

Final Report: Understanding 'the Missing Middle':
Children and Young People With Moderate to Severe Mental
Health Concerns who experience difficulties accessing services

Office for Mental Health and Wellbeing
Youth Coalition of the ACT
Capital Health Network

Acknowledgments

We would like to acknowledge and thank the people and service providers who have contributed to this project. Their involvement and advice have helped us to develop a report that builds the evidence base and deepens our understanding of the challenges experienced by children and young people with moderate to severe mental health concerns, and their families, seeking mental health support and services in the ACT.

We would particularly like to thank the project Working Group representatives from:

- Youth Coalition of the ACT (Youth Co.)
- Capital Health Network (CHN)
- CatholicCare
- Child and Adolescent Mental Health Services (CAMHS)
- ACT Health Directorate - Mental Health Policy
- Community Services Directorate – Children Youth and Families

Contents

Acknowledgments	2
Executive Summary.....	5
Introduction.....	7
Background.....	8
OMHW Review of Children and Young People in the ACT	8
Defining the Missing Middle – A National Issue.....	9
ACT Context	10
Project Approach.....	11
Process.....	11
Mapping Initiatives in Other Jurisdictions.....	11
ACT Sector Consultations.....	12
Mental Health Service Providers	12
Other Related Service Providers.....	12
Project Limitations	13
Project Findings	14
1. Key Characteristics of Children and Young People Who Experience Difficulties Accessing Services	14
Complexity and other comorbidities, including alcohol and other drugs, and homelessness.....	14
Trauma	15
Neurodiversity – Autism Spectrum Disorder (ASD); Attention Deficit Hyperactivity Disorder (ADHD); and Disabilities.....	15
Emerging or Established Personality Disorders	16
Children and young people with limited or no family support or involvement	17
Children Under the Age of 12	17
Young people aged 12 and over	18
Child Protection or Youth Justice Involvement	18
Children and Young People Identifying as LGBTQIA+	18
Children and Young People who are Culturally and Linguistically Diverse	19
Aboriginal and Torres Strait Islander Children and Young People	19
Eating Disorders	20
Young Women	20
The ‘Invisible’ Missing Middle.....	20
2. Service and System Constraints and Challenges	20
Service and System Gaps	21
Workforce Challenges	23
Meeting Demand within Funding Constraints.....	23

Navigating Mental Health Services	24
Limited Referral Pathways.....	24
Barriers to Shared Care and Transitioning Children and Young People Between Services	25
Informal Barriers to Accessing Mental Health Services	25
Access to other Child, Youth and Family Support Services	26
Interaction with the Education Sector.....	27
Interaction with the Private Sector and Commonwealth systems.....	27
In Summary: Why do children and young people with moderate to severe mental health issues experience difficulties accessing support?	29
Related Projects and Initiatives	30
Next Steps.....	36
Conclusion.....	38

Executive Summary

The mental health of Canberra's children and young people remains a key priority for the ACT Government and community. Fifty percent of all mental health conditions arise before the age of 14 years and 75% before the age of 25¹, so it is imperative to ensure that the right supports are available to meet their mental health needs. The wider impacts of COVID-19 on mental health will also remain long after the pandemic has passed.

There is significant national attention focused on the need to improve support for children and young people with moderate to severe mental health concerns, colloquially referred to as the 'Missing Middle'². Locally, this need was echoed in findings of the *Review of Children and Young People* (the Review) undertaken by the Office for Mental Health and Wellbeing (The Office) in 2019. This project builds on the findings of the Review and develops the evidence base to better understand why some children and young people with moderate to severe mental health concerns experience difficulties accessing mental health services. As the Review focused on the experiences of children and young people, this project contributes the additional perspectives of service providers supporting this cohort.

The Office worked in partnership with the Youth Coalition of the ACT and Capital Health Network (CHN) to undertake consultations with ACT service providers across community, private and public sectors that deliver services to children and young people in the areas of mental health, primary health care, alcohol and other drugs, disability, advocacy, education, child protection and homelessness support services. This also included programs that provide targeted support for children and young people who are culturally and linguistically diverse, Aboriginal and Torres Strait Islander, and those who identify as LGBTIQ+. The breadth of services consulted begins to reflect the complex nature of the 'missing middle'.

Consultations identified key characteristics of children and young people who experience barriers accessing mental health supports. These include children and young people with highly complex needs and/or comorbidities, such as alcohol and other drug use, homelessness, complex family dynamics or conflict, risk of perpetrating violence and multi-system involvement. Characteristics also included children and young people impacted by trauma; Autism Spectrum Disorder, Attention Deficit Hyperactivity Disorder, and disabilities; established or emerging personality disorders; eating disorders; limited family involvement; children and young people in specific age groups; and young people who are culturally diverse, Aboriginal or Torres Strait Islander or who identify as LGBTIQ+. These characteristics may intersect and overlap, and these complex needs are often unmet. As one service provider described, 'young people don't come separately from their issues'.

At the service system level, there are service and system gaps and limitations. Key constraints and challenges for mental health services include workforce issues such as recruitment and retention, and difficulties responding to high levels of demand within funding constraints. Barriers to shared care with tertiary services, and difficulties transitioning children and young people between services as their needs change, lead to disjointed service experiences and also contribute to system 'bottlenecks'. More broadly, challenges navigating the sector and inaccessible referral pathways limit young people's service options. Limited child/youth-

¹ WHO, available at: <https://www.who.int/news-room/fact-sheets/detail/adolescent-mental-health>

² <https://www.health.gov.au/resources/publications/the-australian-governments-national-mental-health-and-suicide-prevention-plan>, Pillar 3

friendly engagement strategies and environments create informal barriers to access and engagement, and there is limited collaboration within and across sectors, including with non-clinical support services and family services. Private services are a key component of the mental health sector, but can be difficult to access, particularly for young people with complex needs. Commonwealth systems such as the NDIS, Better Access and MBS, while improving some families' access to support, can also create barriers to accessing services and contribute to workforce issues.

Findings highlighted several broad reasons why children and young people with moderate to severe mental health issues experience difficulties having their mental health needs met:

1. Service and system gaps and limitations;
2. Some children or young people may need more support, or different types of support, than the clinical service response provided by practitioners or services;
3. Children and young people experience difficulties accessing existing practitioners, programs and services;
4. Children and young people experience informal barriers to engaging with services, or do not feel satisfied that their mental health needs were met; and
5. Parents and families may need support to strengthen parenting skills and family functioning.

The ACT child and youth mental health sector sits across the community, government and private sectors, and is also embedded within sectors such as child, youth and family support, education, disability, child protection and justice. Mental health programs receive funding from a diverse range of local funding agencies, such as ACT Health, the ACT Education Directorate, ACT Community Services Directorate and philanthropic agencies, as well as federal funding through sources such as Capital Health Network and Commonwealth departments. As such, supporting the child and youth mental health sector to better respond to the mental health needs of children and young people involves bringing stakeholders together, and incremental change to identify 'what works' to address service and sector constraints and challenges, and to progress and evaluate initiatives. Underpinning this is the need to support a more 'joined up' sector that can participate in shared prioritising and decision-making, and the need to develop person-centred, integrated multidisciplinary approaches.

Building on the co-design approach used in this project, and to progress the development of an Action Plan in response to key findings, a Child/Youth Mental Health and Wellbeing Services Network will be established. This will provide a structured, ongoing, formal mechanism for community, government and the private sector to continue working together to address the complexity associated with the 'missing middle', including to identify and progress key sector priorities, shared decision-making and improve communication, connection and collaboration.

Introduction

Supporting the mental health and wellbeing needs of children and young people is a key priority for the ACT Government and the community more broadly. With the recent pandemic and its impact on mental health and wellbeing, supporting our younger community members and their families is even more critical. Whilst there has been significant investment in services and programs for mental health services and supports, children and young people still find it challenging to access appropriate mental health supports to meet their needs.

The Office for Mental Health and Wellbeing's *Review of Children and Young People* (2019) reported on the experiences and challenges experienced by children and young people in the ACT from birth to 25 years of age across the continuum from mental health promotion and prevention, early intervention, treatment through to recovery. This project was a key Recommendation identified by the community, which identified the need to respond to children and young people with moderate to severe mental health concerns who experience difficulties accessing services (the 'missing middle'). The need for this work has also been reiterated more recently in the 'The Missing Middle' reports by Lived Experience Australia, and the Productivity Commission Report on Mental Health³ also acknowledged challenges for the missing middle.

It is important to acknowledge the psychological and environmental stressors associated with COVID-19, which further increase the importance of this work. Research indicates that the pandemic has exacerbated existing and traditional drivers of parenting stress and couple conflict (such as poverty and inequality; e.g. financial, housing stress⁴), disadvantage, and child, youth and family⁵ mental health concerns. This includes increased rates of stress, worry, helplessness, social issues and risky behaviours (e.g. substance abuse, relationship issues, academic issues, work absenteeism, suicide)⁶ as young people and their families work through emotional, economic and social losses. This amplifies the need for a joined-up response that considers the needs of children and young people and their families in providing appropriate mental health care.

This project aimed to answer the question, 'why do some children and young people with moderate to severe mental health concerns experience difficulties accessing services?'. This project was undertaken as a partnership between the Office for Mental Health and Wellbeing, the Youth Coalition of the ACT and CHN. It involved a co-design process with key stakeholders from the community to contribute to the local evidence base around why children and young people with moderate to severe mental health concerns experience challenges accessing appropriate mental health services and supports.

³ Productivity Commission Inquiry into Mental Health, *vol.1, p.30*,
<https://www.pc.gov.au/inquiries/completed/mental-health/report>

⁴ Sharon Bessell (2021) The impacts of COVID-19 on children in Australia: deepening poverty and inequality, *Children's Geographies*, DOI: 10.1080/14733285.2021.1902943

⁵ Westrupp, E.M., Bennett, C., Berkowitz, T. et al. Child, parent, and family mental health and functioning in Australia during COVID-19: comparison to pre-pandemic data. *Eur Child Adolesc Psychiatry* (2021). <https://doi-org.virtual.anu.edu.au/10.1007/s00787-021-01861-z>

⁶ E.g. Meherali S, Punjani N, Louie-Poon S et al (2021) Mental health of children and adolescents amidst COVID-19 and past pandemics: a rapid systematic review. *Int J Environ Res Public Health* 18(7):3432

Objectives

To:

- Build on the findings from the Review by engaging with service providers to hear their perspectives on the missing middle and to better understand the challenges they experience when supporting children and young people with moderate to severe mental health concerns.
- Provide actions to explore next steps to enhance appropriate support for children and young people with moderate to severe mental health concerns.

Background

OMHW Review of Children and Young People in the ACT

In 2019 the Office undertook a Review of Children and Young people to understand the challenges and issues they experience in relation to their mental health and wellbeing. This review was informed by a comprehensive consultation process with the community, including young people, parents/carers and service providers. The Review's findings provide a better understanding of the challenges and needs of our younger community, concluding with recommendations to government on key initiatives to better support the mental health and wellbeing of children, young people and their families.

A key theme throughout the Review was the need for services targeting moderate to severe mental illness to be enhanced. Young people and their families acknowledged that they find it challenging to locate appropriate services that target moderate mental health concerns before these deteriorate to the point of requiring support for acute mental illness. This theme is not unique to the ACT and has been highlighted as a national issue more broadly, termed the 'Missing Middle'.

The Review found that children and young people experience a range of challenges with accessing appropriate mental health services to meet their needs. It focused on describing these challenges and issues from the perspectives of children and young people themselves and sought to build our understanding of why children and young people may struggle to find support for their mental health and wellbeing. Key findings from the Review included:

- long waiting periods to access services – which can deter a young person from receiving treatment or support;
- affordability – as many services, particularly those in the private sector, are fee-paying services and not all services offer bulk billing; and
- stigma – which is still a key challenge for all ages despite the amount of work by Government and non-government organisations to reduce the stigma associated with mental illness and/or poor mental health. Recognising the importance of stigma reduction, the National Mental Health Commission has been tasked with developing a National Stigma and Discrimination Reduction Strategy across 2022, including a long-term vision for Australia where stigma and discrimination based on mental ill-health are no longer barriers to people living long and contributing lives. This demonstrates

alignment between the work of the Office and this project and the National mental health agenda.

The findings of the Review emphasised that children and young people experiencing moderate mental illness can find it hard to locate a service that provides the level of care to meet their needs.

Findings from consultations undertaken for this project affirmed that the challenges identified in the Review remain true. However, there are additional, significant barriers to accessing mental health support.

Defining the Missing Middle – A National Issue

The Review and this project draw on the Victorian Government’s definition of the missing middle, as described in their submission to the Victorian Royal Commission into Mental Health: a gap for people with moderate mental illness⁷. This definition is focussed on the missing middle within the mental health sector, underpinned by the acuity of mental illness, referring to children and young people who are not able to access the care they require through the primary mental health system alone as their needs are too complex, but are not unwell enough or do not meet the eligibility (or other) criteria to receive support provided by specialised tertiary mental health services. They may have accessed services in the past, however, did not have their needs met whether through the duration of care or level of specialist care to respond to the complexity of their needs⁸.



Figure 1 - 'Defining the Missing Middle' (Orygen, p.2 available at <https://www.orygen.org.au/Policy/Policy-Areas/Government-policy-service-delivery-and-workforce/Service-delivery/Defining-the-missing-middle>)

Recognising the importance of this work, the Commonwealth Department of Health’s National Mental Health and Suicide Prevention Plan (2021)⁹ identified addressing service gaps including

⁷ Victorian Government Submission to the Royal Commission into Victoria’s Mental Health System, 2019

⁸ Orygen, The National Centre of Excellence in Youth Mental Health, Productivity Commission’s Inquiry into Mental Health

⁹ Available at: <https://www.health.gov.au/sites/default/files/documents/2021/05/the-australian-government-s-national-mental-health-and-suicide-prevention-plan-national-mental-health-and-suicide-prevention-plan.pdf>

the 'missing middle', echoing the recommendations of the Productivity Commission's Inquiry into mental health and the National Suicide Prevention Advisor's Final Advice. A core component of this strategy relates to multidisciplinary teams and care coordination to address current systemic issues contributing to the challenges experienced by this cohort.

ACT Context

In 2021 the ACT population size was approximately 432,000¹⁰ with children and young people between the ages of 5 and 24 representing 26% of this total. A further 43,000 people live in regional NSW surrounding the ACT and may access ACT services. During 2021, 11,757 people received support through ACT public mental health services, with 35% under the age of 25, for high-moderate to severe mental health presentations. The rate of community mental health care service contacts per 1000 population in the ACT is highest among young people aged 12-25 than any other age group, with figures that are three times the national average¹¹.

It is estimated that 26% of the total number of people in the ACT receiving mental health medications under the PBS are children and young people aged 5 to 24 years. It is highly likely that some of these young people would be seeking further support through ACT public mental health services but are not always accepted. Data from the 2021-2024 ACT PHN Needs Assessment¹² highlights the barriers experienced by children and young people seeking support, including the need for multi-disciplinary support for children and young people experiencing moderate to severe mental health issues and complexities. In relation to those not receiving support for their mental health and wellbeing, this report highlights the challenges and complexities children and young people face when seeking support, along with the challenges for service providers.

It is worth noting that in relation to children and young people accessing services for moderate to severe mental health issues, we can only capture and report on data related to the public health system and are not able to obtain data related to community services. Until such time that there is data linkage between the multiple organisations, this will always remain a limitation when accessing information for mental health presentations within the ACT.

¹⁰ ABS <https://explore.data.abs.gov.au/>

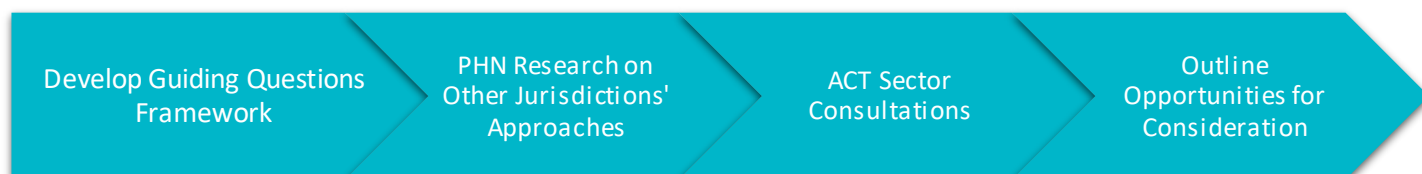
¹¹ AIHW <https://www.aihw.gov.au/reports/mental-health-services/mental-health-services-in-australia/report-content/summary-of-mental-health-services-in-australia>

¹² Available at: <https://www.chnact.org.au/wp-content/uploads/2022/03/Capital-Health-Network-ACT-PHN-2021-24-Needs-Assessment.pdf>

Project Approach

Process

To oversee this project, the Office established a Working Group with key representatives from both government and non-government organisations. The Working Group collaborated to design a project approach to improve our understanding about why mental health supports for children and young people with moderate to severe mental health concerns is such a critical issue for our community. The following project approach was undertaken:



The Working Group participated in planning and workshops throughout the project process to clarify key issues and shape the project's objectives and direction. This included developing guiding key questions to promote a structured approach to identifying the range of key issues associated with the 'missing middle'. High level questions included:

1. Are there shared definitions and typologies of child and youth mental health issues across key stakeholders in the ACT?
2. What child and youth services exist across the stepped care model of mental health in the ACT?
3. How are children and young people supported to access and engage with the mental health service system?
4. What data collection measures are required within services and across the system to better assess how effectively processes are working?
5. Are there any areas that require further research and/or consultation?

Sub-questions included detailed queries regarding the activities, interventions and processes delivered by child and youth mental health services and to whom; the definitions used by services (such as mild, moderate and severe); how transitions between services operate; and what the formal and informal barriers are to engagement for children and young people and for service providers.

The development of these key guiding questions subsequently informed CHN's mapping of initiatives in other jurisdictions and underpinned the focus of consultations with service providers.

Mapping Initiatives in Other Jurisdictions

In November 2020, CHN conducted a small research project to map the approaches of other Australian jurisdictions that target children and young people with moderate to severe mental health concerns. This was informed by research findings from published documents as well as discussions with other Primary Health Networks (PHNs) and key stakeholders across Australia. The research demonstrated that there were some services, programs, models and plans in place in other jurisdictions that target young people experiencing moderate mental health

issues who might fall into the missing middle cohort. This included mobile outreach services, co-location of tertiary and lower acuity services to facilitate stepped care transitions, central intake and assessment functions and care coordination across primary and tertiary mental health care. The majority of programs identified targeted the 12- or 15-25 year age groups. Overall, targeted mental health responses for children and young people with moderate to severe mental health concerns was consistently identified across jurisdictions as an area for service system improvement.

It is important to note that this mapping was undertaken in late 2020 and the service landscape may have changed between then and the time of publication of this report. This mapping did not include an analysis of the effectiveness of noted initiatives. Further research is required to understand which interventions were effective in supporting young people with moderate to severe mental health issues.

ACT Sector Consultations

A key component of this project was to engage with service providers who support children and young people with moderate to severe mental health concerns. This decision was made to build on the information collected through the Review about the needs of children, young people and families by also hearing directly from service providers.

The Office for Mental Health and Wellbeing, Youth Coalition of the ACT and CHN worked in partnership to undertake 27 consultations with service providers between December 2020 and June 2021. This included practitioners and programs across community, private and public sectors that deliver services to children and young people in the areas of mental health, primary health care, alcohol and other drugs, disability, advocacy, education, child protection and homelessness support services. It also encompassed programs that provide targeted support for children and young people who are culturally and linguistically diverse, Aboriginal and Torres Strait Islander, and who identify as LGBTIQ+. The breadth of services consulted, beyond the mental health sector, began to illustrate a picture of the complexity and multidisciplinary nature of supports for children and young people with moderate to severe mental health concerns, a key theme throughout this report.

The consultation process aimed to identify the characteristics of children, young people and families who experience difficulties accessing mental health services and the nature of the barriers they experience; along with identifying service and sector challenges, gaps and constraints.

Mental Health Service Providers

Consultations with mental health service providers centred around better understanding the processes and activities delivered by mental health services to children, young people and families, including what they provide and to whom, the processes they use from referral to exit, and the service-level and system-level challenges, constraints and gaps to service delivery that they experience and/or observe.

Other Related Service Providers

Consultations with service providers that provide other types of support to children and young people with moderate to severe mental health concerns focused on hearing about the nature of the barriers they experience when supporting children and young people to access mental

health services, including the characteristics of children and young people who may experience greater formal and informal barriers to accessing mental health support.

Project Limitations

Whilst the project team made every effort to consult with a range of child and youth service providers, the list of service providers that participated is not exhaustive and may not be considered representative of the multiple sectors involved. Some providers were not available to participate, and the timeframes of this project did not allow for additional consultation in other circumstances.

A key limitation for this project is the minimal engagement with services that provide support to young adults aged 18 and over (i.e. non-youth specific services). While services specifically targeted at young adults (18-25 years) were included, it was not possible to consult with all mental health services for adults aged 18 and over. This is an important limitation, as the barriers for young people aged 18-25 could not be adequately captured. The Review, and this project, identify that further research is required to understand the needs of this age-group, as a crucial transitional period in a young person's life that can have a significant impact on lifelong mental health and wellbeing.

The project team did not have capacity to undertake analysis of program documentation, such as policies and procedures, or service outcome data. This could also form the subject of future research to provide more detail on current service provider responses for this cohort.

This report presents service providers' perspectives of the characteristics of children, young people and families who experience difficulties accessing mental health support but who may already have an existing level of service engagement. As such, it does not report on the characteristics of young people and families with no service engagement and unmet mental health needs. This was described by one service as the 'invisible missing middle'. Further work may be required to understand the mental health needs of children, young people and families who do not engage with services.

Project Findings

The findings presented in this report are presented in the following two sections:

1. Key characteristics of children and young people who experience difficulty accessing services; and
2. Service and system constraints and challenges that present barriers to support.

These sections are discussed in further detail below and form the basis of the recommended next steps arising from this project.

1. Key Characteristics of Children and Young People Who Experience Difficulties Accessing Services

Consultations highlighted a range of characteristics of children, young people and families who experience difficulties accessing mental health services for moderate to severe mental health concerns. These include:

- Complexity and other comorbidities, including alcohol and other drugs, homelessness, and the interaction between other characteristics listed below;
- Trauma;
- Autism Spectrum Disorder, Attention Deficit Hyperactivity Disorder, and Disabilities;
- Established or emerging personality disorders;
- Children and young people with limited or no family support or involvement;
- Age groups – children under the age of 12, and young people aged 12 and over;
- Child protection or youth justice involvement;
- Children and young people identifying as LGBTQIA+;
- Children and young people who are culturally and linguistically diverse;
- Aboriginal and Torres Strait Islander children and young people;
- Eating disorders;
- Young women; and
- The 'invisible' missing middle: Invisible cohorts and issues

These characteristics are explored in more detail below.

Complexity and other comorbidities, including alcohol and other drugs, and homelessness

Multiple service providers reported that children, young people and families with significant complexity experience formal and informal barriers to accessing mental health services and supports. 'Complexity' could include but is not limited to complex family dynamics, including family conflict, family violence and family separation; alcohol and drug use; homelessness; risk of perpetrating violence; and multi-system involvement. It also includes the intersection between these issues, and the other characteristics listed in this document below.

In some cases, children and young people with complex needs do not meet the formal inclusion criteria for services. For example, some programs do not work with young people experiencing homelessness, or with young people at risk of perpetrating violence. Eligibility criteria for services can also be unclear. Young people with comorbid alcohol and other drug use experienced barriers to accessing therapeutic mental health support where their mental health

presentations were seen as caused by their substance use, including detox. In addition to the barriers related to eligibility criteria, young people and families with complex needs also encounter informal barriers, such as difficulties accessing office-based services.

As one service provider described, “young people do not come separately from their issues”, highlighting frustrations with the sector’s limitations in working with young people with complex needs. This could lead to a bouncing of referrals from service to service, compounded by unclear inclusion and exclusion criteria. Service providers reported that young people with highly complex needs experience challenges having their needs met through the private system, which results in a higher reliance on being able to access support through public and community services.

This issue was recently reflected in The National Children’s Mental Health and Wellbeing Strategy,¹³ which reported that children and young people who present with complex needs are often turned away or referred to another service leaving them unable to access support for their needs. Responding effectively to complex needs extends beyond the services provided by the health and mental health system, and into other sectors such as education, justice, child, youth and family support, and homelessness. These relate to the social determinants of mental health and wellbeing and require a multidisciplinary and coordinated service system response.

Trauma

Almost all service providers highlighted trauma as a key issue for children and young people with moderate to severe mental health concerns, including complex developmental trauma, intergenerational trauma and specific experiences of trauma. They highlighted that if trauma is not addressed within childhood, young people may experience a range of negative outcomes, such as further mental health issues, family conflict, disengagement from education, homelessness, and possible involvement in the youth justice system. Despite this, service providers highlighted that there are limited options for specialised trauma services for children in the ACT, which experience long waiting lists. There are no specialised trauma services for young people aged 12 and over. Many mental health services in the ACT cannot work with children and young people where trauma is the primary presenting issue, due to the different type and length of intervention necessary. Service providers also noted the need for mainstream services, including schools, to build their capability to deliver trauma-informed approaches.

Neurodiversity – Autism Spectrum Disorder (ASD); Attention Deficit Hyperactivity Disorder (ADHD); and Disabilities

Some mental health services reported that they can and do work with children and young people with ASD and/or ADHD, where their primary presentation is for mental health concerns. However, this did not reflect the experience of referring agencies. Multiple service providers reported difficulties accessing mental health support for children and young people with ASD or ADHD, even where they feel the child or young person’s mental health presentation is the primary concern.

¹³ *The National Children’s Mental Health and Wellbeing Strategy, available at: <https://www.mentalhealthcommission.gov.au/getmedia/5b7112be-6402-4b23-919d-8fb9b6027506/National-Children%E2%80%99s-Mental-Health-and-Wellbeing-Strategy-%E2%80%93-Report>*

Service providers noted the long waiting lists for ASD and ADHD assessments from paediatricians and through public services, and high costs associated with the private sector, which can lead families to seek assistance from mental health services for assessments. This is outside the scope of many mental health services, who noted the need to provide timely support related to child development for families. Accessing assessments for young people over the age of 12 is particularly difficult. Service providers also noted that where a child or young person may have co-occurring mental health issues and ASD/ADHD, it can be difficult to access mental health services until a diagnosis for ASD or ADHD is either ruled in or out. This subsequently delays mental health treatment.

It was noted by one service provider that Fetal Alcohol Spectrum Disorder (FASD) did not emerge as a key characteristic of children and young people who experience difficulties accessing mental health services but was raised that it may often go undiagnosed in children. FASD may not currently be well understood or recognised and is associated with high levels of stigma. There is considerable overlap between FASD and child/youth mental health concerns.¹⁴

Service providers described challenges associated with accessing NDIS support, including for ASD, and suggested that accessing plans related to ASD has become more difficult due to the high numbers of NDIS applications seeking support for children with ASD. Generally, children and young people may also experience difficulties accessing NDIS plans due to the requirement for diagnosis and 'permanence' of a condition.

More broadly, the underrepresentation of children and young people with disabilities accessing mental health supports was noted, despite the high rate of comorbidity between disability and mental illness. It was felt that this was due to 'diagnostic overshadowing' (in which services become siloed), informal and formal barriers to accessing services, and because the symptoms of mental health may appear in different ways in young people with disability, and not be recognised or taken seriously.

Comorbid intellectual disability is another element of complexity in presentations for children and young people with moderate to severe mental health concerns. This intersects with work currently being finalised by the ACT Health Directorate on a position statement on mental health and intellectual disability, that considers the support needs for this cohort.

Emerging or Established Personality Disorders

Young people with emerging or established personality disorders, who may also have a higher risk of self-harm, experience significant difficulties accessing appropriate mental health services due to the limited availability of appropriate interventions and practitioners, and a perception that their symptoms are 'behavioural' rather than mental health-related. Where young people may present with 'challenging or complex behaviours', they may not be accepted into services or may be exited early, including from residential mental health services.

Service providers noted that Dialectical Behavioural Therapy (DBT) has a strong evidence-base as an intervention for supporting people with emerging or established personality disorders, as a skills-based intervention which is often run as a group program for young people and their parents/family members. They suggested that it adds diversity to the common Cognitive

¹⁴ McLean, S. (2019). *Understanding the impacts of FASD on child mental health*. Emerging Minds, National Workforce Centre for Child Mental Health.

Behaviour Therapy (CBT) approaches used within services, and offers a valuable referral option when young people present to CBT-based services with symptoms of personality disorder.

Existing community DBT programs are difficult to refer into and have long waiting lists and uncertain funding. The University of Canberra WOKE program focuses on early intervention for young people aged 15-21 with early signs of, or who are at risk of developing a personality disorder. This program has time-limited trial funding. Access to the CAMHS DBT program requires young people to already be a CAMHS consumer.

Young people with emerging or established personality disorders may also experience difficulties accessing support in the private sector, due to the high costs of group programs and individual therapy, long waiting lists to access DBT-trained psychologists, and potentially a higher level of complexity requiring more frequent contact.

Service providers advocated for exploration of options for expansion of DBT within the community, to increase access for children and young people who may benefit from this approach. This included the need to review referral pathways for young people with an established or higher severity personality disorder to access existing DBT programs.

Children and young people with limited or no family support or involvement

Service providers highlighted that children and young people are often reliant upon parents or families to help them navigate, access and engage with services, such as finding and booking appointments, providing consent, providing transport and paying for services. This can present challenges for children and young people who do not have this level of family support or engagement. Parents and families may also have varying levels of readiness to engage, depending upon their own mental health, trauma and service experiences, personal circumstances and challenges, and juggling multiple other demands. Services also described barriers supporting children and young people where parental consent was required, including where consent may not be given, or the young person may not want to seek parental consent. The latter was noted as a barrier for young people seeking support related to sexuality or gender.

Children Under the Age of 12

Service providers described increasing numbers of children aged 8-12 presenting within schools and to services with mental health concerns, including potential self-harm and suicidal thoughts. They noted that families with children as young as five years old, who may exhibit violent behaviours, were also presenting to services.

Service providers working in education settings, including in mental health-focused roles, noted that children aged 8-12 can be the most difficult to refer out to other services, due to limited programs working with children in the 'middle years', and the need for intensive support for families.

Mental health programs also noted the need for more support for families with children in this age group to build parenting skills and strengthen family functioning, such as Circles of Security and Tuning into Kids.

Young people aged 12 and over

Service providers noted a significant gap in specialist trauma services for young people aged 12 and over, and a gap for young people aged 12-14 wanting to access counselling related to gender. They described that there are limited family functioning programs that aim to support young people with complex family dynamics, and limited availability of parenting support programs such as *Tuning into Teens*.

Young people aged 16 and over can experience a 'dip' in services, as they transition from child to adult services. At this age, some young people may begin to have less family support to access services, experience additional financial barriers, and difficulties accessing assessments, such as for ASD. One service provider noted that at this point, some young people have 'been through the system' and not had their mental health needs met, and have no options left other than to access the private sector, which excludes those young people who cannot access these services. Young people over the age of 18 also experience financial barriers to accessing services, noting that the barriers for young people aged 18-25 were not adequately captured in this project (see *Limitations* for more information).

Child Protection or Youth Justice Involvement

Service providers described that there are some children and young people with very high, complex needs who appear across multiple systems but do not receive a therapeutic response. In some instances, it can be difficult for children and young people to access a therapeutic response with the public or private sector because it is perceived that they require a more holistic approach and stability (including within their living circumstances) rather than therapy. Most mental health services are also not equipped to support children and young people with primary presentations related to trauma, including complex developmental trauma and intergenerational trauma.

Some children and young people in foster and kinship care can access mental health support through the private sector, if they can access financial reimbursement through Child and Youth Protection Services. However, community-based services described administrative challenges associated with seeking consent where the government holds parental responsibility for children. This was noted as a barrier for Aboriginal and Torres Strait Islander children and young people in the child protection system.

Young people with criminal justice backgrounds or a risk of perpetrating violence also experience barriers to accessing mental health services, including if they are perceived to be 'involuntary' referrals from statutory services. It was also noted that if young people have been prescribed psychiatric medications while incarcerated, they are often unable to continue to pay for the medication or lose their prescriptions after exiting.

Children and Young People Identifying as LGBTQIA+

Service providers emphasised the importance of acknowledging that children and young people who identify as LGBTQIA+ may experience significant mental health challenges and find it challenging to find appropriate compassionate support. A specific service gap was described for young people under the age of 15 seeking support and counselling relating to gender issues.

One service provider noted an escalation in the numbers of young people aged 13-15 seeking this type of support.

Services also described barriers for young people who identify as LGBTQIA+ accessing support in the private sector, due to affordability, waiting lists, and the potential need for parental consent, where a young person may not feel supported or be ready to discuss their experience with their parents. Service providers noted that if young people do not know about, or don't become connected with LGBTQIA+ groups and services in their local area, they may become more isolated and at risk of mental health harm.

Children and Young People who are Culturally and Linguistically Diverse

The difficulties that children, young people and families from culturally and linguistically diverse backgrounds experience in accessing mental health support include language barriers, limited expertise and experience of mainstream services to deliver cross-cultural work, and varying perceptions and views about mental health and wellbeing within different communities. The latter can lead to associated stigma and shame related to help-seeking.

Some referring agencies, such as schools, were unaware of the community-based services that work with culturally diverse families in the ACT and noted the need to have a culturally sensitive place to refer these young people to. However, community-based services working with multicultural communities often experience significant demand and long waiting lists for culturally sensitive therapeutic support. Companion House provides a child counselling program for children and young people from refugee or asylum-seeker backgrounds and prioritises children and families requiring interpreter services and who have more urgent needs, as their service options are otherwise very limited. This program is staffed by two part-time counsellor-advocates, and there was a waiting list at the time of consultations. Additionally, at the time of consultations the Multicultural Hub provided a part-time mental health counsellor, who was fully booked. Funding for this position was only provided for six months, until the end of June 2021.

Service providers working with culturally and linguistically diverse families and communities noted that the parenting and family support programs provided through mainstream services may not always be appropriate for these families. They described parents may not feel comfortable participating in parenting groups with other people from their cultural community, or from other cultural communities, and that an individual approach may be more appropriate.

Aboriginal and Torres Strait Islander Children and Young People

Service providers discussed the significant and enduring impact of intergenerational trauma upon Aboriginal and Torres Strait Islander children and young people, including higher levels of grief and loss, requiring trauma-informed, holistic and long-term support provided by a supported and appropriately resourced workforce. Services discussed the importance of supporting children and young people to build a sense of belonging, identity and cultural connection to supporting mental health and social and emotional wellbeing.

Challenges described by service providers included the high levels of demand experienced by existing Aboriginal organisations in the ACT within limited resources and limited culturally appropriate service options within mainstream settings. Service providers noted that in

addition to ensuring that Aboriginal organisations are adequately funded, non-Aboriginal services need to build their capability to provide culturally sensitive services and to build stronger connections with the Aboriginal and Torres Strait Islander community. More broadly, they noted the importance of building the capacity of mainstream services, including schools, to implement trauma informed approaches.

Eating Disorders

Service providers noted a gap in services for young people with eating disorders, due to a lack of appropriate services available in the ACT, long waiting lists to access existing services, and the challenges created in the conflation of mental health and medical symptoms. Many mental health programs identified that the interventions they provide may not be appropriate for young people with eating disorders and that further analysis of these programs would be beneficial.

Young Women

Although gender was not frequently raised as an issue in accessing mental health services, it was noted that service options for young women can be unclear. Menslink was frequently cited by mainstream services as a valuable referral point for young men who may need a range of support, including for mental health issues, but that similar service options for young women were less available. This needs further clarification to understand if there is a need for a service specific for young women, or if young women access mainstream services and receive appropriate support for their needs.

The 'Invisible' Missing Middle

Service providers noted that in reflecting on the characteristics of children, young people and families they engage with who experience difficulties accessing mental health services, they were identifying those families who already had some level of service engagement. One service described an 'invisible' missing middle: those children, young people and families experiencing mental health difficulties who may not seek help at all, for a range of reasons, such as distrust of services and systems, negative service experiences preventing further help-seeking, complex family dynamics, or because the symptoms associated with their mental health concerns (e.g. anxious or depressive states) may themselves present a barrier to reaching out for support.

2. Service and System Constraints and Challenges

Service providers identified several service and sector constraints and challenges that create barriers to children, young people and their families accessing mental health support. These included:

- Service and system gaps;
- Workforce challenges;
- Meeting demand within funding constraints;
- Navigating mental health services;
- Limited referral pathways;

- Barriers to shared care and transitioning children and young people between mental health services;
- Informal barriers to accessing services;
- Access to other child, youth and family support services;
- Interaction with schools and the education sector; and
- Interaction with the private sector and Commonwealth systems.

These are explored in more detail below.

Service and System Gaps

Consultations highlighted three types of service and system gaps for children and young people with mental health concerns. These include (1) missing services, (2) services with limitations, and (3) non-clinical and complementary services and supports.

Missing services

Key service gaps identified by service providers included an absence of specialist programs and services for young people impacted by trauma, children and young people with co-occurring ASD or ADHD and mental health concerns, support for eating disorders, and therapeutic support for specific cohorts, such as culturally and linguistically diverse children and young people. These service gaps were discussed further throughout Section 1.

Services with limitations

Some mental health services are limited in their scope, eligibility criteria, or capacity to meet demand, which may lead to certain cohorts being excluded from accessing support. This particularly affects children and young people with complex needs, comorbidities, multi-system involvement and specific age groups. Young people under the age of 15 are currently unable to access counselling support related to gender identity through community-based services. Service providers highlighted a need for more outreach-based services, and an expansion of community-based options to access DBT.

Non-clinical and complementary services and supports

Service providers reported that some children and young people may need a higher intensity and/or frequency of support, which may not be met through periodic clinical sessions alone. They highlighted that children and young people may require tailored, coordinated supports. This may include more therapeutic outreach mental health support, potentially with a case management or social support component, which could potentially complement clinical sessions. It may also include coordinated support from clinical and psychosocial services. Service providers identified that barriers to accessing intensive or higher frequency support across the community, government and private sectors may contribute to why some service providers refer young people on to tertiary services. It may also be a contributing factor to why some young people feel their mental health needs are not met through clinical mental health services, including tertiary services.

Workforce Challenges

Both community-based and government services reported difficulties recruiting and retaining skilled clinical staff due to being unable to compete with wage levels in the private sector and within other government directorates, along with staff burnout. This significantly impacts their ability to provide sustained services. Specific challenges recruiting to clinical child trauma roles were noted by multiple providers. Community-based programs that rely upon using bulk-billing private psychologists or general practitioners as part of their organisational model also reported difficulties recruiting to these roles or identified that the number of hours these practitioners could contribute was often very limited.

Service providers described the need to strengthen support for mental health practitioners, to prevent burnout and distress. For some services, high levels of demand could result in very high caseloads for workers, as services sought to reduce waiting times. Where there were barriers to shared care or declined referrals from tertiary services if the mental health needs of a child or young person escalated, this contributed to staff burnout in community-based services, where practitioners supported families through crisis periods, while also supporting other clients.

Service providers highlighted the need to support upskilling and formal professional development pathways, across community and government services, to improve staff satisfaction and retention and increase capability to respond to children and young people's needs. They noted that existing mechanisms, such as service funding agreements, should seek to ensure that staff have appropriate caseloads, and access to professional development through quality supervision and opportunities for reflective practice.

Meeting Demand within Funding Constraints

Child and youth mental health services consistently described difficulties meeting the high level of demand for their service within their existing funding constraints, which led to long waiting lists. Some specialist community-based programs that provide specialised programs to children and young people, such as child trauma, mental health outreach, or programs that work with specific population groups, operate with very small staff teams. They respond to significant demand, including from other sectors making referrals, such as education and child protection. The models used within these programs have not been replicated in the private sector.

Waiting lists for mental health services varied from one to two weeks, up to 18 months. Spending significant time on a waiting list could act as a deterrent for continued or future help-seeking. Furthermore, service providers reported that once a child or young person has 'reached the top' of the waiting list, their mental health needs may have changed and that service may no longer be the appropriate service for them.

One mental health program offers 'Active Hold' support, which provides periodic phone support to families while they are on the waiting list. This may include receiving brief interventions, triaging where possible, or identifying other services that can also support families. For this program, providing active holding support also helped to reduce wait-times, if some families had their needs met while accessing the active hold support. This component of the program was enabled through specific resourcing in the program's contract.

Navigating Mental Health Services

Service providers both within and outside the mental health sector, including schools, described limited awareness and understanding of what programs and services are available, what they provide, and to whom – including the inclusion and exclusion criteria. This impacted on their ability to make referrals and leads to an overreliance on a small number of well-known services, further compounding waiting times for those services, and in some cases, leading to inappropriate referrals. A lack of shared definitions across services about what ‘mild’, ‘moderate’ or ‘severe’ mental health issues refer to also contributes to confusion navigating the sector.

Mental health services discussed the importance of children and young people being matched to the ‘right service early’, to ensure they can access the most appropriate intervention to meet their needs, early in their journey with the mental health system. Where the correct ‘matching’ of services and clients does not occur early, this can lead to negative service experiences, unmet need and impact upon future help-seeking.

The Review found that young people want to feel empowered to support themselves and their friends when dealing with a mental health challenge. This included knowing what services were on offer, how to access the service, and what to expect in terms of the interventions and support that they will receive. Many publications and reports over the years, including the Review and the Productivity Commission’s final Report on its Inquiry into Mental Health, have found that navigating the mental health sector is difficult for children, young people and their families, and this is the initial barrier to help-seeking. The new ACT online youth mental health navigation portal ‘MindMap’ was developed to support children, young people and their families to navigate the mental health sector and find the right supports appropriate to their needs. This service is in the early stages of implementation, and will be evaluated to assess effectiveness.

Limited Referral Pathways

There are several community-based and government programs that support children and young people with moderate to severe mental health issues, that cannot be directly referred to by service providers, private practitioners or families. These include programs such as the two community-based residential step-up, step-down services for young people, and CAMHS programs, such as DBT. Access to these programs requires that the child or young person is already a client of CAMHS or AMHS. CAMHS or AMHS then make secondary referrals to these programs.

Services were aware of clients they felt would benefit from these programs, who were seen as outside the scope of other community-based programs. However, service providers’ experiences were that children and young people needed to reach an acute level of risk or severity in order to be accepted as a client into CAMHS, after which they could traverse the moderate to severe spectrum and receive secondary referrals to these specialist programs. They suggested the need to review referral pathways into some of these programs, to allow some young people to be referred directly, without the need to wait until they are severely unwell.

There was a perception that referrals to tertiary services from practitioners or services may be at a greater risk of being declined, due to these children and young people having some existing

level of support. Where referrals were declined, this could damage the primary health care relationship, especially if the reason for declining was unclear.

Barriers to Shared Care and Transitioning Children and Young People Between Services

A service system based on effective implementation of the stepped care model would enable a young person to 'step up' into a service that meets their higher acuity needs (possibly a tertiary service), or 'step down' into a lower intensity service (such as the community sector) as their needs change. Service providers reported that barriers to shared care with tertiary services prevents the delivery of coordinated support to families, and contributes to a lack of clarity regarding which practitioner or service should 'hold the risk', especially in instances where children or young people become suicidal. Some tertiary services do not provide shared care to clients if they are already engaged with another child/youth mental health service, in order to avoid duplicating clinical support. This can lead to practitioners and services feeling they have limited options other than to exit and refer the child or young person to tertiary services, especially if they do not have the capacity to provide the level of support required. However, they reported difficulties transitioning children and young people between services, due to long wait times or declined referrals.

Difficulties transitioning between services include programs and practitioners 'stepping up' children and young people to tertiary services, as well as tertiary services 'stepping down' children and young people to clinical community-based programs. These difficulties could result in services either exiting clients without the referral being accepted from the subsequent service, or services 'holding' children and young people for longer periods of time. Where programs hold on to children and young people while awaiting support from other services, this can contribute to a bottleneck within the service, preventing new clients from entering.

Mental health services described a lack of 'joined up' service delivery and limited communication between services. These barriers to shared care and service transitions contrasts with best practice evidence that asserts the need to wrap support around children in an integrated, whole of person approach, in the context of their families and communities.¹⁵

Informal Barriers to Accessing Mental Health Services

Service providers identified a range of informal barriers for children and young people accessing mental health services, related to access and engagement, service expectations and experiences, and inclusivity.

Accessing and Engaging with voluntary services

Mental health programs and services across the community and government are voluntary, requiring that the young person actively agree to participating. Service providers reported that the strategies used to engage with young people may act as informal barriers, such as the use of phone calls from private numbers to make appointments with young people, and clinical environments that are not child or youth friendly. They highlighted the opportunity to learn

¹⁵ National Children's Mental Health and Wellbeing Strategy (2021), available at: <https://www.mentalhealthcommission.gov.au/getmedia/5b7112be-6402-4b23-919d-8fb9b6027506/National-Children%E2%80%99s-Mental-Health-and-Wellbeing-Strategy-%E2%80%93-Report>

from and implement active engagement strategies, such as those used by youth workers and youth/family services, to engage 'hard to reach' young people and families.

Service providers also reported that most mental health services are office-based, which creates difficulties for children, young people and families with transport barriers, or who do not feel comfortable accessing office-based services.

Unclear Service Expectations and Experiences

Service providers noted that mental health programs do not always clearly articulate to clients what to expect from their service, including what support and activities they will provide. This lack of clarity can lead to negative service experiences, unmet expectations, or a confusion about 'what happened' during their involvement with a mental health service. These outcomes can act as barriers to engagement, and may deter future help-seeking.

Limited inclusive practices and processes

Services described informal barriers for specific cohorts of children, young people and families, such as those from Aboriginal and Torres Strait Islander or culturally and linguistically diverse backgrounds, and children and young people with disabilities. Language barriers and limited culturally sensitive services often prevent children, young people and families from non-English speaking backgrounds from accessing mental health services. Additionally, services reported the need for increased disability awareness for all services, including physical accessibility of venues, promotional strategies and providing flexible modes of delivery such as in-person, online and outreach.

Access to other Child, Youth and Family Support Services

Recognising the importance of parents' roles as a protective factor in children and young people's lives, service providers described that parents are doing the best they can to support their children, but do not always have the tools, strategies or understanding of how to best support their child's mental health and wellbeing. In some circumstances, child/youth mental health programs may be the first point of call for families seeking support. Service providers described the need for more universal support for families to build parenting skills and strengthen family functioning, as explored earlier in this report. There is also the need to provide timely, early support related to child development for families.

Service providers emphasised that some children and young people with moderate to severe mental health concerns may need additional support to complement clinical support, such as youth outreach, case management and social support. For young people in particular, it was noted that they need support to build social connectedness, build a sense of belonging and to support broader mental health and wellness. This could be supported by improved service awareness of available programs, and opportunities to collaborate across these services, including to provide coordinated clinical and psychosocial support.

Services asserted that supporting parents' mental health and wellbeing has important positive flow-on effects to their children. They expressed support for increasing the availability of holistic family responses, including support for parental concerns such as trauma, substance misuse, domestic and family violence, cognitive impairment, and working with families towards their goals and desired outcomes.

Multiple service providers raised the need for greater availability of parenting programs to strengthen capacity for ongoing parental support as a protective factor for child and youth mental health. This was identified as important to enable parents to support their child's mental health, and to understand their role in their child's mental health and wellbeing journey. Services advocated for the need for more universal supports and parenting programs to build parenting skills and family functioning, including increased collaboration across family support and mental health services. Stepping Stones and WOKE were cited as two positive examples of existing local programs that work effectively with children and young people, and also their parents and family members to improve family functioning.

Interaction with the Education Sector

Schools provide a range of in-school mental health supports for students and their families including school psychologists, counsellors, youth workers, social workers, youth health nurses and other pastoral care, health and welfare roles, and centralised support through Network Student Engagement Teams. The amount and type of support varies across different schools, across primary, high school, college and university, and between education systems (i.e. public and private). Staff in schools play an important role in identifying children, young people and families who may need further support, and in connecting them to support either in the school setting or externally in the community, government or private sectors.

Community-based and government mental health service providers noted that demand from the education sector is significant. Schools also experience their own constraints in being able to provide individual therapeutic support to children and young people, due to the large student populations they are responsible for. Schools expressed some hesitancy to refer to community services, concerned about overwhelming the sector with referrals, and noted difficulties navigating the system. Service providers suggested that there is a need for quick short-term mental health assessments and referrals, tools that young people can use themselves or in group-based programs, and the need to build schools' capabilities to deliver trauma-informed approaches. This included the need for some students, who may access clinical support outside the school, to be able to access more 'holding' within the school environment, focused on supporting emotional regulation rather than behaviour management strategies.

Interaction with the Private Sector and Commonwealth systems

Services described private sector supports as valuable for people who can afford to access them, and who would benefit from the types of interventions available. Commonwealth systems such as the Better Access initiative, the National Disability Insurance Scheme (NDIS) and the Medicare Benefit Schedule (MBS) aim to support children, young people and families in Australia to access subsidised or bulk-billed services, including mental health services within the private sector. While these systems improve access to support for some families, some young people and families are still excluded from accessing services if they cannot afford to pay gap fees or require longer term support. Services reported significant challenges for families trying to access NDIS plans for children and young people with mental health concerns, including trauma, due to the requirement for a permanent diagnosis. Additionally, NDIS plans are subject to review and can be changed at any time. A limited number of young people in the ACT receive NDIS plans for psychosocial support.

Many young people and families may need more frequent, outreach-based, holistic or psychosocial-based support than can be provided through clinical mental health sessions, or a higher number of sessions than supported under the Better Access initiative. For young people with highly complex needs, service providers discussed challenges finding private practitioners who have the breadth of knowledge required, who bulk-bill and who have availability. The funding structure of the MBS may contribute to some private practitioners exercising choice over who they take on as clients. Accessing psychiatrists was noted as particularly difficult, with many having closed books, very long waiting lists, and/or very high fees.

For private practitioners, potential isolation from other services can limit their capacity to be aware of and work collaboratively with other child, youth and family services that could deliver multidisciplinary support to young people and families. Furthermore, the funding structure does not support practitioners to bill to the MBS for case-conferencing, limiting the enabling of collaborative work in the private sector, such as between general practitioners, psychologists and psychiatrists involved in the care of a child or young person.

These systems also impact upon the provision of community and government services due to associated workforce issues. Organisations that rely on using bulk-billing private practitioners as part of their service model, such as psychologists and general practitioners, can experience challenges to recruiting and retaining these positions, primarily due to an inability to compete with private sector wages.

The Commonwealth Government identified the missing middle as a priority cohort in their National Mental Health and Suicide Prevention Plan¹⁶ (2021) to improve the national mental health response. This presents a potential opportunity for cross-jurisdictional collaboration to improve service access for this cohort.

¹⁶ <https://www.health.gov.au/sites/default/files/documents/2021/05/the-australian-government-s-national-mental-health-and-suicide-prevention-plan-national-mental-health-and-suicide-prevention-plan.pdf>

In Summary: Why do children and young people with moderate to severe mental health issues experience difficulties accessing support?

The findings in this report demonstrate that the 'missing middle' is complex: there is no single cohort, or type of mental health presentation, that comprises the missing middle. However, some cohorts of children and young people do experience greater difficulties accessing mental health support. While affordability and waiting lists are significant barriers to accessing mental health services, these are not the only key drivers of the 'missing middle', which is also characterised by service gaps and limitations, challenges accessing and engaging with existing services, and a need for different types of support for children, young people and families (including non-clinical support). Furthermore, the 'missing middle' is underpinned by a range of intersecting system constraints and challenges related to workforce, funding arrangements, service transitions and coordinated support.

Synthesising the findings sections of this report demonstrates that there are several broad reasons why children and young people with moderate to severe mental health issues experience difficulties having their mental health needs met in the ACT. These include:

1. There are some **service gaps**, such as the lack of trauma services for young people aged 12 and over, for young people with eating disorders, and children and young people with ASD or ADHD.
2. Children and young people might need **more than the usual clinical service response** provided through the mental health sector. This may include more frequent or intensive outreach-based support, potentially with a case management or social support component, which could complement clinical sessions.
3. There are appropriate programs and interventions that exist in the ACT, but it is **difficult for children and young people to access them**, for a range of reasons:
 - a. Long waiting lists and affordability barriers
 - b. Inaccessible referral pathways
 - c. Families, workers and schools don't know what services exist or understand what they can provide
 - d. Children and young people do not meet the eligibility criteria (e.g. complexity, challenging behaviours, alcohol and other drug use, ASD / ADHD, homelessness, risk of perpetrating violence)
 - e. Challenges transitioning between services as needs change, and barriers to shared care with tertiary services
 - f. Children and young people often have to be reliant on parents or families to help them navigate, access and engage with services
4. Children or young people experience difficulties engaging with services due to **informal barriers**, or do not feel satisfied that their mental health needs were met. Informal barriers include predominately office-based services, the limited use of child or youth-friendly strategies to actively engage with children and young people, and limited capability to provide culturally sensitive or disability-inclusive services. A lack of clarity for children, young people and families about what to expect from mental health

services can lead to negative service experiences, confusion and **unmet expectations**.

5. In some instances, parents and families would benefit from support to **strengthen parenting skills and family functioning**, rather than or in addition to the child or young person needing a clinical mental health response.

The findings raise several key themes for community and government to consider in addressing the complexity of the 'missing middle'. These relate to:

- Responding to service gaps using effective, evidence-based responses
- Responding to the needs of particular cohorts of children and young people who are formally and informally excluded from services
- Reducing barriers to accessing services, such as affordability, waiting times, transport and reliance on parental support
- Supporting structured and ongoing collaboration within the mental health sector (including community, government and private sectors) and across sectors (such as the mental health sector and the child, youth and family support sector)
- Developing shared definitions across mental health services
- Enhancing practices across services, such as using child / youth friendly engagement strategies and trauma-informed approaches
- Improving system navigation, including supporting appropriate referrals and 'matching' to the right service early
- Improving children's, young people's and families' experiences with the service system
- Addressing workforce issues
- Improving supports for parents and families to strengthen parenting skills and improve family functioning

Related Projects and Initiatives

At the time of developing this report, a number of external projects and initiatives were underway in the ACT that intersect in some way with the issues and findings raised in this document. Effectively responding to these children and young people requires an approach that is aware of and consolidates these different pieces of work. These are briefly summarised below.

ACT Health Directorate's scoping study for a service model for a specialist response for adolescents (12+) with complex needs and trauma histories

There are considerable parallels between the findings of this project and the recent scoping study undertaken by ACT Health Directorate, particularly in relation to the need for multidisciplinary care and a coordinated and connected response to support young people with multiple complex needs, including trauma histories. Following this scoping study, the ACT Government and the Commonwealth have committed to match funding for the development and delivery of a Youth at Risk program to provide a multi-disciplinary response to trauma and coordinated responses to young people with at risk of developing mental illness.

The program aims at supporting a range young people facing different challenges within our community as early as possible to ensure they are provided with the skills, care and support required to enable them to grow, learn, and lead a meaningful and fulfilling life. The key elements are:

- An evidence-guided therapeutic approach that delivers integrated care through a new adolescent trauma service.
- A Territory-wide integrated framework of supports which will develop a coordinated approach, and build increased capability to respond to youth at risk across sectors, settings and professions.

Planning for this service is currently in progress and will incorporate a co-design approach with government and non-government organisations and the broader community.

ACT Mental Health Workforce Strategy

Findings from this project emphasised the need for a supported and sustainable mental health workforce as a key enabler of adequate support for children and young people with moderate to severe mental health concerns. Work is currently being led by the Office to develop an ACT Mental Health Workforce Strategy. Evidence from this project should be embedded in the emerging activities related to the development of the workforce strategy.

Development of a shared NGO Mental Health Outcomes Framework

Work is currently underway between the Office and the Mental Health Community Coalition ACT to work towards a shared Mental Health Outcomes Framework for non-government organisations. Child and youth mental health programs use a range of outcome measurement and goal-setting tools with children, young people and families, to monitor change during their involvement. Different funding agencies, across local and Commonwealth agencies, also have a range of different program reporting requirements. A shared outcomes framework may support services to improve consistency and comparability of outcome data from service provision and drive ongoing quality improvement.

Development of an Initial Assessment and Referral Decision Support Tool (IAR-DST) for use with children and young people

The Commonwealth Department of Health has developed two adaptations of the Initial Assessment and Referral Decision Support Tool to be suitable for use with children (aged 5-11) and young people (aged 12-17). These tools and the associated guidance for use will support integrated assessment and referral across support services and have the potential to strengthen definitions of acuity and levels of care for children and young people and improve referrals to appropriate services. This tool is expected to be released in the coming months for use within primary care and any referral settings.

Legislating to Raise the Minimum Age of Criminal Responsibility

The ACT Government has committed to legislating to raise the minimum age of criminal responsibility from 10 to 14 years of age, and will be the first Australian jurisdiction to progress this legislative change. Work is currently underway to identify and plan what processes,

services and supports will be implemented to support children, young people and families who come into contact with the justice system.

Research to develop a Youth Mental Health Systems Modelling Tool for the ACT

Research is currently underway between the Office and University of Sydney's Brain and Mind Centre on the Right care, first time, where you live Program (the Program). The Program has been developed by the Brain and Mind Centre to co-develop decision-support tools using systems modelling and simulation to provide insights into the unique needs of young people. A transparent co-design process will allow these decision-support tools to take into consideration local priorities, opportunities and challenges such as social and economic drivers of mental health and wellbeing contextualised to the ACT.

The development of this model will assist policy and system planners make more informed choices about 'what works' in supporting improved child and youth mental health outcomes. The co-design of this model involves community, government and academic partners.

Evaluation of MindMap: Youth Mental Health Navigation Portal

The MindMap youth mental health navigation portal was launched in October 2021 and is delivered by Marymead and the Office. It aims to support children, young people and families to find appropriate mental health services in the ACT. While primarily web-based, the program provides access to Youth Navigators who can provide assistance in finding and accessing services, and clinical 'active holding' support to children and young people who require support whilst on waiting lists to access services. An early evaluation of MindMap is currently underway to identify how effectively the portal supports improved navigation and access to services.

ACT Health Directorate Position Statement on Mental Health and Intellectual Disability

ACTHD is currently finalising work on a position statement on improving mental health services for people with intellectual disability. This project incorporates the challenges experienced by children and young people with intellectual disability in accessing services that support their mental health and wellbeing.

Commissioning for Outcomes

The ACT Government is working collaboratively with community partners and people with lived experience to move towards a commissioning environment, across a range of ACT sectors. Commissioning seeks to transform the way that services are commissioned, towards building strong relationships and partnership to deliver services and achieve positive outcomes for our community.

Young People's Journeys around Mental Health and Medical Services Study

Researchers from the ANU have commenced a two-year qualitative study, 'JAMMed', to analyse the healthcare journeys of young people in the ACT experiencing their first significant episode of mental illness. This study will contribute to the local evidence base, by identifying key barriers and enablers to establishing effective, person-centred health care for young people with mental illness.

First 1000 Days Framework

The ACT Government is leading the developing of a First 1000 days Framework that emphasises the importance of the physical and mental health of mothers, fathers and families in building a positive environment for children to grow up in. This reduces adverse child experiences (ACEs) that can directly (abuse and neglect) or indirectly (parental conflict, substance abuse or mental illness) impact children's wellbeing through their living environment. High quality, strong parent and caregiver infant attachment have also been shown to have a positive impact on children's mental health.

Head to Health Kids

Under the ACT bilateral funding agreement, the Commonwealth and ACT governments have committed to co-funding a service to enhance child and family mental health initiatives to improve access to multidisciplinary team care for children aged 0-12 years in line with the National Head to Health Kids Hub model. This model builds on the findings of the National Children's Mental Health and Wellbeing Strategy as a guide to improve achievement of optimal health and wellbeing outcomes for children and their families. This service will involve the use of the IAR-DST for children and funding will begin in 2023-24.

Headspace Enhancement and Expansion

The Commonwealth government have announced funding to enhance the two existing headspace centres in the ACT to increase access to multidisciplinary youth mental health services in the ACT, and to establish a multidisciplinary early intervention service to support young people at risk of developing mental health concerns.

Early Psychosis Youth Service

The Commonwealth government has invested in the establishment of a new Early Psychosis Youth Services (EPYS) site in the ACT. This is now a national service that provides specialist support to young people aged 12 to 25 who are experiencing, or are at increased risk of developing, psychosis. The care provided through EPYS focuses on early intervention, aiming to prevent disruption in a young person's life and lessen the duration of untreated psychosis.

Community-based Early Intervention Service for Eating Disorders

In response to the ACT Eating Disorders Position Statement that was developed in 2018, the ACT Government committed to expand eating disorder services in the Territory. This included funding to establish an Eating Disorders Specialist Clinical Hub (Clinical Hub), establish an early intervention service and develop a Territory-wide model of care for eating disorders.

The Clinical Hub (the Hub) is a specialist community based centralised service for children, adolescents and adults who are experiencing an eating disorder as their primary presenting issue. The Hub's core business includes assessment, treatment, consultation, liaison, education and training, and system integration to strengthen eating disorders services across the Territory. The Hub will act as the central referral point/pathway for eating disorder services in the ACT and provide and support a range of coordinated eating disorder services within the ACT that shift the focus of eating disorders management away from acute inpatient treatment

towards a more flexible, appropriate, and efficient “Stepped Care” treatment model. The Hub was officially launched on 25 January 2022.

The ACT Government and the Commonwealth are co-funding a community based early intervention service for eating disorders to promote help seeking behaviour and early intervention treatment for people in the early stages of developing an eating disorder and those with an eating disorder of low to moderate severity. This builds on from a short term surge-support service that is currently run through Canberra Head to Health, which provides psychological and dietetics support for people aged 12 and above who are showing early signs of disordered eating or who are identified as at risk of developing an eating disorder, but do not yet meet the diagnostic criteria of an eating disorder. The EISED will be operational in the 2022/23 financial year.

In addition to the ACT Government investment, the Commonwealth committed \$13.5 million over three years from the 2021/22 financial year for a Residential Treatment Centre for eating disorders (the Centre) to be established in the ACT. Significant progress has been made towards the establishment of this service, with a model of care endorsed and a preferred location identified. It is expected that the Centre will be operational in 2024.

Next Steps

This project has demonstrated that the 'missing middle' is a highly complex issue, underpinned by service and system challenges and constraints, both within the mental health sector and across the ACT community. Responding to this issue requires bringing stakeholders together to identify, progress and evaluate key priorities. Consultations highlighted the need for improved collaboration, coordination and integrated responses to improve children and young people's mental health outcomes.

1. Establish a Child/Youth Mental Health and Wellbeing Services Network

In partnership, the OMHW, the Youth Coalition of the ACT and CHN will establish and co-chair a Child/Youth Mental Health and Wellbeing Services Network to progress key sector priorities and shared decision-making and improve communication, connection and collaboration. This will provide a structured, ongoing, formal mechanism for community, government, and potentially private services to continue working together to address the complexity associated with the 'missing middle', including by consolidating the various initiatives occurring that relate to child and youth mental health.

Similar networks in other ACT sectors have provided effective mechanisms to ensure shared decision-making and coordinated responses, including to respond to the COVID pandemic. Once established, a key priority for the Network will be to use the findings from this project, and other ACT projects, to develop a shared action plan (see item 2 below) and recommendations for the sector.

This action provides an enabling mechanism to progress suggested service system improvements raised in consultations, such as exploring opportunities for improved shared care and models of managing risk; with a view to delivering more coordinated and integrated support for children and young people. It may be able to identify, prioritise and progress initiatives such as practice frameworks, common language/definitions, and assessment tools.

Chair: Coordinator-General, OMHW; Youth Coalition of the ACT

Timeframe: Commencing in July 2022.

Membership: Mental health and wellbeing services that support children and young people, along with other child, youth and family services that work alongside mental health services to support children and young people.

2. Develop a shared Action Plan to identify and progress key priorities to support children and young people in the 'missing middle', from a whole of community and whole of government perspective.

The Child/Youth Mental Health and Wellbeing Services Network will work collaboratively to develop an Action Plan to respond to the findings of this report. The highly complex nature of the 'missing middle' requires a multi-faceted, coordinated response that considers what is needed to enhance practice, services and the system, and prioritises initiatives for implementation.

An Action Plan may consider opportunities presenting from the findings of this project, such as:

- Developing shared assessment tools and common language / definitions
- Improving shared care and risk management models between services
- Improving referrals and referral pathways to services
- Identifying training and professional development opportunities, such as trauma-informed approaches
- Developing practice frameworks for working with children and young people
- Identifying areas for further exploration, such as 'what works' to appropriately support certain cohorts, such as children and young people with ASD/ADHD
- Identifying opportunities to strengthen supports for families
- Exploring how to best respond to service and system gaps and limitations
- Participating in and informing other related initiatives
- Enhancing the use of research, evidence and evaluation

Using current evidence, strengthening existing initiatives and integrating future programs which have already been committed to is key to enhancing outcomes for our children and young people.

Following the codesign approach used throughout this project, we will continue to work in partnership with key stakeholders to develop and progress these identified opportunities. An Action Plan is necessary in order to ensure that appropriate actions are identified, prioritised and progressed.

Conclusion

The findings presented in this report illustrate the complex nature of the 'missing middle', and the need for multifaceted strategies and approaches across practice, services and the system to improve the mental health outcomes of children and young people. Acknowledging the complexity of this issue is an important first step towards developing strategies and solutions to address this complexity.

The child and youth mental health sector includes a diverse range of programs and services across the community, government and private sectors that are interconnected with other services and systems supporting children and young people. As such, supporting the child and youth mental health sector to better respond to the mental health needs of children and young people involves incremental change to identify 'what works' to address service and sector constraints and challenges, and to progress and evaluate initiatives. Underpinning this is the critical need to support a more 'joined up' sector that is enabled to participate in shared prioritising, decision-making, implementation and evaluation.

As outlined in this report, there are many initiatives already in progress to support the wellbeing of children and young people in the ACT. A key outcome of this project will be the development of the Child/Youth Mental Health and Wellbeing Services Network that was highly supported during consultations with service providers. This will be one step towards supporting services and sectors to collaborate, to support the wellbeing of children, young people and families.

The Office, the Youth Coalition of the ACT and CHN will continue to work together with key stakeholders across the community, government and non-government organisations to advocate for the ongoing enhancements required to support the mental health and wellbeing of children and young people in the ACT.