Conference Report

Shaping the Future Today
National Conference

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Australian Government
Department of Families, Housing, Community Services and Indigenous Affairs

Young People In Nursing Homes National Alliance
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Preamble

Like many other developed countries, Australia has growing numbers of younger people with acquired disabilities. With impairments that derive from the impact of serious injuries or the diagnosis of progressive illnesses, this group has arisen because medical technologies and improved health care can now save lives that once would have been lost to injury; and enables those with progressive illnesses to live longer and with a better quality of life.

These young people represent a response conundrum for disability services systems that have developed around the less complex needs and circumstances of individuals born with disability. With significantly different health and support needs, those with acquired disabilities arrive without warning and can require intensive and immediate responses from different areas of the health, disability and community services systems, often concomitantly. The complexity and intensity of need these individuals present with can, for instance, require complementary access to

- Acute health care
- Extensive rehabilitation and allied health supports
- Nursing levels of care post acute care intervention
- Supported accommodation services that can successfully support complex health and care needs
- Tailor made, high end aids and equipment.

The type of immediate, multidimensional and multi-directional response this group requires is something that all Australians with disability are increasingly expecting to have access to. Throughout the YPINH campaign prior to the COAG YPIRAC program announcement, the public response to media about this issue was ubiquitous surprise that there was, in fact, no system that covered these people outside our limited compensation schemes.

With the medical system now able to keep people with catastrophic injury and disability alive, there is a real expectation that post the acute health intervention phase, the saved life will be sustained with restorative rehabilitation and disability support services. Whether from injury or illness, the YPINH group arrives at the door of the disability system with complex, intensive and immediate needs. To this already heightened mix of response requirements, the time pressure of quick separation from hospital and the health system is often added.

What is starkly obvious is that existing disability services systems are ill-equipped to develop or deliver the interrelated services that are so desperately – and rapidly – needed. Chronic underfunding and rapidly rising unmet demand have instead meant that existing (state) disability systems have focused on a demand management approach where services are delivered according to available funding, rather than the immediate needs of consumers.

For better or worse, the disability support systems are required to pick up long term support for people where other systems refuse or fail to accommodate them. This clearly exposes the lack of continuity in the wider health system that results in younger people having to go to aged care due to lack of capacity.

Crisis driven, reactive and firmly focused on maintaining budgetary and fiscal responsibility, the demand management imperative that drives disability services leaves little capacity to fully meet the health and support services needs of the YPINH target group. As a result, many young disabled Australians enter residential aged care because the suite of supports and services they require are not available. In some cases this is about timing of support provision (particularly for the progressive neurological group); rehabilitation for people with ABI; and aids, equipment and home modifications for all groups.

Previous efforts to address this issue and develop appropriate responses for this cohort have largely focused on the development of new services, such as Victoria's *Slow To Recover* program (STR) that delivers slow stream rehabilitation to young people with Acquired Brain Injury (ABI); that state's HomeFirst initiative that provided up to 34 hours of attendant care support to individuals living in the community with high and complex support needs; or NSW's High Needs Pool which attempted to do the same.

Welcome though these initiative's were, they were developed in isolation from other arms of the service sector and were ultimately unable to keep pace with growth in demand for the services they delivered, demand that increasingly also required more than these initiatives were able to deliver. Once again, the net result has been the increasing movement of younger Australians into residential aged care services.

The Younger People In Residential Aged Care (YPIRAC) initiative

Satisfying the growth in demand for disability supports and services has been an enduring challenge for governments at state and federal levels for many years. Nowhere has this been more evident than in the movement of young disabled Australians into a residential aged care system ill-equipped to meet their needs.

The Young People In Nursing Homes (YPINH) group include young people with a variety of largely acquired disabilities derived predominantly from accident induced injuries, as well as degenerative neurological diseases like Multiple Sclerosis, Muscular Dystrophy and Huntington's Disease. A small number have mental health or intellectual disabilities. Whatever the cause, residential aged care (RAC) settings struggle to support these young people due to a lack of staff trained in their particular support needs; as well as inadequate funding and a lack of access to equipment, rehabilitation and other resources.

At present, some 6,752 young Australians with high and complex health and support needs reside in aged care nursing homes nationally.[1] Many more in the community are at

[1] Department of Health and Ageing, quarterly figures, March 2008.

risk of placement in nursing homes if their health and support needs intensify, or if their informal support arrangements break down.

On February 10 2006, the Council Of Australian Governments (COAG) announced a limited, 5 year response to begin redressing this seemingly intractable issue. Coming at the end of a 6 month investigation the COAG had requested into possible responses to this longstanding and entrenched problem, the initiative required collaboration and financial partnership by all jurisdictions. In moving young people out of aged care nursing homes, the then Federal Government also saw the initiative having capacity to address the crisis in supply of aged care beds that Australia's rapidly ageing population needed.

Initially, the YPIRAC program had only one objective: to move young people out of the residential aged care (RAC) beds they were seen to be preventing frail older Australians from occupying. However, intense lobbying by the National Alliance and others resulted in the addition of two more objectives. The first recognized that some young people in rural or remote areas might choose to remain in RAC in order to stay near family or remain in their communities; or alternatively, because their health did not permit a move to community based supported accommodation. The second acknowledged the need to prevent more young people entering residential aged care going forward.

With an initial target group of young people living in nursing homes (YPINH) under the age of 50 years, this national program's key objectives are thus to:

- assist younger people with disabilities living in residential aged care to successfully move to community based supported accommodation
- improve support services for those who continue to stay in residential aged care and
- minimise future admissions by assisting younger people at risk of entering nursing homes where possible.

Despite the addition of two key areas of endeavour, the initiative's limited funding of $244 million over 5 years remained the same. While the COAG stated that younger people living in residential aged care under 65 years were eligible to participate, the initiative also declared that an initial target group of younger participants under the age of 50 would have priority.

While the COAG's announcement was greeted with relief by the then 6,500 young Australians living in nursing homes (YPINH) and their families, the initiative's time and resource limitations quickly became apparent. In response to questions concerning these limits, the COAG indicated that this response was not intended as a solution, but was conceived instead as a 'first step' towards final resolution of the issue. Furthermore, the COAG indicated that, provided acceptable progress was made, the initiative had capacity to be extended beyond 5 years.

The YPIRAC initiative's design

As a partnership between the Commonwealth and its State and Territory counterparts, the COAG YPIRAC initiative received $244 million in joint funding to achieve its aims over

a 5 year period with the option of extension at the end of the initial phase in 2011. Each State and Territory signed a separate bilateral agreement with the Commonwealth to implement the initiative.

While the shared funding that underpinned the YPIRAC initiative indicated a collaborative approach between jurisdictions, the initiative suffered from a number of conceptual limitations. These have had an adverse impact on its capacity to deliver much needed innovation and service delivery reform for the target group and include:

- *Absence of national oversight*

As a national program, the initiative has great potential to promote productive collaboration in all areas of endeavour, but especially in regard to innovative service delivery for the target group and improved interdepartmental collaboration between health, disability, community services and aged care at both state and federal levels. Its lack of national oversight has meant, however, that the states and territories have been able to fall back on existing infrastructures and methodologies for much of the initiative's implementation. Because of this, the opportunity for jurisdictional collaboration and learning around much needed innovation in service delivery and subsequent systemic reform has been missed. The net result has been a 'more of the same' approach to service development and delivery for the target group.

There have also been haphazard approaches to addressing clinical and service pathways through the engagement of health systems in the States; and even with aids and equipment schemes. The absence of any cohesive plan to evaluate the initiative and revisit its initial assumptions has meant that information flow, national strategy and commitment to strategic progress have also been patchy. Overall there has been little accountability from the initiative back to the target group and to the disability sector.

- *Incapacity to address much needed reforms*

The initiative's predominant focus on moving younger people out of RAC beds has constrained its capacity to address the service system reform that is essential if the YPINH issue is to be finally resolved. Such reform is not only crucial to the YPINH group but has wider application through of its capacity to offer improved access to services and options to *all* Australians with disability.

Political animosity between the then federal government and its state and territory counterparts ensured, however, that the bilateral agreements the Commonwealth negotiated with the States and Territories were more concerned with ensuring that key performance indicators (KPI) were agreed to and rigorously addressed so that federal monies were not potentially 'siphoned off' to other state programs. Punitive financial consequences in the bilaterals merely served to reinforce the importance of the initiative's KPIs to the exclusion of all else for state and territory administrators.

As a result, attending to the KPIs and ensuring that these were precisely met within agreed timelines, ensured that the initiative's capacity to address reform and service innovation or involve the YPINH cohort in the planning and development of the services

they would use, was lost. This overt focus on compliance at the expense of good practice or reform of existing systems, meant that responses were mired in the incapacities of existing disability systems. In addition, some states had such small targets and so little capacity that their total response was only ever to individuals rather than the systemic issues needing address.

If the COAG's objectives are to be properly addressed, it is essential that the system be left in better shape than it was when the initiative began. Currently there is no strategic plan for this to take place. Though a desire for system reform is evident, there is no evaluation framework to enable this and other imperatives to be assessed; or a blueprint or roadmap in place to ensure this is maintained going forward.

- *Little available knowledge or understanding of the target group*

Other than anecdotal evidence, little information existed at the start of the initiative on the needs, expectations and aspirations of the target group. As a consequence, the states and territories spent large amounts of time finding and assessing the needs of those who chose to participate before any response could be offered. While this has increased overall information about of the target group and understanding of the complexity of response required, it has also reduced the initiative's capacity for timely and effective interventions

Poor understanding of the YPINH group's characteristics also led the bi laterals to insist on actions that were in many cases ineffective or inappropriate. One example was the requirement that all YPINH should receive a letter informing them of the initiative's existence and how they might participate. Such a requirement was ignorant of the fact that:

- many young people in nursing homes might be unable to access or understand such a letter
- limited staffing levels in nursing homes meant there was a likelihood that the letters might not reach residents in time or at all
- the placement of their loved ones in aged care nursing homes had made many families highly cynical and dismissive of 'attempts' to offer alternatives and they were likely to reject such overtures out of hand
- nursing homes held only limited information about residents and may not have been able to forward information to family members
- many residents may not have family who could approve participation
- despite the inappropriateness of their placement there, many younger individuals might find it hard to contemplate moving out of RAC in the absence of any tangible idea of what – or where – they would be moving to. This was an unacceptable risk for residents more inclined to trust the devil they knew than the one they didn't.

- *The inability of existing disability systems and infrastructures to address the systemic issues that gave rise to the YPINH issue*

Implementing the initiative required a different approach that accommodated the complex support needs of the YPINH group. Giving this job to state disability services systems

already constrained by chronic underfunding, rapidly rising unmet demand and a demand management approach to service delivery, was always going to be problematic. The structure and intent of the bilaterals and their overarching emphasis on achievement of KPIs; a lack of understanding by all jurisdictions of the particular needs of the YPINH cohort; public servants whose approaches to service development were largely reactive and rarely proactive, only served to compound this state of affairs.

Instead of creating opportunities developed around the needs of individuals with a flexible approach to individualized care, implementation has focused mainly on the development of accommodation services that comply with already extant disability protocols. While this might satisfy the imperative to move set numbers of young people out of nursing homes into the community, it does little to encourage innovative responses in this regard. Nor has it addressed the profound impact on the disability, health and aged care systems of young people remaining in RAC over the longer term, or the prevention of future admissions to RAC by this group.

Without any requirement to deliver innovative responses or systemic reform, the opportunity to deliver improved, targetted services to individuals with disability has been lost.

- *Failure to include the Department of Health and Ageing (DoHA) in the initiative*

The fact that ever growing numbers of young Australians are living in residential aged care makes DoHA one of the nation's biggest providers of disability accommodation. This department also has responsibility for the management of residential aged care facilities and thus the young people living there. Yet DoHA was not included in the initiative or its implementation.

Given the initiative's second key objective to deliver improved disability supports to young people who choose to remain in RAC, DoHA's absence was of particular concern. Practically it meant that residential aged care services had no especial imperative to be involved in the initiative; to collaborate on the delivery of disability services into nursing homes; or to work with disability service systems to develop new responses for young people with complex health and support needs who may look to RAC as a transitory option; or for longer term placement in the absence of nursing levels of support in the community.

- *Movement of young people out of RAC beds without incentive to develop appropriate alternative supported accommodation services*

The initiative's limited funding has meant little capacity to develop the types of alternative supports and accommodation services young people with complex needs require. In their efforts to comply with agreed KPIs, state officials have instead focused on utilizing existing accommodation options and services that are often poorly placed to support the high and complex needs the YPINH cohort presents with.

- *Preventing young people moving into RAC in the future*

Its predominant focus on moving young people out of nursing homes meant the initiative had little incentive to tackle the underlying reasons for young Australians ending up in aged care nursing homes. While eventual entry to RAC may be inevitable for some, the initiative has had little capacity to maintain young people with high and complex support needs in the community for as long as possible, thereby improving health and well being outcomes and reducing downstream costs that inevitably attend in acute care, allied health, disability and aged care services. Yet tackling this should be the initiative's cornerstone.

Failure to do so not only means 'backfilling' of vacated nursing home beds by the next wave of young people with complex support needs. It also escalates costs and makes any move to community based support problematic.

This is for many reasons and can include:

- The loss of community based supports and services previously relied on by the individual. This may include rented accessible accommodation and support workers skilled in the support needs of the individual
- Comparative security of support the nursing home environment offers
- Inability or unwillingness of family members to deliver informal support
- Unknown capacity of community based services to deliver appropriate support going forward
- Unwillingness to trust a disability services system that young people and families often see to have failed them
- Deterioration in health and well being and subsequent inability to return to community based supports

These factors make prevention or diversion of young people away from nursing home placement of fundamental importance to the initiative's success going forward. Instead of the current predominant focus on moving younger people out of nursing home beds, the initiative must concentrate its efforts on preventing young people from entering RAC in the future. Doing so will deliver the systemic and other reforms needed to finally enable younger people with complex health and support needs to remain in the community and prevent the inevitable escalation of costs that will result if a preventative approach is not adopted across the board. Without intense effort here, the systemic reforms needed to resolve the YPINH issue will not be addressed.

- *Declaration of an 'initial target group' of <50 years*

While the YPIRAC initiative was theoretically available to all younger people under the age of 65 years, the program's time and resource limits have resulted in the initial target group (<50) being the only group considered for participation. While the reasons behind inclusion of an age related initial target group are unknown, they may have included:

- Perceptions that this cohort's much smaller numbers increased the chances of success
- Mistaken assumptions that people over 50 were likely to enter or remain in aged care anyway

- Prejudicial thinking that locates individuals over 50 as 'less in need' of disability supports and services because they are approaching the 'aged' interface
- Financial and budgetary constraints regarding available funding for the initiative.

Whatever the reason, the net result has been the exclusion of the over 50s cohort from the YPIRAC program. In some states, eligibility has been so tightly defined that individuals must be under the age of 50 years as at 1 July 2006 to participate. In their defense, many states have indicated that limited funding means they will struggle to deliver for the under 50s group itself, let alone address the needs of the much larger over 50s cohort.

Inclusion of an initial under 50s target group has thus served to reinvigorate one of the main areas of concern in the YPINH issue: a predominant service delivery methodology that provides services according to age not need. As a result, many YPINH who have entered RAC in their 20s, 30s and 40s and aged beyond 50 years waiting for something to be done, have been effectively prohibited from participating.

The YPIRAC's limited funding has thus meant that, despite the inference that an 'initial target group' would be addressed first and those over 50 included later, those under 50 will be the only group participating in the initiative in its present form.

- *Absence of comprehensive and transparent evaluation framework*

The absence of a comprehensive and transparent evaluation framework was a surprise and a disappointment to all stakeholders, but particularly to consumers. There was general agreement that in declaring the YPIRAC initiative to be a 'first step', evaluation was essential to move to the next step and any further steps that may follow.

In particular, the lack of any evaluation data other than compliance data, was clear evidence of the initiative's incapacity to address critical systemic issues going forward. Without any information or feedback for the states to engage with or a national evaluative framework to develop future strategies, the initiative would essentially become an exercise in futility and the jurisdictions' stated commitment to seriously addressing the YPINH issue called into question.

Shaping the Future Today

The *Shaping the Future Today* conference was convened in response to a stated need by Governments and the community sector to revisit the COAG objective for the YPIRAC initiative and to evaluate the strategy, operation and future of the initiative.

The midpoint of the initiative offered a unique opportunity to bring stakeholders together to reflect on progress to date; and to consider this national program's focus over the remainder of what is hoped will be this first 5 year phase.

COAG framed this initiative as a first step towards a solution to the YPINH problem. But the next steps to be taken or the strategies that would be needed were never declared. This has become a defining issue in itself for stakeholders – and one that the conference set out to work through.

When the initiative began, little data was available on the needs, aspirations or existing circumstances of the then 6,500 young Australians living in residential aged care. However, in the 2 ½ years that the initiative has been operational, information with the potential to affect the program's future operations has been garnered. Yet progress on evaluation – always an important element of the initiative's implementation – was not evident.

Stakeholders were, however, aware of differing perceptions and expectations about the program. For example, government agencies were finding it difficult to implement in the early stages because of a lack of knowledge about the target group. One of the first tasks undertaken was, therefore, to identify the target group. Yet providers, advocates and consumers wanted to see rapid service development, packaging of individual solutions and targeted systemic improvement to re-route the traditional pathways for young people into nursing homes.

These varying perceptions and expectations have resulted in an often confused and confusing view of the initiative and its operations by stakeholders.

Shaping the Future Today was planned, therefore, to achieve two overarching objectives. These were to:

- offer stakeholders an opportunity to reflect on and review the outcomes of the initiative thus far; and
- consider what remains to be done in the remaining 2 ½ years of the initiative's life.

Conference participants

The conference was open to all stakeholders and representation from every key group was achieved. A total of 274 people attended the conference over the two days it was held at the Moonee Valley Racing Club's Convention Centre. According to registration information, participant breakdown revealed attendance by the following groups:

- **72** *young people with disability and family members*
  Some of the young people who attended were living in nursing homes, some had moved into community based supported accommodation under the COAG YPIRAC initiative and others were concerned about their future risk of placement in residential aged care.
- **12** *health sector representatives*
  These included representation from the acute as well as the allied health care sectors.
- **11** *policy makers from government and non government organisations*
- **52** *State and Federal Government representatives*
  Representatives from all state implementation teams attended as well as individuals from the Federal Department of Families, Housing, Community Services and Indigenous Affairs and the NSW Office of the Disability Council.

- **42** *advocacy representatives*
  Government organisations including the Office of the Protective Commissioner, Office of the Public Guardian, and the Senior Masters Office of the Supreme Court, as well as NGOs including Family Advocacy, Rumbalara Aboriginal Cooperative and Action for Community Living amongst others, attended.
- **85** *service providers in health, disability and aged care*.

Concept mapping

One of the main objectives of the conference was to enable stakeholders to indicate how the implementation of the initiative had 'measured up' to their expectations and experiences; and to indicate what areas, if any, needed to be included in the initiative's work going forward.

A concept mapping process was chosen as the most effective way of offering conference participants the opportunity to contribute their thoughts and views on the initiative's impact thus far; and to indicate the areas it should focus on over the remaining two to three years of its life. As an enhanced brainstorming method, concept mapping seeks to:

- Identify the broadest possible range of issues around a particular topic
- Organise the ideas identified into a single conceptual framework that does justice to all the distinctions and shades of meaning that members of the contributing group see as important
- Present this in a pictorial diagram that shows the main relationships between the categories of ideas that were developed.

Concept mapping also offered a methodology by which over 3000 individual responses could be grouped and refined into a readily accessible 'map' that identified key areas of concern or need.

The concept mapping process began with registration when participants were asked to identify twelve 'ideas' about the COAG YPIRAC initiative. These forms were submitted via email and fax and the results collated to form the first stage of concept mapping to be used on Day One of the conference.

To complete this process, conference delegates were divided into 3 working groups that they remained in to complete the sorting tasks allocated over the course of Day One.

These groups were:

- government and policy
- consumers and advocacy
- service providers (aged care, disability, health).

Over the remainder of the conference's first day, the ideas submitted at registration were grouped and refined three times by conference participants. The results of this extended

process were delivered to participants at the beginning of Day Two. These results are available in Appendix A.[2]

Conference program

One of the conference's key aims was to cement a sense of continuing collaboration between stakeholders. The YPINH group often requires a wide ranging response from disparate areas of the health, disability, community and aged care service systems. Without a collaborative or partnership approach, successfully responding to these diverse needs is often problematic at best and impossible at worst. Collaboration and effective partnership between stakeholders is thus crucial to the COAG initiative's success at all levels.

Another was to offer participants the opportunity to consider how the initiative could deliver the policy and systemic changes needed to resolve the YPINH issue going forward. Moving younger disabled Australians out of residential aged care services clearly does little to address the systemic changes needed if the YPINH issue is to become a thing of the past and an improved support system delivered for all Australians needing care and support.

The conference program was thus constructed to offer participants an opportunity to:

- understand the challenges the States and Territories confronted in implementing the initiative
- appreciate the diverse responses required within the initiative's time and resource limitations
- review the initiative's achievements to date
- provide a forum for stakeholders to discuss the initiative's present and future development and implementation
- consider those areas the initiative should concentrate on in the remainder of this first, five year phase
- provide input into how the initiative could foster the systemic and policy changes needed to resolve the YPINH issue; and develop a sustainable lifetime care and support strategy that would benefit all Australians with disability.

♦ *Program day one: showcasing achievements in years one and two*

The first day of the conference was designed to review the initiative's implementation and achievements to date. Concept mapping exercises refined the ideas participants had submitted at registration while keynote addresses from the Minister for Families, Housing, Community Services and Indigenous Affairs, Hon. Jenny Macklin MP and Parliamentary Secretary for Disability and Children's Services, Hon. Bill Shorten MP, set the scene for vigorous, wide-ranging and committed discussion of the COAG initiative and its outcomes.

[2] Pages 11-14 of this document.

As part of this process, all state and territory teams were invited to participate in a panel discussion that offered them the opportunity to showcase the initiative's achievements in their respective jurisdictions; and discuss some of the challenges they had faced in delivering a response.

All state teams participated in this presentation and the facilitated discussion that followed.

With representatives from all states on stage, this was an eagerly anticipated and well received part of the conference program. Stakeholders indicated that they were pleased with the opportunity to hear first hand about the processes that had been undertaken in the different states; and to gain a better understanding of the challenges the initiative encompassed. As a result of the panel's comments, many conference participants reiterated the desire for a more open process of information and involvement in the initiative going forward.

The remainder of the first day's program offered conference delegates the chance to hear about the development of processes and services under the COAG YPIRAC initiative. *Showcasing achievements in years 1 and 2* offered presentations in three concurrent streams. As well as discussion about different assessment and planning strategies developed for the YPINH group, these presentations showcased the development of new supported accommodation services in different states and reiterated the need for a variety of 'options on the spectrum' as an essential element of the response required for this group.

Other presentations addressed how individual needs had been met and examined the development of effective diversion strategies that assisted young people with disability to avoid placement in residential aged care and remain living in the community.

- *Program day two: Visioning the Future*

Day Two's focus was the areas the initiative should address over the next 2-3 years. The day began with a report on the outcomes of the concept mapping exercises done on Day One. This was followed by two panel discussions that examined future areas of action for the initiative including the involvement of rehabilitation and allied health resources as part of a successful response; and what a sustainable, equitable and responsive disability services system should look like.

The first of these, *Where health meets disability*, picked up on a clear call in the concept mapping results for the direct involvement of rehabilitation and allied health services in the COAG initiative, both as a way to assist recovery from injury for YPINH; and also to maintain health and well being for this group over the long term.

The second, *Shaping the Future*, was a wide ranging discussion between stakeholder representatives that addressed the essential policy and systemic reforms needed to support a lifetime care approach to the provision of disability services and how this might be sustainably funded.

The afternoon offered a series of sessions in three concurrent streams under the overarching title of *Under the Microscope: Service system improvements.* Presentations covered *Service Innovations, Lifetime care and alternative funding solutions* and *Family voices.*

In concert with the conference aims, the program reflected the need for continuing collaboration and partnership between all sections of the stakeholder community.

Conference outcomes

Over the two days of the conference, participants had the opportunity to listen to state implementation teams discuss their achievements and outline the challenges they face. They also had the opportunity to hear from consumers who had benefited from the initiative; and service providers engaged in delivering new support and accommodation services through it.

In a series of concurrent sessions, participants were also given the opportunity to consider whether the initiative's focus should be altered over the last 2-3 years of this first, 5 year phase; and nominate areas they believed were fundamental to the delivery of the systemic and policy changes they were looking to the COAG YPIRAC initiative to deliver.

Key outcomes of the conference were calls for:

- *Extending the initiative*

The conference recognised that although the initiative has been slow to deliver in the first two years, it still has time and potential to make some significant inroads to improving the systemic response to the YPINH target group. While recognizing the difficulties in getting the program started and understanding the needs and preferences of young people in aged care, many participants agreed that the initiative urgently needed to deliver more outcomes more rapidly to be able to meet its 5 year targets.

While the focus on individuals, particularly those currently in aged care, has been the main focus of the initiative, there has been little attention in most states to the systemic changes needed to address the YPINH problem comprehensively. The focus on the delivery of a narrow range of services to this group was seen to need expanding to include rehabilitation, family support and the targeting of specific programs for the different diagnostic groups.

Without this strategic focus, it was felt that the initiative risked simply replacing those it had moved from aged care with the next wave of young people with complex support needs who would move into these recently vacated aged care beds.

It was also made clear that although the initiative is being run out of the disability bureaucracy, major strategic engagement was needed in the health and aged care systems to create the service pathways needed for this group. The disability system alone is not

yet equipped to meet the needs of this group and deliver on the COAG objectives, so it must engage collaboratively with health and aged care.

The following outcomes detail the specific issues raised in the context of refocusing the initiative to derive the most useful benefits. A number of cases were made for dramatically increased funding from all jurisdictions to the initiative to enable improved responses and faster outcomes for consumers.

- *Funding*

An end to the 'rationing' approach to funding under the initiative that has seen funding delivered according to the numbers of consumers requiring a response, rather than according to need. This rationing approach to policy and/or response has no ability to change the dynamic in the system that led to young people ending up in aged care.

The recent announcement of a COAG investigation into making aged care and disability more distinct from each will have implications for the longevity of focus on YPINH beyond this initiative.

The conference was only too aware that this is a much bigger job than one modest 5 year program can cover, and there were many questions about how future steps would be taken, and how they would be informed, given the lack of a comprehensive evaluation of this first stage.

- *Diversion from aged care*

From the presentations of the State teams through to consumer stories, there was overwhelming agreement that the initiative needed to drastically increase its focus on preventing young people entering RAC through innovative programs that deliver timely and effective responses. This is another area where evidence from the State Team presentations highlighted the lack of a demonstrable overriding strategy. While states such as Victoria have a methodology for diversion and have delivered some good outcomes, other states had little to show. The State presenter from WA was also keenly aware of the importance of preventing or slowing entry into aged care and made the observation in his presentation that diversion was the key to the initiative overall.

Indeed, there was fear that the initiative would be under spent over the 5 years, and targets left unmet. The degree of difficulty in moving people out of aged care has proved to be far greater than first thought in terms of time, resources and capital.

Given the slow progress of the program to its midpoint, the Conference generally agreed that the only way of achieving the overall goal of seeing a net reduction of younger people in aged care was to escalate the effort in diverting people. The inflow of young people into aged care in the first 2 years has outstripped the number moved by the initiative (using the COAG age threshold of 65), so there is a clear need to shift priorities.

- *Inclusion of the over 50's group in the opportunities the initiative offers*

The exclusion of the over 50's group was also highlighted as a major deficiency in the initiative's design, having a large impact on the progressive neurological target group,

many of whom are in this age bracket, who face all the same problems as those under 50 and create all the same systemic blockages. Comment was also made about many younger people who had aged beyond the cutoff point waiting in nursing homes for something to be done.

There was overwhelming support for the initiative to deliver responses according to need not age, and do away with the 'initial target group' approach that sequestered the under 50s from other, equally needy YPINH over this age.

- *Calls for an insurance based approach to the future funding of disability services*

A significant amount of discussion occurred about a social insurance based approach to the funding of disability services as a high level systemic reform that would deliver the lifetime support this group needs; and remove the need to ration services.

Such a scheme would:

- be based on need not age
- include rehabilitation from injury as well as ongoing skill development and maintenance of existing life and other skills via allied health services
- be fully funded
- include aids and equipment
- provide timely and effective responses
- develop a proactive, preventative approach to service development and delivery in contrast to the reactive, crisis driven 'demand management' approach that characterises existing disability services systems
- offer flexible and innovative responses
- involve the people who use the services in their design, development, delivery and ongoing management.

There was also much discussion about the need for a stepped approach to achieving such an overarching national scheme, both in conference presentations around a no fault catastrophic injury insurance scheme as the first step; and in plenary and other sessions where the need to include other groups was examined. The consensus remained that a social insurance based approach to future disability funding and the implementation of a life time care approach were linked and that if a stepped approach was pursued, firm government commitment to pursue subsequent steps was essential.

- *Rehabilitation*

There were unanimous calls from across the stakeholder spectrum for the inclusion of rehabilitation services in the initiative; and for a 're-definition' of the notion of rehabilitation to include the development of a 'lifelong approach' to skill development for recovery from injury and maintenance of health and well being in the YPINH group. 'Life long' was proposed in recognition of the fact that recovery from neurological incident (including Acquired Brain Injury) is not something that happens within a defined period of time but can continue over the life span; and that rehabilitation as a term does not describe the need for continuing skill acquisition or maintenance of existing skills that characterises the YPINH group.

Participant consensus was that without the inclusion of rehabilitative services and comprehensive access to allied health supports going forward, the initiative would deliver a partial response only to the target group, one that would eventually require even more intensive and costly interventions to rectify in the future.

Achieving this would require collaboration between the health, disability and aged care sectors and a renewed focus on proactive interventions for the YPINH cohort going forward.

- *Consumer involvement*

Consumers uniformly wanted far greater input into decision making processes and direct involvement in planning and development of new support and accommodation services. There was concern that service development thus far had simply re-invoked preexisting service responses without due regard for the complexity of need the target group has and the service system's present (in)capacity to deliver the supports young people require.

Strong calls came for the direct involvement of young people and families in the design, development, delivery and ongoing management of new services and a move away from the centralized service planning models currently being used for accommodation services. Consumers wanted to collaborate directly with service providers and disability officials on the delivery of needed services to ensure better targeted responses. There was also enormous frustration expressed at the lack of information available regarding the program itself, progress in implementing as well as where consumers could go if they wanted to challenge the response they were offered.

- *Systemic reform*
  - Stakeholders called for improved collaboration between government departments in health (acute and allied health), disability, housing, aged care et al., especially in the design and implementation of innovative solutions that maintain YPINH in the community; and in the delivery of services.

    Participants were of the firm belief that the pathways for people with complex needs need to be crafted differently to those of the past that have failed this group; and reaffirmed that dedicated work needs to be undertaken in the initiative to create better articulated services to meet the needs of this group more comprehensively. The initiative is seen as a unique opportunity to do this.
  - Improved collaboration and partnership between jurisdictions in addressing policy and systemic issues that directly contribute to the YPINH issue.
  - Better integration of the health, disability and aged care sectors in the development and delivery of responses.
  - Better collaboration with young people and families participating in the initiative.
  - A life time care and support approach to the provision of disability services utilizing a social insurance based approach for funding that enables timely, effective and sustainable responses.

- *Workforce issues*

There was clear concern expressed at the lack of suitably trained support workers capable of supporting those with high and complex needs; and the poor training disability support workers currently receive overall. There was also concern expressed at the transient nature of the existing disability support workforce. Preference was also expressed for greater collaboration between acute care and disability services in the delivery of appropriate training and supports for those with clinical needs including tracheostomy care and other nursing or clinical level skills.

There was general agreement that the initiative's current focus on developing additional and support accommodation services was misguided, ineffective and placed the YPINH cohort at significant risk unless the following was addressed.

- A dedicated career path for disability support workers that enables this work to be an entry level activity to other courses and/or professions
- Improved rates of pay that recognize the vital nature of such work and the responsibility and difficulty often involved
- A variety of responses that acknowledge higher level skill acquisition and training including higher rates of pay; paid study leave to improve knowledge, training and expertise; a system of secondment or work exchange to enable workers to gain practical experience in best practice or innovative service solutions in Australia or overseas
- A supervised training program similar in concept to a trade's apprenticeship where support workers are mentored or monitored by those with expertise.

- *Comprehensive and transparent evaluation*

The conference strongly supported the development of a comprehensive and transparent evaluation strategy that involved all stakeholders at all levels, including consumers. Mention was made of the evaluation of the Commonwealth Innovative Pool by the Australian Institute of Health and Welfare (AIHW) in 2005, as the type of evaluative structure the disability sector was expecting in terms of rigour of analysis and exceptional data delivered.

Since the conference's conclusion, moves to a national disability strategy and the (re)negotiation of a new National Disability Agreement to replace the former Commonwealth State Disability Agreement (CSTDA) reveal that the landscape around the YPINH issue is constantly changing. Recent moves to further clarify and separate disability and aged care also indicate the need for ongoing evaluation to be part of the initiative's future work; and for the initiative's future actions to be revisited and possibly revised as circumstances alter.

The evaluation process also needs to incorporate capacity for consumers to be comprehensively supported in their engagement with the initiative at all levels; assist the states to become more cogniscant of the expectations and concerns consumers have; and develop collaborative strategies that will enable better targeted responses to be developed.

Conclusion

The COAG's YPIRAC initiative has been a welcome start to resolution of the YPINH 'issue' and has certainly delivered better outcomes for a small number of the YPINH cohort. However, without substantial rethinking of the initiative's design; without a comprehensive commitment to innovation in service delivery and systemic reform of the existing disability service system; and without a significantly different approach to implementation that genuinely involves all stakeholders in its work, its capacity to deliver the reforms needed to solve the YPINH issue will not be achieved.

Because the initiative *is* a first step, it has a practical capacity to address its inherent design flaws and deliver a vastly improved and successful program going forward. Key to this will be substantial additional funding investment by all jurisdictions and a firm commitment to *real* collaboration, not only at jurisdictional levels, but also on the ground where the vital work of the disability, health and aged care sectors is delivered.

The conference acknowledged the vast 'talent pool' that the stakeholder groups represented and called for a more constructive and creative use of this group in the initiative's work. Being more inclusive in this way could assist jurisdictions to resolve some of the inherently difficult work that needs to be done around managing consumer expectations that have been raised to new heights by the COAG announcement, but have not yet been satisfied and are consequently in danger of being replaced by frustration and exasperation. If this happens, a new set of management issues will need to be addressed by all jurisdictions.

The COAG's YPIRAC initiative has the potential to deliver one of the most significant disability reform agendas in our nation's history. Jurisdictional commitment to achieving these reforms will not only assist younger Australians with high and complex health and support needs, but will enable all Australians with disability to achieve the lives of dignity and independence they want, and deserve.

Appendix A

Concept mapping results summary

Concept mapping to determine immediate priorities for the COAG Young People in Nursing Homes Strategy

A concept mapping process was chosen as the most effective way of offering conference participants the opportunity to contribute their thoughts and views on the initiative's impact thus far; and to indicate the areas it should focus on over the remaining two to three years of its life. As an enhanced brainstorming method, concept mapping seeks to

- Identify the broadest possible range of issues around a particular topic
- Organise the ideas identified into a single conceptual framework that does justice to all the distinctions and shades of meaning that members of the contributing group see as important
- Present this in a pictorial diagram that shows the main relationships between the categories of ideas that were developed.

Concept mapping also offered a methodology by which over 3000 individual responses could be grouped and refined into a readily accessible 'map' that identified key areas of concern or focus.

The concept mapping process began with registration when participants were asked to identify 12 'ideas' about the COAG YPIRAC initiative in response to a key question. Responses were submitted via email and the results collated to form the first stage of the concept mapping process that was continued over the course of Day 1 of the conference.

To engage in this process, conference delegates were divided into 3 working groups that they remained in to complete the sorting tasks allocated over the course of Day One:

- Consumer focus
- Provider focus (aged care, disability, health).
- Government/Policy focus

Over the remainder of the conference's first day, the ideas submitted prior to and at registration, were grouped and refined three times by conference participants in their respective groups. The results of this extended process were delivered to participants at the beginning of Day 2.

- *Concept mapping process and results*

Key question

Given that the COAG initiative has been conceived as a first step to get young people out of nursing homes, what does the initiative need to do in the next 3 years to achieve its potential and meet the COAG's stated objectives?

Tasks

- Generate ideas (forms prior to and at registration)
- Organise ideas (representative groups during the lunch break, Day 1)
- Rate the importance of ideas (all participants, afternoon Day 1)
- Discuss the results (Morning, Day 2)

Three groups of responses or perspectives

- Consumer focus – 240 statements reduced to 73, then 48 ratings
- Provider focus – 130 statements reduced to 53, then 67 ratings
- Government focus – 19 statements, then 35 ratings

Sorting tasks

Sort the cards into piles using any system that makes sense to you
Rules:

- There has to be more than one pile
- There has to be less piles than there are cards
- Piles with only one card are OK
- There must not be a 'miscellaneous' or 'other' pile. Cards that cannot be sorted should be treated as piles of one card
- Once the cards are sorted think of a name for each pile
- On one of the spare pieces of paper write a name for the pile and clip all the cards together with the name tag on top

Results

Consumer perspective: top 10 statements

Statement	Original Cluster	Importance
National No Fault Insurance Scheme for all severe injuries, particularly catastrophic brain injury (not just motor accidents) based on Victorian TAC model and/or the New Zealand model (ACC)	10	4.49
Drastically improve funding to disability services	10	4.47
National rehabilitation program with lifetime cover, based on Victorian TAC model	12	4.37
Continue to maintain general public awareness (in a relentless manner) of the issues associated with this major concern	5	4.28
Develop a national and properly funded rehabilitation strategy that delivers for recovery from injury and maintenance of health and well-being over the long term	12	4.23
Develop fast, rehab responses poor young people with catastrophic injury. Utilise the expertise of those professionals who are experienced in working with this group (e.g. through Slow to Recover program, Victoria and internationally). Young people are dying while states, such as Queensland, refuse to learn from those who are saving these young lives.	12	4.22

The best support that governments can give family and carers is to set up and properly fund a National rehabilitation scheme and sufficient supported and integrated accommodation services	12	4.21
Rehabilitation is nowhere in this initiative and it must be. For people with neurological disease, rehab is crucial to maintain your health. Yet we can't access it!	12	4.19
Accommodation specifically designed with an appropriate (and appropriately funded!!) support model for people with very challenging behaviours and/or dual diagnosis of neurological condition and psychiatric...	8	4.13
Increase carers allowance to assist in offsetting costs when parents/parents give up or reduce their hours of paid employment to care for a young person	11	4.12

Provider perspective: top 10 statements

Statement	Original Cluster	Importance
We need suitable accommodation options for young people with high support needs	11	4.38
To design service models for people that are based on their assessed and identified individual need, rather than developing a service in the absence of the people who would use the service and in the absence of their individual needs	10	4.27
Involve the target group in all processes and stages	5	4.23
Quality of life!!!	5	4.19
I work in an acute hospital setting. Young people are often transferred straight from acute care to nursing home care, often in the early stages after a life changing diagnosis. There is a need for interim care where rehab is continued, where their long-term needs and abilities can be determined.	6	4.14
Plans for future unmet need, particularly for those with progressive neurological diseases	6	4.11
More support in rural areas for young people	8	4.09
The development of a sustainable income stream to meet the needs of young people with high-level nursing needs into the future	2	3.95
Utilise the dollars allocated more quickly and efficiently - many states are very slow to get things moving and many remain in inappropriate accommodation	2	3.94
The limited number of actual and available places for younger people requiring full nursing care needs to be acknowledged and the path made easier to ensure people's needs are being met	10	3.94

Government perspective: top 10 statements

Statement	Original Cluster	Importance
A closer collaboration between service systems, for example, complex health, HACC and government working together rather than services opting out once someone has a package of support	4	4.58
A focus on preventing admission to nursing homes (RAC)	3	4.42
Commitment by all stakeholders to continue the initiative	8	4.18
Develop individualised accommodation and support models	1	4.09
Improved relationship between health and disability services	4	4.08
Disability services are still finding out about young people at risk of admission very late on. This makes successful planning to avoid admission very difficult. Better relationships with the health-care system are much needed to avoid these situations	5	4.05
Commitment to support people with complex care in the community	2	3.96
More in-home support for people prior to or act risk of entry to RAC	3	3.95

Appendix B
Plexus Consulting's Concept Mapping Report

Shaping the Future Today

Report on Concept Mapping Component

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The 'Shaping the Future Today' workshop

From July 2006, Commonwealth, State and Territory governments entered into an agreement referred to as '**The national COAG initiative for Young People in Nursing Homes**'. Under this initiative a number of substantial programs have been implemented. These programs include:

- offering younger people with disabilities in residential aged care homes a care needs assessment;
- negotiating and providing appropriate alternative long-term care options, where it can be made available and this is what clients choose;
- developing and establishing new services and care options, including improved services within nursing homes; and
- reducing future admissions of younger people with disabilities to residential aged care.

The Shaping the Future Today workshop was held on the 19th and 20th of August, 2008 at the Moonee Valley Racecourse Convention Centre. Its purpose is summarised in its subtitle, "Reviewing the national COAG initiative for Young People in Nursing Homes". The workshop was attended by over 200 people from representing consumers, service providers, advocacy organisations and governments.

A major component of the workshop was undertaking a concept mapping process to obtain feedback from al groups about their perceptions of required future actions if the initiative is to meet its objectives. This report presents the outcomes of that process.

Methodology

The methodology that was used for the workshop was a modification of an established technique called 'concept mapping'. The approach used was a new innovation that has never previously been applied. The methodology is presented in two sections; first is a summary of the standard approach to concept mapping; second is a description of the approach used for this workshop, highlighting differences from the standard methodology.

- *Standard concept mapping methodology*

Concept mapping is an enhanced brainstorming method that seeks to:

a. **Identify the broadest possible range of issues around a particular topic, and**
b. **Organise the ideas identified into a single conceptual framework that does justice to all the distinctions and shades of meaning that the group members see as important**
c. **Present this in a pictorial diagram that shows the main relationships between the categories of ideas that were developed.**

The Concept Mapping System is a process, and uses software, developed by William Trochim in the 1980s.[3] This process differs from other concept mapping processes in that it uses a computer to try and integrate the thinking of **every individual member of the group** in the development of categories. Other processes for concept mapping tend to create winners and losers in terms of how the concepts end up being organised (depending on who is loudest and most forceful in the group).
The process involves three stages.

Concept mapping stage 1: Brainstorming and generating a representative list of statements
In the first stage participants individually list as many ideas as they wish in response to a 'seeding statement' (see next section for the workshop seeding statement).
These ideas were then shared with the group in a process based on the nominal group technique.

Concept mapping stage 2: Sorting and rating
The statements are typed into a computer and printed onto small slips of paper (cards). Each participant is given a full set of statements printed onto cards and is then asked to sort the cards into piles "according to any system that makes sense to you". Participants do this as individuals. They are also asked to give a name to each pile that indicates what the pile is about.

In addition participants are given a list of the statements and asked to rate them according to one or more criteria (in this workshop the criteria was 'importance').

Concept mapping stage 3: Analysis and presentation of results
The data from the participants sorting and rating tasks is entered into a computer and this produces 2-dimensional maps summarising the ideas and the way participants sorted them. The way in which the software produces the maps is imperfect and groups are given an opportunity to refine the maps. They are also asked to agree on a name for each cluster of statements.

- *Concept mapping methodology for this workshop*

Concept mapping is usually undertaken with one group of six to sixteen people. For the purposes of the Shaping the Future Today workshop we wee seeking to involve over 200

[3] Trochim, W. (1989). An introduction to concept mapping for planning and evaluation. Evaluation and Program Planning, 12(1), 1-16.
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Trochim, W., Cook, J., & Setze, R. (1994). Using concept mapping to develop a conceptual framework of staff's views of a supported employment program for persons with severe mental illness. Consulting and Clinical Psychology, 62 (4) p.766-775.
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Trochim, W., Milstein, B., Wood, B., Jackson, S., & Pressler, V. (2004). Setting objectives for community and systems change: An application of concept mapping for planning a statewide health improvement initiative. Health Promotion Practice, 5(1), 8-19.
Trochim, W. and Kane, M (2005). Concept mapping: An introduction to structured conceptualization in health care. International Journal for Quality in Health Care, 17, 3, June 2005, 187-191.

people representing a number of stakeholder groups. This required substantial modifications to the normal process. These are discussed in relation to four stages, a pre-workshop stage of assigning people to groups and obtaining an initial list of ideas, and then the three stages of concept mapping.

Pre-workshop: Assigning people to groups and obtaining an initial list of ideas

As people registered for the workshop, the organisers classified them as consumers or consumer representatives, service providers or government representatives based on the organisation that they were coming from. The boundary between the three groups is by no means hard and fast particularly for advocacy organisations that have both consumer representation and service delivery functions. If there was more than one representative from such an organisation some were assigned to each of the consumer and provider groups. One result is that, while there were many 'true' consumers in the consumer group there were also may professional who have an advocacy role for consumers.

Registrants were sent a PDF form by email (or by mail) which they could fill in and return by email or print and fax back. The form indicated whether they were in he consumer, provider or government group. (A sample form is attached as **Attachment A**.) The form provided space for registrants to provide up to 12 ideas in response to the following instructions:

> On the next page please list up to 12 ideas in response to the following statement:
>
> *Given that the COAG initiative has been conceived as a first step to get young people out of nursing homes, what does the initiative need to do in the next 2 ½ years to achieve its potential and meet the COAG's stated objectives?*
>
> It is okay to give your ideas in any way that suits you, they may be:
>
> - **As broad or as specific as you like**
> - **Problems that need solving**
> - **Specific actions that you think need to be taken.**

The italicised statement is the 'seeding statement' for the concept mapping activity.

All responses received prior to the workshop were collated for use during the workshop. In addition a secondary process was undertaken to obtain ideas from those who were unable to provide them prior to the workshop. A brief from was developed for them to list ideas at the time of registration (**Attachment B**), these were immediately entered and added to the master lists of statements.

Concept mapping stage 1: Brainstorming and generating a representative list of statements

Clearly the process described above replaced most of the initial brainstorming. This process led to a master list of statements that included 240 statements from consumers, 130 from providers and 19 from government representatives.

It was necessary to reduce the numbers of statements for the consumer and provider groups to a number that was workable for the concept mapping process. The full lists of statements are, however, provided as **Attachments C and D**. Table 1 shows the initial numbers f statements, the reduced number and also the number of people who completed importance ratings sheets on the reduced list.

Table 1: Numbers of statements and ratings for participant groups

Group	Initial statements	Reduced statement list	Importance ratings
Consumers	240	73	48
Providers	130	53	67
Government	19	19	35

The reduction of items was done by the consultants. The main basis for omitting items was if there were other items with similar content. Also items that focused on particular disease or impairment groups (e.g. acquired brain injury, Huntington's chorea) were omitted if there was a more general statement that covered the same need. A few disease specific statements were included. The reason for omitting most disease specific statements is that experience has shown that such statements are likely to end up in a group for 'specific diseases' and the content is likely to be lost.[4]

Concept mapping stage 2: Sorting and rating

As per the standard concept mapping method, the statements were typed into a computer and printed onto small slips of paper (cards). In addition ratings sheets were prepared to enable participants to rate the importance of each issue on the following scale:

> ***Rate the statements according to the IMPORTANCE of that issue in meeting the COAG objectives for Young People in Nursing Homes***
> 1 = Unimportant
> 2 = Moderately important
> 3 = Very important
> 4 = Extremely important
> 5 = Essential first priority (Should be one of the absolute first priorities ahead of most other statements on this list).

Prior to the workshop 15 people from each group were identified by the workshop organisers to undertake the sorting task. This occurred during an extended lunch break on the first day.

Each participant was given a full set of statements printed onto cards and was then asked to sort the cards into piles "according to any system that makes sense to you". Participants did this as individuals. They were also asked to give a name to each pile that indicated what the pile was about.

[4] As noted the full list of statements is available in Attachments C and D. The reduced lists are presented in the outcomes of the concept mapping in Table 2, Table 6 and Table 10.

Immediately prior to the afternoon tea break all participants were given an importance ratings sheet according to their group. The number of ratings received is shown in Table 1.

Concept mapping stage 3: Analysis and presentation of results

During the afternoon and night between the two days of the workshop all of the sorting and rating data was entered into the Concept Systems software and the maps presented in this table were produced. Names were given to the clusters by the consultants based on the main idea(s) that underlay most of the items within the cluster. Normally this process would be undertaken by the groups themselves but in lieu of this the consultants sought to use names drawn from the labels that participants who undertook the sorting tasked used for their piles.

The maps were presented to the full workshop in a plenary presentation on the morning of the second day. There was opportunity for questions and feedback and some refinement of the mps occurred as a result.

Brainstorming concrete actions for the next six months

On the morning of the first day the concept mapping process was outlined to all participants in a plenary session. At the same time participants were given an opportunity to complete form listing 'priority actions for the next six months'. The results of this activity are presented in Table 5, Table 9 and Table 13.

- *Interpreting concept maps*

The following two diagrams give a brief overview of the elements of a concept map.

Figure 1: Item and cluster numbers on concept maps

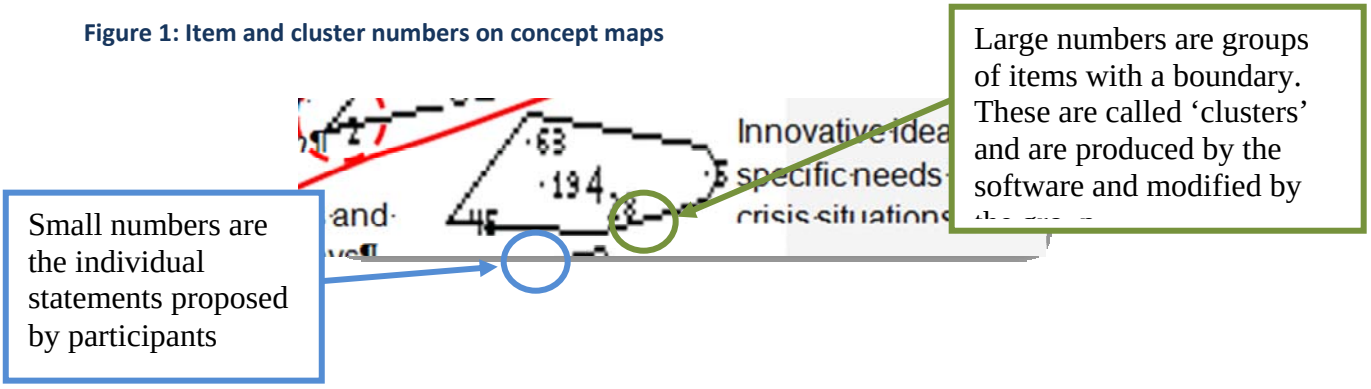
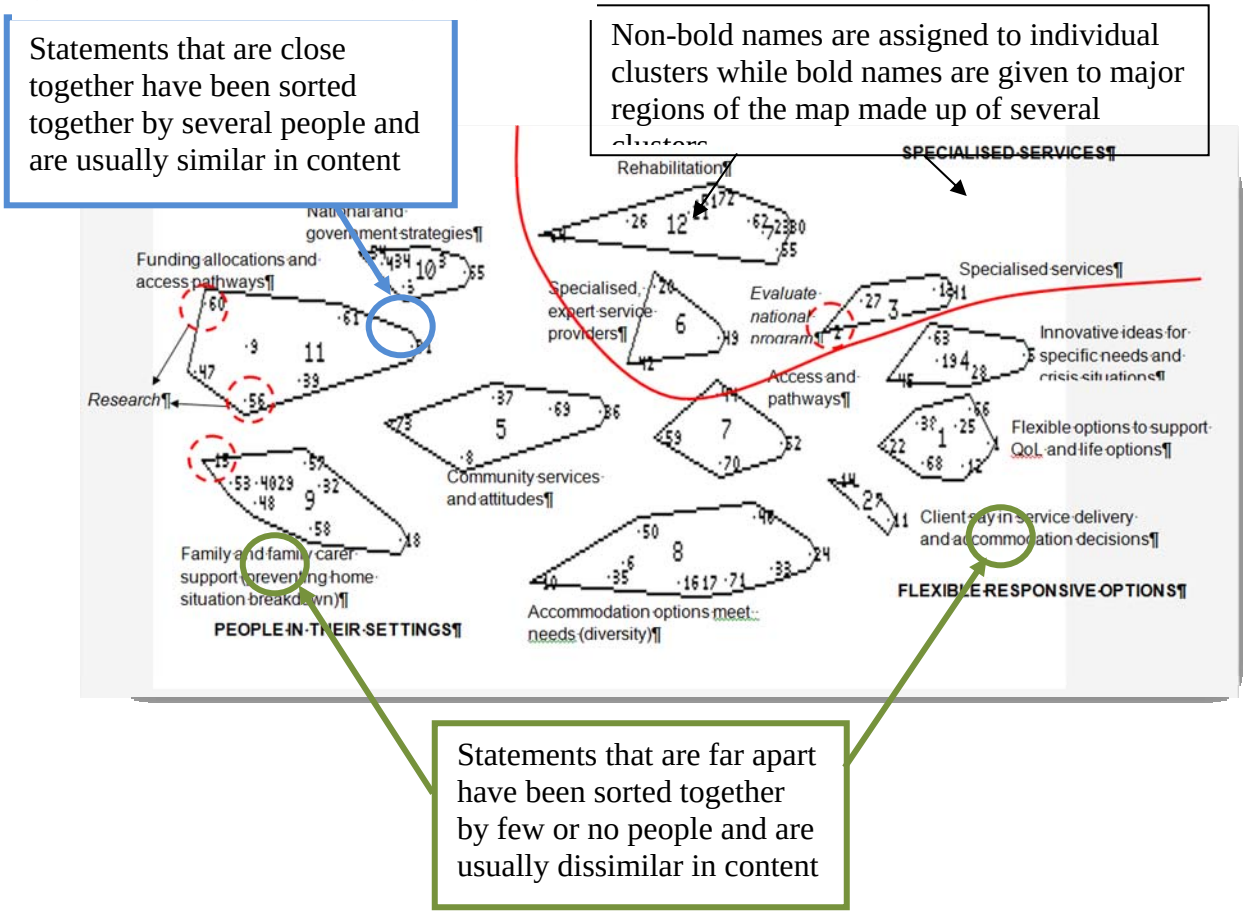


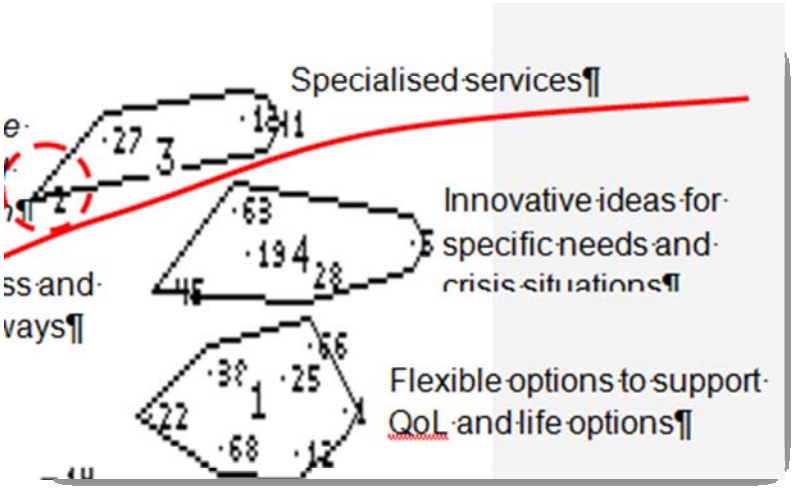
Figure 2: What is what on the concept map



Clusters can form in one of three ways:

1. **They correspond directly to piles developed by some of the group members**

2. **They represent overlaps between two more basic clusters and can be interpreted as aspects of one cluster that have a bearing on a nearby cluster. (e.g. in the picture below the cluster labelled 'innovative ideas for specific needs and crisis situations' can be viewed as subset of both the cluster below it and the cluster above it, a sunset that overlaps and links both)**
3.



4. **Some clusters are formed because they contain ideas that overlap or depend upon any of the other clusters. Sometimes it is difficult to identify what these items have in common other than that they are higher order items that seem to relate to many of the clusters. The clusters at the centre of the map are often like this Common higher order concepts found at the centre of maps are things like 'choice', 'self-determination', 'responsiveness to individual need', 'quality'.**

In examining a concept map it is usually useful to select a cluster near the edge and work clockwise or anti-clockwise around the edge noting how the clusters relate to each other and, in particular, noting any clusters that appear to represent an overlap between two adjacent clusters. While these 'overlap' clusters are often harder to interpret and name they are important as they often add most to the sophistication of our understanding of the question we are examining and to our understanding of how they are connected.

In examining the clusters it is important to keep referring to the lists of items that make up the clusters (Table 2, Table 6 and Table 10).

Once you are familiar the clusters around the edge and any main groups of clusters it is time to consider clusters closer to the centre of the map. A discussed above these are often the most complex and the most 'high order' containing statements that relate to, or depend upon, many of the clusters around the edge.

In the importance ratings maps, clusters with a greater number of concentric circles have higher importance ratings.

- *Consumer group results*

While the consumer group and provider group were approximately equal in size there was substantially more statements from the consumer group. The initial list of 240 statements was reduced to 73. The following tables and results present their results. At the end of this section is the consultants' interpretation of the most significant outcomes. It is important, however, for readers to examine the cluster lists and maps to make their own interpretations.

It is important to remember that for this workshop the 'consumer' group included people from agencies that have a consumer advocacy and representation focus to their work.

Table 2: Statements by cluster for consumer group

	Statement	Clus	Import
1	**Flexible options to support QoL and life options**		**3.6**
1	Planning documents need to be "living" and flexible to meet the changing needs of the person.	1	3.4
12	Assessment for this under 65 age group should be based on needs rather than age so that the most appropriate level of care and support be provided. Currently there are people in the 50 – 65 age bracket who are in "no man's land"?	1	4.1
22	Create targeted programs that strengthen life options for young people with disabilities in the community.	1	3.5
25	Develop a life time care approach to disability support based on need not age	1	4.1
38	Ensure that advocates are included in all YPIRAC programs - whether moving out or remaining in.	1	3.6
66	The initiative needs to trial new and protected pathways to trial to stop young people so we can learn new things not just battle with the old things	1	3.0
68	These residents are entitled to a 'social life'. There must be a program that fulfils these requirements.	1	3.6
2	**Client say in service delivery and accommodation decisions**		**3.8**
11	Ask the younger people what they want	2	4.1
14	Assist with the development of programs that strengthen client and family capacity to manage their own care and the options available to them	2	3.7
67	The residents MUST have a say in who the carers are entering their home. I'm sure you have a day who comes into your home, don't you?	2	3.5
3	**Specialised services**		**3.9**
13	Assessments to be carried out by people experienced in the disability field rather than aged care where often their knowledge of particular disabilities is very limited.	3	3.9
27	Develop a new service model that is locally based and is automatically activated on discharge from the health system that walks beside an individual and their family for life. (TAC support coordinator model for non compensable client group)	3	4.1
41	Establish specialised teams to complete assessment, transition and successfully relocate individuals. This team would provide end to end case coordination including the provision of training and program implementation.	3	3.6

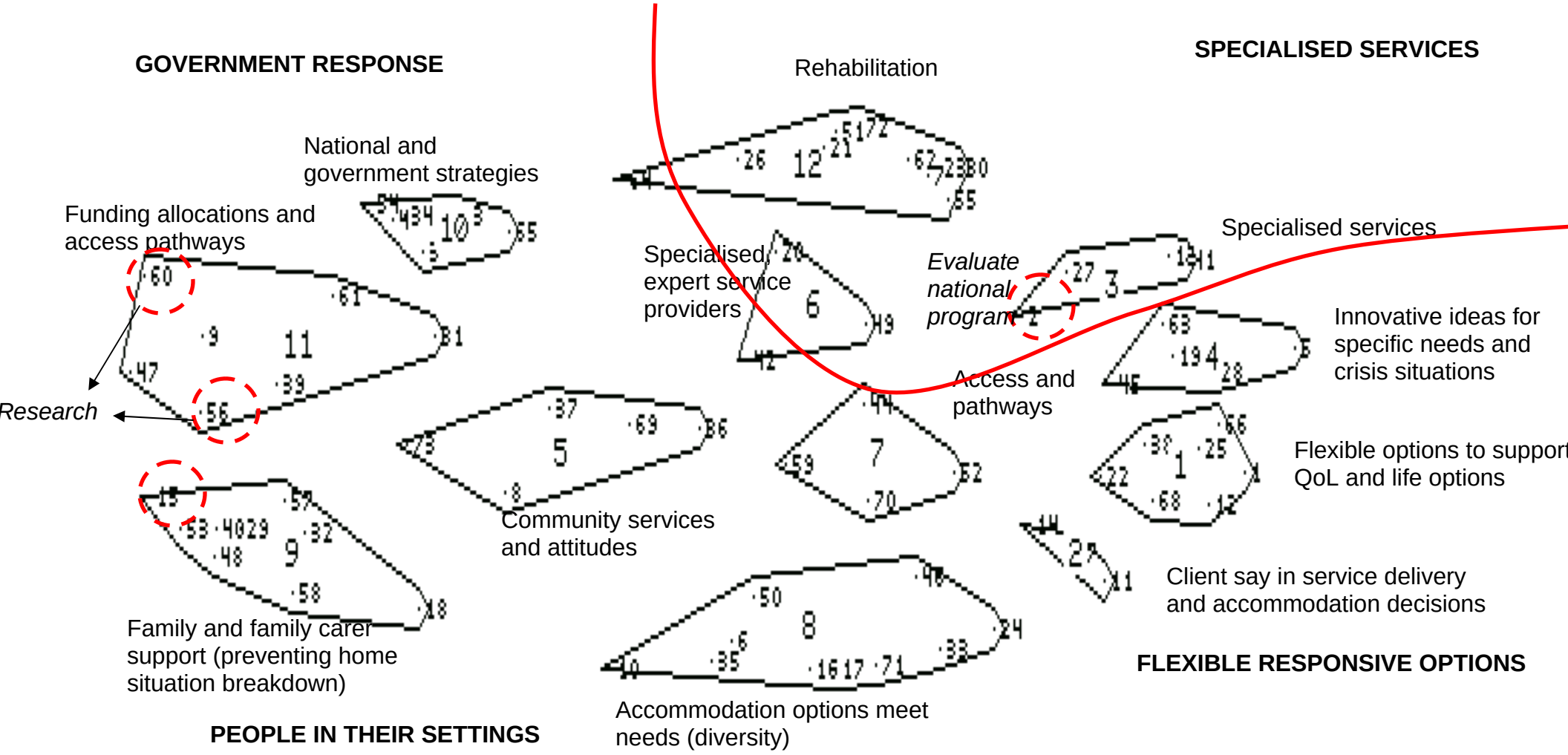
	Statement	Clus	Import
3b	**Evaluate national program**		**3.2**
2	A formal and transparent evaluation of the initiative - where is it up to? What are Government expectations from this initiative	3b	3.2
4	**Innovative ideas for specific needs and crisis situations**		**3.3**
5	A review of nursing home admissions needs to happen quickly. This should look at how people are getting into nursing homes in the first place. Is an ACAT team recommending these placements?	4	3.4
19	Community Integration Program similar to model in Adelaide set up by Roger Rees which utilises community resources eg university students, retired people who are trained as mentors	4	3.1
28	Develop an automatic alert system that is activated as soon as an ACAS approval for residential care is granted for a person under 65.	4	3.4
45	Improved services for young people with mental health issues to prevent potential brain injury from drug and alcohol use and/or suicide attempts.	4	3.2
63	"Specific and robust benchmarks need to be created as part of the agreement. These should include timeframes for implementation.	4	3.6
5	**Community services and attitudes**		**3.9**
8	An increase in the availability of community nursing services, to allow people to remain in the community, in their own home.	5	3.9
36	Ensure that additional support is provided to identify and assist the “divert” group – people living within the community who are at risk of early admission to residential aged care facilities	5	3.7
37	"Ensure that adequate support is available to the complex care clients who often are subjects of admission to aged care because of pre-existing co-morbidities such as mental health problems or substance abuse, or do not have functional informal support within the community.	5	3.6
69	Things take so long to get response, having to go through bureaucrats passing the buck	5	3.8
73	Continue to maintain general public awareness (in a relentless manner) of the issues associated with this major concern	5	4.3
6	**Specialised expert service providers**		**3.8**
20	Consolidate service providers to enable specialist training, allowing staff to feel valued supported and involved.	6	3.6
42	Genuinely collaborate with Health to establish a positive partnership in working to reduce premature admission to age care direct from the acute and sub acute sectors	6	3.8
49	It is impossible to get support workers trained for people with high support needs. Yet we still want to live life to the full. We need to train workers to support people with high needs better.	6	4.0
7	**Access and pathways**		**3.6**
44	Improved co-ordination and networking opportunity between direct care providers (e.g. accommodation providers and in-home support providers, and specialist services such as allied health, nursing, medical, primary care….	7	3.3
52	More day program options for persons with high support needs ABI and residing at home	7	3.8
59	Provide clear, transparent pathways for people to navigate, reduce ambiguity	7	3.6

	Statement	Clus	Import
70	Transition issues - ensure residents have access to new equipment, visit the new community and link with members of that community before moving.	7	3.7
8	**Accommodation options meet needs (diversity)**		**3.7**
6	Accommodation specifically designed with an appropriate (and appropriately funded!!) support model for people with very challenging behaviours and/or dual diagnosis of neurological condition and psychiatric…	8	4.1
10	As this process will take a long time- you need to look at what supports for younger people while in Nursing Homes	8	3.6
16	Becoming a 'community member' - the new home should be easily accessible for all visitors, and within 'wheeling' distance of community services, e.g. cafe, shops etc.	8	3.7
17	Begin to integrate high care needs young people in clusters in normal residential blocks or apartments	8	3.5
24	Develop a continuum of appropriate accommodation options - not one size fits all models!	8	4.0
33	Don't build accommodation and put people into it. Ask people what they want and work with them to make it happen.	8	3.9
35	Embrace diversity in planning for long-term supported accommodation. Options should reflect the diversity of lifestyle choices of those who will be supported.	8	3.7
46	Include all three tiers of government with family/community members and potential residents (where possible) to plan/investigate supported accommodation options, with maximum resident control, with the Pathways Plan.	8	3.4
50	All possibilities for reducing dependence should be explored - e.g. special mattresses, door opening and other devices, communication and emergency contact systems etc.	8	3.6
71	Young people need to be in a house with similar age interests for stimulation	8	3.7
9	**Family and family carer support (preventing home situation breakdown)**		**3.5**
15	Become proactive and preventative by supporting those people who are at home currently and may not be at immenint risk but can very easily become at risk in the blink of an eye.	9	3.7
18	Cheap affordable holiday house to rent that is fully accessible with equipment etc at beach location	9	2.9
29	Develop appropriate supports for all members of the family affected by the young persons injury/illness. e.g. we need to support the children of, the siblings of, the parents of, the grandparents, the husbands, the wives etc	9	3.3
32	Develop peer support programs and ways of disseminating information for families who care for people with high support needs at home. Acknowledge the strengths and expertise of family carers.	9	3.8
40	Establish family counselling/mediation centres to facilitate group or individual counselling to assist families to deal with difficult challenging issues.	9	3.5
48	Involve families as partners in the care of their loved ones, not the sole providers of that care	9	3.7
53	More effective ways of keeping families informed so that their expectations are realistic. Currently many Government brochures don't indicate the reality of the situations.	9	3.4
57	Offer training and learning opportunities for carers to better provide for young people in their care.	9	3.8
58	Provide appropriate respite opportunities for carers, enabling a weekend to three nights break	9	3.9

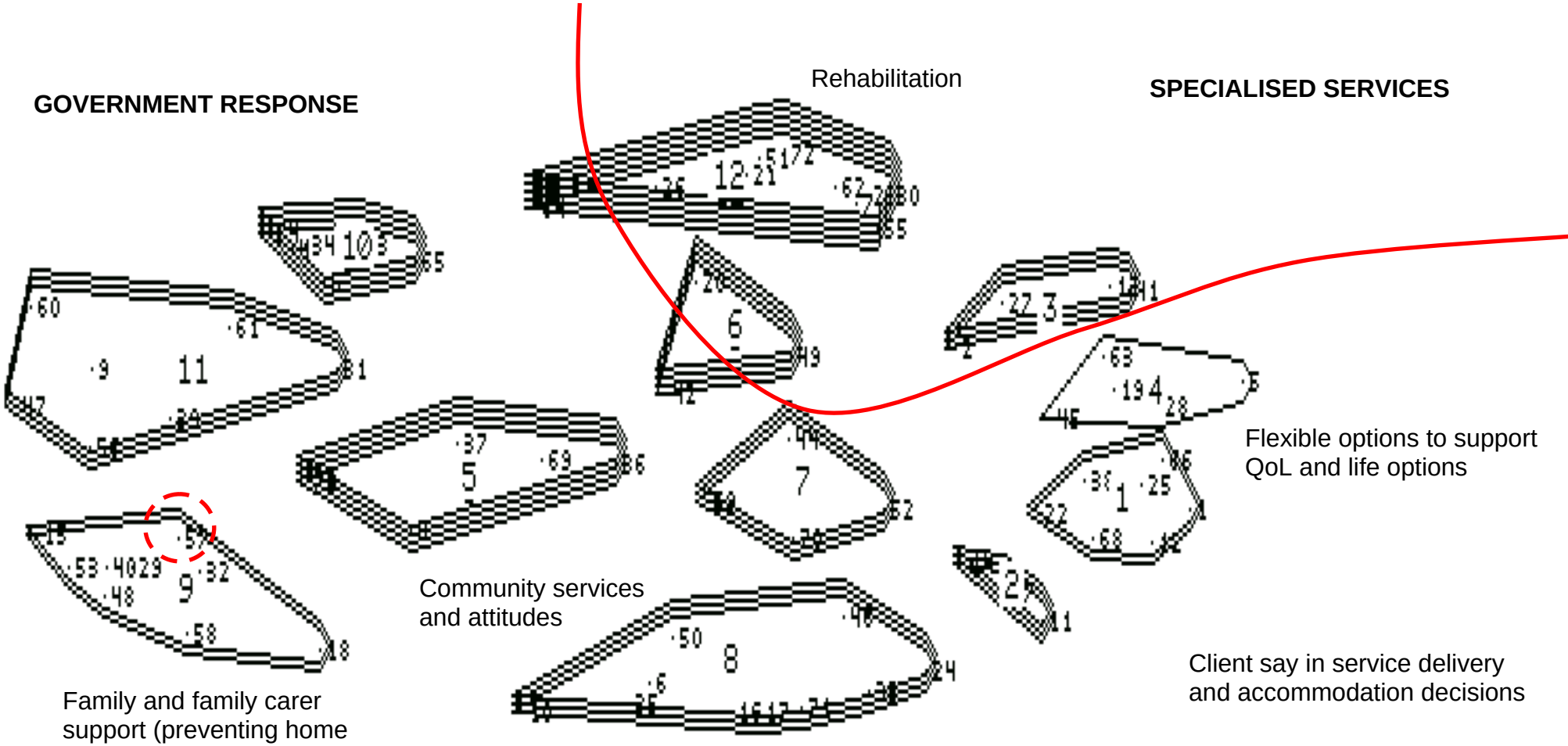
	Statement	Clus	Import
	on routine basis i.e. 6 to 8 weeks.		
10	**National and government strategies**		**3.8**
3	A group to oversee the COAG process, appropriately funded	10	3.1
4	A more streamlined "one shop stop" to accessing Government services and information which is currently very time consuming, is not flexible and often results in getting nowhere. Currently is a maze.	10	3.8
34	Drastically improve funding for disability services	10	4.5
43	Health fund options that would allow insurance for non acute care cover. Eg ABI The way insurance tends to work this would probably be of no use after the fact but may assist others	10	3.1
54	National No Fault Insurance Scheme for all severe injuries, particularly catastrophic brain injury (not just motor accidents) based on Victorian TAC model and/or the NZ model (ACC)	10	4.5
65	The carers that work in these places must be paid decent wages. An increase in wages could give staff the incentive to stay at a place longer	10	4.1
11	**Funding allocations and access pathways**		**3.8**
9	Appropriate advocacy funding to prevent young people re entering aged care places.	11	3.7
31	"Develop pathways within funded programs (crossing state and federal boundaries) that make it easy for consumers to CHOOSE the option and level of support they desire	11	3.7
39	Ensure that funding is allocated for a range of accommodation options (both in built design and support levels) that provide alternatives within the community	11	3.9
47	Increase Carers Allowance to assist in offsetting costs when parent/parents give up or reduce their hours of paid employment to care for young person.	11	4.1
61	Recognition of the impact of cost of care and support on individuals' disposable income. How can inclusion be achieved if a person has no money left even to buy a coffee regularly, let alone pursue more expensive activities	11	3.8
11 b	**Research**		**3.5**
56	New frontiers are emerging in our knowledge and understanding of the brain and its capacity to make new connections. Research and evaluation with YP and families involved must be part of the way ahead.	11b	3.6
60	Provide funding for qualitative research with young people with high support needs and their families. Publish their stories to raise awareness, develop contacts for peer support and build a community of hope.	11b	3.4
12	**Rehabilitation**		**4.1**
7	All severe TBI patients, once stabilised in acute hospital to be properly assessed for rehabilitation in acute rehabilitation setting	12	4.1
21	Convene a national working party on development of rehab services for young people with catastrophic injury. Include family representatives in the working party.	12	3.9
23	Daily rehabilitation and physiotherapy is a must. It is so important that the people who cannot move around receive consistent and ongoing therapy.	12	4.0
26	Develop a national and properly funded rehabilitation strategy that delivers for recovery from injury and maintenance of health and well being over the long term	12	4.2

	Statement	Clus	Import
30	Develop fast, rehab responses for young people with catastrophic injury. Utilise the expertise of those professionals who are experienced in working with this group (eg through Slow to Recover, Vic and internationally). Young people are dying while states, such as Qld refuse to learn from those who are saving these young lives.	12	4.2
51	More and longer term slow stream rehab. services.	12	3.9
55	National rehabilitation program with lifetime cover, based on Victorian TAC model.	12	4.4
62	Rehabilitation is nowhere in this initaitive and it must be. For people with neurological disease, rehab is crucial to maintain your health. yet we can;t access it	12	4.2
64	The best support that governments can give family and carers is to set up and properly fund a national rehabilitation scheme and sufficient supported and integrated accommodation	12	4.2
72	Aim rehab services at improving, as opposed to maintaining client function levels. Aim to attain maximum function	12	3.8

Consumer perspective - cluster map



Consumer perspective – importance rating map



Consumer perspective ratings

Table 3 presents the list of clusters with their importance rating presented in order of importance while Table 4 lists the 20 statements with the highest importance rating.

Table 3: Consumer group - clusters in order of importance

Cl Num	Cl Name	Cl Imp
12	Rehabilitation	4.1
3	Specialised services	3.9
5	Community services and attitudes	3.9
10	National and government strategies	3.8
11	Funding allocations and access pathways	3.8
6	Specialised expert service providers	3.8
2	Client say in service delivery and accommodation decisions	3.8
8	Accommodation options meet needs (diversity)	3.7
7	Access and pathways	3.6
1	Flexible options to support QoL and life options	3.6
9	Family and family carer support (preventing home situation breakdown)	3.5
11b	Research	3.5
4	Innovative ideas for specific needs and crisis situations	3.3
3b	Evaluate national program	3.2

Table 4: Consumer group - 20 most important statements

	Statement	Clus	Imp
54	National No Fault Insurance Scheme for all severe injuries, particularly catastrophic brain injury (not just motor accidents) based on Victorian TAC model and/or the NZ model (ACC)	10	4.49
34	Drastically improve funding for disability services	10	4.47
55	National rehabilitation program with lifetime cover, based on Victorian TAC model.	12	4.37
73	Continue to maintain general public awareness (in a relentless manner) of the issues associated with this major concern	5	4.28
26	Develop a national and properly funded rehabilitation strategy that delivers for recovery from injury and maintenance of health and well being over the long term	12	4.23
30	Develop fast, rehab responses for young people with catastrophic injury.	12	4.22

	Statement	Clus	Imp
	Utilise the expertise of those professionals who are experienced in working with this group (eg through Slow to Recover, Vic and internationally). Young people are dying while states, such as Qld refuse to learn from those who are saving these young lives.		
64	The best support that governments can give family and carers is to set up and properly fund a national rehabilitation scheme and sufficient supported and integrated accommodation	12	4.21
62	Rehabilitation is nowhere in this initaitive and it must be. For people with neurological disease, rehab is crucial to maintain your health. yet we can;t access it	12	4.19
6	Accommodation specifically designed with an appropriate (and appropriately funded!!) support model for people with very challenging behaviours and/or dual diagnosis of neurological condition and psychiatric…	8	4.13
47	Increase Carers Allowance to assist in offsetting costs when parent/parents give up or reduce their hours of paid employment to care for young person.	11	4.12
12	Assessment for this under 65 age group should be based on needs rather than age so that the most appropriate level of care and support be provided. Currently there are people in the 50 – 65 age bracket who are in “no man’s land”?	1	4.11
11	Ask the younger people what they want	2	4.11
27	Develop a new service model that is locally based and is automatically activated on discharge from the health system that walks beside an individual and their family for life. (TAC support coordinator model for non compensable client group)	3	4.06
65	The carers that work in these places must be paid decent wages. An increase in wages could give staff the incentive to stay at a place longer	10	4.06
25	Develop a life time care approach to disability support based on need not age	1	4.05
7	All severe TBI patients, once stabilised in acute hospital to be properly assessed for rehabilitation in acute rehabilitation setting	12	4.05
49	It is impossible to get support workers trained for people with high support needs. Yet we still want to live life to the full. We need to train workers to support people with high needs better.	6	4.03
23	Daily rehabilitation and physiotherapy is a must. It is so important that the people who cannot move around receive consistent and ongoing therapy.	12	4.03
24	Develop a continuum of appropriate accommodation options - not one size fits all models!	8	4
33	Don’t build accommodation and put people into it. Ask people what they want and work with them to make it happen.	8	3.94

Table 5 lists ideas presented by members of the consumer group in response to a request to list priorities for action for the next six months. While action items were requested many participants chose to list priority concerns but with no specific action identified.

Table 5: Consumer group - recommended actions for the next six months

Consumer group – recommended actions for next six months
A lot of waste of funds with bureaucracy
Accommodation – continuum of options must be individualised
Age limits for services are an obstacle / need to be dissolved
Allow people that have currently been identified as wanting alternative accommodation to be engaged in the planning and development process right from the start
Appropriate case management
Assessment of individuals eligibility needs to be independent and outcomes reported back to client/service provider
Assessment tools are different between states
Better disposal of information, cases being flagged
Case management availability
Case managers are overloaded
Change on future admissions
Cheapest tender is not necessarily the best
Choices must be real and valid
Clients need to be (where possible) relocated to more care appropriate accommodation
COAG initiative must look at people aged 50+
Communication and dissemination of information across Australian regarding what practical activities the YPINH alliance has set up
Communication to the young person in residential care to be accessible ie: understandable and timely
Community services to be pro-active and work / assist the participants etc
Consider why the family/carers need to visit the residential facility daily to ensure care needs are met
Consistency by states and within states
Dedicated funding and dedicated responsibility for a dept not spread through a number of dept – health, disability, centrelink etc
Definition of needs changes between jurisdictions

Definitive process for putting forward a program, currently no process – transparency
Develop a more structured method identifying those at risk of being admitted to RAC (screening methods)
Develop life time funding with ability to review and change depending on client changes but not to have to reapply through funding process
Development of transition / continuing care options to bridge gap between when person ready to leave acute care but needing more time
Do not limit ideas generation to those who say what is possible in what can be funded
Early identification of ppl entering nursing homes
Eg: Kingston step down program, need to include accommodation
Every person (especially young persons) should have access to rehab
Exploring interim accommodation options that could be offered to people whilst waiting for new options which will take a bit longer to develop
Focus on prevention
Follow up with the young person in the nursing home
For there to be realistic allocation of resources required by community organisations for both service development and long term sustainability. Currently hidden costs not recognised
From Queensland perspective – no post acute discharge options – slow to recover, 2 facilities based in Brisbane
Funding limitations – need funding models that cover all phases eg: crisis, rehab, transition – longer term care
Funding to be on a level to assist case managers, advocates, aged care facilities that is to improve not be a disadvantage
Future plan as opposed to crisis response
Identification of / mapping of service gaps (not just in accommodation options)
Identify client needs and assist participant / equal level or means of disability
Ie: YPIRAC clients moved from independent living to group living / aged care facilities due to behaviour (as in clients to keep independence)
Inconsistent assessments
Increase focus on diversions prior to entering aged care ie: faster assessment and interventions in acute phases, in Victoria this doesn't seem to be the focus at the moment.
Increased education for staff regarding specific care needs

Issue of interpretation of risk of people entering nursing homes
Lack of infrastructure with housing and lack of government support
Limited options currently support in transition phase in nursing homes while waiting group home accommodation – provide services in nursing homes
Link between health and disability
Liverpool transition services – 90 % discharge to family or to nursing homes
Longevity of program – ensure that beds aren't blocked and then become aged care facilities - ensure that in reach/enhancement programs continue (recurrent funding)
More collaboration needed between organisations nationally
More collaboration required between acute and community
More information provided to residential aged care providers about the assessment process (how to get an assessment for a young person) and what can be provided in terms of enhancement – and how to access this
National campaign to put disability at the forefront of the community in the top 1-5 of public policy
Need for changing attitudes about being creative, harnessing the energy of the federal minister
Need for purpose built facilities with specialist trained staff
Need someone to advocate for people very early in their journey in disability
Need to collate all of ideas of what is possible
Need to determine what has already been done
Need to look at overcoming situations to keep people from entering nursing homes eg: case where resident of group home needs to move to nursing home because no availability of nurse to do injection
Neurodegenerative disability – mechanisms to respond to neurodegenerative group – flexibility and responsiveness to client needs and changes - improve / deteriorating
Next 2-6 months – fundamental human needs not being met – food, warmth, cleanliness, aids – federal / state funding debate
No fault insurance to cover all disability – govt agreement needed to make it happen
Ongoing case management
Open communication about what is going on between health, government, service providers etc
Opportunities between public and private sector
Partition of area of facility to specialise in care for young people

People with decision making power must spend a day with a person in a nursing home
Perhaps the money (funding) does not need to sit with the state government and may be better managed by a different organisation as there are issues with bureaucracy.
Power in this issue must be shared in dialogue – in a two way
Priority should be to find out what to find not find the solutions then fund them – need to ask people what do they want
Program boundaries
Provision/address person centred need particularly re: rehab
Receiving funding through DSQ is very time consuming. There is a lot of uncertainty as to when /if finding available
Refocus on empowerment for the individuals and families from early on in the development of services, rather than selecting the people who will fit in that service. Individuals and families need more say and services need to be more transparent
Resources not only issue, models / policy need to be reviewed
Respite – continuum of options
Service development for 50-60 years old
Services for indigenous people and CALD people need to be developed, the initiative needs to respond to diversity
Significant gap between hospital needs (urgent discharge) and DSC acceptance of funding eg: 5 months - need transitional funding and timeliness of short term funding
Specialisation – re: debate ie: the need for specialist needs to stop now, specialist's responses are needed
State government to be included but should not be the only organisation as the process occurs very slowly with approvals, assessments etc
Stop and review what is happening in other states – what works !! / what doesn't !! – State benchmarking
Stop the neglect – many examples of people in pain/high mortality rates
The plight of the over 50's need to be thought a lot more about
There are ideas but nothing linking to them
To design service models with people that is based on their assessment and identified individual need rather than developing a service in the absence of the people who will use the service
Transition form hospital to step down and then to longer term disability
Transitional care between health, rehab, and longer term disability services / care

Transparent approach on what has been spent, Report from all states and commonwealth
Two separate pools of funding suggested – one for the individuals and the other for the management of funds.
Workforce and flexibility - lack of people and services (long term)

Summary of consumer group results

The main feature of the results from the consumer group is their desire for a universal approach to provision of rehabilitation and service support that does not depend on the cause of a person's disability. This is clear from the content of the items in the two most important clusters (rehabilitation and special services) and of the most important items. (*E.g. the most important item is National No Fault Insurance Scheme for all severe injuries, particularly catastrophic brain injury (not just motor accidents) based on Victorian TAC model and/or the NZ model (ACC).)*

This result is very similar to the results from the provider group but contrasts markedly with results from the government (see discussion on page 43).

The group of clusters at the top right of the map, that are highlighted as focusing on 'specialist services', are viewed as the most important part of the map. The items in these clusters place a particular emphasis on workforce development.

Cluster 8, at the bottom of the map, focuses on diversity of accommodation options. It is surprising that this cluster didn't rate more highly. Indeed many items in the cluster did rate highly but a couple of options, which related to building special accommodation facilities, are clearly controversial as some people rated them 1 out f 5 with the comment 'NO' marked on their form. On the other hand some participants scored these same items at 5 out of 5.

Cluster 5, 'community services and attitudes' rated very highly as it contains items about services necessary to support people to live in the community.

Overall the map gives the impression that participants believe that most problems would be greatly improved through the provision of:

- **Universal rehabilitation provision**
- **A universal insurance scheme**
- **Programs for workforce and specialised service development.**

- *Provider group results*

The initial list of 130 statements from providers was reduced to 53. The following tables and results present their results. At the end of this section is the consultants' interpretation of the most significant outcomes. It is important, however, for readers to examine the cluster lists and maps to make their own interpretations.

It is important to remember that the demarcation between consumers and providers was blurred in the workshop due to the participation of agencies with ambiguous roles such as advocacy services.

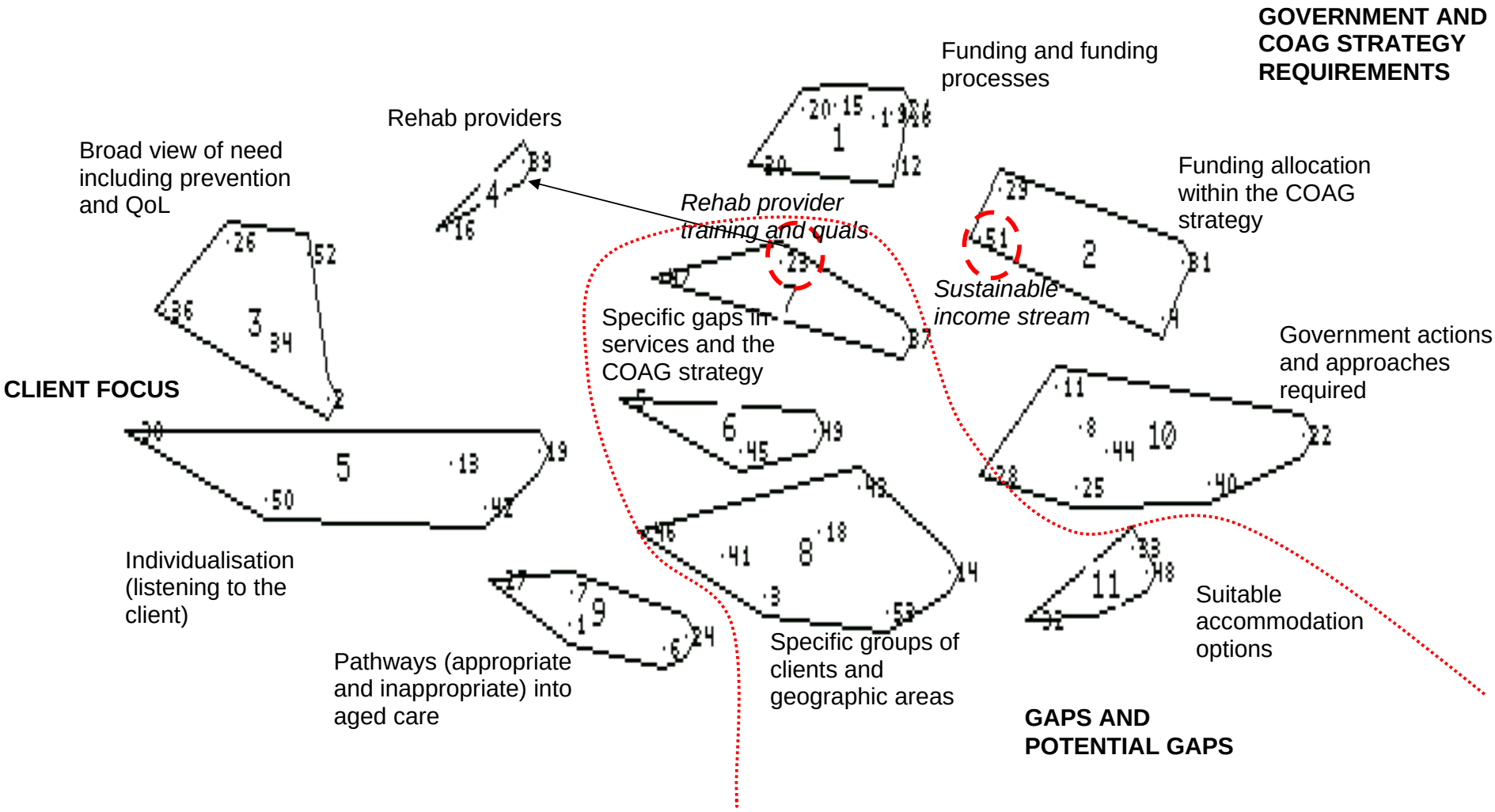
Table 6: Statements by cluster for provider group

	Statement	Clus	Imp
1	**Funding and funding processes**		**3.4**
1	A more efficient process re the Funding for our clients.	1	3.7
9	For the allocated funding and distribution to be managed by an organisation or authority outside of a state government department	1	2.6
10	For there to be realistic allocation of resources required by community sector organisations for both service development and long term sustainability. Currently the hidden costs of new service development are not recognised.	1	3.7
12	Inject more money into the process to ensure objectives are met	1	3.7
15	More funding for recreation.	1	2.9
20	Provide sufficient resources to support purchase of equipment, community access, other items as well as supported accommodation	1	3.9
21	Receiving funding through DSQ is very time consuming. There is also a lot of uncertianty as to when or if funding will be made available. In contrast, the aged care system has been very responsive and the assessment process has been direct and thorough.	1	3.1
30	Utilise the $s to support longer term community rehabilitation options for people who require this.	1	3.7
2	**Funding allocation within the COAG strategy**		**3.6**
4	Ensure as many appropriate providers who lodge tenders have the opportunity to provide services to the target groups, to encourage innovation and broad range of options	2	3.0
29	Utilise the $s allocated more quickly and efficiently - Many states are very slow to get things moving and many people remain in inappropriate accommodation	2	3.9
31	We are hopeful that our clients remaining in an aged care facility will receive additional support. We would like to know when this model of support will commence and whether this support will also be made available to people aged between 51 and 65.	2	3.5
51	The development of a sustainable income stream to meet the needs of young people with high level nursing needs into the future	2	4.0
3	**Broad view of need including prevention and quality of life**		**3.5**
2	Address current situation but also look at prevention of brain injuries	3	2.8
26	The limited availability of suitably trained staff, both attendant care workers and specialist therapy staff such as physiotherapists and occupational therapists who are available and willing to assess and support ypinh.	3	3.7
34	We talk about moving people out of nursing homes as a goal in itself without considering people needs to be close to their families and support networks.	3	3.8
36	Workshops for Carers to help them learn about their clients disabilities and understand them.	3	3.3

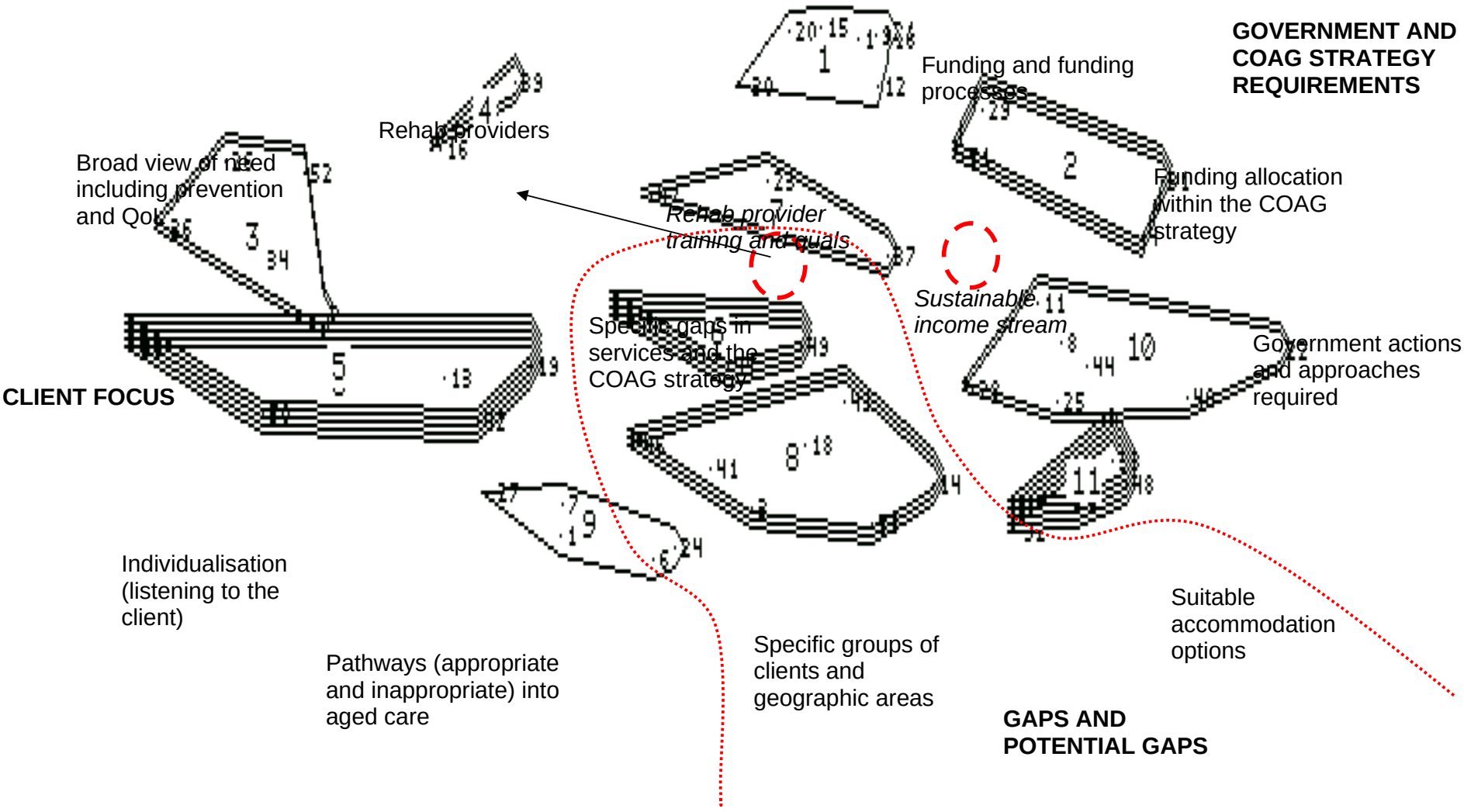
	Statement	Clus	Imp
52	The development of structural / organisational support networks for families/carers so that their capacities to support their family members is sustainable	3	3.8
4	**Rehab providers**		**3.6**
16	More hours for the carers to help their clients rehabilitation process.	4	3.4
39	Access to Allied Health professionals with expertise in this area ie: not limited by cost	4	3.7
5	**Individualisation (listening to the client)**		**3.8**
13	Involve the target group in all processes and stages	5	4.2
19	Provide greater opportunity for a wider range of support services/providers to discuss/submit ideas for different 'model' of providing support based on individual need and preference	5	3.5
38	A commitment for workers to seek and take seriously the young persons and their family, carer knowledge about what accommodation is best for the young persons physical, social, emotional and spiritual wellbeing	5	3.5
42	Coordinated approach – use of multi-disciplinary teams, instead of single providers	5	3.7
50	Quality of life!!!	5	4.2
6	**Specific gaps in services and the COAG strategy**		**3.8**
5	Ensure that assessments are undertaken independently of the Dept / others where there may be the potential for conflict of interest (eg person's current RAC facility) in all states	6	3.1
45	I work in an acute hospital setting, young people are often transferred straight from acute care to nursing home care, often in the early days after the life changing diagnosis. There is a need for interim care where rehab is continued, where ling term needs and abilities can be determined	6	4.1
49	Plan for future unmet meed, particularly for those with progressive neurological diseases	6	4.1
7	**Specific gaps in services and the COAG strategy**		**3.6**
23	That funding models acknowledge the rehabilitation needs of people with an acquired brain injury and not simply their habilitation needs. This may necessitate the development of new qualifications and funding models that are more rehab focused.	7	3.8
37	Extend program to include 50 – 60 years	7	3.5
47	Not a quick fix – must endure	7	3.4
8	**Specific groups of clients and geographic areas**		**3.6**
3	Development of transition/continuing care options to bridge the gap between when a person is ready to leave acute/sub acute hospital but needing more time before ready to engage in "lifetime" planning required by Disability Services	8	3.8
14	It could be useful to explore the possibility of increasing placement options in the acquired brain injury services, which is appropriate for some younger people with Huntington's Disease. At present we only have access to a very limited number of placements (approximately 4 in the state).	8	3.1
18	Younger people with Huntington's Disease present services with unique and complex care needs which need specialplanning.	8	3.3
41	Appropriate for indigenous young people	8	3.9

	Statement	Clus	Imp
43	Create centres of excellence that provides models for the support and potential of YPINH	8	3.5
46	More support in rural areas for young people	8	4.1
53	The need for ongoing multi-disciplinary assessment and reassessment so that care planning, including accommodation needs can be adjusted	8	3.8
9	**Pathways (appropriate and inappropriate) into aged care**		**3.3**
6	Establish entry criteria into nursing homes addressing the age factor therefore having alternative accommodation for people who do not meet the age requirement. For example, only people over the age of 60 are able to enter nursing homes	9	2.6
7	Focus much more on preventative options e. g. ways to prevent people from entering into residential aged care	9	3.9
17	Pathway/services for younger people who do not fit Disability Services eligibility crieria eg those with mental health or disabling illness- this group currelty have no access to MFMC	9	3.5
24	The current eligibility criteria for diverting admissions into aged care facilities excludes most people with Huntington's Disease and we have yet to have a client placed in an age appropriate high care facility.	9	3.1
27	There is need to ensure that the agenda includes all 'younger people in nursing homes'. Younger people in nursing homes extends to people with younger onset dementia.	9	3.6
10	**Government actions and approaches required**		**3.5**
8	For planning legislation (Victorian Planning and Environment Act) to be amended and reworded resulting in exemptions from protracted planning processes. Currently exemptions exist for the use of a building but not for the construction of the building which requires a lengthy advertising and planning process.	10	2.8
11	The limited number of actual and available places for younger people requiring full nursing care needs to be acknowledged and the path made easier to ensure people's needs are being met.	10	3.9
22	Stop wasting time and build more accommodation facilities for young people at risk of entering nursing homes	10	3.8
25	The development of Youngcare at Sinnamon Park and Young Lifestyle Care at Gordonvale (for people with Huntington's) appear to be excellent models, but only provide a limited amount of placements. A model of developing a younger persons unit within nursing homes has been successful in other states and should be considered as an option to meet COAG's objectives.	10	2.9
28	To design service models with people that is based on their assessed and identified individual need rather than developing a service in the absence of the people who will use the service and in the absence of their individual needs.	10	4.3
40	Accommodation – creative & adventurous	10	3.6
44	Find innovative concepts for living	10	3.4
11	**Suitable accommodation options**		**3.9**
32	We need access to wheelchair accessible public housing in a range of places	11	3.8
33	We need suitable accommodation options for people with high support needs	11	4.4
35	Work in partnership to ensure sustainability and appropriate facilities are built	11	3.8
48	Own accommodation for young people so that they do not have to utilize on age care facility	11	3.7

Provider perspective - cluster map



Provider perspective – importance rating map



Provider perspective ratings

Table 7 presents the list of clusters with their importance rating presented in order of importance while Table 8 lists the 19 statements with the highest importance rating.

Table 7: Provider group - clusters in order of importance

Cl Num	Cl Name	Cl Imp
11	Suitable accommodation options	3.9
5	Individualisation (listening to the client)	3.8
6	Specific gaps in services and the COAG strategy	3.8
8	Specific groups of clients and geographic areas	3.6
2	Funding allocation within the COAG strategy	3.6
7	Specific gaps in services and the COAG strategy	3.6
4	Rehab providers	3.6
10	Government actions and approaches required	3.5
3	Broad view of need including prevention and quality of life	3.5
1	Funding and funding processes	3.4
9	Pathways (appropriate and inappropriate) into aged care	3.3

Table 8: Provider group – 19 most important statements

Num	Statement	Clus	Imp
33	We need suitable accommodation options for people with high support needs	11	4.38
28	To design service models with people that are based on their assessed and identified individual need rather than developing a service in the absence of the people who will use the service and in the absence of their individual needs.	10	4.27
13	Involve the target group in all processes and stages	5	4.23
50	Quality of life!!!	5	4.19
45	I work in an acute hospital setting, young people are often transferred straight from acute care to nursing home care, often in the early days after the life changing diagnosis. There is a need for interim care where rehab is continued, where ling term needs and abilities can be determined	6	4.14
49	Plan for future unmet need, particularly for those with progressive neurological diseases	6	4.11
46	More support in rural areas for young people	8	4.09

Num	Statement	Clus	Imp
51	The development of a sustainable income stream to meet the needs of young people with high level nursing needs into the future	2	3.95
29	Utilise the $s allocated more quickly and efficiently - Many states are very slow to get things moving and many people remain in inappropriate accommodation	2	3.94
11	The limited number of actual and available places for younger people requiring full nursing care needs to be acknowledged and the path made easier to ensure people's needs are being met.	10	3.94
20	Provide sufficient resources to support purchase of equipment, community access, other items as well as supported accommodation	1	3.91
7	Focus much more on preventative options e. g. ways to prevent people from entering into residential aged care	9	3.91
41	Appropriate for indigenous young people	8	3.88
3	Development of transition/continuing care options to bridge the gap between when a person is ready to leave acute/sub acute hospital but needing more time before ready to engage in "lifetime" planning required by Disability Services	8	3.83
52	The development of structural / organisational support networks for families/carers so that their capacities to support their family members is sustainable	3	3.82
35	Work in partnership to ensure sustainability and appropriate facilities are built	11	3.82
34	We talk about moving people out of nursing homes as a goal in itself without considering people needs to be close to their families and support networks.	3	3.8
32	We need access to wheelchair accessible public housing in a range of places	11	3.77
23	That funding models acknowledge the rehabilitation needs of people with an acquired brain injury and not simply their habilitation needs. This may necessitate the development of new qualifications and funding models that are more rehab focused.	7	3.76

Table 9 lists ideas presented by members of the provider group in response to a request to list priorities for action for the next six months. While action items were requested many participants chose to list priority concerns but with no specific action identified.

Table 9: Provider group - recommended actions for the next six months

Provider group- recommended actions for the next six months
Awareness campaign on a national basis following on from Bill Shorten's comments involving young people with disabilities
Establish a communication network to allow individuals and families to explore and swap ideas and information

All young people appropriately assessed for rehabilitation.
Assessments to be carried out by people with experience in disability field rather THAN AGED CARE
Need to establish automatic notification to initiate intensive support services for individual and families at the time of injury – immediately after
Immediate expansion of eligibility to include people between 50 and 65 Create a transition plan so that this age group are not left out Currently ACAS will not assess them and YPINH will not accept them
Speed up the COAG initiative by expanding existing facilities to accommodate young people with high care needs and that have expertise already in place. (This will not work in rural areas
Immediately establish facilities to accommodate young people with dementia who have challenging behaviours currently there are no safe options. Recommend a model similar to psycho-genera tic model
Introduce specific training for staff e.g. nurse that deal with care of young people
Concrete needs to be tended to immediately – funding transport, care and activities
Appropriate accommodation being available
Create statues that ensure progress continues and maintain a bi-partisan approach to ensure that the initiative is ongoing
Legal requirements for accommodation irrespective of which government is in power
Stop the current system of crisis driven options i.e. there is a vacancy in X you either take it or miss out. This is not a real choice; current system also stops the opportunities for relationship, real choice not rhetoric
More practical knowledge for support workers rather than university degrees
Consolidation of agencies, outsourcing leads to confusion fragmentation, competition and inefficiency
Alternative models of service delivery
Raise access levels to information and support
Effective case management and consistent process
New appropriate assessment tools for catastrophic injury
Equal access to appropriate therapy for all young people with catastrophic injury-compensable and non compensable
National working party on rehabilitation with equal representation from families and professionals
Immediately convene consumer advisory groups with appropriate powers and communication with minister for the progression of YPIRAV programs in each state
Family and consumer representatives more than one token consumer appointed by bureaucrats on all decision making committees that shape policy and the direction of programs. Development of networks to publicise who these representatives are so that

other families can utilise them as representative and be informed about what's happening.
Seamless and flexible funding from both state and commonwealth funding
Include independent advocates into the process
Sufficient flexibility and funding for people who remain in nursing homes
Independent oversighting body to inform – make sure information is disseminated and get feedback
A more streamlined one shop stop to accessing Government services and information which is currently very time consuming, is not flexible and often results in getting nowhere. Currently is a maze
Additional funding to programs like Slow to Recover that are in tune with ABI needs
Develop appropriate models of respite support that are family centred and family driven
Increase carers allowance to assist in offsetting costs when parents/parents give up or reduce their hours of paid employment to care for young person
New brain research post 2000 overturns the previously held view that the brain is unable to make new connections. We now know that the brain has neuro plasticity and given an enriched environment and support, the brain can continue indefinitely to make new connections and gains. YPINH with severe ABI are often treated as if they are not cognitive not there. It is terrible struggle for the YP and their families /carers. With brain injury increasing and an anticipated normal life span for YP with ABI, we need to acknowledge this next 3 years of the COAG initiative is only a beginning

Summary of provider group results

Overall the emphasis of the most important in the provider map relates to individualisation of services and the provision of a diverse range of service options to appropriately meet a diverse range of needs. Within this general theme of providing diversity there are many specific areas where diversity and flexibility of service provision needs to be improved; these include: accommodation options, acute step-down options, community support options, preventive care and rehab options and options for specific groups (e.g. indigenous).

In clusters 6 and 7 this group identified a number of specific gaps in the COAG strategy, gaps which once again focus on the general theme of individualisation and diversity.

- *Government group results*

It must be said that the number of statements provided by government representatives (19) was disappointing. It was approximately half the number of representatives in attendance which means that very few of the government representatives chose to contribute statements even when given a second chance to do so at the time of check-in on the first morning.

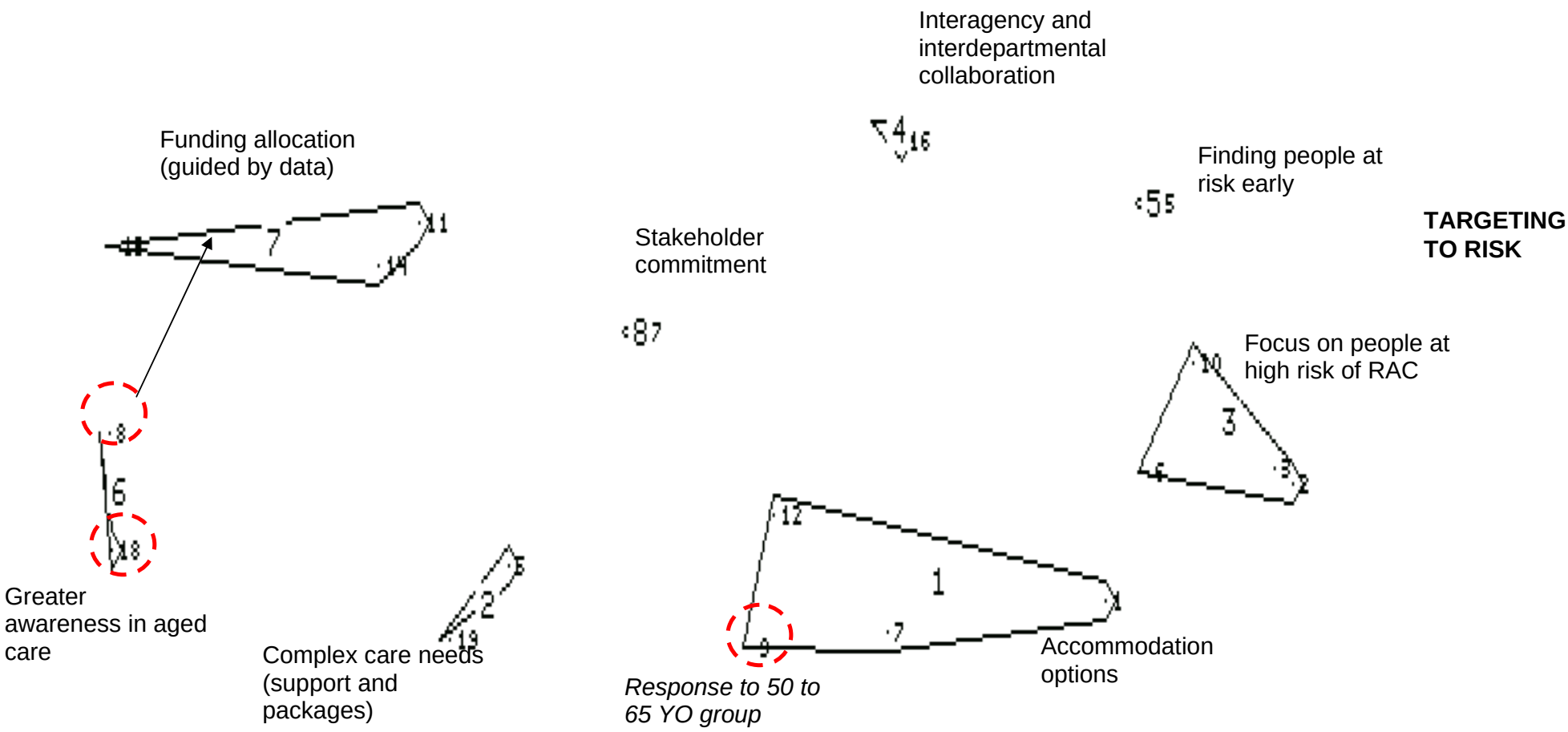
The following tables and results present their results. At the end of this section is the consultants' interpretation of the most significant outcomes. It is important, however, for readers to examine the cluster lists and maps to make their own interpretations.

Table 10: Government group statements by cluster

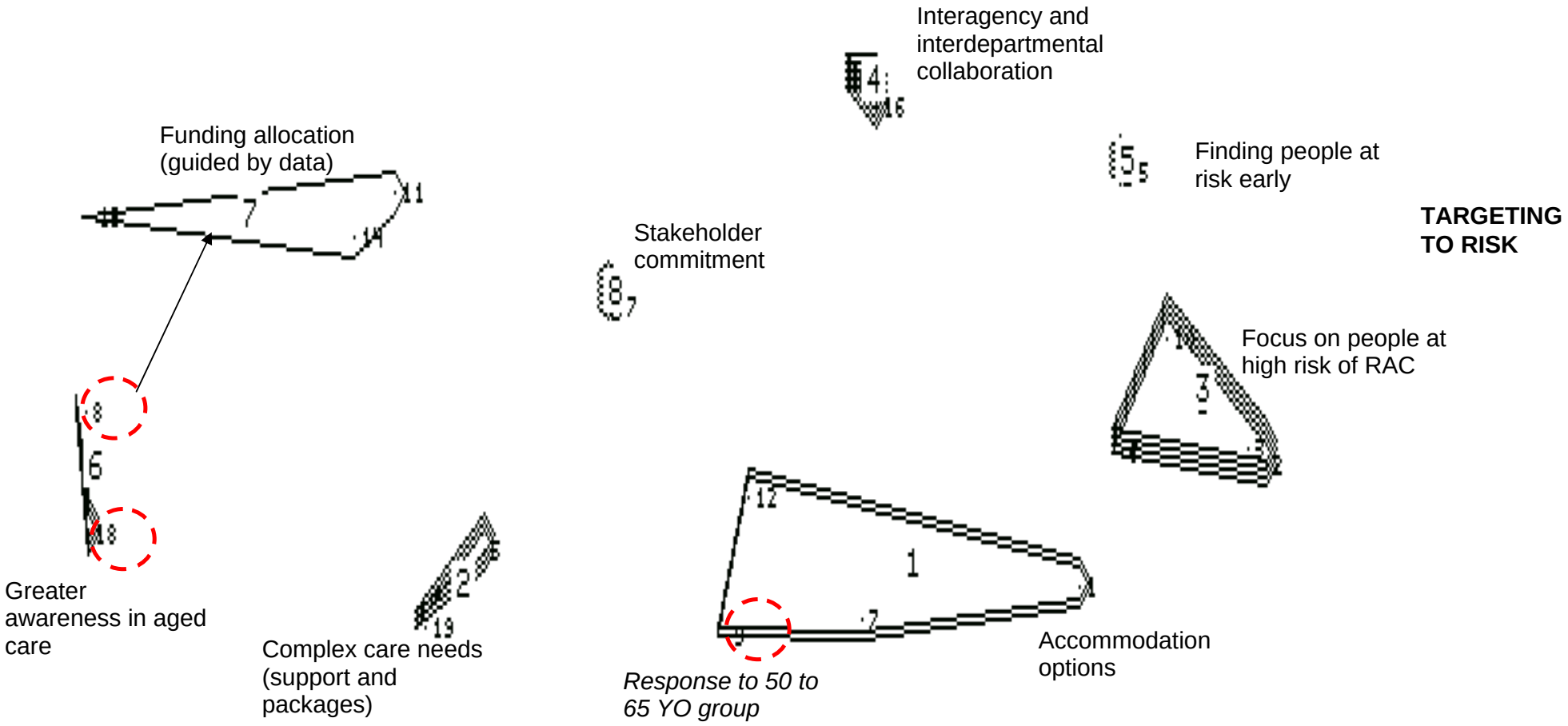
	Statement	Clus	Imp
1	**Accommodation options**		**3.6**
1	Service developments focussing on transitional accommodation and respite	1	3.4
7	Victoria needs more high level care beds - specifically for those with complex medical issues, e.g tracheostomy care. Its difficult for families to even find nursing homes that offer this level of care.	1	3.2
12	Individualised accommodation and support models developed	1	4.1
1b	**Response to 50 to 65 YO group**		**2.8**
9	Consideration of appropriate response to 50 to 65 year old in residential aged care	1b	2.8
2	**Complex care needs (support and packages)**		**3.7**
5	Case management services to support implementation of enhancement packages and plan to alternate accommodation (person centred planners)	2	3.5
19	Commitment to support people with complex care in the community	2	4.0
3	**Focus on people at high risk of RAC**		**3.9**
2	A focus on preventing admission to nursing home (RAC)	3	4.4
3	Priority access to alternative accommodation seems to have been given to younger people already in a nursing home. What about those at risk of entering aged care? Feedback from families is that they may consider putting their family member into aged care just so they are given priority for alternative accommodation.	3	3.3
6	More in home support for people prior to risk of entry to RAC	3	4.0
10	More capital investment in accommodation for people who would otherwise enter RAC	3	3.9
4	**Interagency and interdepartmental collaboration**		**4.3**
4	Improved relationship between Health and Disability services	4	4.1
16	A closer collaboration between service systems, e.g complex health, HACC and Govt working together rather than services opting out once someone has a package of support.	4	4.6
5	**Finding people at risk early**		**4.1**
15	Disability Services are still finding out about young people at risk of admission very late on. This makes successful planning to avoid admission very difficult. Better relationships with the health	5	4.1

	Statement	Clus	Imp
	care system are much needed to avoid these situations.		
6	**Greater awareness in aged care**		**3.7**
8	Quality of life outcome measures in place	6	3.8
18	Greater awareness of younger people in aged care	6	3.6
7	**Funding allocation (guided by data)**		**3.1**
11	It was noted by many that in the last budget an additional $10 million was allocated to this initiative. When can we expect advice on how this is to be spent, where will the accommodation be, who is it aimed at etc?	7	2.5
13	Review and data collection regarding the implementation of high cost diversion support packages	7	3.3
14	increased funding for equipment for people to assist in remaining in their own home	7	3.5
8	**Stakeholder commitment**		**4.2**
17	Commitment by all stakeholders to continue the initiative	8	4.2

Government perspective - cluster map



Government perspective – importance rating map



Government perspective ratings

Table 11 presents the list of clusters with their importance rating presented in order of importance while Table 12 lists the 12 statements with the highest importance rating.

Table 11: Government group - clusters in order of importance

Cl Num	Cl Name	Cl Imp
4	Interagency and interdepartmental collaboration	4.3
8	Stakeholder commitment	4.2
5	Finding people at risk early	4.1
3	Focus on people at high risk of RAC	3.9
2	Complex care needs (support and packages)	3.7
6	Greater awareness in aged care	3.7
1	Accommodation options	3.6
7	Funding allocation (guided by data)	3.1
1b	Response to 50 to 65 YO group	2.8

Table 12: Government group - 12 most important statements

Num	Statement	Clus	Imp
16	A closer collaboration between service systems, e.g complex health, HACC and Govt working together rather than services opting out once someone has a package of support.	4	4.58
2	A focus on preventing admission to nursing home (RAC)	3	4.42
17	Commitment by all stakeholders to continue the initiative	8	4.18
12	Individualised accommodation and support models developed	1	4.09
4	Improved relationship between Health and Disability services	4	4.08
15	Disability Services are still finding out about young people at risk of admission very late on. This makes successful planning to avoid admission very difficult. Better relationships with the health care system are much needed to avoid these situations.	5	4.05
19	Commitment to support people with complex care in the community	2	3.96
6	More in home support for people prior to risk of entry to RAC	3	3.95
10	More capital investment in accommodation for people who would otherwise enter RAC	3	3.87
8	Quality of life outcome measures in place	6	3.75

Num	Statement	Clus	Imp
18	Greater awareness of younger people in aged care	6	3.58
5	Case management services to support implementation of enhancement packages and plan to alternate accommodation (person centred planners)	2	3.5

Table 13 lists ideas presented by members of the consumer group in response to a request to list priorities for action for the next six months. Unlike the other two groups this group generally made recommendations with a clear action orientation.

Table 13: Government group - recommended actions for the next six months

Government group – recommended actions for next six months
A closer collaboration between service systems e.g. health systems, disability systems HACC etc, govt.
Accommodation (new builds – new providers) – Government procurement process very slow
Advance the work to evaluate the outcomes of the COAG YPIRAC initiative - particularly the quality of life outcomes
Case management – need more
Commitment by all stakeholders to continue the initiative post 5 years
Data collection, evaluation and review process, incorporating Quality of Life outcomes measures
Development of rehab/transitional accommodation (post-hospital/acute care) to allow time for appropriate planning (e.g. while they wait for DOH to modify housing to meet the person's needs e.g. a working unit at the back of a CRU/SSA to assist the person to develop their skills/assess skills they have and have support as necessary. Whatever model is decided upon, there needs to be a commitment that it will not get used up for long-term accommodation by homeless people etc.
Engagement of the private business sector (corporate social responsibility) regarding the issue of YPINH e.g. Maurice Blackburn, Youngcare
Engaging the private sector to build modified accommodation to give people with disabilities private rental opportunities
Improve collaboration between service systems e.g. health (acute & sub-acute) disability and aged care
Increased capacity to support people to continue living in the community e.g. access to equipment, range of supports including for those with complex medical needs
Links with hospitals, rehab services, GPs
Local planning regulations - slow, time consuming
More support for diversion packages for people with high support – difficulty getting

staff, complexity of support needs, needs for case management. Need to allow family members to be family members rather than case managers etc.)
Other programs changing criteria because of the YPIRAC program i.e. HACC funded nurses not providing support for YPIRAC client at usual HACC rate
Review relevant protocols and processes to streamline and make them more relevant e.g. DS/ACAS
Work across governments, community and corporate sector to create capital / housing options more quickly
Workforce issues – establishing a highly qualified workforce

Summary of government group results

The results of the government group are is stark contrast to the consumer group in that, while consumers emphasised universality, the government group emphasised targeting, specifically gearing services to people at imminent high risk of admission to residential aged care. They also had a great emphasis on interagency and inter-departmental collaboration, indeed the most important items and clusters related to this issue.

On the left of the map are two clusters which emphasise evidence and data, particularly data driven funding allocation which links again to the concept of targeting.

The key ideas reflect some of the main expectations society ha of governments, specifically that they are careful and accountable in the allocation of tax-payer money.

None-the-less it is easy to see that there is potential for conflict between this perspective and the perspectives of the other two groups.

- *Comparing perspectives of the three stakeholder groups*

This section seeks to highlight a few of the main contrasts between the three groups as well as some of the areas they have in common.

Table 14 lists side-by-side the clusters from the three maps in order of importance. While the table demonstrates something of the differences it is necessary to examine the individual statements in order to fully see the differences in emphasis between the groups.

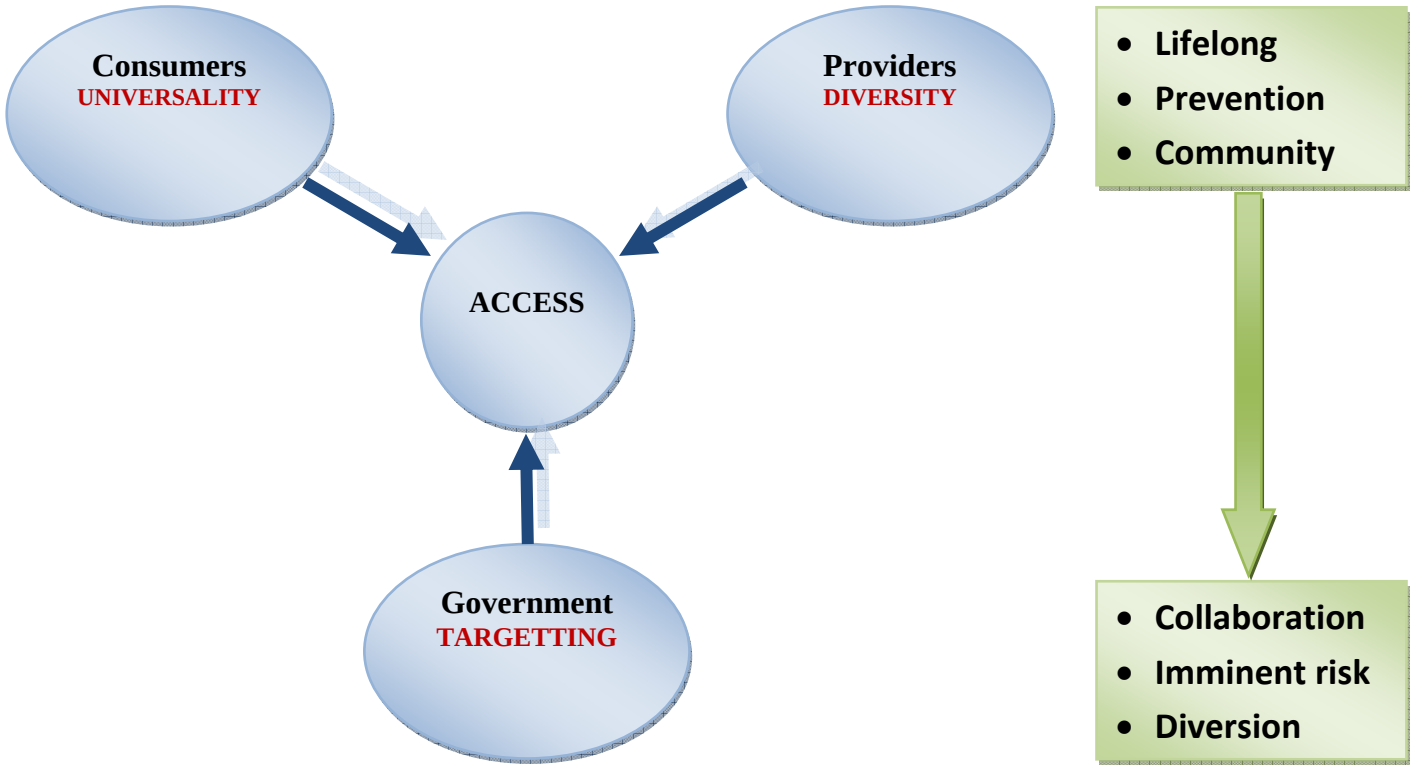
Table 14: Comparison of clusters by importance for all three groups

Consumers	Imp	Cl Name	Imp	Cl Name	Imp
Rehabilitation	4.1	Suitable accommodation options	3.9	Interagency and interdepartmental collaboration	4.3
Specialised services	3.9	Individualisation (listening to the client)	3.8	Stakeholder commitment	4.2
Community services and attitudes	3.9	Specific gaps in services and the COAG strategy	3.8	Finding people at risk early	4.1
National and government strategies	3.8	Specific groups of clients and geographic areas	3.6	Focus on people at high risk of RAC	3.9
Funding allocations and access pathways	3.8	Funding allocation within the COAG strategy	3.6	Complex care needs (support and packages)	3.7
Specialised expert service providers	3.8	Specific gaps in services and the COAG strategy	3.6	Greater awareness in aged care	3.7
Client say in service delivery and accommodation decisions	3.8	Rehab providers	3.6	Accommodation options	3.6
Accommodation options meet needs (diversity)	3.7	Government actions and approaches required	3.5	Funding allocation (guided by data)	3.1
Access and pathways	3.6	Broad view of need including prevention and quality of life	3.5	Response to 50 to 65 YO group	2.8
Flexible options to support QoL and life options	3.6	Funding and funding processes	3.4		
Family and family carer support (preventing home situation breakdown)	3.5	Pathways (appropriate and inappropriate) into aged care	3.3		
Research	3.5				
Innovative ideas for specific needs and crisis situations	3.3				

Evaluate national program	3.2

Figure 3 is an attempt to capture the main differences in emphasis between the three groups. It does so by considering the approaches emphasised by each group to providing access and meeting need. In this regard the consumer group emphasised universality of access to rehabilitation and funding streams, the provider group emphasised the need for a diversity of services to meet a diversity of needs while the government group emphasised targeting to people at imminent and high need. In keeping with these emphases the consumer and provider groups emphasised an approach to keeping young people out of nursing homes that emphasised a long-term, preventive approach based in the community. The government group, on the other hand, tended to focus in the identification of people at imminent risk and on diversion to other residential options.

Figure 3: Emphasis of the three groups on approaches to providing access and meeting need



There are clearly stark differences in the discourse about how to meet the needs of young people at risk of being placed in residential aged care. The results of this workshop suggest that consumers and providers share a similar point of view which is at odds with that of government. The similarity between the consumer and provider perspective may be over-stated, however, due to the substantial overlap between the groups.

Despite the obvious and significant differences there are many areas that all three groups had in common particularly around the need for better collaboration between services and improved inter-departmental and inter-sectoral action.

Attachments

Attachment A: Statement collection form
Attachment B: Supplementary statement collection form
Attachment C: Consumers – Full list of statements
Attachment D: Providers – Full list of statements

Attachment A: Statement collection form

Planning activity for 'Shaping the Future Today' Workshop

Greetings friend,

From July 2006, Commonwealth, State and Territory governments started implementing a new initiative to *reduce the number of younger people with disabilities living in nursing homes*. The initiative's objectives were to:

- **offer younger people with disabilities in residential aged care homes a care needs assessment;**
- **negotiate and provide appropriate alternative long-term care options, where these can be made available and this is what clients choose;**
- **develop and establish new services and care options, including improved services within nursing homes; and**
- **reduce future admissions of younger people with disabilities to residential aged care.**

Substantial progress has been made so far, but it is now important to think about what the next steps should be – your feedback is critical.

Shaping the Future Today gives you an opportunity to have your say.

As a conference participant, you are required to contribute your perspective on how the initiative has progressed thus far and how it needs to be shaped for the future. This process begins now with the return of this form.

At the conference, we will be using a concept mapping process that will synthesize the wide range of views and inform the conference about the effectiveness and potential of the initiative. We are keen to ensure that the conference results in useful outcomes that will take the initiative forward.

To make this process work, we need as many ideas as possible in advance of the workshop. This email form is designed to help you provide your ideas in the easiest way possible.

Once completed, you will be asked to email the form to Plexus Consulting for collation. These collated ideas will form the basis for the workshops on Day 1 of the conference.

Version C1

Instructions

Please note that to read and successfully complete this form you need Adobe Acrobat Reader version 6 or later. You can obtain and install a free copy of this software at http://www.adobe.com/products/acrobat/readstep2.html.

On the next page there is space provided for you to list up to twelve ideas in response to the following statement:

Given that the COAG initiative has been conceived as a first step to get young people out of nursing homes, what does the initiative need to do in the next 3 years to achieve its potential and meet the COAG's stated objectives?

It is okay to give your ideas in any way that suits you. They may be:

- As broad or as specific as you like
- Problems that need solving
- Specific actions that you think need to be taken.

You can use as many boxes as you like, but **please enter ONE IDEA ONLY in each box.**
(Avoid sentences with lots of 'ands'.)

You can return the form by EMAIL by clicking the button that says **'Click HERE to submit by email WHILE THE FORM IS OPEN'** at the end of the form.

If you prefer to hand write your responses, please PRINT out the form by clicking the "Print Form" button at the end of the form and:

- FAX YOUR PRINTED FORM to Colleen Johnson on **03 8660 2377** or
- POST IT to Plexus Consulting, 3/2 Scotia Street, North Melbourne 3051.

Please note, when you click the button that says 'Click HERE to submit by email WHILE THE FORM IS OPEN' a screen may pop up that asks you to select the program that you use to send your email. You will need to select the appropriate program and click 'OK' to send it.

Version C1

Please enter one main idea in each of as many of the boxes as you like. Then return by clicking the 'Submit by email' button. If you wish to hand write your responses please click the 'Print form' button and fax to Colleen at 03 8660 2377.

Idea 1

Idea 2

Idea 3

Idea 4

Idea 5

Idea 6

Idea 7

Idea 8

Idea 9

Idea 10

Idea 11

Idea 12

Thank you for this important contribution and we look forward to seeing you at the workshop

Version C1

- *Attachment B: Supplementary statement collection form*

Planning activity for 'Shaping the Future Today' Workshop

Greetings friend,

From July 2006, Commonwealth, State and Territory governments started implementing a new initiative to ***reduce the number of younger people with disabilities living in nursing homes***. The initiative's objectives were to:

- offer younger people with disabilities in residential aged care homes a care needs assessment;
- negotiate and provide appropriate alternative long-term care options, where these can be made available and this is what clients choose;
- develop and establish new services and care options, including improved services within nursing homes; and
- reduce future admissions of younger people with disabilities to residential aged care.

Substantial progress has been made so far, but it is now important to think about what the next steps should be – **your feedback is critical.**

At the conference, we will be using a concept mapping process that will synthesize the wide range of views and inform the conference about the effectiveness and potential of the initiative. We are keen to ensure that the conference results in useful outcomes that will take the initiative forward.

Please list your three most important ideas in response to the following statement:

Given that the COAG initiative has been conceived as a first step to get young people out of nursing homes, what does the initiative need to do in the next 3 years to achieve its potential and meet the COAG's stated objectives?

Idea 1	
Idea 2	
Idea 3	

Version C1

Attachment C: Consumers – Full list of statements

"During the 2007 election campaign the ALP plat formed for Population-Based Benchmark Funding to help meet unmet needs in disability services – this is noted as a primary function too finance the goals of the COAG initiative, so what is happening on this front?
Planning documents need to be "living" and flexible to meet the changing needs of the person.

a formal and transparent evaluation of the initiative - where is it up to? What are Government expectations from this initiative

A group to oversee the COAG process, appropriately funded

A more streamlined “one shop stop” to accessing Government services and information which is currently very time consuming, is not flexible and often results in getting nowhere. Currently is a maze.

A more timely process for family and friends

A review of nursing home admissions needs to happen quickly. This should look at how people are getting into nursing homes in the first place. Is an ACAT team recommending these placements?

Accommodation specifically designed with an appropriate (and appropriately funded!!) support model for people with very challenging behaviours and/or dual diagnosis of neurological condition and psychiatric…

additional funding to programs like Slow To Recover that are in tune with ABI needs

All severe TBI patents, once stabilised in acute hospital to be properly assessed for rehabilitation in acute rehabilitation setting (eg BIU in RRCS) direct from acute hospital (not via a nursing home – unless that home has …..

All severe TBI patients, once stabilised in acute hospital to be properly assessed for rehabilitation in acute rehabilitation setting [eg BIU in RRCS] direct from acute hospital [not via a nursing home - unless that home has a special wing adapted and staffed by trained dedicated personnel!]

An increase in the availability of community nursing services, to allow people to remain in the community, in their own home.

Appropriate advocacy funding to prevent young people re entering aged care places.

As this process will take a long time- you need to look at what supports for younger people while in Nursing Homes

Ask the younger people what they want

Assessment for this under 65 age group should be based on needs rather than age so that the most appropriate level of care and support be provided. Currently there are people in the 50 – 65 age bracket who are in “no man’s land”?

Assessments to be carried out by people experienced in the disability field rather than aged care where often their knowledge of particular disabilities is very limited.

Assist with the development of programs that strengthen client and family capacity to manage their own care and the options available to them

Become proactive and preventative by supporting those people who are at home currently and may not be at immenint risk but can very easily become at risk in the blink of an eye.

Becoming a 'community member' - the new home should be easily accessible for all visitors, and within 'wheeling' distance of community services, e.g. cafe, shops etc.

begin to integrate high care needs young people in clusters in normal residential blocks or apartments

Bring the funding back from the regions centrally

By the end of the next agreement all young people in nursing homes should be out of nursing homes.

Carers need to be open to alternative suggestions.

Cheap affordable holiday house to rent that is fully accessible with equipment etc at beach location

Community Integration Program similar to model in Adelaide set up by Roger Rees which utilises community resources eg university students, retired people who are trained as mentors

Community Integration Program similar to model in Adelaide set up by Roger Rees which utilises community resources, eg university students, retired people who are trained as mentors

Consolidate service providers to enable specialist training, allowing staff to feel valued supported and involved. This also provides continuity of care for client and family and assists family carers to feel supported without carrying the main burden of responsibility when accessing respite/ home care services.

continue to push for more funding to actually build more facilities for young people

continue to raise community awareness

Convene a national working party on development of rehab services for young people with catastrophic injury. Include family representatives in the working party.

Create facilities for ABIs that use the aged care funding model as the infrastructure already exists

"Create targeted programs that strengthen life options for young people with disabilities in the community.

Daily rehabilitation and physiotherapy is a must. It is so important that the people who cannot move around receive consistent and ongoing therapy.

deliver support according to need not age. it should not matter how old you are. Getting the support you need in a timely and effective manner is paramount

Develop a continuum of appropriate accommodation options - not one size fits all models!

develop a life time care approach to disability support based on need not age

develop a national and properly funded rehabilitation strategy that delivers for recovery from injury and maintenance of health and well being over the long term

Develop a national strategy to deliver appropriate medical and rehab services to people with severe ABI

Develop a new service model that is locally based and is automatically activated on discharge from the health system that walks beside an individual and their family for life. (TAC support coordinator model for non compensable client group)

Develop an automatic alert system that is activated as soon as an ACAS approval for residential care is grantedfor a person under 65.

Develop and resource participative models of planning for supported accommodation and involve future residents (and their representatives)vin the design, service development , philosophy of care and recruiting of staff.

Develop appropriate models of respite support that are family centred and family driven.

Develop appropriate supports for all members of the family affected by the young persons injury/illness. e.g. we need to support the children of, the siblings of, the parents of, the grandparents, the husbands, the wives etc

Develop fast, rehab responses for young people with catastrophic injury. Utilise the expertise of those professionals who are experienced in working with this group (eg through Slow to Recover, Vic and internationally). Young people are dying while states, such as Qld refuse to learn from those who are saving these young lives.

"Develop pathways within funded programs (crossing state and federal boundaries) that make it easy for consumers to CHOOSE the option and level of support they desire
"

Develop peer support programs and ways of disseminating information for families who care for people with high support needs at home. Acknowledge the strengths and expertise of family carers.

Develop shared care models that enable people to spend some part of their week at home and some time away.

Development of tailored accommodation solutions around an identified group of individuals with maximal input from these individuals and their families right from the start – to ensure the location, model and design is…

don;t build accomodation and put people into it. ask people what they want and work with them to make it happen.

drastically improve funding for disability services

Embrace diversity in planning for long-term supported accommodation. Options should reflect the diversity of lifestyle choices of those who will be supported.

Ensure family members/friends and/or advocates have free access to residents (according to individual resident's wishes.

Ensure that additional support is provided to identify and assist the “divert” group – people living within the community who are at risk of early admission to residential aged care facilities

"Ensure that adequate support is available to the complex care clients who often are subjects of admission to aged care because of pre-existing co-morbidities such as mental

health problems or substance abuse, or do not have functional informal support within the community.

Ensure that advocates are included in all YPIRAC programs - whether moving out or remaining in.

Ensure that funding is allocated for a range of accommodation options (both in built design and support levels) that provide alternatives within the community

Establish family counselling/mediation centres to facilitate group or individual counselling to assist families to deal with difficult challenging issues.

Establish specialised teams to complete assessment, transition and successfully relocate individuals. This team would provide end to end case coordination including the provision of training and program implementation.

Establishment of a 'team' of health professionals including allied health, specialist nursing, medical that can be accessed by a range of services vs each service sourcing private therapists and specialist services at exorbitant….

Flexible models of accommodation and care that change with peoples needs and desires.

From personal experience, the cognitive growth and development for a person with severe brain injury starts after the physical/medical issues are manageable. Therefore we need services that can start to assist people when they are ready. This may be 5 years post injury.

funding for this group through this initiative needs to drastically increase

Funding from both Federal and State Governments.

future financial commitment from the COAG to ensure program succeeds and expands over time

Future funding can come from a social care levy

Genuinely collaborate with Health to establish a positive partnership in working to reduce premature admission to age care direct from the acute and sub acute sectors

Greater collaboration amongst services with respect to development of education and training resources for direct care workers, both accommodation and in-home workers

greater focus on system changes - not just individual outcomes

Have appropriate accommodation for younger people- not just one centre in a city. look at regional areas too

Health fund options that would allow insurance for non acute care cover. Eg ABI The way insurance tends to work this would probably be of no use after the fact but may assist others

I cannot stress enough the 'urgency' of the situation. I am tired of hearing 'numbers here and percentages there'. These are 'human beings' and should be treated as so. I should know. I have MS and live in an accommodation unit!

I live in an accommodation unit and accessibility to the train (public transport) is so important. It is my window to the outside world!

I understand that planning and establishment of takes time, but the actual number of people leaving aged care facilities is still very low. I believe the net numbers are still increasing.

I wish the people who are delaying this 'evacuation' of YPINH to really envisage themselves in this predicament. Would they like to be young, cut off from society, in a place where music, culture and generation are different?

Improve pathways, partnershhips and protocols between health and community services. Enhance discharge planning for this group.

Improved co-ordination and networking opportunity between direct care providers (e.g. accommodation providers and in-home support providers, and specialist services such as allied health, nursing, medical, primary care….

Improved services for young people with mental health issues to prevent potential brain injury from drug and alcohol use and/or suicide attempts.

Include all three tiers of government with family/community members and potential residents (where possible) to plan/investigate supported accommodation options, with maximum resident control, with the Pathways Plan.

Include YPIRAC in a broader disability program - "Planned Pathways" - based on the assumption that all adults from say 21 yrs have right to live independently from family. Build in planned transition period from time of acquisition, or post school (for those born with a disability).

Increase Carers Allowance to assist in offsetting costs when parent/parents give up or reduce their hours of paid employment to care for young person.

Increase the capacity of the initiative to include people aged over 50 years old

Individualisation of service models to really meet the needs of each person. Person centred planning should guide the development of service models.

Individualised, integrated community based accommodation models need to be implemented. These need to reflect the diversity of peoples needs.

inform and educate people. make resources available that enable people to deal with the life changing events they confront and enable them to make informed decisions

Inform people of our contact details for social support for Y.P.I.N.H.

Involve families as partners in the care of their loved ones, not the sole providers of that care

it is impossible to get support workers trained for people with high support needs. yet we still want to live life to the full. we need to train workers to support people with high needs better.

It is their 'home'. The residents must be able to create their own 'comforts'.

It seems that there is plenty of money to improve this 'sad' state of affairs, yet there doesn't seem to be 'getting together' between state and federal govts.

Keep participants informed of progress via webpage "What's Happening"

Legislation in Commonwealth and all states of Australia to make wearing helmets compulsory for skateboarders

Legislation in Commonwealth and all states of Australia to make wearing helmets compulsory for skateboarders

Listen to family members and others who represent young people with high support needs.

Listen to young people with high support needs.

Many YPINH with severe ABI and high needs need a 'socio-medical' model of care and support. They need a rehabilitative approach and enriched environment to make the gains that can happen over many years. World Health Organization (WHO) in their International Classification of Functioning, Disability and Health (ICF) 2001 called for Disability and Health to move to a social medical model. Many YPINH with severe ABI need this level of support and care. There is resistance in Disability to any 'medical' model and in some areas of Health to the 'social' model. How can we build bridges to socio-medical models? What does Chris want group has one such model ISBN 978-0-646-49641-2

Maximising independence - all possibilities for reducing dependence should be explored - e.g. special mattresses, door opening and other devices, communication and emergency contact systems etc.

More and longer term slow stream rehab. services.

More collaboration with health dept (NSW) in regard to rehab after ABI

more day program options for persons with high support needs ABI and residing at home

more dedicated strategies to prevent people entering aged care

More effective ways of keeping families informed so that their expectations are realistic. Currently many Government brochures don't indicate the reality of the situations.

more funding for the initiative so we don't have to maintain the rationing culture of the initiative so far

more individualised funding packages

More money and resources for the program so its objectives can be reached

More rehabilitation options, after acute care stage, for person's sustaining an Acquired Brain Injury

More training of staff in care of TBI at all levels: RN, therapists (physio, speech, occupational), AINs ('certificate 4' etc.)

More training of staff in care of TBI at all levels: RN, therapists [physio, speech, occupational], AINs ['certificate 4' etc],

Moving out - a range of existing and/or new options should be explored - not just "move them all into existing services" or "build a new group home to accommodate them".

National No Fault Insurance Scheme for all severe injuries, particularly catastrophic brain injury (not just motor accidents) based on Victorian TAC model and/or the NZ model (ACC)

National No Fault Insurance Scheme for all severe injuries, particularly catastrophic brain injury [not just motor accidents] based on Victorian TAC model and/or the NZ model [ACC]

National rehabilitation program with lifetime cover, based on Victorian TAC model with sufficient funding to cover the roughly equal number of non compensable as compensable clients, to make it equitable

National rehabilitation program with lifetime cover, based on Victorian TAC model with sufficient funding to cover the roughly equal number of non compensable as compensable clients, to make it equitable.

Need to link YPIRAC with others living inappropriately (eg as adults with parents) in the community, to broaden compatibility options and share program funding, and to enable a broader range of options.

New brain research (post 2000) overturns the previously held view that the brain is unable to make new connections. We now know that the brain has neuro plasticity and, given an enriched environment and support, the brain can continue indefinitely to make new connections and gains. YPINH with severe ABI are often treated as if they are not cognitive, not 'there'. It's a terrible struggle for the YP and their families/carers. With brain injury increasing, and an anticipated normal life span for YP with ABI, we need to acknowledge this next 3 years of the COAG initiative is only a beginning.

New frontiers are emerging in our knowledge and understanding of the brain and its capacity to make new connections. Research and evaluation with YP and families involved must be part of the way ahead.

new ways of government purchasing services - contestability is not always the best way of getting the best outcome for the target group - service development in residential services needs to be more consultative and inclusive of end users - new methods should be trialled

No more young people in nursing homes, no new admissions of young people to nursing homes.

Offer training and learning opportunities for carers to better provide for young people in their care.

Ongoing funding, what happens after the end of the five years.

Options for those outside the criteria need to be able to access other supports. this could include those people over the maximum age but under 65 years of age for example.

People over 50 need to be included in this initiative.

Proper rehad programmes to maximize potential

Provide Allied Health Services to meet the rehab needs of YPINH and others with high support needs

Provide appropriate respite opportunities for carers, enabling a weekend to three nights break on routine basis i.e. 6 to 8 weeks.

Provide clear, transparent pathways for people to navigate, reduce ambiguity

Provide funding for qualitative research with young people with high support needs and their families. Publish their stories to raise awareness, develop contacts for peer support and build a community of hope.

Provide training for clinical professionals to broaden their horizons beyond institutional care - thereby creating an environment of institutional care as a position of last resort rather than an immediate direction.

Public education and advocacy for all the above by national and state BIAs

Public education and advocacy for all the above by national and state BIAs

Recognise that accommodation is one option in getting people out of aged care therefore be more proactive in building accommodation built to allow flexible service options and avoid delay in moving people following assessment.

Recognition of the impact of cost of care and support on individuals' disposable income. How can inclusion be achieved if a person has no money left even to buy a coffee regularly, let alone pursue more expensive activities

Recognizing and addressing the need for rehabilitation for ABI/ YPINHs with a view to unburdening the aged care system and maximize an ABI's chances of returning to the community.

Regular communications to clients and families need to be established and maintained

rehabilitation is nowhere in this initaitive and it must be. for people with neurological disease, rehab is crucial to maintain your health. yet we can;t access it

Rehabilitation to continue at acute setting until suitable for ongoing rehabilitation in supported accommodation. Taskforce Independence estimates approximately 60,000 who have a 'profound or severe core activity limitation….

Rehabilitation to continue at acute setting until suitable for ongoing rehabilitation in supported accommodation. Taskforce Independence estimates approximately 60,000 who have a 'profound or severe core activity limitation' and need long term supported accommodation, which is about 10% of official government estimates

reluctance of DADHC(NSW) to employ any nursing staff in a group home situation, when people in a NH obviously need some of this type of care

Resource community development for young people with high care needs. Build the capacity of local communities to be inclusive and supportive of this group. Help communities understand their needs.

Respite services that are appropriate for young people.

Review all protocols between health and disability i.e. RDNS, ACAS to ensure they apply across all situations are are equitable

Safe guards put in place to make sure the YPINH once in the community have appropriate services.

"Specific and robust benchmarks need to be created as part of the agreement. These should include timeframes for implementation.

Start building some housing options in some high numbers areas.(NSW)

Staying in the RAC - seeking innovative ways to enable residents to join community activities - eg supply (small) wheelchair vehicle, to enable volunteers/family members to transport individual residents.

Strategy for addressing the lack of information that exists with social workersand acute care hospitals of an ABI's potential options/resources

Strict monitoring mechanisms must be in place. These must be in place throughout the life of the program, not just an evaluation at the end of the program. These mechanisms also need to measure across jurisdictions.

Support for people who are at home is a necessity to prevent them becoming at risk.

Supportive accommodation in the community e.g. Housing Estate

The best support that governments can give family and carers is to set up and properly fund a national rehabilitation scheme and sufficient supported and integrated accommodation (the staff onsite become the case….)

The best support that governments can give family and carers is to set up and properly fund a national rehabilitation scheme and sufficient supported and integrated accommodation [the staff onsite become the case managers, carer supports and provide the social framework and community setting which is missing in the 'salt and pepper' models where clients can be easily isolated in a wider community

The biggest and most significant issue is that the initiative needs to be funded adequately and appropriately by the FEDERAL GOVERNMENT. without appropriate funding the initiative will always struggle to meet the needs of YPINH

The carers that work in these places must be paid decent wages. An increase in wages could give staff the incentive to stay at a place longer

"The COAG YPINH initiative is prioritizing people under the age of 50 either in RAC or at imminent risk of entering RAC. At the same time, ACAS teams are making it extremely difficult to obtain an assessment to enter RAC for people under 65, leaving those between 50 and 65 in a serious position. We recommend a transition plan which includes consideration of the real needs of people between 50 and 65 and the real levels of accommodation available, ie ACAS policies should be amended to accept people under 65 into RAC while the new accommodation for younger people is being built.

The Commonwealth, State and Territory governments to take a more collaborative and proactive approach in the decision making. While the initiative was a first step many of the ideas now on the table should have been addressed at the beginning.

The Department of Health and Ageing are not intimately involved enough - they need a more formal role

The development of many more community based accommodation options.

The focus on taking people under 50 out of aged care has also meant that people under 50 are currently experiencing great difficulty in getting assessments.

The gap between Disability and Health/Aged care is as great philosophically and practically as the chasm which previously existed between Commonwealth and State Governments to the extreme detriment of YPINH for generations. Most YPINH are in aged care because there is no other option. We must not let that divide between Disability and Health cause the heartache and suffering, and deaths in some instances, that the Commonwealth and State divide has done

The increase in people being supported to live in the community has placed a huge drain on the personal care attendant workforce. This needs to be urgently addressed with increased salaries and a career structure.

the initiative needs to trial new and protected pathways to trial to stop young people so we can learn new things not just battle with the old things

The need for a simple process

The personal care attendant workforce is not adequately trained to meet the needs of people with complex degenerative conditions. There needs to be some work done on standards and training support for this workforce.

The possibility of accommodation facilities and assessments based on the aged care system, for people under the age of 65. Young care facilities from low level care on up to high care, Partnerships could be made with groups that are already accredited and monitored and may already have experience in setting up accommodation for people younger people. This to incorporate a greater number of respite places to support families who continue to care at home. There are existing models of care but there are often issues of on-going funding.

The residents MUST have a say in who the carers are entering their home. I'm sure you have a day who comes into your home, don't you?

The service system must stop serving its needs first and start being proactive and preventative in its approach to the support of Australians with disability

the several parts of the service system health, disability, aged care, allied heath etc MUST work together and collaborate to deliver better outcomes for people with disability

There is a serious lack of respite beds available for younger people with challenging behaviour. We recommend a model based on psychogeriatric facilities, where several beds are available for respite.

There is a significant service gap for people with younger onset dementias who have violent or challenging behaviours. These people present a serious risk to themselves, other patients and staff when they are housed in RAC or lower levels of accommodation. Psychiatric services do not beleive they are suitable for long term accommodation of these people. We recommend that a model based on psychogeriatric facilities be developed for younger people. This would be a secure facility and would include highly skilled staff and appropriate social and recreational activities for younger people.

There needs to be clarity of the eligibility criteria and a mechanism for enforcement across jurisdictions needs to be evident.

there needs to be greater emphasis on information and effective communication with all stakeholders, especially young people and their families

There needs to be more funding packages to enable young people to enter into supported housing

There needs to be recognition, and action, that institutional supports are not the most appropriate support models for most people even those with high support needs. We need to be imaginative and flexible in how supports are provided

There should not be any nursing homes (or other institutions) created for young people. We cannot move people out of one institution into another institution.

These places MUST be accessible to family. I cannot stress how important family and friends are to the mental wellbeing of an individual

These residents are entitled to a 'social life'. There must be a program that fulfils these requirements.

Things take so long to get response, having to go through bureaucrats passing the buck

This supported accommodation to be of various types to suit eg medium-high care facility, hostel, cluster setting etc. on same site to utilise facilities and skilled staff; based on Victorian, WA and overseas models (e.g. UK, Norway…

This supported accommodation to be of various types to suit, eg medium-high care facility, hostel, cluster setting etc on same site to utilise facilities and skilled staff; based on Victorian, WA and overseas models [eg UK, Norway, 'Humanitas' in the Netherlands]

Time-lines and benchmarks for services to be provided need to be set. There appears to be an attitude that all will be achieved "in the fullness of time".

To develop shared care models of support.

To ensure that services are in place to assist families after discharge from the health system.

To fast track the introduction of a no-fault compensation scheme for catastrophic injury.

To have flyers available with information regarding Y.P.G.A (Social support for young people in nursing homes) including contact information.

To increase and enhance slow stream rehabilitation services both home based and community accommodation facility based.

To introduce a no-fault compensation scheme.

Train Disability Support Workers to deliver community based rehabiliation

Transition issues - ensure residents have access to new equipment, visit the new community and link with members of that community before moving.

Transitional living centres to facilitate transfer to more independent (although possibly still supported) accommodation, especially at the stage of transfer from the acute rehabilitation facility

Transitional living centres to facilitate transfer to more independent [although possibly still supported] accommodation, especially at the stage of transfer from the acute rehabilitation facility

use an insurance based approach to funding for disability services that covers catastrophic injury and neurological disease amongst other areas

we have to wait far too long for action in this initiative. people's lives are on the line here yet there is no sense of urgency about doing something

We need both State and Federal to have their commitments and resources to act not talk

we need nursing care available as part of community services for people with disability...not in aged care homes but as part of their community supports!

we should be trying to keep families together not sending them off to group homes

What accommodation is available for people older than 45 years?

What accommodation is available for people with severe behavioural needs?

What accommodation options are available for people with complex care needs e.g. tracheostomy?

What is the age range for young people in Nursing Homes?

When new nursing homes are built, maybe supportive accommodation could be built in for young people with high care needs, but would live completely separately from nursing home residents.

Where young people choose to stay in the aged care system, additional funding be available to provide services for younger people to enhance their quality of life, such as equipment, access to community activities, therapies etc.

Widen the age of the target group

With advances in medical science, many YP with severe ABI who previously died are now surviving. Many are aware, some 'locked in' profoundly disabled bodies and communication systems, unable to speak for themselves. They have a narrow margin of health. If we save them we need to care for and support them to live life as they are.

Would like to see small community settings of perhaps 10-15 persons residing in a mix of housing options on one site

young people and families should be directly involved in development of services they will use

young people and families should be involved in ongoing management of services they use

Young people need to be in a house with similar age interests for stimulation

Young people to be in places where they can re-join the community as equals

Aim rehab services at improving, as opposed to maintaining client function levels. Aim to attain maximum function levels

Aim to achieve a return to society as opposed to a care facility

In Qld there needs to be a care and rehab service that provides to all young people at all levels of care and support – no gaps

Initiate a notification and tagging/following progress system to (a) inform and (b) update government agencies re necessary funding and staffing levels

Provide for more centres aimed at providing care and rehab for young people with A.B.I

Provide separate facilities for younger people either as separate housing or as specific younger units within established nursing homes

Rehab needs to be treated as rehab – not maintenance

Take a look at current situation for younger people including those with dementia who are already in nursing homes. They need more funding to provide extra support, services and activities

There needs to be better information and support services that are easily available- families shouldn't have to go looking for it. Should be provided at the earlier stage

Continue with the task which had been initiated. Endeavour to clearly define the objective and then do something and remind all others to do the same.

Continue to maintain general public awareness (in a relentless manner) of the issues associated with this major concern

Remind members of government and support services that the problems are real and that sympathetic and realistic approaches to problems (rather than bureaucratic ones) are what are needed.

- *Attachment D: Providers – Full list of statements*

A more efficient process re the Funding for our clients.

Address current situation but also look at prevention of brain injuries

Development of transition/continuing care options to bridge the gap between when a person is ready to leave acute/sub acute hospital but needing more time before ready to engage in "lifetime" planning required by Disability Services

Ensure as many appropriate providers who lodge tenders have the opportunity to provide services to the target groups, to encourage innovation and broad range of options

Ensure that assessments are undertaken independently of the Dept / others where there may be the potential for conflict of interest (eg person's current RAC facility) in all states

Establish entry criteria into nursing homes addressing the age factor therefore having alternative accommodation for people who do not meet the age requirement. For example, only people over the age of 60 are able to enter nursing homes

Focus much more on preventative options e. g. ways to prevent people from entering into residential aged care

For planning legislation (Victorian Planning and Environment Act) to be amended and reworded resulting in exemptions from protracted planning processes. Currently exemptions exist for the use of a building but not for the construction of the building which requires a lengthy advertising and planning process. Clauses 52.24 and 52.23 could be reworded in order to meet the intent of purpose building a home in the community for people with a disability.

For the allocated funding and distribution to be managed by an organisation or authority outside of a state government department

For there to be realistic allocation of resources required by community sector organisations for both service development and long term sustainability. Currently the hidden costs of new service development are not recognised.

Given the limited number of high care residential places available for younger people, we will need continued access to the aged care system. The current DSQ/ACAT agreement has at times resulted in significant delays in receiving community support or permanent placement as well as being very time consuming from a service point of view. The limited number of actual and available places for younger people requiring full nursing care needs to be acknowledged and the path made easier to ensure people's needs are being met.

Inject more money into the process to ensure objectives are met

Involve the target group in all processes and stages

It could be useful to explore the possibility of increasing placement options in the acquired brain injury services, which is appropriate for some younger people with Huntington's Disease. At present we only have access to a very limited number of placements (approximately 4 in the state).

More funding for recreation.

More hours for the carers to help their clients rehabilitation process.

Pathway/services for younger people who do not fit Disability Services eligibility crieria eg those with mental health or disabling illness- this group currelty have no access to MFMC

People with Huntington's Disease become increasingly more physically incapacitated as the disease progresses and can remain in an advanced (fully incapacitated) for many years. Despite cognitive impairment, people with advanced Huntington's Disease remain intellectually intact and are therefore aware of their circumstances and the environment in which they live. These are extremely difficult life circumstances for individuals to adjust to and one that often leads to the person experiencing anxiety, depression, ongoing loss and grief and continual frustration. As a result, challenging behaviours are common. Younger people with Huntington's Disease present services with unique and complex care needs.

Provide greater opportunity for a wider range of support services/providers to discuss/submit ideas for different 'model' of providing support based on individual need and preference

Provide sufficient resources to support purchase of equipment, community access, other items as well as supported accommodation

Receiving funding through DSQ is very time consuming. There is also a lot of uncertianty as to when or if funding will be made available. In contrast, the aged care system has been very responsive and the assessment process has been direct and thorough.
Stop wasting time and build more accommodation facilities for young people at risk of entering nursing homes

That funding models acknowledge the rehabilitation needs of people with an acquired brain injury and not simply their habilitation needs. This may necessitate the development of new qualifications that are based on health, rehabilitation and disability. It may also necessitate that funding models need to be more fluid as individuals support needs change due to intensive therapies.

The current eligibility criteria for diverting admissions into aged care facilities excludes most people with Huntington's Disease and we have yet to have a client placed in an age appropriate high care facility.

The Huntington's Disease Association of Queensland has a total of 61 clients living permanently in an aged care facility who are 65 years and younger. Of these 61 clients, only 20 people are eligible for a care needs assessment under YPIRAC's priority criteria. Of these 20 clients, we are only aware of 2 people who have been assessed to date. Consequently, we have very little experience of YPIRAC to date.

The Huntington's Disease Association of Queensland have up to 78 clients living in the community (throughout Queensland) who have support needs ranging from low to high and complex care needs. We will require residential high care options for all of these clients in the future. The development of Youngcare at Sinnamon Park and Young Lifestyle Care at Gordonvale appear to be excellent models, but only provide a limited amount of placements. A model of developing a younger persons unit within nursing homes has been successful in other states and should be considered as an option to meet COAG's objectives.

The limited availability of suitably trained staff, both attendant care workers and specialist therapy staff such as physiotherapists and occupational therapists who are available and willing to assess and support ypinh.

There is need to ensure that the agenda includes all 'younger people in nursing homes'. Younger people in nursing homes extends to people with younger onset dementia.

To design service models with people that is based on their assessed and identified individual need rather than developing a service in the absence of the people who will use the service and in the absence of their individual needs.

Utilise the $s allocated more quickly and efficiently - Many states are very slow to get things moving and many people remain in inappropriate accommodation

Utilise the $s to support longer term community rehabilitation options for people who require this.

We are aware that DSQ have limited experience in supporting people with Huntington's Disease. We would like to contribute towards improving DSQ's staff knowledge and understanding of this complex disease and care needs. The development of a suitable forum for this to take place would be ideal. This would also support a more collaborative working relationship between DSQ and the non-government sector.

We are hopeful that our clients remaining in an aged care facility will receive additional support. We would like to know when this model of support will commence and whether this support will also be made available to people aged between 51 and 65.

We need access to wheelchair accessible public housing in a range of places

We need suitable accommodation options for people with high support needs

We talk about moving people out of nursing homes as a goal in itself without considering people needs to be close to their families and support networks. ie. I am supporting a man who wants to move to an outer suburb of Melbourne but the only available option suitable for him is in the inner suburbs further away from where he wants to be

will there be recurrent funding for young people who move from a nursing home.

Work in partnership to ensure sustainability and appropriate facilities are built

Workshops for Carers to help them learn about their clients disabilities and understand them.

50 – 60 years – does that make it too big task

A commitment for workers to seek and take seriously the young persons and their family, carer knowledge about what accommodation is best for the young persons physical, social, emotional and spiritual wellbeing

Access to Allied Health professionals with expertise in this area ie: not limited by cost

Accommodation – creative & adventurous

Appropriate for indigenous young people

Avoid entry – have solutions in place

Case management role in ongoing monitoring

Communicate concept to all communities

Consider the needs of the 50 – 60 year age group for the next 5 years beyond this project

Continue to consult with consumers and stakeholders to ensure that YPINH's needs are met

Coordinated approach – use of multi-disciplinary teams, instead of single providers

Create centres of excellence that provides models for the support and potential of YPINH

Destroy the culture of YPIRAC

Develop access to therapy options to meet needs

Develop appropriate young peoples nursing homes with capacity to cater for all groups ie: CALD & indigenous

Develop long term sustainable plan

Find innovative concepts for living

I work in an acute hospital setting, young people are often transferred straight from acute care to nursing home care, often in the early days after the life changing diagnosis. There is a need for interim care where rehab is continued, where ling term needs and abilities can be determined

More support in rural areas for young people

Not a quick fix – must endure

Offer greater support in rural areas (home care/personal care services)

Own accommodation for young people so that they do not have to utilize on age care facility

Plan for future unmet meed, particularly for those with progressive neurological diseases

Quality of life!!!

Streamline process

The development of a sustainable income stream to meet the needs of young people with high level nursing needs into the future

The development of structural / organisational support networks for families/carers so that their capacities to support their family members is sustainable

The need for ongoing multi-disciplinary assessment and reassessment so that care planning, including accommodation needs can be adjusted