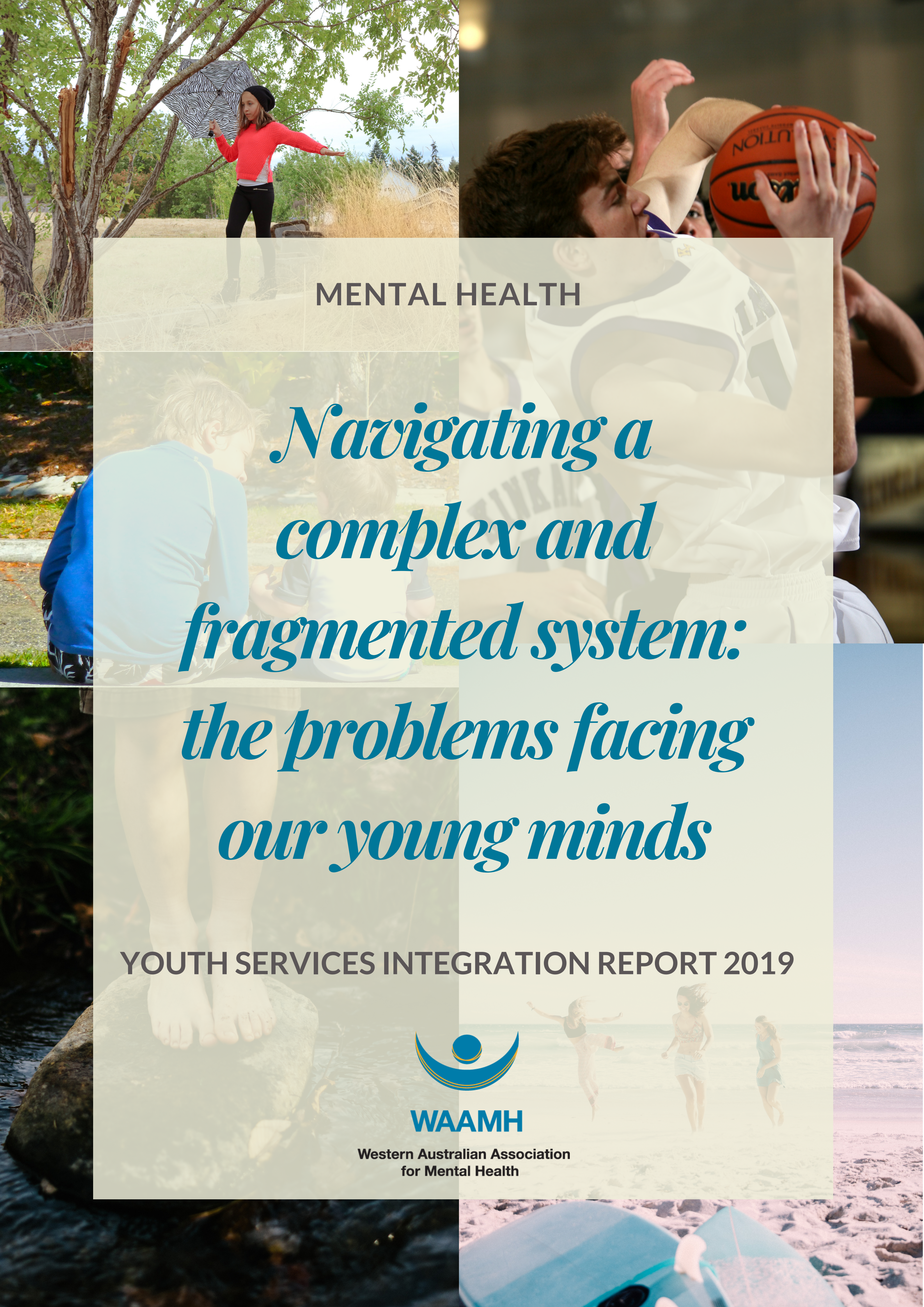


MENTAL HEALTH

Navigating a complex and fragmented system: the problems facing our young minds

YOUTH SERVICES INTEGRATION REPORT 2019

WAAMH
Western Australian Association
for Mental Health

The Western Australian Association for Mental Health (WAAMH) is the peak body for the community mental health sector in Western Australia and exists to champion mental wellbeing, recovery and citizenship.

WAAMH recognises a continuum of supports - built on principles of human rights, recovery, co-production, personalisation and choice, social inclusion and cultural connection - are essential to the promotion, protection and restoration of mental wellbeing. WAAMH promotes, advocates for and further develops this network of supports.

WAAMH's membership comprises community-managed organisations providing mental health services, programs and supports and people and families with lived experience of mental health issues and suicide, with whom WAAMH engages in genuine partnership. WAAMH has a wide network of collaborative relationships at a state and national level.

Acknowledgements
WAAMH wishes to acknowledge the custodians of this land, the Aboriginal people of the many traditional nations and language groups of Western Australia. We acknowledge the wisdom of Aboriginal Elders past, present and future and pay our respect to the Aboriginal communities of today. We thank the Aboriginal elders- Uncle Charlie Kickett and Aunty Helen Kickett who provided the project with advice and guidance.

Thank you
WAAMH thanks the 25 young people aged from 12-25 years who agreed to participate in this project and describe their journey through the mental health system. Many of those young people have had long and difficult experiences and journeys through the mental health system and their willingness to share their stories and discuss what for many were traumatic and difficult experiences is a testament to their resilience and desire to see improvements in the mental health system for other young people.

WAAMH also thanks members of the Project Advisory Group for their commitment to the project and young people's wellbeing more broadly. The dedication from Dr Ashleigh Lin, Mr Warwick Smith, Mr Andrew Kazim, Mr Chris Harris, Mr Ross Wortham, Ms Yasmine Hooper, Mr Samuel Winner, Ms Rikki Battersby, Mr Colin Penter and Mr Michael Jones was essential to the success of the project. Their guidance, patience, expertise and time is appreciated.

We thank all stakeholders from the community managed mental health sector, public mental health sector and other non-government and government agencies who provided assistance and guidance. Your insights, experience and contributions were invaluable to this work.

Suggested Citation
Western Australian Association for Mental Health (WAAMH), Report on the Youth Mental Health Services Integration Project, WAAMH, Perth October 2018.

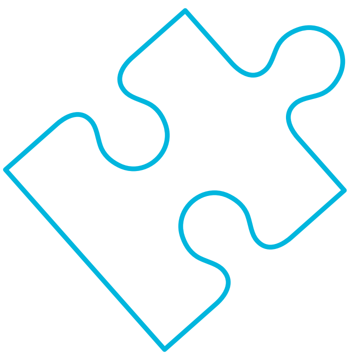
Western Australian Association for Mental Health (WAAMH) PO Box 8482, Perth WA, 6849

T: +61 8 6246 3000
E: info@waamh.org.au
W: www.waamh.org.au

WAAMH appreciates and acknowledged the financial and project support provided to the Project by the Western Australian Department of Finance, Government of Western Australia.

YOUNG PEOPLE NAVIGATING WESTERN AUSTRALIA'S MENTAL HEALTH SYSTEM

KEY FINDINGS



POOR INTEGRATION

Poor integration of youth mental health services in Western Australia is an issue that has concerned young people and their families, service providers, policy makers and clinicians for considerable time.

FRAGMENTED

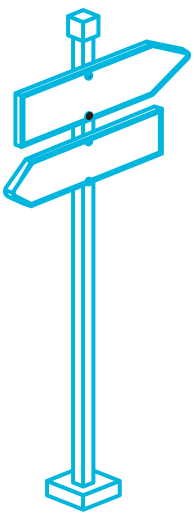
Young people, their families and carers and service providers consistently report that mental health services are fragmented and confusing and difficult for young people to access unless they have reached crisis point.

COMPLEXITY

The result of this fragmentation means young people face significant difficulties navigating a complex mental health system, often when they are feeling most vulnerable. Better service integration is identified as a potential a solution to these problems.

INCONSISTENCY

WA's current mental health system contains a significant number of different services - each with different funding arrangements, different pathways and access points with inconsistent eligibility and entry criteria - all of which are often dependent on an individual's diagnosis.



COLLABORATE

To provide the best long term outcomes for young people accessing mental health care, there needs to be:

1) Better understanding of the experiences of young people, especially those disadvantaged and living in rural and remote areas.

2) Collaboration with young people and their carers to understand what an 'ideal' mental health system might look like.

3) An evaluation of services for cost effectiveness.

WAAMH
Western Australian Association for Mental Health

Research derived from WAAMH's Report on the Youth Services Integration Project, November 2018

CONTENTS

1. EXECUTIVE SUMMARY

Poor integration of youth mental health services is an issue that has concerned young people and their families, service providers, policy makers and clinicians for considerable time.

Young people, their families and carers and service providers consistently report that mental health services are fragmented and confusing and difficult for young people to access unless they have reached crisis point.

In addition, the current mental health system contains a significant number of different services - each with different funding arrangements, different pathways and access points with inconsistent eligibility and entry criteria - all of which are often dependent on an individual's diagnosis.

The result is that young people face significant difficulties navigating a complex and fragmented system. Better service integration is identified as a potential a solution to these problems.

The Youth Services Integration Project was a 12-month project, initiated by Western Australian Association for Mental Health (WAAMH) and funded by the Department of Finance to understand more about young people's pathways through the mental health system and the extent of, or lack of service integration.

The goal was to work with young people with lived experience of the mental health system and related services to visually map their journeys, pathways and experiences through the mental health and related systems. This was done to understand and illustrate how and where services are integrated, or not integrated, to understand what effect that has on young people's recovery journey and to identify strengths and gaps in service integration.

The project used a co-production approach and was led, planned and delivered by young people, including two youth advisors / co-researchers.

The project team developed an innovative journey mapping process to visually track the pathways of 25 young people through the mental health system, including the services and agencies they had contact with. This information was used to develop a framework and set of principles for improved service integration.

2. PROJECT BACKGROUND

2.1. Introduction

In Australia, young people aged 16-24 years have the highest prevalence of mental disorders of any population group, with more than a quarter (26%) experiencing a mental health problem and/or a mental illness each year.[1] Three quarters of mental disorders first emerge in people by their mid-twenties.[2]

A recent study by headspace revealed alarming levels of psychological distress amongst young people, with one in three (32%) of young Australians aged 12-25 years reporting high or very high levels of psychological distress. This is more than treble the rate a decade ago.[3] WA has the second highest percentage of young people reporting very high or high levels of psychological distress (33%) after Victoria (35%).

In Western Australia, mental disorders affect almost a third of young people (31%). One quarter of all attendances to emergency departments in WA for mental health issues are made by young people.[4]

However, young people's access to mental health services is the poorest of all age groups and poor integration of youth mental health services has concerned young people and their families, service providers, policy makers and clinicians alike for some considerable time. They all consistently report that mental health services are fragmented and difficult for young people to access unless they have reached crisis point.

In addition, the current mental health system contains a significant number of different services - each with different funding arrangements, different pathways and access points, with different eligibility and entry criteria - all of which are often dependent on an individual's diagnosis. The result is that young people face significant difficulties navigating a complex and fragmented system.

Better service integration is identified as a potential a solution to these problems.

2.2. Policy Context

In recent times, the concept of service integration in mental health has emerged as a key policy and service priority. Service integration is not a new concept, and concern about the lack of service integration goes back decades. However, the contemporary focus on service integration derives from concerns about fractures in the service and care system for young people that mean individuals 'fall through the cracks' in care, or do not receive the kinds of care they need. Care and services for young people are seen to lack continuity and are fragmented.

---

[1] Mental Health Advisory Council, Youth Mental Health Sub-Network, (2017) *Youth Mental Health Report, Government of Western Australia*, North Metropolitan Health Service Mental Health, Perth, 19 July 2017.

[2] Hamilton, MP, Hetrick, SE, Mihalopoulos, C, et.al (2017) Identifying attributes of care that may improve cost effectiveness in the youth mental health system, *Medical Journal of Australia*, 2017 (10) 20 November.

[3] Headspace (2018) New headspace research reveals alarming levels of psychological distress in young Australians, October 8th, 2018. https://headspace.org.au/news/new-headspace-reserach-reveals-alarming-levels -of-psychological- distress.

[4] Mental Health Advisory Council, Youth Mental Health Sub-Network, (2017) *Youth Mental Health Report, Government of Western Australia*, North Metropolitan Health Service Mental Health, Perth, 19 July 2017.

The Western Australian Mental Health and Alcohol and Other Drug Services Plan 2015-2025 (The 10 Year Plan) recommended the establishment of dedicated youth mental health stream to improve services for young people, and outlines plans and actions for the development of youth mental health services in Western Australia.

In recent years, WA has seen several new programs and services funded and established in development of the youth mental health stream. Additionally, work is being done through several avenues, including the Mental Health Commission and the Youth Mental Health Sub-Network to identify how the dedicated youth mental health stream is to be developed further, and new services commissioned to adequately cater for young people with mental health issues.

The Federal Government plays a significant role in shaping the policy context and service system for service integration in youth mental health. Through the Primary Health Networks, the Federal Government has funded the expansion of the Headspace program, the national youth mental health early intervention service, to more than 100 sites throughout Australia. Headspace provides an entry point to mental health and other services through the engagement of mental health professionals, clinicians and youth workers and youth services, and by referring young people to other appropriate services.

The Federal Government funds Primary Health Networks to develop service approaches for young people with emerging severe and complex non- psychotic illnesses, as well as the headspace Youth Early Psychosis Program and a range of other programs and services for at-risk young people.

2.3. Project Purpose

The Youth Services Integration Project was a 12-month project, initiated by WAAMH and funded by the Department of Finance, to understand more about young people's pathways through the mental health system and the extent of, or lack of service integration.

The goal of the Youth Services Integration Project was to work with young people with lived experience of the mental health system and related services to visually map their journeys, pathways, and experiences through the mental health and related systems. This was done to illustrate how and where services are integrated, or not integrated, to understand what effect that has on young people's recovery journey and to identify strengths and gaps in service integration. This information was used to develop a framework and set of principles for better service integration.

2.4. Project Approach and Method

The project used an authentic co-production approach and was led, planned and delivered by young people, including a youth services project officer and two youth advisors / co-researchers.

The project team developed an innovative journey mapping process to visually track the journeys and pathways of 25 young people through the mental health system, including the services and agencies they had contact with.

More detail about project design and methods are found in Appendix 2.

2.5. Report Structure

This Report has been prepared for the Department of Finance.

Section 3 presents the findings of journey mapping interviews with 25 young people with lived experience of mental ill-health to capture their journey and pathways through the mental health system.

Section 4 provides an overview of the main findings of a literature review on service integration in youth mental health. Section 5 provides a summary of issues identified by service providers during focus groups and interviews. Section 6 discusses key learnings from the project and their implications for service integration.

Section 7 presents a framework and set of principles for better service integration. Section 8 describes project achievements in addition to contract deliverables in the contractual agreement with the Department of Finance.

YOUNG PEOPLE NAVIGATING WESTERN AUSTRALIA'S MENTAL HEALTH SYSTEM

COMMON THEMES

DISCRIMINATION

Based on our interviews conducted with young people, it emerged discrimination was widely experienced both from within the mental health services and from the general public. Young people claimed clinicians were being dismissive of their concerns, talking only to their carer about treatment plans and treating them differently to older adults in the hospital settings.

PRIVACY AND CONSENT

Our mapping exercises exposed differing perceptions between young people and service providers about the limitations that should be exercised when sharing personal information in order to integrate service delivery effectively. Consent processes differed between agencies, with some allowing the client to set the parameters and others that wouldn't disclose the details they would share, with whom, and for how long.

CRISIS MANAGEMENT

Around half of the young people we spoke to had accessed, or attempted to access support through hospital emergency departments and acute inpatient units, which was universally described as "traumatic". People with physical illness were prioritised and those presenting with self-harm or suicidal thoughts were subject to stigmatising language, turned away or left waiting for unacceptably long periods. Online and telephone support services provide the potential for around the clock care for young people, especially those facing additional barriers accessing support.

FIRST POINT OF CONTACT

The first point of reference a young person has with mental health care plays a significant role in their journey, and is often influenced by their capacity to pay for services. While some services provide well supported referral pathways to more appropriate support, others were at the start of of an extremely complex journey with several poorly integrated services. All but one of the 24 young people involved in our study was referred into the mental health system by their GP, a school psychologist or a worker from the Department of Communities.

SUPPORT NETWORKS

Many young people consistently described how their clinician or service's knowledge of support outside their own service was essential to their recovery. These were mainly non-mental health specific, including social groups, support groups and help with employment and housing-related issues. This highlights the critical need for mental health and related services to work more collaboratively offering a diversity of supports for people's recovery.

DIAGNOSIS

A common experience among young people was to be given a diagnosis which went on to impact (and often dictate) the type of services they could access and for how long; the type of treatment and medication they received and the consequences of misdiagnosis. A person's diagnosis changing over the course of their journey due to illness progression and variations between clinicians, dictated their support plan and further complicated the already disjointed pathways.

WAAMH
Western Australian Association for Mental Health

Research derived from WAAMH's Report on the Youth Services Integration Project, November 2018

3. FINDINGS: JOURNEY MAPPING WITH YOUNG PEOPLE

This section presents the findings of journey mapping interviews and journey maps of twenty-five young people who participated in the project.

3.1. Demographic details of young people

The demographic detail of those who participated in journey mapping interviews is shown in the Table below.

Total interviews = 25		(n=24)	100%
Age break down	15-17	1	4.17%
	18-20	7	29.17%
	21-25	16	66.67%
Gender	Male	6	25.00%
	Female	18	75.00%
	other/unspecified	0	0%
Other	No	23	96%
Aboriginal	Yes	1	4%
LGBTIQ+	Yes	12	50.00%
no identification	No	12	50.00%
CALD	Yes	1	4.17%
no identification	No	23	95.83%
Rural	Yes	8	33.33%
Metro	No	16	66.67%
Employment	full time	4	16.67%
	part time	7	29.17%
	casual	2	8.33%
	none	11	45.83%
Education	Year 10	3	12.50%
	Year 12	4	16.67%
	TAFE	9	37.50%
	Bachelors	6	25.00%
	Masters	2	8.33%
Accommodation	with parent/s	7	29.19%
	supported accommodation	8	33.33%
	au pair	1	4.16%
	renting	7	29.19%
	home owner	1	4.16%

Data and demographics from #005 not recorded

More detail about how young people were identified and recruited and the detail of the journey mapping interviews can be found in Appendix 2.

3.2. Key Themes

The findings of the journey mapping centred around several key themes.

3.2.1. Discrimination

Young people are overwhelmingly discriminated against when accessing mental health care and related services. In referencing discrimination, we note the unjust treatment and consideration that young people experience based on their age alone. Of the interviews conducted, this underlying theme has featured prominently in every young person's journey. The discrimination against young people when accessing services is tightly linked, and features in each of the other themes that emerged from the information that young people shared with us.

It is widely acknowledged that those experiencing mental ill-health face discrimination both from the general public, and often from mental health services themselves. In this context, we talk about discrimination above and beyond that which is 'normally' experienced by those with mental ill-health; an additional complex factor added on what we hypothesis to be based on a young person's age, perceived capabilities, and capacity in which they are accessing a service.

Examples provided to us by young people about the ways in which they have been discriminated against included: clinicians and/or agencies talking to the young person's parents or caregiver rather than the young person about their treatment plan, despite the caregiver being more 'unwell' than the young person; clinicians and agencies being dismissive of genuine concerns around privacy and confidentiality and not addressing these when raised by the young person: the young person being noticeably treated differently to older adults in hospital settings and having choices around treatment withheld: diagnoses not made solely based on age: therapy given to the family over the young person as an individual because the 'young person is the problem for the family' and not needing individual therapy.

3.2.2. **Information and data sharing**

Based on the mapping exercises conducted with young people, one of the major themes that emerged was the way in which agencies that young people access shared information, both with other agencies, and potentially with family. Issues around information and data sharing, especially when working in a service that caters for both minors and adults, is hugely complex. Though there are complex issues surrounding the sharing (or not) of a young person's information and data, the interviews conducted with young people put these into two sub-themes: the difference in the agencies versus the young person's perception about what should be shared, and the consent processes used when the agency was sharing information.

i. *Agency versus young people's perceptions*

Throughout the project, the project team spoke with service providers in addition to the mapping exercises conducted with young people. From the data sources utilised, it is apparent that young people and service providers have different perceptions about information and data sharing, the limitations that should be exercised by agencies, and when information sharing is necessary.

In talking to service providers, the ability to freely share a young person's information and data is seen as being paramount to providing integrated service delivery, often without the young person's knowledge or consent. For some service providers, the ability to share information and data in order to provide an integrated service is seen as being more important than the young person's choice about what was shared and with whom. Conversely, young people expressed concerns about how easily agencies share information and data about them and believed that while information sharing was important for service integration, it should be at the discretion of the young person as to what is shared and with whom.

> *"I told [clinician] that I didn't want them to tell anyone that I was coming to [service] because it could make things worse for me at home, but they didn't get it. They told me I was just being dramatic, and it probably wasn't as bad as I thought. I had to move to Perth from the country because my mum found out I was going to [service]…"*

ii. *Consent processes*

Young people acknowledged that agencies sharing information about them was often necessary, and in many instances made their transition between services easier and prevented them from having to re-tell their story – a process traumatising for many young people. However, young people shared with us that the consent processes used by agencies varied, often dependent on whether the service primarily worked with adult or young clients. Further, these consent processes were, to young people, not adequate, and young people either did not consent to information being shared or were not made aware of the extent of information that would be shared when they gave their consent. One young person we spoke to shared their experience of consent processes not being followed, and the consequences it had for them:

> *"I was maybe 16 or 17 and starting to transition. My parents weren't supportive, and things weren't great at home. They called [service] who told them I was a client there even though I didn't say they could do that, and my parents kicked me out of home because of it. They didn't want me to get help for being trans."*

Another young person shared that they experienced different consent processes across different agencies, and how the varied processes either empowered them to make informed decisions about the information that they consented to share or disempowered them by taking the choice away from them.

> *"At one of the services I accessed they gave me a written consent to consult form to sign. I could choose how long I wanted to give them the consent for and the parameters of the consent. At others, they asked for verbal consent, didn't tell me how long that consent would last and what they would share – or ask me to set the boundaries! One service didn't even ask to contact another service. They just did it… thankfully the other one wouldn't talk to them because they didn't have consent…"*

The age of consent raises complex ethical issues for services seeing young people, especially those who are acutely unwell, and those with concerns about family becoming aware of their service usage. While services have a duty of care, they also have an ethical responsibility to maintain confidentiality where reasonable. For many of the young people spoken with over the course of the project, the 'where reasonable' for the agency and the young person, and often care givers or parents, is very much in conflict.

3.2.3. **Crisis Management**

Among the young people we spoke to throughout the project, around half accessed, or attempted to access, support through hospital emergency departments and acute inpatient units. The experience young people shared of these services as a collective was incredibly traumatic, with the individual often reporting feeling worse after attempting to access support.

> *"My parents stopped taking me to the emergency department. There was no point in going, they're not very helpful, kind of just made me worse… my parents would lock me in their bedroom instead to keep me safe when I felt like hurting myself."*

Young people shared how they approached emergency departments and inpatient units in times of crisis in an attempt to keep themselves safe, only to be turned away due to not being 'unwell' enough or having to endure waiting periods over 10 hours long. In some situations, the less than ideal treatment that young people reported had near fatal consequences.

> *"I went to the emergency department because I seriously felt like I was going to hurt myself and I needed some help keeping myself safe. After asking me a bunch*

> *of questions to make sure I hadn't done anything to hurt myself already, they told me they had a room full of people more important than me and to go home. I walked down the street to the train station and tried to jump in-front of a train."*

For other young people who presented to acute services, they noticed the differential treatment received by those presenting with a physical health concern. In an attempt to access the help they felt they needed to keep themselves safe, they shared the actions they would take to be admitted to hospital – or in their eyes – a place that would keep them safe.

> *"Every time I went to the hospital, they would tell me I wasn't unwell enough… but they would ask me if I had taken anything. I saw that people who tried to kill themselves by taking pills got the nurses and doctors attention so that's what I started doing. I just wanted someone to help keep me safe, but I needed to be in that much danger to get the help… so I had to put myself in danger."*

From the collective experience of young people at emergency departments and other acute facilities, the project has started to develop a loose understanding of the way young people are treated when accessing crisis care. Among the most commonly occurring themes have been long waiting times when admitted/not turned away, the poor or stigmatising language used by staff, and the general treatment that causes young people and their families to manage crisis situations at home rather than with medical assistance.

i. *The role of online and telephone services*

It is widely assumed by service providers and those in the mental health sector that young people heavily utilise online and telephone support services. In talking to young people, we found that of those young people who knew of online and telephone supports, few either felt comfortable using them, or knew of the circumstances in which they could be accessed (i.e. on an ongoing basis or in a crisis etc).

For the young people whom did access online or telephone-based supports (n=13), most accessed these in crisis situations only. Of the 13 whom accessed online/telephone-based supports, only one utilised these in an ongoing way.

> *"I contact [online service] sometimes when I feel like I need some more help and it's at night and I don't really want to talk to anyone in person or on the phone. They're pretty good and most of the time I don't have to wait that long to talk to someone. I think they have a file on me now too. At the end of each chat they encourage me to print what we've talked about and take it to my GP so she knows what we've talked about which I do so I don't need to repeat myself with her."*

When asked about why they only used online or telephone-based services in a crisis situation, young people consistently reported how they weren't aware they could access these supports outside of these times, with some of the services they had accessed offering ongoing counselling services. For the young people who did not access online or telephone support service that did know these supports were available to them, they expressed unease about sharing private information with someone they didn't know and couldn't see. For others, the anonymity of online and telephone support services is what made them appealing, particularly in crisis situations.

Worth noting is the discourse around the utility of online and telephone support services in rural and remote areas, both within the metal health sector and politically. Largely, these services are seen to offer a solution to the barriers young people face in accessing support outside of the metropolitan area. However, the concerns raised about online and telephone support services, particularly around lack of awareness of existing services, discomfort of sharing information with someone unknown, and young people not having access to phone credit or internet access came predominantly from those in rural or remote areas.

While some young people find the support that online and telephone services provide to be helpful, especially during crisis situations, in many circumstances these services left the young person feeling more vulnerable and unsupported.

> *“I called [mental health emergency service] because I was feeling unsafe and needed help and that was supposed to be what they were there for. They told me they couldn’t help me and to call the police… so I did. The police came and put me in the back of a paddy wagon even though I had only called them because I was feeling unsafe. They took me to the hospital and handcuffed me to a rail. The nurses left me in a room for a few hours and told me I wasn’t unwell enough to be admitted, so they sent me away.”*

Online and telephone support services provide the potential for around the clock care for young people, especially those facing additional barriers accessing support, While they are used predominantly in crisis situations by the young people we spoke to, a concerted effort to both raise awareness about how these services can be used and improve accessibility for those who face barriers in accessing them are needed. While these have the potential to be helpful for young people, care should be taken not to assume they will be appropriate or immediately accessible for all young people and should be integrated with other services, rather than used as a stand-alone support.

3.2.4. **First Point of Contact**

As demonstrated in the mapping exercises we conducted with young people, the first point of contact a young person has with the mental health care system and related services plays a significant role in their journey. With a variety of ‘first point of contacts’ being accessed by young people, movement within the system and level of service integration is highly variable.

i. *The role first point of contact plays*

A young person’s point of first contact with the system most often determined what sort of support they would access/be referred on to, and how well these services would be integrated. Often, a young person’s first point of contact - or the first service they access - is determined by their capacity to pay for services. While some services as a first point of contact provide well supported referral pathways to more appropriate support, others were at the start of an extremely complex journey with several poorly integrated services. As a general finding, private services as a first point of contact provide a pathway to a more integrated journey (providing the young person can continue financially supporting access), and public services, in particular acute services, tend to be less conducive to an integrated journey.

ii. *Experience with Department of Communities DoC (formerly Department of Child Protection DCP)*

For some young people, contact with Department of Communities (formerly Department of Child Protection or DCP) is a significant feature of their journey through the mental health care system, and determines the support they can access. From the young people interviewed who had contact with DCP, they reported commonly having around one case worker per year due to high staff turnover. In turn, this led to little case coordination for almost all the young people interviewed who had contact with DCP and who had some of the longest journeys mapped.

All young people interviewed who had contact with DCP, described their experience as fragmented, and often extremely traumatic.

> *"I got abused in three of the homes that they put me in and it messed me up. Some people have really helped me since, but there's nothing, nothing that will ever make up for what happened to me because of them."*

iii. *GPs, School Psychs, and DCP as a first point of contact*

For all but one young person, the first point of contact into the mental health care system was with either via general practitioner, a school psychologist/counsellor, or with a worker from the Department of Communities. A young person's subsequent journey through the system often depended on which of these supports were accessed as a first point of contact due to where each would typically refer on to, if that was standard practice. For young people who had a first point of contact with a GP, they were most often referred to a private psychologist, where their capacity to pay for gap fees outside of what was covered under Better Access, subsequent sessions after the annual 10 covered under Better Access ran out and follow up sessions with the GP often became a concern.

For the young people first accessing a school psychologist/counsellor, they were most often referred to either a GP that they did not have/were not seeing on a regular basis, and/or a public or NGO mental health service, often with extensive wait lists and exclusion criteria. When the Department of Communities acted as a first point of contact for young people, their experience with accessing appropriate and timely support was vastly hindered due to the unstable and often volatile relationship the young person had with their worker.

3.2.5. **Networks**

Young people consistently describe how their clinician or service's knowledge of help outside of their own service was essential to their recovery. In particular, young people felt their access to supports that were non-mental health related (such as support groups and other social supports), and support with employment-related issues were essential to their recovery and helping them feel supported.

i. *Access to non- mental health services*

For many young people that we spoke to during the project, much of their recovery came from the additional support they received from services that were not mental health specific. In particular, social support from communities supporting LGBTIQA+ young people and housing and accommodation supports were shared by some young people to be particularly helpful.

> *"I think [group] and [group] actually helped me more than any clinician did because they were people who actually understood what I was going through. My GP didn't know that she could prescribe me hormone blockers, but someone I met at [group] told me about the whole process and which doctors were good to see and which weren't."*

The diversity of supports that young people accessed during their journey highlight the need for mental health and related services to work collaboratively, rather than in competition to best support the needs of the young people they serve. For all young people we spoke to, at least one support accessed was not mental health specific, and generally this service was described as more willing to work with the young person when they were accessing other services – an approach often not seen in mental health specific services.

ii. *Knowledge of services*

With access to non-mental health supports being crucial for many young people and their journey, they shared that clinician's knowledge of services outside of those in mental health, and facilitating access to those, was essential. With a significant proportion of the young people interviewed sharing that confounding factors such as accommodation, drugs and alcohol, the school environment, social, family, and medical support all played a vital role in their journeys (n=23), the need for clinicians to be knowledgeable about the services available to young people outside of mental health support is apparent.

iii. *Employment*

For the young people who were employed, some described the impact that their working conditions had on their mental health. For some, work was a safe place to disclose mental ill-health, and aided in the young person's journey. For others, the experience of holding a job was beneficial for their wellbeing and recovery, but the way they were treated by their employer was not.

> *"My parents were away for the weekend, so it was just me and my brother home. I was supposed to be working that day… but he wasn't doing so well… he was suicidal. I needed to take him to the hospital or at least stay home with him because he had tried to jump off the balcony at least once before. Both me and my parents called my work to explain what was happening and that I wouldn't be able to come in – they told me that if I couldn't get my shift covered, I shouldn't bother coming back…"*

For other young people, a lack of access to employment restricted the services they had access to due to their capacity to pay for these services.

3.2.6. **Capacity to Pay**

Evident in the journey of every young person interviewed was the impact that a young person and their family's capacity to pay for services had on the support they were able to access, and the complexity of their journey. Though many factors impact on the complexity of a young person's pathway and no single factor can be isolated as complicating or simplifying the pathway through the mental health care system and related services, the capacity to pay for certain services, or the inability to pay for them, produces a notable impact on the way services integrated.

i. Access to public versus private services – waitlists and exclusionary criteria

With a few exceptions, clinicians working privately generally seem able to provide more integrated services to the young people under their care. This included providing timely referrals when needed to services with shorter waiting lists that they had knowledge the young person would be able to access, accepting external referrals within shorter time periods than their public counterparts, providing care for extended periods of time, providing appointments at regular intervals, following up with external referrals, and seeking client information pertaining to the young person's presenting concerns. For the young people able to access private clinicians providing these services, the financial burden was significant, but the journey, on a whole, was better integrated.

Conversely, for young people accessing public services, follow up after referral, waiting times for appointments, regularity of appointments when not a regular client and the seeking of relevant information pertaining to the young person's presenting concerns were not a service provided as thoroughly as with private services. Few public and NGOs were the exception to this.

Of note, however, are both the overall quality of care and the length of time spent in the mental health care system regardless of whether the young person accesses public or private services. Though most young people accessed at least one private service in the form of a GP or private psychologist at one point in their journey, and those who accessed predominantly public services took tremendous leadership in their care, the level of clinical care provided by public and private services is arguably on par. When comparing young people accessing public and private services by age, diagnosis, gender, or a combination, there is little difference in the time between when they entered the system, and when they exited. Furthermore, little difference existed between private and public services with providing early intervention services when measured against illness progression, with public services seeming to perform slightly better – perhaps due to many holding a specific prevention and early intervention focus.

Though capacity to pay for mental health care and related services impacted on how well integrated a young person's journey was and the extent to which they were required to self-advocate, across the 25 interviews conducted it did not seem to significantly impact on outcome. Specialist public and NGO youth mental health services, in the case of the 25 interviews conducted show promise as an investment, though these are not without challenges.

3.2.7. **Public Mental Health and Other Services (NGOs)**

Public mental health services, in particular youth mental health services in Western Australia, are often highly complex for young people to navigate. Through talking to young people about their journeys through the mental health care system, both positive and less helpful experiences were shared when young people accessed public mental health or other services.

i. *Psychiatric inpatient units*

Though experiences of accessing psychiatric inpatient units differed across a number of factors, including the service the young person presented to, the concerns the young person was presenting with and the age of the young person, the lack of personal agency over the young person's care remained a constant occurrence. Young people consistently describe the distressing and controlling nature of inpatient units*: "… it was like a prison – felt like a holding cell and there was little access to doctors",* "*they wouldn't let me leave even though a voluntary patient. My girlfriend was outside waiting for me and they lied about her being there – I had only arrived 2 hours earlier", "Nurses told me if I didn't 'get over myself' and calm down they would send me to Graylands…".*

For other young people, they recognised that even though the experience was not a positive one, it was needed in some regards: "they kept me safe when I needed it but also kind of made me worse…".

With psychiatric inpatient units not always providing care specifically for young people, those who had accessed the services they provide commented on how this lack of age specific care impacted on their treatment.

> *"It was hard because you tend to be the youngest person there so it's hard to build peer support and you just see people who are really sick with the same thing you have… it makes you a little hopeless for the future and if you can get better seeing them."*
>
> *"I was wasn't involved in decisions about my care, but I think that was the right thing to do in that situation because I wasn't well enough… in other situations it wouldn't have been ok."*

Young people reported that on discharge from psychiatric inpatient units, they were aided to "find other people I could go and see after I left" with some of them being "outpatient programs I could go to, but they weren't very helpful" suggesting attempts at supporting young people post discharge were made with varying reported success.

ii. *Youth Mental Health Services – Tier two and three*

Non-government youth mental health services providing support for young people experiencing mild to moderate mental ill-health were commonly accessed by the young people interviewed during the project. While the models these services work under are strong in theory and many of the issues raised by young people are due to factors outside of the services' control, such as funding restraints, the experiences young people shared accessing these services were concerning.

A common concern expressed by young people was that for particular services, public reputation is that any young person presenting to the service will be able to access support, and this was not in line with what the service was providing. Young people expressed the difficulty they experienced seeking help from services widely marketed as being a 'one stop shop' for young people with mental health concerns, only in many cases to be turned away with little to no support. For young people who were 'accepted' into these services, they experienced waitlists of varying lengths between triage sessions and an initial appointment with a regular clinician.

Further, many of the young people who had attempted to access these services were subject to varying entry and exclusionary criteria across different centres, despite seeking support within the same organisation. Young people interviewed frequently expressed understanding about the need for them to be on a waitlist. However, the lack of transparency about the actual purpose and limitations of a service, waiting times and exclusionary criteria negatively impacted both the young person's wellbeing, and ultimately their confidence in the service they had intended to seek support from.

When accessing other public youth mental health services, young people shared of how quick fix solutions such as medication with little follow up care were offered, and those who were more 'unwell' prioritised. For one young person, they told of how clinicians would frequently end appointments mid-session because another young person was in crisis.

> *"I would be sitting in my session at [service] and after 20 minutes the clinician would just end the session because they got a call that someone else was more unwell or at risk than I was. Thinking about it now it was kind of a dangerous message to be sending for a few reasons, because it made me think I needed to be more 'unwell' to get help which I made myself, and that other young people were more important than me."*

For many young people who had experience accessing this service, they felt as if the burden of communication was placed on them and their families, with them being responsible for initiating contact and following up with the service for up to six months to check on the status of their referral because the service would not contact them when it had been accepted or declined.

iii. *Youth Mental Health Services – Tier four*

Young people who had accessed public youth mental health services that work with young people experiencing the most acute mental ill-health, reported positive experiences as whole. While waitlists for these services were often longer, the support provided to young people while on them was reported to be comprehensive. Though these services had highly selective entry criteria, the support they provided the young people interviewed, with only 50% being referred from one of the services, was shared to be the most positive and influential in the young person's journey. Typically, these services were highly integrated with others' a young person was accessing and did not impose a limit on the number of sessions a young person was able to utilise. For all young people interviewed that had accessed one of these services, they were highlighted as an example of a service that could be used as a 'gold standard' to replicate in regard to the comprehensive, integrated and supportive care provided.

3.2.8. Diagnosis

A common experience among young people was to be given a diagnosis, or multiple diagnoses, by a clinician. Also common was for this diagnosis to have a major impact on the young person's journey through not only the mental health care system, but other support services that they attempted to access. Impacting on the types of services that a young person could access and for how long, the type of treatment that a young person received, and the way a young person is medicated, the diagnosis that a young person is assigned both at the start and during their journey plays a significant role in the support they receive.

Young people reported that often the diagnosis they were given was incorrect, and the wrongly assigned diagnosis would stay with them throughout their journey.

> *"I saw the psychiatrist once and he diagnosed me with bipolar because my mum had it. I didn't really know what bipolar was, but he gave me a lot of medication for it without telling me what it did or what it was for. I found out later that I didn't have any of the symptoms of bipolar, but that diagnosis followed me to every service and every clinician that I saw. I had to convince them that I didn't have bipolar because one psychiatrist that I saw once for 20 minutes decided it was something I had because my mum did, even though I have none of the symptoms. It's the first thing people try and treat me for now and it's* wrong.*"*

> *"I went to see a neurologist because I was having multiple migraines a week. They wouldn't investigate further and told me there was nothing wrong with me, that it was just my mental health, I was 'being bipolar', and that I was 'too young' for anything to be wrong. After getting worse, I went to another neurologist who did investigate further. It turns out I was having seizures with my migraines and I have epilepsy, not 'stress or anxiety'. That incorrect diagnosis and the misunderstanding around mental health meant my epilepsy – which is really damaging – went undiagnosed for years."*

i. *Variable diagnoses*

The variable nature of the diagnoses that young people are given by clinicians impacted on the timeliness in which they received care, and the care that was given. For some young people, they lived with clinical threshold symptoms that went undiagnosed because one or more services that they presented to hesitated in making a diagnosis. Hesitancy in assigning a diagnosis, for some young people, lengthened the time in which they waited before receiving support and worsened their symptoms.

> "*I thought I had Borderline Personality Disorder and requested that [Child and Adolescent Mental Health Services] assessed me for it. They refused to and said that someone my age couldn't have it. I went to see a really good clinician later who diagnosed me with BPD and actually started treating me and that's when I started getting better. If [CAMHS] had diagnosed me and treated me for BPD I would have started recovering long before I did, but instead they refused because 'young people don't have BPD'. Their refusal to diagnose me literally stopped me from getting the help I needed when I needed it".*

Equally concerning were the journeys where young people reported their diagnosis changing between clinicians, despite presenting symptoms remaining constant. One young person told of an experience where *"[After a suicide attempt] I was misdiagnosed as having BPD…. A different counsellor told me it wasn't depression, just a bit of anxiety."*

While it is acceptable for symptoms and therefore a diagnosis to develop and change over time because of typical disease progression, the experience that young people had was what would be considered atypical. Their symptoms and presenting issues remained constant, and the diagnosis they would reasonably expect to receive should not have varied as much as it did. For the young people interviewed, more than 75% (n= 19) of those that shared a diagnosis had their initial diagnosis changed at some point during their journey. Of these young people, almost all agreed that the most recent diagnosis they had received was the most accurate.

ii. *Diagnosis dictating access to services*

For many people we spoke to, the diagnosis they received often changed the services that the young person had access to. In some cases, a particular diagnosis meant they can access a tier two service, but a different diagnosis means they can access a tier four service, with different tiered services will provide different continuity of care.

> *"I went to a [service] but they told me I was too complex for them. They said, 'we'll do a safety plan but you can't come to this service'. They didn't follow up or anything. It's like I was too much work for them."*

> *"…when I got diagnosed, I couldn't go to that service anymore. I had to go to a different one. I ended up going on a new waiting list for weeks. But the new service was better and I'm still a client there."*

When combined with a young person's diagnosis often changing over the course of their journey due to both illness progression and variations in the way that clinicians will assign a diagnosis, a young person's diagnosis or acuity of ill-health dictating access to support further complicated already disjointed pathways.

4. LITERATURE REVIEW

An initial stage of the project was a scan and review of local, national and international documents, research literature and grey literature[5] on service integration in youth mental health. The full literature review, with references, will be published as a separate stand-alone document. Key findings are summarised here (without references).

4.1. The policy context for service integration

While the intention of policy activity is to improve service integration, mental health researchers and advocates question whether top-down policy initiatives will achieve service integration. The experience of many young people and the views of many writers, researchers and advocates on mental health point to a significant “policy rhetoric-reality gap” whereby gaps exist between the policy rhetoric about service integration and the reality of the experience of young people, parents and service providers.

One concern is that service integration, despite the best of intentions, can become self-serving (e.g. to address a policy imperative, as a top-down requirement imposed by management or funders, to manage costs or as a requirement for funding, or as an organisational solution), rather than being a mechanism to improve young people’s care and outcomes.

4.2. What is service integration

While service integration is highly desirable, there is no universal or commonly accepted definition in the literature and considerable ambiguity exists about the concept. A precise meaning remains elusive and contested. The literature on service integration is plagued with inconsistent use of terms and different professional and disciplinary perspectives. Service integration means different things to different people.

As a result, there is a lack of conceptual clarity about service integration and there is no unifying or universally accepted definition. The danger is that the term becomes so widely used, yet so little understood that it becomes a cliché which has no clear meaning.

Despite this lack of clarity, a guiding principle is that service integration should be centred around the needs of service users. The perspective and needs of the young person should be at the centre of service integration. To be effective, service integration must be people-centred and not driven by structural, organisational or financial (cost efficiency) benefits.

4.3. Types and forms of service integration.

Service integration can take multiple forms. There are different types or forms of service integration and no single “best practice” model of service integration exists for all situations and contexts.

Service integration is unlikely to follow a single path and variations are dependent on the local context in which they are delivered and the intended purpose of service integration. Service integration is complex and time consuming and relies on a variety of strategies occurring at multiple levels. There have been few attempts that seek to understand and describe the full complexity at multiple levels (systemic, policy, organisational, inter-agency and sector, professional, worker).

---

[5] Grey literature is materials and research produced by organizations outside of the traditional commercial or academic publishing and distribution channels. It includes materials prepared by individuals, citizens, service providers, NGOs, government agencies and civil society groups.

4.4. Key Components and criteria for service integration

There is a body of work that points to key components or criteria needed for successful adoption and achievement of service integration. For example, one review identified 16 key criteria for success:

- Find common cause
- Develop shared narrative
- Create persuasive vision
- Establish shared leadership
- Understand new ways of working
- Targeting
- Bottom-up and top-down
- Pool resources
- Innovate in finance and contracting
- Recognise “no-one-model”
- Empower users
- Shared information and ICT
- Workforce and skill-mix changes
- Specific measurable objectives
- Be realistic, especially costs
- Coherent change management strategy

There are few frameworks that identify and specify how all the components combine to support service integration in youth mental health.

4.5. Integration in youth mental health services

Reforms to youth mental health services in Australia highlight the need for integrated approaches to the delivery of mental health and other services for young people across the spectrum. It is widely accepted that service integration should be a fundamental design principle and multi-dimensional process for high quality youth mental health services, since without it, care experiences and outcomes for young people will not be as good as they should be.

4.6. The views of young people and their family members and carers

Young people have strong and consistent views about mental health services and how they should be designed and provided.

Access to services is a critical issue and involves how young people their families and carers gain entry to the appropriate services through the service system. This can involve physical access, affordability and acceptability.

Barriers to access identified by young people are:

- Stigma and low mental health knowledge
- Belief that their circumstances are not severe enough to access services and they should be able to deal with issues themselves
- Poor communication and lack of collaboration between service providers
- Lack of age appropriate services (after hours services, lack of assertive outreach, long waiting lists, being shunted form service to service)
- Lack of support infrastructure for young people and their families/carers to attend services (e.g. lack of transport, lack of money to pay for transport, too many other serious issues to deal with such as housing, money, courts)
- Physical determinants (location and appearance of service, restrictive opening and working hours).

In terms of barriers to access, the 2014 Mental Health Survey of Children and Adolescents found the three most common barriers to seeking or receiving help identified by parents of a young person with a mental health disorder were:

- "couldn't afford it" (33%)
- "couldn't get an appointment" (29%)
- "problem getting to a service that could help" (25%)

Strategies to enhance young people's access can include:

- Reduce frustrations and time delays
- Achieve a seamless referral process
- More timely assessment and referral
- Reduce waiting lists
- Simplified access and entry and assessment procedures
- Enhanced service continuity
- Improving availability and after-hours response
- Provide clear pathways in, through and out of services
- Minimise service gaps and duplications
- Improve collaboration and connections between various agencies.

Wait lists and wait times between the requesting and receiving of services are major concerns. Some Canadian research estimates that 40% of children and youth seeking mental health services wait a year or longer before receiving services.

Young people use many different pathways to mental health services, so services must align with multiple pathways and ensure they are accessible regardless of the pathway used. Lack of continuity of care and fragmented care are perceived as disruptive and unhelpful by young people. This can include repetitive questioning, multiple assessments, waiting times and waiting lists.

Problematic transitions between services are a concern, particularly between child and adolescent and adult services, from acute care to inpatient or residential services to community-based supports, between mental health and primary health services and between mental health and other sectors. Transitions are often poorly planned, poorly explained and poorly executed and accentuate pre-existing barriers young people face. In particular, transitions between CAMHS and adult mental health services are often poorly managed with negative outcomes for young people.

Young people emphasize the importance of a single pathway of care across age, service and organisational boundaries.

4.7. Models of service integration in youth mental health

4.7.1. Australian models

Headspace offers a model of service integration for young people with mild to moderate mental health conditions that has wide support among Federal and State Governments, mental health clinicians and the mental health sector. Headspace centres exist to deliver services to 12- 25-year-olds with mild to moderate mental health conditions in over 100 locations across Australia.

Headspace is a model of service integration where young people access support and services related to mental health, drugs and alcohol, sexual health, physical health, employment and vocational participation and social participation through a single hub (under one roof). The model has several features including:

- A lead agency working with local organisations to draw together different services and areas of expertise in a co-located community-based hub
- Clinical service delivery
- A place-based focus on identified locales and geographical areas
- Local referral network
- Multi-disciplinary staff
- Non-threatening and youth- friendly environment
- Youth and family engagement and participation
- Bulk-billing
- Integration of existing social services including health, education, housing, employment and vocational, drug and alcohol, and justice

Headspace centres are expected to improve service integration through a range of strategies, such as centralised intake and management, a central community-based access point, visiting arrangements of partner agencies and common client management systems. A recent evaluation found that Headspace centres offer a highly accessible service for young people and have improved access and increased engagement of young people with mental health services. The increased engagement is associated with improved outcomes in relation to psychological distress and suicide ideation. The Headspace model is a template for the development of youth mental health service integration initiatives in other countries including UK, Canada (ACCESS Open Minds), Ireland (Jigsaw).

Other models of service integration in youth mental health (and mental health more broadly) across Australia include:

- Co-location, hub or one-stop shop models that offer a single community access point for a suite of programs and services for young people. Services may be provided by multiple agencies or by a single agency providing different and multiple services and may be housed under one roof. In theory co-location and hub models are designed to improve service integration but they don’t guarantee it.
- Stepped Care models (being developed through the Primary Health Networks) which seek to match the intensity of treatment to the severity of the condition. Clients can be stepped up or down into the most appropriate intervention without requiring a new referral or having to navigate a fragmented system by themselves.
- Case management and care coordination models and care navigator model, in which a care navigator is employed to guide young people through the service system
- Lead agency models where a single provider coordinates and supports several different agencies and services to provide a seamless service for young people. These agencies may be co-located, or they may coordinate services across multiple sites but as part of an integrated system of services and care.
- Foyer model, which provides housing to young people which is integrated with education, training, health and other supports.
- Wrap around services, in which a person’s needs are assessed and a comprehensive coordinated suite of services to meet those needs is ‘wrapped around’ the person.
- Individualised funding models enable people to select and coordinate their own services and, in theory are intended to improve service coordination and integration.

4.7.2. International models

The Canadian model of Integrated Youth Services (IYS) aims to transform youth mental health services across Canada. IYS features coordinated inter-disciplinary teams, a stepped care model, youth centred focus and cross sector collaboration that engages health, addiction services, education, justice, social services and philanthropy. IYS includes the ACCESS Open Minds Pan-Canadian network of integrated service sites, as well as provincial projects in British Columbia, Alberta, Ontario, Quebec and New Brunswick, and includes an international knowledge exchange in youth mental health. IYS was established in 2014 and draws on the experience of Headspace (Australia) and Jigsaw (Ireland).

Jigsaw (The National Centre for Youth Mental Health- formerly Headstrong) is a network of 11 early intervention youth mental health services located throughout Ireland designed to transform the Irish response to young people's mental health. The Jigsaw model provides free tangible support and services for young people before they reach the point of acquiring a formal mental health diagnosis.

4.8. The promise of service integration and does it achieve that promise?

The underlying assumption appears to be that service integration is a vehicle for improved outcomes for young people with mental health conditions and that service integration can meet a variety of aims, including reduced fragmentation and improved continuity of care, better access to mental health care, provision of personalised care, improving the health and wellbeing of young people and the cost effectiveness of services.

Whilst service integration has the potential to improve outcomes for young people, the evidence to support the hypothesis above is mixed:

- Some forms of service integration are successful in making services more accessible to clients.
- Evidence on cost effectiveness is poor.
- In some areas, the efforts to achieve benefits from service integration have fallen short of expectations. Achieving service integration is difficult, time consuming and costs money. Many service integration initiatives have not been successful in meeting their objectives and failure rate amongst them is high.
- There is a scarcity of evaluative research about service integration and there have been few rigorous evaluations of integrated service responses.
- Some evidence of effectiveness for vulnerable groups and those with multiple and complex needs is emerging.

An Australian review of studies analysing the effects of youth mental health service integration concluded that: *"… the research effort undertaken to date on youth mental health service integration is not reflecting the importance of the topic."* [6]

The review found that integrated service approaches are associated with positive effects on the quality of care, increased access to a broad range on multi-disciplinary services, increased frequency of ambulatory care per-person-year, reduced medical expenses and increased utilisation of parenting strategies to support youth mental health. However, they found no evidence of the reported cost effectiveness of youth service integration.

---

[6] Kinchin, I, Tsey, K, Heyeres, M & Cadet-James, Y (2016) Systemic Review of youth mental health service integration research, *Australian Journal of Primary Health*, June 2016, 16: 22(4), pp 304-15

4.9. Why is achieving service integration such a challenge

Service integration cannot and does not solve the problem of under-resourced service systems.

Service integration efforts encounter many common barriers, including policy, funding, regulatory and structural barriers which are beyond the control and influence of front-line service providers. For example, contracting and funding mechanisms often work against service integration.

Service integration is time consuming and resource intensive and requires large scale efforts by multiple providers and interested parties to collaborate and work more effectively to enact change at many levels

Other barriers include different organisational and professional cultures, procedures and ways of speaking: inability or unwillingness to share confidential information: problems of communication between agencies and workers: lack of clear role definitions: siloed decision making: potential for service integration to increase staff workloads and multiple integration initiatives targeting the same people or groups can create confusion, frustration, duplication and strain on scarce resources.

5. CONSULTATION WITH SERVICE PROVIDERS

Two focus groups and a series of face-to-face interviews were undertaken with selected agency and service provider representatives to gather their views about service integration in youth mental health, and to promote the project. A list of those interviewed can be found in Appendix 4. The following list is a summary of key themes identified during focus groups.

5.1. Service integration is not a youth friendly term

Service providers said that service integration is not a youth- friendly term. It is term used by services and within government for different purposes. They also said that service integration is not a goal that can be achieved completely. Rather, it is a goal that agencies must constantly strive for and keep working to achieve.

Service providers note that Government policy and service provision is slow to react to the nature of young people's mental health needs. Young people need to be collaborated with – they should be ***equal partners*** in their service journey and need to be put at the centre of the service system.

5.2. Barriers to service integration

Service providers identify a considerable number of barriers embedded in the "service system" that must be overcome to achieve service integration. Hence, even when commitment is strong, service integration is difficult to achieve due to:

- Different statutory responsibilities and roles;
- Agency silos and boundaries;
- Service providers speak different professional and service language;
- Lack of information sharing;
- Different professional values, attitudes and training;
- Different agency policy and practice;
- Lack of resources and time;
- Wait lists;
- Some agencies can be risk averse;
- Lack of services e.g. lack of beds for 16-17-year-olds in some areas; and
- The geography of WA.

Service providers said that funding models and regimes make service integration harder to achieve. Reasons cited included: funding cycles; too many agencies are under-resourced; staff come and go due to short term and insecure funding tied to contracts; pressure to maintain caseloads despite funding cutbacks and restrictions; services lose funding just as they are starting to build relationships with young people and other services with the result that all that is lost; services are funded and then defunded, meaning that services come and go and some good services just disappear; competitive tendering system causes problems including some agencies that present low quotes to win contracts and then have trouble delivering a quality services, and agencies have to compete for a limited bucket of money. Forcing agencies to compete for a shrinking pool of funding is not conducive to the collaborative relationships required for service integration, and; funding is siloed. No joint funding of integrated services.

5.3. Concern about a single model of service integration

Service providers caution against reliance on, or adoption of a single model of service integration in all circumstances and contexts. They argued that imposing a single 'one size fits all' integrated service model in all circumstances will not succeed. Different models and processes are needed that evolve over time, considering the specific context and each young person's circumstances. This might include hub models, case coordinator models, navigator models where a provider follows young people through the system or a model where higher tier services come out to lower tier services where young people have first contact.

Service providers said that hub models don't work everywhere. They work well in some places but consideration should be made for places where they do not work, or where it is geographically unrealistic. Service providers emphasise that shared case management and case coordination is essential to good service integration.

5.4. Service integration is not a panacea to lack of services or problems with service accessibility and quality

A strong message from service providers is that service integration is not a panacea to a lack of services, or lesser quality services.

Participants express concern about the separateness and lack of connect between different parts of the system, each with their own policies, protocols, practices and cultures, including GPs, private practitioners, emergency department, inpatient, acute, public mental health and community-based services.

This is a significant issue at the point where young people exit or cut off from services and must access another service. This can manifest itself in, young people discharged to homelessness, hospitals discharging young people with no follow up or plan, young people being discharged to NGO services who don't have information or capacity and a lack of discharge planning.

Service providers stress the importance of better service integration for vulnerable young people who are not being treated or who receive inadequate treatment (e.g. young people with complex needs; young people with co-occurring issues, including AOD and mental health & autism and mental health). This may be due to systemic issues and glitches, including exclusion criteria, wait lists, lack of diagnosis, young people not considered acute enough, failure to share information and inadequate discharge planning. There are too many transitions across different services with different criteria and transitioning young people to higher tier/needs services can be a problem.

Service providers emphasise the importance of better information sharing between government and non-government agencies as a basis for improved service integration.

The challenges and ease of achieving service integration in rural and remote areas were noted by service providers, however as most acute services are in the metropolitan area, this raises challenges for service integration for young people. Often the young person and their family must travel large distances to access specialist or acute mental health services.

5.5. Service integration and online and e-services

Service providers recognise the benefit of online and e- services for young people, however they said they have the effect of making service integration more complex and harder to achieve and there are concerns about the extent to which e- and online services are or can be successfully integrated with face- to- face to services.

6. KEY LEARNING & IMPLICATIONS

In this section key learnings from the project and their implications for service integration are discussed.

6.1. Is journey mapping a useful process for understanding young people's experience of the mental health system?

While journey mapping is not a new process, the process of visually mapping young people's journeys through the mental health system has not been done before in WA. While some information captured during this process may have been known already, the evidence has not previously been presented in a visual way.

The project aimed to capture young people's journeys through the mental health care system and related services in a comprehensive, non-clinical way. The journey mapping process proved a useful tool, acting as a strong way to not only visually represent a young person's pathway, but capture additional experiences that impacted on a young person's journey such as family influence, housing, socioeconomic status and education.

The process of visual journey mapping provides a powerful visual image of the complexity of young people's journey through the mental health system and illustrates vividly the difficulties and challenges experienced by young people with mental health issues, as well as their experience of service integration.

Journey mapping highlighted that young people's journeys are highly complex, and conversely sometimes do not look as complex as they are. As a tool, journey mapping highlighted 'pressure points' both in an individual young person's journey, and within the system broadly. In particular, journey mapping is useful for understanding the difference between well integrated services and those that are not well integrated, and the impact that moving between regional and metropolitan areas has on a young person's journey. For many young people, journey mapping captured that the addition of more services, whether accessed through a hub model or not, made a young person's journey more complex. Lastly, it highlighted the large number of clinicians and services that were often involved in a young person's journey, and which of these were most helpful to the young person. Further resourcing would allow in-depth analysis on visual journey mapping to determine complexity of system pressure points.

Though the visual journey mapping technique presented many benefits and proved to be a strong information collection method, it was not without challenge. Because of the unstructured nature of the interview, the complexity of the young person's journey, and the discussion being led by the aspects young person wished to speak about, often it was difficult to capture all relevant information that impacted on the young person's journey. For some young people, there were parts of their story that they did not wish to share or have recorded, and a small minority were apprehensive about the process used.

Visual journey mapping required a great deal of investigator skill, both in terms of clinical and research skills, to gather the information required without causing distress to the young person. A significant proportion of the information gathered through the mapping exercises was dependent on the investigator's ability to quickly build rapport with the young person, maintain a 'safe space' to talk about sensitive information, identify areas to further probe while letting the young person guide the conversation, and capture all relevant information that the young person felt comfortable sharing.

6.2. What are young people's pathways and experience of the mental health system and what does that tell us about service integration

The findings show that young people have contact with many services, there is significant movement between and across services and service systems, and navigation is complex and difficult.

Young people have a clear view about the things that agencies do well and the things they don't do well but are rarely listened to in a meaningful way.

Young people demonstrate considerable resilience in the face of adversity and a system that often has shown them nothing but barriers, and many have a strong sense of personal agency, including acting to get services to work together. Many young people recognise they need help and keep going back to see someone else, even after they have had a negative experience. The young people we spoke to have journeys ranging from 2-20 years, and despite challenge after challenge they continue to seek support.

Analysis of young people's journeys through the mental health care system and related services demonstrate that journeys are highly variable, and the level of fragmentation of a young person's experience is dependent on many factors. Numerous determinants impacted on young people's journey's, both when first accessing support, and at all points of help seeking during their journey the high number of determinant's in a young person's journey are hypothesised to be one of the leading factors in the severe fragmentation seen in the journey mapping exercises completed.

Cost of services is a barrier to service integration. Young people navigate parts of mental health system based on cost and ability to pay. This is particularly the case with GP's, Better Access clinicians accessed through Medicare funding and specialist clinicians, such as psychiatrists, physicians, medical specialists, and psychologists. The ability to pay drives choice and shapes their pathway through the mental health system.

From analysis of the mapping exercises, it is evident that individual services vary in how well they are integrated internally and with other services. Further, the service integration experienced by young people when accessing services often varies depending on the tier of service they are accessing, with some tier four services – those providing care for those most acutely unwell – consistently being the most integrated youth mental health services. Described by both young people and staff external to these services was an ability for these agencies to take ownership for their clients. Across interviews conducted, young people also consistently reported higher levels of integrated care when accessing private clinicians.

Integrating services does not guarantee positive outcomes. The findings of this project demonstrate that the quality of services being integrated is critical for service integration.

The journey mapping process demonstrates that for many young people, the quality of many parts of the mental health system are not work effectively for them. For young people who participated in the journey mapping process, their experience is that parts of the mental health system and associated systems not only fail to meet their needs, but often compound their struggle with mental health issues and add to the trauma they experience.

6.3. What is service integration in youth mental health, how important is it and how well is the system integrated from the perspective of young people?

Service integration is plagued by the difficulties of developing an agreed definition and a lack of consensus about what constitutes service integration. There is no commonly accepted definition of service integration and the concept is strongly shaped by the experience and perspectives of different stakeholders, making a unified definition difficult.

While speaking to both young people and service providers it is evident that there is no clear and functional definition of service integration. Further, there is no consensus on a single model of service integration, because integrated services that best meet the needs of young people and their families will vary based on location, presenting needs, access to resources, and the cultural background of the people the service will serve.

Over the duration of the project, young people and service providers were asked to define ‘service integration’, and words such as ‘communication’, ‘connection’, ‘partnership’ and ‘respect’ were used to describe the principles that services should follow when working with young people.

Based on the findings of this project, a user- centred definition is needed that emphasises that the benefits of service integration are focused on young people and service integration is a continuum rather than extremes of integrated or not integrated.

A user centred definition would aim to improve the timeliness, quality, appropriateness and continuity of services and support received by young people with mental health issues, so that they get the support and care they need when they need it, with minimal disruption/dislocation. Service integration is a means to improve young people’s experiences and deliver better outcomes for their lives.

The journey mapping process demonstrates that for many young people, the current mental health system and processes are not working effectively for them. For many young people who participated in the journey mapping process, their experience is that parts of the mental health and associated systems not only fail to meet their needs, but often compounds their struggle with mental health issues and adds to the trauma they experience.

The findings of the mapping and the consultations point to features or characteristics of services that are effective at bringing about better service integration to benefit young people. These include:

- Service integration is accepted as part of their mandate
- The service comprises a multi-disciplinary and interdisciplinary team
- The service draws on a strong clinical support infrastructure
- The service supports assists and follows young people as they move between services and across systems and sectors and has a commitment and willingness to do whatever is necessary to assist young people and overcome barriers
- The service is willing to work with others to find solutions to problems that young people experience
- Staff do what they say they are going to do and follow through with young people and other agencies
- Staff demonstrate “can-do” attitudes and capabilities to work around barriers
- Staff are willing to work together across agency and sector boundaries
- The service values expertise other than their own, including non-clinical and lived experience

- Staff are capable and willing to work with young people with complex and challenging needs
- The service and staff are willing to work alongside mainstream and generalist services to strengthen their capacity
- Staff are skilled and experienced at working with young people with challenging and complex needs
- There is strong leadership and management support for all the above.

6.4. Are there key points in the service system where young people are more vulnerable to inadequate service integration?

The mapping exercises show that services are not well integrated at critical times for young people. For many young people who participated in the mapping process, the current youth mental health system is weakest when they have the greatest need.

As described by young people, these times included: when the young person was most unwell and needed support to navigate an already complex system; after being admitted and discharged from an emergency department or an inpatient unit, and being supported to access community based support and being provided with a discharge plan; when entering a new service, regardless of whether the service has capacity to take the young person on as a client on or not, and facilitating referral to a more appropriate service if the current service is not appropriate; and when accessing multiple services and/or clinicians to maximise information and data sharing with informed consent from the young person.

Interviews with young people and service providers, demonstrated a contrast in the priority for service integration. For service providers, service integration is seen to be a significant priority to improve care for young people. To young people, the aforementioned issues highlight the concerning experiences young people face when accessing services that simply integrating services more effectively will not address.

While young people see service integration as being an essential component to effective clinical practice, the findings of this project show that other issues raised by young people need to be addressed as a priority if service integration is to be effective.

Service integration is often presented as a ‘panacea’ that will fix problems that exist in the system currently. While integrated care is important, so too is addressing concerns raised by young people that providers either do not seem aware of or are quick to dismiss.

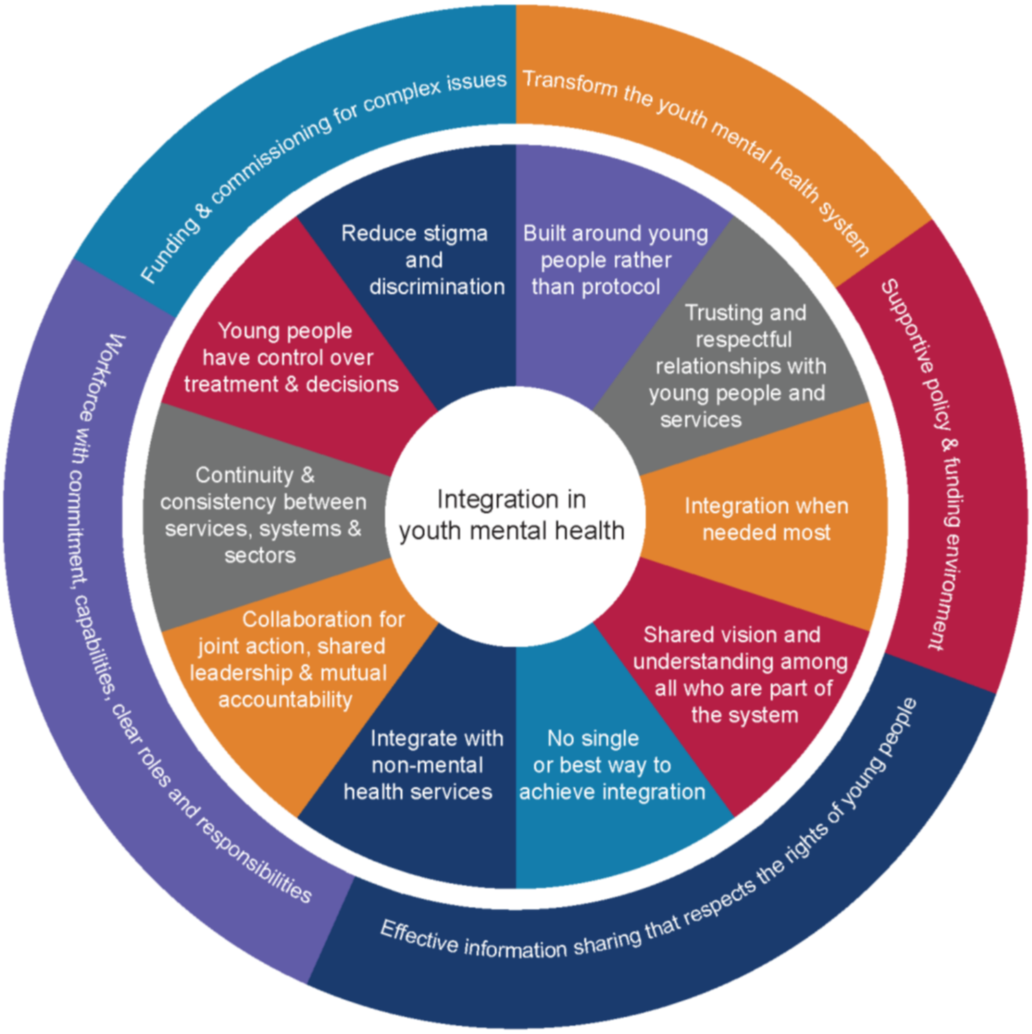
7. FRAMEWORK FOR SERVICE INTEGRATION

A deliverable of the Project is a Framework to provide guidance for service integration. Although there is no single template or model for successful service integration, the findings of this project point to principles that can guide those working to achieve a higher standard of service integration.

The Framework recognises that service integration must be achieved at two levels- client-focused level (looking at the service delivery level) and the systemic or structural level (looking at the policy, funding, institutional and interagency level).

The Framework comprises fifteen principles and suggested actions. The Principles are based on the experiences of young people involved in the journey mapping. Although the Principles are broad, they are 'building blocks' to drive progress toward improved service integration, rather than a set of deliverables. When these principles are present, it is likely service integration will flourish.

The Figure below lays out the Framework of Principles. The outer circle identifies systemic or structural principles and the inner circle includes client-focused or operational principles.



The framework is informed by the Mental Health Commission Charter of Mental Health Care Principles.

7.1. Principles

7.1.1. Supportive policy, funding and organisational environment

Service integration is a systemic and organisational activity and a consequence of a well-designed system. However, the youth mental health system is not designed for integration and often new services are funded and established without thought being given to whether they enable or hinder service integration.

The funding and policy environment should support collaboration and integration, however fragmented policy and different funding priorities between Commonwealth and State Governments and between State Government agencies make the task of achieving better service integration more difficult.

Longstanding structural and systemic barriers to service integration exist, including competitive funding approaches, multiple funding sources, significant central control, agency silos, different diagnostic categories, the changing policy and funding environment, lack of trust between agencies, single agency priorities and different professional values and cultures.

Action

- Ensure cross sector formal commitment to service integration.
- Establish formal cross- agency and cross sector arrangements that enable speedy access to services.
- Provide supportive leadership with a clear and shared vision for service integration.
- Ensure political support and clear policy direction and support for service integration.
- Ensure the alignment of systemic factors such as financing, policy, regulation, adequate funding and time for planning and implementation.
- Establish financing and incentive arrangements that encourage and promote service integration.
- Ensure strong leadership commitment to work with and support multi-disciplinary and different professional values and culture.

7.1.2. Effective communication and sharing of data and information is essential, however, this must respect the rights and concerns of young people

Inadequate communication between service providers and failure to communicate basic information acts as a barrier to service integration. The capacity to communicate, share and co-ordinate information between services and across sectors in a timely manner is critical for service integration and establishing systems for inter-provider communication and sharing of information can make service integration easier to achieve.

Young people have a legal right to confidentiality of their information. Confidentiality is highly valued by young people and is central to building relationships of trust. Assurances of confidentiality improve young people’s willingness to seek help early and disclose sensitive information.

Action

- Young people must be accurately informed with detailed, timely, practical and honest information and services must provide young people with consistent information.
- Correct and reliable information should be provided about how young people can access services, service providers and other supports. Where limitations and are anticipated, this should be communicated clearly.
- The roles of service providers, their capabilities and limitations should be spelled out consistently and clearly.
- Services must provide clear information about the parameters and detail of what can and cannot be done within the service, by individual workers and via available referrals.

This includes providing clear information about service guidelines or expectations, as well as the young person's rights and responsibilities.

- Services should ensure respect for young people's confidentiality in all information sharing and communication.
- Ensure that systems and processes exist for shared data and information and communication and information sharing between services and staff.
- Ensure that information systems and processes foster shared decision making between service providers and young people.
- Service providers should ensure language and tone is respectful, professional and communicates empathy, respect and sensitivity to diversity and experience.

7.1.3. **Transform and reconfigure the youth mental health system**

Attempts to achieve service integration run into barriers created by the institutional design of the mental health system and other systems, including siloed practice, difficulties pooling funding, siloed governance and management systems, workforce shortages, financial stringency, and different professional and agency practices, attitudes, and cultures, to name just a few.

The reality is that achieving service integration for young people with mental health issues in a system that is not designed for integration requires organisational change and improvement at the level of the whole service system, not just change at the service delivery and agency level.

Action:

- Focus on systems change and the consequences and benefits for service integration.
- Encourage and support agencies and service providers to think as one system rather than as single agencies.
- Identify and tackle systemic barriers and policies and the structures and processes of service delivery, as well as the culture and attitudes of service providers that hinder service integration.
- Ensure a long-term commitment to leading, developing and delivering integrated services for young people.
- Use learning from collaborations to drive service and systems re-design.

7.1.4. **Workforce with the commitment and capabilities and clear roles and responsibilities**

Workforce development and training is necessary to ensure the workforce understands the needs of young people and has the skills for service integration. However, there are concerns around the capacity of the workforce to develop and maintain collaborative and integrated practices. The youth mental health workforce must be adequately funded and resourced and capable of working in innovative ways that place the young person at the centre.

Action

- Develop the capacity of specialist mental health providers to work collaboratively and respectfully with agencies in the generalist sector.
- Assist generalist agencies that work with young people to develop stronger youth mental health competencies and capabilities and to be able to work in an integrated way with specialist mental health providers.
- Provide workforce training and upskilling to enable service providers in specialist mental health services and generalist services and primary health services to work collaboratively to achieve service integration.
- Ensure that multi-disciplinary and inter-professional training related to service integration is continuously supported and provided.

- Support collaborative learning among all service providers and other stakeholders to support service integration.
- Service providers have a thorough knowledge and understanding of other relevant services and systems.

7.1.5. Funding, commissioning and contracting for complex issues and complex lives

If the benefits of service integration are to be achieved, then the challenge is for those who fund and commission services to develop funding and commissioning approaches that enable, not hinder service integration

Currently decisions about funding and competitive tendering and procurement create perverse incentives for services not to collaborate and act as a barrier to service integration. Standard commissioning and particularly contracting and competitive tendering are driven by competition which acts as a barrier to service integration. If services have to compete with each other for funding, they are unlikely to trust each other, communicate openly and effectively, share information and work together in ways that make service integration more likely.

One cause of the fragmentation that makes service integration more difficult to achieve is the diversity of funding sources and the different priorities of Federal and State Government agencies.

Services are often driven by the needs, preferences and requirements of funding providers. One consequence is that services are designed and structured in such a way that the young person must fit a service structure defined by funding guidelines, service specifications or reporting requirements, rather than services and support fitting around the needs of the young person.

There is a responsibility on those who fund and commission services to create collaborative approaches to funding, which enable multiple agencies and sectors to work together, rather than compete.

Action

- Provide funding for the development, implementation and maintenance of collaboration and service integration across agencies and sectors
- Ensure budgets contain an allocation for service integration
- Governments and funding providers to develop financing mechanisms that allow for pooling of funding across sectors
- Create funding and reporting incentives that encourage collaboration and service integration
- Allocate funds for training to up-skill staff in service integration
- Make service integration activities a core funded activity
- Ensure staff are able to allocate time to service integration activities
- Ensure a coordinated and collaborative approach between State and Federal Governments funding to support service integration.

7.1.6. Person-centred not protocol- centred and focused on benefiting young people and improving their wellbeing

The overarching purpose of service integration is to effectively respond to the full range of young person’s needs. This requires recognition that addressing the outcomes that matter to young people is a prerequisite for service integration.

Service integration should be organised and coordinated around the needs of young people and give priority to the goal of benefiting young people. Services have to be designed and delivered to meet the mental health and other needs of young people rather than the protocols, guidelines, requirements and expectations of services, providers and funders. Nor can service integration be imposed from the top down, as a managerial directive, as a way to save money or as a solution to funding shortfalls.

The key issue is that services, support and care are integrated from young people's point of view, based on their experience and needs. This requires the active participation of young people as partners in planning, design, management and coordination. Failure to place young people at the centre of integration efforts is unlikely to succeed. If integration becomes another buzzword or an end in itself, rather than a means of achieving better lives for young people, then service integration is part of the problem, rather than a part of the solution.

Action

- Agree that a shared focus on young needs is the primary purpose of service integration and specify the desired results or changes that will be achieved for young people
- Single point of entry for young people when accessing multiple services from different providers
- Designated care coordinators/service navigators ensure continuity of care to young people over time
- Collaboration and coordination between services should enable seamless transitions for young people across different settings, services and sectors
- Services work together to proactively address the needs of young people
- Young people and service providers work together to obtain and understand the necessary information to make appropriate health decisions
- Young people are actively involved in establishing a holistic care plan
- Young have access to their own health record
- Young people are supported to exercise choice and control in line with their own goals and priorities
- Young people are confident that their current and future needs will be met
- Young people are actively involved in decisions about their care and treatment options.

7.1.7. **Address stigma and discrimination and adopt a rights-based approach**

The young people involved in this project describe many examples of discrimination and stigma. The perceived or actual discrimination and stigma that young people describe is based on age but can also be due to cultural and racial background, Aboriginality, homelessness, gender and sexuality. As a result, many young people young feel misunderstood, judged, not listened to and treated with disrespect. This disrupts their engagement with mental health services.

Action

- Build a foundation of respect and recognition of diversity and the distinct needs of marginalised and vulnerable groups of young people.
- Challenge existing power imbalances between young people and service providers.
- Acknowledge, protect and uphold the fundamental rights of young people.
- Respect the rights and agency of young people.
- Protect and improve the safety of young people.
- Ensure young people are treated with respect and dignity.
- Support young people to exercise choice and control in line with their own goals and priorities and display respect for young people's social circumstances and cultural sensitivities.
- Ensure young people make their own decisions and participate in shared decision making about the care and services they receive.

- Ensure that young people are not subject to intentional or unintentional discrimination and stigma.

7.1.8. No single or best way to achieve service integration

Service integration means different things to different people. Integration to one person can be experienced as fragmentation to another. An important distinction is between the young person and the perspectives of provider and managers. Service integration is often a higher priority for service providers than for young people.

There is no consensus on the best approach and no "one size fits all" model or off- the-shelf approach to service integration. Service integration can be achieved through various models of service delivery.

Action

- Agencies need to agree upon the details of their own version of service integration in their own local context. There are a wealth of models and approaches that aim to bring about service integration. The diversity of models or approaches developed with the intent of achieving enhanced service integration includes:
    - Co-location of services
    - Service hubs that provide easy and ready access to a continuum of coordinated services located in one place
    - Care coordinator function and role
    - System navigator roles
    - Multi-disciplinary and inter-disciplinary teams
    - Collaborative care and integrated teams
    - Comprehensive joint assessments
    - Cross sector service provision
    - Stepped care
    - Wrap around services and support
    - Shared accountability for care
    - Centralised information, intake, assessment and referral
    - Joint care and discharge planning arrangements
    - Consortia, mergers, consolidation and joint ownership
    - Integrated and shared information systems and shared clinical records
    - Clinical decision support tools
    - Pooled budgets and joint commissioning
    - Individualised funding
    - Family involvement and participation

7.1.9. Shared vision and understanding among all who are part of the system

Service integration requires a shared and common understanding among all those who are part of the service system. This can include a shared vision, purpose, values, goals and norms and common and consistent language. Having a shared vision, purpose and understanding of the goals of service integration and how it will improve the mental health and wellbeing of young people is essential to align priorities and goals across agencies and sectors.

Action

- Develop clarity about the changes that all partners are trying to deliver for young people.
- Develop skills and commitment to work with different professional values and cultures
- Ensure clarity about the services that need to be linked and/or integrated with other services.

7.1.10. **Trusting and respectful relationships with young people and services**

Young people emphasise the importance of a trusting and ongoing relationship with service providers who display welcoming, caring and understanding attitudes and respect young people’s opinions, ideas and aspirations. They place a high value on service provider’s capacity to listen and treat them with respect and build a relationship of trust over time and they prefer informal approaches and the use of clear language that they can understand.

Young people want service providers who understand their needs and have the necessary expertise to meet them. They also want to be kept informed and for service providers to be up front and honest about what they can and cannot deliver and what the young person can expect. Too often service providers come across as distant, not direct and straight with young people and somewhat arrogant and unhelpful.

Service integration is the result of lasting and sustained relationships between young people and services and between service providers. Strong connections and relationships between service providers and their agencies contribute to improved service integration.

Successful service integration comes down to the willingness and capability of people and agencies to work together. It may take considerable time and effort to create the kinds of relationships that support trust and interconnection of services and resources, to build, maintain and replace relationships, and to establish shared ways of working and common practices. This also requires funding support.

Action

- Establish mutual trust, respect and understanding between all the services involved in the care and support of young people and between services and young people.
- Providers should strive to understand the needs and experiences of the young people they support

7.1.11. **Service integration when it is needed most**

Service integration is critical at key points in young people’s journey, particularly when they are most vulnerable. The findings of the journey mapping demonstrate key points in the service system amenable to better integration.

As described by young people, these include: when the young person is most unwell and needs support to navigate an already complex system; after being admitted and discharged from an emergency department or an inpatient unit, and being supported to access community based support and being provided with a discharge plan; when entering a new service, regardless of whether the service has capacity to take the young person on as a client on or not, and facilitating referral to a more appropriate service if the current service is not appropriate; and when accessing multiple services and/or clinicians to maximise information and data sharing with informed consent from the young person.

Action

- Identify key points in young people’s journey where service integration is most critical.
- Actively support, develop and maintain cross sector networks and relationships.
- Identify points of contact in agencies and relevant sectors to facilitate linkages between mental health services and other sectors.
- Develop detailed knowledge and understanding of relevant agencies and sectors.
- Engage services such as inpatient units and hospital-based services where risk-averse behaviour can create barriers to service integration at times when it is needed most.
- Support staff to work effectively with risk, particularly those environments and practices that encourage and create risk averse practices.

7.1.12. Young people must control treatment and decisions

For many young people, control over their treatment is felt to be given to treating teams and clinicians, with the young person’s wishes a low priority. Young people often describe being treated as though they are incapable of autonomy over treatment decisions. For service integration to be achieved, young people must be respected as partners with services in their recovery process, rather than an inherently vulnerable person.

Action

- Young people are included in service and treatment planning process at all stages
- Young people are respected as individuals capable of providing input, and making decisions about, their treatment plan
- Services to prioritise the desires of young people in terms of service delivery and treatment plans before input from others’ (including guardians)
- Services to enable opportunities for young people to participate meaningfully and provide mechanisms for sharing authority and decision-making in all decisions that directly affect them
- Services should enhance young people’s control and all processes and delivery of supports, services and treatment should only proceed with full informed consent.

7.1.13. Collaboration for joint action, shared leadership and mutual accountability

Service integration rests first and foremost on the willingness of agencies and service providers to work together and to share risk, responsibility and accountability across agency and sector boundaries. Accountability to young people must be a priority.

Action

- Obtain high level endorsement and support to ensure flexibility at managerial, agency and front-line levels to overcome system and agency blockages
- Ensure key decision makers and managers are committed to service integration and system change
- Identify and support champions for service integration
- Ensure cross agency and cross sector effort to build shared and mutual understanding and agreement on language
- Ensure service providers recognise and enact shared accountability and responsibility for outcomes for young people
- Establish agreements that support collaborative and integrated working
- Ensure workload pressures and agency demands don’t prevent staff from committing to service integration activities
- Establish regular and purposive inter-agency and cross sector forums and meetings
- Support shared accountability through formal structures and mechanisms and a shared set of measures to monitor outcomes for young people

7.1.14. Continuity between services, workers, systems and sectors

Young people access multiple providers concurrently across agency and sector boundaries and may go back and forth between multiple settings and agencies. However, they do not want to be passed around from worker to worker or from service to service.

Ensuring continuity between services, workers and sectors is challenging. Young people require continuity of support across services and systems to persist and follow up assistance and to engage with many different parts of the system. Care coordination and support for system navigation from the point of first contact with to the system and as they journey through the system should be assertively provided to enable continuity between and across services and sectors.

Young people can be supported and assisted to navigate the inefficiencies, fragmentation and duplication of a complex system. This can include a single point of contact and/or system navigator or care coordinator to facilitate access to the necessary range of services and supports and linkages within and across the system, particularly when problems or issues arise.

Service integration must bridge the gaps in the system of services, as well support and connect mental health services with the wider systems that exist to serve young people's needs.

Action

- Provide a single point of entry and contact and linkage when young access multiple services from different agencies and providers
- Enable continuity of movement across services and sectors
- Identify service coordinator or navigators to ensure continuity of care for young people across services, systems and sectors
- Place high value on coordination and collaboration between service providers which enables young people to have seamless transitions across services and settings
- Ensure that referrals to and from services are managed effectively to ensure continuity of care and to maximise accessibility timeliness and quality of service
- Service providers actively work together to enable each young person to access services and supports they need and overcome system blockages
- Make available contingency (brokerage) funds to broker solutions where a young person's needs cannot be otherwise met

7.1.15. Tackle social determinants

Social determinants such as housing, employment, income, violence, disadvantage and inequality and the quality of the living environment are key determinants of young people's mental health. This has major implications in tackling young people's mental health.[7]

Service integration is the key to dealing with interconnected issues that affect mental health and which impact on young people's lives such as housing, employment, income, education, alcohol and drug use, physical health, sexuality and gender and violence and abuse.

Service providers must look beyond the mental health system to improve mental health. Non-mental health services play a critical role in achieving and improving mental health and wellbeing and improvements can be achieved by better collaboration and integration between mental health services and other sectors and services serving young people.

The divide between mental health services and services that deal with other aspects of young people's lives continues to be a major barrier to access and wellbeing. The divide is created and maintained by separate funding of services and different professional and systemic practices.

Many young people with mental health and substance abuse issues are not connected to specialist and clinical mental health services and actively avoid contact with mental health services. However, they may be connected to other services such as housing, education, legal, youth services, employment, justice, welfare and income support services. While these services lack the resources and capabilities to meet young people's mental health needs, they play a key role in achieving service integration. This highlights the importance of collaboration

---

[7] Youth Access and Young People's Health Partnership (2015) The social determinants of young people's mental health, United Kingdom, 2015

and integration across sectors to leverage expertise and develop effective pathways for young people.

Action

- Develop models that locate mental health specialists in generalist services that engage with young people, such as housing, employment, health, alcohol and drugs and education e.g. embed mental health clinicians and mental health service providers within generalist services to provide input, specialised advice and consultation liaison
- Connect mental health services with primary health services and other social and community services around the needs of young people
- Ensure funding for non-mental health services to enable them to tackle mental health issues and the social determinants of the mental health issues facing young people.

8. OTHER PROJECT ACHIEVEMENTS

In addition to delivering the contractual requirements of the project as outlined in this report and as defined in the funding agreement, WAAMH staff have undertaken a range of other activities to address issues that have emerged during the project and disseminate the findings of the project.

8.1. Stakeholder briefings and meetings

The project has generated considerable interest and WAAMH staff have met with and briefed a range of stakeholders who expressed interest in the project, including:

- Ms Elaine Patterson (Assistant Commissioner), Mr David Axworthy (Assistant Commissioner) and five staff from the Mental Health Commission
- Ms Linda Richardson, General Manager Place Based Commissioning and Engagement and Ms Helen McMahon, Coordination Manager, Primary Health Network WA/ Primary Health Alliance
- Mr Tony Fotios, Manager Metropolitan Services, Primary Health Network WA/ Primary Health Alliance
- Ms Jodie Green, Acting Manager Country Services, Primary Health Network WA/ Primary Health Alliance
- Mr Warwick Smith and Mr Jason Ellis, North Metropolitan Mental Health Services
- Ms Katherine Brown, Senior Policy Officer, Office of the Commissioner for Children and Young People
- The Honourable Alannah Clohessy, Parliamentary Secretary (to Roger Cook) and staff
- The Honourable Peter Tinley, Minister for Youth and his staff
- The Honourable Sean L'Estrange, Shadow Minister for Mental Health
- The Honourable Terri Butler, Shadow Assistant Minister for Young Australians and Youth Affairs, Federal Opposition
- Ms Eleanor Boffey, Community Engagement Coordinator (headspace Midland)
- Dr Michael Wright, Curtin University
- Uncle Charlie Kickett and Aunty Helen Kickett, Aboriginal Elders involved in the Looking Forward Project
- The Honourable Alison Xamon, Greens spokesperson Mental Health
- Ms Coralie Flatters, Mental Health Lead Site Project Coordinator, WAPHA
- Mr Gareth Simpson, Manager Early Psychosis Youth Service Ruah and David Wray, Manager Mental Health and Wellness, Ruah
- Ms Lesley Pearson, Regional Manager, WAPHA
- Dr Jo Robinson, Orygen & Chloe Merna, WAPHA Suicide Prevention Trial Project
- Staff of the Mental Health Advocacy Service

8.2. WAAMH's role in youth mental health

The Youth Services Integration Project has been an important catalyst for reviewing WAAMH's role in youth mental health.

WAAMH is currently developing a WAAMH Youth Mental Health agenda, drawing on the findings of the project that will indicate how WAAMH plans to disseminate the findings of the project, as well as contribute to the development of the youth mental health stream.

This agenda will outline a set of youth mental health priorities for WAAMH and describe how the findings from the Youth Services Integration Project will be incorporated into WAAMH's priorities in areas such as sector development & training, lived experience involvement, Individual Placement & Support (IPS), advocacy & policy, communications and projects and partnerships.

The findings of the project are informing a new WAAMH project to assist agencies that work with young people with lived experience to ensure that collaborative arrangements they engage in are consumer and carer-centred.

This project will recruit and train a small cohort of consumers and carers with lived experience, including young people, as consumer consultants, to work with interested mental health services to ensure that co-designed collaborative arrangements are genuinely informed by consumers and carers. The project will build on work carried out during the Youth Services Integration project.

8.3. Catalyst for systemic reform to achieve better service integration

WAAMH has ensured that the Youth Services Integration Project is instrumental in creating momentum for systemic reform to achieve better service integration in youth mental health. The Project Advisory Group are actively involved in this.

A collaborative partnership was established between WAAMH and the Telethon Institute, which led to the formation of a consortium of agencies, including Anglicare, Youth Focus, Youth Affairs Council of WA, WA Primary Health Alliance, and University of WA, to develop proposals for projects and funding to drive systemic reform in youth mental health and service integration across Western Australia.

8.4. Involving young people with lived experience

This project was designed, led and implemented by young people and is an exemplar of a co-produced project. Some of the young people involved in this project will continue to be involved in other WAAMH projects and projects undertaken by other agencies.

8.5. Projects meetings and forums

The Youth Project Officer and WAAMH staff have participated in various project meetings and forums and conferences, including:

- Curtin University Building Bridges Project as a project participant, a youth mental health policy representative and a member of the Policy Working Group.
- Attending meetings, conferences and forums arranged by agencies such as Youth Affairs Council of WA, WA Council of Social Services.
- Proving evidence at the Albany hearing of the Senate Inquiry into the Accessibility and Quality of Mental Health services in Rural and Remote Australia.

8.6. Social media and press Reports

Numerous social media posts were generated about the project.

A major story about the project and its preliminary findings appeared in *The West Australian* print edition and online edition during Mental Health Week in October 2018.

9. CONCLUSION

Through mapping the journeys of 25 young people, the project has given voice to significant issues within the youth mental health system. The key themes of discrimination, information and data sharing, crisis management, point of first contact, networks, public mental health and other services, and diagnosis were evident. Based on the findings, consultations and literature review conducted by the project team, an integration framework was developed to begin to provide guidance around service integration.

Evident throughout the project's findings, is that further work is needed to ensure young people receive care that they feel is most appropriate for them. To provide long term best outcomes for young people accessing mental health care, the project team and advisory group recommend continuing the project on a larger scale to: 1) better understand the experiences of more young people, especially disadvantaged young people and those living in rural and remote areas of Western Australia not capture as part of the current project; 2) collaborate with young people and their carers to understand what an 'ideal' metal health system might look like, and 3) evaluate services for cost effectiveness.

Regardless of the scale of any future work, it is clear from both the project findings and the sector more broadly that work around improving youth mental health service integration must continue – both for young people, and those who serve them.

APPENDICES

Appendix 1: Project Advisory Group

The Project Advisory Group provides advice and guidance and comprises the following representatives:

- Dr Ashleigh Lin, Program Head, Mental Health & Youth/NHMRC Career Development Fellow, Telethon Kids Institute, The University of Western Australia
- Chris Harris, General Manager Community Engagement, Youth Focus
- Warwick Smith, Director, Youth Mental Health, North Metropolitan Health Service
- Andrew Kazim, Practice Consultant Youth, Anglicare WA
- Ross Wortham, Chief Executive Officer, Youth Affairs Council of Western Australia
- Yasmine Hooper, Co-researcher/youth advisor, Western Australian Association for Mental Health
- Samuel Winner, Co-researcher/youth advisor, Western Australian Association for Mental Health
- Colin Penter, Projects Lead, Western Australian Association for Mental Health
- Rikki Battersby, Youth Projects Officer, Western Australian Association for Mental Health
- Michael Jones, Manager of Capacity Development and Promotion, Western Australian Association for Mental Health (Chairperson)

Appendix 2: Project Approach and Design

Co-production and Journey mapping

The project used an authentic co-production approach and was led, planned and delivered by young people, including two youth advisors/co-researchers.

The project team developed an innovative journey mapping process to visually map young people’s journey and pathways through the mental health system, including the services and agencies they had contact with.

The project was guided by an overarching social constructionist approach, and the broad methodology followed was in line with thematic analysis.

Project Advisory Group

An Advisory Group was established to guide the project and included representatives from WAAMH, Telethon Kids, Anglicare, Youth Affairs Council of WA, Youth Focus and North Metropolitan Mental Health Services. The youth project officer and the two youth advisors were members of the Advisory Group. The names and details of the Advisory Groups Members can be found in Appendix 1.

The Project Advisory Group met in December 2017, February 2018, July 2018 and September 2018 and will continue to meet after the Project’s completion. The Group will meet again in November 2018 and in early 2019 to discuss and progress the dissemination and implementation of the findings.

Recruitment of Young People

Interview participants were recruited from a range of youth mental health and related services across the Perth metropolitan area, and the south-west of Western Australia and through personal networks and contacts of young people, including those of the project officer and youth advisors. Services engaged with ranged from those working with lower complexities, to severe mental ill-health and psychosocial distress (including young people requiring supported accommodation) between March and August 2018. A small number of participants were recruited via social media platforms such as Facebook.

A full list of the agencies who assisted with recruiting young people can be found in Appendix 2.

In total 25 young people were interviewed. Another 15 young people were recruited who indicated an interest in participating, however for a variety of reasons they chose not to participate.

Inclusion Criteria

For young people, inclusion criteria included being between the ages of 12-25, and having accessed mental health care or related services at any point during their lives.

The entry criteria were as open as possible. Any young person between the ages of 12-25 who was far enough through their journey that they could comfortably share their experiences (as much or as little as they felt), who had accessed a mental health care or related service was able to participate.

The young person was required to be at a point in their 'journey' where sharing information about their experiences would not become overwhelming or distressing, as determined by either the nominating clinician or project staff during participant selection. Young people provided informed consent to participate.

The project team attempted to engage with a variety of young people that had accessed a range of services, including both public and private services, school-based services, specialised mental health services, accommodation support services, hospital-based services and primary care services. Interviews were completed until a broad range of experiences across a variety of services had been captured, and the project team did not think additional interviews with the demographics we were successfully able to engage with would add to the data already gathered.

Participant selection

A purposive sample was recruited to gain insights and experiences from a broad demographic of young people. Through contact and meetings with agencies, the project and its purpose were presented to staff, and service managers, who shared inclusion criteria with clinical staff. When appropriate young people were identified by clinical staff members and indicated a willingness to participate, the project officer was contacted by either the contact person at the service, or the referring clinician who passed on the young person's contact details with their consent.

Young people were then contacted by the project officer and sent further information about the project, along with a brief wellness plan to ensure they were willing and able to participate. All young people were required to provide written consent and to work with the Project Officer to develop a wellness plan.

Once the young person young person indicated their interest in being involved, they were asked to fill out a brief document that asked a few questions around topics that might be distressing for them and how the project officer could best support them if they became distressed.

Once the document was returned, the project officer and young person set up a time to meet and undertake the mapping exercise. Sometimes this took place at WAAMH's office, most often at the agency they were referred from. It was where the young person felt most comfortable.

Young people were reimbursed to cover their time and travel costs.

Role of the Project Officer

The mapping exercises with young people were conducted by the Youth Project Officer, a female with post-graduate qualifications in youth mental health and experience collecting qualitative data with young people. Before conducting each mapping exercise, a relationship was established briefly with young people during the recruitment process.

Mapping process

Each journey mapping exercise took around 1.5 to 2 hours to complete and was extremely informal. After consent forms and a demographic questionnaire were completed, the young person and Project Officer sat down with an A1 sheet of paper and coloured Textas and would start from either the beginning or most recent point in the young person's journey and work from there.

They would talk about how the young person got there, what it was like getting there, who referred them, how they got there, how long they had to wait, what the staff were like, whether they had to retell their story or if the new service already knew, if their family was involved, costs associated, barriers to accessing the service etc.

Young people were asked to discuss their experiences accessing mental health care and related services, and these were visually mapped. Questions did not follow a schedule. This was done because each young person's journey was different, meaning devising an interview schedule relevant to all young people was not possible. Instead, the same initial questions were asked, with probing questions to follow. As a result, young people were 'led' as little as possible.

Each young person worked with the project officer to visually represent their pathway through the mental health system by drawing a visual map of their pathway, all the services they had contact with and their experience with the services. The pathway was colour coded using different coloured pens to represent key aspects of their experience and pathway. In some cases, the young person drew their own pathway completely and in other cases the young person and the Project Officer worked together to draw and visually represent their pathway. Each interview produced a large sheet of butcher's paper showing the young person's colour coded journey through the mental health system.

Data Collection

The interview data collection methods were not based on known, previously published methods. The methods utilised with young people were investigator devised and allowed for maximum flexibility in terms of information gathered about the young person's journey through the mental health care system, how services integrated, and how external factors impacted on this. Probes were used when appropriate to illicit further information. Two additional probes were added at the end of the mapping exercises: 1) 'which service or clinical worked best for you and why?' and 2) 'which service or clinician was least helpful, and what could they have done to work better for you?'.

Data Analysis

Principles from Braun and Clarke’s (2006) thematic analysis informed the analysis, which was undertaken by the whole project team and combined lived experience and professional and policy expertise.

Data analysis was theoretically and inductively driven in that the main themes around service integration were determined before the mapping exercises were conducted, but a set of new themes were also derived from the data. While the mapping exercises with young people were audio recorded, they were not transcribed due to time and cost constraints.

Because of this, data coding was done on mapping exercises completed with young people rather than transcripts traditionally done in thematically analysis. Two sets of analysis were complete on fresh, un-marked printed digital copies of maps. These were based on the analysis being theoretically driven, or what we labelled as analyst driven, or inductively driven, or what we called data driven. Across both sets of analysis, themes were compared within and across groups (type of services accessed, how services were paid for). Theme and coding matrices were used to organise both sets of analysis.

Appendix 3: List of agencies who assisted with recruitment of young people

1. Anglicare WA
2. Foyer
3. Youth Affairs Council of WA
4. Youth Focus
5. Youth Reach South
6. Youth Link,
7. Headspace Midland
8. Headspace Rockingham
9. Albany Youth Support Service and Young House
10. Headspace Albany
11. Drug and Alcohol Youth Service, Mission Australia

Appendix 4: List of agencies involved in face to face meetings and focus groups

1. Sexual Assault Referral Centre (SARC)
2. Mental Health Advocacy Service (MHAS)
3. Department of Education
4. Anglicare WA
5. Foyer Oxford
6. University of WA
7. Youth Reach South
8. Office of the Commissioner for Children and Young People
9. YouthLink
10. MercyCare
11. Youth Affairs Council of WA (YACWA)
12. Perth Inner City Youth Service (PICYS)
13. Aboriginal Health Council of WA (ACHWA)
14. Headspace Midland
15. Headspace Rockingham
16. Albany Youth Support Service and Young House
17. Headspace Albany
18. Youth Focus
19. North Metropolitan Health Service, Youth Mental Health Service
20. WA Primary Health Alliance
21. Mental Health Commission of WA
22. Drug and Alcohol Youth Service (DAYS)
23. Looking Forward/Building Bridges Project
24. Orygen
25. RUAH
26. Telethon Kids Institute
27. WA Network of Drug and Alcohol Agencies (WANADA)
28. WA Association for Mental Health (WAAMH)

Appendix 5: List of agencies identified by young people during journey mapping interviews

(i.e. Agencies with whom they had contact)

1. Various private psychologists
2. Various private psychiatrists
3. Various private general practitioners
4. Various specialist physicians
5. Private Occupational Therapist
6. Acupuncturist
7. eheadspace
8. Headspace Rockingham
9. Headspace Albany
10. Headspace Fremantle
11. Headspace Midland
12. Headspace Osbourne Park
13. Headspace Joondalup
14. Headspace Broome
15. ED Princess Margaret Hospital
16. ED Fiona Stanley
17. ED Royal Perth Hospital
18. ED Swan Districts Hospital
19. ED St John of God Midland
20. ED Albany Hospital
21. ED Armadale Hospital
22. ED Sir Charles Gairdner Hospital
23. ED Joondalup Hospital
24. Fiona Stanley Youth Unit
25. Graylands Psychiatric Hospital
26. Marian Centre
27. Perth Clinic
28. Bentley
29. Melbourne Clinic
30. Hollywood Hospital
31. UWA Counselling Service
32. Curtin Clinic
33. Kids Helpline
34. Mental health Emergency response line
35. Lifeline
36. Directory Assist
37. Youth Futures
38. Youth Accommodation Support Service
39. Y-Shac Rockingham
40. Homes West
41. YoungHouse
42. YouthBeat
43. Foyer Oxford
44. The Sexual Assault Resource Centre
45. Perth Voices Clinic
46. Centre for Clinical Intervention
47. Child and Adolescent Mental Health Service
48. YouthFocus (Perth)
49. YouthFocus (Albany)
50. BeyondBlue
51. YouthLink
52. Rise
53. Employment Edge
54. YouthReach South
55. Youth Hospital in the Home
56. Wanslea
57. Navig8/Mission Australia
58. Department of Child Protection
59. Freedom Centre
60. Amity Health
61. Albany Youth Support Association
62. Hillside
63. Palmerston
64. Anglicare WA
65. RUAH
66. 360 Health
67. Perth Inner City Youth Service
68. Drug and Alcohol Youth Service

Appendix 6: Consent Form-Adult providing own consent

Project Officer	Rikki Battersby
Project Team	Colin Penter, Mike Jones, Yasmine Hooper, Samuel Winner

Declaration by Participant

I have read the Participant Information Sheet.
I understand the purposes and risks described in the project.
I have had an opportunity to ask questions and I am satisfied with the answers I have received.
I freely agree to participate in this project as described and understand that I am free to withdraw at any time during the project without affecting my future employment.
I understand that I will be given a signed copy of this document to keep.
I understand the interviews will be audio recorded and transcribed for the purpose of analysis.
I agree to be contacted by the project officer by my preferred method of contacted, as stated in my wellness plan, to check in post interview
I agree to complete a wellness plan

Name of Participant (please print) ____

Signature ______________________ Date ______________________

Declaration by Project Officer[†]

I have given a verbal explanation of the project, its procedures and risks and I believe that the participant has understood that explanation.

Name of Project Officer[†]
(please print) ____

Signature ______________________ Date ______________________

[†] A senior member of the project team must provide the explanation of, and information concerning, the project.

Note: All parties signing the consent section must date their own signature.

Declaration by treating staff member or centre staff member[†]

I have received a verbal explanation of the project, its procedures and risks and I believe that both myself and the participant have understood that explanation.

Name of Staff member
(please print) ____

Signature ______________________ Date ______________________

Email address:

Form for Withdrawal of Participation - *Adult providing own consent*

Project Officer	Rikki Battersby
Project Team	Mike Jones, Colin Penter, Yasmine Hooper, Samuel Winner

Declaration by Participant

I wish to withdraw from participation in the above project and understand that such withdrawal will not affect my relationship with The Western Australian Association for Mental Health

Name of Participant (please print) ____________________

Signature ____________________ Date ____________________

Reason (if verbal withdrawal only):

Declaration by Project Officer

I have given a verbal explanation of the implications of withdrawal from the project and I believe that the participant has understood that explanation.

Name of Project Officer[†] (please print)____________________

Signature ____________________ Date ____________________

[†] A senior member of the project team must provide the explanation of and information concerning withdrawal from the project.

Note: All parties signing the consent section must date their own signature.

Appendix 7: Young People’s Wellness Plan

WELLNESS PLAN

Name:
Phone:
Email:
Date of birth:
Gender and pronoun:
Preferred method of contact:

Emergency contact
Name:
Relationship:
Phone:

Dietary requirements/allergies:

What are some of the signs and symptoms we should look out for to know if you’re becoming distressed?

Are there any topics or situations that make you particularly uncomfortable, stressed, or might trigger your symptoms? Would you like us to avoid these topics?

If you become distressed or increasingly uncomfortable during the interview, what can you do? What steps would you like us to take to help you feel safe again?

Appendix 8: Demographic Questionnaire

Pronoun (e.g., he/she/they):

Age:

Age first accessed a service:

Current living arrangements:

Highest education level attained (e.g., high school, cert, diploma, bachelors):

Employment (e.g., casual, part-time, full-time):

Number of years accessing services for mental health related concerns (mental health or other support services e.g., GP's, psychologists, counsellors, online and telephone supports):

Have you ever accessed online supports such as forums or e- or telephone counselling services?

Do you identify as any of the following?

- **LGBTIQ+**
- **Aboriginal or Torres Strait Islander**
- **CALD**