

Person-Centred and Consumer Directed Mental Health Care: Transforming Care Experiences

Produced for the National Mental Health Commission by the Mental Health and Suicide Prevention Research and Education Group, University of South Australia.

Online Appendices

Appendix 1: Consumer and carer experience and perspectives

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1.1 Consumer experience trends identified through Your Experience of Service survey data

The major public sources of reporting regarding consumer experience of public mental health services are provided by national level reporting of the Your Experience of Service (YES) survey. This is a 26-question survey that consumers complete during care. This data provides a useful context for the PCC experiences discussed in the report.

The Australia Institute of Health and Welfare¹ publish some aspects of annual data trends on the YES survey.¹ Some of these results are based on the 'overall quality of care question' in the survey, while other results are calculated across the respondent's scores of 22 of the survey's 26 questions. The total is then calculated in a comparison with average responses to the 22 questions and multiplied by 100. This provides an overall score out of 100. The nationally agreed marker of positive experience of care is a score of 80 or above.

There are a significant number of limitations and qualifications involved in interpreting YES survey result trends. These include the number of surveys completed, the diverse contexts of service settings, and differing survey distribution methods and time periods used by states. Also, YES surveys are not administered in all states and territories. The AIHW advises to interpret the patterns with some caution given these limitations.

Some states also provide more detailed reporting of YES results according to specific service types and areas, the areas of experience with higher or lower ratings. It is worth summarising some of the evident trends from these states. Recent data on 2019-2020 included the states of NSW (22,325 surveys) and Queensland (3311 surveys), with Victoria not reporting due to the COVID-19 Pandemic¹.

Trends¹ on consumer experience from 25,636 YES surveys from 68 service organisations for these two states indicate that:

- » On the YES overall single quality of care experience question, on reporting their experience of admitted care (in hospital) 87.0% of consumers in NSW and 76.0% in Queensland rated the care they received as 'Good', 'Very good' or 'Excellent'.
- » On the calculated score (across 22 questions), 70.1% of NSW consumers and 49.5% of Queensland consumers reported a positive experience of service in admitted care.
- » The reports of positive experience of care are higher in ambulatory (community) settings, than admitted care. Here 89.7% of consumers in NSW and 92.1% in Queensland reported their care as 'Good', 'Very good', or 'Excellent'. In the overall calculated score, 80.3% of NSW

¹ Please see AIHW (1,2) for a summary of methods for calculation of scores and also for limitations on the interpretation of YES survey results

consumers and 81.3% of Queensland consumers reported a positive experience of care in these settings.

- » In residential settings, with only Queensland data available, ratings reflected similar patterns, with 92.3% of residential care consumer respondents in Queensland rated the care they received as 'Good', 'Very good' or 'Excellent'. On the overall calculated score 80.3% of consumers completing surveys in Queensland reported positive experiences of service.
- » Positive experience of care ratings drops when consumers are under mental health treatment orders in hospital settings. In NSW, a lower proportion of consumers under orders (involuntary) provided positive ratings of care. This was 65% compared to 76.2% for voluntary consumers². (67.6% for those with legal status not recorded. For Queensland respondents, the proportion of consumers with a positive experience of care score was also lower for involuntary status consumers: 45.5% compared to 53.8% for voluntary consumers, and 54.5 % status not recorded.
- » In community/ambulatory care settings, a similar pattern was observed. In Queensland, the proportion of consumers with a positive experience score was 87.5% for those with voluntary status compared to 70.4% for people with an involuntary status. NSW reports a matching trend³.

The AIHW Consumer perspectives on mental health care reports 2018-2019² includes data from Victoria (2760 surveys) on YES survey patterns. This shows similar rating levels of experiences of service to the above. In admitted care, 74% of consumer respondents rated their experience of care as good, 'Very Good' or 'Excellent', based on the single overall care experience questions. In terms of the calculated score, the proportion of consumers expressing a positive rating dropped to 53%. For involuntary Victorian respondents, the positive rating of care drops to approximately 40% when considering admitted care. In ambulatory (community) care, the single question rating showed that 88.1% of respondents expressed a result of 'Good', 'Very Good' or 'Excellent'. The calculated score drops to 76.5% for involuntary consumers, and the calculated result falls to 64.1% of people expressing a positive care experience.²

These trends clearly indicate that a very significant number of consumers do not feel they have positive experiences of care in involuntary contexts, especially when admitted to inpatient units.

² Voluntary legal status means consumers receiving care who are not under a mental health treatment order.

³ This data is not detailed by the AIHW¹.

State-based reports

There are published state-based reports⁴ for YES survey results for Queensland,³ NSW⁴ and WA,⁵ with each report varying in style, content and analysis. These reports often reveal more detailed trends on differences between services as well as rating on different YES PCC categories, and high and low scoring questions. These reports use the combined percentage of responses rated as 'Very Good' or 'Excellent' as a measure of positive experience. As a summary these reports reveal that:

- » NSW has the best performance rollout,^{4 5} of YES surveys. In 2019-20, 23000 were returned. (34% of all hospital consumers and 4% of all community). This is much higher than other states.
- » The contribution of Aboriginal and Torres Strait Islander people in reporting states is significant, with approximately 10% of completed YES surveys expressing the views of Aboriginal and Torres Strait Islander consumers. In NSW, Aboriginal people have lower ratings of 'Very Good' or 'Excellent' experiences of service in community settings (73%) compared to non-Aboriginal people (81%). These lower ratings occurred in some specific domains as defined by NSW Health. These include lower ratings in the respect, individuality, and safety and fairness domains.⁴
- » Reporting states appear to collect data on gender diversity using the YES question of 'Other' for gender. In NSW, consumers identifying their gender as other (1%) have lower levels of positive experience of service in community services (76%) and hospital services (54%) compared to consumers overall (80% and 70% respectively).⁴
- » Each reporting state has some YES survey categories that score lower in terms of ratings than others. In NSW⁴ and Queensland,³ the categories scoring the lowest across community teams and hospital care were 'information and support' and 'making a difference/impact'. These results suggest areas for improvement in the levels of information support provided to consumers and reflect consumer evaluations on the outcomes of care for health and wellbeing.
- » No states appear to provide an analysis of YES trends according to urban and rural differences.

⁴ At the time of writing, we have not been able to identify detailed YES survey reports for public services in Tasmania, Victoria, South Australia, ACT or Northern Territory. Some detail on specialist public mental health services YES results may be available in state based annual mental health reports.

⁵ Note: NSW Health has published 2021 YES Survey with more recent data. We have used the 2019-20 data report to align with AIHW reporting.

Overall, the state-based reports indicate a general trend where many consumers report positive appreciation towards the quality of care they receive and the ways in which practitioners value personal preferences, cultural identity and support for involvement. At the same time, the survey patterns clearly identify that improved practices are required to lift the quality-of-care experiences for consumers using hospital-based services. There are various domain areas unique to states and local services that require development. These include improved information provision, peer support service availability/access and impacts on making a difference. Improving quality of experience of people being treated via mental health orders is a priority, as well as improved quality of service for Aboriginal and Torres Strait Islander people. A stronger effort may be required to generate data regarding the experience of care for LGBTIQ+ people and consumers and carers living in rural and regional areas.

1.2 Consumer and carer peak perspectives on care pathways and supports

Various consultation reports, submissions and reports of state-based consumer and carer peak bodies indicate key areas of required improvement for PCC and or CDC experiences and outcomes in specialist public services. As peak bodies operate as systems advocates, the key points expressed often reflect the views of people who have experienced service gaps, poor quality care, trauma within services and other iatrogenic harms. The positions of state-based consumer peaks therefore, significantly express the views of people who have experienced involuntary care, and care over long periods of time. Consumer peaks also express views grounded in recovery and empowerment perspectives, and champion the development of peer workforces and models of care. Carer peak bodies provide another perspective, one that promotes better supports for carers, inclusion of carers in care planning, and improved crisis responses that support the consumer and family.

The following themes have been generated by summarising three consumer peak body reports^{6 7 8} on improving the design of urgent and acute care mental health settings. These themes reflect important aspects of PCC and CDC specific to mental health.

- » Promoting consumer agency and choice in care decision making and reducing inflexible, inaccessible service rules and criteria, and involuntary care. Lived experience is valued and heard.
- » A focus on ensuring that consumers feel safe from their perspective, including a focus on gender and cultural safety. Avoiding practices of surveillance.
- » Improved use of kind, connecting and compassionate language; avoiding judgement, stigma and misgendering.
- » Increased staffing by lived experience workers.
- » Management and governance of services are lived experience led or feature robust levels of inclusion.

- » Physical, social and psychological settings which are welcoming, warm and less clinical.
- » Person-centred approach based on compassion, empathy and connection; being listened to, believed and respected.
- » Trauma-informed settings, practices and communication.
- » A holistic approach which includes wider social determinants of mental health and wellbeing, and an 'intersectional' connection with wider services and community.
- » Diversity of programs and activities such as art and music therapies, recreation, gym access and sensory supports.
- » Improved information provision about services and how to access them.

Carer peak bodies also cite a range of key issues about family/friend carer experience and the development of person and family centred approaches. As an example, the following themes were summarised from analysis of two recent carer peak body reports by Tandem⁹ and Mental Health Carers NSW.¹⁰

- » Providing a range of supports to help carers in their caring roles, including respite, information and system navigation and counselling for working through change, loss and grief.
- » A focus on family wellbeing; helping families building social connections, manage stress and learn self-care practices.
- » Better inclusion of carers in care and discharge planning, so that carers can support practices such as safety planning. Providers should also be able to skilfully work with conflict situations and maintaining relationships between consumers and carers where their respective wishes may be opposed.
- » A focus on social or relational recovery; seeing the consumer in the wider family and social context, and working to build capacities and connections for long term relationships and valued social roles.
- » Supports for specific groups regarding diagnosis, cultural, gender diverse or aged related needs and experiences. This includes better recognition of diverse family models and friendship networks.
- » Education about mental health issues and services and how to best provide support to consumers.

- » Wrap around supports for families experiencing crisis, including suicide and conflict related crisis.
- » Improved information sharing practices with carers, including permission to share carer information to other services.
- » Improved employment of carer peer workers to support families, provide learning and navigation supports.
- » Better levels of carer involvement in organisational governance for safety and quality improvement and recording of carer experience.

1.3 Person-centred and consumer directed care across diverse communities

One of the enduring challenges for large health services and systems is to effectively understand and respond to diverse community groups. This means that the planning and organisation of person-centred, or consumer directed services needs to be grounded in a diversity approach as opposed to staying at a generalised level. Recognition is also needed towards established areas of lived experience and community leadership within specific communities, as well as representative organisations, services, programs, approaches and research that can inform, and be connected within, health systems.

The literature discussing access and engagement across diverse communities is immense. Therefore, it is impossible to document key themes and experiences without losing important nuances and content. The following descriptions about PCC or CDC for specific communities offers a window for understanding some common issues, preferences and engagement strategies for organisations. These understandings can then be expanded via real connections and relationships with consumers, carers and communities.

Aboriginal and Torres Strait Islander communities

Aboriginal and Torres Strait Islander communities possess strength and resilience in the face of ongoing experiences of colonisation, marginalisation, trauma and racism. The experience of mental health issues needs to be seen in this context. Significant disruption to cultural and social practices and connection through legislative approaches (e.g., The Stolen Generations) has resulted in intergenerational trauma for many Aboriginal and Torres Strait Islander people. Furthermore, a history of discriminatory practices and mistreatment from Western medicine providers has often created distrust in medicine and health care for many Aboriginal and Torres Strait Islander people. Poor experiences of services cause further discontinuation of care plans and disengagement from services. Aims to improve social and emotional wellbeing outcomes for Aboriginal and Torres Strait Islander people need to recognise these historical events before healing can occur.

Western ideas of mental health typically do not reflect/align with Aboriginal and Torres Strait Islander understandings of wellbeing. As an example, the approach of Social and Emotional Wellbeing is often used as opposed to 'mental health' as this more accurately accounts for the relevant historical, social and cultural context. Person-centred mental health care for Aboriginal and Torres Strait Islander people is centred on the themes of self-determination and community control of health services and programs. Aboriginal and Torres Strait Islander communities are able to govern and direct the way they provide and receive mental health care. There are specific frameworks of understanding, practice, engagement, and service delivery that shape person-centred and consumer directed care considerations. These include:

- » Recognising that Aboriginal and Torres Strait Islander people have distinct ways of seeing lived experience and can provide guidance from this perspective. This includes shared experiences of grief and loss, racism and trauma, and guidance regarding self-determination, appropriate service responses and hope for the future.¹¹
- » Recognition of the impacts of ongoing racism, trauma, and exclusion which continues to impact Aboriginal people's social and emotional wellbeing, experiences of services, and willingness and ability to access services.
- » Recognising Aboriginal and Torres Strait health leaders that work across academic, policy and service settings to provide guidance on social and emotional wellbeing, suicide prevention and improvement to mental health services across age groups. The Gayaa Dhuwi (Proud Spirit) Declaration is an important statement for guidance and context.¹²
- » Working with policy frameworks on social and emotional wellbeing¹³ and using Aboriginal and Torres Strait Islander definitions of health, wellbeing and care to plan, deliver and evaluate services.¹⁴
- » Recognition of the effects of trauma and the history of colonisation, while also acknowledging that Aboriginal and Torres Strait Islander people have skills and knowledge to heal.
- » Funding and supporting Aboriginal Community Controlled Health Organisations (ACCHOs) and networks to care for Aboriginal and Torres Strait Islander people via appropriate approaches and models as well as supporting Aboriginal health programs embedded in public health services.¹⁴ Both ACCHOs and embedded Aboriginal health teams play important roles in supporting community to access acute and community level specialist/primary care.
- » Creating space for Aboriginal and Torres Strait Islander people to direct care to enhance cultural safety within programs, including traditional methods of care (e.g., use of traditional healers, and culturally designed activities).

Asylum seekers and refugees

People of asylum seeker and refugee background are at increased risk of adverse mental health outcomes (including feelings of distress, hopelessness and despair) and suicidality.¹⁶ Contributing to this are various factors before and during migration as well as post-arrival in host countries: histories of torture and/or trauma, exposure to war and conflict, violence, poverty, being held in detention, separation from and ongoing concern for family, loss, discrimination, restrictive immigration policies, poor living conditions, social isolation and prolonged uncertainty associated with work permits and visa status.¹⁵ At the same time, these groups face increasingly unique challenges with seeking and accessing mental health support compared to the wider Australian population.

The mental health needs and rights of refugees and asylum seekers have historically been overlooked and are still not as well understood as other groups. Before considering the unique support needs of these groups, it is also important to recognise that access to basic resources may be a barrier to seeking mental health services and supports. These include language and mental health literacy barriers, and cultural customs around seeking support, but also practical barriers, such as access to the internet or transport. Added to this, many people of asylum seeker and refugee background face day-to-day challenges with practical aspects of living (securing housing, navigating in a new community, obtaining clothing and resources for children, insufficient finances, visa status and legal appointments, etc.). Therefore, mental health needs are overlooked or may not be seen as a priority by the person. As such, mental health care and supports need to be considered within a holistic perspective of the individual and their community, their wider needs and protective factors.¹⁶ Some specific considerations for PCC for people of asylum seeker and refugee background include:

- » Access to information and education: translated mental health resources are available from sites such as Beyond Blue.¹⁷ Such Information should move beyond how to identify mental health concerns and also include practical information for how to seek and access care, confidentiality processes, what entitlements are available and the role of different mental health professionals (e.g., [Embrace multicultural mental health](#) categorises services across Australia).
- » Access/referral pathways to services and coordination of care: this may be through non-traditional pathways compared to mainstream services, such as through resettlement services (such as the [Australian Red Cross](#) and the [Australian Migrant Resources Centre](#)) as well as through case workers, education/employment services, legal support workers or various other volunteer organisations (including religious and cultural services). This also highlights the need for engagement and communication between multiple sectors and services, including protection and social services, legal support and education, as well as engaging with outreach services to reduce access barriers for 'at-risk' groups (e.g., LGBTIQ+, young people) and co-designing alternative service delivery approaches with the communities of interest.¹⁶
- » Confidentiality: language is an obvious access barrier and working with interpreters is important for providing services in the person's preferred language. However, considerations need to be

given to confidentiality (many language group communities are small, and many people will be known to each other, often making it difficult to have an anonymous interpreter).

- » Involving support from family and friends: for many, family and friend networks will be limited due to separation, whereas others may have access to a wider community support systems. Either way, consideration needs to be given for diverse cultural understandings of mental health (including help-seeking stigma) and appropriate customs and norms for accessing mental health care.
- » Safety and quality in mental health care: for many, mistrust of authority due to past and ongoing experience of conflict and trauma, coupled with limited Western mental health literacy, can make understandings of mental health treatment and intervention difficult. Therefore, these factors need to be taken into consideration when engaging in informed decision making for mental health care and treatment options. Awareness and consideration of the potential for re-traumatisation also need to be at the forefront of care (e.g., the context of emergency mental health care, and the potential re-traumatising impact of mental health treatment orders).
- » Education and training for health professionals, service providers and volunteers: Including both cultural awareness/responsiveness training and mental health training (reflective of diverse cultural explanatory models of mental health). Service providers need education and training specific to the complex needs of people of refugee and asylum seeker background. For example, tailored suicide prevention training can take into account the unique experiences of suicide among these groups and provide upskilling in culturally appropriate and trauma-informed suicide prevention strategies.¹⁸ Translated training and resources for community leaders is also important.¹⁶

LGBTIQA+ communities

A disproportionate number of people from the LGBTIQA+ community in Australia report poorer mental health outcomes, self-harm and suicide attempts than the broader population.¹⁹ Mental health issues in the LGBTIQA+ community are strongly linked to discrimination and marginalisation. Barriers to accessing and continuing use of health services for LGBTIQA+ communities include not wanting to be outed, precarious living situations, changes to family and social connections due to discrimination, and lack of understanding or acceptance of their gender identity by health service providers.^{20 21}

Principles of PCC are relevant to people within the LGBTIQA+ community because people want to receive care that is sensitive to their identity, and in the case of trans people, gender affirming.²² Seemingly minor stereotyping and misgendering actions by practitioners can have a significant impact on the way LGBTIQA+ people engage with mental health service providers, damaging the provider-consumer relationship and reducing the effectiveness of care. Specific considerations for PCC in the context of LGBTIQA+ communities include:

- » PCC for LGBTIQ+ people needs to include principles of cultural and organisational safety. People need to feel that they are safe to express their identity. For trans people particularly, the experience of crisis intersects with worries about identities being understood.
- » Practitioners need to acknowledge that the LGBTIQ+ community is diverse within itself; no two experiences of queerness are the same.
- » For LGBTIQ+ young people particularly it is important to clarify their understanding of service provision, clarify limitations to confidentiality and seek permission around disclosure of information.
- » Facilitate the idea that LGBTIQ+ people may wish to receive support from 'family of choice' rather than their biological family for their own safety.²²
- » Recognition of the intersectionality of LGBTIQ+ and other aspects of identity (migrant, ethnicity, nationality and religion).²³
- » Recognition and connection with the work of LGBTIQ+ groups and peak organisations. These groups provide important advocacy, peer support, mentoring and sector research leadership that can guide inclusive practice.²²

Infants and families in the perinatal period

The perinatal period (from conception to the first year after birth) is a time when women, their partners and infants/other children may require mental health support. Currently one in five women will experience perinatal anxiety and/or depression. Suicide remains the leading cause of maternal death in Australia. Certain groups of women and families will require greater and more individualised support in the perinatal period. Various psychosocial factors are known contributors to adverse mental health outcomes for women, including those who are isolated by distance or culture, or those experiencing life stressors and/or multiple traumas (including historical and current birth traumas). These include people of Aboriginal and Torres Strait Islander background, single parents, migrant women, women experiencing intimate partner violence and LGBTIQ+ parents.²⁴

Principles of PCC are relevant to women in the perinatal period, however, the term '[women-centred care](#)'²⁵ is often used in this space to highlight the unique needs and rights of women/families and their personal circumstances during this life stage. The two concepts share many similarities, but there are also some specific mental health considerations in the perinatal period:

- » Access to information and education: the [Centre of Perinatal Excellence \(COPE\)](#) and [Perinatal Anxiety and Depression Australia \(PANDA\)](#)²⁶ provide translated resources and information to parents about adjusting to parenthood, looking after yourself (including recovery journeys and stories), postnatal mental health conditions and getting help.

- » Resources and supports for dads and partners: Beyond Blue's [Dadvice](#) website,²⁷ as well as their resource, [Emotional health and wellbeing: A guide for new dads, partners and other carers.](#)²⁸
- » Resources and supports for children (e.g., older siblings) of parents with a mental illness: [Emerging Minds](#)²⁹ provides specific support for young people.
- » Timely access to early intervention: mental health screening during antenatal and post-natal health checks.
- » Coordination and integration of care, confidentiality and referral: considering the needs of the whole family system, including social and psychological needs (e.g., attachment between caregivers and infant/s); coordination of screening, care, treatment and support between GP, CaFHS, public and private perinatal and mental health services, as well as individual-specific supports (e.g., Aboriginal health services and migrant health centres).
- » Involving support from family and friends: the need for health professionals and support services to consider cultural understandings of mental health (stigma and shame) and cultural norms regarding involvement of others.
- » Safety and quality in mental health care: informed decision making regarding the impact of pharmacological therapy on conception, foetus and/or a breastfeeding infant; and the impact of hospitalisation on the wider family (e.g., in some areas specific mother-baby units are available to support relationship and attachment development, but beds are limited).
- » Access/pathways to services and care: for those living in rural/remote areas, and those requiring specialist services and knowledge, such as for LGBTIQ+ people.
- » Education and training for health professionals: the [Centre of Perinatal Excellence \(COPE\)](#)³⁰ provides education and training in perinatal mental health nation-wide; however, greater awareness and consideration for cultural practices and diversity regarding pregnancy, birth and parenting, and the importance of these for mental health outcomes, is needed.

Older people

Australia's aging population continues to grow with expectations that the number of people over the age of 65 will double by 2057.³¹ While many older people enjoy fulfilling and satisfying lives, approximately 15% experience mental illness, most commonly depression and anxiety³². Psychosocial factors common to the older person can contribute to the development of these mental illnesses including loss of identity, loss of relationships, poor physical health and pain. Understanding a person's individual experience, recent changes that have occurred in their lives and background history is paramount in becoming aware of the factors which may be contributing to an older person's mental health. This information is not always sought and too often the older person reports symptoms that are overlooked or disregarded and accepted as 'normal signs of aging'.

Ageism is widespread and impacts a person's sense of self, opportunity and choice. Society stereotypes older people and discriminates against them based on their age and this can be internalised by the older person, silencing them, and preventing them from speaking up. This stigma is experienced two-fold when an older person also experiences a mental illness.

Principles of person-centred care can improve the experience of the older person with mental health issues when they are accessing health care and can include:

- » Access to information and education: shared power and responsibility is upheld when the consumer has access to evidence-based treatment options and is at the centre of the care planning process. The consumer actively engages in decision making which aims to improve their overall health. Information will be related to the person about health care interventions which address mental and physical health issues and can include therapies, medications, alternative therapies, hospital vs community-based care and respite care. Enhancing the older persons autonomy and control over their daily lives maintains the persons independence; being informed and having access to information enables the person to be able to make choices based on evidence.
- » Access/referral pathways to services and coordination of care: coordinating health care services when the consumer's needs change or their health deteriorates can cause confusion about where to find the appropriate care. Navigating the health care system with the older person is challenging and trying to maintain a balance between safety and autonomy means using a flexible approach to ensure the personal preferences of the older person are respected. The GP is often the first point of contact and works closely with the consumer's support network to find the right care at the right time. Often this may require the GP, consumer and their family to work closely with an inter-professional team of health care providers including mental health services, medical specialists, pharmacists, hospital or community-based teams and non- government supports.
- » Confidentiality: sharing of essential information between health care providers and family members ensures a coordinated approach to health care delivery. Respect ought to be given to

the consumer above all. Confidentiality may be required when engaging with family members who may be suspected of causing harm to the person or abusing them either psychologically, physically, or financially. Health care professionals must know how to keep the older person safe from abuse. They should also know the process for reporting abuse.

- » Involving support from family and friends: supportive family members act in many roles providing care to the older person with mental illness, including as their carer, advocate and relative. Involving the consumer and family members in shared decision making ensures the individual needs of the consumer are met. This requires health professionals to respond and actively engage with supportive family on a regular basis to review progress and make changes to the care plan or personal goals when needed, and keep family and friends updated on changes.
- » Safety and quality in mental health care: speaking up and having a voice as it relates to the quality of care received by older people in mental health services has been found to be shamefully ignored. Consumers and families must have access to reliable and safe lines of communication for reporting problems related to poor quality care and know their concerns will be treated seriously, discussed in relevant committees, acted upon and outcomes fed back to them outlining the improved changes to practice.
- » Advocacy groups offer support to older people and their families by providing information, education and advocacy on the rights of older people accessing care in the community or hospital setting.
- » Education and training for health professionals: health care professionals ought to be trained in therapeutic responses to behavioural and psychological symptoms of dementia. It is imperative to implement strategies which minimise distress, prevent restrictive practices and improve the use of trauma-informed care approaches. Promoting education for health professionals which identify the impact of trauma on the lived experience of people accessing mental health care will address discriminatory attitudes in health care workers, promoting best practice in the delivery of mental health care of older people.
- » Older people may have experience with consumer directed care approaches through Commonwealth aged care programs such as My Aged Care.

People with disability

There are many consumers using public mental health and psychosocial disability services who experience other areas of disability. This includes physical, sensory and developmental disabilities. The experience of life with disability exposes some groups to higher levels of distress and the development of mental health issues. Children and young people with Autism Spectrum Disorder (ASD) and carers, often face difficult experiences in education systems and other areas of social connection. Both young people and adults with ASD have higher rates of mental health issues such as anxiety disorders and depression, as well as higher prevalence of suicidal ideation and self-harm.³³

Service providers in mental health require significant awareness as well as policy and service practices for successful inclusion and accessibility of people with disability. This includes suitable policy commitments, access to disability supports and expert guidance that can assist consumers and carers engaging with the service. In Australia, there are traditional service and funding boundaries between primary health care, state public health systems and disability services. Service boundaries across psychosocial disability, health and other disability support organisations need to be clearly defined and coordinated to support families and consumers to have experiences of continuity. It is important that boundaries do not generate barriers and frustration where families have multiple providers involved in care. Many consumers and carers living with disability benefit from specialist advocates and lived experience organisations^{34 35} which promote inclusive policy, provide advice of preferred practices and provide peer supports directly to/for/with communities.

Inclusion of people with ASD in mental health care

Some specific practices for inclusion of people with ASD in mental health care include:

- » Ensuring care is individualised, with the practitioners learning the specific communication, sensory and processing needs of the person.^{36 37}
- » Encouraging continuity of the practitioner and sessions over time³⁷ with structure and predictability in meetings.³⁶
- » Identifying where people and carers are being bounced between service areas and working for better links with disability services that the person receives.^{36 37}
- » Identifying and working through barriers that may be heightened in people with ASD including anxiety, mistrust, impact of physical/sensory environments. Creating comfortable environments and flexible service processes are important.³⁷
- » Encouraging training of practitioners on ASD related communication, lived experience and adapting therapeutic approaches. They should become skilled at working with the person to address the mental health issue of concern and not the person's autism or other developmental traits.³⁶

- » Improving communication skills by using clear and direct language, being comfortable with silence and a slower pace if needed (given processing needs).³⁶
- » Using recommendations for care that is practical and focused on the present and offering concrete examples for dealing with issues and problems.³⁶

Young people

Adaption of PCC principles for Child and Adolescent Mental health Services have been recommended across health settings. Rates of young people aged 12-17 experiencing a mental illness in 2013-14 corresponded to 14%. Data from the National Health Survey 2017-18 indicates 26% of young people aged 15-24 reported having a long-term mental or behavioural condition, with anxiety (17%) and depression (12%) being the most prevalent.³⁸ Despite recent increases in the provision of mental health services to Australian young people (12-25 years), a reduction in the prevalence of mental health distress has not yet been observed.³⁹

The low rates of engagement for young people seeking help for their mental health depends heavily on the accessibility of the service and how the service can meet their unique needs. Youth specific services have been developed based on these needs and offers support which promote engagement with person-centred care principles. Fostering positive experiences is fundamental to young people continuing to connect with care.

A recent systematic review on factors influencing person-centred care for children, young people, and families summarised qualitative evidence from 23 studies on the topic. Recommendations identified by professionals, service users and carers were similar to that for PCC delivery to adult populations and include:

- » improving the information provision for service users and carers within mental health services.
- » respectful listening and validation of people's needs and preferences, particularly youth and family members.
- » practical training for professionals in working within a PCC framework.
- » finding the balance between service users' autonomy and parental involvement while observing confidentiality principles.⁴⁰

Similarly, qualitative findings on the perspectives of young people on what makes for youth-friendly mental health services point out the following key recommendations:

- » Developing more useful consumer information for youth and family members including explanations of how a therapy session is organised, information on legal obligations and confidentiality.

- » Allowing conditions for consumers to share their stories and preferences.
- » Engaging with caregivers and school counsellors as they play a central role in promoting help-seeking for young people.
- » Increased flexible service delivery options, including flexible and immediate appointments, increased online support, home delivery of services and assistance with transport.⁴¹

Other strategies to assist in engaging young people in PCC delivery might be:

- » Adopting a trauma-informed approach at the point of care, considering the impact of trauma on engagement, and supporting young people to feel safe and in control over treatment approaches and decision-making.
- » Considering family relationships and complexities and previous negative experiences with the mental health system that can limit family and young person's engagement with care.
- » Reflecting on how to build rapport considering potential biases clinicians might have on specific cohorts of young people and considering strategies to improve relationships with young consumers.
- » Ensuring services are youth friendly, easily accessible, culturally safe, inclusive and supportive.⁴²
- » Acknowledging the dual challenge that youth from culturally and linguistically diverse backgrounds face in dealing with the tasks of adolescence whilst growing up between different cultural rules and expectations.
- » Clinicians must engage in open dialogue about the influence of the young person's cultural background on their understanding of wellbeing and recovery and be aware of the influence of their own cultural biases and perceptions at the point of care delivery.
- » Building up and understanding of the young person's unique cultural understandings and beliefs about family relationships and structure, significant life events and situations, culturally based health practices, and specific cultural or religious practices.
- » Considering the layers of complexity in supporting youth from refugee backgrounds who might have experienced persecution, displacement, loss and forced separation from family. These people may require ongoing and multidisciplinary support to address their specific health and psychosocial needs.⁴³
- » When supporting LGBTIQ+ young people it might be important to understand whether gender identity and sexual orientation issues are pressing issues to their distress.

- » Acknowledging that LGBTIQ+ people might have experience ostracism and discrimination which can influence their engagement and ability to disclose. Facilitating a sense of control in decision-making, as well as being transparent in conversations around confidentiality, is recommended to give the young person a sense of agency over their 'coming out' experience.⁴⁴

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