



Queensland *Joint Solutions Forum*
Parliamentary Annexe, Parliament House Brisbane
28 February 2014

Young Queenslanders living in long stay health care facilities and their families joined representatives from the health, disability and housing sectors at the Queensland ***Joint Solutions Forum***, organised by the Young People In Nursing Homes National Alliance.

Convened to inform and discuss Premier Campbell Newman's call for the Departments of Health; Communities, Child Safety and Disability Services; and Housing and Public Works to deliver a Joint Action Plan that addresses the issue of young Queenslanders living in hospitals and long stay healthcare facilities, the Forum heard from young people living in these facilities; their families; the cross sector team collaborating on the Action Plan; as well as representatives from the National Disability Insurance Agency. The Forum was one of the outcomes of the Queensland ***Joint Solutions Leaders Roundtable*** the Alliance had convened in December 2013 to inform the Joint Action Plan's development.

In welcoming the eighty-plus Forum participants, the Alliance's National Director, Dr Bronwyn Morkham, spoke of the keen interest in the Action Plan that was reflected in the cross sector and community representation in the room. In commenting that Queensland's situation of young people "stuck" in hospitals and other health managed services is mirrored in other states, Bronwyn called for new and creative thinking to deliver an Action Plan that would establish Queensland as a leader in the field.

Bronwyn also acknowledged the bi partisan support the forum had received through the presence of Mr Mathew Crossley from Minister for Communities, Child Safety and Disability Services, Tracey Davis' office; and Mr Greg Fowler from Opposition Leader, Annastacia Palaszczuk's office; and the support of the Departments of Health; Communities, Child Safety and Disability Services; and Housing and Public Works through the participation of the Departments' Action Team members.

Session One

Leading the day's discussion was a panel comprising the Queensland Public Advocate, Jodie Cook, Queensland's Anti Discrimination Commissioner, Kevin Cocks and Carl Champney and his mother Colleen. As a ten year resident of long stay facility, Casuarina Lodge, and one of the young people the Action Plan will look to assist, Carl was clear in his expectations that it would deliver the life in the community he craved and the allied health supports he needs to continue his recovery from an Acquired Brain Injury.

Carl told the Forum that he "... could walk when I went to Casuarina Lodge. Then my physio was stopped and I can't walk now. I've gone backwards." Carl finished by calling for the allied health supports people in his position needed to be made available immediately and across the board.



Colleen Champney reminded participants of the daily struggle families waged to get the disability supports and health services their loved ones needed and the emotional and physical toll this takes. Colleen finished by speaking for all families present when she declared her hope that the Action Plan would finally deliver the help Carl and others in his position so desperately needed to enable these young people to finally have their chance for a decent life.

In speaking of the recommendations made in her *Long Stay Patients in Queensland Health Care Facilities* Report, Public Advocate Jodie Cook called for genuine collaboration between disability, health and housing programs and reiterated her desire to work with the Action Plan team to ensure its success. Jodie also commented on the need for the Action Plan to look systemically and commit to assisting people immediately and where they are living now.

Anti Discrimination Commissioner, Kevin Cox, joined Jodie in reaffirming the need for collaboration and partnership across the board and called the Forum's attention to Australia's obligations under the UN Convention on the Rights of Persons with Disabilities, reminding participants that the issue of young people living in long stay healthcare facilities was essentially one of human rights and could not be ignored. Kevin concluded by reminding the Forum that resolving the issue of young people stuck in health facilities is not just a problem for government but is one that we all need to commit to resolving.

Session Two

The Forum then heard how health services viewed the issue from respected clinician, Professor Harry McConnell, and Amanda Hendren, one of the state's remaining dual disability coordinators working in the health and disability fields. In speaking about the need for partnership between health, disability and housing services, both Harry and Amanda indicated their expectation that the Action Plan would start to develop the integrated service pathways young Queenslanders with complex health and disability support needs required to maintain their health and well being in the community.

In commenting on the urgent need for action, both health practitioners called for collaboration with the NDIS immediately, with Prof McConnell declaring that he was "ready right now" to work with the Scheme. As well as the detrimental impact on young people stuck indefinitely in health services, Harry also spoke of the significant cost of inaction to health budgets and the need for families to be involved as partners in the care and support of their loved ones.

Amanda Hendren then spoke of her work with health and disability programs to deliver the 'joined up' service responses young people with complex health needs require on discharge from hospital. Despite the mutual benefits to all stakeholders, Amanda expressed her frustration at cross sector barriers to realising these important outcomes that include significant program under resourcing as well a lack of skilled personnel. She called on both health and disability programs to put coordinators in the field mandated to pursue collaborative outcomes for younger people and to work across and within sectors, as a matter of urgency.



Harry McConnell supported Amanda's call for integrated service pathways as solution, saying that without them, people fall into a chasm between disability and health. As part of the solution, Harry proposed a Ministry for Integration Services be established with a separate budget and responsibility for establishing collaborative working arrangements between programs to deliver the outcomes individuals with complex health and disability needs require. With doctors shortly to be required to work to Key Performance Indicators (KPIs), Harry suggested that working to KPIs on delivery to people with disability could lead to improved outcomes for all concerned.

Harry concluded by stating that while our present way of doing things is ineffective, inefficient and very expensive, the Action Plan offers a great opportunity to turn things around and to begin advance work with the NDIS.

Session Three

The Forum then heard from an Action Plan Panel. Professor Karen Nankervis from the Department of Communities, Child Safety and Disability Services who leads the team, was joined by Dawn Schofield from the Department of Health and Helen Cluff from the Department of Housing and Public Works.

Karen began by telling the forum that the Action Plan has been on the agenda since July 2013 when the Ministers for Health and Communities, Child Safety and Disability Services and their departments were tasked to deliver a joint Action Plan that would develop and implement transition plans for people in long stay accommodation. This process is just getting off the ground at present and includes the Department of Housing and Public Works and also Treasury at officer level. A governance plan for the Action Plan across the three departments is being developed; and the Action Plan Committee has just commenced meeting to start implementation.

The key points made by the Action Plan Team included:

- The Action Plan's initial role will be to identify people living in health care settings and work with them and their families on individual transition plans. This work will start in the coming year.
- Short term funding for 20 people who are willing and able to move has been made available. The immediate priority for the Action Plan is to move people from acute settings.
- Systemic issues arising from the work with the 20 identified individuals and related to the health/disability services interface, will be noted and reported to the responsible Ministers.
- Full implementation of transition plans that will see people move to alternative arrangements is most likely to occur beyond the start of the NDIS in 2016.
- The Action Plan is a five year plan and while the team is aware that some individuals in acute and sub-acute settings are in a position to move now, others will require

more time and additional service development before transition is feasible. The Action Plan's role is to work through these issues with the people concerned.

- The Department of Communities, Child Safety and Disability Services wants to accurately identify the needs and circumstances of individuals within its regional structure. A Department of Communities, Child Safety and Disability Services representative will be identified in each region to take the lead in these transition efforts.
- While the early funding for the Action plan's work with the 20 people has been secured, Treasury will need an accurate indication of need from those remaining in healthcare facilities if additional funding is to be secured to deliver the Action Plan. Data collection will be needed to inform this. The team also hopes to identify responses that can be managed within existing resources; and assess how existing resources could be better integrated and directed across sectors.
- An assessment process will be developed, and the team is conscious of the variety of factors to be considered for each person, including availability of accommodation and support; ongoing management of health issues including mental health; and required service development.
- Regional centres would be supported to develop solutions under the Action plan in the longer term.
- Outcomes of the planning process will inform Queensland's preparation for the NDIS. The Action Plan team also anticipate that the Plan's work will inform the bi lateral agreement Queensland will negotiate with the National Disability Insurance Agency for rollout of the NDIS.
- In regard to housing and its alignment to the Action Plan, the forum was informed that the Queensland Minister for Housing and Public Works is keen to develop a range of options inside and outside the social housing area; and to assisting people to sustain their tenancy so that people live where they choose. This includes people with disability and their families.

A number of questions were put to the panel from the forum that focused largely on structural and systemic issues related to long stay residents of healthcare facilities, rather than individual cases.

Many questions were about housing policy and eligibility including one about the requirement for people to have a package of funding before they could secure housing. This remains a major barrier for people with disability to obtain secure housing with people with good informal support also caught in this catch 22.

In recognising that a finite number of allocations were made each year in housing, Helen Cluff was not aware of a formal policy to that effect, but offered to talk individually about the issue with people during the break. Helen went on to say that while the wait list for housing is now down to 1900, people are still missing out and it is extremely difficult for the



Department to decide who are those in most need. She concluded by saying that this was also true for the collaborative work on the Action Plan.

Another housing question concerned the strict application of income/assets tests for public housing that has served to exclude people with lump sum compensation from public housing. The compensation preclusion was said to be keeping a number of people from moving out of healthcare settings. Helen agreed that this was problematic but indicated was one of many issues that the Action Plan process had, was the opportunity to address issues like this through its cross-department approach.

In answer to a question on the adequacy of funding for the Action Plan, the panel answered by saying that the cross department structure had some start up money as well as the opportunity to prove the need for more resources and submit jointly. Options for extra resources would be fed back to the Ministers and a joint submission may be developed. The team indicated that the Action Plan would not be a Memorandum of Understanding between disability and health as the team saw this as too restrictive.

On the subject of funding for acquired brain injury, the Panel indicated that specific programs fund this area as well as Queensland Health through its 17 Hospital and Health services networks. The majority of these funds are delivered through service agreements that are activity based.

In closing the session, Bronwyn noted that no other jurisdiction is attempting a collaboration between departments in this way. She also reaffirmed the unique opportunity for government departments to not only work with each other, but also with organisations from the health and disability sectors who had close relationships with the young people living in healthcare facilities, organisations that could help identify workable solutions to systemic barriers.

Session Four: Address by Liz Cairns, National Disability Insurance Agency (NDIA)

Liz Cairns, General Manager, Operations at the NDIA gave a highly relevant presentation about the imperatives around the NDIS and the Scheme's introduction to Queensland in 2016.

Liz began by reiterating that as a social reform, the NDIS is rights based and relates directly to the United Nations Convention on the Rights of Persons with Disabilities and National Disability Strategy. She indicated that the Scheme not only has to deliver on its rights agenda, but also on the value proposition of the Productivity Commission Inquiry report into Disability Care and Support. In this regard, the NDIS is a part of the solution for people with disability in Australia, but only a part. Other service systems need to contribute and collaboration between sectors is vital part of this work.



Liz summarised the early learnings from the NDIS Trial sites in others states, indicating that the Scheme has:

- Inherited many years of underfunding and a lack of development
- Been able to move a few people out of nursing homes in Barwon, BUT they had homes to return to
- Kept people out of nursing homes - and it's been better and cheaper to do so
- Been able to support people and their families to remain at home for longer through increased funding and more flexible supports
- Been able to improve the quality of life for people who are in nursing homes through support for community access and participation, equipment and therapy support provided in situ
- Been able to encourage thinking about different options. One example was the three friends who want to try sharing a flat together but had not been able to pool their funding packages under the old system. Individuals have not been confident to exercise choice in the past, as it had been ruled out too often. The Scheme is providing this confidence about choice through the planning process
- Also been able to gain leverage through opportunities for whole-of-government projects. One example is early transition support for children in care up to 18 years of age.

Liz then turned to challenges the NDIS has faced and is still working through and how these challenges could be managed in the longer lead time to the introduction of the scheme in Queensland.

She commented that

- Disability systems have had a poor understanding of the investment approach to providing lifetime disability supports
- Disability programs have lacked a person-centred approach to policy and quality assurance. Standards monitoring and compliance underpins of current accreditation and is not sufficient. This is a key reform area in the transition.
- Poor and fragmented data collection is a major impediment to good planning.
- Part of the data gap is being able to quantify the gap between current funding budget and the needs of participants. Work is needed in this area as a first priority as getting good data and the lead-in time for planning is significant. This cannot be left until 2016.
- Treasury actuaries must be at the table for both the Action Plan and the planning for the scheme introduction. This is essential to influence decisions about funding. Without this the true impact of funding design is difficult to establish, making it difficult to argue for the persuasive Return on Investment business case.

- The move to individualised funding means that a co-design approach with people with disability and families is critical to success. This is a significant shift as there is a lack of a rights agenda across the sector
- On this basis, developing a principles-based approach to the Queensland Action Plan that can guide overall system reform is recommended
- Lack of service options is a big barrier to progress. Congregate care is the only experience and the only expectation for many people the Scheme has encountered. New and different options are needed and people and their families need to see, hear and touch different options. A recommendation would be to build exploration of new approaches into the Queensland strategy, something that could be done by leveraging off the resources of the YPINH Alliance and expertise of entities like the Transport Accident Commission in Victoria and its development of the Abbotsford apartment initiative.
- Lack of specialist support expertise and options for people with high and complex needs has been evident. This capacity needs to be built and through the Action Plan, Queensland has an opportunity to Invest in this now. Liz also made the point that some existing funding is higher than it needs to be and is simply not spent wisely. Liz quoted an example of a person who required a two-person transfer and had a support program that required two workers for transfers. This was more far expensive than a single worker and a ceiling hoist. But the old disability system would not provide the hoist, and funded the more expensive support option instead.
- The NDIS can make better sense of the cost/benefit/quality trade off indicated in the previous point. Stories like these are frequently encountered and are important to showcase to Treasury actuaries to support better preparation for the NDIS; and demonstrate the benefits of early and wise investment that can deliver efficiencies over the long term.
- Sector capacity is a major issue in all the trial sites, particularly in the shift from block funding to individualised, fee-for-service funding. It has also been difficult to generate flexibility, have providers working across sectors, and confront the lack of technology and innovation. It will be important to invest wisely in sector readiness.
- Historical 'capture' of clients by providers can create difficulties in the transition phase, so one approach may be to review provider contracts for flexibility.
- It is essential to invest in participant and family readiness. Many people in the trial sites have been unprepared for planning and/or implementing their plan.
- Transparency and inclusive consultation is invaluable. The lead in to the NDIS needs to include all stakeholders to limit unexpected barriers and blockages.
- As part of preparation, research into innovative support approaches, technology and service delivery will be very helpful. It's important not to reinvent the wheel. It's also advisable to partner with other jurisdictions and schemes that have done this previously in close liaison with the NDIA to share ideas and benefit from our experience in other sites.



Given the interest in interacting with the Action Plan team and Liz Cairns, the agenda was altered to extend the panel question and answer session. Forum participants were offered the opportunity to email responses to a series of 'table questions' after the forum had concluded. These responses are summarised in the appendix to this report.

Session Five: Open Discussion and Panel Session

Queensland Public Advocate Jodie Cook opened the discussion in the second half of the forum by highlighting that the Action Plan was the beginning of an important change process and its approach needs to be different to the operation of related programs. This means being more open to new things and not being risk averse. Jodie also called on the Action Plan process to avoid putting square pegs into round holes, instead identifying what isn't working, being honest about the barriers that exist and encouraging and funding creative solutions. In essence, Jodie argued, the team should aim for achievement, have high expectations of success and not be captive to self imposed constraints.

Jodie also highlighted the importance of addressing the systemic issues as well as responding to individual needs, reminding participants that there had been some good solutions raised earlier in the forum.

In the health area, she supported the proposal by Professor McConnell to increase and improve localised health solutions by setting KPIs for health service staff and executives about provision for people with disability. In addition, she believed the housing register could also be used in a more tailored and proactive way to work with people to negotiate housing solutions that don't necessarily rely on social housing.

In points that were well received by the forum, Jodie also called for diligence in the use of scarce resources, cautioned against over bureaucratising the Action Plan processes and for transitional costs of assessment, approvals and allocation to be funded from within departments so that they as part of the cross sector collaboration the Action Plan embodied.

Questions raised in the second panel session were directed to the Action Plan team and concerned the status of people in healthcare facilities such as Jacana Lodge and Casuarina Lodge, including

- How the Action Plan intends to address the level of unmet need for health and disability services for current long stay residents when its stated priority is to focus on transitions for 20 people
- Address and management of contradictory messages coming from health networks and the Department of Communities, Child Safety and Disability Services about how the Action Plan will impact residents. Some families had been advised that the facility their family member lives in is scheduled to close and they have been required to seek alternative accommodation while the Action Plan is planning a longer term planning and transition process with individuals.



- Identification of people and families keen to engage with the Action Plan team and participate in reviews and transition planning when direct contact with residents had not occurred yet.
- Management of expressed choices by residents and families to stay in their current facilities and not relocate to community services.

The team acknowledged that communication with residents and families was an area that needed improvement and there was inconsistency between the Action Plan and the health networks messages, explaining that this was because the Action Plan team was in the early stages of planning and implementation; and was developing communication protocols that would improve this situation.

Dawn Schofield from the Department of Health assured families that Health networks had the data to identify each person that needed to be contacted; that immediate unmet need for therapy services would be something that would be raised with the Health Networks; and that this was within the scope of the Action Plan over the longer term. Dawn said that the team would welcome collaboration with local health services on the needs of individuals; and that the issue of choice was one the Action Plan team takes seriously, their processes fully enabling these issues to be worked through in detail with each resident and family.

Comments came from participants about the need to work on blockages in the system and to support collaborative opportunities across the board.

One participant spoke at length about the fact that health networks who had long stay residents with disability knew them well and were well placed to work with the residents on needs assessments and transition. This person felt strongly that their local connections and service networks were essential to effecting a positive response for residents; and that these should not be displaced by centralised processes. A greater focus should be placed on the connections between programs at the regional level as there would be significant differences across the regions and with particular populations.

Views were expressed on the critical need to address systemic issues contributing to blockages in health; and the lack of synergy between the health and disability systems. There was unanimous agreement that unless these issues were tackled at their source, beds vacated by people transitioning back to the community would be backfilled by others who faced the same risk of becoming long stay patients because nothing in the system had changed.

One participant raised the issue of the quality of information available to individuals and families in the community – particularly those not directly linked with organisations. For these people, their life planning depends on having a clear view of what the future holds, and how the transition to the scheme will occur – will it be a seamless run up, or will it be a case of haves and have nots as some groups in Queensland have said?



Questions were also raised about the veracity of information. Comment on the NDIS is coming from a wide range of commentators, making it very difficult to discern what to believe. The point that, with so much at stake, it is essential that someone – either the Action Plan team, the NDIS or someone empowered by them – take charge of communicating the detail of the transition to Queenslanders, was unanimously supported by forum participants.

The panel acknowledged that accurate information is very important and that while both the NDIS and the Department of Communities, Child Safety and Disability Services would certainly work on this, it remained difficult to completely control all areas of the public debate. The key was to aim for transparency.

A representative from the Department of Communities, Child Safety and Disability Services mentioned the NDIS readiness initiative within the Department, advising that many of the issues that had been raised were being addressed through this group inside the Department. It was suggested that, given the goodwill of organisations from both the health and disability sectors represented at the forum, there needed to be a way for the community and services sector to work collaboratively with the government team on preparation for the NDIS in Queensland.

A Department representative indicated that a major NDIS conference was taking place the following week in Brisbane and that while this event was sold out, other opportunities would be made available for the sector to be consulted. Some participants felt, however, that because of the importance of the transition process, there needed to be more of a partnership approach to this reform than the traditional government consultation model. This theme was reiterated in responses to the discussion questions provided to the Alliance following the forum.

The main issues raised with Liz Cairns in this final session concerned how the NDIS would engage in Queensland; asked for her views on how the experience of the trial sites could be brought to bear on the Action Plan; and preparation for the NDIS generally. Liz reiterated the key points she had made about the need to prepare comprehensively given the complexity of the transition and returned to the themes of good data collection; engaging with stakeholders - particularly people with disability and providers; and ensuring there was strong dialogue with central agencies in government, particularly Treasury.

Close

In concluding the day's proceedings, the forum was asked to reflect on what would underpin the success of the Action Plan. Each participant was asked to state what they considered to be the single most important element to ensuring sustainable long-term change for individuals living in health facilities. The responses offered have been grouped into the following three broad categories.



The Action Plan and NDIS transition

- Collate data accurately
- More creativity
- Ensure culturally appropriate responses
- Promote individualised funding in health as well as disability services
- Include respite as part of the solution
- Make the Action Plan a coherent solution
- Don't chop and change policy direction on a whim
- Make sure the Action plan IS action! Stop accepting conversation as action
- Recognise Aboriginal people - equity and others in regional areas
- Ensure honesty and transparency in the Action Plan
- Solution may not be that difficult – LISTEN
- Provide real housing options
- Stop wasting money keeping people in health institutions
- Address immediate need and recognise the desperation of long stay residents to move
- Don't forget the social needs/relationships of long stay residents and include community access for people in health settings in the early scope for the Action Plan
- Engage treasury to calculate the cost of neglect
- Ensure there is a sustainable cost model matching the plan to attract the funding required
- Do what the people want, not what government think they want
- Recognise the compounding cost of neglect
- Stop placing people in aged care while the Action Plan and NDIS develop
- This is essentially about human rights – these issues are relevant to mental health too
- Don't waste the government mandate and commitment for change – it's all too rare
- Stop say no – be honest and find solutions
- Take calculated risks
- Must collaborate with services, advocates and people with disability.
- Should not be government only Action Plan
- Good communication essential with all parties
- NDIS – Check the Department of Communities website – March NDIS conference
- Need to bring about a major attitude change to these young people
- Timeliness of responses – don't leave people hanging in the Action Plan when they have waited for so long to even get noticed

People with disability and families

- Involve People with disability, Give people confidence,
- Individual focus,
- Be person centred,
- Communicate well with the individual and family,
- Respect for the privacy of individual,
- Provide information and offer sustainable choices to people,
- Provide assistance with planning,
- Provide real choice of accommodation,

- Don't underestimate the importance of advocacy,
- Maintain connection to family and community and culture , spirit as well as the body
- Don't ignore current unmet need of the current residents of health facilities
- Give control to families and individuals
- Provide options and good planning for sustainability
- Set high standards for accommodation services and match with inspection
- People want an appropriate and secure standard of life
- Long-term plan needs to change with the person – capacity to do planning as a process not just an event
- Recognise FASD impacts as disability issues
- Individuals and families together - support families as well in decision making and planning

Service Coordination

- Coordination with a mandate
- Cooperation between silos
- Breaking down silos
- Integrated approaches
- Whole of government approach with sectors
- Partnership and collaboration the key to success
- Mandatory training of health facilities about disability
- Provide training for health workers to increase their understanding of the disability system and the holistic needs of these young people
- Need to be able to escalate cases in acute settings to get buy in for long term support and good discharges
- Include wide group of people in planning – collaborative planning is needed from both service areas

Forum wrap up

The forum was well supported by the disability and health sectors and the Alliance was particularly pleased to welcome the participation of so many key regional health service representatives. The presence of a large number of residents and their families was also welcomed for the opportunity to hear directly from those most affected by this enduring issue. .

The demand for the event was very strong and the participation of so many different people and organisations on the day was a demonstration of how keen people are to get involved in the Action Plan and the wider transition to the NDIS.

The human rights aspects of this work were strongly put early in the agenda and were referred to often in discussion. The NDIS presentation also reinforced that the Scheme had empowerment of participants through choice and reform at its heart; and highlighted the complex task ahead to make the transition to the NDIS in Queensland. In responding, departmental representatives indicated that the Action Plan was an important part of the transition for those people with complex needs in Queensland.



Participants indicated they had heard about the Action Plan but were keen to hear about it in more detail. Being able to hear about the NDIS directly from a senior NDIA representative was also appreciated.

Liz Cairns presentation was well received and feedback from participants indicated that they were gratified to hear that the NDIS had commitment to features that people at the forum valued, such as choice, individualised funding, funding based on need and underlying social values. Many participants said they want these values expressed in the Action Plan in order to embed them well in advance of the NDIS and make for a seamless transition.

A number of participants agreed with Professor McConnell when he said he was ready now for the NDIS and that Queensland needed to start now. Participants recognised that there is a lot to do in preparation, but called for an articulated transition process where processes in health and disability services with a more individual focus, could be introduced.

A recurring theme raised in the forum and in later feedback was that of a desire for the health and disability sectors to partner and collaborate on the work of both the Action Plan and the transition to the NDIS. This came through in discussion but also very strongly in the feedback the Alliance received from participants in answer to the discussion questions. Participants believed that the health services supporting long stay residents had a body of expertise that could assist the work of the Action Plan team and that collaboration with the services sector generally (both health and disability) was essential to delivering positive outcomes.

Another key theme raised was the need to address the systemic issues that lay behind the group of long stay hospital patients. Many participants were under the impression that the Action Plan would include the development of strategies to identify and resolve key barriers and blockages across the two sectors through the departments of Health and Communities, Child Safety and Disability Services working together.

Many participants expressed disappointment that the initial focus was on such a small group of people and were worried that, despite their urgent need, most people would miss out.

A number of health representatives said that they would like to be able to work across departments at the service level to complement the work of the departments. Some said that they needed to be engaged in other ways than traditional department consultation as they felt they had a lot to offer.

The third theme that came through strongly was the need to find ways for individuals and families to participate in the Action Plan and the transition to the NDIS, not only in the role of clients and residents but as contributors to ideas and strategies.



The Alliance thanks all presenters for their willingness to take part in the forum.

We particularly thank the Action Plan team: Karen Nankervis, Dawn Schofield and Helen Cluff; and Liz Cairns from the NDIA, for their willingness to engage openly with participants and extend the Q and A session; and Jodie Cook, Kevin Cocks, Professor Harry McConnell, Amanda Hendren and Carl and Colleen Champney for their thoughtful contributions.

The Alliance will continue to liaise with participants around the rollout of the Action Plan.

We welcome feedback and further information on the issues raised in the forum.

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Appendix

Responses provided to the forum discussion questions

Below are the responses received by email and telephone to the discussion questions put to the forum. Some of the points below are consolidated where similar points on the same topic were received.

Q1. In addition to working with some individuals and families through the Action Plan, what else is needed to ensure that Queensland has the necessary systems in place (particularly outside disability services) to achieve effective outcomes for people under the NDIS?

NDIS readiness

- Use the time 2014 – 2016 to develop collaborations between Government departments, NGO's and private organisations that can deliver the reform that is required. Governments cannot deliver the scale of the Action Plan or the NDIS on their own. The Departments need mature relationships with the service and advocacy sectors that are more than just consultation or service contracting, but include a joint commitment to reform. In the short term, these collaborations can inform the Action Plan.
- The Action Plan is part of Queensland's preparation for the NDIS and really needs to do more than just move 20 people. We know how to transition people out of institutions. As described, the program is not going to provide enough scale or commitment to real reform to take us forward. What we need the Action Plan to do is to address the causes of why people are stuck in healthcare facilities as well as fix things for some people. Then there will be an understanding of how the NDIS can work with health. If we don't confront this now, we won't be able to solve in in 2016.
- Articulate the pathways that the Action Plan wants to establish and get the right departments, services and people around the table to work out how to make it happen. This needs to also map out how people living in healthcare facilities and their families can participate.
- Families need quality information and transparency regarding the plans for NDIS arrangements in Queensland. It's no good governments keeping this to themselves. Access to more user friendly information and community education needs to be available to families to highlight the fact that under the NDIS, supports deemed 'reasonable and necessary' as opposed to a person's 'whole of need', is what may be met to decrease reliance on funded supports where appropriate.
- Recognise the health issues of the people in long stay health facilities and work out ways that this can be managed so their health doesn't regress, causing them to end up in hospital again.
- The NDIA needs to complete carefully negotiated contracts with each of the 17

regions of Queensland Health; the 11 Medicare Locals; all DSQ and Housing regions to define threshold accountabilities and to set year on year objectives for performance of all parties from now through to 2016 and beyond. While the key to the whole inter-systemic structure and processes will be the relationship between NDIS and the individual participants, there needs to be a tangible, shared understanding of threshold capacities by all departments and programs likely to interact with NDIS participants.

- Person centred funding allocation should be implemented ASAP in Queensland by the Department of Communities, Child Safety and Disability Services to align itself with the NDIS model. The NDIS needs to work closely with the Queensland Health Department between now and 2016 to align operations so that people don't get stuck in hospital.
- Queensland needs to ensure that mechanisms are in place to manage family expectations of what the NDIS will do or mean for them, including what can be realistically classed as a disability support.
- In the lead up to the NDIS the Action Plan needs to make sure that no one person slips through the cracks in the system, something that has happened on many occasions in the past. Getting the process correct from the onset will save many people heartbreak and despair and will also prove to be more cost effective. Collate accurate comparative data on how much is it costing to support individuals with disabilities in health facilities as opposed to supporting them in the community and provide this to the Queensland Treasury and the NDIS to secure future funds.
- A serious investment is needed in public housing or incentives with the private rental market as well as the development of community and neighbourhoods.
- Specifically address the people and issues identified in the Public Advocate's report, and compare this information along with identification of additional people in healthcare facilities with the cohort mapping and modelling the Queensland Government will already have done in costing their contribution to the NDIS. This is where the Action Plan can be well targeted.
- The Action Plan and the NDIS readiness committee need to engage more than just policy people in these discussions. As seen in the forum, both the people directly involved (individuals and their families) and frontline staff have an expectation and right to be involved, both in generating ideas and implementing responses to the challenges leading to the NDIS.

Capacity building

- Undertake capacity building of all individuals and families within this cohort to enable them to thrive through the move from congregate care arrangements; and unlock and see future possibilities.

- Developing processes to map information about the types of support available to individuals and families from acute to primary health care. Linking people with what is already happening.
- Make an investment in developing specialist rehabilitation throughout the state. Build the capacity of rehabilitation services and build a skilled workforce in the health system to deal with people with complex disability. Engage Queensland Health to ensure there is a strategy for interface and service development to complement the NDIS.
- Also develop workforce capability in the disability sector, particularly in the provision of care to those with complex and challenging needs in the community. Develop cultural competence to work with aboriginal people.
- Better integrate health and disability services so disability services can be delivered into health and aged care facilities, and health services (such as allied health services) can be delivered to people in disability service settings or at home to ensure that people get their needs met wherever they are.

Interface

- It is essential the interfaces between other services (such as Transport, Education Employment etc), **but particularly health** and the NDIS, are well developed. The roles and responsibilities of each has to be clearly stated and access to these mainstream services must be facilitated so people do not experience burdensome bureaucracy and unacceptable waiting lists.
- Integrate data systems across health and disability (e-health extended) to build information and be able to share information to reduce assessment burden and to promote seamless supports.
- Develop local level partnerships to inform and interact with the policy level work between departments to ensure a relevant systems approach to implementation of the Action Plan and the NDIS.

Q2. As well as government, what part can individuals, families and the wider health AND community sectors contribute to this work to ensure it is practical and timely and considers regional and other issues?

Participation of individuals and families

- Government needs to utilise the skills and experience of the individuals and their families and those working with people with a disability to ensure smooth transitions and sustainability. These individuals have an important role in working in collaboration with the community sector and government. They can focus the minds of others, involve the wider community, share positive and practical transition stories, and keep the issue in the public's mind. Advocacy representation should be included especially where some residents have no family or 'voice'. Participation should involve peer support so that families and residents who have been through transition can support others.
- Individuals, family members and staff who have worked with and understand the residents have a wealth of knowledge and understanding about key issues. The Action Plan needs to create a formal role for families and individuals. They, along with their regional health services can be integral to ensuring that the Action Plan has a coherent and resourced long term strategy to address all identified people who will require support to transition out of health facilities.
- The NDIS seems to have a strong focus on putting people with disability at the centre of decisions. However, we are not yet at that point with the Queensland system. This is a great opportunity to reform and prepare for the NDIS. This could be done region by region with local health services so that the experience of staff who know the residents is not undermined by people with new ideas who lack any understanding of the specific needs of residents.

Contributions of the community and health sectors

- The robust and dynamic primary health care partnerships brokered and developed through Medicare Locals will be a very important key to the ongoing viability and further development of the full range of Primary Health Care services needed by NDIS stakeholders/clients – particularly in regional areas. These are critical for rehabilitation and health workforce capacity in regional areas. The NDIS needs to invest in developing relationships and protocols here as this sector can deliver big dividends for the scheme and people with disabilities that can't be achieved any other way than through a partnership. Regionally, it is important to recognise support services may be limited to a select number of organisations and as such, need to be deliberately engaged and included in the transition.
- The NDIS needs to invest intensive work on building neighbourhoods that are nurturing and welcoming for people with disability that will have benefits for all of community. An investment of funds and local development personnel together with an ongoing media campaign will assist with this enhancement.

Q3 What is the single most important element to ensuring sustainable long-term change for individuals living in health facilities?

- A new approach must be adopted that sees government, the community sector, people with disability, their families and advocates working together to ensure sustainable accommodation and support for people with a disability with high and complex needs is achieved. Sufficient recurrent funding is also needed to deliver a sustainable individualised funding stream for services required for these individuals to have a good life.
- The Action Plan must articulate its 5 year strategy and be transparent about how it is going in meeting its targets. Transparency and on-going communication are imperative for all parties involved as residents and families need to feel secure about their future. This needs to recognise and provide for the delivery of rehabilitation and other health services. This point also goes for the transition plan for the introduction of the NDIS. There must be opportunities for people outside government to have input.
- Developing detailed interfaces and pathways across the health and disability systems, including such features as including disability outcomes as part of the KPIs of Queensland Hospital and Health Services Boards and executives within their reporting measures.
- Capacity building for people with disability and their families in preparation for the NDIS and for them to participate in the Action Plan. Also capacity building for the provider sector to be able to meet future requirements.
- Community coalitions and support alliances need to be built in each region via perceptive and persistent community development work (service clubs, churches, significant employers, unions, producer bodies, industry associations etc.) This will bring a broader and deeper knowledge base to communities, as well as some gains in cash and in-kind resourcing for both the Action Plan and the NDIS. But overall, a climate needs to be generated in which civil society knows that it is richer for the experience of having the developing NDIS.
- Queensland needs to ensure that, in conjunction to planning for the NDIS, immediate consideration and investment in appropriate infrastructure (such as a range of accommodation options) for people to transition into, with the *necessary funds committed* is required. These accommodation options need to be aimed primarily at the cohort of people who are at risk of entering a health facility or who are currently in one, in order to eradicate the institutionalisation of people with a disability.



Forum participants

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