



**NSW Joint Solutions Leaders Summit
Macquarie Room, Parliament House, Sydney
24 October 2012**

Leaders from the health, disability and aged care sectors in NSW met in the Macquarie Room, Parliament House Sydney, to discuss options for coordinated care pathways for young people with complex support needs at the NSW **Joint Solutions Leaders Summit** convened by the Young People In Nursing Homes National Alliance.

NSW Minister for Disability Services and Minister for Aged Care, the Hon. Andrew Constance, opened the Summit. Also attending were Minister Constance's parliamentary colleagues, Hon. Marie Ficarra, Parliamentary Secretary to the Premier; and Hon. Melinda Pavey, Parliamentary Secretary for Regional Health.

Minister Constance spoke about the outcomes delivered by the Council Of Australian Governments (COAG) Younger People in Residential Aged Care Program (YPIRAC) in NSW; the relevance these outcomes have for successful delivery of the National Disability Insurance Scheme (NDIS); and forthcoming completion of YPIRAC capital projects in NSW to ensure the gains from YPIRAC are not lost as we move towards the NDIS. He also acknowledged the need for greater collaboration between NSW health services and the Commonwealth to deliver the coordinated supports required by the YPINH cohort.

In reiterating his government's commitment to improved collaborative effort between disability and health services, Minister Constance further indicated his intention to see this important area addressed as part of NSW's National Disability Insurance Scheme Launch Site in the Hunter region. Minister Constance also expressed his desire for the Alliance to contribute to work on the health/disability interface, particularly in regard to the Hunter Launch Site.

Following the Minister's address, Dr Bronwyn Morkham provided a summary of the YPIRAC program and the central learnings that had emerged. In cautioning that these risked being lost in the rush to the NDIS, Bronwyn reminded those present that YPIRAC was a single disability program response nationally that had met some of the needs of this group, but had also highlighted gaps in service pathways for young people with complex care needs.

In particular, Bronwyn mentioned the lack of rehabilitation services available to people both in the community and also in aged care that had been highlighted by the initiative and expressed the hope that the NDIS would begin to address this significant service shortfall. Bronwyn also commented on the full funding of customised equipment as another element of the YPIRAC initiative that had delivered a significant positive impact for clients of the program, but that had been discontinued at the conclusion of the initiative.



While full funding of customised equipment and a number of other effective features of YPIRAC, including the Continuous Care Pilots in NSW and Victoria, were not picked up by disability services programs nationally, Bronwyn reiterated that they are support models that are directly applicable to the NDIS development; and that there is evidence and experience from YPIRAC that must find its way into the launch sites.

Bronwyn made the additional point that development of care and support pathways across health, disability and aged care programs has been the focus of Community and Disability Ministers attention since YPIRAC ceased taking new clients in 2011. While Ministers have committed to developing workplans to guide this work in each jurisdiction, progress has been patchy. As the NDIS will require these program connections, there is an urgency to develop them for use both within the launch sites, as well as elsewhere.

Bronwyn further noted that the process of joining up programs is a more complex task than it appears due to entrenched bureaucratic structures and the lack of a clear mandate. Although the logic and economic arguments for doing so are compelling, Bronwyn confirmed that the silo approach remains the norm, leaving deliberate policy leadership as a prerequisite if progress is to be achieved.

In referring to comments made at the Victorian *Joint Solutions Summit*, Bronwyn acknowledged those by ex Victorian Health Minister, Rob Knowles', who stated that such moves need ministerial commitment. Rob indicated that while things could progress at the officer level within departments, without ministerial directions and agreements, there is a clear risk that connections developed don't last.

Bronwyn concluded by saying that a recommendation from both the Victorian and Tasmanian *Joint Solutions Summits* strongly supported a joint budget bid by their respective State Health and Disability Ministers to invest in initiatives designed to join up the relevant health and disability programs. Savings and efficiencies could be identified and the creation of programmatic pathways could be prioritised within such a collaborative effort. This approach would also demonstrate the ministerial commitment needed in this area.

Ms Michelle Brown, a young woman living with Multiple Sclerosis, then addressed the Summit. Michelle was a participant in the Continuous Care Pilot (CCP) undertaken as part of the YPIRAC initiative in NSW. With the aim of maintaining young people with progressive diseases in the community and preventing their admission to aged care services, the CCP used a risk management approach with a care coordination methodology to deliver the supports required by participants with progressive diseases in a timely manner.



Michelle spoke of the benefits 3
the CCP delivered for her through its partnership with Macarthur Rehabilitation and Aged Care Services and Ageing, Disability and Home Care's (ADHC) disability services division. She described how she had experienced 64 hospital admissions in the year prior to joining the CCP and how her health and well-being had stabilised as a result of the CCP's coordination of health and disability supports.

Michelle also described how, since the program had ended, her health was once more in question because of the difficulties she faces in trying to access needed care supports without the coordinated input of the CCP. Michelle described the financial and emotional strain on her family that the lack of coordinated input had delivered; and indicated that without this approach, the NDIS would not be able to deliver the services she needed. Michelle concluded by asking Summit participants to find the solutions that she and other young people in her position so urgently required.

The Summit then heard from a panel of health practitioners and family members who discussed the service gaps they had experienced. Panel members included Dr Adeline Hodgkinson, Director of the Brain Injury Rehabilitation Unit at Liverpool Hospital; Mr Denis Ginnivan, Director of the South West Brain Injury Rehabilitation Service in Albury and Policy Consultant with the Rural Health Alliance; Ms Jane Watson, parent of a young man with an ABI living in an aged care facility; and Ms Michelle Brown.

Dr Hodgkinson spoke of the lack of capacity and coordinated care she faces when trying to transition young people to the community post rehabilitation. Dr Hodgkinson mentioned one young man who, after sustaining his brain injury (ABI) at age 15, was still in the Unit today, 3 years later.

Apart from the hospital's daily bed cost of \$1100, this young man's continued presence in the unit means 6 people are denied access to rehabilitation annually because health dollars are being diverted to provide accommodation in a hospital setting for him. Dr Hodgkinson also indicated that the money spent on accommodating this young man in an acute care bed thus far, was enough to purchase his own home for him to this point.

Dr Hodgkinson also spoke of the need to redefine rehabilitation. She mentioned another individual who refused to undertake facility based rehabilitation but was continuing with his rehab by successfully attempting a rehabilitation program of activities of daily living at home.

Denis Ginnivan spoke of the difficulties rural and regional areas face with a chronic lack of resourcing and the need for individuals to leave their families and communities to access urgently needed rehabilitation in city centres. Denis spoke of



efforts to engage a private provider to establish a live-in rehab service in Albury in an effort to manage growing demand for rehabilitation services in the region. 4

Denis also indicated growing concern about the NDIS' inability to meet complex support needs in regional areas because of workforce and other systemic issues in these areas including lack of rehabilitation programs. He mentioned that despite a view that health services should deliver rehabilitation for young people, these programs were often non-existent in health because of a lack of resourcing and capacity.

In describing the situation her son, Jock confronts in an aged care facility without the resources to adequately care for him, Jane Watson spoke of the frustration she experiences in her efforts to get Jock the appropriate care he needs, through either a home-care package; or via placement in an appropriate community supported accommodation service. At one stage through the YPIRAC program, Jock was promised a place in a home at Lidcombe, but this project didn't proceed.

Despite receiving limited funding through YPIRAC to assist with community access and provide equipment, Jock has lost much of the capacity he regained in hospital post his injury, because the aged care service lacks the capacity to sustain it.

Jane continues to be grateful to the aged care facility Jock lives in but was damning in her comments regarding disability services inability to deliver the supports her son needs, despite her considerable and continuing efforts to work with them to achieve this.

Following morning tea, Summit participants heard from ACIL Tasman's Dr Yuan Chou about his work to describe the cost to government and the community when coordinated care pathways are not delivered; and the socio-economic benefits that result when they are. In undertaking this work for the Alliance, Yuan has worked from a series of live case studies to make his calculations. The case studies were based on taking a real life risk management approach, utilising competent case coordination, timely service provision from multiple programs and practical support of families.

Yuan presented the preliminary data from his analysis that showed the project methodology and a number of case study costings. Across the 9 case studies, for example, the average system savings (mostly accruing to the health system) was \$1.35m per lifetime. This was in addition to improved quality and length of life for each of the cases. Feedback from participants was that the cost estimates Yuan presented were very conservative, and that in real life, cost savings were likely to be much larger. Summit participants further confirmed their hope that the NDIS would



improve the current paucity of available data; and that improved development of service pathways would result. 5

Participants then broke into small groups to consider a series of questions concerning development of coordinated care pathways and improved collaboration by health, disability and aged care services to achieve these.

These questions included:

1. Do opportunities exist presently for joining up health, disability and aged care programs in NSW?
2. How do we take advantage of these opportunities?
3. What barriers might we face in developing cross program pathways and how do we overcome them?

The following points were made in answer to the issues raised by these questions.

- Unanimous agreement was declared on the need for proactive collaboration by health, disability and aged care services to contribute expertise and funding to develop coordinated care pathways for those with complex care needs.
- Concurrent and united calls for NSW Health and Disability Services Ministers to commit to dedicated partnership between health and disability services to develop care pathways for young people in nursing homes group were made.
- Summit participants recommended that NSW Health and Disability Ministers make a joint budget bid for shared funding to develop coordinated care pathways in the next NSW Budget.
- As part of the budget bid, participants called for development of a dedicated tertiary coordinator workforce to link and manage services across program and portfolio boundaries.
- Universal recognition of the waste of resources and lives resulting from the current lack of coordinated care pathways for younger people with complex needs was declared.
- Recognition of the significant financial and systemic burden health services carries because of the lack of capacity and/or expertise in disability services responses was indicated.
- Unanimous support for the NDIS Hunter Launch Site to pursue active collaboration with health and aged care services and include younger people living in aged care facilities and hospitals as part of its remit, was also declared.
- Significant concern was expressed that the NDIS was developing as a disability only program.



- Strong and unanimous support was declared for the NDIS to pursue active partnership with other program areas, particularly health, aged care, education, housing, transport et al. 6
- In focussing on the development of coordinated care pathways for all its clients, participants unanimously called for the NDIS to acknowledge the urgent need for health services involvement in general, but community based health services in particular, as part of the scheme's development.
- A call for greater community involvement in the development and delivery of the NDIS was agreed to.
- Agreement by all participants that the 'D' be removed from NDIS in an effort to declare the initiative as a life time care and support enterprise, not the singular disability program it is in danger of becoming.
- In contrast to the current practice of single program eligibility only for the YPINH cohort, participants called for multi-program involvement with concurrent eligibility for *all* programs for those with complex health and other support requirements; and for programs to maintain their commitment and funding as other, multiple program areas come online.
- Instead of 'integrating' individuals with disabilities and progressive diseases into their local communities, there was a clear call for communities to proactively engage with people with disability. One example was for supermarkets and other retail outlets to address accessibility issues regarding proximity and display of product lines as well as site access. Similarly, transport entities need to consider how to make their offerings of use to those with disabilities.
- Calls were made for aged care facilities to work proactively with disability services to deliver interim or transition options for young people with complex care requirements. Doing so depended on strong commitment and funding and practical involvement by health services in partnership with disability and aged care.
- Participants called for a greater focus on people rather than programs and reiterated that 'joining the dots' could be achieved by focussing on the person.
- Unanimous agreement was declared that funding should be determined in terms of outcomes rather than 'plans' and, again, focus on the person not the program the funding was coming from.
- Participants were united in their recognition of the value of rewarding collaborative pathway development across programs.
- A concerted call to capitalise on the evident understanding and desire to 'make a difference' that exists across program areas was made; and to hold



this goodwill to account 7

through delivery of coordinated care pathways. The need to soften and 'blur' program boundaries to deliver more flexible, person focussed care pathways was also acknowledged.

- Recognition that financial imperatives are important for government at macro and micro levels; and that delivery of coordinated care pathways can successfully deliver significant socio-economic benefits to government and the community was agreed.
- Unanimous calls for improved and collaborative data collection across program areas with data made widely available, were made.
- All groups made strong calls for improved flexibility in service design and delivery with service providers and government agencies committing to more proactive and collaborative interaction.
- The need for greater community involvement in rural and remote service design and response, was accompanied by recognition that local communities have a greater capacity than their metropolitan counterparts to financially and personally support local initiatives; and that this should be acknowledged and factored in to service development in regional, rural and remote areas.
- Recognition of the importance of geography was made: that staying close to family and within community is often crucial to the health and well being of those with impairment.
- A call for development of transition service models for people going into group homes
- Participants noted the need for reform of the purchasing and design arrangements for future group homes to incorporate greater community involvement in these smaller, locally based services.
- In calling for health and disability services partnership, participants identified the need for overlap and articulation, not duplication of these vital services.
- Further calls for activity based funding and the active involvement of local district health services were made, though recognition of the ongoing nature of health reforms currently in play meant that this call was yet to be recognised and supported systemically.
- Summit participants also identified the following extant barriers to improved collaboration and partnership and called for these to be addressed as a matter of urgency:
 - ❖ Inadequate funding by both state and federal agencies in all program areas but particularly disability. Disability funding seems to have 'stalled' nationally as attention to development of the NDIS has increased.



- ❖ Lack of integration 8
between state service delivery areas such as health, disability, education, justice and transport.
- ❖ Lack of coordinated responses for those with dual and multiple disabilities.
- ❖ Age as a determinant of service response and program eligibility, rather than need. This includes the age 65 aged care service eligibility, despite the aged care sector's incapacity to support the needs of those with complex disability over 65 years; cessation of child services at 18 years with no transition to adult services in disability, health or education; <50 years as determinant for priority access to disability services in Victoria. Without priority and in the face of inadequate resources, services will never be delivered for those without priority, as those possessing priority status jump over those without it. Comment was also made that in light of inadequate aged care funding, the advanced average age of those successfully accessing aged care services was 80-85 years plus, leaving those in the 65-75 year age range in no man's land, without access to disability and/or aged care services at all.
- ❖ The current proposal that eligibility for the NDIS only includes those aged <65 years at the onset of disability. While decrying this reiteration of the current 'broke and broken' system and calling for it to be removed, comment was also made that with the aged care reforms currently in play, a truly national life time care approach involving health, disability and aged care services was possible, and synergies between the two reform programs need to be identified and built upon.

In concluding the Summit's proceedings, the Alliance's National Director, Dr Bronwyn Morkham, thanked participants for their contributions and indicated the Alliance would be seeking meetings with Minister Constance and Parliamentary Secretaries, Marie Ficcaro and Melinda Pavey to disseminate the Summit's conclusions; and seek government commitment to improved collaboration between program areas in disability, aged care and health particularly, that would advance the development of coordinated care pathways for the YPINH cohort in both the Hunter launch site and statewide.