

## Queensland Health Consumers Collaborative

# COMMUNIQUÉ

### No. 7 - May 2018

*Welcome to the Queensland Health Consumers Collaborative (Collaborative) newsletter. The Communique is a means for the Collaborative to inform the community of their role and ongoing progress.*

The Queensland Health Consumers Collaborative is a joint initiative between Health Consumers Queensland and Queensland Health. This strategic, high level Collaborative is informing embedding of consumer partnerships at every level of planning, policy, delivery, monitoring and evaluation of services provided by Hospital and Health Services and the Department of Health. The Queensland Health Consumers Collaborative is chaired by Health Consumers Queensland, which is funded by the Queensland Government.

### The Collaborative's 2018 work plan

The Collaborative's first meeting for 2018 was held on 14 February focusing on the 2018 work plan. The group confirmed the key priorities for the year will be:

1. Advancing Health 2026 – inform into and feedback on initiatives relevant to consumers
2. Value Based Healthcare – continue to inform into value-based healthcare strategy and initiatives, and improve health literacy across the system
3. Building Consumer Capacity – supporting statewide consumer leadership
4. NDIS Interface with health system – maximise opportunities for consumers to benefit from the NDIS.

Health Consumers Queensland Chair Mark Tucker-Evans led the conversation about the 2018 work plan. The discussion included how to ensure consumers in rural and remote areas are consulted; how to continue to build consumer capacity; and a general concern about the NDIS not coping with demand and the need to increase advocacy in this area.

It was agreed the next Collaborative meeting in May would focus on the interface between the NDIS and health. Collaborative members would have the opportunity to provide strategic advice on current initiatives aimed at stopping people falling through the cracks during and after transition.

Other issues covered in this meeting included an overview of the upcoming Clinical Senate meeting in March by Chair Mark Tucker-Evans; a presentation on value-based healthcare for Queensland by Queensland Government Healthcare Purchasing Strategy Director Jane Partridge; and an update and discussion on the Patient Travel Subsidy Scheme (PTSS) Reform Project by Innovation and Enhancement Unit Manager Simone Ryder.

*We acknowledge the Traditional Custodians on whose land we deliver a service and pay our respects to the Elders past, present and future.*

### IN THIS ISSUE:

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- The NDIS and health

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## The NDIS and health

The Collaborative held a breakfast forum on Wednesday 9 May at Christies Conference Centre in Brisbane with a focus on the interface between the NDIS and health.

The attendance list and agenda were developed in conjunction with Queenslanders with Disability Network (QDN), with a focus on the consumer/carer members of the Collaborative and representatives of key consumer groups sharing what the key issues are from patients, around the interface issues and how they're affecting people.

Senior representatives from Queensland Health, Department of Communities and the National Disability Insurance Agency were in attendance, to hear first-hand consumer concerns and to then have an opportunity to respond to feedback and share some of the work already being done to identify and remedy gaps.

A group discussion then explored the next steps of how to continue to work together to ensure consumers and consumer organisations are kept informed as the NDIS rollout continues throughout the state.

### SUMMARY OF CONSUMERS/CARERS FEEDBACK

Consumer/carer representatives outlined personal and shared stories about the many barriers and difficulties in navigating the new NDIS system and how so many Queenslanders with disabilities were struggling to access the right support and services.

The overwhelming feedback from the Collaborative's consumers and carers was that there are profound challenges to access the new system and undertake effective pre-planning and planning in order to implement appropriate packages.

Points of concern include:

- Poor provision of information about the scheme and how to access.
- Lack of support to get diagnosis of disability or evidence to support access.
- GP assessment often not adequately completed.
- Wait times to get specialist assessments stretching on for months or years.
- Challenge for families/consumers to identify goals and ideal supports.
- Lack of coordination and support to pre-plan/plan (including Local Area Coordinators not being in place 6 months prior to roll out in some locations).

- Lack of cultural appropriateness of assessment tools and intake processes.
- Appeal advocates overwhelmed with requests.
- Additional support required to support those experiencing the greatest disadvantage to ensure they aren't further left behind.
- Urgent need for clarity on NDIS or Queensland Department of Health responsibility to provide services such as wound management, continence aids, home modifications, respite, nutrition, epilepsy care, diabetes management, podiatry and palliative care.
- A significant number of barriers were identified including lack of consistent information and answers; poor integration of records and communication between agencies/departments; long delays to transition out of hospital; interface with aged care not working well; and concern around the adequacy of support for people with mental health issues.

### WHERE TO NEXT

'Nothing about us without us' was a sentiment expressed during this meeting, as was the importance of involving consumers in identifying issues and finding solutions.

Identified follow-up actions include:

- QH to action requests for consumer/carer representation on the QH NDIS steering committee and the senior officials working group's health sub-working group.
- HCQ to liaise with QDN to inform into issues including the Queensland Transition Advisory Group.
- HCQ and QDN to seek a meeting with the Health Minister, to directly advise on the interface issues from a consumer/carer perspective.

There is a clear need to continue education and training for all involved, including increasing health literacy for clinicians and consumers/families. For health professionals this requires a change in mindset around function and participation, not just diagnosis.

### 2018 MEETING DATES

The Collaborative's remaining dates for 2018 are 8 August and 7 November.

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