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Results…
National Roundtable on Lifetime Care and Support

Melbourne
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Young People In Nursing Homes National Alliance

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

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

Key discussion areas included

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

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

Life time care and support (LTCS)

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

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

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

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

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

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

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

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

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

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

Assessment and planning

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

Areas of assessment should include

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

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

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

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

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

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

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

In short, assessment and planning should incorporate

- Proactive risk management approaches
- Regular review of assessment skills and approaches regularly

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

Health and clinical input

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

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

Consumer input

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

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

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

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

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

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

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

Research and results

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

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

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

Disability/aged care divide

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

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

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

Conclusion

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

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

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

The following points were unanimously agreed.

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