

# Queensland *Joint Solutions Leaders Summit*Parliamentary Annexe, Parliament House Brisbane 3 December 2013

Convened by the Young People In Nursing Homes National Alliance, the Queensland *Joint Solutions Leaders Summit* brought leaders from the health, disability, housing and aged care sectors in Queensland together to discuss the urgent need for coordinated care pathways for young Queenslanders with complex support needs.

Meeting in the Parliamentary Annexe overlooking Parliament House Brisbane, senior executives from Queensland's Departments of Health; Communities, Child Safety and Disability Services; Housing and Public Works, were joined by Queensland's Anti Discrimination Commissioner, Mr Kevin Cocks; Queensland's Public Advocate, Ms Jodie Cook; representatives from Medicare Locals and the National Disability Insurance Agency; and clinicians and health workers who confront the need for joined up services every working day.

### Context

In concert with the tabling in the Queensland Parliament of the Public Advocate's Inquiry Report into young Queenslanders with disability in long-stay healthcare facilities, Premier Campbell Newman has called for an "action plan" to be developed to move these individuals into community settings with access to the health and other supports they need. With this in mind, the Queensland *Joint Solutions* roundtable was specifically structured to offer participants the opportunity to contribute their expertise, knowledge and practical suggestions to the development of this important action plan.

Karen Nankervis from the Department of Communities, indicated that she was leading a team to implement the action plan mandated by Premier Newman; and that she and her team were keen to start meeting with individual long stay hospital patients and their families as a starting point.

Over the course of the roundtable, participants engaged in frank and open discussion of the issues involved in bringing program areas in health, disability, housing and aged care to greater collaborative effort around development of integrated service responses; and how this could proactively inform development and delivery of the action plan.

### Current state of play in Queensland

To open the discussion and provide a Queensland context to proceedings, the Alliance's National Director, Dr Bronwyn Morkham, asked Public Advocate, Jodie Cook, to reprise the findings of her recent Inquiry into *Long Stay Patients in* 



Queensland Health Care Facilities. Jodie indicated that while data had been hard to come by, the 271 individuals that had been identified in these facilities were costing approximately \$76.28m to support per annum; and that despite this significant investment, these individuals remained institutionalised and without access to the life opportunities they should be taking up.

Drawing on his clinical experience, Prof. Harry McConnell commented that these 271 individuals were the 'tip of the iceberg' and did not include the many people currently in acute hospital settings awaiting provision of longer term placement; and the support arrangements required for effective discharge. Prof. McConnell cited numerous cases where individuals beyond the response capacity of the existing human services system had been given \$1m annual packages, and placed in settings with 24 hour care and no community access that he called 'community prisons'.

Prof. McConnell called for decisive action and was joined in this call by Queensland Anti Discrimination Commissioner, Kevin Cocks, who reminded the meeting that this issue has had a long history that included the introduction of community based attendant care in Australia. He outlined the particular Queensland perspective, but framed the issue as fundamentally one of human rights.

Kevin also stressed that previous attempts to solve the YPINH problem date back to 1986, when the first attendant care programs were established by the Commonwealth. The shift of responsibility to the States in the 1990s saw jurisdictions take over this important area of policy, but doing so with little experience with disability services or understanding of the policy imperatives at the time.

Discussion then centred on examples of integrated service responses already underway in Queensland that the action plan might consider. The Spinal Cord Injury Response program or SCIR, was identified as a stand out example that had joint funding from Queensland Health and Disability Services; utilised the separate expertise of both programs to deliver integrated service responses to individuals with spinal cord injury; and maintained contact with people accessing the program over the long term.

A member of the team developing the action plan, Chris Moretti, had previously worked as one of the SCIR program managers and was able to give a comprehensive outline of the program's design and continuing evolution to meet the needs of its clients.

Chris explained that SCIR came about because of strong consumer advocacy and a political realisation that the economic and social costs of long stays in hospital and a lack of community support were unsustainably high; and that a coordinated intervention could deliver better outcomes more sustainably. Roundtable



participants noted that there are similarities between the genesis of SCIR and the current situation with people with disability living in inappropriate healthcare settings in Queensland. It was noted that solutions to the current situation need the same ingredients that made SCIR successful – political commitment, thoughtful multi program design, skilled service delivery and strong consumer input.

In responding to a question about similar programs for Queenslanders with Acquired Brain Injury (ABI), Jennifer Cullen, CEO of Queensland's Acquired Brain Injury organisation, *Synapse*, indicated that two key groups had been identified in the Public Advocate's Report requiring immediate responses. These were those who had missed out on deinstitutionalisation efforts in Queensland in the 80s and 90s; and individuals with acquired brain injuries unable to access rehabilitation and other services who had been discharged from acute care settings to 'step down' services and basically forgotten.

Jennifer indicated that while the state's Acquired Brain Injury Outreach Service (ABIOS) did a good job assisting people with ABI with transition back to the community, further work was needed to ensure there was a comparable program to SCIR for people with ABI in Queensland that could deliver the resources and services individuals needed to recover capacity post injury. She then spoke of a Synapse Supported Accommodation Innovation Fund (SAIF) project in Cairns that is looking to create a culturally appropriate, long term housing option for fourteen people who are currently long stay residents of the Cairns Base Hospital. Jennifer reiterated that 'joined up' health and disability services are essential if aboriginal people are to have the opportunity to return to country and their communities.

In supporting the need for better partnership and collaborative work practices between health and disability programs, Mary Fenn from Metro North Health Service spoke about the protocol she had helped develop between Metro North Health and Disability Services in this region. In discussing this important agreement, roundtable participants were clear that while the need for integrated service responses has been clearly demonstrated, delivering this through the Queensland Action Plan is a multidisciplinary issue that requires a whole-of-government approach and commitment of all agencies and government program areas to its delivery. A call was made for government to take a more holistic approach to resolution of this enduring need.

The meeting discussed a range of ways of going about this and there was a sense that the key State Government agencies present were open to collaboration with the community sector, something that was warmly welcomed by sector representatives present. Given that the Public Advocate's office has done research into the issue, close collaboration by the Public Advocate's Office with Health, Disability and Housing executives on the action plan, was seen to be of clear importance.





# Themes for change

Participants agreed that creating an integrated service response for people with disability and health needs is an important but complex task that has defied previous policy efforts. A key point made was that within the different program areas, there was generally poor understanding and little working knowledge of how other program areas work, including their constraints as well as their capacities. Developing detailed cross program knowledge was seen to be essential if genuine partnership was to be achieved.

As example, Prof. McConnell revealed that it is common for people working in Queensland health programs to assume that Disability Services Queensland (DSQ) has its own health service response for people with disability. As a result of this misconception, health program workers are always confounded when asked to continue providing essential health supports to individuals with disability post discharge and in community settings, thinking that they can rightly pass this responsibility to DSQ.

Prof. McConnell also indicated that because of the disability system's incapacity to offer an on-demand support response post discharge from acute care, he has noticed that some health services have even become reluctant to admit people with disability due to the risk that the health service may be left 'holding the baby' and providing de-facto long term accommodation for the individual with disability. This was, in fact, a denial of essential health services. Harry also talked about the different languages and practices that occur across the health and disability sectors, particularly the inability of disability services to understand and follow up on clinical recommendations made by medicos.

Roundtable participants overwhelmingly agreed that traditional disability support services and health services are not substitutable, one for the other; and that a person needing services from both sectors should be able to receive these services concurrently to meet their needs over the life course. There was also common agreement that work to design integrated service responses for the identified group of long stay hospital patients, needs to underpin a systemic cross-program methodology that can complement the emerging NDIS and ensure that efforts to solve the short term problem have longer term impacts.

It was acknowledged that many of the community based health responses that people with complex needs require, simply do not exist in the community at present. The meeting agreed that there was an urgent imperative to develop these services, but particularly rehabilitation and specialist allied health outreach services.

There was general agreement amongst participants that integrated service responses like these needed to be done *with* the NDIS, both as a way of working for the future and to build a new culture of collaboration in preparation for 2016 and



beyond. It was further agreed that the lead up to the start of the National Disability Insurance Scheme in Queensland (2014-2016), offered an ideal opportunity to trial delivery of integrated approaches with health, disability and housing programs, as well as with aged care where relevant, ahead of the Scheme's start.

In welcoming this approach, National Disability Insurance Agency (NDIA) representative, Cath Halbert, encouraged state health, disability and housing representatives to start working with the agency now and not wait till the start of the Scheme in Queensland in 2016, to begin collaborations.

A key theme of service coordination was explored following a contribution from psychologist, Amanda Hendren, from the South Queensland Mental Health Cluster. Amanda spoke of the need for individuals with knowledge, expertise and the skill set required to liaise across programs, to be developed so that the particular needs of individuals can be identified and met.

In commenting that she had observed Amanda undertake this role in meetings with health, disability and aged care representatives developing discharge options for young people with complex needs, Bronwyn described this work as *wrangling*. This skilled work requires a dedicated person with a good working knowledge of specific disability, health and other programs, able to negotiate with these services to provide their responses to individuals. Such a person also needs to have the capacity to support continued program collaboration around construction of integrated support responses for individuals.

The meeting supported the description of cross program coordination as wrangling, as it is describes the intensity and complexity of the task with patients with complex needs. It was agreed that this role is critically important to the delivery of integrated service responses for individuals with complex needs; the prevention of hospital readmissions; and enabling otherwise disparate programs to work collaboratively and effectively together. As such, participants agreed that a key reform should be to mandate such positions to broker cross-program service packages; and locate these mandated positions within health regions.

The point was made clearly that because of the web of different and sometimes conflicting eligibility criteria for various services, in concert with service staffs' lack of knowledge of what goes on outside their own area, that a coordinating function is essential. Left to their own devices, service programs are not only unable to readily devise the joined up responses individuals require, but are more likely to resist the multi program outcomes that are needed. Embracing complementary roles would therefore result in programs sharing commitment and capacity for designing individual and flexible packages for people.



This wrangling role has been trialled and found to be successful in a number of pilot programs within the YPIRAC initiative and it was suggested that such a role could be built into the Queensland Action Plan. Dr Wayne Sanderson, representing the Queensland Central Medicare Local, suggested that the Medicare Locals would be interested in trialling a joined up approach as part of the implementation of the Queensland Action Plan.

With regard to the NDIS, such a trial could also inform the longer term design of the NDIS Local Area Coordinator and Planning roles.

Comment was then made that the task of progressing joined up responses needs to be informed by current good practice being undertaken by providers and individuals from the health and disability sectors, such as SCIR; as well as those undertaking the kind of coordinating work being done by practitioners like Amanda. Wayne Sanderson and Joanne Paringatai from the Medicare Local sector spoke of the emerging importance and potential of the Medicare Locals to assist in this area.

It was noted that development of these important joined up service responses should not just be left to government and service providers, but involve families as genuine partners in their design and delivery. Families are essential to the long-term support of people in the YPINH group and participants agreed that is short sighted to leave them out of the service planning process. Various participants mentioned that providers and government worked in isolation from families far too frequently.

Wayne Sanderson's comment that a key element of this strategy must be to identify how the joining up of services can be done in rural and remote areas, was not lost on the meeting. It was agreed that developing a capable workforce is a key element in solving this dilemma and that this is something that the NDIA has a parallel interest in.

The final point made by Karen Nankervis and others was that it was important to ensure that the action plan was able to offer real choice to individuals and families and not end up replicating the worst institutional features of the historical options currently in place. In recognising that communications around the action plan and its intent would be extremely important, it was acknowledged that previous deinstitutionalisation projects had not managed this well, resulting in misunderstandings and conflict that could have been avoided. Collaboration with community organisations and advocacy groups were seen to be important and useful, particularly in this area of the strategy.





To conclude the roundtable, participants were asked to identify one thing that they thought the action plan should consider and/or incorporate. These singular options included:

- Ongoing collaboration with the NDIS to deliver responses for individuals and their families in long-stay healthcare facilities.
- The crucial importance of community engagement and provision of information/education to support the Action Plan's efforts.
- Development of service level protocols, systems and procedures similar to the protocol developed in collaboration with Metro North Health services and Disability Services.
- The need to build on what is already in place such as the SCIR, ABIOS and Spinal Outreach Team (SPOT) services.
- Reconfigure existing facilities as transitional services to enable transition to the NDIS.
- Develop pathways relevant to the NDIS that address funding systems and compatibility with relevant other programs such as health, housing, aged care and employment.
- Capacity building through the NDIS Sector Development Fund offers an important opportunity to trial alternatives. This point was reiterated several times.
- As part of sector development, design a working trial similar to the Medicare Local demonstration project in Central Queensland.
- Expand the number of agencies and sectors involved in integrated pathway development. In other words, sector development must include more than just government representatives and be expanded to include sector peaks, health networks, consumers and the community.
- The use of accessible and more easily understandable language is critical to engaging with the community.
- Development of the several capacities of families and individuals with disabilities to make informed decisions about opportunities they may be presented with.
- KPIs should be developed for all doctors and health service CEOs to ensure their accountability for their responses to individuals with disability.
- Development of integrated responses should be enacted at the consumer level, the service level and the policy level.
- The development of the National Injury Insurance Scheme (NIIS) is critical to the continued evolution and success of the NDIS. The NIIS also has capacity to





lead development of rehabilitation and allied health responses that both schemes will need to access.

- Instead of simply "fixing the problem" of the individuals identified in the Public Advocate's Report, the action plan must be designed to have a strategic and reform driven impact on the wider health and disability systems.
- Investigate social development bonds as a way of supporting strategic reform across programs and silos.
- Workforce development is a critical component of strategic reform and must include education and skill development across a range of new areas involving health and disability services, to support individuals with complex health and other support needs in the community.
- Assessment and planning processes must include brokerage funds and access to other resources to meet immediate needs identified in the assessment process.
- Development of a skilled coordinator or 'wrangler' workforce with
  - A mandate to work across programs;
  - Working knowledge and understanding of the different programs, their operations and constraints and capacities; and
  - A desire to foster collaboration and partnership by programs with each other and with consumers.

In concluding the Summit's proceedings, Bronwyn thanked participants for their contributions and mentioned that interest in the roundtable had been so high that the Alliance had needed to turn away individuals from the health and disability sectors who had been very keen to attend.

As a result of this broader interest and of the need to support development and delivery of the Queensland Action Plan, Bronwyn indicated the Alliance would be holding a larger event around development of integrated service pathways in the first quarter of 2014 in Brisbane. As well as senior officials from government programs, this next event will involve service providers, Not-For-Profits and consumers with the aim of informing human services programs and the community about the task Karen and her team are addressing; and to build understanding and support for their efforts.





## **List of Roundtable Participants**

- Mr Alan Blackwood, Director of Policy & Innovation, Young People In Nursing Homes National Alliance
- Mr Kevin Cocks, Queensland Anti-Discrimination Commissioner
- Ms Jodie Cook, Queensland Public Advocate
- Ms Jennifer Cullen, CEO, Synapse, Brain Injury Association of Queensland
- Ms Mary Fenn, Assistant Nursing Director, Community Interface Services, Patient Flow Unit, Royal Brisbane & Women's Hospital, Metro North Health Service District, Queensland Department of Health
- Mr Greg Fowler, Health Advisor to Ms Annastacia Palaszczuk, Leader of the Opposition
- Ms Elly Gardner, Information & Support Officer, Young People In Nursing Homes National Alliance
- Ms Cath Halbert, General Manager, National Transition Office, National Disability Insurance Agency
- Dr Ros Harrington, Lecturer in Occupational Therapy, Australian Catholic University
- Ms Amanda Hendren, Psychologist, Dual Disability Coordinator, South Queensland Mental Health Clinical Cluster, Queensland Department of Health
- Prof Harry McConnell, Professor of Neuropsychiatry, Clinical Sub Dean at Griffith University School of Medicine and Director of Neurosciences at St. Vincent's Hospital, Brisbane. Chair of the South East Queensland Regional Disability Advisory Council
- Mr Chris Moretti, Senior Program Officer, Behaviour Support and Complex Clients Team, Clinical Innovation and Governance Support Unit, Centre of Excellence for Clinical Innovation and Behaviour Support, Queensland Department of Communities, Child Safety and Disability Services
- Dr Bronwyn Morkham, National Director, Young People In Nursing Homes National Alliance
- Prof Karen Nankervis, Assistant Executive Director, Centre of Excellence for Clinical Innovation and Behaviour Support, Queensland Department of Communities, Child Safety and Disability Services
- Ms Joanne Paringatai, General Manager, Health Services, Medicare Local, Greater Metro South Brisbane
- Ms Lee Anne Rogers, Director, NDIS Planning and Implementation, Queensland Department of Communities, Child Safety and Disability Services
- Dr Wayne Sanderson, Chair Corporate Governance, Board of Directors, Central Queensland Medicare Local
- Ms Dawn Schofield, Director, Strategic Policy Unit, Policy and Planning Branch, System Policy and Performance Division, Queensland Department of Health