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Australian Commission on Safety & Quality in Health Care (ACSQHC)

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Subject: Health Literacy Consultation

Dear Sirs

The Mental Health Coordinating Council (MHCC) is the peak body representing community managed organisations (CMOs) in NSW. Our members provide a range of psychosocial and clinical services, support programs including advocacy, education, training and information services with a focus on recovery-orientated practice. MHCC's membership consists of over 200 organisations whose business or activity is wholly or in part related to the promotion and/or delivery of services for the wellbeing and recovery of people affected by mental health conditions. We work in partnership with both State and Commonwealth Governments to foster recovery and social inclusion for people affected by mental illness, participate extensively in policy and sector development and facilitate linkages between government, community and private sectors in order to affect systemic change. MHCC also manage and conduct research projects and develop collaborative projects on behalf of the sector. MHCC is also a registered training organisation (MHCC Learning and Development) delivering nationally accredited mental health training and professional development to the workforce.

MHCC is also a founding member of Community Mental Health Australia (CMHA) the alliance of all eight State and territory community sector mental health (MH) peak bodies. CMHA was established in 2007 in recognition of the shared activities, challenges and potential to effect change of the state and territory community sector mental health peak bodies and their respective memberships of more than 800 non-government community managed organisations (NGOs/CMOs) nationally. The primary goals of CMHA is to build a viable and sustainable community managed mental health sector and to promote the value and outcomes delivered by community managed mental health services based on a philosophy of recovery and social inclusion.

MHCC thank the Australian Commission (ACSQHC) for providing us with the opportunity to comment on the Consultation Paper, and we congratulate them on this important piece of work.

The Commission is seeking views on the consultation paper itself, including the content, relevance and accuracy of the issues and examples raised in the paper; any gaps in the information or examples provided; and any areas that could be strengthened. We respond as follows:

The consultation makes clear in the executive summary that it sets out to embed health literacy into high-level systems and organisational policies and practices; provide clear, focused and useable health information and effective interpersonal communication and integrate health literacy into education for consumers and healthcare providers. The paper also identifies the importance of ensuring consumers participate at all levels of healthcare provision, planning and evaluation. However, whilst the paper supports 'person-centred approaches' to care, it implicitly assumes a hierarchy of expertise which fails to recognise that people with lived experience of mental and physical health conditions may be experts in how their needs can be best met, which may be at odds with a medicalised view of what might be 'best or appropriate' for them. Therefore, MHCC stress the importance in this endeavour to improve quality and safety, to particularly focus on improving mental health literacy so that consumers can maximise autonomy and self-determination with regards to their care, and be supported to make decisions where possible. Mental health literacy is necessarily informed by principles of 'Recovery' (Appendix 1, p.8) in order to uphold what constitutes best practice in the mental health field.

The 2007 Australian National Survey of Mental Health and Wellbeing estimated that mental or substance use disorders affect as many as one in five people in any 12-month period.[i] There are a number of factors affecting help seeking and these interact to determine when and how people seek help for mental health problems.[ii] They include structural factors, such as having sufficient treatment resources available and individual factors, and include mental health literacy.[iii]

The term 'mental health literacy' originated as an extension of the concept of 'health literacy'. [iv] Nutbeam (2000)[v] noted that 'health literacy' has been referred to in the health literature for at least 30 years, and is recognised as an important aspect of health promotion. In contrast, a focus on mental health literacy has been neglected. The term 'mental health literacy' was first coined by Jorm et al (1997) [vi] who used it to describe 'knowledge and beliefs about mental disorders, which aid their recognition, management or prevention'. However, since that time, what constitutes best practice has substantially altered in the field of mental health and psychosocial disability and we emphasise for consideration as part of these deliberations, the Principles of Recovery, and Recovery Orientated Practice (Appendix 1, p.8). What must necessarily be taken into account are cross disciplinary philosophies of practice and considerations of evidence-based practice in the context of the interface between health and mental health across service sectors and systems, policies and protocols.

MHCC Learning and Development offers an interactive two-day professional development course **Mental Health Connect.** Unlike other mental health literacy training, Mental Health Connect focuses on understanding the real life experiences of people living with mental health difficulties and how workers can maintain hope and provide the best support to assist others to achieve their goals, discover meaning and purpose and find their unique path towards recovery. The difference between this course and Mental Health First Aid (MHFA) is that MHFA works as an emergency response to people experiencing a mental health crisis whereas Mental Health Connect focuses on the recovery process and day to day needs of people living with a mental illness and how people can provide the best support. Unlike other training in mental health participants have the opportunity to work with trainers who are 'experts by experience' as they share aspects of their own recovery journey from mental illness. This unique learning experience enables participants to acquire essential skills in supporting people with mental illness to maintain hope, achieve their goals; find meaning in their lives and work towards recovery from mental illness

In relation to differing concepts of what constitutes mental health literacy an area of particular controversy is that of compliance with mental health 'treatment' (the taking of psychotropic medication in order to stabilise a mental health condition) which may in fact be extremely detrimental to the physical health of the individual, and is often a matter of considerable contention between service providers and consumers. Frequently consumers are assessed as having 'poor insight' and in need of enhanced mental and physical health literacy in order that they might better understand how to 'manage their illness.' Whilst clearly this may often be necessary, this aspect of health literacy needs to be explored particularly with regards to different perspectives of care and treatment; support, supported decision making and self-determination; dignity of risk and risk assessment.

MHCC recommend that the ACSQHS review an in depth study of mental health literacy conducted in by Reavley and Jorm (2011) National Survey of Mental Health Literacy and Stigma, Department of Health and Ageing: Canberra.[vii] The aims of the study were to conduct a national survey in order to assess whether there had been changes in recognition, treatment beliefs, stigmatising attitudes and other aspects of mental health literacy. The survey had two components: a general community survey involving those aged 15+ years and a youth survey involving those age 15 to 25 years. (This study is not referenced in the consultation paper).

MHCC suggest that this health literacy consultation paper would be augmented if consumer scenarios particularly focussing on the interface between mental health and physical health for people with complex conditions were provided that reflected how mental health literacy might enhance outcomes. MHCC would be willing to provide some examples if required.

Seeking views on future directions, including suggestions and options to increase individual health literacy and improve the health literacy environment.

MHCC strongly urge the ACSQHC to conduct consultations with consumer mental health peak bodies and consumer advocacy services nationally and in each state. For example the National Mental Health Consumer and Carer Forum (NMHCCF) is the combined national voice for consumers and carers participating in the development of mental health policy and sector development in Australia. The NMHCCF aims to improve the wellbeing and quality of life of mental health consumers and carers throughout Australia through promoting their rights; creating a responsive, recovery focused service system; and through supporting innovation in service delivery appropriate to different life stages.

MHCC recommend that the ACSQHC review the language proposed in future documents so as to align itself with Recovery Orientated language when developing communications. MHCC has produced a language guide which could assist this process which is available from our website.[1]

The physical health of consumers has been neglected for decades. Due to poor health care, people with mental illness are more likely to develop chronic diseases at a younger age, have increased drug and alcohol use, experience greater lifestyle risks, develop complex health needs and co-morbidity due to untreated conditions, are less likely to get evidence-based

[1] MHCC. 2013, Recovery Orientated Language Guide. Available at: http://mob.mhcc.org.au/media/5902/mhcc-recovery-oriented-language-guide-final-web.pdf

treatments and health checks, face barriers in accessing services and die 15-20 years earlier than the general population.

MHCC have been promoting the physical health needs of people living with a mental illness since the establishment of the Physical Health Reference Group in 2010, which comprises a broad range of representatives from Community Managed Organisations working for mental health including: NEAMI National, Schizophrenia Fellowship, SANE Australia, New Horizons, Mental Health Association NSW. A MHCC research project is underway entitled: *Delivering physical health programs in the community Managed Mental Health Sector*, undertaken in partnership with the University of Sydney. The Project aims to better understand the current status of physical health programs within the community managed sector, the challenges and barriers to improving physical health outcomes for people with mental health conditions and the necessary steps required to assist CMOs to work more effectively with consumers and carers to support them to self-manage their physical health. MHCC are happy to provide the ACSQHS with findings as they become available.

The consultation paper

 Did you find the consultation paper useful? Why or why not? The paper provides a very comprehensive overview of health literacy, with the exception of explicating the interface between mental health and health. It assumes that the terminology 'health' covers all aspects and seemingly assumes that circumstances across disciplines, service sectors and systems are comparable. It is important that discussion acknowledges differences in the various sectors and recognises the power differential experienced by consumers engaging with a range of public, private and community-based mental and physical health services, particularly those people who receive services involuntarily under the mental health legislation enacted in each jurisdiction.

 Were the concepts regarding health literacy clear and understandable? The concepts are clear and understandable, but as already mentioned there are some fairly strong assumptions about what constitutes appropriate care and what health literacy means, and this must be understood in the context of complex mental and physical health difficulties and psychosocial disability.

 Is there any terminology that needs further exploration or explanation? As mentioned previously MHCC recommend that Recovery Principles (Appendix 1, p.8) and Recovery Language Guide[2] be utilised to inform the ongoing work in relation to mental health literacy.

 Are there any concepts that need further exploration or explanation? MHCC recommend that the Commission consider the National Recovery Mental Health Framework, due for release in August 2013; as well as reviewing the work undertaken as part of the National Contributing Life Methodology Project, which both can usefully inform the development of a health literacy environment.

[2] MHCC Recovery Language Guide, 2013. Available at: http://mob.mhcc.org.au/media/5902/mhcc-recovery-oriented-language-guide-final-web.pdf

 Would any of the approaches or strategies outlined in the consultation paper be particularly suitable or unsuitable for you or your organisation? The three approaches (embedding health literacy into systems; effective health information and interpersonal communication; integrating health literacy into education) suggested in the consultation paper are all relevant to MHCC as the peak body supporting the dissemination of information to member organisations and more widely across the mental health and human services sectors. The approaches will also assist in providing material to be included in educational materials as part of our learning and development offerings as a registered training organisation to the sector/s.

 Are there additional significant Australian or international initiatives or strategies that need to be highlighted? MHCC recommend the ACSQHC consider the collaborative work undertaken by MHCC and the NSW Consumer Advisory Group (CAG) in developing a recovery-oriented service provision quality improvement resource for mental health services. The Recovery-Oriented Service Self-Assessment Toolkit (ROSSAT) has been designed to assist organisations and staff to: assess their level of recovery oriented service provision; reflect on both individual and organisational practice in relation to recovery oriented service provision and identify and work on areas requiring improved practice in delivering recovery oriented services. This tool promotes integration of recovery orientated mental health literacy at its core.

MHCC are currently undertaking Stage 2 of the project which aims to refine the Recovery-Oriented Service Self-Assessment Toolkit (ROSSAT) in order to increase the usability, feasibility and validity of the toolkit, and progress our understanding of its psychometric properties. More specifically, this project aims to establish the face validity and the initial components of construct validity, namely content and response process validity, of the two key ROSSAT tools: Tool for Organisations (T4O) and Tool for Workers (T4W).[3]

We also highlight the work of Larry Davidson and colleagues, [viii] describing a keystone of transformation processes as the protection and respect of the rights of adults with serious mental illnesses in the USA. This reflects important considerations for health literacy in policy and practice.

MHCC likewise recommend to the ACSQHC the resource: Scottish Government (2009) Health Literacy – A Scoping Study Final Report.[4]

Scotland has in some respects led the way in reducing stigma and discrimination surrounding people with mental health conditions by its media campaigns. The evaluation of the “SEE ME” campaign is available on their website.[5]

[3] MHCC, 2010, Recovery-Oriented Service Self-Assessment Toolkit (ROSSAT). More information available at: http://www.mhcc.org.au/rossat/

[4] Scottish Government, 2009. Health Literacy. Available: http://www.scotland.gov.uk/11810843-62E5-42F8-9ECF-06C61E9AC309/FinalDownload/DownloadId-E1AEA6F056F4779437C860DF8F21DD6E/11810843-62E5-42F8-9ECF-06C61E9AC309/Resource/Doc/296717/0092261.pdf

 Are there barriers to addressing health literacy in the Australian context that need to be explored further? There are a number of barriers including a lack of resources to educate the workforce particularly in relation to mental health literacy (which to date has barely had any specific fund allocation). Whilst some work has been undertaken in mental health literacy through Beyond Blue and Black Dog, these campaigns relate primarily to depression and anxiety and other aspects of mental health and psychosocial disability have been largely ignored.

We emphasise that an important area of focus for ACSQHS is literacy in the context of the introduction of Disability Care. At this point in time there is a disconnection between the health and disability sectors and their different understandings of and use of language. This highlights a need for improvement to coordination and communication and presents an important opportunity for ACSQHS to address this gap across service sectors.

There are also difficulties in relation to culture; distance; and modes of delivery which may not be readily accessible to certain groups for a variety of reasons including a shortage of appropriately trained workers in certain locations, who can work with particular cultural groups. This particularly applies to Aboriginal communities in remote areas.

Future directions

 How could you or your organisation work better to address health literacy? Who needs to be involved in this work? MHCC advise ACSQHS that they continue to embrace ongoing quality improvement as part of skills improvement and workforce capacity building as identified in the organisations strategic plan.[6] However, community managed organisations are resource poor and subsidies are necessary to support them engage with their local communities in order to foster health literacy (e.g., schools, rotary, cultural groups etc.).

Consumers, the health system and health literacy: Taking action to improve safety and quality

 What type of tools or support would you need to help you address health literacy in your organisation? We have evidence that MHCC member organisations have greatly valued the Recovery Language Guide previously referred to in this submission. We would welcome grant funding to support the development of addition health literacy resources, such as: a guide to definitions across mental health and psychosocial disability; and understanding of trauma-informed recovery-orientation.

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[5] Scottish Government, SEE MEE CAMPAIGN. Available at: http://ec.europa.eu/11810843-62E5-42F8-9ECF-06C61E9AC309/FinalDownload/DownloadId-53E89196030964DD3E45AED1C748D393/11810843-62E5-42F8-9ECF-06C61E9AC309/health/mental_health/eu_compass/reports_studies/seeme_report.pdf

[6] MHCC Strategic Plan 2010-2014. Available at: http://www.mhcc.org.au/documents/What%20we%20do/2013-Strat-Plan-FINAL-web.pdf

 Are there activities, frameworks, strategies or protocols that could be provided that would help your organisation to address health literacy? Is there infrastructure or support that could be provided that would help your organisation to address health literacy? MHCC undertakes a diversity of policy and sector development activities that strongly focus on promoting health literacy across the community managed mental health and human services sectors. This is evident in the broad range of learning opportunities and qualifications available. [7] MHCC would welcome subsidies and scholarships for people to attend our generic mental health literacy course **Mental Health Connect** (a 2 day workshop) available throughout the year, which can be facilitated in a diversity of locations nationally.

We would also welcome grant funding to further develop the Mental Health Connect training for specific groups. This generic training for the community-based mental health and human service workforce has already been developed targeted at LGBT communities and the age-care sector. However, it is particularly important to develop further modules for the Aboriginal and CALD workforce as well as for CMOs supporting youth, the homeless and people transitioning from prison. Associated to this we recommend the establishment of subsidies and scholarships for those working with those groups to undertake such training opportunities.

MHCC strongly advocate a national literacy campaign. We recommend ASCQHS review Queensland Government's campaign (launched in 2011) with $8.5 million to tackle the impact of stigma on the lives of people experiencing mental illness. The campaign, 'Change our Minds', included television and print advertising urging people to think about the impact their behaviours and attitudes have on people living with mental illness. [8]

 Do you have any suggestions for how a national approach to health literacy could be developed? The rhetoric has been that expensive targeted media campaigns do not work all that well. However, we suggest that great success was achieved through TV commercials related to for example: HIV/AIDS; smoking and substance abuse/motor accidents. There is also clearly some success with certain groups, particularly young people when a sports or high profile celebrity promote a health issue (e.g., Kylie Minogue / breast cancer screening).

 What do you think should be included in a national approach to health literacy? MHCC are particularly keen to see promotion of mental health literacy that dispels the myths, reduces stigma and discrimination, and reduces fear and encourages engagement with people who live with mental health difficulties.

Mental and physical health literacy must be disseminated in a way that enables us all to connect with our mutual humanity. The strong message would be that we all need friends and that we should celebrate difference and diversity and not be frightened of people who may experience the world differently to ourselves.

[7] MHCC Learning and Development information available at: http://www.mhcc.org.au/learning-and-training/default.aspx

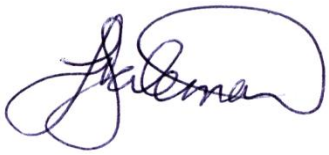
[8] Queensland Government. Available at: http://www.changeourminds.qld.gov.au/

 What could the Commission do, at a national level, to help support organisations to address health literacy? As identified earlier we recommend subsidies and scholarships provided to community based services so that the workforce can be supported to undertake mental health literacy training, namely Mental Health Connect.

MHCC thanks the ACSQHC for their interest, and express their willingness to be consulted with regards to the development of health literacy materials in the future.

For further information concerning this submission please contact Corinne Henderson, Senior Policy Officer at E:corinne@mhcc.org.au or T: 02 9555 8388 ext 101.

Yours sincerely



Jenna Bateman
Chief Executive Officer

Appendix 1

Principles of recovery-oriented mental health practice

From the perspective of the individual with mental illness, recovery means gaining and retaining hope, understanding of ones abilities and disabilities, engagement in an active life, personal autonomy, social identity, meaning and purpose in life, and a positive sense of self. It is important to remember that recovery is not synonymous with cure. Recovery refers to both internal conditions experienced by persons who describe themselves as being in recovery—hope, healing, empowerment and connection—and external conditions that facilitate recovery—implementation of human rights, a positive culture of healing, and recovery-oriented services, (Jacobson & Greenley, 2001, p. 482).[ix]

The purpose of principles of recovery-oriented mental health practice is to ensure that mental health services are being delivered in a way that supports the recovery of mental health consumers.

1. Uniqueness of the individual

Recovery oriented mental health practice:

- recognises that recovery is not necessarily about cure but is about having opportunities for choices and living a meaningful, satisfying and purposeful life, and being a valued member of the community
- accepts that recovery outcomes are personal and unique for each individual and go beyond an exclusive health focus to include an emphasis on social inclusion and quality of life
- empowers individuals so they recognise that they are at the centre of the care they receive.

2. Real choices

Recovery oriented mental health practice:

- supports and empowers individuals to make their own choices about how they want to lead their lives and acknowledges choices need to be meaningful and creatively explored
- supports individuals to build on their strengths and take as much responsibility for their lives as they can at any given time
- ensures that there is a balance between duty of care and support for individuals to take positive risks and make the most of new opportunities.

3. Attitudes and rights

Recovery oriented mental health practice:

- involves listening to, learning from and acting upon communications from the individual and their carers about what is important to each individual
- promotes and protects individual's legal, citizenship and human rights
- supports individuals to maintain and develop social, recreational, occupational and vocational activities which are meaningful to the individual
- instils hope in an individual's future and ability to live a meaningful life.

4. Dignity and respect

Recovery oriented mental health practice:

- consists of being courteous, respectful and honest in all interactions
- involves sensitivity and respect for each individual, particularly for their values, beliefs and culture
- challenges discrimination and stigma wherever it exists within our own services or the broader community

5. Partnership and communication
Recovery oriented mental health practice:

- acknowledges each individual is an expert on their own life and that recovery involves working in partnership with individuals and their carers to provide support in a way that makes sense to them
- values the importance of sharing relevant information and the need to communicate clearly to enable effective engagement
- involves working in positive and realistic ways with individuals and their carers to help them realise their own hopes, goals and aspirations.

6. Evaluating recovery
Recovery oriented mental health practice:

- ensures and enables continuous evaluation of recovery based practice at several levels
- enables individuals and their carers to track their own progress
- ensures that services demonstrate that they use the individual's experiences of care to inform quality improvement activities
- require that the mental health system reports on key outcomes that indicate recovery including (but not limited to) housing, employment, education and social and family relationships as well as health and well- being measures

Reference: Recovery Principles have been adapted from the Hertfordshire Partnership NHS Foundation Trust Recovery Principles in the UK.

Delivery of care – Standards

It is necessary that that the principles are supported by the mental health standards that 'incorporate recovery principles into service delivery, culture and practice providing consumers with access and referral to a range of programs that will support sustainable recovery'.

National Mental Health Standards: Standard 10

10.1 Supporting recovery
Criteria

10.1.1 The MHS actively supports and promotes recovery oriented values and principles in its policies and practices.
10.1.2 The MHS treats consumers and carers with respect and dignity.
10.1.3 The MHS recognises the lived experience of consumers and carers and supports their personal resourcefulness, individuality, strengths and abilities.
10.1.4 The MHS encourages and supports the self-determination and autonomy of consumers and carers.
10.1.5 The MHS promotes the social inclusion of consumers and advocates for their rights of citizenship and freedom from discrimination.
10.1.6 The MHS provides education that supports consumer and carer participation in goal setting, treatment, care and recovery planning, including the development of advance directives.
10.1.7 The MHS supports and promotes opportunities to enhance consumers' positive social connections with family, children, friends and their valued community.
10.1.8 The MHS demonstrates systems and processes for consumer and carer participation in the development, delivery and evaluation of the services.
10.1.9 The MHS has a comprehensive knowledge of community services and resources and collaborates with consumers and carers to assist them to identify and access relevant services.
10.1.10 The MHS provides access for consumers and their carer(s) to a range of carer-inclusive approaches to service delivery and support.

[i] Slade, T. Johnston, A., Oakley, Browne, M.A., Andrews, G. & Whiteford, H., 2007, National Survey of Mental Health and Wellbeing: methods and key findings. Aust N Z J Psychiatry 2009; 43:594-605.

[ii] Rickwood DJ, Deane FP, Wilson CJ, When and how do young people seek professional help for mental health problems? The Medical Journal of Australia 2007; 187:S35-9.

[iii] Jorm AF, Korten AE, Jacomb PA, Christensen H, Rodgers B, Pollitt P, "Mental health literacy": a survey of the public's ability to recognise mental disorders and their beliefs about the effectiveness of treatment. Med J Aust 1997; 166:182-6.

[iv] Jorm AF, Korten AE, Jacomb PA, Christensen H, Rodgers B, Pollitt P, "Mental health literacy": a survey of the public's ability to recognise mental disorders and their beliefs about the effectiveness of treatment. Med J Aust 1997; 166:182-6.

[v]Nutbeam D. The evolving concept of health literacy. Social Science & Medicine 2008;67(12):2072-2078.

[vi] Jorm AF, Korten AE, Jacomb PA, Christensen H, Rodgers B, Pollitt P, "Mental health literacy": a survey of the public's ability to recognise mental disorders and their beliefs about the effectiveness of treatment. Med J Aust 1997; 166:182-6.

[vii] Available: http://pmhg.unimelb.edu.au/11810843-62E5-42F8-9ECF-06C61E9AC309/FinalDownload/DownloadId-D4DCBC9EC572F60F1947F6A17BAC9277/11810843-62E5-42F8-9ECF-06C61E9AC309/research_settings/general_community/?a=636496

[viii] Larry Davidson, l., Flanagan, e., Roe, d. & Styron, T., 2006, Leading a Horse to Water: An Action Perspective on Mental Health Policy, Yale Program for Recovery and Community Health, ClinPsychol 62: 1141–1155, 2006.

[ix] Jacobson, N & Greenley, D. 2001, 'What Is Recovery? A Conceptual Model and Explication.' Psychiatric Services 2001;doi: 10.1176/appi.ps.52.4.482. Available: http://ps.psychiatryonline.org/article.aspx?articleID=85752