Senate Inquiry into the

National Disability Insurance Scheme Bill 2012

Submission by the
Young People In Nursing Homes National Alliance

January 2013

Summary and recommendations

While recognising the evolutionary nature of the National Disability Insurance Scheme (NDIS), the Young People In Nursing Homes National Alliance believes the NDIS Bill 2012 needs to build key features into the Scheme design to meet the requirements of both the launch phase, longer term operation and community expectation.

The Alliance makes comment and recommendation in the following areas.

1. Age restrictions

The age restrictions the Bill presently contains will marginalise key groups of people whose support needs cannot be met by disability services alone; and/or cannot be met outside the NDIS.

Recommendation:
Amend the Bill to allow:

- *Those Scheme participants ageing over 65 years who are resident in aged care to remain as Scheme participants*
- *Individuals acquiring a severe and profound disability over the age of 65 to become Scheme participants if their disability support needs cannot be met outside the Scheme*
- *The Scheme to collaborate with other program and portfolio areas, such as health, aged care, education, housing, employment et al., on development and delivery of integrated service responses needed by Scheme participants with complex clinical and other support needs that cannot be met by disability services alone.*

2. Scheme interfaces

The Bill details how disability services packages only will be planned for, funded and administered. It does not describe how the Scheme will interface with other portfolio areas or service programs.

The Bill does not indicate how the Scheme will address the need of the Young People In Nursing Homes cohort for responses from health and aged care services.

Nor does the Bill outline the key policy responsibilities of the Scheme.

Recommendation:
The Bill must be amended to include capacity for the Scheme to develop collaborations with other program areas and jurisdictions including health, aged care and housing.

The Bill must be further amended to include development of integrated care pathways for individuals needing responses from multiple jurisdictions and portfolio areas.

3. Disability Service Organisations or Plan Management Agencies (DSOs/PMAs)
Disability Service Organisations or Plan Management Agencies (DSOs/PMAs) must be mandated by the Scheme to engage with and manage interfaces between disability, health, aged care, housing, employment, education as well as other program interfaces Scheme participants require; and pursue integrated care responses as part of planning and plan management provisions.

Recommendation:
The Bill must be amended to provide DSO/PMAs contracted by the Scheme to pursue and negotiate integrated care arrangements; and define these functions as part of the Scheme's overall capacity.

4. Workforce
A better trained workforce is urgently required to manage individuals with complex clinical and other needs including catheter care, bowel care, PEG feeding, pressure care and tracheostomy care.

Recommendation:
The Bill be amended to include specific provisions for the Scheme to develop new training regimes and qualifications for workers supporting those with complex clinical and other support needs.

5. Rehabilitation as early intervention
The Young People In Nursing Homes cohort requires access to rehabilitation and habilitation services to recover from injury; manage disease exacerbation; and maintain function and slow disease progression.

As part of its interface with other portfolio and program areas, the Scheme must have capacity to collaborate with health services to develop and deliver these vital supports as part of partnered arrangements that can deliver clear socio-economic benefits to both.

Recommendation:
Section 25 of the Bill (early intervention) be amended to include provision of rehabilitation/habilitation services by the Scheme where these services do not exist or cannot be sourced from health services; and/or are needed to build skills, maintain independence and community engagement as part of participant requirements. This is particularly in reference to participants with Acquired Brain Injury (ABI) and Progressive Neurological Diseases (PND); and to enable collaboration with health services (including negotiating co-funding agreements) to develop these services to the mutual socio-economic benefit of both programs.

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1. Introduction

The Young People In Nursing Homes National Alliance welcomes the opportunity to provide a submission to the Senate's **Inquiry into the National Disability Insurance Scheme Bill 2012**.

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 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.

Since 2002, the Alliance has argued for a lifetime care approach to development of supports and services for disabled Australians; for collaborative arrangements between programs and portfolio areas including health, aged care and housing to provide the integrated service pathways YPINH and others with disability require; and an insurance based approach to funding of lifetime care supports and services.

In congratulating the Federal Government for its commitment in getting the NDIS to reality, the Alliance recognises that there is a long road ahead in developing the Scheme and shifting entrenched expectations and industry practices, as well as government and community responses to people with disability.

The Alliance offers the following comments on the draft National Disability Insurance Scheme Bill 2012 and will focus narrowly on a number of key issues relevant to the Young People In Nursing Homes (YPINH) group.

Previously, the Alliance has contributed two submissions to the Productivity Commission's Disability Care and Support Inquiry[1]; and a report on the next steps for the Young People In Residential Aged Care Initiative (YPIRAC) for the Community and Disability Services Ministers' Conference (SCCHDS) through the Department of Families and Housing, Community Services and Indigenous Affairs (FaHCSIA).[2]

Many of the themes covered in detail in these reports are revisited more briefly in this submission, but we would refer the Inquiry to these documents should it require case studies or deeper analysis of these issues.

Identified by the Productivity Commission as a key target group of the NDIS, the Alliance reaffirms that Young People In Nursing Homes require a suite of support services from multiple jurisdictions and program areas. In fact, the approximately 6,500 young Australians with disability who presently occupy 5% of residential aged care beds nationally, do so precisely because the coordinated services they require are not available.

The NDIS' present configuration as essentially a disability services funding mechanism, will only satisfy a part of the care requirements of participants with complex clinical and other support needs (such as the YPINH group), who require an integrated care pathway.

In order for there to be true reform around the NDIS for people with a disability, there must be a genuine and dedicated effort to move away from a programmed 'silo' approach to service delivery; and a move to a more integrated or coordinated one. This needs to be done by capacity building and reconfiguring citizenship and service alignment across the community.

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[1] No. DR 1601: *Submission to the Productivity Commission Inquiry into Disability Care and Support*; and No. DR 1062: *Submission to the Productivity Commission's Draft Report into Disability Care and Support*. See online http://www.pc.gov.au/projects/inquiry/disability-support/submissions#top (accessed 24/01/2013)

[2] *YPIRAC^2: The Next Steps Report to FaHCSIA*. See online http://www.ypinh.org.au/reports (accessed 24/01/2013).

2. General Points

- *The Bill's age restrictions will marginalise key groups of people whose support needs require services from other portfolio areas including health; and whose needs cannot be met wholly outside the NDIS. A mechanism needs to be found whereby individuals with severe and profound disability can be accommodated in the Scheme without risking the Scheme's integrity.*
- *While the Bill details how disability services packages will be planned for, funded and administered, there is very little about how the NDIS will interface with other portfolio areas or service programs. Nor does the Bill detail the key policy responsibilities of the Scheme. At the commencement of the Scheme in July 2013, there will be at least 6,500 individuals under 65 resident in residential aged care services across Australia with many more at risk of placement there in the absence of coordinated care responses. Yet the Bill contains no indication of how the Scheme will address the needs this group has for responses from health and aged care services.*
- *The Bill allows for the advent of Plan Management Providers, but does not detail their structure or their roles beyond implementing participant plans. The Productivity Commission introduced the notion of intermediaries called Disability Support Organisations. The Alliance believes that these organisations can play a significant role in the reform of the system of care and support. But more work is required to define their functions as part of the Scheme's overall design.*

3. Age restrictions

To meet the age requirements that establish eligibility for the NDIS, Section 22 indicates that a Scheme participant must be aged under 65 years when the access request is made. After this age, the Scheme intends to refer the individual with disability to the aged care system for assistance and support.

The Alliance remains deeply concerned about the inequity this provision will entrench; and with the diminished capacity of the aged care system to respond to the different needs of those with disability, a cohort the aged care system is not resourced to support.

At present, aged care services are resourced to deal with the needs of frail older Australians in the end stages of life. They are not resourced to manage the needs of individuals with disability and are particularly poorly placed to manage the needs of those:

a. Ageing with a disability
b. With complex clinical and other support needs
c. Parents with disability who need to remain in the family home raising their children.

Because of its different mandate and resourcing, aged care cannot provide some of the vital supports individuals with disability require, including:

- Customised equipment or assistive technology
- Rehabilitation services to recover from injury, manage disease exacerbation and maintain functional capacity[3]
- Community access, including supporting community participation in a range of ways.

In addition to these significant constraints, aged care staff in general are not sufficiently trained to manage the different needs of those with disability, including those with complex clinical and other support needs.

Aged care also has a very different funding system based on a different set of imperatives to those individuals with disability require. As a result, residential aged care has no minimum staffing levels.

In supporting its prescribed cohort of frail older Australians in the end stages of life, aged care operates with staffing levels that are well below those that operate in disability services; and well below those required to support individuals with severe and profound disability and complex clinical and other support needs.

The result of this systemic difference is often a loss of functional independence in those with disability living in aged care settings where, because of the latter's lower staffing levels, those with disability may, for example, be given continence aids instead of being assisted to use the toilet; or develop pressure sores because of insufficient staff to attend to 2 hourly turning. Consequent deterioration in health and well being is a common, if unintended result and has led to pressure care becoming a major issue of concern, as well as a key cost driver for both health and aged care in their responses to this group.

Placing individuals with disability in the aged care sector *without* the required services and supports with regard to rehabilitation, equipment, adequate staffing levels and community access, will have negative personal and systemic consequences that include:

- Denial of service access and deteriorating health in individuals
- Repeat hospitalisations and concurrent escalation of costs within the health care system generally and acute health programs particularly

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[3] While the Alliance understands that the National Injury Insurance Scheme (NIIS) is likely to provide for those suffering catastrophic and traumatic injury, it is unclear at this point whether individuals who suffer Acquired Brain Injuries (ABI) from so called "non traumatic" events such as a brain stem injury, a burst brain aneurism, or a hypoxic brain injury resulting from an asthma attack, a diabetes induced hypoglycemia or juvenile stroke will, in fact, be covered by the NIIS. If they are not, the NDIS must develop capacity to provide these vital services.

- Added burdens on aged care services
- Cost shifting to health programs.

Finally, residential aged care (RAC) services are predicated on residents entering at, on average, 80-85 years of age; and remaining *in situ* for a comparatively short time of 6 months to 2 years. Younger people, who enter aged care before 65 years, commonly remain in the aged care system for many years more than the 2-year maximum frail older residents are expected to use the aged care system for.

3.1. Enabling Scheme access for individuals ageing in place

The Bill currently removes NDIS eligibility for individuals with disability over 65 years of age living in aged care.

This effectively condemns those individuals who may have entered aged care at a younger age, but who have aged to or beyond 65 years while waiting for an alternative response or a return to the community, to remain in age care, reliant on a system that is not only unable to appropriately care for them, but to remain in it for many years longer (20-30 years in some cases) than the aged care system has been designed for.

The Alliance therefore remains deeply concerned that if the NDIS Bill remains as it is and offers no capacity to support individuals with disability over 65, it will result in a cost shift to aged care that the latter will not be able to meet; and ensure a deliberate widening of an already growing service gap.

As a significant social reform, the NDIS should be meeting the disability care and support needs of applicants with 'severe and profound disability' *regardless of their age*, while the aged care system should respond to the aged care needs of individuals as per the Aged Care Act. The provisions of Section 34 would guide the design of supports for those with disability over 65 years, taking into account what the health and aged care systems should provide in a complementary support program.

Simply continuing this age cutoff through the NDIS Bill does *not* ensure that Aged Care will respond with complementary adjustments to their system that may allow the needs of people in this cohort to be met. While policy pressure to address this anomaly may build over time, thousands of people will be denied essential services in the interim with consequent adverse impacts on their health and well-being. The cost of managing these adverse health impacts will be borne by the service system somewhere, most likely – as it is at present – by health services and, particularly, by acute care.

The Alliance believes that for the Scheme to simply refuse access to individuals in this group because it expects other program or portfolio areas to 'comply with their legislated requirements', ignores the fact that these program areas may have little or no present capacity to meet the needs of those with profound disability; and may never have had such capacity at all.

As the YPIRAC initiative showed, many people age beyond notional age cut off points while they wait for a response. The fact that the NDIS as Scheme is set for full operation in 2018, will mean that many people eligible for the Scheme and living in nursing homes or in receipt of aged care supports now, may well have aged beyond 65 waiting for the Scheme to come to them.

In the Alliance's view, maintaining the age cut off for this group is socially and economically irresponsible and, as present practices in these areas already demonstrate, leaves far too much to chance.

As an alternative approach, the NDIS should, under its early intervention provisions (Section 25), allow access for people who have a diagnosis of a listed degenerative condition (such as motor neurone disease MS or post-polio syndrome), even if at age 65 they do not yet need formal support services. If the Agency accepted that their condition was likely to deteriorate in coming years to a point where they would require services, they could be deemed a participant but have planning for support suspended until required.

Without such commitments and considerations, the arrangements proposed in the Bill instate a perverse incentive for people approaching 65 years with these conditions to exaggerate their functional incapacity in order to gain access to the NDIS.

The Alliance thus believes that individuals with disability who age beyond 65 years while living in residential aged care or receiving community aged care services because of a lack of appropriate alternative options, should be eligible to continue in the NDIS and receive additional supports.

In this light, the Alliance recommends the following amendments to the Bill:

3.2. Section 29(1)(b)

This clause declares that individuals who turn 65 years of age and are living in residential aged care or receiving community aged care when they do, will immediately and automatically become ineligible for the NDIS.

The Alliance recommends changing this clause to enable those who age beyond 65 years while living in residential aged care or using community aged care services while waiting for Scheme assistance, to retain eligibility for the Scheme.

3.3. Enabling Scheme access for people over 65 years whose disability care and support needs (the remit of the NDIS) cannot be met in other areas of the service system, particularly aged care

Those diagnosed with progressive diseases such as Motor Neurone Disease, or who sustain a brain or spinal cord injury, provide a case in point. Individuals with onset of these conditions over the age of 65 years are presently ineligible for the NDIS according to the Bill. As the Scheme is presently conceived, a referral to aged care will ensure the following:

- The individual will be denied the supports and services they need at a time of acute crisis and distress
- Aged care will be unable to respond with the supports and services required to maintain the individual at home and with loved ones
- If an individual is placed in aged care without the supports they need and which aged care cannot deliver (customised equipment, higher staffing levels et al), their health will deteriorate and placement in acute care (including recurrent hospitalisations) will result in concomitant escalation of costs for the health and aged care systems.

In other words, the service system will carry the costs somewhere. However, if the NDIS can provide the needed responses in a timely and effective manner, across the board costs may be curtailed.

The Alliance thus strongly supports amendment of the legislation to include capacity for the Scheme to support those individuals over 65 years whose disability care and support needs cannot be met by the aged care system and/or other community service systems. The Productivity Commission has already identified this group and made provision for them in its costing and Scheme design recommendations. They included those whose needs would be optimally met within the NDIS, but who are not otherwise eligible[4]

The Alliance recommends that Section 22, Age requirements, be expanded to enable the NDIS to support those people over 65 with severe and profound disability whose disability care and support needs cannot be met by the aged care system and/or other community service systems.

3.4. Managing extant service gaps as reform imperatives with other service areas

Leaving the age cut off strictly at age 65 will mean that the NDIS further entrenches a major service gap for people with a disability. (See Clause 29(1)(b) of the Bill). The aged care system cannot meet the needs of Australians acquiring a disability over

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[4] Identified as Tier 3(c). See *Report into Disability Care and Support,* Productivity Commission, Vol 1: 160.

the age of 65, whether an Acquired Brain Injury (ABI), Spinal Cord Injury (SCI) or a neurological disability; nor can it meet the needs of those ageing with severe and profound congenital disability.

A case that exemplifies this was broadcast as part of ABC Radio's *PM* program on January 23 of this year. It involved a Queensland individual, Geoff Haigh, who fell awkwardly and suffered an incomplete quadriplegia as a result. Able now to move his arms but not his hands, Geoff now requires significant assistance with all aspects of daily living.

Unfortunately for Geoff, his disability was incurred 3 months after his 65th birthday.

As a result, Geoff is ineligible for the up to 65 hours of support he could have received from Queensland disability services 3 months earlier, leaving him eligible for a maximum of only 15 hours of support from the aged care system now – an amount well short of what he actually requires. Geoff despairs that his family now has to pick up and attempt to fill the evident gaps in his care.

He said, " It's a real threat to my wife who's not young herself. And she's being asked to be the carer on those nights that we don't qualify for somebody, and to do all the other things that might be needed during the day…We've worked both our lives together and now we're being treated as we feel as second class citizens."[5]

The fact that disability services is better able to support the needs of those with disability after 65 years has also been reflected in the Council Of Australian Governments (COAG) cross invoicing arrangements that have been negotiated by the Commonwealth with the States and Territories in recent times.

Acknowledging that, in some cases, the states continue supporting individuals with disability beyond the age of 65 years; and that the Commonwealth has provided supports through its aged care services to individuals with disability under 65 years because of the disability services system's inability to provide necessary supports in a timely and effective manner, these cross invoicing arrangements are intended to reimburse each jurisdiction for the cost of providing services that are technically outside each jurisdiction's remit.

That these arrangements exist indicates the incapacity of aged care to effectively respond to the needs of individuals with severe and profound disability and complex clinical and other support needs; as they also point to the inability of disability programs *on their own*, to meet the needs of the same group. These arrangements also serve as a reminder that the NDIS Bill has yet to indicate how the Scheme

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[5] See transcript of interview, ABC Radio's *PM* Program. Broadcast January 23 2013. Transcript available online at http://www.abc.net.au/pm/content/2013/s3674407.htm Accessed January 23 2013.

should respond to COAG arrangements that, like these, are already in play.

The spirit of the cross invoicing arrangements does, however, offer precedent for similar collaborative arrangements to be negotiated by the Scheme with other jurisdictions and program areas. It is important to be able to meet participant needs, even if their total needs straddle multiple programs. This may require funding coordination, funding collaboration or even funding joint service developments.

As one example, Victoria's *Slow To Recover Acquired Brain Injury Program* (STR) delivers excellent results in terms of rehabilitation and recovery from brain injuries and does so very cost effectively when functional capacity regained and a concomitant reduction in associated long term care costs is considered as a direct result of the STR program.

While the National Injury Insurance Scheme (NIIS) is likely to respond to the rehabilitation and support needs of those suffering traumatic brain injuries, individuals suffering hypoxic brain injuries from asthma or diabetes induced hypoglycemia, may not be eligible for the NIIS and may look to the NDIS for support.

While it has been suggested that it is the role of the health sector to provide rehabilitation services, it is a fact that the type of slow stream rehabilitation required in these instances is not delivered by health services nationally. This represents a significant service gap that the NDIS may be called on to respond to for those with such acquired disabilities. Indeed, investing in these services as part of early intervention considerations, may well lead to reduced care costs for the scheme over the longer term.

Yet if the NDIS remains as it is and offers no capacity to support individuals with disability over 65 it will result in a cost shift to aged care that the latter will not be able to meet; and ensure a deliberate widening of an already growing service gap.

As part of systemic reform efforts, the NDIA should consider negotiating specific cost sharing agreements with the Department of Health and Ageing (DoHA), particularly as part of long term arrangements for this group and in the absence of these services in the Health portfolio.

In this respect, the NDIA needs capacity to pursue funding arrangements with other jurisdictions for classes of participants (i.e. people in residential aged care turning 65) or individual participants (such as Education programs for school age children with disability), dependent on their circumstances.

In other words, the Alliance believes that if the NDIA pursues reform imperatives to advantage the Scheme and ensure the latter's socio-economic sustainability, it must pursue whole of government reform and not simply reform in one area of the service system that may have consequent adverse impacts on Scheme participants, as well as those areas of the service system involved.

The Alliance supports amendment of the Bill to enable the NDIS to pursue partnership and collaboration arrangements with other service and program areas to the mutual benefit of participants, the Scheme and the community.

4. Scheme interfaces

While community engagement of participants is a key objective of the NDIS, the delivery of disability service packages is only one ingredient in achieving genuine and sustainable engagement in the community. Yet because the Bill presently conceives the NDIS as a provider of disability supports only, these supports seem to be conceived as an end in themselves, rather than the *means* to an end of achieving a more active life in the community for Scheme participants.

People with disabilities are citizens who will use many other community services. Yet we currently have a fragmented, uncoordinated and chaotic collection of service areas (health, education, aged care, housing and disability to name a few) that Australians with disability have to navigate.

The YPINH group routinely need disability supports, including equipment and attendant care services. But they also need health interventions and rehabilitation; and some currently live in aged care facilities. The impact of this is that in the majority of cases, YPINH require concurrent supports from these three portfolios. Outside compensation schemes, it is rare that people receive services from all three and have their responses delivered in a coordinated manner.

Although it is common for disability services to be relied on as gap fillers or to compensate for the lack of other services, disability services are not substitutable for services from these other programs. Where disability services *are* used to compensate for a lack of other services, the result is diminished health and well-being and an escalation in health costs that could be avoided if integrated care services were available.

In other words, disability services cannot, on its own, create better outcomes for individuals with complex clinical and other needs. Nor can it create connections between essential program areas. It is absolutely critical, therefore, that the NDIS avoids falling into the same trap as that of the system the NDIS is replacing.

The experience of the YPIRAC initiative is a compelling case in point. Despite the evident need for collaboration with health and aged care programs particularly, the YPIRAC initiative was rolled out nationally as a disability only program. As a result, participants in this program by and large received bulked up attendant care services, some equipment and community access funding.

Despite the declared preferences and expectations of YPIRAC participants, new accommodation services developed under YPIRAC's aegis simply reiterated disability's 'tried and true' group home accommodation model but failed to include the clinical oversight and expertise that residents of these services needed. In many cases, these services were charged with managing PEG feeds, catheter care, pressure issues and even tracheostomy care but without the requisite capacities and oversight required. This has resulted in adverse health incidents that should have been avoided; deterioration in the functional ability of residents; and sadly, some deaths.

In every case, the disability service provider acted with the best of intent and delivered care to the best of the provider's capacity. It is simply that disability services, by itself, did not have the expertise or capacity to deliver the suite of responses (including clinical responses) these residents required.

The results of the Continuous Care Pilots (CCP), undertaken as YPIRAC initiative trials in NSW and Victoria, provide a stark contrast. The CCP trials involved active partnership and collaboration between disability and health services; and the development of integrated care pathways for individuals with complex clinical and other support needs. Disability providers received comprehensive input and support from health personnel regarding the health needs of residents, with the result that supports were delivered in a timely and effective manner.

As a result, residents in these coordinated care services (and their disability providers) avoided the pitfalls that were common in YPIRAC services that did not experience this level of integration.[6]

Because of our experiences with the YPIRAC initiative and the CCP trials, the Alliance strongly believes that simply bulking up disability services and individualising supports (as welcome as that is), will not directly change this environment and lead to improved health and well being for those with complex clinical and other support needs.

Unless participants with these needs have a comprehensive NDIS plan that includes consideration of integrated care responses; and unless plan developers are cognisant of the need to investigate and involve integrated care responses as part of plan development actions, we risk repeating the all-too-common scenario where individuals will have a disability plan, a hospital plan, and a range of other plan

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[6] See Continuous Care Pilot Evaluation reports for NSW and Victoria. Available online at http://www.ypinh.org.au/reports (Accessed 24/01/2013)

responses from various program areas – all of which exist in isolation from each other and from the individuals they are supposed to support.

While some Scheme participants will certainly be in a position to coordinate the various program responses themselves, our experience of the YPINH group – as evidenced by the CCP Pilots – is that skilled coordination is essential.

Whether it be rehabilitation, aged care, education or employment, the NDIS will need to ensure there are connections between programs at two key levels:

1. **Participant level** – the suite of services being used by participants need to be coordinated at the community level into a coherent model of support that makes sense to them, and meets their needs comprehensively.
2. **Systems level** – service programs need to be actively engaging with each other around their key responsibilities for classes of people; and have the capacity to develop boundary protocols and joint-funding initiatives.

What is essentially required from the participant's point of view is to have a comprehensive plan with complementary responses from a range of programs if required.

These connections to join up service areas must be active at every stage of the service delivery cycle – in the planning, in the delivery and in the review of services and plans. It is essential that organisations skilled in this area undertake this active coordination with the participant and do so on the ground.

To do this, the NDIS needs to not only have an active policy development capacity (something that is not highlighted in the Bill at this point), but also have capacity for the active coordination of participant programs with other program areas where needed.

For the YPINH cohort and other particular groups within the NDIS (such as those with progressive diseases), a coordinated pathway or an integrated model of supports is required. In such an integrated model, different programs can contribute as needed and many times, can do so concurrently. Far from diminishing the need to coordinate these pathways, individualising disability supports makes it all the more necessary that the NDIS proactively undertake this key responsibility.

Disability supports can be individualised and purchasing decentralised. But where these supports bump into hard-edged programmatically funded systems and are incompatible, many participants will struggle to negotiate their way through without sophisticated advice and advocacy.

Feedback from Alliance members is that while interest in self-managing their funding is low, the desire for competent services that are well coordinated is high. Those members who have concurrent services from multiple programs are more concerned about how the whole suite of services are delivered, rather than how disability services are being reorganised. For this group, the DSO/PMA is a critically important element of the reform.

Even though it will not duplicate or assume funding responsibility for these other programs, the NDIS can and should fund coordination. This is consistent with the NDIS taking an insurance-based lifetime responsibility for its participants. However, the Scheme needs specific mandate to do this via the legislation…something that is absent in the current Bill.

To facilitate better connections between programs for YPINH particularly, key changes are needed to the Bill in the following areas:

4.1. S31 – Principles relating to plans

(k) *Provide the context for the provision of disability services to the participant, and, where appropriate, coordinate the delivery of disability services where there is more than one disability provider*

The Alliance recommends changing this provision to read:
Provide the context for the provision of disability services to the participant, and, where appropriate, coordinate the delivery of support services where there is more than one related service being provided.

4.2. S32 - CEO must facilitate preparation of participant plans

(1) *If a person becomes a participant the CEO must facilitate the preparation of the participant's plan.*

The Alliance supports inclusion of an additional clause to the one contained in Clause S32, *viz:*
If a person becomes a participant the CEO must facilitate the implementation of that participant's plan.

It is important that this responsibility is located with the CEO so that the Scheme design incorporates a high degree of interest in the comprehensiveness of supports for participants; and in the performance of companion programs. The success of these other programs in contributing to participants' goals will be of direct actuarial interest to the Scheme.

4.3. Division 3 – Plan Management Providers

Clause S43(3)(b) – plan management provider

This clause needs a great deal more detail and should include direct reference to the Productivity Commission's work on Disability Support Organisations. This is where much of the community interface can be generated, particularly in the first 10 years of the Scheme as it develops.

5. Disability Service Organisations/Plan Management Providers (DSO/PMA)

The Alliance is concerned that without separation of the roles and responsibilities of service providers and Plan Management Agencies (or Disability Service Organisations), the risk of commodification for Scheme participants is real. This is something identified by the Productivity Commission in their report in which they recommended that Local Area Coordinators (LACs), should not be located within service providers and that Disability Service Organisations (DSOs) or Plan Management Agencies (PMAs) should be located separately from the service provider sector.

To fill this role and ensure that Scheme participants' citizenship is fostered and supported, the NDIS must have capacity to define and locate organisations that are not service providers, but are mandated to foster and support "citizenship/community" endeavours and provide a range of advice, information and complementary supports to Scheme participants, including service brokerage and provider management.

While achieving community engagement for Scheme participants is a key objective of the NDIS, the provision of disability service packages is only one ingredient in achieving genuine and sustainable engagement in the community.

DSO/PMA's could create a structural alignment between the Scheme and the community that is critical to the long-term sustainability and viability of the Scheme. The shared social objectives of the DSO/PMA sector will be fundamentally different to the commercial relationship between disability service providers and the NDIS.

Commodification of Scheme participants is a very real risk if community engagement remains solely a market driven pursuit of disability service providers. Over time, community engagement activity may be passed over or diminished by other service delivery and commercial imperatives.

Central to the success of the NDIS is that people with disability do not, over time, become defined by their disability and characterised either by being a funded service user; or valued by the community by virtue of the size of their funding package.

Without a sector that is independent of the service provider market that is mandated to work on community/NDIS interfaces, commodification of people with a disability will become common.

While the DSO/PMA role has been expressed largely as a financial intermediary in the Productivity Commission's report, there are compelling reasons to expand and strengthen the role of the DSO/PMA to enable them to influence companion service programs, take a lead role with community engagement and undertake a level of provider management with the specialist disability provider market.

A DSO/PMA that has responsibility for the following functions will be able to promote the achievement of citizenship outcomes with the *assistance of* support services, rather than the support services becoming an end in themselves. These functions include:

- Community connections and engagement
- Ensuring coordination and cohesion of the NDIS package with other service and program areas including health, housing, education, transport, aged care, employment et al
- Mediating long-term support delivery via a role with provider management.

This structure can also work to create greater rigour around community services as well as improve service expectation and delivery from other program areas; and proactively manage the risk that the NDIS will wear through the cost of failure by these other service and program areas.

Even with one funder for disability services, the service system for people with a disability will still be relatively complex, with people needing to access a range of health and community services, as well as information and family support. Detailed work will need to be done at the individual level to design and coordinate services across program areas, as well as systemic work undertaken to define and negotiate the service pathways. Particular skills and knowledge for some groups of participants will need to be retained and supported outside the service delivery market in the NDIS.

The Alliance believes these informal connections are priceless for this group and should not be lightly given up or usurped by paid service provision.

In a defined role for the DSO/PMAs, their functions should include:

- Case planning, coordination and lifetime care management
- Jointly managing assessments with the 'claims' manager in the NDIA
- Carer support and advising on community networks

- Provider management vis-à-vis care plans
- Secondary consultancy for providers
- Information and advocacy
- Financial intermediary services
- Service development and innovation in service design
- Collaboration with other program areas to deliver the integrated supports and services that many Scheme participants will need
- Community Development
- Peer support
- Provider management
- Research and evaluation.

5.1. Individual choice

The expanded DSO/PMA role would enable individuals to opt in to the level and types of supports they require (including choosing their preferred DSO), from seeking simple information, through to full blown financial intermediary services or comprehensive lifetime support management. These are the types of support that should not be 'for sale' to participants or service providers but should be voluntary, such as peer support for example.

The DSO/PMA would also be available to people deemed ineligible for admission to the NDIS, to provide information, referral and other services.

5.2. Advocacy

The practice of advocacy would substantially alter under the proposed arrangements. In a fully funded environment, the imperatives of the independent advocacy we currently have in Australia would be less about service access, and more about system compliance, provider behaviour, policy gaps and systemic change. It is important to retain an independent advocacy sector for human rights compliance across the community.

The DSOs/PMAs would assist individuals to negotiate with providers, broker agreements and plans with the NDIA, assist in reviews of decisions and advocate for service access outside the NDIA provider market. DSOs/PMAs also have a potential role in ensuring assessment briefs are appropriate and well targeted.

Recommendation: The Alliance recommends that Division 3 of the Bill – Managing the funding for supports under participants' plans – be expanded to include provisions that define the role and functions of DSO/PMA as independent organisations distinct from service providers that can assist participants as well as *work at the community interface.*

6. Workforce

It is well recognised by service providers, unions, service users and governments, that there are serious workforce issues in the disability sector. These manifest in the difficulty service providers have in attracting and retaining staff – especially skilled staff; and the a high turnover within the workforce as workers make decisions not to remain in the industry. Poor wages and working conditions, a preponderance of casual and part-time work, a lack of workplace training and professional development opportunities and a society that places low value on care work, are all part of the reason for the poor workforce capacity the NDIS will confront.

Despite a plethora of inquiries and projects examining the problem or attempting to tackle parts of it, we are no closer to the reality of a sustainable and dependable workforce skilled in the supports of individuals with disability, including those with complex needs.

Where they exist or are required, qualifications such as the ubiquitous TAFE *Certificates 3 and 4 in Disability Work,* are universally condemned by service users as poorly designed; often ineffective in delivering understanding or the support skills required; do not achieve the outcomes Australians with disability expect; and are often undertaken by workers already undertaking support work in the field and therefore without adequate training or qualification. Many individuals with disability have indicated the standards these qualifications deliver are so bad that they prefer a completely untrained worker they can train in their needs themselves.

While this may be acceptable for an individual able to successfully undertake this training, not everyone has the capacity to do so.

Furthermore, for individuals living in the community with complex clinical and other support needs requiring, for example, management of tracheostomy and catheter care, PEG feeds, bowel care regimes and pressure care, Certificates 3 and 4 are absolutely inadequate. It has been the absence of these vital skills that has already led to the death of some individuals with disability living in community supported accommodation services.

The development of a viable workforce for Australians with disability; and a specialist workforce 'subset' skilled in the needs of the severe and profound cohort, including management and delivery of clinical support needs, is an imperative for the Scheme's future viability and sustainability.

Calvary Healthcare's submission to the Productivity Commission's 2011 *Inquiry into Disability Care and Support* reiterates this requirement in its comment that

> *High quality, responsive care can only be provided when there is a shared understanding of the client's goals and a framework which supports informed decisions, enables the implementation of plans and underpins the skill base of the relevant workforce. Health care and disability support need to work synergistically with the client and their family.*[7]

As something needed to address the needs of those Scheme participants also residing in aged care, the development of this specialist workforce again provides impetus and an opportunity for the Scheme to collaborate with other program areas in a partnered approach to delivery of an appropriately skilled workforce.

7. Rehabilitation as early intervention

> Effective rehabilitation is valuable in its own right, due largely to its ability to reduce the cost of care...If we as a society propose to save the lives of those who acquire a traumatic brain injury, rehabilitation has not only a moral justification but is also a very real way in which costs can be saved within the health system.[8]

Advances in medical science and our world-class health system mean that more Australians are surviving catastrophic injuries and living longer with progressive diseases than ever before. But they are doing so with significant and growing levels of disability.

For many Scheme participants then, rehabilitation services will be a crucial component of their care and support plans. Yet the NDIS Bill does not contain capacity for the Scheme to provide these much needed services itself; or partner with health services to develop and deliver the rehabilitation responses Scheme participants may need.

While rehabilitation[9] is acknowledged as an essential service response to aid recovery from injury and exacerbation of disease for this group, these critical services are not presently included in the suite of NDIS service responses, despite Scheme eligibility for individuals with severe and profound disability and complex needs. Instead it seems that rehabilitation is considered the responsibility of health

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[7] Mathers, S. Submission to the Productivity Commission's *Inquiry into Disability Care and Support*. Submission 46: 2.

[8] Acil Tasman, *Oats Street Facility Redevelopment. A Social Cost Benefit Analysis,* November 2010: 23.

[9] *Rehabilitation:* treatments designed to facilitate the process of recovery from injury, illness, or disease to as normal a condition as possible. *Habilitation:* the process of supplying a person with the means to develop maximum independence in activities of daily living through training or treatment. See *Online Medical Dictionary*, at http://medical-dictionary.thefreedictionary.com/rehabilitation Accessed January 13 2013.

services and the latter must be compelled to deliver these services to Scheme participants requiring them.

A lack of rehabilitation and consequent increase in dependency is one of the key reasons young Australians continue to be enter nursing homes. Yet our nation's enduring lack of investment in rehabilitation services has led to cost blow outs borne by health, disability and aged care services, costs that are ultimately borne by the community.

The advent of the NDIS and the NIIS offers a generational opportunity to redress this.

7.1. Rehabilitation in the NIIS

The inclusion of rehabilitation as part of the National Injury Insurance Scheme's (NIIS) core suite of services means that not only is there a significant difference in what the proposed schemes are offering people with disability; but that this difference reiterates the core inequity of our current, broken service system, in which how a disability is acquired determines the services that are received.

This disparity not only creates a fundamental problem of equity that is anathema to the principles behind the NDIS. It also means that a significant number of Australians with disability will be crucially disadvantaged if rehabilitation services are not included in a functional NDIS.

These individuals include those with

- Hypoxic acquired brain injuries (from drug overdose, near drownings, diabetes induced hypoglycaemic attacks, stroke, cardiac arrest) who require rehabilitation to aid recovery from injury; and
- Chronic and progressive neurological diseases like Multiple Sclerosis, Huntingtons and Parkinson diseases who need rehabilitation to assist with recovery post disease exacerbation, slow disease progress, maintain crucial 'life' skills (continence, mobility, flexibility et al).

This group includes those outside the purview of the NIIS but with a disability acquired as a result of disease or hypoxic brain injury, who remain eligible for assistance through the NDIS. For these individuals, rehabilitation is a critical ingredient of their recovery; can slow disease progression; and has a consequent capacity to deliver reduced care costs over the long term through improved independence and well being in Scheme participants as Brightwater Care Group's socio-economic review of its rehabilitation services demonstrated.[10]

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[10] ACIL Tasman, *Oats Street Facility Redevelopment. A Social Cost Benefit Analysis,* November 2010.

7.2. *Participant expectation*

The Productivity Commission identified young people with complex clinical and other support needs as a priority group for early intervention in the NDIS. Rehabilitation is an essential early intervention service for this group and its persistent absence is one of the main reasons young people continue to be placed in nursing homes. When the Younger People In Residential Aged Care (YPIRAC) program attempted to address the issue of young people with complex care needs without the active involvement of the health system and delivery of rehabilitation options, it simply fiddled around the edges and failed to address desperately needed reform. The NDIS cannot afford to make the same mistake.

The complex needs group merely typifies the services that any individual with disability would expect to access if need arose. Those with congenital disability will also have need for rehabilitation/habilitation services and will expect these crucial services to be available to them through the NDIS when needed.

If the NDIS fails to include rehabilitation services as part of its funded service program; and fails to work with Health to ensure this vital health service is delivered, the genuine reform of the service system that the NDIS *should* be attempting, will not happen.

7.3. *Community expectation*

Following the success of the NDIS campaign, high expectations exist in the community that the NDIS will deliver the services that those with complex support needs will require. Indeed, a growing number of groups in the acquired disability sector are highly attuned to the need for the NDIS to include rehabilitation as part of its ambit.

These groups are concerned that rehabilitation is largely absent from the foundational work being undertaken by the NDIS and that the broken system of supports it is emerging from, is simply being reiterated by a scheme that was supposed to be so much better.

Recognising this community expectation, the 3 June 2012 edition of the *Sunday Age* contained an article on the need for rehabilitation for individuals with spinal cord injury. In light of recent medical advances, the article discussed the need for rehabilitation services to focus more on regaining function, rather than current efforts that emphasise adjusting to limitations imposed by injury. The article stated that while

> Government funding is pitiful…the announcement that a National Disability Insurance Scheme will begin in up to four locations across Australia in July next year has brought renewed hope.

> Senator Jan McLucas, the parliamentary secretary for disabilities and carers, admits "in Australia, people with disabilities [currently] do not get the support that they should". *While full details of the scheme remain undetermined, the potential of the new insurance-based scheme to cover the costs of outpatient rehabilitation programs is exciting.*[11]

7.4. Productivity Commission assumptions

In its Report on *Disability Care and Reform*, the Productivity Commission assumed that rehabilitation would be provided by the health system. Yet there is very little public rehabilitation infrastructure to draw on to deliver this service.

An even starker reality is that over the years, health systems have routinely avoided providing slow stream rehabilitation for people with complex needs, the result being that the existing service system contains no capacity to service those who will soon be eligible for NDIS funded services. Even national health reforms currently underway have failed to address the development of desperately needed rehabilitation infrastructure across the country.

As a result, the NDIS has been left with a dangerous reliance on a health system unable to deliver the functional rehabilitation services that are urgently needed.

In the absence of capacity in the health sector, the NDIS must work with health to develop these vital service responses. Unless the NDIS takes on rehabilitation as a benefit within the scheme, development of the necessary infrastructure and appropriate interface arrangements will not happen. Indeed, by ignoring rehabilitation as part of the chain of services and supports for its clients, the NDIS is imposing significant current and future costs on itself *and* denying valuable recovery opportunities to those it should be assisting.

7.5. Recognition of need for rehabilitation services

With the young people in nursing homes (YPINH) issue as one of its terms of reference, the Senate's 2005 Inquiry into Aged Care, noted that "The importance of rehabilitation is not limited to those with acquired brain injury. Those suffering from degenerative diseases also require therapy."[12]

The Inquiry's Report further indicated, "…rehabilitation services for people leaving hospital need to be expanded…"[13] as an essential part of the transition process to

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[11] Emphasis added. *Sunday Age*, Fairfax Publishers, Melbourne, 2 June 2012. Online at: http://www.theage.com.au/national/walking-with-hope-20120602-1zopa.html Accessed June 2, 2012.

[12] Senate Community Affairs References Committee, *Quality and Equity in Aged Care*, Canberra 2005. Section 4.66: 98.

[13] Op. Cit: 7.41: 179

home or other community based services. Recommendation 26 reiterated this conclusion by calling on "…the Commonwealth and the States and Territories [to] work cooperatively to reach agreement on…mechanisms, including a funding formula, to provide rehabilitation and other disability-specific health and support services, including specialised equipment…"[14] to young people with disability needing this assistance.

This view was repeated in the *Younger People In Residential Aged Care (YPIRAC) Mid Term Review* which concluded that supporting those with complex needs "…requires harnessing the interface between health, rehabilitation and disability support services…[and] identified this as a key challenge…" for future programs.[15]

The Report further noted that people with complex needs and their families should be placed "…inside of and with clear access to the health and rehabilitation systems and specialist frameworks that have been designed to promote recovery for this population"[16] and that the need for increased program focus in this area had been identified by some jurisdictions.[17]

7.6. Supporting evidence of benefit

There are numerous Australian and international studies attesting to the long term benefits of rehabilitation. Most recently, in its 2010 socio economic cost benefit analysis of rehabilitation for people with ABI using Brightwater Care's Oats Street Rehabilitation Service in WA, Acil Tasman found a return on rehabilitation investment of 4:1.[18] That is, an annual cohort of 20 people receiving an average of $6.2 million in treatment costs, returned $25.67 million in benefits to the community over the course of their lives.[19]

In its analysis, Acil Tasman stated that because of the reduction in care costs delivered by rehabilitation, a cost that is shared by the community at large "…it is mostly the community, not the clients, who benefit from the rehabilitation process."[20] The potential for reduction in long term care costs and consequent benefit to the NDIS, is obvious.

To achieve these benefits though and because of the often-small window of opportunity available, rehabilitation needs to be delivered in a timely manner. Our

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[14] Op. Cit: 4.173: *xix.*

[15] FaHCSIA, *Mid Term Review, Younger People in Residential Aged Care (YPIRAC) Program*, Canberra, June 2009: 43.

[16] Ibid.

[17] Ibid.

[18] The Oats Street study focussed on benefit derived in 3 key areas: Cost savings through a reduction in the number of hours of care required; higher earnings through the increased ability to work after rehabilitation; and benefits to the person with ABI through improved quality of life.

[19] Op. Cit: *vi*

[20] Ibid.

current rehabilitation service system – both public and private – does not have capacity to do so for all those who will be eligible for assistance through the NDIS and the NIIS. Significant expansion of the existing service system is needed to address this increased demand for rehabilitation services.

7.7. Should rehabilitation be provided by Health, the NDIS or both?

There is a valid perception that if the NDIS is to remain a viable scheme, other program areas such as Education, Employment and particularly Health, must continue to deliver on their legislative responsibilities and not default to the scheme simply because the NDIS has capacity to buy services.

At present and with the possible exception of funding for Victoria's *Slow To Recover: Acquired Brain Injury Rehabilitation* program (STR), most rehabilitation services are part of funded state Health services' responsibilities.[21] From this point of view, provision of rehabilitation services is seen to be Health's responsibility, with the NDIS maintaining vigilance to ensure Health does not bill the scheme for services that are part of Health's mandate.

Yet while Health and acute care hospitals are seen as the natural providers of rehabilitation services in the public sector, they do not provide the type of slow stream rehabilitation and habilitation services that NDIS clients are likely to need.

What acute care *does* provide is limited, fast track rehabilitation aimed at assisting with discharge from hospital to home or to other services. Under intense pressure from limited resources and budgets and skyrocketing demand for services and beds, hospitals will often only offer fast track rehabilitation to those judged able to take advantage of it. If an inpatient cannot demonstrate capacity to take advantage of fast stream rehab, they are rejected and denied further rehabilitation.

As a result, there are numerous examples of individuals who, because of an assumed lack of capacity, are denied fast track rehabilitation but go on to make small gains and demonstrate potential to recover further despite this. Their capacity to make significant long-term gains is, however, likely to be permanently compromised because they have not received the rehabilitation they required when it was most needed.

At present, Victoria's *Slow To Recover* Program for young Victorians with ABI; NSW's Brain Injury Rehabilitation Units (located in acute care hospitals and some community settings and funded for motor vehicle accident victims only); and Brightwater's Oats Street Rehabilitation Service in WA are probably the only

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[21] While STR's funding comes from Victoria's Disability Services, this is due to the program's aim of preventing young people with ABI being placed in aged care.

comprehensive state based rehabilitation services that exist outside the private sector.

Rehabilitation and its benefits are thus poorly understood and commonly seen as an expensive and dispensable luxury, rather than the essential health service they are. As one example, one of the first areas to suffer cuts when health budgets are reduced - to the enormous frustration of rehabilitation specialists and detriment of their patients - are rehab beds.[22]

NDIS clients, including those with hypoxic ABI and those recovering from exacerbation of disease, require different forms of rehabilitation than that acute care currently offers; they need it delivered in a timely manner – the capacity for which acute care does not have; and over a longer timeframe than acute care can provide. As it is presently conceived, acute health care cannot provide the rehabilitation services this cohort requires, despite their eligibility for these funded supports through the NDIS.

7.8. Private sector rehabilitation services

While the private sector can deliver rehabilitation for those who can afford to pay, these services are not extensive and many states do not have comprehensive private sub acute rehabilitation services in place for Health – or the NDIS – to turn to.

Victoria probably has the best private sector rehabilitation service system, developed through the capacity of that state's Transport Accident Commission to purchase services for Victorians of any age injured in motor vehicle accidents. In a similar vein, the advent of NSW's nascent Lifetime Care and Support Authority[23] may help a private rehabilitation service system to grow further in that state over time.

So while limited private sector options may exist in most states, questions exist about their capacity to provide the services that will be needed for purchase.

Further and despite the anticipation that they would, recent health reforms have not addressed the need for rehabilitation and habilitation services through a national rehabilitation strategy.

For these reasons and because the NDIS must provide equity of response, there is a comprehensive case to be made for the NDIS to partner with Health services to

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[22] Dr Kath McCarthy, immediate Past President of the Australasian Faculty of Rehabilitation Physicians in conversation, Sydney, June 2011.

[23] The NSW *Life Time Care and Support Authority* is a no fault motor vehicle insurance scheme that provides support for NSW residents injured in motor vehicle accidents. Not as comprehensive a scheme as the Victorian TAC (injuries must be sustained within NSW' state boundaries to be covered by the LTCSA whereas the TAC covers Victorians injured anywhere in Australia), the LTCSA may – like other state fault based and no fault motor vehicle schemes – be rolled into the NIIS.

develop and deliver the service infrastructure needed to provide slow stream rehabilitation and other habilitation services nationally. Growing service capacity in this way would benefit Health, the NDIS and the community. Most significantly, it would benefit individuals with disability who will otherwise be left out in the cold and without the opportunity to regain capacity once again.

The Productivity Commission identified the need for significant sector reform in its report. The NDIS has a responsibility to be more than a bigger and better funded reiteration of the broken and fragmented service system we currently have in place. Instead, the Scheme has an obligation – and a mandate – to provide the leadership and the vision needed to work with Health and the NIIS to deliver this reform and ensure the rehabilitation services that are so greatly needed for Scheme participants, are developed.

8. Conclusion

In Summary, the Alliance sees great promise in the emerging NDIS, but take the view that the Bill needs to look to the long term design of the scheme; and establish structures that will serve it well over time. Despite the fact that the launch sites also need to be governed by the legislation, the Scheme's key design features should be stated clearly in the legislation, even if this creates pressure in the transition phase.

It is also imprtant that the Bill recognises that the NDIS exists alongside other serivce programs and community infrastructure and must not set up the NDIS as a default "island" program that trades in a single program area. One of the chief responsibilities of the drafters is to ensure that the Scheme interfaces are recognised and that provisions are made for a policy-making function.

Equally, a high profile research and evaluation function needs to be created by the Bill that can enable the NDIS to collect and mediate the evidence it needs to be a leader in the community as well as being a competent and respected lifetime support scheme.

The Alliance recognises that the NDIS rules can complement the Bill and deal with the detail required for various scheme operations. But on the issues we have raised in this submission, it is important that the Bill contains principles and provisions that create high expectations.

People with disaiblities have been forced to live with low expectations all around them. This Bill offers an opportunity to set the bar much higher.

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