW ADHC Attendant Care Program: Direct Funding Project Evaluation, Social Policy Research Centre, Disability Studies and Research Institute, August 2008
[4] Op Cit p3
[5] Op Cit p5, p41
[6] Op Cit pp22-26
[7] Op Cit p42

Decision Making That Addresses All Needs

It is acknowledged that it is likely the person with a disability is in the best position to determine the supports they most want and value and what is the best way for them to be delivered. However, there is also the possibility that, like every other person in the community, they may not have the clinical/technical expertise to advise and/or assist in assessing **all** needs and developing the most appropriate tailored package of supports. Choices that may appear to have the best outcome in the short-term (for example deciding that the expense of having a registered nurse change a supra-pubic catheter is not really justified or the family deciding that there is no need to engage a psychologist to develop a behaviour management plan) may have unintended consequences on the service user's long-term health and wellbeing.

Additionally, anecdotal reports from ACiA membership suggests as people with a disability attempt to 'normalise' their lives as much as possible, a significant number may disengage from broader health services. Again, this may have unintended consequences on the service user's long-term health and wellbeing. Should a provider be linked via funding, that provider can facilitate and advocate that the service user access appropriate health and welfare services.

Therefore, whatever the model/s chosen, the Scheme will need to implement processes where:

- Clinical/technical expertise to advise and/or assist is provided
- Any possible conflicts in care or support priorities between the person with the disability, his/her Carers and service providers can be resolved so the best overall outcomes can be achieved for the service user

Potential Impact on the Workforce

Also to be widely considered are the potential implications for the attendant care workforce. With fewer overheads, it may be possible to pay workers higher rates. However, as services are delivered 'remotely' and in the intimacy of a person's own home, there is already a complex web of relationships between an attendant care worker and a service user. However, when the one person is both employer and service recipient, consideration needs to be given to how the relationship can be effectively managed.

For example, who does the attendant care worker turn to for support if they believe that they are performing care tasks that are beyond the scope of their role? It may be said that this is no different to an employee working for any small business. But the role of providing care makes the employer-employee relationship much more complex as the employer is also the service user. And unlike OHS issues, where WorkCover is the governor of compliance, there really is no such equivalent agency for the attendant care worker to turn to when they have concerns are about clinical issues, or scope of role. Indeed, how do attendant care workers learn about the scope of their role, if they have no previous experience or formal qualifications?

(Also refer to Sections 6 (Workforce) and 7 (Quality))

Potential Impact on the Attendant Care Industry

ACiA understands the sentiment behind the comment from the Issues Paper that service providers must deal with "... uncertainty ... similar to that faced in all markets in which consumers make individual choices ..." (p23). However, this 'market' has some marked differences to other consumer-driven markets. No other health, care or support industry, which deals with vulnerable people in their own homes or community, is currently unregulated. ACiA is working hard with the industry and funding bodies to try to address issues to improve the professionalism and accountability of providers, particularly through our ACiA Certification to the Attendant Care Industry Management System Standard (ACIMSS). However, there is still a long journey to go before ACiA realises its vision of an industry that is respected and known as a provider of quality services. Therefore, at a time when increasing demands are being made on providers to ensure high quality care and support is delivered, it is interesting to see models of care and support delivery being proposed that are likely to push the attendant care industry back to something like a 'cottage industry'. ACiA wishes the Commission to fully consider the impact of any model where an uncontrolled and disparate group of individuals are providing increasingly complex services.

(Also refer to Sections 6 (Workforce) and 7 (Quality))

6. Workforce Issues

Employment in the social and community services workforce expanded by 66.2 percent in the decade to 2006, compared with national employment growth of 19.2 percent[8]. Despite this rapid growth, the sector is still characterised by a chronic shortage of workers. The difficulty in attracting workers to the community sector is well documented[9], as are the numerous reasons for this.

Value Placed on Work

While it is not the only issue, it is clear that the value of the work undertaken by all employees in this sector, but particularly in community based services, continues to be undervalued. This is despite:

- The increasing complexity of the work being undertaken
- The special range of skills required to complete the tasks competently and in a such a way that there is respect shown (as the service is being delivered in the person's own home or community) and so the service 'adds value' to the quality of the person's life
- The unsocial and erratic nature of the work

[8] *Profiling non-government community service organisations in NSW: Summary Report*, Social Policy Research Centre, University of New South Wales, July 2010, p 1

[9] ACOSS (2010) *Australian Community Sector Survey 2008-2009, p6*

The lack of value is shown primarily in rates paid by funding bodies for services. This impacts of course on the wages paid to workers, but also affects what resources can be put into developing and nurturing what is essentially a remote workforce.

Conditions

Another issue is the uncertainty of work hours. The increased focus on meeting individualised needs and program-specific funding also adds challenges. As 'peak' service request times are early morning and early evening, workers can have large gaps in their schedules. Additionally, if the program funding stops or changes, or the person wishes to alter their services, so does the employment. It is difficult for most workers to live with this level of uncertainty and hence they will seek work in a more stable environment. Another area that contributes to uncertainty is the capacity of a funding model to respond to instances where the service user enters respite or hospital, and the resulting need to retain workers during this period. In a context where recruitment of suitable staff is difficult, a funding model that does not address the need to retain staff will result in those workers seeking alternative employment, and then the probable lack of staff to resume care when the service user returns home.

Also impacting on the retention of workers is the lack of regulation and disparity between providers in terms of the quality of support that is given to workers (refer also to Section 7). In particular, funding is generally not given to train workers to gain the skills required to meet an individual's needs or to attend meetings/ongoing training. This means that either the provider organisation has to pay the worker salary (unfunded) to complete this training or the worker has to agree to attend in their own time. This is of course a little unreasonable to expect of worker who is only receiving $20per hour.

In the case of self-directed funding, there is likelihood that the employer (that is, the service user) will determine the skills requirements of their workers on the basis of their own care needs. As such, there is less incentive to allocate funds towards broader training programs that would enhance the worker's capacity to work with clients with other disabilities etc. Consequently, there is a tendency to limit training to the needs of the service user, which fosters a 'cottage industry' workforce.

Due to the type of work, that is remote from supervision and support, it can also make it harder for workers to feel well-supported and supervised.

Career progression is also an issue, as it is for every casual workforce in Australia.

Public/Not-For-Profit/Private Providers

ACiA represents all attendant care service providers so has no particular opinion as to the structure of services providing services. However, ACiA does believe that the same standards of service delivery should be expected of **all** providers. In addition, almost half (47 percent) of community service organisations around Australia are private[10] and yet

[10] *Profiling non-government community service organisations in NSW: Summary Report*, Social Policy Research Centre, University of New South Wales, July 2010, p 1

most government policy continues to regularly exclude this sector in policy discussions. Two examples of the impact of this are:

- As private providers cannot access the same fringe benefits as not-for-profit organisations, they potentially have greater issues to face with workforce recruitment and retention
- NSW ADHC has recently launched some initiatives to try to attract workers to the industry, including the development of an online career service to assist with the advertising for and recruitment of workers. However, this service is unavailable to private providers

Attendant Care Worker Training and Qualifications

ACiA conducted a survey of its members last year on the issue of training and qualifications. Most providers stated that they generally employed people with a Certificate III. However, this appeared to not be because of the skills or knowledge that workers had obtained, but because it demonstrated some level of commitment to the work to be undertaken. They therefore mostly felt that they still had to train staff 'from scratch'. Major issues surrounding the attainment and value of these qualifications were:

- For each and every service user, individualised training is still always required
- The wide range of subjects that are offered in Certification courses means that careful examination of the qualification is required to know if anything relevant had been covered
- Despite having been deemed 'competent' on a topic, providers felt that workers generally needed to be trained again and again. Some therefore questioned the rigour of the competency assessment

In no way should this be interpreted as ACiA not supporting training such as Cert III. As noted above, where these programs are conducted thoroughly and competency assessed with rigour, workers have the opportunity to gain a broad range of knowledge and skills that begins to professionalise the workforce as a whole.

Ability to Meet Future Workforce Demands

Given that the industry is already facing significant workforce shortage, it is difficult to consider how a great increase in workforce demand could be met with the current system. ACiA believes that this position will not change unless considerable changes to pay and conditions are supported.

Possibility of Productivity and Efficiency Gains

If care and support is to be individualised, it is also difficult to consider how productivity and efficiency gains can be made for the individual workforce. However, ACiA believes that major gains can be made to productivity and efficiency through reduction of the current burdensome administrative demands on providers.

Streamlining reporting requirements and quality evaluation requirements (refer to Section 7) would assist in this. It is also likely that this streamlining will be facilitated by making the Scheme National rather than State/Territory based as no matter what the intention, each State/Territory will likely wish to adapt the requirements and providers will need to comply with eight different requirements.

Possible Strategies

Pay
The National Pay Equity Case (affecting the *Social, Community, Health Care and Disability Services Industry Award 2010)* that is before Fair Work Australia may make a substantial difference to the salaries paid to workers in the community. However, if that wage increase is not fully funded, the only option will be for services to be affected.

Funding
While ACiA understands that the Commission must balance affordability against service delivery, ACiA encourages the Commission to ensure that:

- Any major changes to wages are fully funded and that the value of workers in this area continues to be better recognised
- Consideration is given to the substantial costs and difficulties of managing a remote workforce, especially if the focus is on 'individualised' and 'program-based funding'. These should be considered in the rates paid to provider organisations and hence workers

Attracting and Training the Workforce
It is clear from the recent NSW ADHC career project, that government intervention to promote the industry to the public as a possible career choice can have some benefits. However, other models in industries that have struggled to improve their image could also be considered. For example, the meat-processing industry has considerably changed its perception in its workforce target group through a comprehensive, long-term, National, training program that has led to a more professional workforce.

If there is to be further investment in National training, the subject selection must be carefully considered and rigorous assessment of competencies must be enforced.

7. Service Quality Standards

ACiA fully endorses the need for services to be assessed to determine if they are delivering high quality care and support that is focused on individual needs. It is acknowledged that the industry is still largely unregulated and there is a lack of consistency in service delivery. While attempts have been made to introduce quality systems, to date these have not achieved what was hoped for. For example, in the recent 'Shut-Out' Report[11] ACiA was disturbed, but not necessarily surprised, to see the disability service system being characterised as "broken and broke".

ACiA believes these shortfalls arise for a number of reasons:

- Most quality requirements have been state or funding program focused and have been conducted by internal staff who do not necessarily have extensive auditing

[11] "Shut Out: The Experience of People with Disabilities and their Families in Australia" August 2009, p 3

expertise. While some disability services have moved to external certification, they are still state-based. Hence, some of our members have to address up to 13 different funding body requirements. This means that providers tend to have to focus on the 'red-tape' of compliance rather than delivering improving care and service
- Many of the quality systems/requirements do not focus on service governance or management. This may have a substantial impact on the effectiveness of the service as a whole, particularly the effective management of risks and staff
- The only quality programs that had been Nationally available were 'generic' and hence were not focused on the specific requirements of the industry in terms of service delivery or were focused on the processes of care delivery rather than the outcomes of care

Hence, in order to address this clearly unsustainable audit/evaluation effort with questionable outcomes, ACiA developed a National quality certification system specifically for the attendant care industry that we believe has met most funding body quality requirements to date. 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).

ACIMSS:
- Meets the current National Standards for Disability Services and the Interim Standards, as well as each State-adapted set of Disability Standards
- Focuses on many of the issues raised in the Shut-Out report with an emphasis on individualised care and respect for the human rights of the service users
- Focuses on the key issues required to deliver high-quality, individualised care in the community including effective organisational governance and management and appropriate, low risk service delivery with positive care outcomes
- Is suitable for services delivered in the person's home (whether their own property or a 'group' home as per CSTDA 1.04) and within their community (eg community access, vocational support)
- Is suitable for the delivery of services for any type of disability

ACiA's program began in 2009 and our experience to date has been that the organisations who have implemented the ACiA Endorsed Certification to ACIMSS system have been able to demonstrate improved quality of care and service delivery outcomes.

Therefore, we strongly recommend that the Scheme does NOT attempt to develop its own internal quality requirements that would considerably add to the 'red-tape' for the industry, without clearly appreciable outcomes. Instead ACiA would 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 National Scheme only then needs to 'map' their requirements against the available systems and address any specific program gaps, rather than commencing to develop internal or external systems from 'scratch'.

Similar models could also be developed for other types of service delivery.

8. Governance

National or State Scheme
ACiA strongly believes that the Scheme should be administered Nationally. This is to encourage equity and consistency across Australia. If each State or Territory was given carriage of the Scheme, no matter what the intention, each State or Territory will likely wish to adapt the agreed systems and there will be eight different Schemes with eight different sets of requirements.

Stakeholder Consultation
For such an important and extensive Scheme, ACiA believes that there needs to be a variety of consultation mechanisms utilised. We believe there should be an advisory board that provides overall direction to all aspects of the Scheme. As it is likely that attendant care will form a significant part of the services provided by the Scheme, ACiA would like to suggest that we had a representative on this Council.

In addition, there should be expert National panels established that can provider formal direction to the Board and Advisory Council on specific aspects of the Scheme. These panels could include for example; a service user council, rehabilitation best practice advisory group, community care and support solutions, return to work facilitation and equipment prescription.