The focus of the Review is threefold:

1) How can the system be improved within the existing framework;
2) How can the health education given to undergraduates ensure it is relevant & responsive to consumer/carer needs; and
3) How can education & training and its accreditation, help create the workforce of the future that Australia needs.

My “lived experience” as a Consumer, Carer for my brother with a learning disability and genetic neurological degenerative disease, and as a Consumer/Carer representative, I believe, gives me the necessary insight to see firsthand how the system is “failing”.

There are “gaps” in the system for our most vulnerable. If we can get the health system right for our most vulnerable we get it right for all of us. Engaging with Consumers/Carer’s, having them share their own personal stories, lived experience, with undergraduates will build empathy within health services, this is a great educational tool. We learn more from each other on a personal level, than from a text book. https://www.youtube.com/watch?v=go9UNW9csDU

The main difference with training would be for health professionals to be trained around behavior and attitudes towards all consumers, especially those with disabilities, and their Carers. Personal Centred care, or the Patient Experience is becoming internationally accepted as a vital part of health service delivery resulting in better health outcomes, reduced stays in hospitals, increasing a consumers health literacy (which is generally lacking in the general population), thereby reducing health costs to Governments and the community at large. https://www.researchgate.net/profile/Kevin_Fiscella/publication/45461791_Why_the_Nation_Needs_a_Policy_Push_for_Patient-Centered_Health_Care/links/00463514318643ca25000000/Why-the-Nation-Needs-a-Policy-Push-for-Patient-Centered-Health-Care.pdf

As per the International Alliance of Patients’ Organizations - “ Healthcare must be designed and delivered to meet the needs and preferences of patients. Greater patient responsibility and usage will lead to improved quality of life, a more cost-effective system and, ultimately, better healthcare for everyone.” https://www.iapo.org.uk/ and https://www.iapo.org.uk/sites/default/files/files/IAPO_declaration_ENG_2016.pdf.

The Beryl Institute defines patient experience as the

The sum of all interactions, shaped by an organization’s culture, that influence patient perceptions across the continuum of care.

https://www.youtube.com/watch?v=hoUXDsgC-0q and https://www.youtube.com/watch?v=iBLQnThJ6w0
The National Registration & Accreditation Scheme for Health Professionals (“NRAS”) has six key objectives:

1) Protection of public safety;
2) Enable the mobility of the workforce across Australia;
3) Ensure high quality education & training;
4) Assess overseas trained health practitioners to ensure that they meet Australian standards;
5) Promote & ensure “equal” access to health care services for all Australia’s, equally; and
6) Grow a responsive, sustainable and flexible health care workforce – on going education & training.

The six points detailed above, ensure the safety of the Australian public when they access health care across the broader health services system. Also bearing in mind the National Safety & Quality Health Service Standards (“NSQHS”), to which hospitals are accredited too every two years.

The 10 Standards of the NSQHS are:

1. Governance for Safety & Quality;
2. Partnering with Consumers;
3. Preventing & Controlling health care associated infections;
4. Medication Safety;
5. Patient ID & Procedure Matching;
6. Clinical Handover;
7. Blood & blood products;
8. Preventing & managing pressure injuries;
9. Recognising & responding to clinical deterioration;
10. Preventing falls & harm from falls.


However even today, it appears that many health professionals are not adequately trained, up skilled for all scenario’s that health care is delivered in the community at large. Especially, disability accommodation service providers, whom I see as “quasi health providers” as they care for vulnerable people with complex health challenges on a 24 hour 7 day a week basis.

This vulnerable group have higher mortality rates than the general population, support staff are difficult to attract to the sector, and difficult to retain once in the sector. The highlighted National Standards above, being 2, 4, 8, & 10 are, in my opinion, big risks to this vulnerable group and therefore also a risk to the whole health sector.

The health system is difficult to navigate for the public, especially for people with a learning disability, their Carer’s (Mums, Dads & Siblings) & Support Workers. There appears to be inadequate attention to understanding a person’s limitations when engaging with the health system and a lack of understanding by health professionals of the capacity and diversity of the disability service system. The Disability Sector is not like the aged care system where qualified health care providers, such as nurses, are on staff. Health provider’s work in silo’s and often do not “share” information with the view to building collaborative health teams. Please see - http://www.healthnetworks.health.wa.gov.au/network/disability.cfm

Perhaps the independent review of the NRAS would like to consider the risk and impact on the health system as a whole in the future if this urgent unmet need is not met for this vulnerable group, who often live in a NFP/Disability Accommodation Service Provider group homes.

The Disability Sector is a growing sector (http://www.acnc.gov.au/ACNC/Publications/Reports/CharityReport2015.aspx). Our health professionals must be aware of this growing sector and demands that it will place on the health system. If this issue is not addressed, the mortality rate in this group will continue to grow, increased demand for hospital beds resulting in increased costs to the Australian Health Care budget.
CONSUMER EXPECTATIONS

There is an increasing demand from informed, educated consumers to deliver health care in meaningful ways to them as individuals. More consumers want health care in the home, via new technologies, Consumers want to be in control of their own health care, informed to make their own decisions, informed choices. They want to “partner” with the health care providers. Increasing their health literacy is an important part of health care, and a growing concern that health care providers need to be able to “educate” their patients.

Pursuant to the World Health Organization – patient centered care -

http://www.wpro.who.int/health_services/people_at_the_centre_of_care/issues/en

“What do consumers expect from an accreditation system for health care professionals:

1. Robust key performance indicators to ensure skills are actual skills & not just ticked boxes;
2. Communication, communication, communication – common sense, empathy, collaborative teams;
3. Increased health literacy;
4. Health care professionals to work in a team environment rather than a silo mentality;
5. Ongoing professional development of health professionals to keep abreast of new clinical guidelines

https://www.nice.org.uk/”

BARRIERS FOR CONSUMERS INVOLVEMENT

The major problem for consumers is “time”. Many consumers, and I was one, didn’t want or need to know about health matters, health literacy until they really need to know. Until you or your loved one, experience a health problem personally you’re not really aware.

For consumers on committees it is also the time commitment, or perceived time commitment, confidence, fear of speaking up and believing their voice is important. Training of consumer reps by patient organizations such as Health Consumers Council WA, other State bodies, and Consumers in Health Forum is important, and could be the same training given across Australia.

EMBEDDING CONSUMER ENGAGEMENT & INFLUENCE WITHIN THE ACCREDITATION SYSTEM

SUMMARY

Consumers and Carer’s, need to be involved in every training facility, committee, panel for accreditation of health professionals and Government Department across Australia. This includes all Universities, Australian Medical Colleges, Allied Health Trainers Facilities, Disability Support Worker Training Facilities, Accreditation Boards, APHRA. This will add to the independence of the accreditation and registration system for health professionals.


Consumers and Carer’s with a ‘lived experience” are vital educators of our health professionals. The value that we can add to the overall education of health professionals and undergraduates is priceless.

There are opportunities within the Disability Accommodation Service Providers for Universities to have placements for graduates within disability NFP organizations. I know personally of one organization in Perth that provides opportunities for approximately 20-30 graduates from OT, Speech & Physio from Curtin University to do work placements each year. Perhaps the independent reviewer could explore the possibility of similar opportunities for other health professional graduates such as doctors, nurses, dieticians etc. This would provide a very good experience of working with our most vulnerable citizens. Should you wish further information please contact me.
The most important training that is needed of our current and future health workforce is the building of a culture of building empathy. This is still lacking at the “coal face”. Health Services do lead from the top, but the challenge is how to embed the culture at the “coal face” across the entire health system.

Thank you for the opportunity to contribute to this most important review of the NRAS. I hope that in some small way my views as a Consumer/Carer will add value to the discussion.