Developing a 'fit for purpose' mental health care system for 21st century children and young people

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THE ISSUE

Despite increased awareness-raising around mental health, and improving access to quality mental health information, children and young people continue to face significant challenges in maintaining their wellbeing and mental health.

When children and young people are asked to talk about mental health, their focus is on their everyday experiences. These can include pressures in their family lives, at school, or within their community. They often describe coping with poor physical health, experiencing bullying, facing discrimination and exclusion, handling complex family structures, and navigating relationships with peers, partners, family members and teachers.

Some children and young people report feeling unsafe in their community and school environment. They describe experiences that do not align with their expectations of inclusion and participation. Others describe barriers to their participation in music, arts, sport and other organised community activities; involvement that it is well recognised as a protective factor in maintaining wellbeing and mental health.

Children and young people's lives are shaped by certain issues and pressures unique to them. As 21st century citizens they live with the complexity of navigating the digital world. They live with generational concern regarding the climate crisis – in particular the frustrations around the lack of action being taken to mitigate its impact both locally and globally by those who hold the levers for change. They also talk about uncertainty around the future due to pressures relating to the increasing costs-of-living and declining levels of trust in both social institutions and political traditions.

Children and young people say they do not always feel heard or believed by adults. This further undermines their trust in other people, the systems they live in and the services they're offered, often designed and delivered with little or no input from them.

Children and young people talk about trying to support their friends or family members while managing their own mental health. Many young people report that support becomes available 'too late' – often only once their mental health has escalated to a 'critical' or 'crisis' point. Others say they feel ill-equipped to adequately support themselves or friends when they need to, and want more practical knowledge and skills to do so.

The Commissioner for Children and Young People promotes and advocates for the rights, development and wellbeing of all children and young people in South Australia, with a special focus to engage with and listen to children who aren't usually heard.

Commissioner for Children & Young People

With their informal support networks often overstretched, young people identify a range of barriers that make it difficult for them to seek more formal 'help' when this is needed. Their firsthand experiences include facing long waiting lists, being required to obtain parental facilitation or consent, and seeking services that are largely inaccessible without a referral.

Where formal support is available, it can feel overly focused on 'treatment' rather than on taking preventative approaches and providing strategies that enable young people to maximise their wellbeing beyond a particular episode or incident. Young people also report that services don't adequately acknowledge or address the issues of generational concern causing many young people varying levels of hopelessness and helplessness.

Children and young people's views and experiences point to a fragmented system that is not delivering the help they need when they need it. Neither is the current system delivering help where children and young people can access it easily or affordably.

BACKGROUND

It is estimated that of the overall levels of mental illness experienced in adulthood, more than 50% is likely to have begun sometime before the age of 14 years.[1] Identifying and addressing mental health challenges experienced during childhood is not only essential to supporting healthy and hopeful children and families – it also bears long-term social and economic benefits across the lifespan.

The United Nations Convention on the Rights of the Child obligates governments and civil society to ensure all children have access to what is required for them to live, survive, develop, and have a say in the decisions affecting them.

To meet these obligations, children and young people must have access to a mental health care system that:

– Includes holistic measures aimed at preventing and protecting children, families and communities from mental ill-health and emotional difficulties.

– Provides a continuum of services to children and young people with mental health challenges, including those with disability, trauma and/or complex needs.

– Provides education, health and community supports to children and young people when they are distressed, worried and finding it difficult to live their best lives.

Because children and young people have been born into a century characterised by rapid social, economic, civic, technological, and environmental change, the fundamental structure of mental health care services must change too.

As the most digitally literate and globally connected generation to ever live, young people have unprecedented access to information and relationships that cross continents and ideological lines. This not only shapes their meaning of identity and agency, it also shapes their views and expectations of systems and services – including those designed to support their wellbeing and mental health.

A 21st century mental health care system needs to sit within a rights-based framework to have relevance and usefulness to the lives of 21st century children and young people.

The promotion and protection of mental health must be the foundation upon which a new system of mental health care is built, embedding principles of participation, voice, and agency.

Tackling poor mental health and the distress it brings is a top priority for children and young people. Given the interplay of factors influencing their wellbeing, efforts to improve children and young people's mental health must consider all aspects of their lives; their education, health, safety, relationships, parental mental health, and other social, economic and community factors. This means moving beyond the experiences children and young people are having with current clinical services, and instead embracing an approach that matches with the priorities and expectations these 21st century citizens have in relation to supporting their wellbeing and mental health.

KEY MESSAGES

Young people have said:

1. **Bulk-billed health care in Australia is now virtually non-existent.** This is making it extremely difficult for young people who often cannot afford the gap payment required. For those who can afford professional support, waiting lists are often 'months and months' long, meaning their mental health will often get worse while they wait.

> ❝ **The waiting list is weeks and many cannot pay for those services. Many of my friends have to choose between paying rent or treating their mental health problems which is not okay." – 16 year old**

2. **Health care systems and services can be a hit-and-miss experience.** Young people want more supportive and welcoming services that are culturally safe, gender and identity-affirming, and trauma-informed. They want to be able to see GPs and mental health specialists together in one place, mainly because moving between services is difficult.

> ❝ **There is a limited understanding [of] how to access mental health services among young people. Many resources such as a GP provided mental health plan are not made known to young people, who want to access this type of service but are unsure how to." – 15 year old**

> ❝ **Currently not enough services for when help is reached out. Patients in the health system must be treated as people not as problems." – 17 year old**

3. **School-based mental health support does not generally provide the kind of mental health support young people say they want and need.** It can be hard to access, varies in quality, and does not consistently respect children and young people's privacy and confidentiality. It is often too focused on education outcomes and academic wellbeing, rather than on relationships and other important aspects of a young person's life that are impacting on their capacity to stay engaged with their education.

> ❝ **I was an A grade student and then started having mental health issues. All I was told was '[it] sucks to be younger, get yourself fixed because year 11 and 12 are important, you don't want to **** that up.' Like I could just control my mental health like that." – 16 year old**

4. **Young people, particularly those living in regional and rural locations, say that access to mental health services does not respect their individual privacy or maintain confidentiality.** They say it may involve 'the whole town' finding out about their business and/or waiting months for any supports to arrive, if any.

> ❝ **There is not enough support for children with mental health issues. While I have support now, I waited for months for this and during this time I was falling apart and nearly ended it multiple times and I believe my mental health worsened because of no support." – 15 year old**

5. **Barriers to 'help seeking' include persistent stigma and stereotypes related to mental health, a lack of information about what to expect from services, or what is expected of young people interested in accessing them, not feeling heard or taken seriously when they do, and fear of breaches to privacy and confidentiality that undermine young people's trust in adults and the services they offer.**

There is also an assumption that parents and guardians will support their child or young person's attendance at appointments and be willing and/or able to cover the costs involved, which is not often the case.

> **It made me feel awful like no one wanted to help me and that people had given up on me because the hospital also rejects me I don't talk to anyone I just get sedated and put into a room by myself. But also with cahms there was no confidential everything I said to them they told my mum everything." – 16 year old**

> **don't assume that our parents and guardians do the right thing by us sometimes they are the problem not the solution. There is an issue concerning parental consent especially when it comes to mental health as the parents could be part of the reason or a restrictive. As well as cost..." – 18 year old**

CURRENT CHALLENGES

The experiences of mental ill-health and the associated stigma it can bring, can have a significant impact on a young person's developing sense of identity. For many young people, feeling well or 'getting better' is not about having no signs of illness, but is more importantly about being who they want to be.

Acknowledging the fluidity and diversity of young people's gender and sense of identity and then tailoring care and support services accordingly is key to developing a contemporary strengths-based mental health care system.

Young people today have unprecedented access to information, tools and resources related to mental health. With this comes a whole vocabulary that adults may not be aware of. It also provides opportunities to connect with other young people and celebrities, both locally and globally, sharing views and experiences, seeking validation, advice and sometimes leading to self-diagnosis. While this can be empowering, the sheer volume of information can be overwhelming, and some young people can find the use of diagnostic tools and terms more alienating and frightening than helpful. Further, the quality of information is variable, and does not always lead young people to connect to further professional support when it may be required.

Children and young people have identified a range of challenges to maintaining their mental health.

These challenges cause them distress and concern, and in some instances can exacerbate their mental ill-health. It is often the cumulative impact of the challenges that is the problem. They seek supports that offer more than just a clinical or medical treatment. They want supports that will address their development and mental health in a holistic way, prioritising health promotion and prevention above the treatment of their symptoms.

> **Train GPs better in mental health b/c I have been to 3 different doctors + had incredibly bad experiences w/ them and [been] very belittled." – 16 year old**

> **Ways to de-stigmatise mental health issues. Recognising and ending the double standards with mental health between different genders. Understanding the connection between mental and physical health (especially for those with chronic illness.)" – 16 year old**

Young people have raised concerns about mental health supports only being available once things reach a 'critical level' or 'crisis point'. The current system requires a young person to be experiencing severe symptoms before they can access the next level of care.

This leaves many young people feeling as though their situation is 'not yet bad enough' to seek formal support. It is an approach that is creating a divide between primary and tertiary services that results in a 'missing middle' of children and young people whose needs are not being met. They are either considered to be too unwell for primary care, or not unwell enough for tertiary services.[2] This cycle of unmet need is not only distressing for young people and their families but can also result in significant social and economic costs over the longer-term.

> 66 **If people asked if I am generally ok more, and don't get mad if I say i'm not ok lol."**
> **– 16 year old**

> 66 **if grown ups believed us because sometimes they just think we are exaggerating."**
> **– 13 year old**

A range of stakeholders describe a lack of information and supports for families and carers seeking support for young people who require ongoing intensive treatment, care and support. Others have raised concerns about the absence of after-hours service options available to young people experiencing a mental health crisis outside of hospital emergency departments.

Young people involved with crisis services have described being caught in a system that requires them to 'get worse to get better'. They would like to see a system that provides youth-specific alternatives to hospital emergency departments, and which actively connects young people and their families to resources and services designed specifically for them.

> 66 **There's no support for people in between. in hospital you only get help if you are severe otherwise you get kicked back out into the real world with no help or supports." – 16 year old**

There are significant barriers to seeking and receiving support for children and young people who have a range of disability, trauma, and complex mental health needs, and who therefore require a range of services across disciplines. Families, service providers, and other advocates have raised particular concern about children

and young people living with intellectual disability and autism who are being denied mental health care because their 'behaviours of concern' are deemed 'disability-related' rather than mental health related.

Some children and young people have described experiences of being in mental health service environments that failed to uphold and promote cultural safety. The focus on a medical and clinical approach, rather than on a more holistic social or cultural approach, currently makes accessing culturally safe care particularly difficult for Aboriginal and Torres Strait Islander children and their families. Culturally and linguistically diverse young people and their families, and those from refugee, migrant or asylum seeker backgrounds are also impacted in this way.

Research consistently shows LGBTQIA+ young people have disproportionately poorer mental health outcomes when compared to the general population and that these outcomes are linked to higher likelihood of experiencing stigma, discrimination, social exclusion and harassment.[3] This highlights the need to ensure safe, identity-affirming and rights-respecting environments for all children and young people.

> 66 **I think people don't talk about the connection between outside influences (aka disabilities, discrimination, abuse, sexuality, gender, race) and how they can impact your mental state differently."**
> **– 17 year old**

> 66 **[We need] a class where we learn from people who have experienced [mental illness] and gotten past it..." – 14 year old**

> 66 **More education on mental health to help get rid of the stigma and know how and when to seek help. Better School counsellors. Professionals (should) take students seriously and be private."**
> **– 15 year old**

NEXT STEPS FOR DEVELOPING A MORE CHILD AND YOUTH-FOCUSED MENTAL HEALTH SYSTEM

The unique experiences of children and young people in the 21st century must inform the design and operation of a child and youth-focused mental health care system. A fit-for-purpose mental health system must acknowledge the intersecting forms of discrimination and stigma that exist, and actively work in the cross-over areas of identity, wellbeing, chronic illness, disability, physical health, mental health, relationships and aspirations.

A 21st century mental health system that will work for 21st century children and young people needs to shift from taking children and young people away to a place where mental health support services are delivered, and instead be more about a response that supports children and young people with mental health concerns or illnesses in their daily situations.

Such an approach would ensure they are still able to engage with friends, school, sports and community activities in safe and familiar environments that are well supported by the people they love and who love them.

This new system would actively undo some of the approaches being used in the current system, which is heavily geared to responding to behaviour escalation and crisis rather than recognising and focusing on the importance of prevention and early intervention.

A 21st century mental health care system and services must be underpinned by the values and actions already identified by children and young people as being essential to their wellbeing and mental health; namely kindness, inclusivity, participation, and trustworthiness.

KIND mental health systems and services...

– recognise and uphold the rights of children and young people as stakeholders and consumers who require a range of approaches according to their different ages and developmental stage.

– engage with and build positive relationships with children and young people to increase the likelihood of applying preventative approaches and early identification and intervention.

– promote positive attitudes and behaviours toward maintaining mental health in children and young people while simultaneously managing better supports for mental ill-health when this is needed.

– recognise that first impressions matter, and that children and young people interact with systems, services, and people in a series of 'firsts' when they are unwell, while a health professional providing a service may be doing what they've been 'trained to do' for the thousandth time.

INCLUSIVE mental health systems and services...

– ask about a child or young person's life experiences, including their family dynamics and other important aspects of their identity without making assumptions about their situation or beliefs.

– look beyond age and acknowledge and validate the social roles and contributions made by children and young people as leaders, workers, athletes, friends, siblings, umpires, volunteers, carers, etc.

and acknowledge their competency and capacity as experts in their own lives.

– actively address the specific barriers children and young people have identified as impacting on their capacity to gain support for mental ill-health.
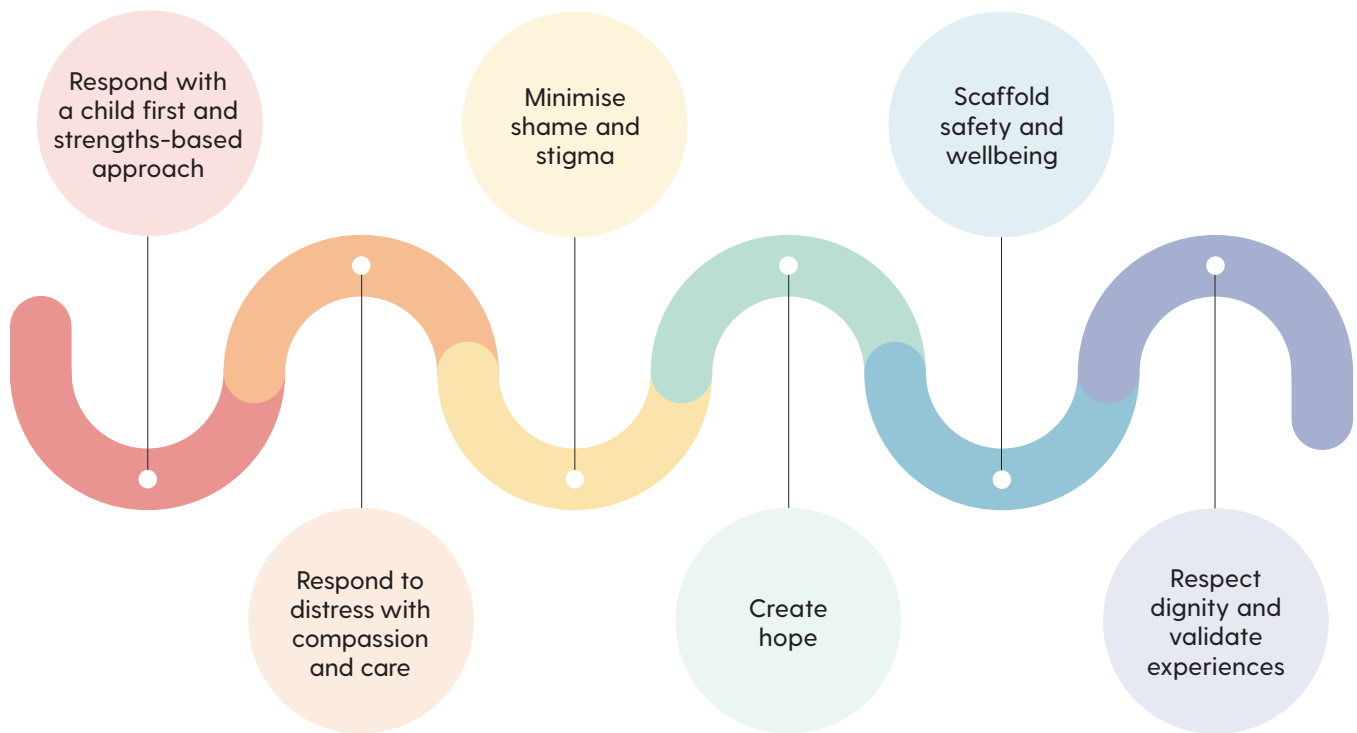
PARTICIPATORY mental health systems and services...

– embrace their role in developing children and young people's health literacy, ensuring they receive information in ways they can understand, and which reflects their own life experiences.

– provide time, space and opportunities for children and young people to be listened to, feel heard, and know what has happened based on their participation.

– respond to what's most important to children and young people, even when this differs from an adult's perceptions or experiences.

TRUSTWORTHY mental health systems and services...

– educate children and young people about confidentiality, privacy, and consent, to ensure they develop an understanding of their rights that includes recognising when these principles are not being upheld.

– identify and implement initiatives so children and young people can feel safe, seen, known and valued in healthcare environments.

– provide easy-to-understand information and options that respect children and young people's culture, identity and individual right to privacy and confidentiality.

– understand, uphold, and explain to children and young people that they have a right to good quality health care and that this includes being heard and informed about what care and treatment is being proposed.

PRINCIPLES OF A CHILD AND YOUTH-FOCUSED MENTAL HEALTH CARE SYSTEM

Respond with a child first and strengths-based approach

Minimise shame and stigma

Scaffold safety and wellbeing

Respond to distress with compassion and care

Create hope

Respect dignity and validate experiences

Children and young people have said that above all else they want a mental health care system that shows compassion.

To embed compassion within the service delivery model, the following principles should underpin a new child and youth-focused mental health care system:

– **Respond with a child first and strengths-based approach.** Adapt to the individual's needs and by guiding health services away from asking children and young people 'what is wrong with you?' to asking 'who are you?'.

– **Respond to distress with compassion and care.** Assume a child or young person's distress is genuine, and that it requires a caring and compassionate response; not just a diagnosis and standardised treatment plan.

– **Minimise shame and stigma.** Do everything possible to positively engage and connect, restoring the respect and dignity of the child or young person seeking support, ensuring every interaction with them is meaningful.

– **Create hope for every child or young person.** Connect with and build hope for each child and young person seeking mental health services and support.

– **Scaffold safety and wellbeing.** Focus on creating safety and wellbeing as described by the child or young person across all aspects of their lives, including at school, in the community, at work and at play.

– **Respect dignity and validate experiences.** Assume adult words and actions have an impact, so ensure that everything that happens around a child or young person respects their dignity and validates their experience.

RECOMMENDATIONS

Effective mental health promotion and prevention depends on outcomes in a range of areas that go beyond the mental health care system.

They include education, housing, employment, justice, and child protection. Considering interventions beyond mental health care services is therefore critical to ensuring South Australian children and young people can access the support they need, in places they're already connected to; thereby enabling them and their families to benefit from low cost, low intensity services wherever possible.

A more coordinated, multi-system response to the prevention and intervention of mental health care and support is required; one that actively connects children and young people and their families with pre-existing resources and services, working to bring these services to where they are rather than taking children and young people away from their support systems and loved ones.

This shift in approach would involve schools, community partners and different levels of government working alongside professional and peer workforce teams who are there to listen to and guide children and young people problem solve their individual circumstances and experiences. Such an approach to provision of mental health care services would support children and young people to be safe, supported and hopeful 'in place'.

Specifically, a 21st century mental health care system for children and young people must:

1.
Consider the unique issues and pressures shaping children and young people's mental health today, placing them in the context of the social, political, economic, environmental, and digital changes that are constantly occurring.

2.
Acknowledge the intersecting forms of discrimination and stigma that exists, and actively work in the crossover areas of identity, wellbeing, chronic illness, disability, physical health, mental health, relationships and aspirations.

3.
Provide a continuum of 'joined up' infant, child, youth, and family mental health care services that are developmentally age-appropriate from newborns through to 18-year-olds and their families, delivered in integrated settings that children and young people are already in.

4.
Invest in local responses, activities, opportunities, and preventative programs and networks that support children and young people in the places they already feel they belong; not in 'unknown' environments that may add extra levels of anxiety and remove them from the 'known' supports they need and depend upon.

Endnotes

1   Kessler et al. Lifetime prevalence and age-of-onset distributions of DSM-IV disorders in the National Comorbidity Survey Replication. *Archives of General Psychiatry* 62, 6 (2005): 593-602. https://doi.org/10.1001/archpsyc.62.6.593.

2   Orygen, 2021. Defining the Missing Middle. https://www.orygen.org.au/Orygen-Institute/Policy-Areas/Government-policy-service-delivery-and-workforce/Service-delivery/Defining-the-missing-middle/orygen-defining-the-missing-middle-pdf.

3   Productivity Commission. Mental Health Inquiry. Volume 2, p. 93. Available at https://www.pc.gov.au/inquiries/completed/mental-health/report/mental-health-volume2.pdf