

Public Submission Cover Sheet

Please complete this sheet and submit with any attachments to the Sustainable Health Review Secretariat

Your Personal Details

This information will be used only for contacting you in relation to this submission

Title Mr Miss Mrs Ms Dr Other

Organisation Disability Health Network, Department of Health

First Name(s) Fiona

Surname Payne

Contact Details



Publication of Submissions

Please note all Public Submissions will be published unless otherwise selected below

- I do not want my submission published
- I would like my submission to be published but remain anonymous

Submission Guidance

You are encouraged to address the following question:

In the context of the Sustainable Health Review Terms of Reference listed below, what is needed to develop a more sustainable, patient centred health system in WA?

- Leveraging existing investment in Primary, Secondary and Tertiary healthcare, as well as new initiatives to improve patient centred service delivery, pathways and transition;
- The mix of services provided across the system, including gaps in service provision, sub-acute, step-down, community and other out-of-hospital services across WA to deliver care in the most appropriate setting and to maximise health outcomes and value to the public;
- Ways to encourage and drive digital innovation, the use of new technology, research and data to support patient centred care and improved performance;
- Opportunities to drive partnerships across sectors and all levels of government to reduce duplication and to deliver integrated and coordinated care;
- Ways to drive improvements in safety and quality for patients, value and financial sustainability, including cost drivers, allocative and technical efficiencies;
- The key enablers of new efficiencies and change, including, research, productivity, teaching and training, culture, leadership development, procurement and improved performance monitoring;
- Any further opportunities concerning patient centred service delivery and the sustainability of the WA health system.

Submissions Response Field

Contextual Information

In 2012, it was estimated that 18.5 per cent of the Australian population had a disability. This number is projected to continue increasing due to the ageing population and increases in chronic health conditions.

Despite the overall improvement in the general population's health, the gap between the health of Australians with disability and those without disability remains large. Current data from the Australian Institute of Health and Welfare suggests almost 50% of people aged 15-64 with severe or profound disability report poor to fair health compared to five percent without a disability. They are:

- 3 times more likely to experience chronic health conditions
- 6 times more likely to have mental health problems
- 3.5 times more likely to consult specialists
- 5 times more likely to seek allied health support
- twice as likely to be obese
- twice as likely to be smokers

Consultations with people with disability, their families and carers consistently highlighted the difficulties they experienced accessing health care that met their needs and identified the following as barriers:

- poor information flow or disregard for information provided, particularly at transition or transfer of care
- lack of awareness, understanding and knowledge of disability by healthcare providers, including communication skills
- health information resources not provided and distributed in user-friendly ways
- uncoordinated or poorly planned transition of care between health and disability providers or the community, and
- lack of knowledge on healthcare needs and services available for individuals, carers and disability service providers to be able to advocate.

People with disability must be recognised as a large and diverse population who experience significant disadvantage in accessing health care that meets their needs. Their right to access health care that achieves this aim is enshrined in the United Nations Convention on the Rights of People with Disabilities, which recognises that disability arises from the combination of impairments and barriers that “hinder...full and effective participation in society on an equal basis with others.” In acknowledgement of the need to fulfil this obligation, the Australian Government National Disability Strategy 2010-2020 includes health and well-being as one of its six priority areas for action, seeking the outcome that ...People with disability attain highest possible health and wellbeing outcomes throughout their lives.’

There is a strong rationale for a disability health focus which includes health disparities that exist for people with disability, acknowledgement that people with disability are best placed to input to the design, planning and delivery of their supports and services to ensure barriers to health care are removed, legislative obligations and local, state and national strategic directions.

Leveraging existing investment in Primary, Secondary and Tertiary healthcare, as well as new initiatives to improve patient centred service delivery, pathways and transition

People with disability access primary health care services more often than the general population, and many experience significant barriers in doing so. HealthPathways WA are seen as an important way for GPs and other clinicians to provide inclusive health care to this population group, and can be further enhanced with information of the specific needs of people with disability when these Pathways are being developed by the WA Primary Health Alliance (WAPHA).

A small investment in a resource to ensure these Pathways made specific consideration of the needs of people with disability would build capacity within a mainstream resource to better meet the needs of this

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group.

Children with disability and their families experience significant challenges in transitioning from paediatric to adult services. Whilst a Paediatric Chronic Conditions Transition Framework was developed in 2009, its implementation has not been successful. Further work is required to develop and pilot alternative ways of supporting this transition, noting some condition specific services have achieved relative success e.g. cystic fibrosis and some alternative models are being trialled e.g. Fiona Stanley Hospital Transition Coordinator. In addition, we encourage uptake of the draft WA Youth Health Policy 2018-2023 (developed by the WA Child and Youth Health Network) once finalised as this addresses transition from paediatric to adult services.

Ways to encourage and drive digital innovation, the use of new technology, research and data to support patient centred care and improved performance

It is difficult to obtain quality data about the use of health services by people with disability because there is currently no requirement to capture information about the disability unless it is considered to complicate the admission. While this is likely the case in many instances, the lack of system wide training for doctors about the importance of recording such co-morbidities, means this is likely to be significantly under reported. System wide training for those clinicians responsible for diagnosis could lead to better identification of disability as a complicating factor in admission, thus enabling funding to better match resource utilisation.

Similarly, an electronic health record the patient is able to use in all health environments would enable better coordination of care, reduce administrative burden and potentially enable people with disability to play a more active role in managing their health care needs and services.

Opportunities to drive partnerships across sectors and all levels of government to reduce duplication and to deliver integrated and coordinated care

The Disability Health Network (DHN) is an innovative approach towards achieving better health outcomes for people with disability that is underpinned by a formal partnership between the Department of Health and the Department of Communities, Disability Services in Western Australia. The DHN was established in 2012, by the Directors General who committed personnel and resources to this unique initiative, in response to continuing demand from a range of sources for the voice of people with disability, their family and carers to be heard by clinicians.

The DHN operates using a model of influence, where people with disability, their family and carers are at the centre of all activities, including an Executive Advisory Group, which determines priorities, reviews outcomes, shares information and fosters collaborative networks, Working Groups that progress agreed work plans, consultations to inform policy development and presentations to share, connect and improve.

From its inception, the DHN has been all about partnerships. This includes partnerships between diverse groups of people with disability coming together to identify a common need for their voice to be heard by clinicians, partnerships between clinicians and people with disability to understand the issues and the solutions, partnerships between community service providers and health services to develop better pathways for coordinated care and ultimately, the partnership between two government agencies to create and support the DHN. The aim of these partnerships is to improve health outcomes for people with disability by reducing or removing the barriers they experience in accessing health care that meets their needs.

The DHN continues to influence systemic change both internally and externally in a range of ways, including the establishment of the WA Disability Health Framework 2015-2025 which provides direction for WA Health and its partners on policy development and service delivery to achieve improved health outcomes for people with disability.

Ways to drive improvements in safety and quality for patients, value and financial sustainability, including cost drivers, allocative and technical efficiencies

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A key way in which the DHN has improved service delivery in our community has been the identification and cultivation of champions of change both within our community (health services) and external to it. Within health, we have used the energy and positive outcomes achieved by some of these individuals to canvas support, inspire action and lead change. In many instances, the champions of change are people with disability themselves, their family members and carers who share their experiences to raise awareness, suggest solutions and contribute to cultural change. The mantra 'Nothing about us, without us' is alive and well in the DHN.

People with disability, their family and carers consistently report difficulty navigating and coordinating the many services and supports they require across a range of systems including health, disability, primary health and mental health. This issue is compounded by the lack of connectivity between these systems, especially with regards to information exchange. This lack of effective communication results in increased costs (staff, tests, equipment, opportunity), time delays and ultimately, poorer health outcomes for people with disability. Care Coordination is identified as being an enabler of inclusive health care and while there is not yet a shared understanding of the concept across health, significant value could be gained by developing a framework/standard of care/policy directive that provided a clear and transparent process for ensuring 'joined up services' within health and across other service areas.

Allied Health clinicians in particular provide a pivotal role in working with people with disability, often providing services closer to home and promoting co-ordination across sectors. The Disability and Aged Care sectors are undergoing massive reform and it is important that navigation across sectors facilitates transition to the most appropriate service provider and that gaps within the sectors are identified as part of a cross sector care co-ordination strategy. Improving mental health and hospital disability liaison services in WA would reduce the disjunctions between health, disability, and mental health in WA. Examples of initiatives include the DHN Hospital Stay Guide and the work of the Agency for Clinical Innovation in NSW.

Social determinants of health such as housing and preventative health care/health promotion are vital. Programs are often not appropriately targeted to people with disability so there is a need to identify and fund tailored programs that address health disparities with a preventative focus. The Disability Services Commission funded Health and Well-being Projects undertaken by Nulsen and Brightwater are successful pilots.

The key enablers of new efficiencies and change, including, research, productivity, teaching and training, culture, leadership development, procurement and improved performance monitoring.

Building workforce capability has been identified as a key priority in the WA Disability Health Framework 2015-2025 (Framework). To this effect the DHN has developed a Toolkit for Change to promote inclusive health services across the WA health system. This comprehensive suite of resources is available to assist health practitioners and other interested stakeholders to utilise the Framework and other DHN documents in their service planning and delivery of health care for people with disability. Dissemination and embedding of the Framework and Toolkit are key enablers for change. DHN resources are available on their website http://ww2.health.wa.gov.au/Articles/A_E/Disability-Health-Network

There is a challenge in a large system with many competing demands on time available for teaching and training. Ensuring health workers recognise the rights of people with disability to access quality health care must be a central part of the induction of all health staff, as must opportunities for values based training and education around patient centred care. Influencing the undergraduate curriculum to recognise the needs of people with disability as part of the diversity of the human experience is an important role for the health system, given it is a significant employer of health professionals

Any further opportunities concerning patient centred service delivery and the sustainability of the WA health system.

The 2011 Clinical Senate Debate 'Clinician – do you see me?' provided a patient centric mandate for the voice of people with disability, their families and carers to be heard and valued within health. Since that

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time, the DHN has worked hard to achieve its vision of 'An inclusive Western Australian health system that empowers people with disability to enjoy the highest attainable standard of health and wellbeing throughout their life'. Central to this purpose has been the Commitment to Inclusive Engagement which requires consultation with people with disability to be underpinned by the principles of respect and rights, inclusion and transparency. This document has now been used in the development of the Department of Health 'You Matter: engaging with consumers, carers, community and clinicians in health' resource and has informed the work of other engagement documents. The continued acknowledgement of the value of lived experience and resources to support the voice of these people to be heard are important ways to ensure patient centred service delivery.

The Clinical Senate provides a valuable opportunity for clinicians to comment on key issues, with equal contributions from all clinicians, including doctors, nurses and allied health representatives from all health services. The debate and outcomes from Clinical Senates should be supported and align well with strategic priorities. The DHN is an example of the effectiveness of achieving outcomes from the Senate.

Another opportunity exists with the Health Consumers Council (HCC) for a small investment in training and support for people with disability to be informed consumers of health services. This should be done in conjunction with a disability specific organisation such as PWDWA, but in the interests of building mainstream capacity, would be led by HCC.

Patient Opinion is seen as another important opportunity for people with disability, their families and carers to be heard within the health system. The Network has held discussions with the CEO of Patient Opinion to ascertain the accessibility of the product, and was encouraged by the planned release of modifications to enable people with limited reading skills to use pictures to tell their story.

The National Disability Insurance Scheme (NDIS) is a new way for people with disability to get the care and supports they need to live a better life. The NDIS recognises that everyone is different and gives people with disability choice and flexibility to plan for their current and future needs in order to live a good life. The interface between the NDIS and mainstream services is guided by the legislative framework for the Scheme and reinforced by the principles outlined in the Applied Principles Table of Supports (APTOS). Approved by the Council of Australian Governments (COAG), the APTOS emphasise the importance for NDIS to integrate and coordinate with mainstream systems, including health, to optimise outcomes for people with disability.

This is in line with the National Disability Strategy 2010-2020, that recognised the need for greater collaboration and coordination by all governments, industry and communities to address the challenges faced by people with disability.

WA Health has the opportunity to support patient centred service delivery for people with disability through the development of clear pathways between health, disability and other service systems i.e. mental health and aged care. This is an opportunity to strengthen partnerships between the sectors in order to develop a shared understanding and explore opportunities to integrate service systems, to be more targeted and better meet the needs of people with disability. This will lead to better patient outcomes and a more sustainable WA health system.