

**youngpeople
innursinghomes**
NATIONAL ALLIANCE
Shaping the future today



Submission to the Productivity Commission's Inquiry into Disability Care and Support

**Young People In Nursing Homes National Alliance
September 2010**



The Young People In Nursing Homes National Alliance welcomes the opportunity to contribute to the Productivity Commission's public inquiry into Disability Care and Support.

The Alliance is a national peak organisation that promotes the rights of young disabled Australians with high and complex clinical and other support needs living in residential aged care facilities or at risk of placement there (YPINH™); and supports these young people to have choice about where they live and how they are supported.

The Alliance's membership is drawn from all stakeholder groups including YPINH, family members and friends, service providers, disability, health and aged care representatives, members of various national and state based peak bodies, government representatives, and advocacy groups.

We encourage a partnership approach to resolution of the YPINH issue by State and Commonwealth governments; develop policy initiatives at state and federal levels that promote the dignity, well being and independence of YPINH and their active participation in their communities; and ensure that young people living in nursing homes and their families have

- a voice about where they want to live and how they want to be supported
- the capacity to participate in efforts to achieve this, and
- 'a place of the table', so they can be actively involved in the service responses needed to have "lives worth living" in the community.

As the pre-eminent national voice on this issue, the National Alliance's primary objectives are to

- Raise awareness of the plight of YPINH™
- Address the systemic reforms required to resolve the YPINH™ issue and address the urgent need for community based accommodation and support options for young people with high and complex needs
- Work with government and non-government agencies to develop sustainable funding and organisational alternatives that deliver 'lives worth living' to young people with high and complex clinical and other support needs
- Provide on-going support to YPINH, their friends and family members.



THE YOUNG PEOPLE IN NURSING HOMES COHORT

Approximately 6800 young Australians with disability presently occupy a not insignificant 5% of residential aged care beds nationally because our existing disability service system cannot provide the supports and services they need.

Many more young Australians are at risk of placement in aged care if this situation continues and the disability system remains unable to respond to their complexity of need; and integrate the clinical and other supports these young people require.

It is for this reason that, since 2002, the Alliance has consistently argued for a life time care and support (LTCS) approach to service development and delivery for these young people; and for an insurance based approach to funding to support this methodology.

Because of their complexity of need and requirement for clinical input, the Alliance believes that a life time care approach directly involving health and disability services as partners in the delivery of care for these young people is essential.

The Alliance also believes that until a comprehensive LTCS service system is operational, the aged care services system will need to partner with health and disability services in the delivery of care for this group from time to time.

Key features

Characterised by disabilities acquired as a result of catastrophic injury or through progressive neurological diseases, these young people require service responses from not one arm of the service system but several, including health, disability and sometimes aged care amongst others.

They arrive at the door of the disability system without warning and require immediate and often intense responses that the service system, in its current form, cannot deliver in a timely or effective manner. Data received from aged care providers indicate that the majority of younger residents in aged care are categorised as high dependency.¹

Recent studies have also concluded that

[YPINH] have high levels of complex health conditions which require daily care and a range of specialist expertise and equipment...accommodation services

¹ Of a total 6,505 residents under 65 in June 2006, the majority or 4,911, were categorised as high dependency (RCS 1-4); the remainder or 1,594 were considered low dependency (RCS 5-8). *Source:* AIHW analysis of DoHA Aged and Community Care Management Information System (ACCMIS) database. Australian Institute of Health and Welfare, *Older Australia at a Glance*, 4th Edition, Canberra, 2007: 135.



need to develop strategies and supports to integrate management of these complex health requirements.²

Previous studies indicate that the population breakdown of young people in nursing homes group with acquired disabilities is

- *Acquired Brain Injury (ABI)* 30%
- *Physical Disability* 27%
- *Neurological* 23%
- *Intellectual/psychiatric* 20%³

These figures also include a large number of people with high needs without speech who are particularly at risk.

ABI was the primary disability group of close to half (46%) of all Younger People In Residential Aged Care (YPIRAC)⁴ service users in 2007–08. This compares with 4% of Commonwealth State Territory Agreement (CSTDA) service users with ABI as a primary disability group. Two in five YPIRAC service users (40%) had neurological disability with or without another type of disability. This compares with 13% of CSTDA service users with neurological disability.⁵

The poor representation of this group within disability services shows the service gap that exists and underscores the need for a better articulated, whole of government, life time care approach to service responses. Delivering such a response will not only benefit the YPINH group; it will benefit all Australians with disability who are increasingly expecting to access these same 'joined up' service responses.

Having an able bodied life before injury or illness delivered significant, lifelong impairment means the YPINH group has different expectations around service responses to those living with a congenital disability. These young people expect to access the rehabilitation needed to restore health and independence; and to live in the community as other able bodied young people do.

² Winkler, D., Sloan, S. and Calloway, L. *Younger People In Residential Aged Care. Support needs, preferences and future directions*, Summer Foundation for the Victorian Department of Human Services, Melbourne, 2007: 26.

³ See *The ABI Strategic Plan*, Victorian Department of Human Services, Melbourne, 2001.

⁴ The Younger People In Residential Aged Care (YPIRAC) initiative is a 5 year, joint Federal/State program that was intended to be a first step to resolution of this longstanding and entrenched problem. The first tranche concludes in July 2011.

⁵ AIHW, Australia's Welfare 2009. 9th Biennial Welfare Report of the AIHW, AIHW, Canberra, 2009: 169-172.



USING A LIFE TIME CARE AND SUPPORT APPROACH TO INFORM DISABILITY SERVICE DEVELOPMENT AND DELIVERY

Position statements

- ♦ In its current form, the existing disability service system is unable to deliver timely and effective responses for the severe and profound group, including those with high and complex clinical and other support needs.
- ♦ There is urgent need for a better integrated, 'joined up' service response involving the various arms of the service sector, including disability, health, aged care and housing, partnering to deliver the supports required. A Life Time Care and Support scheme (LTCS) should take a lead role in the development of such an articulated system and in its ongoing development and review.
- ♦ An integrated Lifetime Care and Support scheme should support those individuals with severe and profound need unable to receive the responses they require through the existing disability system.
- ♦ A new lifetime care scheme can neither be a total replacement of, nor a life buoy for the existing suite of disability, health, education transport or housing services.
- ♦ To prevent a new lifetime care **scheme** being a resort of first and only choice, or the default funder for all disability requirements; to prevent funding gouging and reliance on the scheme as the only option, the other service system arms must be compelled to deliver what they are established and required to provide, approaching the scheme for assistance only after their legislative requirements to deliver services have been exhausted.
- ♦ An integrated lifetime care **system** needs to be developed that incorporates the other arms of the service system including disability, health, aged care, housing, education, transport et al. Such a system should include a range of schemes and funding programs, of which a new, no-fault insurance scheme for people with severe and profound disability should be a key part. This new no fault insurance funding scheme must see itself as a leader, providing strong leadership, vision and innovation to set the benchmark for other parts of the lifetime care system.
- ♦ The relevant COAG instruments in health, education, transport, aged care and disability et al, need to take account of this new scheme through the National Disability Strategy and encourage an integrated approach across jurisdictions.
- ♦ An LTCS scheme must not reside in disability services but be located in a separately



constituted, legislatively derived authority (a National Lifetime Support Commission).

- ♦ If an LTCS scheme is developed, funding to the extant disability system must be maintained and grown to service individuals with disability with less severe and profound impairment who are outside the purview of the new LTCS scheme.
- ♦ If an insurance levy is introduced to fund an LTCS scheme, funding to the existing disability system must be maintained and grown separately to ensure increased capacity.
- ♦ Funding derived from an insurance levy, whether directed to support an LTCS scheme or to disability more generally, must be maintained in a separate, legislatively bound authority and not be part of disability services.
- ♦ Every year, over 700 Australians are catastrophically injured to such a degree that they need care and support for the rest of their lives. Motor vehicle accidents account for approximately half of these injuries. Over 70% of those injured are under 30 years of age.⁶

The Alliance believes that, in the short term at least, a new disability insurance scheme cannot include other CTP schemes for the reasons following. The Alliance does believe, however, that a new no fault authority must be established to bring existing fault based schemes to no fault status; establish benchmarks for no fault services that reflect those established by the Victorian Transport Accident Corporation (TAC) *or better*; and harmonise existing no fault schemes, again ensuring that in this harmonisation, *standards and services reflect those of the TAC or better*.

As a funding base for an LTCS system, a newly developed **disability insurance scheme** should not include existing CTP schemes for WorkCover and motor vehicle accidents. Existing CTP schemes must remain separate. They have very different rules, benefits and schedules. Most importantly, they are a mix of fault based and no fault entities.

Extant fault based motor vehicle schemes, such as those in WA, SA and QLD, must be brought to no fault status. Benchmarks for these schemes should be no less, but potentially better than, those employed by the Victorian TAC. Similarly, time limited WorkCover schemes, such as Queensland WorkCover's 5 year limit to coverage, must move to deliver support for the life course as other schemes around the country presently do.

Until harmonisation of existing no fault and fault based schemes is achieved, people who are ineligible for their state fault based scheme should be funded by the LTCS. However, the LTCS scheme should recover this cost from the relevant state government.

- ♦ An LTCS scheme should be a stand alone scheme dealing only with the severe and profound

⁶ Walsh, J., Dayton, A., Cuff, C. and Martin P. *Long Term Care. Actuarial Analysis on Long-Term Care for the Catastrophically Injured*, PwC, Sydney, 2005: 2.



population; providing for the latter's needs exclusively; and underwritten and fully funded by a precisely targetted disability insurance levy. As the scheme grows and matures, it may, however, consider partnering with state based disability services to provide top up funding in specified areas that other services arms are unable to deliver, but that are required to maintain the health and wellbeing of the individuals in question. If this is to be done, each case should be considered on its merits. To ensure equity, recovery rights need to be established for the LTCS for cases where it ends up funding a person who is eligible but rejected by other government programs.

- ◆ The new LTCS scheme's funding should be kept separate and *not* be held as part of general revenue. A separate legislative entity must hold and invest the LTCS scheme's funds and provide oversight.
- ◆ The new LTCS scheme must have protocols in place to work with other arms of the service system and coordinate responses with health, disability, aged care, housing et al; ensuring these service arms maintain effort as part of a continuum of care.
- ◆ The new LTCS scheme needs to integrate a system of community based lifetime care management that can assist the scheme to manage lifetime care programs, determine partial and full eligibility, and assist eligible individuals with community support inside and outside the scope of the scheme. The successful operation of the new scheme depends of this function being available, capable and connected to community infrastructure. This is an important design feature in that it can be articulated with existing case management methodologies to soften the border between the LTSC and the mainstream disability system. It is the lack of guaranteed lifetime planning and access to services that makes the current system deficient, so making lifetime care planning an entitlement across both systems will create a significant systemic improvement.
- ◆ A new life time care and support scheme should have a declared view of itself as
 - An innovator in LTCS thinking, research and practice.
 - Holding a leadership position relevant to the service system.
 - A developer of innovative service responses *in partnership* with service providers, not-for-profit organisations and others.
 - A developer of best practice benchmarks, quality controls et al.
 - A researcher with declared interest in innovation in service practices and trialling of alternatives.
 - An entity whose purpose is to enhance and support learning, understanding and collaboration in all areas of the service system.
 - An organisation that facilitates and requires evidenced based approaches for funding.
- ◆ In summary, a newly developed life time care and support scheme should



- Take lifetime responsibility for individuals with severe and profound need only.
- Start small, supporting those unable to obtain timely and effective responses from existing resources; and potentially grow to incorporate existing service system features over time from disability, aged care and health; and as the latter move towards delivery of a coordinated long term approach for their consumers. (We note Dr Anna Howe's submission to the Inquiry (Submission 59) and recognise the increased capacity of 20% that she estimates can be created in existing disability services through applying a new revenue stream to a targeted group of individuals with catastrophic injury. In our view, however, this initial group should be larger than the one suggested in that submission and include people with neurological conditions and children with significant disabilities. Maintenance of funding to the National Disability Agreement sector must be maintained to enable this to occur).⁷
- Be party to COAG agreements that require existing service programs to deliver their agreed responsibilities and have recovery rights from these programs if this does not occur.
- Embody flexibility in planning and service design to deliver individually targetted responses that can adapt to consumers' changing needs and life circumstances. Individual budgets.
- Incorporate a range of purchasing structures including individual budgets, financial intermediaries and/or direct provider funding. These are merely point of purchase decisions but will deliver flexibility and choice for consumers.

SERVICE SOLUTIONS FOR THE LTCS COHORT

Because of their complex interacting clinical and other support needs; their expectations and aspirations; their need for immediate access to resources from different arms of the service system, the YPINH group have been beyond the capacity of the existing system. Where people with similar disabilities are compensated, the problems of service access are not as acute. Service development and pathways have, however, remained sluggish, largely market driven and without systemic planning.

Delivering better service responses for this group will, however, have clear flow on benefits for *all* Australians with disability as they raise the bar in terms of service response, effectiveness and possibility, thus delivering an improved service system better able to respond to the needs of every Australian with a disability. Providing a new revenue stream that enables the creation of alternative services (including equipment services) will increase capacity in the aged care system and provide greater allocative efficiency in the health system.

⁷ Howe, A. *Submission to Productivity Commission Inquiry into a Long Term Disability Care and Support Scheme*, June 2010: 2-3.



Our experiences with the Council Of Australian Governments (COAG) Younger People In Residential Age Care (YPIRAC) initiative have revealed not only where service gaps exist and what systemic reforms are required to resolve them; they have also enabled a clear view of those service responses required to effectively respond to the needs of disabled Australians with severe and profound needs.

The Alliance believes that an LTCS scheme that

- delivers a joined up service response involving the health, aged care, disability, education, transport and housing arms of the service system
- uses lifetime support coordination to deliver a forward looking and comprehensive approach to service development and delivery that incorporates a risk management approach (See Appendix A, *The CCP Pilot Final Report*, in this regard)
- delivers a continuum of care across all arms of the service system but especially those of health, disability and aged care and
- *operates as an adjunct to the existing service system*, rather than replacing it, can deliver the kind of lifetime care presently missing from the service system at large.

The design of the LTCS must guard against the scheme becoming a default funder of services for which other areas of the service system have a responsibility. Due to resource constraints and demand management imperatives, service programs have become expert at border protection and demand diversion in the current system and will actively cost shift to the scheme if there is the smallest opportunity. As citizens, eligible individuals should be able to access a range of services in health, education, transport, aged care, housing et al without having to have the scheme 'buy' entitlement. The scheme needs to complement these areas of community egress and interaction; and not be required to take over their existing portfolio responsibilities, as doing so would place unreasonable financial burden on the scheme and risk the commodification of scheme members or claimants.

In this sense the LTSC must be a companion piece to the National Disability Strategy in addressing the life opportunities, as well as the service gaps, for people with disabilities in Australia. Although eligible people may have severe and profound support requirements, they should not be defined just by their service needs and their place in a no-fault scheme. Their citizenship needs to be respected and honoured by the community and encouraged by the LTCS. It is vital that this be a feature of the scheme as there is the ever-present risk (demonstrated by private sector behaviour around compensation schemes) that people can become market commodities for service providers.

The Alliance believes a **National Lifetime Support Commission (NLSC)** should be created and structured as described in Figure 1. Comment on the various aspects of this new entity, follow.

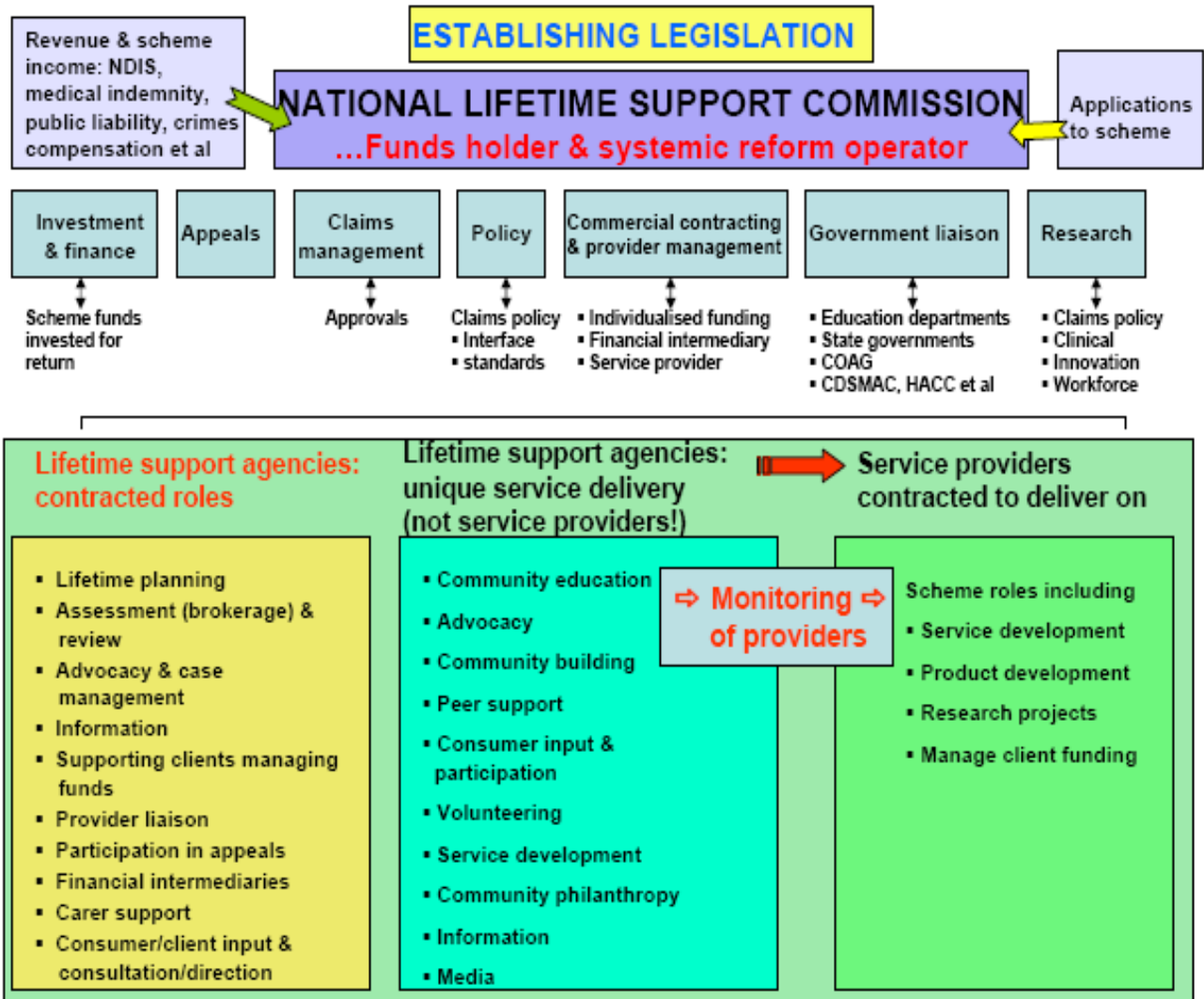


Figure 1 Organisational Chart, National Lifetime Support Commission



National Lifetime Support Commission

The cornerstone of a new LTCS should be a National Lifetime Support Commission that is empowered by legislation to run a no-fault lifetime care scheme for people with severe and profound disability; as well as perform a range of other important functions. It should be separately constituted and have its own Board that reports to the Federal Parliament. At the national level, it can be the governing body of a network of State and Territory offices that would run claims management; manage Lifetime Support Agencies and service providers; and negotiate with other local service programs. It should also have a national reform and coordination mandate.

Because of the fragmented state of disability care programs in Australia, there is a need to embark on a program of national reform of long term care. The new Commission is the body that would undertake this reform in much the same way that the Health and Hospitals Commission has done in the health care area.

Much of the discussion around an LTCS is how it may develop to absorb other disability programs. A reform platform must be developed, however, before any expansion or harmonisation occurs. The Commission needs to assume leadership in developing such a platform; and informing it through a dedicated research program. Research into long term care is extremely thin in Australia and should be made a priority through the Commission to inform reform and service development; and develop and support a vibrant long term care research community. In this respect, the Commission could even lead a lifetime care Cooperative Research Centre (CRC) program.⁸

This is an essential but longer term aim, so this function can run alongside the scheme's extant claims function.

The Commission will not only undertake this reform work in the long term care area, but also interact with similar reform programs in other community areas at State and Federal levels of Government. It will also need to be a key player in the implementation of the 10-year National Disability Strategy.

⁸ As described in the Productivity Commission's *Research Report into the Contribution of the Not-for-Profit Sector*, a Cooperative Research Centre Program is open to research in any field that has a strong end-user focus. The CRC program should provide development support for collaborations between NFPs, government agencies, business and research organisations to develop proposals for undertaking research and trials to address areas of major social concern. See Productivity Commission, *Research Report into the Contribution of the Not-for-Profit Sector*, Australian Government, Canberra, January 2010: xxxviii.



As part of its work, the Commission will need to establish Lifetime Support Agencies (LSAs) that will carry out its key work. These LSAs will, amongst other roles, be charged with

- assessing eligibility to the scheme;
- determining claimant need and developing lifetime planning to support identified needs;
- managing brokerage funds available for immediate and urgent service interventions;
- maintaining viable and effective working partnerships with service providers accredited under the scheme;
- convening Claimant Advisory Groups (CAGs) comprised of individuals with information pertinent to a claimant's health, well being and needs; and including acute care and allied health professionals, GPs, specialists, family members, service providers, advocates, disability specific member organisation representatives, as well as the claimant him or herself et al;
- managing information flow to claimants, family members, providers and CAGs;
- developing and sustaining effective networks and partnerships with all areas of the welfare and service systems;
- monitoring effectiveness of lifetime plans and coordinating plan reviews as required or requested;
- supporting development and trialling of innovative service responses with service providers, claimants, family members, CAGs and others;
- contract service providers and others, including allied health providers, to deliver specified services to claimants through the scheme.

Despite there being major disappointment with the disability system and its capacity to deliver services in a timely and effective manner, some not-for-profit organisations are delivering innovative activities to their members and communities. This activity will be of critical importance to the National Lifetime Support Commission's success and we have drawn heavily on the Productivity Commission's *Research Report on the Contribution of the Not-for-Profit Sector* to highlight the strategic value and importance of these organisations and their work for the National Lifetime Support Commission going forward.

Key components of the National Lifetime Support Commission

Policy

The National Lifetime Support Commission should

- Promote innovative policy development that investigates and promotes best practice.



- Assess and develop best practice benchmarks, quality controls and service delivery methodologies.
- Develop a specialist workforce skilled in the needs of the severe and profound cohort, including management and delivery of clinical support needs.
- Address systemic reforms not only within its own purview, but within the service system more broadly and at a national level.
- Be identified as the peak reform body for long term and lifetime disability care and support across Australia and internationally.
- Develop a long term/lifetime care and support research agenda.

Scheme income and revenue

Scheme income and revenue is derived from a range of sources including

- NDIS: a social insurance levy from general taxpayer contribution similar to the Medicare levy
- Crimes and other compensation payouts
- Medical indemnity
- Public liability
- State Government contributions (a sliding scale based on current no-fault coverage and other gaps that the LTCS is required to fill in its first iteration).

Applications to scheme

Application to the scheme should be made through a 'claim form' process that requires a range of assessments, proofs and demographic descriptors. Any person or organisation can make a claim, by application to one of the contracted Lifetime Support Agencies (LSAs).

As soon as an application is received, a Lifetime Support Coordinator (LSC) is appointed to filter the claim and request assessments, reports and other information required to assess eligibility and need. While ultimate decisions about eligibility must reside with the LTCS, the claimant's service needs and configurations can be managed by the LSAs. Capacity to defer active service responses until required should be part of the eligibility and planning processes.

Given the different disability types that may be covered by the LTCS, it is unrealistic to assume that a single assessment methodology will be feasible to determine entry to the scheme; or to determine needs during the life of a claim. Different medical specialists, health professionals as well as advocates, individuals and families will all need to be involved at various points of the eligibility and claims management process. A claim form entry system that allows the input of



whatever specialist or generalist is required to provide information is a more practical and preferred solution to determinations than a rigid assessment model.

Once eligibility is established, a planning process begins that will

- Establish immediate level of need
- Identify associated risks to the health and well being of the individual in the short, intermediate and long term
- Develop a plan that manages identified risks; and articulate those services and other interventions required to do so
- Contract service providers to deliver the suite of services required and
- Monitor and review the plan's effectiveness.

Investment and Finance

To ensure maximum return on the Commission's income, managed investment of funds via a specialist advisory board similar to the Victorian Funds Management Corporation (VFMC), should be established. The VFMC provides centralised funds management for Victorian TAC, Work Cover and State Trustees funds.⁹

A similar entity is required to invest and manage the Commission's income from which claims will be funded.

Appeals

A National Lifetime Support Commission (NLSC) must be flexible and 'porous' enough to address the myriad of ways in which its members will require a considered response; and manage changing needs in response to altered health, well being and life circumstances.

If 'whatever is reasonable' is its considered response¹⁰, the appeal process should address how the scheme might potentially fail to support the health and well being of claimants if an appeal is not upheld.

The scheme also needs to be mindful of the variations in need that will occur in the severe and profound group. In other words, what is essential for one person may be a non essential item for another.

⁹ For further information see the VFMC website at <http://www.vfmc.vic.gov.au/>

¹⁰ "A rigorous reasonableness test" is part of the determination of response used by the Victorian TAC.



As one example, air conditioners are essential to deliver the dry cold air in summer that many people with disease related impaired breathing require, especially those on ventilated support. For those without these conditions, however, an air conditioner has relevance to overall comfort in summer and may not be considered an item essential to maintenance of health and well being.

Claims Management

The overall process of claims management for the scheme should entail the following steps:

- Application is made to the National Lifetime Support Commission by claimant; family member; service provider; member organisation; advocate; health, disability, aged care representative via the Lifetime Care Agencies.
- A Lifetime Support Coordinator is assigned to determine eligibility for each application and manage the planning aspects for the applicant once eligibility is approved. One key advantage of utilising existing specialist disease and disability organisations is that they are already active in the existing service system; and can provide support to the applicant whether their application to the LTCS is successful or not. In the case of unsuccessful applications to the scheme, the LSCs can refer to other agencies or areas outside the scheme for assistance.
- Once eligibility is established, lifetime planning commences using a proactive, risk management and lifetime support methodology.¹¹ A limited brokerage fund is available to claimants on acceptance into the scheme. This fund is to provide immediate responses where urgent need is identified.

Planning and assessment should involve all relevant persons with information pertinent to the individual including GPs, allied health personnel, specialists, acute care personnel and providers, service providers family members, employers et al.

All information obtained must be maintained and available to all participants (including the claimant and family members) so that a body of knowledge about the claimant is maintained. This ensures that as members of this “claimant advisory group” or CAG change, the information gathered is maintained, kept up to date and available to new members coming on board. The Lifetime Support Coordinator is responsible for maintaining and managing this body of information.

- Lifetime Care Agencies have access to an urgent need brokerage account to provide a fast (but limited) response to urgent unmet need identified by the Lifetime Support Coordinator during the application process; or while other decisions are being made in the life of a claim.

¹¹ Where a lifetime support methodology does not presently exist, one will obviously have to be developed. This is something that the scheme itself should research and progress.



The Lifetime Support Coordinator submits a considered plan to claims management for final approval and/or negotiation or review. The Lifetime Support Coordinator should be mandated to include elements in the planning process that are community based and do not require scheme funding, but for which support services can enable participation. This can include family and volunteer roles, participation in education or other activities, healthcare, or employment.

It is important that plans are multi-dimensional and include steps to interface with other parts of the community and service systems. In almost all cases, there will be a requirement to manage complementarity with other program areas (such as education, health, aged care, employment etc) so the Lifetime Support Coordinator will need to be an active negotiator with and for the claimant and the scheme around these interfaces to ensure maintenance of effort and delivery of outcomes.

- On approval, the Lifetime Support Coordinator recruits service provision from the accredited provider group and/or other accredited personnel for service response and training. Providers must be subject to a separate approval and accreditation process established by the scheme.
- As the claimant's support plan is activated, the Lifetime Support Coordinator monitors the support plan's effectiveness; and reviews progress with the claimant advisory group (CAG) to ensure the claimant's support plan is properly targeted to identified need and/or apparent risks. The Lifetime Support Coordinator maintains a clear information flow to all members of the CAG and is available to them for updates as required. The Lifetime Support Coordinator can also call on the expertise of this group to refine the claimant's support plan as needed.
- The Lifetime Support Coordinator monitors and adjusts the support plan as required. The LSC also manages the review process as required or requested by individuals, families, guardians, service providers and clinicians.
- Where a claimant's decision making is impaired, the Lifetime Support Coordinator will consult with guardians, friends and families, clinicians et al and where the individuals' preferences can be expressed, take these into account.
- The role of the Lifetime Support Coordinator is dynamic. Once the support plan is fully operational and running smoothly, the Lifetime Support Coordinator steps back, becomes less actively involved and less 'visible'. When changed needs are identified or further discussion is required or warranted, the Lifetime Support Coordinator becomes fully operational again and remains actively involved until the support plan is running smoothly and responding to the claimant's identified needs once more.
- A key role of the Lifetime Support Coordinator is to exert the authority of the National Lifetime Support Scheme to ensure that outcomes are delivered to the claimant and the



scheme; and to ensure that other programs are aware and participating in the overall lifetime support plan. As well as being an advocate and case manager, the Lifetime Support Coordinator will also need access to a fully functioning, independent disability advocacy sector to assist where other programs are resistant or failing.

This independent advocacy will also be a safeguard to hold the Lifetime Support Coordinators and the scheme more generally to account. While the resuscitation and capacity building of the disability advocacy sector remains the job of the National Disability Agreement signatories, it is an important adjunct to the establishment of the National Lifetime Support Commission and its work.

This is an ongoing, iterative process that should not have predetermined review dates, but be flexible enough to incorporate constant adjustment as needed.

Commercial contracting and provider management

In undertaking commercial contracting and provider management through its Lifetime Support Agencies, the National Lifetime Support Commission should

- Develop a provider management function that includes
 - ♦ provider accreditation and approval
 - ♦ provider audits
 - ♦ contracting of service development and delivery to accredited providers
 - ♦ encourages research and trialling of innovative service development and delivery with accredited providers
 - ♦ requires adherence to world's best practice standards
 - ♦ prevents commodification of disability and individuals with disability by the for-profit sector
- ensures providers meet identified needs
- incorporate essential workforce and other training by utilising its Lifetime Support Agencies to contract and monitor service delivery
- deliver training modules for skilled workforce development.

Although it should require standards compliance from providers that it funds, the National Lifetime Support Commission should not be a standards monitor.

Government liaison

As an agency with a clear mandate to develop a national lifetime care strategy and innovative service responses, the National Lifetime Support Commission needs to lead the development of



a lifetime service *system* for the nation; and collaborate with state and federal government departments including health, disability, aged care, housing, transport, education et al.

We already have entitlement based systems for health (Medicare), pharmaceuticals (Pharmaceuticals Benefit Scheme), employment (Job Services Australia), aged care and school education and compensation/insurance schemes. The National Lifetime Support Commission needs to find a place beside these and the existing disability services system, and

- Must be an integral part of state and federal government planning for disability, health and aged care, housing, education, transport, justice et al
- Have input into relevant ministerial councils where its reform brief is relevant including the following councils and fora
 - ♦ Council of Australian Governments (COAG)
 - ♦ Health, Ageing, Community and Disability Services Ministerial Council (HCDSMC) including
 - Australian Health Ministers' Conference (AHMC) and its subsidiary Australian Health Ministers' Advisory Council (AHMAC)
 - Community and Disability Services Ministers' Conference, (CDSMC) and its subsidiary Community & Disability Services Ministers' Advisory Council (CDSMAC)
 - Ministerial Conference on Ageing
 - ♦ Ministerial Council for Federal Financial Relations
 - ♦ Housing Ministers Conference
 - ♦ Local Government and Planning Ministers Council
 - ♦ Ministerial Council for Tertiary Education and Employment
 - ♦ Australian Transport Council
 - ♦ Workplace Relations Ministers Council.
- Have State/Territory branches to
 - ♦ liaise with State and Territory jurisdictions around differing needs and requirements
 - ♦ promote and improve quality in service response through leadership and partnership with the States and Territories.
- Play a lead role in bringing fault based motor vehicle insurance schemes to no fault status and harmonisation (if desired) with other schemes.



- Play a lead role in delivering harmonisation of all WorkCover schemes to world's best practice standards including lifetime support.
- Gather and provide data to government (both federal and state jurisdictions) to compliment future planning of services in health, aged care, disability, housing et al.
- Coordinate with the States and Territories on the development of rehabilitation and habilitation services for the severe and profound group including development of a national framework for rehabilitation services. The Commission should take a lead role in partnering and coordinating efforts with health, disability and aged care peaks in delivering this work.
- Participate directly in the Commonwealth's Health and Hospitals Reform Program.
- Participate directly in aged care reform programs.
- Have membership of Local Government Authorities (LGA) and work with these authorities on articulation of Home and Community Care (HACC) services where required; and until Victoria signs up to the national HACC Agreement.
- Work with trade unions, employers and others on skilled workforce development for the severe and profound cohort, including
 - ♦ delivery of clinical and complex support needs and other systemic reforms
 - ♦ retention of skilled workers
 - ♦ development of career pathways for skilled workers to aid in retention
 - ♦ development of accredited training modules for skilled workforce development.

Research

As an identified leader in lifetime care and support, the National Lifetime Support Commission must develop and deliver a comprehensive research agenda.

Research, as an integral part of targetted and innovative service development and delivery, is something that has been sadly lacking in disability services. The need to deliver a better articulated and integrated services system that can support the high and complex clinical and other support needs characterising the severe and profound group, is a critical component of the National Lifetime Support Commission's work. The Commission must establish a comprehensive research agenda that

- Promotes evidenced based research.
- Collaborates with other organisations in Australia and overseas on research and development of innovative service responses and trialling of same.



- Collaborates with not-for-profit organisations, service providers, industry representatives and consumer groups to trial innovative, alternative approaches.
- Seeks international as well as national research collaboration in key areas.
- Collaborates with health, aged care, housing, education, disability services et al to deliver comprehensive data sets that indicate trends in need and effectiveness of articulated service responses.
- Develops best practice in service design and delivery; and innovation in service response.
- Collaborates with its Lifetime Support Agencies to develop training modules for skilled workforce development and retention.
- Invites and includes consumer input in its research portfolio.

To fulfil this function it may be appropriate to create a Lifetime Care Co-operative Research Centre to govern research in this area and ensure its translation into service provision and the wider community.¹²

Lifetime Support Agencies (LSA: contracted roles)

In proposing that not-for-profit (NFP) member organisations become Lifetime Support Agencies, the Alliance believes these organisations can make a unique contribution that is not similarly available in other commercial or for-profit enterprises. This is a view that is confirmed and reiterated in the Productivity Commission's Research Report into the *Contributions of the Not-For-Profit Sector*.¹³

The Commissioners' comments are instructive in this regard. In their report, they indicate that not-for-profits utilise processes that are "...participatory, inclusive, quality focused and accessible..."¹⁴ The Report goes on to say that these processes are "central" because they

- ♦ engender trust and confidence in the organisation, enhancing the reach and quality of the activities undertaken
- ♦ facilitate access to resources from multiple stakeholders including volunteer workers, as well as access to funding and in-kind resources, as NFPs can provide value to those making these contributions
- ♦ build the capacity and capabilities of staff, volunteers, members and clients for effective engagement over time, including their knowledge and ability to influence the design of future activities.

¹² See Productivity Commission, *Contributions of the Not-For-Profit Sector*, Research Report, Australian Government, Canberra, January 2010: XXXVIII, XLIX, 224, 380 et al.

¹³ Productivity Commission, *Contributions of the Not-For-Profit Sector*, Research Report, Australian Government, Canberra, January 2010.

¹⁴ Op.cit: 16.



These 'quality' processes contribute to achieving the outcomes of the NFP, including what might be incidental outcomes such as improved community connections. In some areas of activity, process, in particular for maintaining trust, can be critical to achieving outcomes.¹⁵

The report goes on to quote from submissions made to the Inquiry including the following:

***Trust and continuity** of relationships is essential. It is the establishment of trust through the continuity of staff and service provision that builds the basis from which change can happen. ... [The] degree of trust rises with extent of trustworthiness of information about the trustee. It is this element of trust where the NFP sector has an advantage over the for-profit sector and why the capacity to deliver such programs is as strong as it is. (SDN Children's Services, sub. 160, pp. 10-11)¹⁶*

In this section, the Commissioners conclude by quoting Billis and Gennerster (1998) who argue that "...NFPs have a comparative advantage in delivering services where the motivation to address disadvantage, and knowledge of and sensitivity to client needs, are in scarce supply. In NFPs there is often a blurring of stakeholder roles, reducing the gap between clients and those delivering services, and between workers and management."¹⁷

When value for money is discussed, not-for-profits are again the declared winners in the Commissioners' view. They say

The choice by government to involve NFPs as providers involves consideration by government of value for money. Discussed in detail in chapter 12, value for money considerations should include:

- *cost-effectiveness of service delivery — and the extent that this depends on the development of relationships with clients*
- *complementarity or joint-production with other services — which can enhance client wellbeing beyond that arising from the particular service being funded*
- *spillovers (positive and negative) associated with the service delivery — these arise as a by-product that affects others in the community, such as the utilisation of a community centre as a base for services for other groups, and the benefits that flow on from improvements in the lives of individuals as a result of their engagement with NFPs*
- *sustainability of the service delivery and/or client relationship, where the longterm effectiveness depends on the continued presence of the provider.¹⁸*

¹⁵ Ibid.

¹⁶ Ibid.

¹⁷ Ibid.

¹⁸ Op.cit: 32.



The Alliance concurs with the Productivity Commission when it says in its Report that not-for-profits contribute by

- *service delivery* to members or clients
- *exerting influence* and initiating change in economic, social, cultural and environmental issues
- *connecting community* and expanding people's social networks
- *enhancing community endowment* by investing in skills, knowledge and physical, social, cultural and environmental assets for current and future generations
- *and that while NFPs may pursue one, some or all of these purposes*, their outcomes can interact with others in shaping the eventual impact.¹⁹

In declaring NFPs as drivers of social innovation, the Commission says "The purpose-driven nature of NFP activities can give freedom to explore new approaches to achieving that purpose, allowing them to take risks where failure is accepted as part of learning. In addition, scope to try new things can be a highly valued part of what the NFP offers to its stakeholders. Indeed, some see NFPs as leaders in social innovation."²⁰

Furthermore, because social innovation often requires multi-part and collaborative approaches, the Commission's Report identifies NFPs having a unique role to play because they can embrace and take note of responses from different stakeholders. The Report declares that

Not only multidisciplinary views are required, but views from different stakeholders.

The client, their family, the local community, the school, the youth centre, and the welfare agency for example, all have valid and valuable input required to understand the problem. Second, a solution must be designed that will adequately balance all aspects of the problem, recognising that they interact in complex ways. Success in an experiment or trial may be the only way to be confident that a proposed solution will be effective.

Third, implementation must allow for adjustments to suit the different situations that arise with location, clients and other variations from the model. This will often require action on a number of fronts, requiring collaboration between a range of organisations.²¹

In proposing that not-for-profit member organisations are ideally suited to form the National Lifetime Support Commission's **Lifetime Support Agencies**, the Alliance wholeheartedly supports the Productivity Commission's statement that community organisations have a comparative advantage in this area.

¹⁹ Op.cit: 29.

²⁰ Op.cit: 238

²¹ Ibid.



As an organisational type, NFPs have a number of characteristics (in terms of what motivates their decision making, their structure, sources of finance and workforce) that distinguish them from other forms of agency (chapter 2).

Billis and Glennerster (1998) argue that the distinctive characteristics of community organisations give them a comparative advantage in delivering human services where the motivation to address disadvantage and knowledge of, and sensitively to, client needs are in scarce supply. The authors suggest that this is most likely to be the case in relation to personal and societal disadvantage and particularly in those cases where personal and societal needs are combined.

What appears particularly important to the comparative advantage of NFPs in delivering these types of services is their reach into the community and community participation in decision making processes.

The Alliance believes that not-for-profit member organisations with expertise in supporting individuals with high and complex clinical and other support needs are ideally suited to deliver the assessment, planning and monitoring processes that consumers with severe and profound need will require to successfully engage with the Lifetime Support Commission and its services. These organisations include such entities as Multiple Sclerosis Australia, Huntingtons Australia, Parkinsons Australia, Spinal Cord Injuries Australia, Australian Quadriplegics Association, Muscular Dystrophy Australia, Motor Neurone Disease Australia amongst many others.

As the Productive Commission's Report into the not-for-profit sector indicates, these organisations have the capacity to deliver key services as Lifetime Support Agencies that for-profit organisations are not well placed to deliver, including, amongst many

- ♦ Volunteers to maintain community involvement and commitment
- ♦ Provision of information to scheme members and the general community
- ♦ Community awareness raising
- ♦ Philanthropic input and in kind support
- ♦ Development and delivery of training modules in the clinical and other support needs of the severe and profound group. These organisations already have significant expertise in the support needs, expectations and aspirations of their members; and are best placed to develop this into training modules that can become part of the Commission's best practice approach to training and service delivery
- ♦ Collaboration with other agencies and service providers on improvements in best practice in service development and delivery
- ♦ Compilation and maintenance of comprehensive information on each claimant they 'manage' through the lifetime support process
- ♦ Host and support specialist Lifetime Support Coordinators.



Locking in the existing specialist disease and disability NFP organisations would provide the link between the scheme and the rest of the service system at the community level; and would safeguard against the commercial imperatives that could so easily undermine the social goals of the disability movement and the Scheme itself.

By creating a lifetime support model that goes beyond the strict borders of the scheme, it means that eligibility for the scheme is less of a holy grail for people, and capacity remains to be supported elsewhere in the system (utilising the additional capacity created by the scheme's additional revenue). It also harnesses the community capital of these organisations in implementing the scheme's programs into an already complicated community service environment; and enables continued roles for philanthropy and volunteering which remain essential parts of our society.

While becoming a Lifetime Support Agency may not be for every NFP organisation, those who do wish to undertake this work will have to comply with a range of criteria to become accredited agencies with the Commission. Some of these criteria include

- 10-15 years active experience as a specialist disease disability agency
- Maintenance of a volunteer program
- Demonstrated expertise in and delivery of community education
- Provision of peer support through active peer support programs
- Demonstrable skills in lifetime care management including assessment and planning
- Active and articulated networks in the clinical, community and government sectors
- Active relationship and collaboration with the philanthropic sector
- Demonstrated expertise in media communication
- Has state wide coverage and capacity.

Service Providers

The Alliance believes a clear difference must exist between Lifetime Support Agencies who deliver assessment and planning services for the National Lifetime Support Commission's clients or claimants and monitor the delivery of services by providers; and service providers responsible for the timely, effective and efficient delivery of services to the Commission's clients.

The Alliance also believes that member organisations who have an existing service provision arm, should not be able to become accredited Lifetime Support Agencies until they have divested themselves of their service provision responsibilities. In other words Lifetime Support Agencies cannot be service providers and vice versa. Those agencies that are currently engaging



in service provision as well as other peak body roles, may need to transfer their service provision roles to separate corporate entities, including social enterprises.

Service providers must comply with a clearly articulated accreditation process and commit to maintaining compliance with the National Disability Standards.

In short, service providers

- Are contracted by the National Lifetime Support Commission's Lifetime Support Agencies to deliver designated services.
- Cannot be Lifetime Support Agencies. Member organisations with service provision capacity cannot become Lifetime Support Agencies until their service provision capacity has been divested. In other words, a service provider cannot be a Lifetime Support Agency and vice versa.
- Have their service development and delivery monitored by Lifetime Support Agencies.
- Must comply with designated training of support workers in the delivery of support and according to defined criteria and accreditation protocols.
- Must be willing to work with families and claimants to refine service delivery and outcomes.
- At a minimum, must be conversant and compliant with the National Disability Standards.
- Must be accredited and approved as service providers by the National Lifetime Support Commission.

Eligibility for individuals with severe and profound impairment

Once a claim is accepted by the National Lifetime Support Commission and the need for response is established, the individual becomes a claimant of the scheme, including those

- Recovering from catastrophic injuries that involve acquired brain injuries and spinal cord injuries.
- Diagnosed with progressive diseases. An individual may make application to the scheme on diagnosis of a progressive disease but choose to defer the scheme's active involvement until need arises through the disease process. However, for many with progressive disease, early interventions may prevent disease exacerbation and/or slow disease progress. These subtle iterations of need will need to be established and examined by a Lifetime Support Coordinator skilled in the particular disease process.
- Experiencing episodes of disease exacerbation.



Eligibility is established through

- Application to Lifetime Support Agencies who must establish severe and profound impairment (or capacity to develop such impairment in the case of progressive diseases) according to clear eligibility criteria.
- If eligibility criteria are not met, the individual exits the application process at that point. An appeals process is available to individuals refused access to the scheme.
- Once eligibility is established, a Lifetime Support Coordinator is appointed and a transparent and broad ranging planning and assessment process is activated.

Risk management as an integral component of lifetime support

Together with the MS Society and Calvary Healthcare Bethlehem in Melbourne, the Alliance recently participated in a Continuous Care Pilot (CCP) that examined potential benefits for individuals with progressive diseases when a risk management methodology was used to manage health and well being.²² Undertaken through the Younger People In Residential Aged Care (YPIRAC) initiative, a copy of the Victorian CCP's Final Report is included in this submission in Appendix A. This pilot was also successfully undertaken in NSW and its Final Report is forthcoming.

The success of this methodology is described in the Victorian CCP Pilot's Final Report and forms the basis of the Alliance's belief that adopting a risk management approach to identify short, medium and long term risks to an individual's health and well being will result in

- improved outcomes for individuals with severe and profound need
- integral roles for individuals and families in planning and service delivery
- cost savings for the Commission (and the service system more generally) through amelioration of risk and associated cost blowouts
- improved efficiencies and effectiveness as the service system delivers proactively by identifying and delivering on identified risks
- improved collaboration, partnership and understanding between the disparate arms of the service system
- more efficient and effective use of the existing service system with accompanying cost savings
- reduction in the impact of disease progression and anticipated appropriate increments to services that might accompany such progression

²² Calvary Healthcare Bethlehem and MS Australia, *The Continuous Care Pilot Final Report*, Melbourne, December 2009.



- support for individuals with progressive diseases and their families to become better informed about disease pathways and better able to address future planning issues as a result.

Workforce: development of a Lifetime Support Coordinator workforce

Life time Support Coordinators (LSC) are part of a new, highly skilled and specialised workforce that is required to develop and delivery lifetime support. As well as their key involvement in the assessment of eligibility, need and management of the planning process, LSCs will have

- Authority to engage with all arms of the service system and develop partnered responses.
- A brief to develop and maintain effective networks in all arms of the service system.
- A broad ranging brief to 'think outside the square' in delivering effective, timely and financially efficient service responses.
- Capacity to collaborate with all those with information pertinent to the health and well being of claimants including acute care personnel, GP's, specialists, allied health professionals, service providers, advocates, member organisations, claimant's family members and the claimant his or herself.
- Have capacity to recognise the need for innovative responses; collaborate in the design and delivery of innovative responses; and provide in depth reports on the net results of innovations to the scheme and others as required.

Lifetime Support Coordinators will

- Assess claimants' eligibility for membership of the scheme.
- Manage a small brokerage fund for each claimant to deliver immediate responses if urgent need is identified.
- Develop and manage agreed service responses with claimant and family, service providers and others with necessary input into desired outcomes.
- Maintain a 'watching brief' on service responses and be ready to activate more intensive involvement if required or requested.
- Provide information if an appeal is mounted regarding denial of scheme eligibility or involvement.
- Maintain and manage all information and data pertinent to the claimant and to those services developed and delivered by the scheme for benefit of the claimant.
- Have capacity to recognise the need for innovative responses; collaborate in the design and delivery of innovative responses; and provide in depth reports on the net results of innovations to the scheme and others as required.



- Receive pay and conditions commensurate with the skill set required to carry out this role.

Workforce development: support workers skilled in delivery of care to individuals with high and complex clinical and other needs

The existing disability support workforce is poorly trained to deliver support to individuals with disability but particularly lacks the skills and capacity to support those with high and complex clinical and other support needs.

The National Lifetime Support Commission must

- Recruit workers with capacity to learn subsets of clinical care as well as other support need requirements
- Provide a defined career path for skilled workers where skills gained through accredited training can form part of nursing or other higher level qualifications
- Deliver improved pay and conditions to attract and retain highly skilled workers
- Develop accredited training in the needs of the severe and profound group including training in delivery of clinical support needs.

Social insurance funding base for disability service delivery

The Alliance has worked on development of a social insurance base for disability funding since 2002 and has included calls for such a levy in submissions to

- the Productivity Commission's *Review of Pricing Arrangements in Residential Aged Care* (2002/03);
- 2004's *Senate Inquiry into Aged Care*;
- the 2005 *Senate Inquiry into the Funding and Operation of the Commonwealth/State/Territory Disability Agreement*;
- 2006's *Senate Inquiry into the Provisions of the Medibank Private Sale Bill*; and
- the 2008 *House of Representatives Inquiry into Better Support for Carers*, amongst others.

The Alliance also convened a meeting of national peak organisations and the state Executive Directors of Disability on the need for such a scheme in 2007.

We have also worked with the Victorian Government to develop a no fault catastrophic injury insurance scheme as an expansion of the existing Victorian Transport Accident Commission (TAC).

The operation of the YPIRAC initiative has only reinforced the fact that if money is simply 'washed' through the existing system, nothing will change. If a social insurance levy is to be



introduced, resources, expertise and pathways need to be developed and in place on day one. Governments – both state and federal – have a clear responsibility to begin developing this infrastructure now so that when funding from a social insurance levy comes online, the services it needs to buy will exist and be available in the not-for-profit as well as the for-profit sectors.

The Alliance believes that a social insurance funding scheme should

- Operate as an adjunct or companion scheme to the existing disability service system. The disability system should be left to do what it already does. Removing the severe and profound group should release significant capacity back to the existing disability system. In other words, the scheme should have a home in the fabric of what already exists.
- Be limited to those with severe and profound needs.
- Should not absorb existing CTP schemes into a social insurance base for funding. Existing schemes, including Victoria's TAC, NSW's LTCA, Tasmania's MAIB, as well as state based WorkCover authorities, all have different structures, benefits and risk based premiums that should be maintained separately and continue to deliver services for their client bases.

Infrastructure development

While it is widely acknowledged that the existing disability service system is badly in need of reform, we cannot afford to wait for a social insurance base for disability funding to be delivered to subsidise these reforms; or for reform to begin only once alternative funding arrangements are in place.

There is an urgent need to begin addressing service gaps now and delivering the service pathways we know are needed for Australians with severe and profound impairment.

It is also clear that the advent of innovative new service responses, or the address of systemic reform areas, will not succeed in and of themselves without government commitment to fix existing infrastructure deficits in education, transport, health, social housing et al. In other words, we cannot introduce a new scheme over the top of the existing service system mess we currently have.

Developing a better integrated, better targeted and more responsive service system requires major heavy lifting be done in raising awareness and developing understanding in all arms of the service system, but particularly disability in its relation to health and aged care. None of the service arms know or particularly understand the others because they have never had to and while this may have been acceptable in the 19th century, it is no longer viable – or acceptable – to do so in the 21st.



State and Federal Governments have a responsibility to develop the capital and service infrastructure needed for the scheme to buy its services from. Indeed, governments need to anticipate that a social insurance scheme will look to purchase services from them and start developing these now.

The Productivity Commission needs to make this point in the interim or draft report of this Inquiry. Failure to prepare for the implementation of a lifetime care scheme by building capacity now, risks extensive delays and potential cost shifts later.

Whether Governments adopt a lifetime care scheme or not, the status quo is unsustainable and change of some kind will result because of increased demand for disability services.

This is an area where Governments and the community cannot stand still, and the dangers of seeing the lifetime care scheme as a silver bullet that will solve all problems for all people all of the time; of waiting for it to begin; and of not beginning reform in the interim, are real and potentially damaging.

Service and infrastructure development must, however, acknowledge and exist within the framework of the Commonwealth's National Disability Strategy that will be announced later this year.

These service 'pathways' will also require extensive mapping to establish service gaps and negotiation with the health, housing, aged care and disability sectors et al to deliver comprehensive suites of service options for individuals with severe and profound impairment.

As one example, there is clear and urgent need to develop a range of step up/down services for individuals with Acquired Brain Injury (ABI) on discharge from acute care and to continue their recovery. Failure to do so will make room for service development and delivery to be market or demand driven, rather than developed according to evidence based and best practice approaches.

This is already starting to occur. As one example, there has been a reduction in provision of rehabilitation services available for purchase by one state's predominant CTP scheme over the past 12 months. A not-for-profit provider with no experience of brain injury rehabilitation or management, has identified this service gap and moved to fill it by importing an overseas model of rehabilitation and care that is inferior to two already well established, evidence based and successful Australian rehabilitation service responses. This new service is only available to compensable individuals.

Age as a definition of access to services



The Alliance questions the wisdom, viability and responsibility of limiting any scheme to those with disability acquired before the age of 65.

The YPIRAC initiative has already demonstrated the negative impact of such age related limitations and the drastic intensification of need and consequent blow out in costs that results when individuals are denied proactive responses because they have aged beyond a particular point.

While the Alliance understands the concern that the huge increase in costs associated with age related disabilities may bring, it does not support the reinvigoration of our extant 'apartheid' system of support that exists through the current Australian disability/aged care interface of 65 years of age.

When 65 years was chosen as the definition of aged to introduce Australia's first Aged Care Pension by the Queensland Government in 1907, life expectancy was approximately 55.2 years for men and 55.8 years for women.²³ Few were expected to reach 65 years and draw a pension.

Now, however, life expectancy sits at around 82-85 years²⁴ and some 3,400 Australians are aged 100 years or older, a number expected to swell to 78,000 by 2055.²⁵ As a result, Australia is experiencing a demographic phenomenon in which its citizens enjoy the fourth longest life expectancy in the world; and a major shift is occurring in the number of people living to be more than 100 years of age.²⁶

Given these facts, using 65 years as a demarcation for access to services via a Lifetime Support Scheme and/or a social insurance levy, seems questionable, especially as the aged care sector is moving to embrace its own social insurance levy for aged care service provision post the age of 65 years.

Fundamentally, this is all about need related to disability and community capacity, of which age should not be a factor. Designing the National Lifetime Support Commission as a complementary scheme rather than a comprehensive scheme, means that the aged care system still has an important role to play and can continue to fulfil its role where appropriate.

Where an older person acquires a catastrophic disability unrelated to natural ageing, then the scheme should meet those needs. Where a joined up response is required, a way of negotiating

²³ Australian Bureau of Statistics, ABS Cat. No. 3302.0; ABS Cat. No. 3105.0.65.001.

²⁴ Ibid.

²⁵ Australian Bureau of Statistics, ABS Cat 3201.0 - Population by Age and Sex, Australian States and Territories, June 2009.

²⁶ Ibid.



joint funding of planning and required services is not only a desirable outcome, but a highly intelligent and responsible one too.

Whether the general public will agree to pay for two additional social insurance levies remains to be seen. But there would seem to be a case for one decent 'whole of life' levy to be considered if this came to pass.

Further information:

This submission was prepared with the assistance of Alliance members MS Australia and Brainlink Services.

If further information or clarification is required, please contact
Dr Bronwyn Morkham
National Director, Young People In Nursing Homes National Alliance

Alan Blackwood
Policy and Community Partnerships Manager, MS Australia



Bibliography

AIHW analysis of DoHA Aged and Community Care Management Information System (ACCMIS) database. Australian Institute of Health and Welfare, *Older Australia at a Glance*, 4th Edition, Canberra, 2007.

AIHW, Australia's Welfare 2009. 9th Biennial Welfare Report of the AIHW, AIHW, Canberra, 2009.

Calvary Healthcare Bethlehem and MS Australia, *The Continuous Care Pilot Final Report*, Melbourne, December 2009.

Howe, A. *Submission to the Productivity Commission Inquiry into a Long Term Disability Care and Support Scheme*, June 2010.

Productivity Commission, *Contributions of the Not-For-Profit Sector*, Research Report, Australian Government, Canberra, January 2010.

The ABI Strategic Plan, Victorian Department of Human Services, Melbourne, 2001.

Walsh, J., Dayton, A., Cuff, C. and Martin P. *Long Term Care. Actuarial Analysis on Long-Term Care for the Catastrophically Injured*, PwC, Sydney, 2005.

Winkler, D., Sloan, S. and Calloway, L. *Younger People In Residential Aged Care. Support needs, preferences and future directions*, Summer Foundation for the Victorian Department of Human Services, Melbourne, 2007.



Appendix A

Calvary Healthcare Bethlehem and MS Australia, *The Continuous Care Pilot Final Report*, Melbourne, December 2009.