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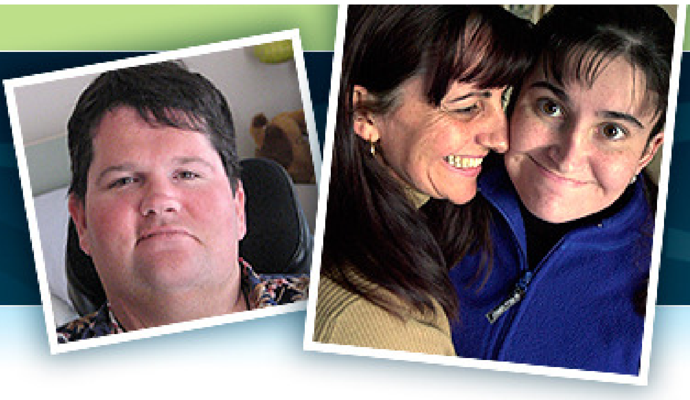

Response to the Productivity Commission's Draft Report into Disability Care and Support

The Young People In Nursing Homes National Alliance

May 2011

The Young People In Nursing Homes National Alliance congratulates the Commissioners on their draft report into Disability Care and Support.

While the Alliance supports the general thrust of the report, we believe that scheme design elements as outlined in the draft report can be improved; and the links with existing community sector infrastructure can be harnessed to make the NIIS and the NDIS schemes more effective and viable.

The key element that the Alliance believes needs to be comprehensively reviewed is that of the Disability Service Organisations – a key part of the Alliance's construction of these new schemes in its first submission. As the front end of the new schemes, these vital organisations need to do much more than just the role of financial intermediary that was ascribed to them in the draft report.

In the Alliance's view, these organisations are key to the success of the new schemes because of their capacity to provide comprehensive and inclusive assessment and planning, manage service providers, ensure plans are being implemented appropriately, promote and involve local community and volunteers and, most importantly of all perhaps, proactively manage consumer and provider expectation around what the scheme can or cannot deliver.

Two schemes

The Alliance congratulates the Commission on its recommendation of two schemes: one for the catastrophically injured and another for those with severe and profound disability. Establishing a separate scheme for the catastrophically injured will not only require our existing mix of fault and no fault injury schemes to be better aligned under an NIIS. Removing some of the most costly individuals to rehabilitate and support over the long term will enable an NDIS tailored to the long term care needs of those with differently acquired disabilities to be a viable reality. With each scheme having different realities and imperatives (such as income replacement and common law in the NIIS), these two schemes represent a more pragmatic option than one single mega scheme.

Numbers of individuals with severe and profound disability and consequent scheme viability

The Alliance appreciates the difficulty of collecting adequate data to inform development of these schemes, the NDIS in particular. We are concerned that a lack of available and relevant data may suggest lower number of eligible people than has been indentified in the Draft Report; and thus, a notionally lower cost of developing the schemes as a result. This is of particular concern regarding those with acquired disabilities. As previously able bodied individuals, these people (including those within the YPINH cohort) often do not identify as "disabled" in such population surveys as the Australian Census.

While we hope the development of an NDIS and an NIIS will significantly address this current lack, we also reiterate the need to trial interface engagements, the development of service pathways and other coordinated trials to get a clearer idea of need (including unmet demand) and the costs this is likely to deliver to the schemes.

Because of the disability sector's poorly developed understanding of lifetime care and support, its view that more funding will solve all the current system's problems – a position increasingly supported by state governments desperate to solve their own systemic problems - and the enduring lack of appropriate and functional service infrastructure, regional or state-wide trials of the new scheme(s) prior to national implementation, run the very real risk that these will take place within the current dysfunctional disability mindset.

Trialling alternative approaches, particularly risk management approaches to assessment, planning and service delivery; service pathways and collaboration between service interfaces; as well as properly establishing the Disability Service Organisations, would not only alleviate these concerns and deliver important data; they would also ensure that these landmark schemes start from the best position possible.

YPINH as priority group

The Alliance is pleased that the YPINH™ group has been indentified as a priority group for these new schemes and that early interventions will apply to these young people. Evidence is clear that early interventions offer the best approach to both recovery from catastrophic injuries and exacerbation of illness experienced by these young people; and to management of their long term care needs.

We believe the schemes proposed will deliver the certainty of response required to support the life time care needs of this group, as well as other Australians with disability.

We further believe, however, that the quantum of necessary funding the Commission has designated to deliver life time care and support for those with severe and profound disability, may be understated. Further work on service costs, transference of unpaid to paid care under the NDIS and the exact impact of the interface agreements with other programs will be needed before an accurate figure can be derived.

We understand the difficulty the Commission faces in estimating unmet need and any consequent cost estimates for NDIS service delivery especially. Both schemes will clearly need an extended 'shake down' period in which data can properly be gathered, the cost of needs evaluated, and service agreements (including schedules of costs) undertaken with providers of services, equipment and other resources negotiated and renegotiated.

That said, this work should be commissioned and actively pursued with State Governments and key community organisations as soon as the final report has been accepted by Government. The design choices that are made in determining the scope and operations of the Scheme are likely to have their own consequences. The better integrated the schemes are with the not-for-profit sector; the greater the resistance to cost shifting that can be applied; the more that eligible individuals can access the full range of community supports available to all Australians, the lower the cost and overall risk to the schemes.

65 years as eligibility boundary

The Alliance does not agree with the imposition of a 65 years age limit for access to services under an NDIS. While we understand concerns regarding cost blow outs due to ageing related support needs, too many of our members acquire their disabilities in later life.

Being diagnosed with MS or acquiring a brain injury at 66 is no different to being diagnosed with these impairments at 18 or 34 years of age. What will be different, though, is the available response if 65 years is retained as an eligibility boundary for the new scheme(s).

When 65 years was chosen as the definition of aged in 1907, average life expectancy was around 58 years. Today, average life expectancy is around 90 years and Australians are living longer and with better health as they do.

As the Younger People In Residential Aged Care initiative demonstrated, use of age as an eligibility mechanism that results in denial of vital services to individuals simply because they have aged beyond an arbitrary point, can have dire consequences. The end result under YPIRAC was often deterioration in health and, consequently, even greater imposts on the health, aged care and disability systems than would have been the case otherwise.

Our existing service system already delivers responses according to age, not need. To simply reiterate this system via an NIIS and an NDIS will be to miss an important reform opportunity that could see disability and aged care services aligned in a more complementary manner in the future.

One answer may be for the scheme to take account of equity as well as eligibility and provide partial eligibility for some services to applicants in this position. If, for example, an electric wheelchair is all that stands between a 67 year old returning home after exacerbation of an MS episode, the scheme could fund the wheelchair and leave aged care services to provide on going support.

Transition issues

The draft report has rightly raised a number of issues regarding the transition to the new arrangements.

Given the fragmented state of disability services and the poor interface pathways that exist at present, there will need to be some high profile transition projects put in place to break up some of the current barriers and entrenched practices. There will be many areas that will need these kinds of ‘leadership’ or ‘demonstration’ projects to deliver the workforce, the service efficiency and the planning and lifetime care management systems required.

Rather than simply trialling a cut down version of an NDIS in a region, it may be more useful to identify the transitional paths from the current system to the new one and choose a range of areas that need to be developed in order to make this possible. These projects can be started as soon as the key priorities are established, and would include:

- DSO organisational structures
- Lifetime Care and Support (case coordination and management) methodology
- NDIA claims management methodology
- Consumer involvement in care planning
- Cross sector planning (in education, health and aged care, for example)
- Workforce development
- Assessment methodologies vis a vis DSOs

One that is particularly relevant to the YPINH cohort is the joining up of health, aged care and disability services to ensure that the right mix of services from each service area is available in the right measure to people in this group.

One of the key reasons that young people are placed in aged care is that there is no spare capacity in the disability system, and that planning and recovery take more time that the system can accommodate. Even with additional funding availability in an NDIS, there will still be the need to access program areas outside the scheme (such as hospitals and aged care homes) as transitional arrangements.

It will be some time before a fully responsive market exists that can deliver these services directly to the scheme, so for this transitional period the Scheme will need to access programs and infrastructure that exists in separate program areas.

Regardless of whether YPINH are in aged care or at risk of entry to aged care, it may be that the scheme will need to fund aged care services to deliver some of the services required by these individuals. Given the large number of young people already in aged care, it is unrealistic to think that all of them will move to alternative services in the foreseeable future, so aged care will remain an essential part of the service response to the YPINH group well into this century.

The NDIA will need to embrace this reality and work with the aged care sector to expand its range of service offerings to younger people. A new revenue stream and policy imperatives could incentivise aged care providers to deliver much improved services to younger people. This is something that the NDIA will have to drive as an early scheme priority. It would also sit within current government thinking around expansion of aged care services to new areas of business and revenue streams.

Funding aged care transition programs will be a useful way of building capacity in the system, and enabling people to access step down services within the aged care system while alternative service options are explored.

Currently the Aged Care system provides transition care programs for older people enabling them to leave acute care settings while waiting to go to an appropriate residential care setting or recover to go home. Developing a range of pilots in transition (or interim care) for younger people with disabilities will be required as early as possible so that the facilities and expertise is in place for the scheme at large.

The Alliance would recommend that the Departments of Health and Ageing (DOHA) and Families, Housing, Community services and Indigenous Affairs (FAHCSIA) negotiate these pilots with disability and aged care providers in 2012 as a way of preparing the sector for the introduction of the NDIS, but also because it is sorely needed.

There are precious few of these interim care/rehabilitation facilities in Australia, and the ones that are there are largely blocked due to the lack of exit points to community services.

Interfaces with other service areas

The Commission's identification of crucial interfaces between the various arms of the service system including those between disability and health, are areas that obviously need to be managed carefully and proactively to ensure each service area delivers on its responsibilities.

We agree and would also make the point that proactive partnerships and collaborations between health and disability programs at the service level as well as the policy level are essential to develop and deliver the suite of services YPINH™ require. In other words, defensive management of these interfaces by any of the several protagonists involved, such as health, disability, aged care and housing, will only reinforce the existing deficient state of play.

Cross program interfaces cannot be allowed to be purely policy driven instruments that deliver the poor translation we currently see. The NDIA will need significant powers of persuasion and creativity to make these agreements work. The NDIA will not only need the mandate of Governments to make these interface agreements work, but will also need the support of sector organisations and consumer groups to make the agreements effective.

The new schemes must take a proactive stance to interface engagement. The NDIS, in particular, must seek to initiate change and encourage the development of innovative ways of engaging with other service arms so that the integrated service responses not only required by the YPINH™ group, but increasingly expected by any Australian with a disability, can be delivered. Such partnerships and collaborations will not also assist during any transition period; they also have capacity to lower long term scheme costs by encouraging partnered contributions that will deliver benefits to all collaborators.

Managing these interfaces successfully and proactively is something the Alliance believes the Disability Support Organisations are best placed to undertake. The DSOs will confront the needs of clients for buy-in these other areas. They will also have to negotiate appropriate responses and will be well placed to promote systemic reforms of benefit to all service areas.

Employment and education services outside the schemes

The Alliance does not support the inclusion of employment services and education services as part of an NDIS or NIIS funded program response. These service areas already exist and while they may not be as effective as they could be, replicating them or including them in an NDIS is not warranted. Instead, we need to make these community based programs responsible for what they should be doing, not offering them an easy out by inclusion in an NDIS or an NIIS.

Again, the Alliance believes that negotiating and partnering with these service areas, as with services in health, disability and aged care, are roles that Disability Support Organisations can successfully undertake. Doing so goes to the heart of expectation management amongst clients, providers and other service areas with their own legislative responsibilities to deliver.

Rehabilitation essential in the NDIS

While rehabilitation is a clear benefit in the NIIS, the Draft Report does not identify rehabilitation as a benefit type in its description of the NDIS.

Therapy services are listed as a service type in an NDIS, but it is not clear whether rehabilitation (in particular slow stream rehabilitation) is going to be covered in the scheme. While this is something that an NIIS would deliver, it is also an integral part of the services an NDIS must deliver for individuals requiring habilitation or slow stream rehabilitation services to maintain life skills and/or slow disease progression.

The enduring lack of slow stream rehabilitation has been identified as a key cause of admission to aged care and increased disability in the YPINH group. This is especially the case for those with progressive neurological diseases as well as those young individuals acquiring hypoxic brain injuries from near drownings, stroke, hypoglycaemic coma in diabetes et al and who may not be eligible for an NIIS. Slow stream rehabilitation is currently a major service gap and is something that the NDIS must purchase for its clients as part of their ongoing recovery and support.

At present, the health sector provides limited fast stream rehabilitation to individuals able to demonstrate capacity to recover. It does so only in acute care hospital settings for short periods of time or specialist rehabilitation services in anticipation of discharge to full function and return to community living. The health sector does not provide the important components of recovery that slow stream rehabilitation, in particular, can deliver.

Young people with progressive neurological diseases and those with acquired brain injuries not supported in the NIIS, cannot access the slow stream rehabilitation services they need via the health system. The NDIS must provide this essential component to not only promote recovery from acquired hypoxic brain injuries, but maintain the health and well being of its consumers over the long term.

In short, rehabilitation is required for recovery from

- hypoxic Acquired Brain Injuries that may not be covered by the NIIS including near drownings, strokes in young people, drug overdoses, asthma attacks et al
- exacerbations or episodes of progressive neurological disease like Multiple Sclerosis, Parkinson's and Huntington's diseases etc
- and to maintain health and well being over the long term for people with progressive neurological diseases

Rehabilitation is absolutely essential for the YPINH cohort and must be a funded service in both an NIIS and an NDIS. Not providing this in the NDIS may lead to increased applications to the NIIS for coverage (including litigation) by clients of the NDIS and the rehabilitation services the NIIS delivers.

Providers must be providers only

The Alliance believes that providers must be providers of services only.

They cannot undertake additional roles such as advocacy, fund brokerage and assessment. Doing so will deliver a clear conflict of interest that ultimately disadvantages clients and puts scheme sustainability at risk.

Low to moderate levels of impairment

As outlined in the Draft Report, individuals with severe and profound impairment will be covered under an NDIS. Those with catastrophic injury will be covered by an NIIS. While the Draft Report mentions Tiers 1 and 2 as part of an NDIS, these tiers are respectively largely concerned with provision of information including raising awareness in the broader community of disability and its impacts (tier 1); and referral to other service areas for response (tier 2).

The Alliance is concerned that the scheme as outlined in the Draft Report, does not address the needs of those with low to moderate support needs. These may include individuals who have made a significant recovery from, for example, an ABI but who still require some supervision to live their lives successfully and safely. If the scheme does not support these individuals in tier 3, and tier 2 is inappropriate or inadequate to their needs, where will their support come from?

Those with low to moderate levels of need could well be catered for by state government disability structures that have been relieved of the need to support those with high and complex needs.

Assessment

The Alliance does not support an assessment 'toolkit' containing certain assessment 'tools' as the only assessment option. Instead, the Alliance strongly supports a proactive, risk management approach to assessment of need and planning of responses for all clients of the two schemes.

Such an approach relies on skilled (tertiary) assessors who gather information from a wide range of sources (including assessment 'tools' as needed), to build a clear picture of an individual's current situation, current risks in play as well as any short, medium and longer term risks that may be 'coming down the pipeline'.

Planning for these risks and putting responses in place to activate when the risk 'arrives', delivers better outcomes for scheme clients, can potentially reduce costs through proactive case coordination and program and sector collaborations; and enhance the scheme's viability as clients become more aware of their potential and future needs and become involved in planning for them. This is especially the case for the YPINH group, many of whom never get the opportunity to think ahead and come to terms with the life they may lead in the future.

Information recovery from a wide range of sources should include input from family, friends and social networks; professionals in health, disability and allied health (including clinical assessments and other applied results), service providers, advocacy and information organisations, employers et al. "Assessment Tools" used in this process should include whatever is needed to deliver a comprehensive picture of the health and other risks the individual faces going forward

Once a clear and complete picture of the individual's circumstances is in hand, planning to address issues/risks over the short, medium and long term can be undertaken and appropriate responses put in place.

Market forces as drivers of systemic reform

The draft report's apparent concentration on market forces to drive program and systemic reform as well as the development of appropriate service responses, is of clear concern to the Alliance and its members. The Alliance believes this expectation is misplaced.

As the Victorian Transport Accident Commission's (TAC) example shows, reliance on market forces to drive system reform can be dangerous and counterproductive unless actively managed. The Alliance is aware of the fact that some private providers, who have made TAC dependent on them over time, have stopped providing key clinical services to the TAC. Reasons include a 'lack of economic viability' for the provider; or that these individuals are just 'too hard' to support. As a result the TAC has had to develop a separate structure to buy and own its own high care accommodation in order to obtain what the market has failed to deliver. In some cases aged care accommodation is considered for TAC clients due to the lack of available options. This is not a consequence of a lack of money (as it is in the public system) but a lack of appropriate service development.

An over-reliance on market forces also risks the potential commodification of NDIS clients. One of the clear risks with a fully funded scheme is that the reliance on paid care or buying of services for all aspects of daily life will do just that and effectively commodify scheme clients.

As the UK's experience shows[1], it takes more than market mechanisms to create a desirable and sustainable support environment. Making financial arrangements the key relationship between a service user and a service provider puts the end user at real risk of commodification under such an arrangement. Instead, schemes should encourage and make provision for families and friends to continue their involvement and provision of care to their loved ones as they are willing and able to do; and support community engagement (and support) as part of an individual's broader citizenship.

Life time care and reform

In a similar vein, the report's acknowledgement of the need for reform in a number of areas but its lack of a declared framework to achieve this is also of concern. While such considerations may well be beyond the scope of the inquiry, they are fundamental to the successful introduction of both an NIIS as well as an NDIS.

To encourage discussion of what a life time care and support methodology might entail, the Alliance convened a national roundtable on this important topic at the start of April, earlier this year. Representatives from the disability, health and aged care sectors attended, as well as members of peak organisations, advocacy groups, providers, no fault motor vehicle scheme delegates and government representatives. The complete results of the roundtable are attached as an appendix to this submission. A briefing document that provided an overview of life time care and support schemes operating elsewhere was also provided to roundtable participants prior to the meeting. A copy of this briefing paper is also attached to this submission.

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[1] See http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_121508. Accessed May 16 2011

In brief, the roundtable's outcomes included the following agreed observations

- An individual is not simply a single person but is an amalgam of family, friends, work colleagues, neighbours, clinicians et al. A Life Time Care and Support (LTCS) scheme, such as an NDIS, must enable input and contribution from all these support sources.
- Funding alone will not deliver much needed outcomes. As one example of this, the Younger People In Residential Aged Care (YPIRAC) initiative simply added additional funding to the disability system but did nothing to encourage or promote systemic reform. The "business as usual" response from disability services nationally did no more than develop more of the responses that had contributed to the birth of the YPINH™ issue in the first place. A LTCS scheme must include transparent and flexible engagement with those who directly and indirectly impact the individual's life including family, friends, employers, providers et al; as well as health, disability, allied health and clinical input.
- LTCS is inherently dynamic. Schemes must be flexible enough to respond to important life transitions between
  - Rehabilitation (in/out)
  - Work
  - School
  - Living arrangements
  - Palliation
- Formal and informal partnerships or collaborations are at the heart of developing and delivering the suite of responses a properly responsive LTCS scheme would manage. These can involve collaborations between health, disability, housing, aged care agencies, clinicians, family, colleagues, neighbours, providers et al
- In developing an NIIS or an NDIS, we will move from a system of need to one of certainty of response. Rather than *entitlement* to response, LTCS should be about the ***rights* of participants to responses because rights carry responsibilities**. This may help manage the transition from our current, crisis driven system to one where certainty of response exists; and also assist with management of client and provider expectation.
- It is critical to properly understand the individual's situation re: health, family, work, expectations, aspirations. In other words, there is more to adjusting to disability than just getting formal assessments and service plans right.
- **Strong support was expressed for the role of disability support organisations as detailed in the Alliance's submission, to be the 'front end' of any scheme and to**
  - establish eligibility
  - provide a suite of outcome based assessments and planning options
  - advocacy and expectation management services
  - some limited brokerage services to deliver timely responses immediately after assessment and planning is completed
  - scoping and engagement of suitable service providers

  - delivery of peer support and other ‘informal’ services
  - information and education including that concerning available options/choices
  - proactively manage service interfaces between disability, health, aged care, housing et al
  - deliver ongoing community based case coordination to get applicants underway; and to manage the dynamic nature of life needs over time
  - involvement of volunteers and social networks
- Located within DSOs, case coordinators
  - undertake assessment across a range of areas and bring in relevant assessors (health, allied health, clinical, legal) as required. Assessors must be briefed according to the individual’s identified needs (e.g. maintain family unit, establish small business, making a will, deliver physical, rehabilitative, other supports). Other assessment needs to include how people can re-engage with their lives, communities, families, workplace (if relevant and desired)
  - broker and manage service provision and providers
  - manage client and provider expectation
  - liaise with and coordinate other service areas input and contribution including employment, education, health, aged care as needed
  - maintain a ‘watching brief’. That is, they are available and can activate as and when required, or at regular review intervals, but remain ‘dormant’ otherwise.
- DSOs and case coordinators manage the tension between what people may want or expect from the scheme; and what the scheme can reasonably deliver: i.e. inform/manage expectations while still ensuring that plans are in place to meet emerging needs.
- Strong support for a proactive, risk management model of case coordination to manage scheme members changing needs over the life course
- Declared view that the scheme should not internally manage case coordination/management, advocacy or dispute resolution. A number of the functions of the NDIA could well be decentralised to place the planning function within the Disability Service Organisation (DSO), close to the person and their community. The DSO would also be in a better position than the NDIA to work with the dynamic of formal/informal supports needed to deliver quality of life and outcome. This would also reduce the levels of disputation evident in comparable schemes where case management and funding decisions sit in the funding body. Internal case management was seen as a conflict of interest.
- DSOs were considered an essential filter between the commercial interests of providers and the objectives of the scheme. This filter can mediate what can be a one dimensional relationship that is driven by funding more than it is about delivering outcomes.
- DSOs should

- Be Not-For-Profit, block funded by government and contracted to the NDIA to perform all the listed functions
- Continue to offer their current mission driven offerings
- Form an effective coterie around the scheme, and share the difficult responsibilities of scheme viability and meeting client need. This is the key tension in the scheme, and the DSO model as defined by the Alliance in its first submission to the Inquiry, may provide a unique way of safeguarding the key roles currently performed by the NFP specialist organisations as well as the integrity of a new scheme.

  It would also create a values based buffer between the commercial imperatives of providers and the scheme operation - a very important design imperative with a scheme of this scale.

The approach validated at the Alliance's National Life Time Care & Support Roundtable has also been recognised in the UK where the focus of 'social care' is on improving the lives of those with disability through building stronger local communities.[2] The UK Government's recently launched *Vision for adult social care: Capable communities and active citizens*, sets out how the Government wants to see services delivered for people; delivers a new direction for adult social care; and puts personalised services and outcomes 'centre stage'.[3]

The UK Government's vision for a modern system of social care is built on seven principles that the NDIA, NIIS and NDIS could easily adopt. These are:

- **Personalisation:** individuals not institutions take control of their care. Personal budgets, preferably as direct payments, are provided to all eligible people. Information about care and support is available for all local people, regardless of whether or not they fund their own care.
- **Partnership:** care and support delivered in a partnership between individuals, communities, the voluntary and private sectors, the NHS and councils - including wider support services, such as housing.
- **Plurality:** the variety of people's needs is matched by diverse service provision, with a broad market of high quality service providers.
- **Protection:** there are sensible safeguards against the risk of abuse or neglect. Risk is no longer an excuse to limit people's freedom.

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[2] See http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_121508 and http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/@ps/documents/digitalasset/dh_121668.pdf Accessed May 16 2011.

[3] See http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_121508 Accessed May 16 2011

- **Productivity:** greater local accountability will drive improvements and innovation to deliver higher productivity and high quality care and support services. A focus on publishing information about agreed quality outcomes will support transparency and accountability.
- **People:** we can draw on a workforce who can provide care and support with skill, compassion and imagination, and who are given the freedom and support to do so. We need the whole workforce, including care workers, nurses, occupational therapists, physiotherapists and social workers, alongside carers and the people who use services, to lead the changes set out here.[4]

As part of this new approach, the UK's sector wide statement of intent, known as "Think local act personal', embodies the sector's commitment to this collaborative approach. [5]

There is clearly much more analysis and decision making required before a viable scheme can be confidently designed and implemented. However, the Commission's work has taken a conceptual reform vision and given it practical form.

The final report will hopefully refine the design recommendations to deliver a viable and evidence driven case to Government.

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[4] Ibid.

[5] See http://www.thinklocalactpersonal.org.uk/_library/Resources/Personalisation/TLAP/THINK_LOCAL_ACT_PERSONAL_5_4_11.pdf Accessed May 16 2011

Appendix A

a) Results of the National Roundtable on Life Time Care and Support

b) Life time care and support discussion paper

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Results…
National Roundtable on Lifetime Care and Support

Melbourne
7 April 2011

Young People In Nursing Homes National Alliance

ABN 25 121 748 169
www.ypinh.org.au

On April 7 2011, the *Young People In Nursing Homes National Alliance* convened a national roundtable on life time care and support. The aim of the roundtable was to promote discussion of the concept of life time care and support; identify key elements of a successful long term care system; and consider system interfaces that would need to be articulated to ensure sustainability of such an approach.

Over 40 representatives from the disability, health and aged care sectors attended, as well as members of national peak organisations, advocacy groups, service providers, no fault motor vehicle scheme delegates and state and federal government representatives.

Key discussion areas included
- The need to develop responsive lifetime care and support models to work with insurance based lifetime funding schemes (eg NDIS)
- Problems and issues with case management methodologies in the current service system
- Life time care and support as an alternative approach
- Key components of a functioning and responsive life time care system
- Sustainability and funding of long term care
- Cross program linkages and partnerships between service sectors
- Proactive risk management approaches within life time care and support
- The importance of informal care and social networks
- Consumer participation and control of service management
- Successfully moving from our program driven case management system to a responsive life time care and support approach
- The workforce profile of lifetime care and support co-ordinators.

The outcomes and agreements produced at the roundtable have been grouped into the following themes.

Life time care and support (LTCS)
Individuals with high and complex clinical and other needs (including chronic diseases) make up a growing group within the service system. Responding to people with these conditions requires collaboration and partnership between all areas of the service system including health, disability, aged care, housing, education, employment. The expertise to do this well across multiple program areas is very patchy in Australia. While

compensation systems utilise a lifetime claims management approach, much needed community based and long term case management models do not exist.

Our current fragmented approach cannot meet ongoing needs. At present, collaboration between the service arms exists largely in name only and assessment and planning are done according to budgetary constraints and program capacity, not according to an individual's identified needs.

A sustainable life time care and support system must focus on delivering the full suite of supports over the life course with collaboration and partnership with health especially, as well as other service arms. An integrated health and social model of care is fundamental to such an approach.

A viable life time care and support system needs to think more broadly than just the funding and buying of services. If lifetime care is about whole of life support, it must focus on

- The dynamic nature of support and fundamental need, consequently, for flexibility of response
- Health, well-being and life of the individual and
- Delivering 'lives worth living' rather than lives lived according to program and funding availability
- Collaboration and partnership with all areas of the service system
- Capacity as well as incapacity of individuals
- Needs based assessment
- Outcome based measures
- Case management and coordination that requires a 'new breed' of tertiary case coordinators to 'walk the journey' with individuals and families
- Tension between the client/family and the system's outcomes
- Once 'in' the system, individuals remain, irrespective of programs and age
- Information provided should not require repeating. Forms should be filled out once
- Information about choice and understanding the consequences of choices must be available
- (Re)habilitation is an essential program component to enable functional improvement over time and/or maintenance of health and well being
- Being person focused rather than system or funding focused
- Address the psychological aspect of disability/care support

- Allow individuals to be ‘dormant’ in the system (ie not requiring services or other interventions) without being outside it
- Be flexible and porous with regard to other service areas such as health, aged care, disability and housing and promote partnership and collaboration between these areas
- Think national act local. People live locally; they don’t live nationally. Similarly, assessment, planning, provision of services et al should all be operating at a local level and in the environment the individual usually engages in/with.

A comprehensive LTCS system should have a view of itself as a dynamic change agent, delivering improved support practices to recipients as well as leadership to the service sector. It should deal in best practice and encourage research.

There was strong support for the placement of LTCS management being community based. While the TAC and ACC both had internal case management models, participants felt that the opportunities to maintain vibrant local service neworks and maintain close relationships with individuals provided a compelling argument. Some also voiced the view that internal case management roles in these schemes are inherently conflicted.

The mandate and responsibility of community based LTCS agencies can be managed via contract with Government and/or the proposed NDIA to ensure that they maintained appropriate practices.

Assessment and planning

Assessment must be needs based and establish what an individual needs and wants before planning can begin. Preparation (including gathering of information from a variety of sources) is the most important part of the planning and assessment process. It also need to be dynamic and closely linked to the service management function and the individual and their family.

Areas of assessment should include

- health needs including (re)habilitation , equipment, clinical support needs
- support requirements in all areas (at home, at work, to sustain work, legal, education et al)
- the integration of formal services with informal supports and social networks (including family, friends, neighbours, work colleagues)

- identification of existing, short, medium and long term risks with appropriate planning to address these risks, and prepare for them

Current planning practices are mostly concerned with those individual's needs that can be quantified and which only relate directly to the service program that is directing the assessment. A LTCS approach requires we look at the person as a whole, including their family's needs and expectations. Resources and services in all service areas must be identified and brought together as part of planning process. To do this, we need to look outside the square and outside usual funding options to deliver the quantum of care and support required.

Team based care, rather than several individuals acting independently of each other, delivers the best options in this regard. We need to 'pull together and work together' to achieve the best results for each person. Planning ahead and the use of a proactive, risk management approach to assessment and planning of care, can identify short, medium and long term risks, reduce crises and the costs that are otherwise born by the service system when crises erupt unexpectedly.

Specialist case management is an essential part of the successful planning and management of care. Care coordinators, with responsibility to oversee assessment, planning and implementation processes, as well as coordinate involvement of other service areas and the team delivering care, are vital to success. These Coordinators need to be conversant and influential across program areas, particularly in health and disability programs.

Good communication between all those involved in the planning and assessment process is obviously essential for successful planning and implementation of care. Protocols to share information between all service areas are similarly a very important part of successfully delivering life time care and support. We can make better use of other methods of communication including e-health resources

Delivering life time care and support requires a sustainable workforce, skilled in the needs of those with complex support requirements.

In short, assessment and planning should incorporate
- Proactive risk management approaches
- Regular review of assessment skills and approaches regularly

- All information pertinent to the individual: gathered from family, social networks, employers, clinicians
- Flexibility and choice in choosing accommodation
- Decision making should be collaborative and include a formal structure where appropriate
- Seamless entry and exit from programs or scheme
- Assessment integrated with ongoing care management and consumer involvement
- Palliative care as well as support services
- Case coordinators who can
    - 'Travel the journey' with the individual
    - Think outside the square; be innovative and creative in designing responses
    - Be active or dormant as needed
    - Prioritise as well as plan
    - Identify and plan for short, medium and longer term risks
    - Negotiate with family and social networks
    - Maintain a watching brief to ensure all areas of support function
    - Negotiate input and outcomes with service areas in health, disability, aged care, housing et al including multiple program eligibility if required
    - Listen, reflect, respond
    - Operate locally, coordinate nationally

Health and clinical input

Specialists and medical professionals (including GPs) struggle to 'stay abreast' of available options for people in their care. Their knowledge of what can be delivered or is feasible in the community/home is limited. This is why a collaborative approach is so important. Health representatives (specialists, clinicians, allied health representatives et al) must have opportunities to contribute their particular knowledge and expertise as part of the planning process.

Access to rehabilitation is essential for those with high and complex needs. Rehabilitation should be seen as an investment that can deliver reduced costs over the longer term

Consumer input

While the idea of person centred approaches is accepted, putting such approaches into practice can be difficult. At present, we do not assess, plan or implement plans from a

person centred point of view. Responses are made according to established guidelines and/or what funding is available, not what the individual wants or needs.

From this point of view, the ‘system’ looks at the bigger picture: tensions around funding, program availability, staff and unmet demand. It can forget the person who is the very reason for the system’s existence.

Putting the consumer at the centre of assessment and planning can be problematic. Specialists and other health professionals don’t ‘know’ the individuals…they deal with a ‘case’ not a person, and they keep changing.
When someone is first disabled – whether through injury or illness – many specialist and health professionals are involved, delivering a “wall of sound” of advice and information that is almost impossible for the individual to interpret and/or come to terms with. This makes it very difficult for an individual to understand what their needs are likely to be and what options might be available to them.

Consumer input into what is wanted/needed must be a priority. Peer support and advice can play an invaluable role in providing information, support and assisting with readjustment

Entitlement or rights and responsibilities?

Strong support was indicated for a rights based LTCS scheme, rather than an entitlement scheme. A rights based approach was preferred because rights bring responsibilities and can assist with managing expectations of consumers as well as providers. A similarly constructed lifetime care and support management methodology will assist the funding scheme to work positively with stakeholder expectations over the long term.

Infrastructure

With moves to consider insurance based funding approaches such as a National Disability Insurance Scheme, there was recognition that the service system infrastructure such a scheme will need to interact with, does not exist at present. Strong support was expressed for the development of that infrastructure to start immediately. This not only includes LTCS models but also aids and equipment supply chains, provider management models, consumer decision making supports and policy integration.

Research and results

Because a LTCS system must be outcomes driven, a strong research base is needed to support its efforts. Trialling of pilots and action research approaches that involve participants directly in the *process* of research, as well as its results, was considered valuable.

Like other areas, the research base of a LTCS system should be flexible, dynamic and have capacity to think outside the square.

The Roundtable was of the view that the proposed NDIA should be looking to manage a range of demonstration projects to establish the new systems and organisations required for the NDIS. It was agreed that this needed to begin in early 2012, and closely involve State and Territory Governments.

Disability/aged care divide

The Roundtable was keen to avoid an artificial age barrier in the design of an LTCS. Key questions raised included:

- Why do we maintain an aged based service response?
- Why does 65 years remain a definition of aged when average life expectancy in Australia is nearly 90 and Australia anticipates 50,000 people over 100 years of age by 2050?
- Why move to aged care at 65 years when it offers less than disability?

Roundtable participants were clear that we need to work on transitional arrangements and capacity building to increase capacity in the aged care sector for younger people who choose/want to remain in that system. There is also the need to enable the NDIS to utilise the aged care service infrastructure as a transitional accommodation arrangement for people while tailored long term community options are established.

Conclusion

The Roundtable offered a unique opportunity to discuss the potential for a life time care and support system in Australia; and consider the key components needed to make this a viable reality.

Participants from a broad cross section of policy and program areas in health, aged care, housing and disability as well as federal and state governments and no fault motor

vehicle and work cover schemes, found common agreement around what should be included and how care should be devised and delivered in such a system.

The following points were unanimously agreed.

- A long term LTCS management approach to match reformed funding schemes, such as those suggested in the Productivity Commission's Draft Report into Disability Care and Support, was highly recommended
- A viable **and operational** LTCS infrastructure is an absolute precondition for an NDIS to be effective
- An LTCS infrastructure would contain the central expertise that the service system (as well as the NDIS bureaucracy) would rely on – and would become the go-to part of the wider system for all stakeholders.

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Lifetime care discussion paper

Introduction – defining lifetime care

This paper discusses lifetime care (LTC) options and opportunities within the Australian and the international context. The paper is comprised of four parts:

- **Part 1 –** discusses selected international models of lifetime care, factors of these models influencing access to lifetime care and considering lifetime care from other jurisdictions in the Australian context.
- **Part 2 –** describes the key features of lifetime care insurance schemes (Australia and New Zealand).
- **Part 3 –** discusses opportunities and barriers for lifetime care in Australia.
- **Part 4 –** discusses elements of international schemes that have potential to support improved delivery of lifetime care in Australia.

Johnson and Ucello describe lifetime care as a 'service for people who need assistance on a regular basis because of chronic illness or physical or mental disabilities'.[i] In this paper the term lifetime care will be used to refer to all the supports (both formal and informal) that a person may require. The term will be used to refer to the supports themselves rather than any funding systems that may be in place to enable access to supports.

Part 1 - International models of lifetime care

Models of lifetime care across the Western worlds are evolving in response to changing funding and policy environments and client expectations. In Australia over the past decade both government and disability support providers have responded to developments in contemporary disability practice, particularly a focus on peoples' abilities, person-centred planning, engagement of natural supports and community participation.[ii,iii] At the same time demographic shifts, particularly the aging of populations and increased employment participation of women (the traditional providers of unpaid care for people with a disability and the elderly) has also changed the landscape and the means of supporting people with a disability to remain living in their community and living the life that they choose.

In response to these various drivers and shifts the disability support sector has begun re-orientating services to enable them to become more flexible, individualised services that are responsive to the aspirations and needs of their clients. Disability support agencies are moving from a charity to a business model of operation, from block funding to increasingly individualised funding. The disability sector is in the process of adapting to operating within an individualised funding model in a competitive business environment.

1.1. Identifying fundamental differences between different models of lifetime care

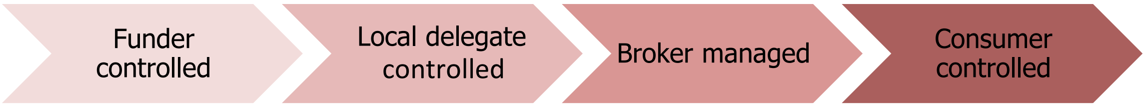
At first glance there appears to be a great deal of variation between models of lifetime care in Europe the United States and Australia.

These differences can be grouped into three broad themes:

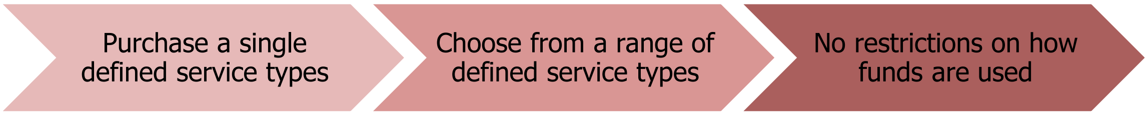
- Who controls the funds to purchase supports;
- The level of restriction over how funds may be used; and
- The degree of choice a client has regarding when where how and by whom services are provided.

Each of these themes can be considered as a continuum.

The degree of control over funds

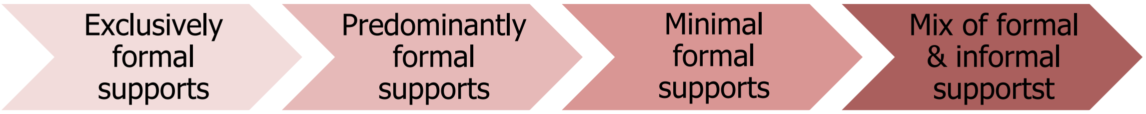


The level of restriction over how funds may be used



The degree of choice a client has regarding when, where, how and by whom services are provided.

In addition, the balance of formal and informal supports that a person accesses impacts on the extent to which these supports are responsive to the person's support needs or to which the person's life is defined by the supports they receive.



Using this framework to consider and compare lifetime care models from different jurisdictions can provide a useful mechanism by which to differentiate between elements of a lifetime care model that are essentially cosmetic and identify features that result in fundamental differences in how consumers experience lifetime care.

For example, the Transport Accident Commission (TAC), Victoria's transport accident insurance scheme, and the United Kingdom's (UK) direct payment option for lifetime care appear quite different. Under the TAC scheme the funder holds monies for lifetime care supports and pays providers directly,[iv] under the UK direct payment scheme funds are held by the client who employs or directly purchase supports.[v] Yet under both schemes the client is able to make choices about the types of supports that they receive within scheme approved funding and from a defined list of support types. In both schemes the client is also able to make choices about by whom, how, when and where services are delivered. However, the ease with which a person can make such decisions may vary even within the models that are broadly consistent, with schemes where the funder holds monies sometimes requiring approval to vary the type of service provided.

In some environments a high degree of choice about service provision is tied to the client managing the funds to pay for those supports; for example, in the United States and Germany. In the United States the ability to choose support workers is tied to participation in 'Cash and Counselling,' a Medicaid waiver program of funding where consumers are provided with vouchers to purchase supports from a less limited range of options than under the Medicaid Program. In other jurisdictions clients can make choices about when, where, how & by whom services are provided without needing to manage the funds to pay for these services; for example, Sweden's social insurance scheme,[vi] no fault transport accident schemes in Australia[vii] and New Zealand's more broad based accident insurance scheme.[viii]

In Australia current taxation laws and funder accountability requirements mean that self-managers of funds, who employ their own staff, are employers and small business managers. Not all people wish to take on this responsibility. While some Australians with a disability may wish to manage the funds for support services and directly employ support staff others may not.

The creation of a lifetime care insurance scheme does not necessarily mean that the disability sector's approach to funding service responses will be applied to the funding of supports under the scheme. There is a risk, as demonstrated by historical practices in the lifetime care insurance sector of individualised planning focused on services funded by the scheme, client needs being defined in terms of deficits, ongoing rehabilitation in the absence of clear functional outcomes and little focus on participation, especially in relation to work.

This services driven approach to planning, once used at schemes including the TAC and the Accident Compensation Corporation (New Zealand), resulted in the funding of ongoing therapy services well beyond the time during which they are effective, lives built around receiving treatment and therapy rather than around participation, low employment participation post injury and social isolation with Attendant Care the consequent single response accessed by participants. For some clients in these schemes Attendant Care workers were the only social contact outside of their immediate family or household.[ix]

More recently these schemes have adopted the disability sector's approach to funding services via basing responses in:

- Person-centred planning, rather than service-based planning;
- Peoples' abilities and needs, not just injury consequences and deficits;
- The achievement of ordinary lives, rather than on-going rehabilitation and therapy; and,
- Participation in the wider community using informal supports and community responses, as well as funded responses.

A summary of key features of selected lifetime care schemes operating internationally is contained in Appendix 1.

A map of the various types of lifetime care schemes operating in Australia and internationally and the degree of control they afford consumer in relation to selecting support options and how services are provided is contained in Appendix 2.

1.2. Other factors influencing access to lifetime care

Regardless of who controls the funds a range of other factors also influence the supports that a consumer will receive. Cultural and government expectations regarding the role that a person's family and personal network ought play in providing (both paid and unpaid) support will influence the amount of unpaid support that the person receives and (when the person is the fund controller) whether the person uses their personal budget to employ friends and family or choses to employ other support workers. In addition the local labour market also strongly impacts on a person's access to personal 1:1 support. Regardless of who controls the funds, local labour shortages may constrain both agencies' and individuals' capacity to employ workers and fill shifts and to fulfill consumer preferences regarding workers, such as culture language and gender considerations.

The profile of the consumer population also influences the funded lifetime care available in a given jurisdiction. Scheme eligibility criteria for no-fault transport accident schemes are typically not restricted by severity of injury or level of disability.[1] This results in a broad range of support responses for scheme participants (from short term domestic services to lifelong 24 hour/day care) and influences the provider market to offer a range of support services to respond to the needs of this broad client group. The population of people receiving state funded disability support is less diverse, as demand management strategies mean that resources are directed to consumers with the highest support needs and/or least access to informal supports and/or other target groups such as ageing carers. Limits on the amount of funding available to individual consumers and the varying rules governing the use of that funding influences the types of support options the provider market offers to this client group.

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[1] (although access to specialist claims management and support services is limited by injury in some schemes – Refer to Appendix 3).

While most funding in Australia is directed to people with very high support needs, including people living in a residential care facility, Australian jurisdictions have in place a series of programs to address the needs of people with lower support needs. These programs have a range of objectives including:

- Reducing the risk of demand for higher cost out of family home support;
- Improving participation outcomes; and
- Sustaining families who it is recognised provide the bulk of care.

1.3. Considering lifetime care from other jurisdictions in the Australian context

In examining lifetime care models in overseas environments it is important to consider not just the key features of the model but the context in which they were developed and operate. Environments in Europe, the United Kingdom and the United States may not always be directly comparable to Australia.

1.3.1. United States – Cash & Counseling

In the United States Cash & Counseling is a Medicaid waiver program that provides the consumer with vouchers to purchase a capped dollar amount of services from consumer or agency employed workers and, more recently, these vouchers can also be used to purchase some aids & equipment as an alternative to personal support.[x]

Cash & Counseling evolved in an environment where access to Medicaid funded support services by eligible consumers was highly restricted by a range of issues including:

- Worker shortages and Medicaid agencies having difficulties recruiting worker.,
- Industrial relations issues. The Medicaid Agency workforce is highly unionized and Medicaid services are almost exclusively provided 9am – 5pm, Monday – Friday.[xi]
- Program restrictions. At the time Cash & Counseling was introduced federal Medicaid legislation restricted Medicaid funds to being used for hands on personal support only and not substitutable services such as adaptive technology or domestic services.[xii]

The degree of regulation of the US Attendant Care agency market has resulted in Cash & Counseling consumer employed support workers being paid significantly lower rates and receiving fewer benefits than their agency employed counterparts. Most Cash & Counseling employed workers are known to the client and trust and satisfaction reports are high on both sides.[xiii] The program has not been shown to increase the overall amount of support that a person receives; rather, it increased the proportion of paid care and reduced the proportion of unpaid care provided.[xiv]

In effect Medicaid programs have not altered the range of lifetime care options available to clients but have provided payment to friends and family members for some of the care that they provide.[xv]

1.3.2. Germany – self managed funds

In Germany clients can choose from a capped level of agency provided support, direct payment of a fixed amount of cash or a combination of the two. In 2003, 76% of recipients chose the direct payment option. In marked contrast to the US system where people receive vouchers and not cash, the German Government pays the capped amount directly to the client and does not require that funds provided be used to purchase long term care services. Further, beneficiaries do not have to account for their spending. The capped amount of cash is provided to the client to enable them to directly fund both support and other expenses such as adaptive technology. Direct payments are calculated based on an hourly rate that is half the cost of agency provided services. In Germany this support is almost always provided by family members and in effect the direct payment acts as a carer payment. The formal service system is comprised of agency based 1:1 attendant care as this is the only service that is purchased outside of consumers' circles of family and friends. No formal quality assurance program is in place for consumer purchased care, based on the belief that people known to the client are more likely to provide a high standard of care.[xvi]

1.3.3. United Kingdom – self managed budget

In the United Kingdom clients have a choice of using agency provided support funded under the national disability support scheme that is administered by local councils, or self-managing a budget. Unlike Germany, consumer managed budgets in the UK have restrictions on employing family and household members to avoid self-managed funds transitioning unpaid care to become paid care.[xvii] Both consumers whose funds are council managed and those who manage their own funds may access a defined range of other services. The range of support options for consumers managing their own funds is broader than that for consumer accessing council managed funds and includes some options that could be considered personal living expenses, such as holidays and the personal costs participating on leisure activities.

1.3.4. Discussion

The constraints, or lack thereof, on how funds for support may be used influence the types of support that people with a disability are able to purchase. For example in an environment where funding may be used to employ support workers in an unregulated labour market and where there is high unemployment funds tend to drift towards being used to purchasing 1:1 support at a reduced hourly rate. Unregulated labour markets in times of high unemployment put downward pressure on wages but this does not always result in dollars being stretched further through improved purchasing power as budgets are often calculated based on assumptions that hourly rates for directly employed workers will be less than for agency staff. This is a factor in calculation of amounts for Cash & Counseling vouchers and for total amounts of direct payments in both the Netherlands and Germany.[xviii]

A predominance of self-managed funding in a particular jurisdiction may also act to reduce funder imperatives to improve client outcomes or constrain growth in the cost of support services. The funding cap of a self-managed budget acts as the mechanism for managing growth in both costs and long term liabilities. Changes in client outcomes do not automatically translate into adjustments to self-managed budgets. Self-managed funding systems may result in individual clients being price takers and may reduce the ability of funders to be price setters or to partner with providers, for example in quality improvement or labour market programs. Self-funded programs rely on the ability of clients to make judgments about whether their needs are being met and about quality issues and can rely on their ability to hire and fire as a means of managing non-performing workers. The use of family members may reduce the client's likelihood of firing a worker, but overall clients receiving Cash & Counseling report high levels of satisfaction with their carers and reported adverse incidents is no greater for this client group than it is for clients who use agency provided support.[xix]

As each client is purchasing services individually this may result in difficulties for consumers in sharing support even though financial and social benefits may exist if they do so. For example, two clients requiring low level support to access the same neighbourhood shops may wish to access shared support for this activity but not be able to connect with another consumer with similar needs. Funders in Australia have made some attempts to support these arrangements but their use outside of group support situations (shared residential care and shared support at community group programs) is limited. However, the enhanced use of co-ordination strategies such as online client registers may make this possible for a broader range of clients in both funder-managed and self-managed environments.

When introduced without other systemic reforms the impact of consumer-managed funds on the flexibility of service responses may be limited. The availability of skilled workers, the predictability of the client's day-to-day support needs and the presence of behaviours of concern[2] also impact on the ability of support to be provided in a flexible way. Some current funder arrangements (e.g. the TAC daily support option for attendant care[xx]) allow for flexibility of shift length in the same way that self-managed funding arrangements may.

Part 2 - Lifetime care insurance schemes (Australia and New Zealand)

In Australia lifetime care is funded by a range of schemes. In the states where compulsory third party insurance includes access to lifetime care funding on a no-fault, whole-of-life basis, these schemes fund responses to ongoing needs. In states with fault-based schemes, funding for these supports is from common law settlements provided the injured person can prove the negligence of another party. Under these fault-based schemes car drivers and others injured in accidents where a third party cannot be found to be at fault must rely on National Disability

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[2] Challenging behaviours

Agreement (NDA) funding. Lump sum settlement monies from common law payments are often exhausted within the lifetime of the injured person leaving them with insufficient funds to continue purchasing supports and reliant on state funded system.[xxi]

For injuries and disabilities not covered by insurance (such as in CTP or workers' compensation schemes) access to funded services is via state administered, NDA funded services. State funded services have varying eligibility criteria, although all are linked to criteria of severe and profound disability, and the extent to which funding is provided on an individualised basis varies from state to state. In states, such as Western Australia, where individualised funding and consumer managed funds are long standing programs, the provider market has evolved to meet a range of consumer needs and to provide a range of flexible support options. In states, such as Victoria, where the use of individualised funding and consumer directed funds is a more recent development, consumers may have access to individualised funding that affords them more flexibility but find that the availability of alternative flexible supports is limited as the market is still adapting to the new funding environment.

In states with fault-base lifetime care schemes, services for eligible clients are mostly managed by the insurer prior to settlement of the person's claim. After the claim has been settled the client manages the monies that they received in the lump sum settlement and the services that they purchase with these funds. A fault-based scheme sets a cap on funding of the amount of monies paid in the common law claim. In a no-fault scheme, once a client's claim has been accepted and liability for injuries accepted the management of funds used occurs though individual claims management processes. In no-fault schemes the need to maintain scheme viability (in no-fault lifetime care schemes attendant care comprises the bulk of liabilities) means that funders have strong imperative to manage unit costs to quality outcomes and service utilisation levels. Resources are directed to management of service utilisation via claims management processes and individualised planning processes and provider performance via contract management activities such as quality and compliance audits. In fault-based schemes this imperative is less strong as once a client's lump sum settlement monies are exhausted they cannot seek further funding from the scheme and become reliant on the state disability services funding and system.

A summary of key features of lifetime care insurance schemes in Australia and New Zealand is contained in Appendix 3.

Part 3 - Lifetime care in Australia: opportunities and barriers

The introduction of a national insurance scheme for lifetime care and support presents a range of issues that may be considered as barriers or opportunities depending on stakeholder perspectives and how these issues are addressed in the development and implementation of the scheme.

To facilitate consideration of these issues the model used to review international and Australian schemes in section 2.1 of this discussion paper has been used, that is issues are discussed in relation to:

- Who controls the funds to purchase supports;
- The level of restriction over how funds may be used;
- The degree of choice a client has regarding when, where, how and by whom services are provided; and
- The extent to which supports are responsive to the person's support needs or to which the person's life is defined by the supports they receive.

For ease of consideration, workforce and provider issues are discussed separately. How these issues are managed will impact on how funds are used, how supports are provided and the extent to which supports are person centred.

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Issue	Opportunities	Barriers
1. The degree of control a consumer has over funds to purchase supports	For the scheme to: • Implement mechanisms that enable consumers to control funds should they wish to do so & provide infrastructure & support to enable this to occur (e.g. IT systems, supported decision making) • Develop mechanisms to offer to consumers a range levels of control over funding (e.g. funder, local delegate, broker or consumer) • Create funding systems that do not disadvantage consumers who choose not to manage their funds	• That consumer controlled funding options are used as a means to reduce costs and liabilities rather than increase consumer choice and control. Consumer controlled funding is implemented without other sector reforms and does not increase the range and quality of supports available • Lack of scheme support may cause consumers to become price takers, reducing the purchasing power of consumers with self-directed funding • IT and supported decision making systems do not effectively support consumers to self-manage funds resulting in consumers not renewing self-funding agreements

2. The level of restriction over how funds may be used.	For the scheme:
	• Use person centred planning processes to ensure that the provision of supports is:
	  ◦ Based on person-centred, rather than service-based, planning
	  ◦ Responsive to peoples' abilities and needs
	  ◦ Focussed on the achievement of ordinary lives
	  ◦ Focused on the use of informal supports and community responses, as well as funded responses
	• To (both directly and via peak bodies & lead
		• Increasing the range of people who are able to access funds and the amounts of funding that consumers are able to access may result in consumers purchasing more of the same without resultant increases in the client centeredness of the supports or the level of participation by the client
		• Consumers may wish to buy a broader range of supports but (particularly in the early years of as scheme) these may not be available because of market concentration of service types and the geographic isolation of some consumers
		• Multiple parallel funding and support systems

Issue	Opportunities	Barriers
	agencies) partner with the community and disability support sectors to broaden the range of support options available (both funded and informal/ community based) to people with a disability	currently exist resulting in a fragmented sector across a relatively small population in Australia. A new funding stream for LTC may introduce a new fragment to the sector rather than facilitate the development of a more unified, co-ordinated range of supports available to consumers who may have access to funds from a variety of schemes
3. The degree of choice a client has in relation to service provision	For the scheme to: • Develop mechanisms to provide funding on a flexible basis to increase the flexibility & portability of supports for which it can be used • Partner with provider peak bodies to develop & implement strategies to enhance the flexibility of service delivery • Develop and implement spending control mechanisms that promote consumer choice and support provider flexibility and have minimal claims management requirements.[3] • Introduce funding models to enhance the use of episodic care for people with fluctuating needs, where consumers are confident support can be increased in times of needs and they will be less likely to try to hold onto	• Increasing the incidence of consumers purchasing more of the same types of services may result in the growth of existing service types at the expense of new models of support • Consumers moving from an environment of limited choice to an environment of increased choice may not be able to access the decision making support to exercise this increased choice, where this is required

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[3] Such as limits on total amount that can be spent in a nominated period, and defining a range of supports which may be purchased.

Issue	Opportunities	Barriers
	care, when it is not needed. - Create a funding environment in which supports can be delivered in a way that is responsive to consumers' individual preferences and needs	
4. The extent to which supports are responsive to a person's support needs or define a person's life.	- For the scheme to support activities to enhance the capacity of the broader community to provide support, rather than seeing this support being seen as a specialised service requiring the use of specialised support services only. - For the scheme to partner with peak bodies and lead agencies to continue working with the generic service & support sector, challenging the perception that the provision of support to a person with a disability is necessarily a specialised service requiring a specialised provider on an ongoing basis	The availability of increased amounts of funds to a broader range of people may further reduce their engagement with the community by: - Replacing engagement with natural and informal supports with that of formal funded supports - Reducing the community and generic support sectors' perception that supporting people with a disability to participate in and contribute to the community is everyone's responsibility, in an environment with fewer restrictions on access to funding for supports.
5. Workforce capacity and capability.	Reorient workforce to make support services provision a career of choice. For example: - Capitalize on the increasing demand for flexible working arrangements with the more flexible service delivery that will be required under an individualised funding model.	- Competition for workers is high in all sectors of the workforce, including the community & disability support sectors. Within this sector labour shortages currently exist nationally and particularly in rural areas. The disability support sector is in direct competition with other sectors of the labour market such as retail & hospitality. Worker

Issue	Opportunities	Barriers
	• Develop and enhance career paths and job opportunities. • Redesign jobs to have links to gaining qualifications and achieving career development.	shortages and the competition for workers across all sectors in a competitive employment market may impact on peoples' capacity to purchase supports as skilled support workers may be difficult to recruit and retain. • Within the existing provider market, shifts may be difficult to fill. • Within a redeveloping support sector, staff may be difficult to recruit & retain at all levels of an organisation.
6. Provider issues	For the scheme to work with the sector to support the development of hub and spoke models for back office service delivery and infrastructure costs (particularly ICT and asset management) to support the ongoing viability of small agencies, maintaining market diversity and choice.	Increased availability of funding may encourage the entry of for profit providers into the market. This combined with the move from charity to business model of existing providers may result in some long standing providers no longer being viable.

Part 4 - Elements of international schemes that have potential to support improved delivery of lifetime care in Australia

There are several elements of international and Australian state based lifetime care schemes that have the potential to support improvements in the delivery of lifetime care in Australia.

- Consumer controlled funds (cash) of a fixed dollar limit with no spending restrictions or reporting and reconciliation requirements – the German & Swedish models[4].
- Consumer controlled funds (cash) of a fixed dollar limit with defined spending restrictions and reporting or reconciliation requirements - The UK as well as the TAC, Western Australia & Victoria (individualised funding agreement clients) model.
- Enhanced use of the generic and community sectors (either within consumer controlled funds or funder controlled funds). Strengthening of this element would need to be tempered by funders not requiring these sectors to comply with an additional layer of Quality Improvement and reporting requirements.
- The use of a local agency controlled model of funding to support sector development and partnerships to be responsive to both consumer and industry needs at a local level.
- Enhanced use of person centred practices in planning and delivering supports for all clients regardless of the degree of control that they exercise over their funds.

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[4] Subject to the development and application of objective eligibility criteria to avoid this type being accessed by people for whom it was not intended.

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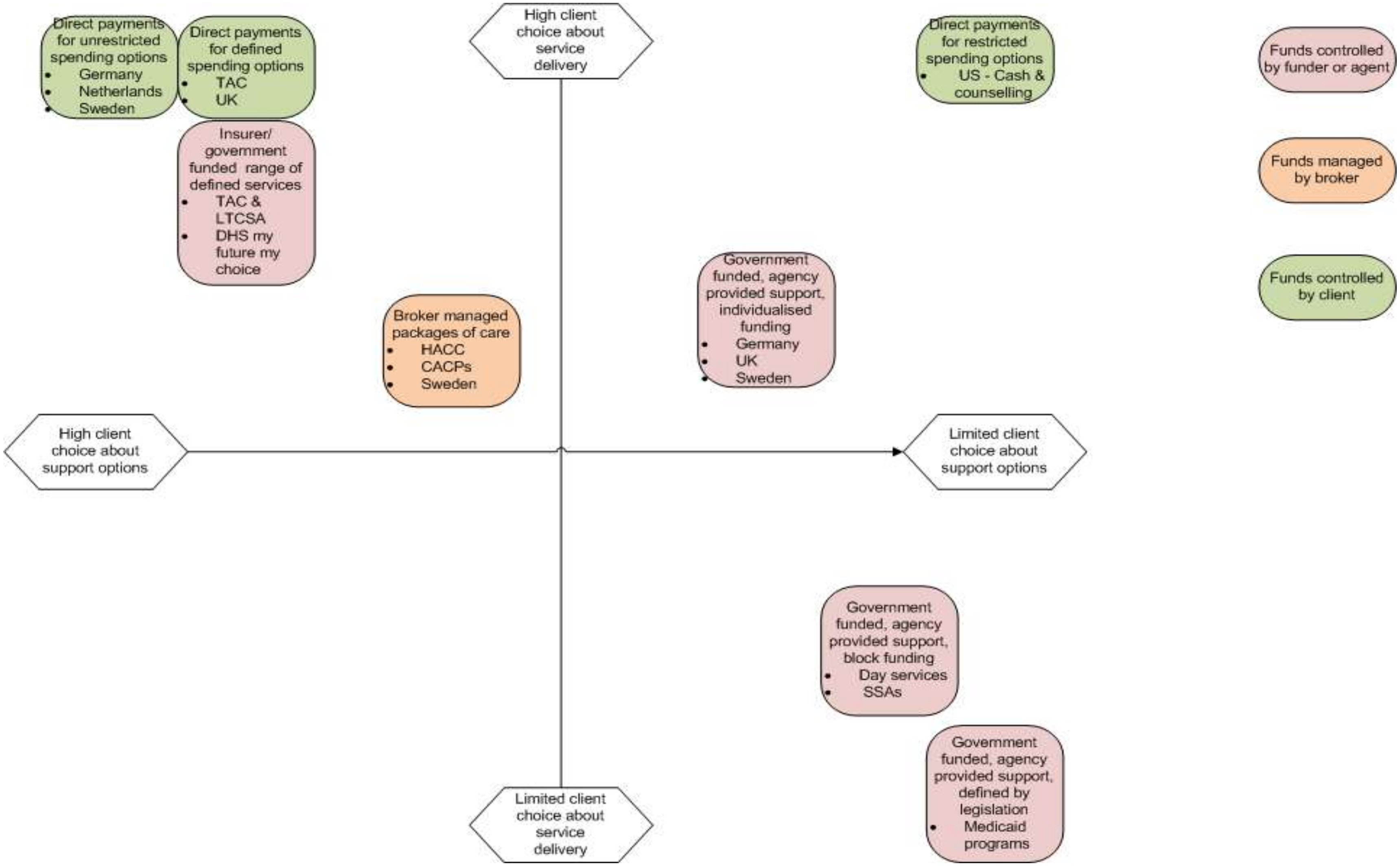
Appendix 1 State funded models of lifetime care (European and North American contexts)

Country	Scheme	Funding model	Funding cap	Service range	Employment of family members	Consumer accountability	Quality Program
United States	Medicaid	Funder pays provider	Yes	Personal 1:1 support from registered agency & limited range of adaptive technology	Not allowed	N/A - accountability rests with funder and provider	Y
	Cash & Counseling	Consumer provided with spending vouchers	Yes	Personal 1:1 support, domestic services & limited range of adaptive technology.	Allowed	No – voucher system controls spending options & levels	N
Netherlands	Government social insurance scheme	Funder pays provider	Yes	Personal 1:1 support from registered agency Other defined services covered by social insurance scheme	Not allowed	N/A - accountability rests with funder and provider	Y
	Personal budget	Direct payment of cash to consumer	Yes	Personal 1:1 support & other defined services covered by social insurance scheme	Allowed	Yes – regular accountability & reporting requirements	N
United Kingdom	National government scheme	Funder directs funds to local council who pays provider	Limited to cost of residential care	Personal 1:1 support from registered agency Other defined services covered by social insurance scheme	Not allowed	N/A - accountability rests with funder and provider	Y
	Direct payments	Direct payment of cash to consumer	Limited to cost of residential care	Personal 1:1 support & other defined services covered by social insurance scheme Personal expenses & leisure participation costs	Not allowed	Yes – regular accountability & reporting requirements	N
Germany	Social insurance funded services	Funder pays provider	Yes	Personal 1:1 support from registered agency Other defined services covered by social insurance scheme	Not allowed	N/A - accountability rests with funder and provider	Y
	Direct payments	Direct payment of cash to consumer	Yes	No specific requirements	Allowed	No	N
Sweden	National social insurance scheme	Funder pays provider or co-operative manages funds	No	No specific requirements	Allowed but uncommon for cultural reasons	N/A - accountability rests with funder and provider	Y
	Direct payments	Direct payment of cash to consumer	No	No specific requirements	Allowed but uncommon for cultural reasons	No	N

Appendix 2- comparison of degrees of consumer control across different models of Lifetime care



Appendix 3 Lifetime care insurance schemes (Australia and New Zealand)

State	**Insurance Scheme**	**Managing Authority**	**Scheme type**	**Access to funding for lifetime care**	**LTC services funded**	**Provision for consumer controlled funding**
NSW	Motor Accidents Scheme	Motor Accident Authority	Common Law Scheme	No	N/A	No
		Lifetime Care & Support Authority	No Fault lifetime care scheme	MAA scheme participants with defined injury types & severity based on standardised clinical & functional assessment	Defined range of uncapped 1:1 & shared support options	No
Victoria	Transport Accident Scheme	Transport Accident Commission	No Fault lifetime care scheme	TAC scheme participants with defined injury types	Defined range of uncapped 1:1 & shared support options	Individualised funding agreements with defined spending limits, spending options & reporting requirements
Tasmania	Motor Accident Insurance Scheme	Motor Accident Insurance Board	No Fault lifetime care scheme	MAIB scheme participants assessed by the MAIB as requiring daily care	Defined range of uncapped 1:1 & shared support options	No
Northern Territory	Motor Accident Compensation Scheme	Territory Insurance Office	No Fault lifetime care scheme	MACA scheme participants assessed as having >60 % whole person impairment	Attendant care is capped at 32 hours per week	No
Queensland	Motor Accident Insurance Scheme	Motor Accident Insurance Commission	Common Law Scheme	No	N/A[5]	No
South Australia	Motor Accident Commission	Allianz S.A.	Common Law Scheme	No	N/A	No
Western Australia	Motor Vehicle (Third Party Insurance) Scheme	Insurance Commission of Western Australia	Common Law Scheme	No	N/A	No
New Zealand	Accident Compensation Scheme	Accident Compensation Corporation (National Serious Injury Service)	No Fault lifetime care scheme	ACC scheme participants with defined injury types	Defined range of uncapped 1:1 & shared support options	Trial to commence in 2011

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[5] Under Australia's three common law schemes, defined services may be funded by the insurer on a without prejudice basis prior to the claim being settled. These payments are later ducted from the lump sum common law settlement.

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