7. CARE FOR ALL

7.1   Lesbian, gay, bisexual, transgender and intersex mental health

International and Australian research has found that lesbian, gay, bisexual, transgender and intersex (LGBTI) people suffer from mental health disorders at a significantly higher rate than the heterosexual population.

In a national survey of the health and wellbeing of lesbian, gay, bisexual and transgender Australians, the proportion who had been diagnosed by a doctor with depression in the past three years ranged from 25 per cent of male respondents to 50 per cent of transgender men. Anxiety was also common, with 17 per cent of men and 34 per cent of transgender men reporting a recent diagnosis.[176]

In a separate NSW study, more than two in five LGBTI young people surveyed had thought about self-harm (41 per cent) or suicide (42 per cent). In addition, 33 per cent of young respondents had harmed themselves and 16 per cent had attempted to take their own lives.[177]

But the higher risk of mental illness and suicidal behaviours among LGBTI people is not the direct result of their sexuality, sex or gender identity; rather, it flows from the stigma, discrimination and marginalisation they experience. This is sometimes referred to as minority stress and occurs across genders, and in both youth and adult populations.[178]

There have been recent improvements in legislative equality in Australia, such as the Commonwealth Sex Discrimination Amendment (Sexual Orientation, Gender Identity and Intersex Status) Act 2013, and advances in the general acceptance of lesbian, gay and bisexual people and, to a lesser extent, of transgender and intersex people.

Despite these improvements, there is still a very high experience of homophobic[179] and transphobic[180] discrimination and exclusion, both within families and in the broader society. LGBTI people continue to be a very marginalised group.

Initiatives outside mainstream services

In NSW and nationally, initiatives addressing the mental health and wellbeing needs of LGBTI people include:

- the National LGBTI Health Alliance (the peak national body for health organisations and individuals focused on LGBTI issues)
- mindOUT! (the National LGBTI Mental Health and Suicide Prevention Project aimed at reducing suicide rates)
- ReachOut by the Inspire Foundation (offering help to young people who are LGBTI or questioning)
- Twenty10 (offering a range of support services)
- ACON (helping the LGBTI community to improve their mental health and wellbeing through health promotion, peer support and advocacy).

Despite these initiatives, mainstream services remain largely inattentive to the mental health needs of LGBTI communities and tend to focus on individual psychological intervention rather than on community-level responses. There is also a lack of recognition and support for the resilience of the LGBTI community in the design and delivery of services and programs.

Disparities must be addressed

ACON's Mental Health and Wellbeing Strategy 2013–2018[181] sets out the building blocks to improve mental health care among LGBTI communities and several of these relate to recommended actions elsewhere in this Plan, such as:

- strong service delivery partnerships
- implementing mental health and wellbeing promotion campaigns
- developing and documenting referral pathways
- providing health service and occupational education to promote social inclusion
- providing direct individual and carer support
- continued advocacy on behalf of the community in relation to mental health.

Actions in other parts of this Plan will also have an impact on the mental health and wellbeing of LGBTI people, provided their implementation takes into account the needs of this community. These include actions outlined in:

- *Building community resilience and wellbeing,* p. 25
- *Suicide prevention,* p. 36
- *Integrating mental health and drug and alcohol responses,* p. 72.

Actions

7.1.1 Agencies should ensure that the needs of LGBTI communities are considered in mental health and suicide prevention planning and that policies, tools and health promotion resources are inclusive of LGBTI communities.

7.1.2 Ensure that health providers, employers and other organisations are aware of the availability of LGBTI cultural awareness and inclusion training and that staff receive training.

7.1.3 Improve the accessibility of services by reaching out to LGBTI communities and tailoring services where necessary.

7.1.4 Continue to improve partnerships with LGBTI organisations, promote inclusion and respond to evidence and data showing unmet population need.

7.1.5 Improve research, population surveys and routine data collections by including appropriate gender and sexuality indicators.

7.2 Multicultural NSW

NSW is multicultural.[182] About 1.8 million people who now call NSW home were born outside Australia[183] in more than 250 countries and 25 per cent of us speak a language other than English at home.[184] With 3.1 million (or 45 per cent) of us having at least one parent born overseas[185], we have a rich array of experiences to guide our understanding of what mental health and wellbeing means for different communities.

While the self-reported prevalence of mental illness is slightly lower for people born overseas (about 18 per cent of men and 20 per cent of women) than for people born in Australia (about 20 per cent of men and 24 per cent of women)[186], research suggests the process of settlement may have a detrimental effect on the mental health of some migrants.[187] This is often linked to the stressful process of acculturation, language and social difficulties, and struggles in finding employment.[188] Some data shows that people from refugee backgrounds may experience significant levels of psychological distress compared with other Australians.[189] But the research available is limited and does not provide a coherent account of the mental health of these population groups.

While the experience of migration varies hugely and mental health is likely to vary among people from culturally and linguistically diverse (CALD) backgrounds as much as it does within the population at large, we also know that particular experiences – such as living through violent conflict in your country of origin – place some at higher risk of mental illness.[190] [191] The stigma about mental illness that still exists within established CALD communities can also make individuals reluctant to seek help for themselves or their loved ones.[192] [193] [194]

Some families have lived in fear in their countries of origin and endured hardship and danger to come to Australia. This can be particularly stressful for children.[195] Being pulled away from a familiar culture and its traditions, and adapting to a new one, can also undermine a child's mental health and wellbeing.[196] Children are far more likely to thrive when they have a positive sense of belonging to both cultures and when their new school and community environments support this.

It is also important to recognise the mental health and wellbeing needs of second and subsequent generation migrants. While the experience of second generations varies according to their parents' country of origin, they too can experience stress in finding their identity between their family's traditional culture and the culture of the society in which they now live.

We need to know more about mental health and wellbeing in our CALD communities so that appropriate information, tools, services and other resources can be directed where they are needed most.

There is also an urgent need to address language barriers and cultural differences and sensitivities. This means mental health services, government and other relevant agencies need to be far better informed about cultural differences and needs about mental illness. It will require comprehensive training, and people from CALD backgrounds who have lived experience of mental illness will be invaluable to the process.

Mental health services also need to capitalise on the language skills of their workforce, including employing people who speak more than one language and valuing existing staff who speak more than one language.

We must also look for ways to make multilingual, culturally skilled staff more readily available in areas with smaller populations. The Transcultural Mental Health Centre will have a vital role here.

Speaking the language of promotion

This Plan is as much about mental health and wellbeing as it is about mental illness. As such, efforts to enhance the resilience of CALD communities through mental health promotion and community initiatives will need to provide for cultural and linguistic diversity. The best way to do this will be to work directly with CALD communities, including community leaders and cultural advisers.

Providing culturally relevant information will allow people to make informed decisions about their mental health, wellbeing and recovery.

Mental health services and organisations need to ensure they work collaboratively with people from CALD backgrounds, their families, friends and community groups to ensure initiatives to engage with those communities are meaningful, respectful and sustainable.

Actions

7.2.1 Consider the needs of CALD communities in the development of local mental health and wellbeing promotional activities as described under *Building community resilience and wellbeing*, p22*.* These activities should look to strengthen the capacity of ethno-specific community organisations to support people with mental illness within their communities. These activities should provide community organisations with appropriate referral pathways to mental health services.

7.2.2 Ensure that the development of mental health and suicide prevention policies, tools and health promotion resources take into account the particular needs of CALD communities. This will include the use of inclusive language that expressly acknowledges CALD communities. Such considerations should form part of service planning, especially in locations where there are larger CALD communities and in relation to issues that are of special concern to CALD communities, such as trauma-informed care.

7.2.3 All staff responsible for the delivery of services where there is a significant cohort of people with a lived experience of mental illness should receive cultural competency training in relation to the mental health needs of CALD communities. Given the higher incidence of exposure to trauma within CALD communities, this training is to have particular regard to the principles of trauma-informed care.

7.2.4 Develop tools to enable a more objective measurement of access and equity for mental health services by CALD communities. These tools will need to be responsive to the needs of CALD populations and readily accessible by the workforce. Information gathered should be incorporated into the population-based planning undertaken by local action groups to inform service development and responses.

7.2.5 Given the changing demographics of CALD communities, not only with emerging communities from new patterns of migration but the intergenerational effects of culture and trauma, there is a need to improve our understanding of:

- the prevalence of mental illness among CALD communities
- the capacity of CALD communities to identify and respond to their mental health needs
- the systemic requirements to enable the mental health and broader service sector to respond appropriately.

These issues should be considered in the context of setting priorities under the *NSW Mental Health Research Framework*.

7.3   Mental health and intellectual disability

People with an intellectual disability account for about 1.8 per cent of the population and experience significant disadvantage.[197]

Intellectual disabilities involve deficits in both intellectual and adaptive functions, affecting how well a person copes with everyday tasks. The impact of intellectual disability on a person's functioning varies greatly from person to person and increases if the person also has a mental illness. People with an intellectual disability experience very poor mental health compared with the general population.[198] It has been estimated that up to 40 per cent of people with an intellectual disability have experienced a mental disorder of some kind.

People with a mental illness and intellectual disability also experience increased physical health issues that are compounded by difficulty accessing health and mental health services. Compared with the general population, people with an intellectual disability experience significantly lower rates of participation in preventive health initiatives, illness and disease detection and treatment of physical and mental health problems.[199]

There are significant implications for carers, who form the backbone of support for people with an intellectual disability because of the shortage of appropriately skilled services. This is especially the case where the person with an Intellectual disability experiences mental illness and associated challenging behaviours.[200]

People with an intellectual disability are also poorly catered for within the prison system unless they also have a mental illness. While there is a Justice Health service for health concerns, including mental illness, there is no equivalent Justice Disability Service. Corrective Services has developed some good programs for people with an intellectual disability but these are limited in number and the locations in which they are available.

What is happening now
People with an intellectual disability are more likely than others to experience mental illness, and yet access to mental health services for people with an intellectual disability is limited and falls far short of that for the general population.

People with an intellectual disability and mental illness face a range of barriers to service access, including communication difficulties and atypical and complex presentations. There is also a lack of training, leading to a lack of confidence on the part of mental health professionals and poorly developed interagency service models. There can also be a perceived difficulty in applying a mental health recovery framework to the care of individuals who have a permanent disability such as an intellectual disability. The danger is that some clinicians may not believe a person with an intellectual disability is capable of successful mental health recovery and therefore may not invest the effort required.

The structure of services means people are falling between the gaps in services, with neither the health nor disability systems taking full responsibility. And they do not have the appropriate skills to address the complexity presented by people with intellectual disability and mental illness.

The situation is further exacerbated by the lack of adequate resources in both sectors. The NSW Ombudsman found that as a result of this silo culture and a lack of an appropriate model of care for treating mental illness in people with intellectual disability, hospital rehabilitation units were in effect becoming long-stay units for them as there was no appropriate step-down level of community support.[201]

Addressing these issues has proved complex and may temporarily become more so as we move from a state-based disability service system to a national model of individualised packages with the introduction of the National Disability Insurance Scheme. This scheme is a welcome development and will offer consumers greater choice and control in how their non-clinical care and support is provided and managed. However, the reforms mean Health will lose its counterpart NSW agency – Ageing, Disability and Home Care. This issue is further described in *Broader context of reforms,* p. 118*.

E-tool supports better mental health care for people with intellectual disability

An innovative e-learning website developed by the Department of Developmental Disability Neuropsychiatry (3DN) at the University of NSW and funded by the NSW Government provides an avenue for service providers and carers to access up-to-date information on intellectual disability and mental health. The initiative provides extra training for health and disability professionals so they can provide expert care to people with intellectual disability and mental illness.

The education tool – available at www.idhealtheducation.edu.au – is the first of its kind in Australia. It aims to promote best practice in mental health care and to build the capacity of the workforce to prevent people with intellectual disability and mental illness falling between the cracks of the two systems. People with an intellectual disability have the same mental health concerns as everyone else, and this tool encourages inclusion of people with an intellectual disability and a person-centred approach in line with the National Disability Insurance Scheme.

NSW reform activity to date

In recognition of the particular needs of this group, the NSW Government established a Chair of Intellectual Disability Mental Health at the University of NSW in 2009. Working closely with NSW Health and Ageing, Disability and Home Care, the chair's primary purpose is to improve supports for this cohort.

Projects undertaken since its establishment include the e-learning supports outlined above and, more recently, the development of *Accessible Mental Health Services for People with an Intellectual Disability: A Guide for Providers*. This outlines principles and practical strategies to develop inclusive and accessible services. This work is an important step towards a more integrated approach between disability and health services.

Why change must occur

While pockets of expertise in supporting the physical and mental health needs of people with intellectual disability exist in NSW, their scarcity and lack of integration with mainstream services remain a problem. NSW can now build on this work by taking steps to implement the guide and undertaking further work to develop the models of care.

The implementation of the National Disability Insurance Scheme will offer the potential for improved services for those who are eligible, provided we achieve appropriate integration and partnerships among clinical mental health services and community-managed and private service providers.

For this key group, this Plan offers the opportunity to address long-standing systemic issues relating to access and co-ordination of care and support and ensure that the potential of the National Disability Insurance Scheme is realised.

Actions

7.3.1 Ensure that Local Health Districts and community-based services implement Accessible Mental Health Services for People with an Intellectual Disability: A Guide for Providers.

7.3.2 Ensure that adequate training in the recognition, assessment, referral pathways and treatment for people with an intellectual disability and mental illness is given to all staff in mental health and disability services. Such training will need to include particular reference to adopting reasonable adjustments in clinical approaches and adopt a recovery-oriented approach.

7.3.3 As part of the NSW implementation plan for the National Disability Insurance Scheme, develop strategies to change from the present partnership between NSW Health and other state services with Ageing, Disability and Home Care to one with the community-managed and private sectors. This will need to take account of the impact on:

- joint projects
- memorandums of understanding
- co-developed guidelines
- relationship management
- dispute resolution
- systemic and strategic planning.

7.3.4 Develop a recovery-oriented model of care for the provision of public mental health services to people with an intellectual disability that:

- builds the capacity of mainstream community and inpatient mental health services
- increases specialist capacity to meet more complex needs
- facilitates joint planning by disability services, mental health and other relevant services, including in relation to referral and treatment pathways and collaborative responses where intellectual disability and mental disorders coexist.

7.3.5 Develop accessible information for people with an intellectual disability and their families and carers about mental health services.

Future direction

A sharper focus is required on policy and program development for the mental health needs of children and young people with an intellectual disability. This should include tailored prevention and early intervention programs and services that offer timely and skilled mental health assessment and intervention.

7.4 Eating disorders

While predominantly affecting adolescent girls, eating disorders occur across all genders and ages, with increasing diagnoses in younger and older people. Although data is limited, it is estimated that the lifetime prevalence of eating disorders is 9 per cent for the whole population and 15 per cent for women.[202]

In 2012, 913,986 people in Australia had eating disorders, or about 4 per cent of the population[203], including an estimated 289,560 in NSW.[204] Of these, 3 per cent had anorexia nervosa, 12 per cent had bulimia nervosa, 47 per cent had binge eating disorder and 38 per cent had other eating disorders.[205]

Anorexia nervosa has the highest mortality rate of any psychiatric disorder and eating disorders generally have an overall mortality rate of 20 per cent.[206] The high death rate is due to the physical complications of eating disorders and a highly elevated risk of suicide.

Gaps in service availability, poor service integration, and regional differences have been identified[207] with significant barriers to access in regional and rural communities due to social stigma, lack of professional expertise in treating eating disorders and lack of services. For example, many cases of binge eating disorder are misdiagnosed and treated as obesity. Although someone with binge eating disorder will often present as 'obese', the traditional treatment of dieting is not only unlikely to be successful but can cause significant further harm.

The estimated socio-economic cost of eating disorders in Australia in 2012 was $69.7 billion, including productivity costs of $15.1 billion and burden of disease costs of $56.2 billion, comparable to the costs of anxiety and depression.[208]

Special circumstances

The NSW Government has addressed eating disorders with the NSW Service Plan for People with Eating Disorders 2013-2018. The plan[209] has the following aims:

- ensuring every health service which may be a point of entry to eating disorder care has the capacity and capability to provide all necessary services for people who have, or are at risk of developing, an eating disorder
- ensuring every health service has the capability to link with and be supported by specialist eating disorders expertise
- ensuring eating disorder outpatient programs are accessible within the patient's Local Health District on a flexible basis to allow patients to transition between general and intensive outpatient treatment
- increasing access by expanding services (adult, child and adolescent)
- funding the development and expansion of tertiary eating disorder services and support throughout the system; dissemination of high-level clinical skills; support of best practice for eating disorders; and maximising the use of limited tertiary beds.

Despite a recent increase, there are still insufficient specialist beds to meet the needs of the population, particularly in regional centres.

The impact of this is exacerbated by the lack of community-based services. As with any other psychiatric disorder, an integrated continuum of care is required based on a step up/step down model with varying levels of support – ranging from inpatient episodes (for medical stabilisation) through to residential care, day programs, intensive outpatient programs, sessions of outpatient service, and community-based recovery support. In most instances, re-feeding, development of healthy eating and exercise behaviours and addressing the psychological aspects of the illness are best addressed in a community-based, non-hospital environment.

What community supports are available have usually been developed for mental health problems more generally, and therefore do not take into account the fact that treatment for eating disorders normally takes a long time. For example, the Commonwealth-funded Access to Allied Psychological Services – ATAPS – and Better Access programs provide access for a limited number of psychology sessions (generally 12 and 10 respectively) whereas a person with an eating disorder is likely to require significantly more sessions over an extended period. Withdrawing treatment prematurely may increase the risk of relapse. The criteria for funding treatment must take these circumstances into account to ensure that people with eating disorders have access to evidence-based treatment for the recommended duration.[210]

In 2012 the National Eating Disorders Collaboration developed two reports for the Commonwealth Department of Health and Ageing. The first looked at gaps in service delivery for eating disorders and the second focused on prevention and early intervention. Unfortunately, at the time of writing, these reports had not been publicly released, which limits the extent to which their content can inform service development nationally and in NSW.

Broad-based understanding

Given the complexity of the relationship between the physical, psychiatric, nutritional and functional aspects of eating disorders, their safe treatment requires close co-ordination of care across a number of disciplines, either through multi-disciplinary teams or specific mental health care co-ordination roles.

However, there is a documented lack of confidence among clinicians, including GPs and emergency department personnel, in addressing these disorders. While the NSW Government has improved access to online training, clinicians require ongoing supervision and access to case conferencing provided by specialists at a tertiary level.

Training of a broad base of clinicians will be particularly important to effectively develop and implement prevention and early intervention programs, which are now under-developed in NSW. Prevention programs can reduce risk and early identification and intervention of each episode of illness significantly enhances sustainable recovery and reduces cost. Preventive programs need to include comprehensive family education about eating disorders, early warning signs and positive behaviours to reduce risk.

An eating disorder has a significant impact on all family members, including parents, partners and siblings. Long-term sustainable recovery requires a supportive family structure and, as such, providing education and support to develop resilience in each family member and the family as a unit is essential. Family members and carers can be essential partners with the treatment team and should be included as such, as well as being supported in their own right.

Actions

7.4.1 Ensure the statewide implementation of the NSW Service Plan for People with Eating Disorders 2013-2018 with priorities including: improved data collection; nurturing and disseminating a strong evidence base; workforce development; and promoting integrated and collaborative approaches.

7.4.2 Ensure that local mental health and wellbeing promotion activities (see *Building community resilience and wellbeing,* p. 25) and the basic training in mental health literacy provided to government employees and service providers (see *Build the capacity of services to respond therapeutically,* p. 51) include material about eating disorders.

7.4.3 Ensure that adequate training in the recognition, assessment, referral pathways and treatment of eating disorders is provided to all staff in mental health services.

7.4.4 Prioritise the development of community-based models of care for eating disorders from early intervention, to treatment, to recovery-focused services.

7.4.5 Advocate for the Commonwealth Government to fund uncapped or a minimum of 40 extra psychology sessions per calendar year for people diagnosed with an eating disorder under existing programs (such as Access to Allied Psychological Services – ATAPS – and Better Access) to enable them to access individual and group sessions.

7.4.6 Advocate for the Commonwealth Government to fund extra sessions with dietitians for people diagnosed with an eating disorder under existing programs (such as the Chronic Disease Management program) to enable them to access appropriate care.

7.5   Borderline personality disorder

It is estimated that borderline personality disorder (BPD) affects about 1 to 2 per cent of the population.[211]

People living with BPD often experience distressing emotional states, difficulty in relating to other people and self-harming behaviour. BPD is often misunderstood, which leads to negative attitudes, most significantly among some health professionals.[212] This is a barrier to people with BPD getting the care they need, resulting in their being marginalised within, or turned away from, existing service systems and mental health facilities. This effect is compounded by a paucity of resources and trained staff to meet their needs.

While the proportion of people living with BPD who access mental health services in NSW is not known, internationally the prevalence has been estimated at up to 23 per cent of outpatients and up to 43 per cent of inpatients.[213] People who experience severe BPD may also have symptoms of other mental illnesses, engage in more suicidal behaviours and experience higher rates of suicide.[214]

The difficulty in accessing appropriate services experienced by people living with BPD has broader implications. It is often the case that the intensity of mental health issues experienced by people with BPD is absorbed by carers in a way that also significantly affects the carer's mental health.[215]

These poor outcomes for those with BPD and those who support them must be addressed.

Interaction with services

The interactions with service providers of people living with BPD are characterised by chaotic personal circumstances, ambivalence towards treatments and supports, challenging interpersonal coping styles and a poor response to many traditional mental health treatments and interventions.[216]

People with BPD present to hospital emergency departments as well as to mental health and drug and alcohol services. Generally, inpatient health services provide crisis management which may include short-term admission for safety and assistance to reduce distress.[217] Recently, NSW Health has undertaken initiatives to improve the care of people with BPD. These include pilot projects, such as the Project Air Strategy for personality disorders in partnership with the University of Wollongong, to give clinicians the knowledge and skills to ensure people's experience of care, and what happens as a result of that care, is positive.[218] Though still a work in progress, new therapeutic approaches, through a combination of psychological therapy and medication for symptom relief, have achieved better outcomes. These approaches are articulated in the National Health and Medical Research Council's Clinical Practice Guideline for the Management of Borderline Personality Disorder (2012).[219]

Changing our approach

Despite these advances, there are still issues about the capacity of some mainstream mental health services to manage BPD and engage in the service redesign needed to respond better to this group of people.[220] Through appropriate care and treatment, we can redirect people from our hospital and emergency systems and provide care in the community.

The compassionate, holistic, person-centred approach to mental health is the way forward across the board. Services and staff members need to be oriented and educated to help people with BPD, recognising that specialist services are required for the most complex cases and to provide consultation support more broadly. This would include increased access to Commonwealth psychology services.

Carers, family members and the community are an important part of this equation. If the nature of the condition and its treatability are better understood, we are likely to reduce stigma and greatly improve access to services.

Actions

7.5.1 Ensure that Local Health Districts and community-based mental health services adopt and implement the Clinical Practice Guideline for the Management of Borderline Personality Disorder (2012).

7.5.2 Ensure that the local mental health and wellbeing promotion activities (see *Building community resilience and wellbeing,* p. 25) and the basic training in mental health literacy provided to government employees and service providers (see *Build the capacity of services to respond therapeutically,* p. 51) include material in relation to BPD.

7.5.3 Ensure that adequate training in the recognition, assessment and treatment of BPD is provided to all staff in mental health and drug and alcohol services.

7.5.4 Promote and progressively roll out community-based models of care for the treatment of BPD, such as that developed by the Project Air Strategy.

7.5.5 Advocate for the Commonwealth Government to fund extra psychology sessions per calendar year for people diagnosed with BPD under existing programs, such as Access to Allied Psychological Services (ATAPS) and Better Access, to enable people to access both individual and group sessions.