Victorian *Joint Solutions Leaders Summit*
K Room, Parliament House, Melbourne
9 August 2012

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

Dr. Bronwyn Morkham, the Alliance's National Director, welcomed those present and asked each person to briefly introduce themselves, outlining their role and what outcomes they hoped to obtain from the morning's proceedings. A desire to address some of the major service system blockages experienced across programs emerged as an early concern.

Dr. Morkham then introduced Victorian Parliamentary Secretary for Health, Hon. Nick Wakeling, to officially open the Summit. In representing Hon. Mary Wooldridge, Victorian Minister for Community Services, Nick spoke of the need to further improve health and disability services' cross portfolio involvement and collaboration; and the need to better integrate service responses for those with complex support needs.

Nick also spoke of his government's positive view of the Council Of Australian Governments (COAG) Younger People in Residential Aged Care Program (YPIRAC) initiative and its outcomes in Victoria, including growth of service capacity in regional and metropolitan areas as one of the clear benefits. He also spoke of the Victorian Government's support for the National Disability Insurance Scheme (NDIS) and their desire to have one of the NDIS launch sites in Victoria. Nick concluded by saying that health and disability program areas were looking forward to the outcomes of the Summit; and to progressing work for the YPINH cohort, work that had obvious significance for the success of the NDIS.

In thanking Nick for his welcome and his presence as a participant, Bronwyn Morkham then provided an overview of the YPIRAC initiative and the significant learnings that had resulted from this national program. As well as acknowledging the considerable improvement in sector capacity the initiative's dedicated funding had delivered in Victoria, Bronwyn declared that despite the program's design shortcomings, it had succeeded in shining a light onto a forgotten and largely unknown group.

Bronwyn also referred to the *Next Steps Report* the Alliance had been asked to write by the Council of Australian Governments Standing Council on Community, Housing and Disability Services (SCCHDS). This Report, delivered in early 2011, argued for a continuation of the YPIRAC initiative to consolidate the significant learnings that had

been delivered by the initiative by the end of its first five year term. Amongst others, these learnings included:

- The clear need for proactive collaboration and partnership between disability, health and aged care services.
- A Life Time Care coordination model to deliver comprehensive cross program management capacity for the YPIRAC cohort via assessment, service design and oversight of service delivery.
- Use of specialist tertiary Care Coordinators to assess eligibility and support needs, manage the planning process, and oversee service delivery for YPIRAC[2] participants.
- The need for jurisdictions to work quickly to ensure YPINH become eligible for fully funded equipment, including high end pressure care, as part of State and Territory Aids and Equipment schemes.
- Implementation of community based slow stream rehabilitation programs in all states.
- On discharge from acute care, service protocols that ensured
    - rehabilitation/habilitation services are part of support packages for participants exiting acute care
    - protocols with aged care that enable (re)habilitation services to be delivered in aged care
    - proactive partnerships with health re delivery of rehabilitation, nursing and allied health resources in the community.

Following Bronwyn's presentation, Summit participants heard from a panel of health and aged care practitioners who discussed the service gaps they experienced and the waste this delivered across all program areas.

Panel members included Ms Sue Race, Divisional Director, Subacute & Residential Aged Care Services, Western Health; and Dr Susan Mathers, Head of Neurology, Calvary Health Care Bethlehem. Ms Brenda Wells, Director of Nursing, St Michael's Nursing Home, Murrumbeena, was to have joined the panel discussion but was unable to attend. Dr Morkham, who had worked with Ms Wells and a number of young people who had resided at St Michael's, joined the panel in Brenda's place.

In facilitating the panel discussion, Alan Blackwood asked Sue Race to begin by outlining some of the cases Western Health had recently dealt with and the impact these had had on Western Health's acute care capacity. Alan asked Sue to comment on the fact that health services make a significant investment in these young people by saving lives and restoring health as much as possible. Yet longer stays in hospital

can be counterproductive, resulted in diminished health for long stay inpatients and escalation in health costs consequently.

In responding, Sue spoke particularly of a young man with volatile insulin dependent diabetes who had already sustained several hypoxic brain injuries as a result of hypoglycaemic coma.

Sue noted that his family had transferred "James"[1] from another state to Victoria in an attempt to access the rehabilitation he had not been unable to access in his home state. She also commented that while her patient was now in his eighth month as an inpatient in hospital, only the first three months in hospital had been required to stabilise his health. Without options for transition to the community, the last 5 months James had spent in hospital had been purely about providing expensive accommodation because community placement with capacity to support James' health and other support needs, was non-existent.

Sue further indicated that the longer he stayed in hospital, the more James's mental health deteriorated and that presently, and in addition to the daily bed cost of a private room, the hospital had been forced to 'special' James to manage deterioration in his behaviour and his resultant attempts at self harm. Because 'specialing' involved provision of a trained mental health nurse with James 24/7, this was being undertaken at an additional cost to the hospital of $1500 per day on weekdays and $2000 per day on weekends.

Sue indicated that the overall cost to the health service thus far, was in the order of $500,000 plus, an amount that could have provided substantial community accommodation, support and rehabilitation had an appropriate "joined up" care pathway existed.

As far as rehabilitation required by her patient, Sue mentioned that while the hospital had undertaken 'fast track' rehab in its acute care setting, hospital therapists had decided James was not able to benefit further from this type of short term, intensive rehabilitation. As a result, few dedicated health services other than monitoring of medication and management of behaviours of concern was being undertaken by the hospital while they tried to find a community based solution to transition James to.

Sue concluded by expressing her frustration and that of other senior managers at Western Health who regularly find themselves confronting these situations. She commented on the attempted suicide by two other young men, forced to remain in hospital for extended periods because the community placements they needed were

[1] Not his real name.

not available; and the escalation in health costs that had resulted. Sue also indicated that despite repeated attempts to collaborate with disability services on solutions for patients like these, disability services lack of capacity and inability to deliver clinical oversight meant health services were left "holding the baby" at considerable and ongoing cost to government and the community.

Alan then turned to Bronwyn Morkham, standing in for Brenda Wells, for comment on the situation Sue had just outlined. Bronwyn indicated that the Alliance had been involved with James and his family across two states and continued to advocate for the integrated service response he needed to recover. Bronwyn indicated that Brenda and St Michael's had been willing to take this young man as an interim placement to facilitate his discharge from hospital. But a precondition was a funding commitment from disability services to augment the nursing home's lower staffing levels and ensure the rehabilitation services and community access James required, could be delivered.

Bronwyn indicated that in case conferences attended by Western Health, St Michael's and regional disability representatives, Brenda had requested a funding commitment in writing from disability services. Unfortunately, however, disability services was unable to make any funding or other commitment to facilitate James transition from acute care.

In an attempt to sustain James' health and well being, Western Health had offered to fund these services for one month to facilitate matters and progress development of a transition plan for James; and as a gesture of good will indicative of its commitment to James' wellbeing. Victorian Disability Services then agreed to contribute a small disability funding package that had accompanied James when he moved to Victoria from his home state and make these funds available to the nursing home to enable rehabilitation, management of behaviours of concern and community access to be delivered.

While these efforts were welcome, Bronwyn reiterated that a coordinated care pathway was still absent for James after these funds expired; and that at this point, St Michael's had been clear it would not be able to maintain James as a resident in their aged care facility without disability services funding and other inputs.

Alan then turned to Dr Susan Mathers and asked her to speak about the collaborations she had undertaken with health and disability services and the benefits these had delivered. Alan also asked Susan to comment on whether these experiences had this changed Susan's practice and that of Calvary Health Bethlehem around delivery of best practice in tertiary care.

In responding, Susan spoke of Bethlehem's participation in the Continuous Care Pilot (CCP) undertaken in Victoria as part of the YPIRAC program in that state; and the clear benefits this had delivered to CCP participants as well as to health and disability services. The CCP used a risk management approach with a care coordination methodology to develop and deliver the integrated care pathways individuals with progressive diseases required to manage their health and other support needs, remain at home in the community and avoid placement in aged care.

Susan mentioned that by collaborating with disability services, health was able to more effectively prevent repeat hospitalisations and improve and/or sustain the health and wellbeing of its patients with progressive diseases. She indicated that this collaboration had also improved the capacity of disability services to understand how to better support individuals with complex health and other needs; and implement training of disability support workers to achieve this.

Susan compared the CCP with other care coordination programs that Calvary Bethlehem has completed. As one example, the *Coordinated Care in Motor Neurone Disease* project predated the CCP but achieved similar positive results where clinical oversight was provided to skilled regional advisers coordinating programs for individuals and families.

Susan was adamant that the body of evidence in the neurological disease area for supporting a joined up approach over the disease course, is compelling; and that keeping people with complex and rapidly changing needs at home with their families can be done using this coordinated multiprogram approach.

Susan concluded by indicating that she had presented the results of both programs to various professional associations including the Royal Australasian College of Physicians and the Australian and New Zealand Association of Neurologists. In every case, members of these organisations had been impressed with the results obtained and supportive of improved collaboration with other areas, including disability services, to develop improved care pathways.

In summing up, Alan indicated that the panel session had outlined examples of the desirability and feasibility of providing joined up approaches for this group of people with disabilities, as well as highlighting the gross inefficiency of not doing so. The panel agreed that the best location for coordination of this type was at the community level; that skilled local coordinators can make things happen; but that they must have the right specialist health input to achieve this.

In James' case though, there is still the issue of co-funding that is a barrier to achieving a sustainable – and suitable – outcome for him. Programs need to be able

to share the cost of comprehensive programs for this group of people whose needs cannot be met in one program alone.

The panel agreed that more evidence is not required as 'proof of concept' – the evidence presented by the panel indicated that this work has been done. But what is needed is a way for collaboration to occur at the system level between ministers and departments with ministerial support and commitment to achieve this.

Following the panel's deliberations, former Victorian Minister for Health, for Housing and for Aged Care, Hon. Rob Knowles, addressed the Summit. Rob spoke about his work to develop Victoria's *Slow To Recover Acquired Brain Injury Rehabilitation Program* (STR) 15 years before. This program remains the only one of its kind in Australia and uses allied health experts in physiotherapy, speech and occupational therapy to develop a rehabilitation program for young, non compensable Victorians with an acquired brain injury (ABI). Attendant care support workers are then trained to deliver the program. Allied health specialists provide on going monitoring and review and adjust the program according to the individual's progress and changing needs. The STR program remains a cost effective way of delivering slow stream rehabilitation in community settings.

Rob indicated that he had demanded collaboration from a range of different portfolios including Health, Aged Care, Disability, Housing and Transport to develop this unique but needed program designed to address the growing number of young long term hospital stay patients in Victoria's acute hospitals. The burgeoning numbers of long stay hospital patients was due both to a lack of integrated care pathways to the community; as well as a lack of appropriate services to deliver the rehabilitation and other supports these young people required.

Rob indicated that his brief to senior officials was to come back to him with a collaborative response that could demonstrate sustainable benefits. In commenting on the still significant lack of coordinated pathways and collaboration between program areas, Rob stated that without strong ministerial understanding and commitment, achieving such partnered outcomes was extremely difficult. He said that although senior officials were often well intentioned, it was simply not possible to achieve material reform without political commitment from the relevant Ministers.

In concluding his remarks, Rob 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 can be compelling, 'silo-ed approaches' remain a powerful barrier to change that necessitates deliberate policy leadership to make progress.

Despite this, Rob reiterated that the development and continued presence of the STR program was a clear demonstration that truly collaborative efforts across portfolios were possible; as well as of the significant socio-economic benefits in doing so.

Following Rob's presentation, Summit participants moved into small groups to consider a series of structured questions about service gaps and barriers that continued to confound efforts around systemic reform. Results of the groups' deliberations included the following:

- There is a clear need to identify transferrable good practice and promote it around both the health and disability sectors.
- E-health provides opportunities to link health and disability needs and interventions across sectors including the potential to be predictive about the care trajectory and address early intervention assessments.
- New networks are needed for services from different sectors. Medicare Locals may be a good avenue for coordinating and facilitating networks
- Cultural issues between departments remains a significant barrier.
- Systemic change and reform efforts needs political will to succeed.
- Different geographical areas have different cultural issues.
- There is a need to understand changing needs and points of intervention across program areas.
- There is also a concomitant need to understand the two tiers outlined in the Productivity Commission's Report on the need for an NDIS; and an urgent need to establish the interface between them.
- The Victorian Department of Human Services (DHS) High and Complex Care Initiative would have learnings about how to fund and coordinate services across programs. These need to be investigated.
- Health programs may need to individualise some of its funding programs over time. Examples from the UK exist and have pertinence here.
- An integrated front end to the 'system' is urgently needed, particularly for people with acquired disability. Recognition was made that this is one of the objectives informing DHS' current restructure.
- The existing lack of transparency about the way funding programs work, particularly in disability, must change, with greater transparency becoming a feature of service design and delivery.
- As the Western Health example highlighted, a serious wastage of resources results from the current silo approach. A 'fiscal carve up' to generate better systemic efficiency is urgently required.

- A more comprehensive risk management approach to managing complex programs is needed.
- Sectors and programs need dedicated ways of communicating with each other at the agency level as well as with clients.
- With aged care reforms on the table, there is a clear need to find synergies between the aged care and disability reform programs, particularly around the design of gateways as entry points.
- Programs working with people across all portfolio areas need to have a better understanding of the actual experience of the individuals they work with; how their disability impacts the individual and their family; and what impact other programs, eligibility issues or service gaps have on individuals with disability and their families.
- Pooling of individual packages to enable tailored solutions for groups of people will need strong local coordination.
- Service-to-service links must be encouraged without waiting for policy progress or cross agency collaboration as this can be excruciatingly slow. The Victorian CCP showed that regional networks of services can deliver good links and flexibility but these need to be nurtured through expert case coordination.
- In rural and remote areas good connections exist between health, disability and aged care services where even the sharing of workers can happen. This offers a viable model for other areas, and could offer some leadership for dealing with workforce challenges.
- The health sector must understand the health needs of people with disabilities, and not shift responsibility back to disability programs that lack any clinical capacity. The health response needs to continue past the hospital door and into the community, and be available over the life course. To achieve this, health programs must be willing to be collaborative with other programs.
- A call for Victorian Disability and Health Ministers to make a joint budget bid for development of coordinated care pathways in the next Victorian budget, was strongly and unanimously supported by participants.

In drawing the day's proceedings to a close, Dr. Morkham thanked Nick Wakeling for his participation and commitment to renewed collaboration between disability and health services especially.

Bronwyn also thanked participants for their engagement and their contributions to finding the solutions so urgently needed. She reiterated that the Alliance would seek

meetings with relevant Victorian Community Services, Aged Care and Health Ministers to inform those Ministers of the Summit's findings; seek their commitment to proactive partnership and collaboration between the program areas; and development of coordinated care pathways for those with complex support needs.