National Aids and Equipment Reform Alliance Submission to the

Productivity Commission Inquiry into a Long Term Disability Care and Support Scheme

10 September 2010

Introduction

The National Aids and Equipment Reform Alliance strongly supports the establishment of an insurance-based Long Term Disability Care and Support (LTDCS) scheme for people with severe and profound disabilities.

This submission focuses on one of the essential components that will be required in such a scheme: the provision of aids and equipment. Most people with severe and profound disabilities will require access to aids and equipment, and the related structures and processes to ensure that appropriate equipment is provided in a timely manner. Appropriate and timely provision of aids and equipment is a significant component in ensuring that Australia fulfils its obligations as a signatory to the UN Convention Rights of Persons with Disabilities.

The eighteen national organisations endorsing this submission on behalf of the Alliance are listed in Appendix A. The Alliance is a new collaboration of peak groups from healthcare, disability, aged care, as well as veterans and children's services (including consumer/carer, professions and service providers). It has been formed to address the range of aids and equipment issues across all jurisdictions.

In the absence of a national aids and equipment policy framework there is currently an inefficient and often ineffective patchwork of over 100 separate equipment schemes operating in Australia with inconsistent patterns of funding and service delivery. While there is a major aids and equipment reform imperative required in Australia that the Alliance is addressing, this submission aims to alert the Commission to the most relevant issues within the terms of reference of the current inquiry. Details about the Alliance and its national reform agenda for aids and equipment is attached as Appendix B.

Aids and equipment is a fundamental enabler for people with disabilities in all aspects of their lives, in much the same way as other disability services. It is mostly miscast as supplementary to other disability services, and is not fully recognised as a genuine service in its own right. For many people equipment can facilitate independence and enable them to engage in the community and increase self reliance. However the existing disability equipment schemes for people with disabilities are underfunded and cannot meet demand, consequently their processes are more focused on gate-keeping and prioritisation of need than on appropriately meeting equipment needs, and are therefore not useful models for consideration by the Commissioners.

Scheme Design

As a no fault scheme the Alliance can only assume that it will operate in a similar way to the TAC and ACC with an individualised focus and full funding responsibility, with the ability to fund a suite of support services that would include aids, equipment and assistive technology.

Having worked with austere and poorly arranged equipment schemes in Australia, the Alliance strongly supports a design that utilises a threshold test for services to eligible people based on reasonableness and relevance as is the case with the TAC, rather than one that caps benefits and uses rigid lists to determine the specific items of equipment that can be funded by the scheme. We believe a rigorous test of the reasonableness of support requests can

allow tailored services to be created (including aids and equipment) that can fulfil client goals. The most successful approach to the delivery of aids and equipment is one that is flexible, timely, meets clients' needs, and is sustainable.

While the Commission is clearly focused on the design of a new scheme as outlined in the terms of reference, we note that the scheme will need to exist as a complementary entity to other service systems in the community (such as Medicare, aged care, PBS etc) and as well as serving its own interests, will need to take part in (and sometimes lead) reform initiatives that cover areas of its operation. Aids and equipment is one of these areas that is going to be subject to cross-jurisdictional reform in the coming years, and as a future major player, the scheme has a role to play. We note the comment in the Issues Paper that the Commission would not like to see the scheme operate either as an island program or duplicate existing program infrastructure, and the Alliance believes that this is exactly the dilemma facing the 100 or so equipment programs in Australia.

An End-to-End Aids and Equipment Program

To maximise effectiveness and appropriate use, minimise abandonment of equipment, and help ensure the sustainability of the LTDCS Scheme's aids and equipment service, a broad set of services and infrastructure is essential. Basic elements of this end-to-end approach include:

- Information about aids and equipment services
- Simple access to the system with a single front-end for consumers, carers and their families
- Effective assessment incorporating individual requirements, choices and preferences
- Referral
- Prescription
- Design and customisation
- Trial
- Supply
- Training
- Maintenance
- Replacement
- Recycling
- Research, development and innovation

Some of the key subsets of this end-to-end approach are outlined below.

Supply Chain and Purchasing Arrangements

The capacity to purchase equipment on a relatively large national scale will enable the Scheme to achieve some efficiencies in relation to bulk-purchasing of some standard items in regards to both equipment and related services. Consideration should be given to working closely with other national or large aids and equipment programs in Australia to increase these efficiencies of scale, and particularly in relation to providing coverage in rural and remote areas.

Extensive duplication and the concomitant inefficiencies across numerous programs is a serious problem currently for suppliers, funders and consumers, and ideally the LTDCS Scheme should not further contribute to this. An ideal structure would utilise LTDCS Scheme internal funding and approval processes, with actual equipment and related services supplied by linked-up national procurement and local delivery supply structures.

In regards to bulk purchasing of equipment, this should certainly be done when possible and appropriate. But this must not lead to a one-size-fits-all program where individual equipment needs are not met appropriately.

The Alliance recommends that the Commission examine the purchasing arrangements used by other schemes (particularly the ACC, TAC, DEEWR workplace modifications scheme and DVA) to develop a model that can deliver value for money, consumer standards, reliability of delivery, repairs and maintenance and consumer choice. These schemes have individualised approaches to equipment supply.

The State and Territory schemes are based more on a programmatic response and have significant design issues that impede their success, most notably a lack of adequate funding. Co-payments are very high in some of these systems (up to 78% for some products in some schemes) and are a major deterrent to efficient and effective supply.

Given that many people utilising the existing schemes go without prescribed equipment because they cannot afford the co-payment, and because equipment is as much a service response as other disability services, we would recommend that there be no co-payments for approved equipment in the proposed scheme. There may be an argument for some opportunity for negotiated co-payments for certain home and vehicle modifications as each one will have different circumstances, but the applicability of the reasonableness test will sort out these cases.

Quality Control

An effective end-to-end system will require a good supply chain and a skilled and available workforce. It will also require quality control processes to be established and monitored. Key elements of this will need to focus on equipment standards and credentialing of service providers.

At a minimum it would be expected that all equipment provided would meet Australian or equivalent international standards where they exist, and the process would involve credentialed staff. A degree of flexibility is required as not all equipment has been through the Australian Standards process, often due to cost or innovation issues. While a more streamlined process to accept items that meet international standards is not yet in place, it is underway, and this will assist.

The Australian Rehabilitation and Assistive Technology Association (ARATA) is in the process of developing a credentialing process for the workforce, but this is in progress and seems most likely to initially credential and support individual providers. Significant work will be needed before a system for accreditation of service provider organisations could be developed. Currently there is high reliance on academic and professional qualifications (such as Occupational Therapists and Physiotherapists), but there is also a recognised need for

specific skills and expertise in relation to particular kinds of equipment such as wheelchairs and communication aids.

While it is well outside the scope of the Commission to resolve these issues, and likely to be outside the scope of the LTDCS Scheme as well, the LTDCS Scheme will need to incorporate these developments as they occur, and hopefully be part of the dialogue in their development.

Deciding on What Equipment will be Purchased and Supplied

It will be essential for the Scheme to establish processes for deciding what it will and will not fund in relation to aids and equipment.

The Alliance strongly recommends that decisions are based on what clients need, and not on a restrictive list of 'eligible' equipment, and that this includes home modifications, home appliance modifications and vehicle modifications when deemed appropriate.

Transparent and robust approval and appeal processes will need to be in place to ensure that what is being provided is needed and appropriate, and that the Scheme maintains its sustainability.

Current research and best practice regarding provision of aids and equipment is predicated on a partnership model which combines the expertise of professionals with the expertise and preferences of consumers, and the Alliance strongly supports that such an approach be embedded in the Scheme.

In establishing a process for clients and families to appeal particular decisions, it is essential that this does not replicate existing medico-legal models in most compensation schemes, and moves instead to a more robust model that incorporates expertise from consumers, their families, and experienced and skilled independent professionals.

Timeliness is often a critical feature, and delays create additional health risks as well as sometimes making equipment redundant before it reaches the client. This is particularly the case for children and some people with progressive conditions such as motor neurone disease or multiple sclerosis. So it is essential that the decision making processes – from initial identification of need through to actual supply/fitting/training – is not unduly complex or slow and allows for an anticipatory approach for people with rapidly progressive conditions and for children. Some programs have implemented two-tiered structures to help manage this, with some equipment immediately available on 'prescription' and other more complex and costly equipment requiring review and authorisation.

'After Sales' Services

It will be essential for there to be follow-up and review processes after equipment is provided, so ensure appropriateness, enable adjustments/modifications, and provide any additional training and support to clients and families in the use of the equipment.

A key aspect of this is also planned maintenance, and unplanned repairs. This will require an available and skilled workforce, and utilisation of a national supply chain and local service network. Accessing expertise in the right location is as common logistical problem for existing aids and equipment programs. Given the breadth of different aids and equipment required, and the level of expertise to fit, service, train users, maintain and repair equipment a very strong 'after-sales' logistics framework will be essential. And again, rural and remote areas pose particular challenges.

Also, recycling of equipment is facilitated with a good after-sales program, and evidence from other schemes such as Enable NZ which provides aids and equipment services for the ACC in NZ indicates that substantial savings can be achieved with a well developed recycling program linked to a national supply and service structure.

Timeliness is also a critical feature of after-sales services. If a wheelchair has a flat tire, a hoist does not work, a communication aid fails – the client is often 'held prisoner' and their life grinds to a halt until it is fixed. So whatever after-sales structure is put in place, it must be capable of a quick response across all geographic locations.

Research, Development and Innovation

Aids and equipment are constantly being improved, with ongoing new developments and innovation. The Scheme needs to support this process and should consider establishing an innovation and evaluation fund. This would help ensure that clients have access to the most effective aids and equipment for their needs; would promote an evidence base in the use of new (and established) equipment on offer; and may assist in establishing a local aids and equipment industry (particularly focused on the high-end/high cost equipment, nearly all of which is currently imported). This may also be valuable in ensuring that the skills and expertise are available to maintain and repair some of the new generation equipment now on the market.

In addition, an assistive technology reference group could be established to evaluate proposals and conduct research on changing technology. This group would comprise key industry operatives, academics, engineers and consumers.

Conclusion

There is good evidence that the delivery of appropriate and timely aids and equipment to those that need it can: improve the quality of life for those with functional impairments and their carers and families; reduce residential care admissions; reduce family carer injuries and stress; increase participation in employment and education; reduce hospital admissions; and shorten hospital stays (AIHW 2006 & 2003; Audit Commission 2004, 2002 & 2000).

An initial investment in the right aids and equipment at the right time can head-off down-stream and more expensive costs, as the case study below indicates. The LTDCS Scheme, if fully funded, would be able to deliver appropriate equipment and create savings.

A Pressure Care Case Study

This case study demonstrates the kind of inefficiencies and adverse health outcomes that occur within the current fragmented and underfunded system. The proposed scheme would be able to deliver clinically recommended services to individuals and avoid perverse cost shifting purely because it would have funding and program responsibility located in the one place. This would result in a range of improvements and system offsets.

In 2001 it was estimated that $350 million is spent on caring for patients with pressure ulcers. The inpatient recovery time for a serious pressure ulcer is measured in months or even years. In 2001 the cost of each pressure ulcer was $61,000[1]. Using the CPI (which is less than the medical CPI), this has increased by 18% since 2001, and in 2007 would have cost over $412m annually.

While not all pressure ulcers can be prevented, many are caused by inadequate equipment, notably seating and mattresses. Providing the correct pressure relieving equipment is not optional for the individual, however the waiting times and limits on types of products make it so.

It is common for people with MS with pressure ulcers unable to get the right equipment to spend up to 6 months in hospital recovering. Such a stay costs in the vicinity of $80-100,000, and can result in increased community care costs and carer burden upon discharge. The purchase of an $8,000 mattress and good seating in addition to self management support can prevent such episodes. Saving just one hospital admission per lifetime for a person at risk of pressure ulcers justifies the investment.

This highlights the fact that it is false economy for government to short-change aids and equipment schemes. This example is but one that demonstrates that it is more expensive and resource intensive to avoid providing the right equipment than to provide it. The fact that it is represented by cost shifting rather than cash deficits perhaps explains why it has been tolerated for so long.

The fact that we have allowed one of the lowest cost programs (PADP) to cost shift to the most expensive (hospitals) is poor economic and health policy.

[1] Australian Wound Management Association. Clinical Practice Guidelines for the Prediction and Prevention of Pressure Ulcers. West Leederville WA, Cambridge Publishing, 2001

The aids and equipment component of the LTDCS Scheme will become one more of the over 100 existing aids and equipment schemes in Australia, and become part of the overall national spend on aids at equipment currently estimated to be $4.5B. We are hopeful that as a national scheme it will take some of the pressure off existing programs, and provide a model of a large-scale national aids and equipment program which demonstrates the value of scale providing aids and equipment and the capacity to effectively deliver at a local level.

The Alliance is well placed through its members to provide additional information and assistance to the Commission in relation to aids and equipment, and our membership will submit further data and information to the inquiry in the coming months. We look forward to working with the Commission on developing recommendations and a framework for operationalising a LTDCS Scheme.

References

AIHW 2006, *Therapy and Equipment Needs of People with Cerebral Palsy and Like Disabilities in Australia*, Cat. No. DIS 49, Australian Institute of Health and Welfare, Canberra.

AIHW 2003, *Disability: the use of aids and the role of the environment*, Cat. No. DIS 32, Australian Institute of Health and Welfare, Canberra

Audit Commission 2004, *Assistive Technology: Independence and Well-being 2*, The Audit Commission, London.

Audit Commission 2002, *Update: Fully Equipped*, The Audit Commission, London.

Audit Commission 2000, F*ully Equipped: The Provision of equipment to older or disabled people by the NHS and social services in England and Wales*, Promoting Independence 2, The Audit Commission, London.

Appendix A: Organisations Endorsing this Submission on Behalf of the National Aids and Equipment Reform Alliance

Carers Australia

Australian Rehabilitation and Assistive Technology Association (ARATA)

Independent Living Centres Australia (ILCA)

Australasian Faculty of Rehabilitation Medicine

National Committee on Rehabilitation Engineering of the College of Biomedical Engineers of Engineers Australia

Australian Federation of Disability Organisations (AFDO)

Association of Occupational Therapists Australia

Cerebral Palsy Australia

Multiple Sclerosis Australia (MS Australia)

Young People in Nursing Homes Alliance (YPINH)

Australian Healthcare and Hospitals Association (AHHA)

Pharmacy Guild of Australia

National Disability Services (NDS)

Children with Disability Australia (CDA)

The Returned and Services League of Australia (RSL Victoria)

Vision Australia

Independent Rehabilitation Suppliers Association (IRSA)

Motor Neurone Disease Australia (MND Australia)

Appendix B: National Aids and Equipment Reform Alliance Foundation Document

The National Aids and Equipment Reform Alliance

Background

There is good evidence that the delivery of appropriate and timely aids and equipment to those that need it can: improve the quality of life for those with functional impairments and their families; reduce residential care admissions; reduce family carer injuries and stress; increase participation in employment and education; reduce hospital admissions; and shorten hospital stays.

One in ten Australians use aids and equipment, and national expenditure is approximately $4.5B. However, there is not a national strategy or policy framework to provide a coordinated and rational approach to ensure adequate access, and efficiency in the provision of aids and equipment.

Current arrangements are seriously flawed, as findings from numerous reviews and inquiries over the last 30 years have demonstrated. Recent reports such as *Shut Out* and the Disability Investment Group's *The Way Forward* have again found ongoing and systemic failures in the delivery of aids and equipment across Australia.

The consequences of this are:

- Although many people have their needs met, too many have unmet, partially met or inappropriately met needs
- Lost productivity and reduced participation in all aspects of life including: personal aspirations, employment, education, family and community life
- Cost shifting to individuals and families who can least afford it through high co-payments for some equipment, limited lists of available equipment in public schemes (often including no or very limited funding for home and vehicle modifications); and a patchwork of eligibility requirements
- An ad hoc and uncoordinated patchwork of over 100 aids and equipment programs, with dysfunctional consequences such as equipment provided to assist at work not being able to be used in the community or at home
- Cost shifting to more expensive down-stream services
- High levels of administrative and structural inefficiencies
- Inability to deliver on a range of commitments and obligations, including the UN Convention on the Rights of People with Disabilities, and the intended outcomes of the National Disability Agreement and the National Disability Strategy.

In short, the outcomes are poor for individuals, their families, communities and governments.

Governments are unable to effectively deal with these consequences and the changes required without our engagement in a robust reform process.

Major policy and structural reform is required to ensure that aids and equipment are available as and when they are needed. If this can be achieved it will deliver significant benefits to individuals, families, communities and service systems through improved health and independence, increased productivity and reduced health, community care and residential aged care costs.

From a policy perspective it is essential that the timely and effective provision of aids and equipment moves from the fringes of public policy to a more central position which recognises that it is an essential service and fundamental prerequisite to achieving a more inclusive society and the intended outcomes of many government programs and policies across portfolios and jurisdictions.

The first step in achieving reform is the development of a national aids and equipment policy framework and strategy.

The Alliance

The National Aids and Equipment Reform Alliance (NAERA) has been formed to coordinate and resource the work required to promote the development and implementation of a national aids and equipment policy framework and strategy.

The Alliance is a focal point for developing an agreed national agenda and strategy, and will play a coordinating role across members as the campaign for change goes forward. It will be essential for members to undertake policy activities in their own right, but in a coordinated way to maximise impact.

The Alliance is also a centralised point where resources can be developed and shared, as well as a portal for communication across Alliance members, and for coordinating and managing the campaign as it goes forward.

A National Aids and Equipment Alliance Reform Alliance will:

- Present a unified and articulate case for the development and implementation of a national policy framework and strategy, and related reforms
- Be outcome driven and able to communicate clearly with government, providers, consumers/carers and other stakeholders
- Commit to short and long term strategies for change
- Be supported by a national secretariat that resources the Alliance's work related to the establishment and implementation of a national aids and equipment policy framework and strategy

There are now key opportunities available to get aids and equipment onto the policy agenda more substantially. This includes: the Productivity Commission's Public Inquiries into both Disability Care and Support, and Caring for Older Australians; Health and Hospital Reforms; National Disability Strategy; and revising responsibilities between state and Commonwealth governments regarding aged care and disability. There are also reviews and redevelopments underway of some of the state-level aids and equipment programs, and other opportunities will arise over the next few years.

So it is vital that we move quickly to build a strong Alliance to work together to provide the necessary focus and commitment to the ongoing research, policy and campaign work essential to moving aids and equipment up the policy agenda across relevant government portfolios.

Principles for Aids and Equipment Reform

The primary goal of the Alliance is to promote and inform the development and implementation of a national aids and equipment policy framework and strategy.

The Alliance believes the following principles should underpin the national policy framework and strategy:

1. Equitable access to aids and equipment must be based on need, irrespective of capacity to pay, age, geographic location, living arrangements and cultural background. This includes improving access for Aboriginal and Torres Strait Islanders.

2. All Australians must have timely access to good quality aids and equipment that addresses their needs across their lifespan and holistically across all areas of life.

3. Consumers, and where appropriate their families, must be involved in all aspects of securing aids and equipment to meet their needs: at an individual level, service delivery level and policy level.

4. Aids and equipment must be portable across all life domains and jurisdictions, including: across states and territories; and across programs, such as disability services, community care, health, education, employment, residential care, and recreation.

5. Administrative and economic efficiency of delivering aids and equipment must be increased by: creating a

more unified and rational supply chain; investigation of national purchasing arrangements; increasing competition and consumer choice; and meeting required standards.

6. Aids and equipment policy frameworks, delivery systems and processes must be underpinned by evidence of their effectiveness in achieving the above principles and in meeting Australia's commitments and obligations under the UN Convention on the Rights of People with Disabilities, and the intended outcomes of the National Disability Agreement and National Disability Strategy.

Key Elements of an Aids and Equipment Reform Agenda

At a minimum, achieving the above principles will require:

1. Improved and broadly applied structures and processes to:
   - ensure ease of access and use for consumers and their families (and professionals);
   - reduce jurisdictional boundaries and duplication of administration; and
   - improve purchasing power, distribution and supply, without reducing competition and consumer choice.

2. More universally applied policies and related structures and processes must also be developed to determine:
   - Who is eligible for publicly funded aids and equipment?
   - What is the appropriate mix of public, private, insurance and philanthropic funding?
   - Which aids and equipment should be available for public funding, including vehicle and home modification, in relation to effectiveness, standards, and cost/benefit analysis?
   - Co-payment and safety-net arrangements?
   - Integration with other systems/programs?

   Currently two Australian service delivery models can be drawn on that provide demonstrably effective and workable solutions to these kinds of structural and procedural requirements: Medicare and PBS.

3. To do this effectively will also require consideration of:
   - Amalgamation and simplification of the numerous aids and equipment programs into a more rational and inter-connected set of programs, including the use of shared and over-arching administrative frameworks with local delivery;
   - Consideration of re-alignment of the roles of the Commonwealth, states and territories in the funding and delivery of aids and equipment across the health, disability, aged care, education, employment, housing, sport/recreation, justice and other relevant portfolios.

4. Numerous recent reviews of the major state-level aids and equipment programs have tended to make a similar set of recommendations which also have salience when considering a national policy framework and strategy. Key issues include:
   - Consolidating/centralising multiple issuing centres into a single service with local outlets
   - New administrative structures and processes, and IT platforms to streamline and improve processes and data collection regarding:
     - Assessment
     - Applications
     - Prioritisation
     - Funding
     - Managing waiting lists
     - Dispute and complaints processes
     - One phone number, one email address
     - State-wide procurement AND recycling
     - Improved/unified equipment maintenance and repair delivery systems

5. An end-to-end approach is required when providing aids and equipment. It is not as simple as just providing a piece of equipment, the whole process needs to be considered to maximise effectiveness and appropriate use, and minimise abandonment of equipment. Basic elements of this include:

- Information about aids and equipment services
- Simple access to the system with a single front-end for consumers and their families
- Effective assessment incorporating individual requirements, choices and preferences
- Referral
- Prescription
- Design and customisation
- Trial
- Supply
- Training
- Maintenance
- Replacement
- Recycling

6. An accurate assessment of the level of demand for aids and equipment, and determination of the national costs and benefits of aids and equipment, to clarify the level of public funding needed, and strike an appropriate balance between public/private expenditure.

7. Investigation of an industry development plan for the Australian aids and equipment manufacturing industry, including establishment of related research and innovation capacity.

8. Establishment of a national research program, including: improved data collection; evaluation of aids and equipment program processes and outcomes; and research into the personal, family, social and economic impacts of aids and equipment.