Youth Recovery Language Project

Literature Scan and Report

May 2016

mhcc
mental health coordinating council

Mental Health Coordinating Council
Building 125, Corner of Church & Glover Streets
Lilyfield NSW 2040

PO Box 668
Rozelle NSW 2039

For any further information please contact:

Corinne Henderson
Senior Policy Advisor
Email: corinne@mhcc.org.au
Tel: (02) 9555 8388 # 101

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To cite this document please apply the following protocol:

Mental Health Coordinating Council 2016, *Youth Recovery Language Project: Literature Scan and Report, Authors: Henderson, C & Waters, D, Sydney, Australia*

Table of Contents

Acknowledgements

The Mental Health Coordinating Council (MHCC) with the assistance of Dearne Waters, a Bachelor of Applied Social Science student in her third year at the Australian College of Applied Psychology (ACAP) undertook the Youth Recovery Language (YRL) Project.

MHCC wish to thank the Youth Recovery Language Reference Group for their important contributions to the project. The Reference Group contributed their extensive experience and expertise concerning young people with lived experience and their perspectives of 'Recovery', and shared how those working with young people might better communicate with them. We acknowledge that the support provided was vital to the success of ensuring the deliverables were forthcoming.

The following organisations and individuals participated in the Reference Group and/or provided Peer Review:

- Victoria Blake, User Experience Researcher, Reachout
- Kathi Boorman, Service Director, Child and Youth Mental Health Service (CYMHS) Mental Health Drug and Alcohol, Macquarie Hospital
- Lorna Downes, Short Course Coordinator, MHCC
- Corinne Henderson, Senior Policy Advisor, MHCC, Project Manager
- Dr Rosemary Howard, Child/Adolescent Psychiatrist and MHRT Member
- Amanda Jones, Provisional Psychologist, Sydney Women's Counselling
- Jamie Lee Nolan, Consumer, WEAVE
- Charles Tabone, Cluster Manager, RichmondPRA
- Rheza Tan, Service Manager, Chatswood Headspace
- Emma Tseris, Lecturer, Social Work and Policy Studies, Faculty of Education and Social Work, University of Sydney
- Dearne Waters, ACAP, Student on work-placement at MHCC

The project could not have achieved its stated outcomes without the generous assistance of consumers, peer workers, other staff members and managers from the two organisations that agreed to facilitate/ participate in the focus groups. We also thank students on work-placement at WEAVE who assisted MHCC in facilitating a focus groups.

MHCC gratefully thank staff, peer workers and consumers from:

- Weave, Surry Hills Sydney
- Headspace, Gosford, NSW, Central Coast Local Health District

Lastly and by no means least, MHCC acknowledge the many researchers and contributors both internationally and in Australia whose work informs and underpins the literature scan, report and recommendations.

Executive Summary

MHCC conducted a study entitled *Recovery Orientation in Youth Mental Health and Child and Adolescent Mental Health Services (CAMHS)* in 2014. This study sought to investigate the experiences of young people, their families and carers and the mental health service providers that they engage with to better understand what 'recovery' meant for them.

The study found that the recovery approach generally applies to young people, but that an important aspect of inquiry to progress was the development of language guidelines to reflect the perspectives of young people concerning recovery, mental health and associated issues. What became apparent during this second stage of the project is that while youth mental health services are well informed about the needs of young clients, adult mental health services and other agencies working more generally with young people, need information about communicating with young people and understanding what is important to them in the 'here and now'.

The project chose to focus on young people (adolescents and young adults) as a project that included children was outside of the brief of the inquiry, and because young people frequently engage with mainstream adult mental health services. This focus continued through both stages the project.

The **Youth Recovery Language Project** that followed set out to scan the literature concerning youth perspectives of recovery. Its principle focus was to determine the language used by young people in Australia to describe their lived experience of mental health difficulties. The project looked at how the workforce could enhance their understanding of young people, improve rapport and build relationships though more targeted communication.

The project's primary objective is to build on an existing resource - MHCC's *Recovery Oriented Language Guide* to build capacity of workers across mental health and human services and other related contexts (e.g. tribunals, legal service settings, primary health care). The aim is to improve outcomes for young people living with mental health conditions in the community as well as in public mental health settings.

This report provides an overview of the limited literature available on the subject of youth perspectives in Australia and internationally. Used together with the earlier literature scan, both informed the development of interview questions for two focus groups consisting of young peer workers and consumers engaged with community managed organisations. The scan of the literature plus an analysis of themes from the focus groups will later be translated into commentary and suggested language that reflects youth perspectives to be incorporated into MHCC's *Recovery Oriented Language Guide*.

MHCC acknowledge the limitations of the study in terms of participant numbers, groups and breadth of age, all of which may be considered as undermining the recommendations. However, we propose that the evidence found does support findings in the literature and feedback from the sector.

MHCC anticipates that the revised *Recovery Oriented Language Guide* will enhance outcomes for young people and improve understanding between workers and the young people they seek to support. By communicating in ways more relevant and empathic to a young person's developmental stage of life, it is hoped that young people can establish trusting and supportive relationships with service providers. These relationships will lead to greater satisfaction with the services they receive and empower them to fully participate in the development of their own plans for ongoing care and support.

Background

In 2014, the Mental Health Coordinating Council (MHCC) completed the *Recovery Orientation in Youth Mental Health and Child and Adolescent Mental Health Services* (CAMHS) study.[1] The project was initiated by MHCC and MH-Kids (the policy and planning unit for child and adolescent mental health in NSW, responsible for CAMHS (renamed Child and Youth Mental Health Service (MH CYPS) in 2015); NSW Children of Parents with a Mental Illness (COPMI) Program; Parenting Program for Mental Health; Safe Start; and School-Link). The project set out to particularly investigate the experiences of young people, their families and carers and the mental health service providers that they engage with, to better appreciate what 'recovery' meant for them.

Since recovery was originally defined from the perspectives of adult mental health consumers and their families and carers, the project sought to identify whether these concepts also applied to the developmental framework of young people experiencing mental health support. The study considered how the key concepts of recovery might be translated into language that young people could understand and connect with.

The study found that the recovery approach does indeed apply to young people; however, it discovered several areas of work to be further investigated. One such area was to further develop language guidelines that reflect recovery from the perspective of young people. The study clearly identified that the adult mental health services sector, as well as services and agencies working more generally with young people, need support material pertaining to communicating the principles and concepts of recovery to young people.

Project aim

The project set out to progress a recommendation of the earlier project. This included investigating the language utilised by young people concerning their 'lived experience', to determine where commonalities and differences occur in respect to adult recovery language and perspectives.

In order to assist mental health workers and others to enhance their understanding of youth perspectives and improve rapport and build relationships though better communication, the objective is to develop a resource that builds on the MHCC's existing *Recovery Oriented Language Guide* to inform workers across mental health services and programs (including youth services). It also aims to inform a broad range of human services in other contexts (e.g. tribunals, legal service settings, primary health care, housing, employment and education) and to improve outcomes for young people living with mental health conditions in the community as well as inpatient settings.

This report presents the process undertaken to inform and update MHCC's *Recovery Oriented Language Guide* by identifying the scope of issues and challenges experienced by workers supporting young consumers (with regards to language).

The literature scan sought to map the relevant evidence used to define recovery oriented practice for young people and identify the language effective in promoting recovery concepts when communicating with young people. The literature scan was also used to inform the process of examining and analysing the concept of recovery as it pertains to the young people consulted.

[1] Mental Health Coordinating Council 2014, 'Recovery Orientation in Youth Mental Health and Child and Adolescent Mental Health Services (CAMHS)'. Available: http://www.mhcc.org.au/media/50501/mhccrecoveryforyoungpeople-discussionpaper.pdf

The scan guides the development of an updated language guide to include aspects specifically relevant to young people. The information gathered will also be integrated across MHCC learning and development products where working with young people is the focus.

The MHCC Recovery Oriented Language Guide

MHCC published its *Recovery Oriented Language Guide*[2] in 2013. It represents an acknowledgement of the importance of recovery-specific language within the community mental health sector. It set out to inform both mental health community managed organisations and the broader community on recovery focused language relevant to consumer and carer perspectives. The guide highlights the importance that language can play in a person's recovery and provides some examples to support that journey.

MHCC is further developing its *Recovery Oriented Language Guide* to include material relevant to young people with lived experience (which often dates back to childhood). The organisation hopes to reduce the ambiguity and confusion resulting from the struggle to identify appropriate language when communicating with young people. Some literature suggests that the recovery-oriented approach applies to young people, adults and older people, however the language used to communicate the concept needs to be relevant to a person's developmental stage of life. The approach to language also needs to be culturally appropriate and take into consideration any cognitive difficulties a person may be experiencing. This may vary according to where they are in their recovery journey.

Terminology such as 'connectedness', 'consumer' and 'empowerment' are terms characteristically referred to when referencing recovery concepts. MHCC identified from the focus groups conducted during the earlier study: *Recovery Orientation in Youth Mental Health and Child and Adolescent Mental Health Services (CAMHS)* that these terms were confusing for young people. Thus, alternative language either needed to be identified from young people or developed through consultation with them.

One of the objectives of this second stage of the youth recovery project was to scan the available literature, both national and international, on youth experiences and their understanding of recovery. The recovery approach has been somewhat accepted and promoted across the mental health service sector in Australia (primarily in community managed services). However, this scan found limited evidence of the use of the recovery approach related to specific recovery-oriented language when working with young people.

Definition of Recovery

The concept of recovery originated from a grass roots mental health consumer movement that emerged during the 1960s responding to the drive to place consumer perspectives at the centre of service delivery. It continues to develop in Australia and internationally.[3]

The *Australian National Framework for Recovery-Oriented Mental Health Services* [4] defines personal recovery as "being able to create and live a meaningful and contributing life in a community of

[2] Mental Health Coordinating Council 2013, 'Recovery Oriented Language Guide'. Available: http://mob.mhcc.org.au/media/5902/mhcc-recovery-oriented-language-guide-final-web.pdf
[3] Davidson L & Roe D *2007,* 'Recovery from versus recovery in serious mental illness: One strategy for lessening confusion plaguing recovery', *Journal of Mental Health*, UK
[4] Department of Health and Ageing (ed.) 2013, 'A National Framework for Recovery-Oriented Mental Health Services: Policy and Theory', Commonwealth of Australia, Canberra, ACT.

choice with or without the presence of mental health issues." [5] Personal recovery differs from clinical recovery, in that it seeks to empower and connect with the consumer rather than focus, as clinical recovery does on the absence of symptoms.[6]

Over the past five years the concept of recovery and the acceptance of recovery orientation as an approach has become increasingly more broadly accepted. This is evidenced in for example the National Mental Health Commission having promoted a strong consumer and carer focus. This change was motivated by the concepts of a 'contributing life' and a 'recovery oriented approach' for persons with mental health conditions and psychosocial disability. This is described in the Australian *National Recovery Framework: Guide for Practitioners and Providers and the National Recovery Framework: Policy and Theory*. Likewise the *NSW Community Mental Health Strategy 2007-2012* [7] highlights the recovery oriented approach as key to improving consumers' experiences and outcomes.

A demonstration of 'recovery's' broader acceptance is reflected in the amendments to the *Mental Health Act 2007* (NSW) [8] proclaimed in September 2015. The Act now includes 'recovery' as an approach, for example in the Principles of care and treatment in the Objects of the Act (s.62).[9]

Whilst MHCC thoroughly endorse the concept of recovery as generally understood and accepted by consumers, carers and the community mental health sector, the authors wish to acknowledge tensions in contemporary discourse that investigates what recovery means from a sociological, policy and political perspective, but more importantly from a consumer perspective when engaging in a system that now supports the goal of 'recovery' as central to outcomes.[10] Rather than enter into this discourse, which is outside of the project brief, what this study sets out to do is privilege the voices of young people by asking them what recovery looks like from their perspective, and what language they might preference to describe their experiences.

Literature Scan

Search methods

A literature search of recovery-related terms and research articles pertinent to recovery-oriented practice in the youth mental health space was conducted utilising online databases.

Keywords and phrases included: "young people", "youth", "mental illness", "mental health", "recovery", "recovery orientation", "recovery oriented language", "mental health language", "communication", "trauma", "gender", "sexuality", "culture", "disability", "suicide", "communications and technology", "power", "Australia", "United Kingdom", "Scotland", and "United States of America".*

These terms were either used singularly or in various combinations.

In searching the literature the following methods were used:

[5] Ibid.
[6] Ibid.
[7] NSW Ministry of Health 2007, 'NSW Community Mental Health Strategy 2007-2012', North Sydney.
[8] *Mental Health Act 2007* (NSW).
[9] NSW Health Information Bulletin, 'NSW Mental Health Act 2007, Amendments, July 2015'. Available: http://www0.health.nsw.gov.au/policies/ib/2009/pdf/IB2009_006.pdf
[10] Pilgrim D & McCranie A 2013, *Recovery and Mental Health: A Critical Sociological Account*, Palgrave Macmillian Education, UK.

Journal database searches included: PsycINFO, PsycARTICLES, Academic Search Premier, Psychology and Behavioural Sciences Collection, and SAGE Psychology Journals.*

*Google Scholar and Google were also searched using the aforementioned keywords and phrases.

Topic areas

The original study *Recovery for Young People: Recovery Orientation in Youth Mental Health and Child and Adolescent Mental Health Services (CAMHS), Discussion Paper,* undertaken in 2014 presented a background to the concepts and issues based on a review of the literature. The existing concepts of recovery philosophy and recovery-oriented practice were defined and compared to current models used for working with children and young people who access mental health services. It also contained a summary of concerns expressed in existing literature about the application of recovery principles to children and young people. The Discussion Paper also outlined the findings from consultations conducted with young people, parents and caregivers; and mental health professionals who work with children and young people. Their perspectives on the utility of recovery concepts and recovery-oriented practice for the needs of children and young people was discussed.

The paper also suggested practice guidelines to assist with the implementation of recovery-oriented practice and provided recommendations for further work needed to assist with the implementation of recovery-oriented practice in mental health services for children and young people. All stakeholders believed that the involvement of families in the care of children and young people is of critical importance. All groups identified various ways in which families aid and support children and young peoples' mental health and general wellbeing. It was also identified that families need various supports in order to effectively provide support and continue to look after the wellbeing of the family as a whole. It became clear from consultations that there is a delicate balance to be navigated between support and protection needs, and the empowerment of children and young people to continue along the important developmental trajectory towards increasing independence and individuation from parents.

Because this important role of family and carers was extensively covered in the first project, this study focuses on the other topic areas In order to establish aspects of a young person's lived experience identified previously but not addressed in the consultation that may impact their perspectives of recovery. Key studies were identified in relation to nine main topic areas, including:

1. Cultural and orientational factors
2. Trauma and young people
3. Empowerment/ sharing power
4. Gender and sexuality
5. Suicide and self-harm
6. Disability
7. Living with a parent with a mental health condition
8. Communications and technology
9. Communicating with young people

Key studies were also identified that provide evidence around experience of working with young people and best practice approaches in the context of the topic areas.

The mental health of young people in Australia

One in four young Australians aged 16–24 years experienced mental health difficulties in 2007, according to figures released in 2010 by the Australian Bureau of Statistics. The figures in the ABS survey are expressed in terms of disorders, and are presented here to demonstrate the prevalence of conditions young people experience rather than label young people with diagnoses at a young age, a practice counter to the recovery approach.

According to the ABS, anxiety disorders were the most common, affecting 15% of young people, with post-traumatic stress disorder the most commonly experienced anxiety disorder (8%). Substance use disorders affected 13% of young people with harmful use of alcohol the most common substance use disorder (9%). Almost one-third of young women had a mental health disorder compared with around one-quarter of young men. Young women were more likely to have anxiety or affective disorders while substance use disorders were more common among young men.[11]

Cultural and orientational Factors

The *NSW Child and Adolescent Mental Health Services Competency Framework* [12] identifies the importance of mental health workers being culturally sensitive to young people when working with them: for example, appropriate non-verbal communication, eye contact and body posture. The consideration of specific cultural implications when communicating with young people is essential in order to effectively promote their recovery. For example the concepts of identity, empowerment, meaning, and purpose may be challenging for young people from diverse backgrounds and support systems.

In June 2012, the Scottish Government produced a guide for anyone who works directly with children and young people. The Guide, *Getting it Right for Every Child* [13] published in 2012, focuses on building a competent workforce that is committed to continued individual development. This will ensure that unfamiliarity with the presence and prevalence of mental health difficulties amongst young people is avoided where possible. The Guide also highlights the importance of cultural sensitivity when communicating with young people and their carers. However, it does not provide practical examples in how to do this. In addition to cultural considerations, the authors of the Guide propose that gender is also an important aspect to consider when communicating with young people.

The cultural divide between child/youth and adult mental health services was identified by one UK study (*Mind the Gap*) to be substantial. Services for children and young people tend to focus on a person-centred and a positive family-oriented approach, whereas adult services characteristically focus on either crisis or symptom management. [14] Likewise, there is a significant difference between the orientation and language used by child and adolescent mental health workers and the adult mental health workforce in Australia.

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[11] Australian Bureau of Statistics 2010, 'Mental Health of Young People: 2007 National Survey of Mental Health and Wellbeing' (SMHWB). Available: http://www.abs.gov.au/ausstats/abs@.nsf/Latestproducts/4840.0.55.001Main%20Features12007?opendocument&tabname=Summary&prodno=4840.0.55.001&issue=2007&num=&view= [Accessed: 24.02.2016].

[12] NSW Ministry of Health 2011, 'NSW Children and Adolescent Mental Health Services Competency Framework', North Sydney, NSW.

[13] Scottish Government, 2012, 'Getting it right for every child', Edinburgh, UK.

[14] Swaran S Navina E Sireling L & Stuart, H 2005, 'Mind the gap: the interface between child and adult mental health services', *Psychiatric Bulletin* 2005.

Child and adolescent practitioners are characteristically person and family centred (systems focused), collaborative and developmentally orientated, and work from a strengths-based perspective. However, this does not necessarily translate into recovery language per se.[15]

In the study, young people and their families expressed feelings of loss and described the experience of "a sense of 'culture shock' "as they attempted to navigate the transition to a starkly different adult system. [16]

The study also noted the reluctance of young people to embrace change. It found the heightened sense of anxiety around the change of services and systems should be addressed by educating the support workers in how to communicate with young people and their families. This is especially important during the initial transition between youth and adult services. Adolescents with mental health problems are poorly served by mental health services, since responsibility for care often falls between child and adult services. Within the UK, there is no consensus on how service boundaries should be delineated. [17]

Trauma and young people

A census report on young people and drug use conducted in Victoria (2013)[18] found that, compared to young men, young women had "experienced significantly higher levels of psychosocial complexity". Young women are more likely to experience physical, emotional and sexual abuse, as well as housing problems, drug abuse and mental health issues. Likewise, they are twice as likely to self-harm or attempt suicide. The numerous safety concerns of young women at risk were highlighted, and while the report provides no reason or information relating to the disparity, it did acknowledge the need to advocate and provide specialist services to support young women. Educating young women on the elements of recovery such as connectedness, hope and optimism for the future seeks to address this imbalance. This, in turn, emphasises the need to use gender-informed recovery oriented language.

Important to mention here is that while young women more prominently feature in the research concerning experiences of all forms of trauma and abuse, this should be considered in the light of less evidence as a result of lower reporting to police on the part of young men. This further highlights the need for a gender-informed language and communications approach enabling young men greater opportunities to access support. [19] [20]

Some of the most common reasons for young people experiencing homelessness are poverty leading to housing crises, domestic and family violence and relationship/family breakdown.[21] The number of homeless young people aged 12 to 18 decreased from 26,060 in census week 2001 to 21,940 in 2006.

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[15] Victorian Government Department of Human Services 2012, 'Family-centred, person-centred practice: A guide for everyday practice and organisational change', Department of Human Services and the Department of Education and Early Childhood Development.
[16] Ibid
[17] Ibid.
[18] Kutin J Bruun A Mitchell P Daley K & Best D (SYNC) 2013, 'Technical Report: Young people in AOD services in Victoria, Victoria-wide results', Youth Support & Advocacy Service, Melbourne.
[19] Covington S Griffin D & Dauer R 2011, *A Man's Workbook: A Program for treating Addiction*, John Wiley & Sons, UK.
[20] Covington S & Bloom, BE 2006, 'Gender-responsive treatment and services in correctional settings', in Leeder, E (ed), 'Inside and out: Women, prison, and therapy', Pathways to Prison Report, 2006, *Women & Therapy*, 29 (3/4), pp 9–33.
[21] AIHW, 2012, 'Specialist Homelessness Services 2011-12'.

Overall, the rate of youth homelessness across the country represents 11 cases per 1,000.[22] It is estimated that 90% of young people who become homeless have their first experience of homelessness when they are aged 15 or younger.[23] Since many young people have become homeless as a consequence of trauma they may no longer have or want family contact. Services need to be particularly sensitive to the diversity of experiences amongst young people when talking about what may be helpful to a person's recovery journey. [24] Young people may find it extremely difficult to talk about or disclose their trauma history.

MHCC have identified that children and young people who are exposed to trauma may find it particularly difficult to cope with the significant impacts of trauma due to their developmental stage.[25] The effects of trauma may manifest in a number of ways including the development of a mental health condition and coexisting difficulties. Physical health difficulties including somatoform symptoms or disorders and tendencies towards social isolation, both from family and friends, may also develop.

Often, young people experience trauma at school. The impacts of bullying, harassment and violence may become apparent because of difficulties with fellow students, truancy and isolative behaviours or through resisting authority at school or at home. Such difficulties may lead to the young person engaging in substance abuse or misuse or inappropriate sexual activity. Adult support is paramount during such times. Young people need to feel safe when engaging with services and workers - they need reassurance, and feel supported to develop and maintain a sense of hope.[26] The single most significant predictor that an individual adult will experience a mental illness is a history of childhood trauma.[27]

Research strongly indicates that trauma experienced in childhood increases the possibility in adulthood of poor mental and physical health. Childhood trauma was also found to affect quality of life outcomes, including education and financial security, and increase the likelihood of substance addiction, suicide, self-harm and risk of interpersonal violence.[28] These problems may be exacerbated by the difficulties young people face in communicating as a consequence of experiencing trauma itself. These may include difficulties with memory, concentration and dissociation. In young people, resistant, negative and antisocial behaviour is often a survival strategy. In the absence of a trauma-informed approach,[29] these behavioural manifestations may be exacerbated and prolonged. This highlights the need for organisations to ensure their staff are informed and appropriately trained concerning trauma-informed care and practice.[30] It is not only imperative that mental health services are familiar with appropriate language when working with

[22] Salvation Army, Youth Homelessness Website. Available: http://www.salvationarmy.org.au/en/Who-We-Are/our-work/Homelessness/Youth-homelessness/#sthash.ryldpJtS.dpuf
[23] Chamberlain C. & MacKenzie D 1998, Y'outh Homelessness: Early Intervention & Prevention', Australian Centre for Equity through Education.
[24] Morrison Z 2009, 'Homelessness and sexual assault', Australian Institute of Family Studies, *ACSSA Wrap* No. 7, 2009. ISSN 1833-1483. Available: http://www.aifs.gov.au/acssa/pubs/wrap/w7.html#implications
[25] Fergusson DM & Mullen PE 1998, 'Long-term effects of Child Sexual Abuse', National Child Protection Clearing House. Available: http://www.aifs.gov.au/nch/issues9.html
[26] Substance Abuse and Mental Health Services Administration 2013, 'Tips for Talking With and Helping Children and Youth Cope After a Disaster or Traumatic Event: A Guide for Parents, Caregivers, and Teachers', USA.
[27] Dunne M Purdie D Boyle F & Coxeter P 2005, 'Childhood sexual abuse linked to sexual dysfunction later in life for both men and women', University of Qld School of Population Health.
[28] Bowie V 2013, 'Trauma-informed care', *Youth Studies Australia*, vol. 32, no. 4, pp 81-83.
[29] MHCC propose that a trauma-informed approach is one that considers the history of trauma experienced by a consumer and seeks to collaborate with the consumer and service providers to ensure service and program delivery is supportive, effective and avoids re-traumatisation.
[30] MHCC 2013, 'MHCC Recovery Oriented Language Guide', NSW, Australia.

young people who have experienced trauma, but that other human service sectors such as housing, education and employment, and the community are likewise aware and informed. [31]

When creating a trauma-informed guide for services for mothers and children experiencing homelessness, Prescott et al.,[32] found that "a mental health consumer defines safety as anything that minimises the loss of control, and applies to all aspects of their social, physical and emotional life". However, the guide does not identify whether the definition from the perspective of young people is similar or different. [33]

The encouragement of discussion among staff, consumers and carers around 'safety' and what that means for individuals, provides an opportunity for policies to be developed and generates awareness about consumer needs. Consumer and carer engagement is paramount in order to ascertain how a young person may feel, and what they experience in relation to their personal and emotional safety when they deal with the mental health and human services sectors. For example, how workers verbally convey safety and handle disclosures needs to be part of those conversations and consultations, and those discussions need to be sensitive to a person's developmental stage of life.[34]

Empowerment

A qualitative study on the empowerment of young people with psychosis suggests that young people greatly value personal empowerment when accessing mental health services.[35] Further, this study found that young people believe that experiencing empowerment is the primary contributing factor to their individual recovery. The study also noted that young people and their families appreciated mental health workers who communicated "in a jargon-free and non-patronising manner", [36] as this helped them feel both respected and heard.

Unsurprisingly, young people also stressed that they lost confidence and trust in mental health workers who did not listen to them. In their 2013 study with voice-hearers, Romme and Morris [37] identified that the support a mental health professional provides to a young person needs to be based on an attitude of acceptance for the individual.

However, the evaluation of *Right Here* [38] by the Institute for Voluntary Action Research (IVAR) found that empowerment was as much about young people 'finding themselves' and being provided a safe and supportive environment where they could develop and grow as people. From 2011 onwards, participation broadened to a more blended 'growing through doing' approach. Being involved with activities where it was possible to observe the effect of a person's involvement over

[31] MHCC 2013, 'Trauma-Informed Care and Practice: Towards a cultural shift in policy reform across mental health and human services in Australia: A National Strategic Direction', Authors: Bateman, J & Henderson, C (MHCC) Kezelman, C (ASCA). Available: http://www.mhcc.org.au/media/32045/ticp_awg_position_paper__v_44_final__07_11_13.pdf
[32] Prescott L Soares P Konnath K & Bassuk E 2008, 'A Long Journey Home: A Guide for Creating Trauma-Informed Services for Mothers and Children Experiencing Homelessness', Rockville, MD: Center for Mental Health Services, Substance Abuse and Mental Health Services Administration; and the Daniels Fund; National Child Traumatic Stress Network; and the W.K. Kellogg Foundation.
[33] Op. cit. MHCC 2013.
[34] Op. cit. MHCC 2013.
[35] Grealish AP 2013, 'Qualitative Exploration of Empowerment from the Perspective of Young People with Psychosis', *Clinical Psychology & Psychotherapy*, vol. 20, no. 2, pp. 136-148.
[36] Ibid.
[37] Romme M & Morris M 2013, 'The recovery process with hearing voices: accepting as well as exploring their emotional background through a supported process', *Psychosis* vol. 5, no. 3, pp. 259-269.
[38] Mental Health Youth Foundation 2015, 'How does mental health-informed youth work empower young people to make change happen?' Available: http://www.mentalhealth.org.uk/our-work/research/right-here-programme/right-here-empower-young-people/

time, on the overall shape and direction of those activities, was vital for young people in discovering their own power to influence events. The evaluation of *Right Here* made clear that for young people, empowerment is not the same as simply being offered an opportunity to speak on your own or others' behalves, and not simply a matter of being encouraged to 'have your say'. Young people, especially those who have had difficult or challenging life events or conditions, require a mixture of support, encouragement, feedback and validation to become comfortable in their own capacity to take control of situations.

Once young people felt that their opinion was listened to and respected, this, in turn, influenced them to further explore and try out this 'voice'. For some young people, this growing confidence came from exploring mental health-related issues and wellbeing activities; for others, it came from being involved in supportive and inclusive youth work-informed spaces. This involvement helped them to form stable relationships with project workers and other young people.

Gender and Sexuality

According to *The third national study on the sexual health and wellbeing of same sex attracted and gender questioning young people* (2010),[39] Australian same sex attracted and gender questioning young people experience high levels of verbal and physical homophobic abuse within their school and local communities. The study identified the strong links between the abuse experienced and the development of mental health conditions, self-harm, suicidal ideation and suicide attempts. The study acknowledged the crucial support from family, friends and professionals that eased the impact of the abuse experienced by young people.

In the 2014 University of Western Sydney research paper *Growing Up Queer*,[40] gender variant and sexuality diverse young people admitted to having depression, suicide ideation and attempted suicide as a result of experiencing bullying or harassment due to their sexual preferences.

Some research participants in this study [41] admitted that they found it difficult to discuss their sexuality with health professionals as they felt that they were often unsupportive or homophobic/transphobic. The research recommends that education and training regarding sexual health and effective communication skills be provided to health professionals working with young people in order to provide as much support as possible.

Suicide and self-harm

While suicide rates among young people have declined in recent years, the Australian Bureau of Statistics (ABS) notes that suicide is still high among young people. In 2013, 148 deaths by suicide were recorded for males aged 20 – 24 years, [42] equating to 17.7 per 100,000 people. The number of female deaths by suicide for the same period and age group was 52, equating to 6.5 per 100,000. These figures do not in any way reflect the high numbers of young people who experience suicide ideation on a regular basis. Nor does it include the young people whose coping mechanisms reflect the depth of despair they experience even though they may not complete suicide. The

[39] Hillier L Jones T Monagle M Overton N Gahan L Blackman J & Mitchell A 2010, 'The third national study on the sexual health and wellbeing of same sex attracted and gender questioning young people', Australian Research Centre, *Sex, Health and Society*, La Trobe University, Melbourne.
[40] Robinson KH Bansel P Denson N Ovenden G & Davies C 2014, 'Growing Up Queer: Issues Facing Young Australians Who Are Gender Variant and Sexuality Diverse', Young and Well Cooperative Research Centre, Melbourne.
[41] Ibid.
[42] Australian Bureau of Statistics 2015, 'Causes of Death', Australia.

statistics also do not take into account ambiguous deaths as a consequence of unexplained car accidents or deaths from substance abuse.

Suicide and self-harm continue to remain a prevalent issue [43] for young people. It is imperative that mental health workers are mindful of avoiding the use of negative language that stigmatises and discriminates when discussing young people's experiences and actions. By reframing the conversation and how we reference suicide and self-harm, Beaton, Forster and Maple (2013) propose that we can promote the concept of recovery.[44]

Child sexual assault is associated with two and a half times the rates of mental 'disorder'. [45] This includes being two to three times more likely to have an anxiety, mood or eating disorder; four times more likely to attempt suicide and sixteen times more likely to have a sleep disorder. [46] It is vital that the language used to talk to young people considers the young person's perspective of what is happening to or around them; what this means to them; and taking into account how they express the distress they may be experiencing. [47]

Disability

The literature on perspectives of young people with disability and coexisting mental health difficulties is almost non-existent. However, according to research conducted by KidsMatter in 2010, children and young people with physical disabilities have a "higher likelihood of developing mental health problems than those without disabilities". [48] The study also identified the high prevalence of mental health conditions among young people who are hearing impaired or have cerebral palsy, epilepsy or chronic physical health conditions. The report emphasised that support and attitude of carers and workers significantly contributes to improving resilience and promotes good mental health and wellbeing in young people with disabilities.

KidsMatter highlighted the need for workers and carers to foster an inclusive, communicative environment where young people with disabilities are empowered and encouraged to meaningfully participate in their community. This was identified as key in promoting the mental health and wellbeing of young people. When families, schools and communities take steps to understand the child's individual needs, build on their strengths, and provide supportive and respectful environments, children with additional needs can experience good mental health and their potential for learning can be maximised.

[43] Flinders University Research Centre for Injury Studies 2010, 'Youth Suicide and Self-Injury Australia', Available: http://www.nisu.flinders.edu.au/pubs/bulletin15/bulletin15sup.html/
[44] Beaton S Forster P & Maple M 2013, 'Suicide and language: why we shouldn't use the 'C' word', *In Psych,* Australian Psychological Society.
[45] Fergusson D Horwood L & Lynskey M 1997, 'Childhood sexual abuse, adolescent sexual behaviors and sexual revictimization', *Child Abuse & Neglect*, 21(8), pp 789–803.
[46] Chen LP et al. 2010, 'Sexual Abuse and Lifetime Diagnosis of Psychiatric Disorders: Systematic Review and Meta-analysis', *Mayo Clinical Practice*, July, 85(7), pp 618–629. Available: http://livingisforeveryone.com.au/uploads/docs/LIFE-Fact%20sheet%2023.pdf
[47] Lifeline, Website. Available: http://livingisforeveryone.com.au/uploads/docs/LIFE-Fact%20sheet%2023.pdf
[48] Dix K Shearer J Slee P & Butcher C 2010, 'KidsMatter for Students with a Disability: Evaluation Report Ministerial Advisory Committee: Students with Disabilities', Centre for Analysis of Educational Futures, Flinders University, Adelaide, SA.

Living with a parent with a mental health condition

According to on UK study,[49] more than one third of all adults in the UK who experience mental illness are also parents. It is estimated that in the UK around 175,000 children are caring for parents who are ill or disabled.[50] According to Australian studies, as many as one in eight young Australians with a mental health issue has a parent who also experiences a mental illness.[51] According to a detailed analysis conducted by Maybery et al.,[52] it was determined that between 21 and 23 per cent of Australian children live with at least one parent with a mental health issue.

Until more recently, medical research in particular highlighted the negative impacts of parental mental illness on children and tended to pathologise the issue as well as focus on risks to children; these included "the risk of children inheriting mental illness or developing learnt behaviours; as well as attachment disorders following poor or ineffective parenting, particularly when mothers experienced mental illness" (Antony, 1970).[53] Few studies adopted approaches that relied on the first-hand accounts of children themselves.[54]

Where adults experience mental illness and they are also parents it is not uncommon for their children to be undertaking some form of caring responsibility. The likelihood that children will be undertaking long term caring that is disproportionate to their age or level of maturity increases where parents with mental illness are also lone parents, experience poverty, low income, or the impacts of social exclusion.[55]

Parents have an important role in maintaining the mental health of their children. This might be challenging when a parent has a mental health condition, particularly when mental health practitioners and other health professionals are so 'patient focused' that they can overlook the needs and responsibilities of their patients' children.[56] Young carers and their families require both family focused interventions and dedicated services for children to help them cope with their caring roles. Caring can have long term negative consequences for children when their responsibilities and needs are overlooked.[57]

Children of Parents with a Mental Illness (COPMI)[58] is a national organisation that promotes better outcomes for children and families where a parent experiences mental illness. COPMI has established an online 'Gateway to Evidence that Matters' (GEMS)[59] to provide a summary of recent Australian and international research regarding children (aged 0-18 years) of parents with a mental

[49] Aldridge j 2008, 'Children who care for parents with a mental illness: A UK perspective', Department of Social Sciences at Loughborough University.
[50] Ibid.
[51] Wilson C 2010, 'Help seeking for young people with mental health problems in families with a parent who experiences a mental illness, Graduate School of Medicine, University of Wollongong NSW.
[52] Maybery D Reupert A Patrick K Goodyear M & Crase L 2005, 'Vic health research report on children at risk in families affected by parental mental illness', Victorian Health Promotion Foundation Mental Health and Wellbeing Unit.
[53] Anthony E J 1970, 'The impact of mental and physical illness on family life. American Journal of Psychiatry, 127 (2), 138–46.
[54] Parrott L, Jacobs G & Roberts D 2008, SCIE research briefing 23: 'Stress and resilience factors in parents with mental health problems and their children', London: Social Care Institute for Excellence, pp 1–9.
[55] Getting it Right for Every Child: Available: http://www.scotland.gov.uk/Topics/People/Young-People/childrensservices/girfec
[56] COPMI, Gateway to Evidence that Matters (GEMS). Available: http://www.copmi.net.au/professionals-organisations/what-works/research-summaries-gems
[57] Sturges J S 1978, 'Children's reactions to mental illness in the family', Social Casework, 59 (9), 530–536.
[58] Children of Parents with Mental Illness (COPMI). Available: http://www.copmi.net.au/about-copmi
[59] COPMI, Gateway to Evidence that Matters (GEMS), Edition 15. Available: http://www.copmi.net.au/professionals-organisations/what-works/research-summaries-gems

illness, their parents and families. While research in this area is growing, there is a lack of evidence-based practice when working with families affected by parental mental illness.

The GEMS have been prepared as a resource for those specifically working in the field, and aims to provide a synthesis of available research that can guide and direct practitioners by highlighting current research and practice gaps. The GEMS promote the collection, interpretation and integration of valid, recent and relevant research from around the world, based on the views and experiences of those researching, working and living with parental mental illness.

The literature proposes that therapeutic intervention must involve the young person as an active collaborator in a recovery plan that empowers them to manage their family context. Help-negation may be misunderstood by all parents and might be challenging for parents with a mental health condition to address. Promotion of appropriate help-seeking must focus on increasing the quality of relationships between a parent and their children. Effective communication with the young person regarding their parent is paramount. [60] Stressing that it is imperative that young people receive the appropriate communication, support and prevention and early intervention services, based on the concepts of recovery, to reduce the development of mental health conditions, the authors found no literature that encapsulates language that young people relate to concerning all these issues as identified by them.

Communications and Technology

Recent evidence by the Young and Well Cooperative Centre shows that young people are increasingly comfortable using technology-based communications to discuss their emotions and experiences.[61] It would appear that the absence of social cues such as facial expressions and gestures provides young people with an opportunity to disclose serious or sensitive information in what they perceive as a less-judgmental environment (where they can meet and converse with like-minded people).[62] Health practitioners have noted that meeting young people in a space where they are comfortable can help build rapport and improve communication, even when online.[63] Having discarded the formalities of meeting face-to-face, online communication can seemingly offer a frank and sincere discussion about mental health problems.

A study conducted by Eysenbach et al., in 2004 on the efficacy of virtual communities found that young people participate in online peer support networks because they are easily accessible, and provide specific information that match their needs. They were also found to foster a sense of freedom.[64] Evidence also suggests that online internet forum participants tend to manage their health conditions better, with positive social and medical outcomes noted.[65] However, the evidence also highlighted the risk associated with non-health professionals providing misinformation on the forums, and young people taking advice that has no evidential basis.

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[60] Australian Family Relationships Clearinghouse, 2008, 'Family relationships and mental illness Impacts and service responses', Issues paper: Number 4, Authors, Robinson, E Rodgers, B & Butterworth, P.
[61] Eysenbach G Powell J Englesakis M Rizo C & Stern A 2004, 'Health related virtual communities and electronic support groups: systematic review of the effects of online peer to peer interactions', *British Medical Journal,* vol. 328, no. 7449, pp. 1166.
[62] Campbell AJ & Robards F 2012, 'Using technologies safely and effectively to promote young people's wellbeing: a better practice guide for services', NSW Centre for the Advancement of Adolescent Health, Westmead and the Young and Well Cooperative Research Centre, Abbotsford.
[63] Ibid.
[64] Op.cit. Eysenbach et al., 2004.
[65] Campbell AJ & Robards F 2012, 'Using technologies safely and effectively to promote young people's wellbeing: a better practice guide for services', NSW Centre for the Advancement of Adolescent Health, Westmead and the Young and Well Cooperative Research Centre, Abbotsford.

Dr Andrew Campbell and Fiona Robards of the Young and Well Cooperative Research Centre in Sydney,[66] report that young people are comfortable using 'emoticons' and other forms of technology-based communication to convey their feelings. When communicating with young people online, adults need to ensure they are familiar with this 'shorthand' in order to provide the most appropriate support and information. A misinterpretation of graphics, symbols and the vernacular could cause undue confusion, close communication channels and spark a breakdown of rapport when supporting a young person on their recovery journey.

The anonymity the online community provides is powerful and there are several websites and forums supporting young people in the mental health space. However, the Young and Well Cooperative Research Centre identified a lack of resources and online tools based on the recovery concept.

Communicating with young people

The stigma attached to the label 'mental' is well established. In recent history, the word mental has been used in negative contexts, but more recently it has been used as a positive term within youth culture to communicate what is cool or exciting. In 2006, Australian researchers from several universities, Wisdom, Clarke and Green (2006) [67] suggested that for young people the term 'mental health' sends a message that the problem lays in their mind and elicits a fear of being labelled or judged as 'mental' by friends and family.

Reading and Birchwood (2005) suggest that without active support and assistance, young people may disengage from services and their recovery journey.[68] Other literature highlights the importance of adults displaying empathy and a supportive interpersonal approach when working with young people.[69] Active listening skills were acknowledged as paramount to effectively engage with young people, with open body language such as leaning forward, nodding and smiling proven to be helpful when interacting. Similarly, Reading and Birchwood found that incongruence was identified as a substantial barrier, especially when there is a mismatch between verbal and non-verbal communications.

Fischer et al.,[70] recently developed guidelines to support adults when discussing mental health issues with young people. The *Development of Guidelines for Adults on How to Communicate With Adolescents about Mental Health Problems and Other Sensitive Topics: A Delphi Study* acknowledges that there is little information available to support the mental health community when working with adolescents. The guidelines note that an Australian Bureau of Statistics report in 2010 showed that one in four young people accessed some form of mental health service in the previous twelve months.

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[66] Campbell AJ & Robard, F 2012, 'Using technologies safely and effectively to promote young people's wellbeing: a better practice guide for services', NSW Centre for the Advancement of Adolescent Health, Westmead and the Young and Well Cooperative Research Centre, Abbotsford.
[67] Wisdom J P Clarke G N & Green C A 2006,, 'What teens want: barriers to seeking care for depression', Adm Policy Mental Health, Vol. 22, 133 – 145 cited in Rickwood, Deane & Wilson, 2007, 'When and how do young people seek professional help for mental health problems?' Medical Journal of Australia, Vol 187, no. 7.
[68] Reading B & Birchwood M 2005, 'Early intervention in psychosis', *Disease Management and Health Outcomes*, vol. 13, no. 1, pp. 53-63.
[69] Davis J & Huws-Thomas M 2007, 'Care and Management of Adolescents with Mental Health Disorders', *Nursing Standards,* vol. 21, no. 51, pp. 49-56.
[70] Fischer JA Kelly, CM Kitchener BA & Jorm AF 2013, 'Development of guidelines for adults on how to communicate with adolescents about mental health problems and other sensitive topics: A Delphi study',

The guidelines also note that young people may find it difficult to trust and disclose sensitive information to people they do not know and would rather speak with friends and family than a professional, hence the importance of the guidelines. The guidelines include suggestions such as planning an approach and being mindful of body language during the conversation.

Another guideline is to be aware of talking "with" the young person, rather than "at" them and not trivialising the adolescent's feelings. While these guidelines are informative, they do not identify suggested key terminology or phrases adults might use when communicating with young people about their mental health condition and recovery.

The *NSW Child and Adolescent Mental Health Services Competency Framework* [71] also identifies the importance of mental health workers being culturally sensitive to adolescents when working with them; for example, appropriate non-verbal communication, eye contact and body posture. The consideration of specific cultural implications when communicating with young people is essential in order to effectively promote their recovery. For example, the concepts of identity, empowerment, meaning and purpose may be challenging for young people from diverse backgrounds and support systems.

Summary

> *There is a significant lack of research and evidence regarding the mental health and social and emotional wellbeing of Australian young people.*
>
> Australian Research Alliance for Children and Youth Report Card: The wellbeing of young Australians, 2013. [72]

The authors also found that there was little evidence in the literature of a recovery oriented approach and language that young people use to describe their experiences. Similarly the authors found that there was very little material that looked at lived experience of young people either in youth or adult mental health contexts or as carers of parents with mental health conditions. However, the *Australian Research Alliance for Children and Youth Report,* identified that appropriate language "assisted a young person's recovery journey", [73] but did not articulate what language was used. Some support resources for the workforce engaging with young people with mental health conditions were identified as well as numerous self-support materials for young consumers. Some of these resources are listed in Appendix 6.

Working together to build a positive rapport by using appropriate language is vital to the recovery journey. This journey can be one of engagement and support if the workforce is given the materials and resources to effectively communicate with young people.

Consideration of aspects such as the environment and methods young people use to communicate and obtain information is of utmost importance. The anonymity and safety that online groups provide is clearly important to young people.[74] Unfortunately, due to the nature of

[71] NSW Ministry of Health 2011, 'NSW Children and Adolescent Mental Health Services Competency Framework', North Sydney, NSW.
[72] Australian Research Alliance for Children & Youth 2013, 'Report Card: The wellbeing of young Australians', Canberra, ACT.
[73] Ibid.
[74] Campbell AJ & Robards F 2012, 'Using technologies safely and effectively to promote young people's wellbeing: a better practice guide for services', NSW Centre for the Advancement of Adolescent Health, Westmead and the Young and Well Cooperative Research Centre, Abbotsford.

the online space, there is danger of misinformation and/or lack of expertise, which may stall or halt the recovery process.

Culture and gender are important factors affecting language and need to be considered when working with young people. Well informed and sensitive professionals can offer the respect and trust that young people need to successfully navigate their recovery. The significance of providing relevant and carefully considered recovery-oriented language is a key competence required to support staff as they work with young people on their recovery journeys.

Particular groups to be especially aware of include young people with parents with a mental health condition, those contemplating or with experience of suicide, and young people who have experienced trauma. Having difficulty with trust and feeling unsafe, including people with various cultural backgrounds, are also identified as groups requiring specific support. All of these have been identified as experiences or areas in which further research is required.

The MHCC *Recovery Oriented Language Guide* has the potential to be expanded to include information to improve communications with young people, ensuring that language used makes sense to them. This includes language that avoids labelling, prevents discrimination and minimises stigma, whilst supporting the recovery journey. Such language may incorporate colloquial speech rather than the formal recovery terminology such as 'consumer', 'empowerment' or 'connectedness'. Language that is age appropriate should also articulate where there may be commonalities and differences to adult concepts of recovery.

Given the lack of research evidence available, this review has assisted in highlighting and affirming the development of the project to ensure that all sectors working with young people may benefit from incorporating age appropriate recovery oriented language in an effort to support individual recovery journeys.

Consultation process

MHCC sought to conduct consultations with young people to enable them to identify language that reflects their experience and preferences with regards to language. Members of the YRL Project Reference Group assisted the MHCC and the student on work placement in organising focus groups at their facilities.

MHCC highlight the limitation to the study due to considerable difficulty in recruiting participants from a number of services. MHCC's intention had been to recruit many more participants with a diversity of lived experience that spanned across youth age range and engagement with services. MHCC also had difficulty in recruiting a diversity of young people from different cultural groups. Only one participant identified Aboriginality as part of their cultural heritage and lived experience.

Information Statement Forms were provided in advance to all focus group participants. Please refer to Appendix 3 for further details.

Consent forms were developed and distributed to all focus group participants. Signed copies were securely stored at MHCC following the focus group sessions. Please refer to Appendix 4 for further details.

Focus Groups

Consultations were conducted through two focus groups at two organisations. The first focus group was held at **WEAVE Youth and Community Services**. WEAVE is a not-for-profit service working with disadvantaged young people, women, children and families in the City of Sydney and south Sydney. This focus group was a mixed group of six young service users (over 18) who frequent WEAVE for support and engagement with fellow consumers and support workers. A support worker and student social worker also participated in the group.

The second focus group was held at **headspace in Gosford**. headspace Gosford works with local young people aged 12 – 25 years and focuses on general health, mental health, alcohol and drug services, education and employment. The lead agency of headspace Gosford is the Central Coast Local Health District with additional support services provided by Central Coast Children and Young People's Mental Health, Medicare Local Central Coast NSW (now Central Coast Primary Care), Youth Connections, the Brain and Mind Institute and the ORS Group. The service has onsite GPs, nurses, psychologists, drug and alcohol workers, counsellors, social workers and various support staff to assist young people and their carers as quickly and as efficiently as possible.

The young people that participated in the headspace Gosford focus group comprised of five peer workers and two service users. We were given to understand that these participants had been engaged for some time with the service, and that the peer workers had in fact been clients of the service. The peer workers were all over 18, but we did not confirm the age at which they engaged with the service.

Methodology

A series of questions was developed based on the information analysed in the first stage of the project, which clearly identified that participants related to the CHIME principles. The acronym CHIME – Connectedness, Hope and Optimism about the future, Identity, Meaning in life, and Empowerment was a useful structure from which to build the questions (Appendix 5).

The information gathered from the literature mapping process was also used to inform the development of interview questions. These questions were utilised in consultation focus groups with young people and youth peer workers in order to explore their lived experience of mental health conditions. The questions also covered engaging with services and the stigma and discrimination young people experience both internally and externally.

An information statement summarising the purpose of the focus group and the project was developed and distributed to the host organisations and the participants prior to the commencement of the focus groups. So too was a consent form by which participants were advised of the confidentiality of the group, the consultation process and the audio recording of the discussions.

The questions were posed in focus group settings that were both safe and comfortable and designed to encourage honest and straightforward feedback. The sessions lasted approximately 1½ hours and were recorded to ensure accurate post-session analysis. The sessions were then transcribed and compared resulting in common themes and responses identified. The recordings were subsequently deleted as outlined in the Information Statement and Consent Form supplied to all participants.

Inclusion Criteria

Participants:

- Peer workers with lived experience of 'recovery' providing support to young people with mental health conditions
- Young people living in the community with mental health conditions with a history of lived experience over some years including childhood

Exclusion Criteria

- Patients in acute mental health settings
- Consumers under 18 years of age

Focus Group Themes

The following information was compiled following the focus group sessions and represents the broad themes important to young people when discussing their recovery and working with support services and staff.

CORE THEMES

- When a young person is well there is less swearing. They're "doing good", relaxed and clear-headed
- When a young person is not well there is general swearing, "stuff's going shit" or "everything's fucked"
- Music is the common resource that helps young people feel grounded and well. Sport and general hobbies were also referenced
- Feeling heard and respected is vitally important to young people

CONNECTEDNESS

- Feeling connected = face-to-face and online interaction with people, music, sport and nature
- Other terms of connectedness include bonding, having a 'deep and meaningful' (D & M)
- Both groups insisted on the importance of authenticity and congruence of the support worker when seeking to connect with the young person

Note: the following suggestions come with the caveat that this material is based on limited participation with young people in the focus groups. As a consequence, only two focus groups consisting of twelve participants were possible to organise and may not reflect the diversity of young people in terms of developmental age and cultural differences. Some readers may judge that this undermines the validity of recommendations. Similarly the suggested language is also limited due to the small number of participants involved.

Suggested language pertaining to Connectedness:

- How's everything?
- Are you spending any quality time with people?
- Would you like to have a D & M session?
- Are you seeing your mates?
- Do you feel connected to your mates?
- Is there anything else that's worrying you about this?

HOPE and OPTIMISM

- Both groups discussed the difficulty at times for young people to have hope in the future – it often seems too big and daunting
- Both groups agreed that 'hope' is a good word and fits well
- Optimism is a complex word that should not be used
- The term 'goals' is too big and can be overwhelming

Suggested language pertaining to Hope and Optimism:

- Replace 'optimism' with 'positivity' e.g. "Recovery is all about positivity"
- "Recovery is about you deciding how you want to move forward"
- When discussing 'goals' reference 'steps forward' instead e.g. "what are your steps forward?" or "what are you looking forward to doing?"
- Short term language is really useful

IDENTITY

- Diagnosis of a mental illness can become the young person's identity
- Young people often don't know who they are so being told to "be yourself" is unhelpful

Suggested language pertaining to Identity:

- You say that you feel shit - Ask open questions such as "what made you feel like shit today?"
- "What is important to you that makes you feel comfortable?"
- "Is there something that makes you feel good about yourself?"

EMPOWERMENT

- To be supported in recovering
- To be listened to, taken seriously
- Dignity of Risk is being allowed to make mistakes and not be judged for them
- Both groups referenced experiences of not being provided with all of the information regarding their illness and treatment options when dealing with mental health workers, which disempowered them

Suggested language pertaining to Empowerment:

- Using the phrase "shared decision-making"
- "Do you feel you have a voice when discussing your treatment plan?"
- "What would you like to ask?"
- Being allowed the "freedom to make your own mistakes"
- To be allowed to make bad decisions and to learn from your mistakes

OTHER TERMINOLOGY

Recovery – Can be a confusing term. Suggest using language that suggests that a young person's "Recovery journey is about figuring out who you are and what you want – there's no start or end point".
Consumer – Replace with "young person" (a person with lived experience)
Peer – A helpful term as it's used in the school environment and young people are familiar with it.
Peer Worker – Is a person with lived experience of mental health issues who supports young people as a staff member of a service.

Concluding findings and commentary

It is imperative that mental health services are familiar with appropriate language when working with young people who experience mental health difficulties and may also have experience of trauma. It is also essential that other human service sectors such as housing, education and employment are likewise aware and informed.

Whilst acknowledging the limitations of this study in terms of participant numbers and cultural diversity, MHCC propose the following findings be considered as recommendations for an approach to trauma-informed recovery oriented practice when working with young people. These will be included in the revised version of the Recovery Oriented Language Guide.

- When communicating with young people it is essential to be mindful of appropriate non-verbal communication, eye contact and body posture. Above all sincerity is paramount. Young people quickly understand when someone is using language that they would not normally use. Young people stress the importance of authenticity and transparency. Use language that is real and familiar rather than imitate young people.

- Sharing of power is a key element in an individual's recovery journey. Young people say that they feel this intensely. By supporting shared decision-making young people can develop a sense of control over their lives and their recovery. Appropriate language is vital in communicating a sense of self-determination.

- Using non-clinical language should be used where possible to help anyone better understand all aspects of their condition, care and treatment. This is no different at any stage of life. Feeling powerlessness when experiencing any kind of mental or physical health condition can be overwhelming. It is important to always give a person, whatever their age experiencing cognitive difficulties, the time and space to question what has been said and state their point of view.

- Young people are no different to adults engaging with support workers in expressing the importance of collaboration and openness. This is largely achieved through a sense of connectedness, and feeling respected and heard.

  What is particularly meaningful is displaying a genuine interest in people and their lives. Asking "how's everything going?" can be a good way of opening the door to a conversation about anything that they may need to talk about.

- When a person, and particularly a young person, is asked to formulate recovery goals and is unable to list concrete objectives, this can result in them feeling judged, stupid and useless. Whilst instilling hope is vital to everyone, some young people feel overwhelmed when asked to think about the future. For young people particularly, an alternative approach is to refer to 'steps forward' rather than 'goals'. For example, "what do you think might be helpful steps forward?" or "what are you looking forward to doing?" Young people are often figuring out who they are and what they want of life and don't want to be cornered.

- Whilst not wanting workers to feel uncomfortable or requiring them to use language that they would not normally use, they need to understand that swearing or 'bad language' is a prominent feature in the vocabulary of many young people – both when things are going well and when things are challenging. A young person may say "I feel crap" or "this is shit" or "I'm fucked". Enabling conversation that is accepting of this language is important in establishing rapport with a young person.

Key Terms

A Consumer is a person with personal lived experience of mental illness who is accessing or has previously accessed a mental health service.[75] Within a child and youth mental health context, both the parents and the child or young person may also be described as people with 'lived experience'.

Diversity is inclusive of but not limited to the diversity among people with respect to culture, religion, spirituality, disability, power, status, gender and sexual identity and socioeconomic status.[76]

Peer Work is the fastest growing occupational group in the mental health workforce. Peer services are a core component of a genuinely recovery based service. Peer work, peer workers and peer workforce includes all workers in mainstream or alternative mental health services or initiatives who are employed to openly identify and use their lived experience of 'recovery' as part of their work. Peer support workers provide support for personal and social recovery to people with mental health problems, including in acute mental health services, housing, supported employment, community support and so on.[77]

Psychosocial disability is an internationally recognised term under the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD). It is used to describe the characteristic outcomes for a person with a mental health condition attempting to interact with a social environment that presents barriers to their equality with others. Psychosocial disability may also describe the experience of people with impairments and participation restrictions related to mental health conditions. Conditions can include the loss of or reduced ability to function, think clearly, experience full physical health and manage the social and emotional aspects of their lives.

Somatisation is a tendency to experience and communicate psychological distress in the form of somatic symptoms and behavioural features. More commonly expressed, it is the generation of physical symptoms of a psychiatric condition such as anxiety.

Trauma-informed is the re-conceptualisation of traditional approaches to health and human service delivery whereby all aspects of services are organised around acknowledging the prevalence of trauma throughout society. `Trauma-informed' services are aware of and sensitive to the dynamics of trauma as distinct from directly treating trauma per se.

[75] Australian Health Ministers 2003, 'National Mental Health Plan 2003–2008', Commonwealth of Australia, Canberra, ACT.
[76] State of Victoria, Department of Health 2013, 'National Practice Standards for the Mental Health Workforce 2013', Victorian Government Department of Health, Melbourne, VIC.
[77] Interrelate 2013, 'Peer Workforce in Mental Health: Part 1: Proposal to Develop an International Consensus to the International Initiative for Mental Health Leadership (IIMHL)', National Empowerment Center (NEC), Lawrence, MA.

Appendices

Appendix 1

Summary of general discussion

Recovery Language	FOCUS GROUP 1 Consumer Language/Response	FOCUS GROUP 2
Can you describe what 'well' is for you?	Energised Relaxed Clear-headed Able to focus on things Feeling fresh Well drunk	Fucking awesome/epic Less swearing Doing good Stuff's going good
Who are the people that you connect with?	Mates Family	
What could someone say to be helpful	Use slang Listen not try to solve	
If you don't feel well, how do you tell people that?	Shit happens Don't say anything and just wait until it stops Don't care Go see a doctor Try to catch things early and ask for help Weigh things up – do I tell someone or try to deal with it on my own? Usually try and keep it to myself	Stuff's going shit Generally swearing Everything's fucked Not feeling really well
What words do you use when you tell someone?	Sometimes won't talk at all and might write things down instead	
Unhelpful comments	Couldn't offer much Offer solutions and advice rather than just listen and offer support	

Recovery Language	FOCUS GROUP 1 Consumer Language/Response	FOCUS GROUP 2
	Often offer same thing to everyone rather than individualistic approach	
What makes you feel connected?	Chatting to people at Weave Have a drink at the pub with everyone Mates Family Same enemies Sport – football, bond over football clubs with brother and friends Movies Animals - My cat is my friend x 2 Nature – massive help with my recovery. Helps ground me. Always there. Puts things in perspective Ocean Fire Music – chills me out, energises me Skate	Face-to-face interaction Online communities e.g. gaming, social media
Connectedness		Bonding, deep and meaningful (D & M) Bonding, going to have a bonding session D & M (Deep and meaningful) Comes back to the individual and the specific language they use
Connectedness - Examples of questions to ask and/or language to use:		Going to have a bonding session Are you seeing your mates? Are you spending any quality time with people? How's everything? – open questions Are you spending any quality time with people?

Recovery Language	FOCUS GROUP 1 Consumer Language/Response	FOCUS GROUP 2
		Is there anything else that's worrying you? Direct questions are good
Connectedness – what not to do		Don't try to be too friendly, it comes across as insincere Don't try to use language you clearly wouldn't use normally. Eg "Cool". It feels forced and makes young people clam up. Feel manipulated. Lose respect Try to refrain from using clinical words
What makes you feel that someone's really listened to you? When do you feel understood?	Saying "it's okay" Not trying to say "when I was your age…" Workers who suggest not to take everything so seriously – can be helpful or unhelpful	Feeling heard **"**Do you feel like you've been heard?" – *heard* is a good word Feeling Respected = staff being genuine, not using cool language, being clear and using plain language especially around side effects of medication In hospital setting, transparency is paramount. Especially when discussing side effects of medication – preventing YP making informed decision. Talk to young person, not to their guardian/parent
What's a tip for helping a mate feel better?	Have a drink together Focus on this second and breathing – it'll pass. Don't think about yesterday or this morning – just now Get off the drugs	

Recovery Language	FOCUS GROUP 1 Consumer Language/Response	FOCUS GROUP 2
	Come up with distractions – go for a walk Mindfulness Gym/exercise – wakes me up, feel healthy, gym buddies	
What else gets you energised (apart from exercise)? **What makes you feel grounded?**	Loud music	Music Sport A hobby or outlet
Hope & Optimism	Hard to see how hope fits in when it's difficult to think too far ahead in the future Hope is a good word	Replace optimism with positivity = "Recovery is all about positivity" Positive thinking Hope is fine
Goals?		The term "goals" is too big. It's too far in the future. Suggest using **"**What are your steps forward?" "What would you like for yourself?" Is too overwhelming. Suggest "what are you looking forward to doing?" (…in the next couple of weeks) Short term language is really useful
Recovery	Confusing term "recovered" not straightforward – you're adding life experiences to make yourself better and don't really recover as such Recovering from something bad/negative	Recovery journey is about "figuring out who you are" – no start or end
Identity	Mental health identity It's a security blanket – identify with their illness	Young people often don't know who they are

Recovery Language	FOCUS GROUP 1 Consumer Language/Response	FOCUS GROUP 2
	People get so entrenched in their illness which takes away from their identity	"tell me a bit about yourself" is a terrible question There's no right way to ask What made you feel like shit today? Being told to "be yourself" is unhelpful
Empowerment		"Do you feel you have a voice?" "Shared decision-making"
Dignity of Risk – how would you describe that?		"Freedom to make your own mistakes" "To be allowed to make bad decisions and to learn from your mistakes"
Have you had an experience of being stigmatised or discriminated against?	Yes Trying to access help – moving to Sydney was thrown between services and hospitals and no one would help me until I found Weave Policy prohibited from helping, too understaffed, didn't fit into a category, poor referral experience Language is clinical and YP don't understand what the words mean Think I'm dangerous	
Eg of getting what the worker is saying/describe how it was helpful	Explaining People have not been open with them about medication Experience of being ignored and being disrespected	Transparency is paramount and often missing when working with young people Experience of patronising staff and keeping information from them
How do you take power over your own lives?	Go with the flow – not let things get to you Block the world out In hospital involuntarily, trying to give me ECT, able to stand up for myself, questioned and wanted to try medication first	

Recovery Language	FOCUS GROUP 1 Consumer Language/Response	FOCUS GROUP 2
Peer		Term is helpful as it is used at school so we have something in common. Not related to gender
Peer worker		Lived experience (of mental health issues)
Consumer		Young person (a person with lived experience) – more personable, less of a distance/hierarchy between clinician and consumer. It's personalising the interaction

Appendix 2 - Participant Information Sheet

YOUTH RECOVERY LANGUAGE PROJECT

What is the project about?

You are invited to participate in a project concerning Recovery Language as understood by young people experiencing mental health and coexisting conditions.

You have been invited to participate as an important contributor to this project, because of your lived experience and because of the variety of services you engage with.

This Participant Information Statement provides an overview of the project so you can decide if you would like to participate. Please read this statement carefully and ask any questions you might have.

The project will involve a consultative process to engage with youth workers and service users to determine what constitutes youth recovery language, and how that information might be reflected in a resource to inform practice.

Who is running the project?

Dearne Waters is conducting this project under the supervision of Senior Policy Advisor, Corinne Henderson at MHCC as a work placement project. She is undertaking a Bachelor of Applied Social Science Degree at ACAP.

What will the study involve for me?

MHCC will be conducting a number of focus group interviews of youth peer workers and consumers during which they will ask participants to reflect on a number of pre-designed questions.

These questions will be approved by the person in the organisation that has authorised the consultation.

What is the record-keeping and confidentiality process?

MHCC will record the interviews. The recordings will only be kept until the material has been analysed by the two interviewers.

The names of participants will not be recorded either in the notes or the final report. The key theme findings will result in the expansion of the recovery language guide.

The organisations (not the individuals) involved in this project will be acknowledged in the report.

The project report and language guide will be available to you following publication.

How can I obtain further information?

If you would like to know more information at any stage during the project, please contact:

Dearne Waters on 02 9555 8388 #133 or email dearne@mhcc.org.au
Corinne Henderson on 02 9555 8388 #101 or email corinne@mhcc.org.au

Appendix 3 – Consent Form

YOUTH RECOVERY LANGUAGE PROJECT

I ..... [PRINT NAME], agree to take part in the focus group interview.

In giving my consent I state that:

- I understand the purpose of the focus group interviews, what I will be asked to do, and any risks/benefits involved.
- I have read the Participant Information Statement and understand I can withdraw my consent and participation at any time without prejudice.
- The project team members have answered any questions that I had about the project.
- I recognise that participating in this project is on a voluntary basis.
- I understand that being in this interview is completely voluntary and I do not have to take part. My decision whether to be in the interview will not affect my relationship with the organisation.
- I am aware that I can refuse to answer any questions I don't wish to answer that that I can stop the interview at any time.
- I acknowledge that all information collected about me is stored securely and then erased as outlined in the Information Statement.
- I understand that MHCC will publish their findings which will be publicly available.

Your signature indicates that, having read the information provided above and in the Information Statement, you have decided to participate.

....

Signature of Participant **Signature of Interviewer**

.....

Date

Appendix 4 – Interview Questions

1. What kinds of services have you/ and those you support come in contact with?
2. Can you describe what 'well' is?
3. If a person you support doesn't feel well, how do they communicate this?
4. What words do you use to describe mental illness?
5. In the past, what did people say that was helpful or unhelpful?

Regarding connectedness, we think this is about needing other people in our lives. What do you think it is?

Have other people been important in helping you get well?

Who were the important people?

What's a better word for connectedness, or do you like this word?

How important is it to have a mate stick around when things are shit?

Is family support important to those you support? To you?

In your experience, how do you know someone has listened to you and gets what you're saying?

Regarding hope and optimism, we think this is about setting goals and having a positive outlook for the future. How about you?

When things are going bad for a client, what do you try to say or ask?

What tips would you give a mate or a client who's having a bad time?

What gets you excited and want to get up and go?

Any other words that come to mind when you think about hope and optimism?

Identity – we think this is about rebuilding a positive sense of self. How about you?

What would you like said about you?

Have people in services said things to you that seemed unfair?

Any other words or phrases that come to mind?

Is it necessary that the person supporting you understands what's important to you? (Interests, family, goals etc.)

Any other words that come to mind instead of meaning and purpose?

How would you describe empowerment?

What helps you make your own decisions and speak up for yourself?

How can workers help you feel safe?

Recovery Postcards

Please consider the postcards and if comfortable, write a comment or reflection on the back of it. You're welcome to share these or keep the comments to yourself.

Appendix 5 – Further Reading: fact sheets, websites

Fact Sheets

- **Headspace**
  Headspace has a resource library containing several fact sheets for consumers, carers and professionals. The resource library can accessed at http://headspace.org.au/resource-library/category/young-people

    - Trauma - http://headspace.org.au/assets/Uploads/Trauma-web.pdf

    - Sexuality and mental health - http://headspace.org.au/assets/Uploads/Resource-library/Young-people/Sexuality-and-mental-health-web.pdf

    - Sex and sexual health - http://headspace.org.au/assets/Uploads/Sex-and-Sexual-Health-web.pdf

    - Gender identity and sexual health - http://headspace.org.au/assets/Uploads/Resource-library/Young-people/Gender-identity-and-mental-health-web.pdf

- **ReachOut**
  ReachOut features helpful articles and fact sheets for young people and their support network which can be accessed at http://au.reachout.com/dealing-with-people-knowing-about-your-mental-illness

- **Minus18** is an organisation supporting same sex attracted and gender diverse (SSAGD) youth and provides several online tools and resources for young people at https://minus18.org.au/index.php/resources/view-all

Websites and Apps

- **ReachOut** have produced two apps for mobile devices to help young people manage anxiety and stress. Further information can be found at http://about.au.reachout.com/anxiety-reducing-technology-2015/

- **WEAVE Youth and Community Services** run the Survival Tips campaign, outlining the coping strategies people employ as they face difficult times. Further information regarding the campaign is available at http://www.weave.org.au/b/index.php/our-programs/weave-survival-tips/#.VbBJGqSqpBc

- ***beyondblue*** has launched a major campaign to empower teenagers to take action if they are experiencing depression or anxiety. Parents can also play an important role in protecting the mental health of their teenage children, with help from *beyondblue's* information for parents.

  The campaign comes as a new survey reveals that four out of five Australian teenagers think people their age may not seek support for depression or anxiety because they're afraid of what others will think of them. Available at:

https://www.beyondblue.org.au/about-us/news/news/2015/06/01/new-campaign-will-help-young-australians-realise-their-brains-can-have-a-mind-of-their-own-and-remind-parents

- **Orygen Youth Health** has numerous online resources. Available: http://oyh.org.au/training-resources/free-downloads-youth-mental-health-resources

- **Black Dog Institute BITE BACK website** is a new and evolving website which aims to improve the wellbeing and mental fitness of young people, based on the principles of positive psychology – the science of optimal functioning. BITE BACK is a unique place where 12-18 year olds can discover ways to amplify the good stuff in life with specially designed online activities and quizzes that can give members feedback and track progress over time. They can anonymously share real stories, read up on important issues and news, check out videos, blogs and interviews with interesting people, and enter fun competitions. Visit BITE BACK at http://www.biteback.org.au/

- **KidsHelpLine** provide a raft of useful information links. Available at: https://www.kidshelpline.com.au/teens/get-help/who-else-can-help/helpful-links/depression-mental-health.php

- **Youth beyondblue.** Depression and anxiety are among the most common mental health problems experienced by young people. Available at: https://www.youthbeyondblue.com/

- **Awaken Youth.** Mental Health Resources. Available at: http://awakenyouth.com.au/youth-mental-health-resources/

Appendix 6 – Comment on Five Central (CHIME) Recovery Processes

Connectedness is especially important for young people due to a developmental need to actively define and redefine themselves via their relationships with others. Connectedness and the health of the social systems around a young person are also crucially important due to the continuing support and developmental needs of young people. All stakeholders participating in the consultations expressed a major focus on the overall health and support needs of the families of young people, the school environment and the importance of age group peers. In addition accessibility, affordability, flexibility and age appropriateness of health services for both mental and physical health were a focus of concern.

Hope and optimism are of crucial importance for young people and their families. All approaches commonly used to promote mental health in young people incorporate these principles as an inherent part of good care. All stakeholder groups proposed that hope is important for young people and their families and work to promote hope.

Identity was seen as a complex area for young people. Identity is fluid in young people, particularly in adolescence, and the promotion of a positive identity and prevention of an 'illness' identity was seen as crucial. A developmental approach was also seen to be critical. Participants in the consultation thought that it was important to ensure that young people did not feel undue pressure to fully form their identities prematurely.

Meaning and purpose was seen as important for young people, but again developmental factors need to be taken into consideration when this is discussed with young people and their families. The young people felt that they were already under enough pressure to decide on long term life directions and thought that workers should emphasise shorter term goals and connection to valued activities. Workers were also concerned that given too much pressure, young people may take on the goals of others rather than developing their own.

1Empowerment of the young person as a part of their family was seen as crucially important. Stakeholders, including young people, believed that young people need decision-making support as they are not developmentally able to make all necessary decisions, particularly concerning health care. For young people, empowerment was seen to be more around being heard and consulted as a key person in the decision-making team. Some young people felt very strongly that they were a part of their family system and that decisions could not be taken outside of this system.

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