Response ID ANON-KHGT-NSBT-5

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Introduction

1 Which category below best describes you?

Other, please specify below

Other, please specify::
Employee of a NGO, Peak Body

2 Do you identify as Aboriginal or Torres Strait Islander?

No

Demographics

3 As an employee, or a volunteer/advocate, which category below best describes the type of organisation you work for or represent?

Other, please specify

Please specify::
Peak Body and Community Service Provider

4 For the organisation you work for, or represent, which category below best describes the type of sector this organisation is in?

Not for profit

Other, please specify::

5 Does the feedback you provide to this survey represent your own individual perspective, or a group/organisation?

A group/organisation perspective (please specify below)

Name of group/organisation::
Carers Assosciation of WA Inc.

Vision, Purpose and Guiding Principles

6 To what extent do you agree/disagree that:

the framework clearly describes the purpose and what it aims to achieve:
Agree

the framework clearly identifies who is intended to use it:
Agree

7 To what extent do you agree/disagree that the Guiding Principles:

are clear and concise:
Agree

provide sufficient information to help guide policy development, service implementation and/or decision making.:
Neither agree nor disagree

are relevant to people with disability:
Agree

8 What (if anything) is missing or could be added to improve the overall vision, purpose or guiding principles?

Comments:
Executive Summary
What is the anticipated time frame for the Phased Approach – page 5?
How will practical advice will be delivered in relation to implementation of the framework – will there be an implementation reference group to do this work?

The framework should outline not just collaboration with people with disability, their families and carers but also emphasise WA Health and Disability Sectors learning from carers ‘lived experience’. Add a recommendation to use consumer and carer representatives to inform the planning delivery and evaluation of health promotion, preventative health programs and health service delivery in relation to people with disability and their carers. This needs to be an ongoing activity

which does not stop with the production of the Framework and needs to be adequately costed, coded and funded to provide carer representative input and training as part of any implementation of the Framework.

Suggest that the Disability Liaison Role recently piloted be a recommendation within the Framework's implementation.

4. Purpose and Goals: This section could emphasise not only understanding the health needs of people with disability and their right to effective services and care but also their support networks, including family/carers. Many people with disability are supported extensively by their networks therefore it is important that a holistic view of their network is made and that appropriate supports or referral pathways are also in place for the family and/or carers of the person with disability. It is important that the carers own wellbeing is supported so that they can continue in their caring role (Cummins, Hughes, Gibson, Woerner & Lai, 2007).

Carers do not readily self-identify as such (McMahan & Carson, 2010; O'Connor, 2007), therefore systems to identify not only the person with disability but their carer(s) are key to knowing who to involve in decision making (WA Carer Recognition Act, 2004).

5. Guiding Principles: Under continuous improvement, suggest refer to/ or in line with the National Safety and Quality Healthcare Service Standards.

Introduction Section of the Framework

9 To what extent do you agree/disagree that the Framework:

provides a succinct overview of the barriers faced by people with disability in meeting their health needs:
Agree

clearly describes why change and systemic improvement are needed within the disability health sector:
Agree

Priortity Areas

10 To what extent do you agree/disagree that the priority areas:

reflect the current areas where change is required by the health system and community to facilitate improved health and wellbeing for people with disability:
Neither agree nor disagree

clearly identify what action is needed to achieve change:
Neither agree nor disagree

are based on current evidence:
Neither agree nor disagree

identify actions that could be feasibly implemented:
Neither agree nor disagree

adequately describe what organisations can do to support change:
Neither agree nor disagree

11 What (if any) priority areas are missing from the Framework?

Comments:

12 If you wish to, please provide any other feedback you have about the priority areas listed above.

Comments:
6. Priority areas- Introduction.
Regarding the diversity of the population of people with disability, it is rare that anyone regardless of having disability or not has no support network– under a social model of disability, if it is identified that a person has no support network this should be identified as a social issue which may have impacts on the persons health and wellbeing, particularly their mental health, which may in turn have an impact on their physical wellbeing (Kawachi & Berkman, 2001; WHO, 2014.)

With regards to people who live in group homes or nursing homes (now more commonly referred to as aged care facilities) and who require considerable support it should be added from the staff but also from the family/carer (Davis, Gatleu, Marchbank, Masolin & Cornish, 2011). Many service providers fail to recognise that people can still be in a caring role when the people they support do not live with them or live in supported accommodation, however the carer may still be assisting with transport, administration, decision making and other supportive activities including emotional support. This should also be listed under barriers regarding carer identification.

6.1 Include people with disability and the planning, development and implementation of health services – need to add and their carers (National Safety and Quality Health Service Standards, 2012; Carers Recognition Act, 2004)
It is important to add carers here as they will be providing support to the person with disability both during the hospital stay and once leaving a health service; often the carer acts as an advocate for the person with disability. In addition carers have their own needs separate to the person with disability such as for information, education, and training and for their own support e.g. counselling.

Recognition of carers should be mentioned within this section. Lack of carer identification and systems (both paper and ITC) to support/record this is a barrier to

carer engagement. Carer self-identification is also an issue as many carers will see their caring role as being part of their relationship and therefore not realise that there are supports and services available to them in their role as a carer. Health and Disability staff require training on the Carers Recognition Act 2004 and The Western Australian Carers Charter.

6.3 Note that carers are defined as a 'hard to reach' group in the WA Health Promotion Strategic Framework 2012-16

6.4 Inclusive Health Care
Add carers to the first point regarding support mechanisms, if the carer is not supported and engaged for example with discharge planning this may lead to adverse events for the PWD. Each of the points throughout this priority area could have carers mentioned alongside the PWD noting, where appropriate, to highlight that it is not a given but may be of benefit for example during discharge planning.
Add mention of transition from Paediatric to Adult Services – carers often report that this is a very difficult time both for the PWD and the carer in terms of having clear treatment plans compared to when they were in the Paediatric system. It is importance that the role of the carer is recognised and they are appropriately involved in decision making alongside the person with disability as appropriate in line with the Carers Recognition Act 2004.
Under this priority, mention should be made of hard to reach or marginalised groups which have already been identified such as people with disability and their family/carers who are Aboriginal and/or Torres Strait Islander, Culturally and Linguistically Diverse, also people with disability who are also carers (in co-caring or otherwise known as mutual caring situations) and who are LBGTIQ. Also identification of Young Carers including Siblings is important to ensure that support mechanisms are put in place early.

System Influencers

13 Are there any other potential barriers that need to be addressed in the Framework?

Yes

If yes, please list any other barriers below.:
Yes, the lack of consistent identification of carers in health and disability services processes and systems.

Confusion is created by the term 'carer' being used to described paid support workers. At all times the term carer should be used consistent with the definition under the Carers Recognition Act 2004 and the Carer Recognition Act 2010. This confusion can lead to the health service engaging with the support worker (particularly when the person with disability lives in supported accommodation) at the expense of the family or friend carer who usually knows the person with disability over their life span. It is vital that this delineation be emphasised and reinforced through adequate identification and documentation processes so that it is clear to health and disability staff. This issue stems, in part, from the curriculum provided to Disability and Health undergraduate or certificate level students, which at times, still refers to a paid support worker as a carer. There needs to be systemic advocacy at a national level to address this so that curriculum is in line with National and State (WA) Carer Legislation.

It is commendable that this clear delineation has been made in the glossary of the Framework.

General Feedback

14 To what extent to you agree/disagree that the WA Disability Health Framework:

will provide direction for future policy development and service delivery within the WA disability and health sectors:
Agree

will assist with improving the quality of services available to people with disability:
Agree

has the potential to lead system-wide reform for people with disability:
Strongly agree

will foster a broader understanding of the health needs of people with disability:
Neither agree nor disagree

aligns with other national and international policies aimed at people with disability:
Agree

is easy to understand:
Agree

will help provide a voice for people with disability:
Neither agree nor disagree

15 Overall, how effective do you think the WA Disability Health Framework will be at providing direction for organisations/agencies on policy development and service delivery towards better health outcomes for people with disability?

Moderately effective

If you wish to, please provide comment to support your answer.:
The effectiveness of the Framework will be dependent on a subsequent clear implementation plan to ensure that it provides adequate direction and practical advice to service providers. It also needs to incorporate how the principles of the framework will be promoted and communicated to people with disability and their support networks i.e. carers in an accessible way so that they are empowered by their rights within the principles.

For example one action could be to ensure clear pathways for people with disability and their family/carers in being referred to/accessing the National Disability Insurance Scheme where appropriate. Whilst the Scheme is not designed to provide health services, the impacts of having a self-directed, individualised plan providing work, personal care and social and community interaction opportunities to person with disability may have indirect benefits to their health and wellbeing. The NDIS participant plan can also support training related to the caring role that may enhance the carer's ability provide care where appropriate (NDIS, 2015).

General Feedback

16 What (if any) do you believe are the gaps or limitations with the WA Disability Health Framework?

Comments:
The Framework, whilst it is not in scope to be able to address socioeconomic disadvantage, could refer to it as a factor which contributes to chronic disease (Australian Institute of Health and Welfare, 2009).

Under Roles and Responsibilities – it should be added that Health Services and community/disability organisations should be responsible for mapping their compliance with the Framework to identify gaps in consultation with and training and services for people with disability and their family/carers. This should be placed before the next step which would be to apply the principles through implementation. When implementing the Framework it would be useful for organisations to have a tool similar to the ACSQHC Accreditation Workbook for Hospitals which provides examples of best practice to aim for and which would allow for identification in any gaps in the service's ability to the implement principles of the Framework.

Also under roles and responsibilities, where referring to people with disabilities, their families and carers, it would be a large undertaking to ensure these groups have a baseline understanding of the Framework and also to self-advocate during accessing health services. This could be reworded and placed under the role and responsibility of the sections leading up to this to say that it is the Organisation, Executive Officers, Managers and Supervisors responsibility to ensure that staff are aware of the Framework and understand how to communicate the Framework to the person with disability, their family and carers including their rights under the Framework. They should also ensure that staff have the information and support/resources required to make guided referrals for the person with disability their family and carers to supports, including advocacy services. Carers are often time poor, stressed and primarily concerned with the health and wellbeing of the person they are supporting at the time of accessing a health service. Whilst some people with disability and their family and carers are skilled in self-advocacy and this is to be encouraged, many others will require referral for assistance in this area.

17 Should you have any further comments concerning any aspect of the WA Disability Health Framework please provide these below.

Comments:
Carers WA commend the use of the social model of disability – however there appears to be little reference to these factors throughout the document. We suggest that more information on addressing attitudinal, communication and the social environmental factors are highlighted and addressed within the Framework. This could include training for health staff by people with disability and their family/carers regarding their experience of accessing health services, for example, what works well and what doesn't.

Information/education is required for health staff which broadens disability to include functional disability rather than diagnosis related such as psychosocial disability as being a potential barrier to preventative health and accessing health services (WHO, 2011)

Under 8.1 Legislation and Policy – suggest add 'Standards' to this heading

List extra or amend legislation/policy/standards as follows;

- National Safety and Quality Healthcare Service Standards
- Language Service Policy 2011
- Under the Carers Recognition Act 2004 add 'and The Carers Charter'
- Mental Health Act 1996 (Note: The Mental Health Act 2014 is anticipated to commence from November 2015)
- Mental Health Standards 2010
- Paediatric Chronic Diseases Transition Framework

Question: Is there a reason that Appendix 2 is listed separately to this section?

8.3 Voice of the consumer, carer and family
Carers WA are funded by WA Health to recruit, train, support and place independent Carer Representatives on Government Health and Mental Health Committees to represent the views of the wider carer community. This enables health services to ensure that people with lived experience are having input to the planning, design, delivery and evaluation of services. Information on this program and the value of independent Carer Representation more broadly should be made readily available to Health and Disability related Committees to ensure the carer voice is heard alongside the consumer voice. This is a requirement under Standard 2: Partnering with Consumers of the National Safety and Quality Healthcare Service Standards

Page 22: Lack of knowledge on healthcare needs and services available for individuals, carers and disability service providers to be able to advocate. Suggest change 'advocate' to be able to 'refer to'

Issues on flow of information, under Hospital Staff Perspective
Please note the barrier of not having carers identified in key pieces of documentation such as nursing admission and discharge planning documents.

Page 25: Regarding Standard 2 – Please note that Partnering with Consumers refers to consumers and carers. Standard 2 and the other standards are equally important……..for people with disability and carers.

Page 26 - 9.4.1 – Data and Research
It is also important to identify and understand the population of carers who support people with disability.

Page 27 – 9.4.2 Research
Research on disability should be inclusive not only of people with disability but also regarding their support networks e.g. families and carers. Carers WA can be involved in creating research agendas around carer issues as well as other representative organisations of people with disability. Young Carers and Siblings (of all ages) of people with disability should be noted as a target group worthy of further research as they usually have the longest relationship with the person with disability.

9.5 Individual, community and organisational capacity
Leadership to foster a culture of disability and carer inclusive policy and services.
Include carers under self-advocacy, disclosure and determination.

Page 35: Relevant legislation and policy linkages
Include National Carer Strategy.

Making it happen

18 If you have any suggestions for some effective ways of communicating the Framework broadly to all stakeholders across WA, please list these below.

Comments:
Carers WA have approximately 15,000 carer members, 1,337 Facebook likes and 66,802 eBulletin distributions to Carers/ Service Providers – we are able to promote the Framework to carers via our Facebook page and eBulletin.

Submission References

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WA Carer Recognition Act (2004).