Final Report

Health Consumers Alliance of SA and Health Economics and Social Policy Group, UniSA

Youth Mental Health Consultation Project

July 2016

For more information please contact:

Kathy Mickan

Manager – Consumer and Community Engagement

kmickan@hca.asn.au

Mark Loughhead

Engagement and Partnerships - Mental Health

Mark.loughhead@unisa.edu.au

Contents

1. Executive Summary

This report documents the outcomes of a youth mental health consultation and research project which was completed during 2015-16 by the Health Consumers Alliance (HCA) in collaboration with the Health Economics and Social Policy Group (HESPG) at the University of South Australia. The aim of the project was to speak with young people about their experiences of mental health care, and hear their perspectives on how pathways to care and service design could be improved. Between July 2015 and March 2016, 6 focus groups and 1 individual interview were conducted with a total of 32 participants. Partnering organisations, which supported the involvement of participants, included Local Health Networks, community sector organisations and high schools. Participation included young people from a variety of age ranges, locations (e.g. urban and rural), and cultural backgrounds.

The project resulted in a diverse range of views about the experience of care, with a considerable focus on suggestions and ideas for how services may be better designed and promoted, for instance to school communities.

HCA and HESPG would like to acknowledge and thank the young people who participated in this project and generously shared their experience. We also thank the many organisations who connected with us and helped young people to be involved. Finally we would like to acknowledge the NHMRC for the Partnership Project Grant (APP1055351) that supported this work.
Following is a summary of key themes and understandings from the project.

Deciding to get help

- Young people recognise that they need help in different ways. Some contact services when their distress becomes too much – others are encouraged and supported by their friends who know what to do. Parents may or may not play a key role in accessing help. It depends how well they understand mental health issues.
- Student counsellors can provide a key role for providing support and helping to arrange appointments. It is important for student counsellors to be well trained in mental health and to be clear about privacy and confidentiality with students. Strategies for engaging parents and families in culturally informed ways are important for a positive experience of a service.
- There are many influences shaping the decision of young people to attend early appointments. Some of these are about stigma or shame, uncertainty and fear about what will happen at a service, or what being diagnosed will mean, and whether they will be judged by clinicians and/or by parents, friends and family.

Services used

- Student counsellors, GPs and psychologists were the services most used by participants. Overall there was a wide range of services used. These included community services, youth health services, non-government mental health programs, hospital units and emergency departments.

Experiences that discourage young people

- Within a service, the behaviour of administration staff and the engagement skills of therapists influence whether young people feel comfortable and welcome. There are many subtle ways young people are discouraged. Sometimes they don't feel they are understood, or don't connect with the therapist. Having a therapist of the opposite gender can affect engagement, and a decision whether to return or not. Sometimes, therapists go too fast with questions, produce an overwhelming work plan, or simply 'go through the motions'. Sometimes administrative staff are not understanding about appointment cancellations and attendance issues.
- Young people talked about the time it can take to get a clear understanding of their mental health issues. The diagnosis needs to make sense and fit their experience. Diagnostic language can be a barrier. In hospitals, clinicians need to spend adequate time with their clients.

Staying with a service

- Young mental health consumers stay with providers when the intervention works, or when clinicians provide another tool or strategy when one isn't working. They also need to feel confident in the knowledge and skills of the therapist. Young people pick up on genuine care, appreciating follow up calls, emails and texts between appointments, or being able to call when needed, or receive home visits. They also value assistance by culturally significant community members (religious leaders, community elders) who can support them with their learning and growth during recovery.
- Different interventions are useful for different people. Young people reported positive and negative outcomes from medication, mindfulness and cognitive behavioural therapy. Groups, activities and arts based practices should be offered, within traditional therapeutic settings as well as school communities. Care needs to be personalised.
- It takes time to get results for significant mental health issues. Young people want more than 12 sessions within a mental health care plan. This limit becomes a continuity of care issue where they may have to wait for long periods to access the subsidised service.

Services need to be better designed

There are many ways services can be located, designed and delivered so it is easier for young people to access and stay connected with them. Many suggestions for these are provided later in the report.

2. Background

This project developed from a partnership between the Health Consumers Alliance (HCA) and the Health Economics and Social Policy Group (HESPG) of the University of South Australia. A critical component of the partnership involved HESPG contracting HCA to facilitate and report on a series of conversations with young people on their experiences of mental health care.

From HCA's perspective, the project was a timely opportunity to help promote consumer views in a context where South Australia's mental health services for young people are being reorganised. This includes the development of Youth Mental Health Services, the redesign of the model of care with Children and Adolescent Mental Health Services, and changes to primary mental health funding and services within the evolution of Primary Health Networks.

From HESPG's perspective, the project was a critical component of a larger National Health and Medical Research Council funded Partnership Project with SA Health to develop a workforce and service plan for infant, child, adolescent and youth mental health services. Hearing from young consumers about how services have worked for them – what has been effective, what service providers have said and done which encouraged them to stay with a service, and what has made the pathways to care easier, became a central aspect of considering the optimum service design and practitioner roles and qualities required in a reformed mental health system.

The project was formalised as a research project through the UniSA Human Research Ethics Committee. The approach taken was to invite young people to participate in focus group discussions with a standard list of questions. We invited young people from ages 12 to 25, with lived experience of mental health issues and service use. We wanted to take a big picture view of service use, and included supports such as school counselling, online information and discussion groups, use of primary care professionals and specialist services such as hospital care.

A focus was on inviting young people who are members of groups that experience heightened life stress and disadvantage. This included young people living in country areas, being of refugee or culturally and linguistically diverse (CALD) background, young Aboriginal people, lesbian, gay, bisexual, transgender or intersex (LGBTI) identified, or those with

experience of Guardianship of the Minister. We designed the questions of the project to reflect the concepts of Consumer (patient) Experience[1] and Experience Based Co-Design[2], which encourage reflections on experience of service pathways, and consumer memories of what impacted positively or negatively for them. Draft questions were written in consultation with a small group of consumer advisors.

3. Consultation and reporting methods

Focus groups were organised and directly promoted to participants through HCA's information networks across the youth sector and wider health consumer and service networks. Additionally, organisations supporting young people were invited to assist in hosting focus groups.

The focus groups were organised via an introduction to the purpose and background of the project and the nature of involvement. Two facilitators, one each from HCA and HESPG guided all but one focus group which was HCA only. Participants were encouraged to speak in third person as an alternative to sharing personal experience. Group rules about safe sharing, privacy and respect were agreed to prior to starting each session. Focus group questions are provided in Appendix 1.

Young people participating in focus groups could receive assistance for transport and were provided with a $40 gift card in recognition of their contribution and time. Focus group discussions were audio recorded and transcribed to assist the quality of the analysis and reporting. Ethical safeguards ensuring informed consent, emotional safety of participants, follow up contact, information about services, privacy, anonymity in reporting and storage of information were practiced. An email list of participants and or supporting organisations was compiled for sending out reports about the project.

Participants

A total of 6 focus groups and 1 individual interview were conducted with 32 young people participating. Partnering organisations included Local Health Networks, Community sector organisations and high Schools. Participation included young people from a variety of age ranges, locations (e.g. urban and rural), and cultural backgrounds. Target groups included young people living in country areas, identifying as refugee or CALD background, young Aboriginal people, LGBTI identified, or those with experience of Guardianship of the Minister. The project experienced challenges in engaging with young people from these groups. Additionally, groups arranged through HCA and via partners attracted many more young women than young men.

[1] See for example Wolf et al (2014) for definitions.
[2] See for example Cranwell et al (2015) for an example of this methodology in mental health care.

Table 1 provides information about age range, gender and group background.

Table 1: Profile of participants

Gender	
Female	25
Male	6
Transgender/Intersex/Unsure	1
Age	
12-14 yrs	8
15-18 yrs	18
19-25 yrs	6
Sub groups (not exclusive)	
Aboriginal young person	9
Refugee /CALD	7
LGBTIQ	3
Country SA residents	9

Analysis and writing

The transcripts of each group/ interview were firstly assessed for identifying details (names of participants, workers, towns etc) which were removed or de-identified.
Participants were given a pseudonym (fictional name), which could be used when quoting their perspective in the report. The age range of the participants (within 3 categories 12-14, 15-18, 19-25 years) was also indicated on transcripts.

Transcripts were analysed on a question-by-question basis to identify key ideas and themes shared between participants. Titles for the themes reflected the language used by participants. The analysis then brought themes together from the different focus groups to gather the different ideas expressed and to see where perspectives and experiences were common or diverse. Common perspectives were grouped under key themes.

This approach helped to emphasise what matters to young people whilst also not losing sight of individual and unique experiences. The outcomes of the groups/interview are presented in order of the nine questions used. Quotes are used extensively to highlight the participants' experiences and voices. To protect the privacy of participants, pseudonyms are provided with age range. The researcher/ author's narrative is kept brief to introduce the themes and provide a summary understanding for readers.

4. Consultation outcomes

4.1 How do young people decide that they need to get some help?

Life becoming bit unliveable

A number of participants spoke about the experience of coming to understand that they needed to seek help because of the impact and intensity of their distress:

> "I found that it was just at a point where life was getting a bit unliveable. It was just getting really difficult to get by, so at that point I just thought I can't manage, I've got to get some help. **Q: so it was a sense of distress?** A: Yeah, well that's it; it's like you get to a point where you just want to get help. Well that's what I felt" (Charlotte, 24).

> "I found it got to the point where I needed help when I couldn't function as a normal human being, like couldn't sleep, couldn't get up to do anything, couldn't eat, couldn't do my work or anything. Just basically I became room-bound and didn't go anywhere, didn't do anything and that was when it was really time to get help" (Shannon, 19).

Tomorrow you're going to the doctor

Some participants talked about the role that friends had played in encouraging and supporting them to seek help. An aspect of this is friendship networks that had information and knowledge of what service to visit:

> "...with me it usually, like, starts when you're quite young so you kind of think that what you're going through is normal. So for me, I actually had a friend tell me, like, okay, tomorrow you're going to the doctor and you're going to – you're going to ask – she, like, had a – she knew a place that I could go. So – which actually another friend had been to as well. So it was, like, word of mouth of where to go….., like, as your symptoms progress and they get worse you're kind of like, yeah, why is this happening?" (Rosie, 24).

> "So, even like my Australian buddy, kind of, pushed me to go to the counselling service"(Saja, 24).

One participant talked about isolation and trying to make friends through attention seeking behaviours – which 'doesn't help because they think you need help'. She suggested that people around encouraged her to connect with youth health services which was a positive experience for her.

Parents could tell

For other participants, their parents were the main catalyst for seeking help:

> "….Mum noticed because my Dad had mental illness, so, but it was really (psychological care) like expensive, and we couldn't afford her, and after that I just didn't get help for a very long time and then when I was, like, 13, 14, I finally started getting into that because it was really obvious that I had an eating disorder. So that's what – but I'd obviously been living with mental illness that whole time and then I just like, I was coping with an eating disorder through puberty and that's when I got help (Emily, 19).

> "It's not actually quite easy to say that there is something wrong with you. Yeah, it's pretty, actually, difficult because you don't want to admit to yourself that, yeah, you're ill, sad, I guess….– my mum tried to get me to go to a psychiatrist and stuff plenty of times and I flat out just wouldn't go, because I didn't want to admit there was things wrong with me. So it's more to do with family, of being supportive and stuff like that."(Isaac, 18).

Experiences of parents were mixed however with a number of participants suggesting their parents didn't believe there was any need to organise formal help. Where this was the case, young people relied on themselves or friends to arrange.

Talked to school counsellor or teacher

Some participants talked positively about the role of school counsellors, with one student indicating that she was invited to an appointment after the counsellor saw that she was upset in the school setting. Other comments included:

> "…talk to a person about it – someone you trust. Like teachers…. (Lesley, 16)

> "…well, the main problem was I was failing my course. So a lot of my course co-ordinators said that I should go and, um, you know, um, just sit down and get some help….(my school counsellor) she definitely thought I needed some outside help" (Saja, 24).

Discussion about school counsellors raised student concerns about confidentiality, and the experience of being subjected to school rumours about why they needed to access supports. The privacy issues also related to parents involvement. In the cross cultural situation, involving parents may generate further difficulties (e.g. parents being ashamed or misunderstanding) for the young person. Helpers need to be culturally informed.

Online information

Finally, participants identified the internet (e.g. Beyond Blue) as an anonymous but useful source of information that guided their decision to seek help.

Take home messages

Our learning from participant responses to this question is that there are various ways young people come to the point of making contact with services. Young people talked about supportive relationships being central and also people having awareness about the issues, symptoms or signs. Support people and consumers themselves need to have confidence that chosen providers can offer effective assistance. Participants indicated the period of time from awareness/recognition of issues through to making the decision to seek help varied significantly.

4.2 What are the services or people that you have visited to get help?

> "I mean, I've only got a psychologist, a doctor, a psychiatrist and soon to be a dietician" (Sara, 14).

We asked this question to gauge the range of services that participants used and to see whether young people were using a range of services for their care. The general trends were that primary and specialist services were used by many participants, with GPs and psychologists being very common. Young people receiving support from specialist services tended to emphasise these clinicians as their main form of assistance.

Some participants were students of a high school with a program called Doctors on Campus. These young people spoke very positively about the convenience of accessing a GP at school - "it's easier being on campus because then you don't have to actually tell anyone else, like your parents about it until you want to" (Anaya, 15).

Below is a list of services identified by participants:

Primary Care

- General practitioners
- Headspace
- Psychologists – private and via general practice mental health care plans

School Settings

- Teachers that they are close with
- School Counsellors
- Doctors on Campus

Community Health Services

- Aboriginal Family and Youth Services
- Aboriginal Community Controlled Health Services
- Streetlink Youth Health Service
- Youth Health Services (Women's and Children's Health Network)
- Marion Youth Service

- Shine SA

Specialist Services

- Child and Adolescent Mental Health Service (CAMHS)
- Department of Psychological Medicine
- Youth Mental Health Services
- Caseworkers in public Community Mental Health Services
- Psychiatrists – public and private
- Mental Illness Fellowship of South Australia
- Beyond Blue New Access
- Women's and Children's Hospital
- Adult Inpatient Units
- Assessment and Crisis Intervention Service (ACIS) – Mental Health Triage
- Emergency Departments

Telephone Lines

- Suicide Help Line
- Lifeline
- Kids Helpline

Online Services

- Beyond Blue
- Headspace Online

4.3 When young people have decided they want or need to see a doctor or psychologist, what might be some things which stop them from going?

Collectively, young people told us that there are many things which influence their decisions not to follow up and attend an appointment. Some themes were about self-perceptions and others about undermining comments from people around them. Many reasons revolved around stigma, but some were about not being understood, uncertainty, or not wanting to trouble parents.

Hard to ask for help

> "I think the main problem with people not going for help is that it's hard for you to start asking people to help, because after you actually get across with them it actually gets a lot easier and then after a while you just – but it's actually really hard to engage with someone that you don't know, or maybe you do know, and then talk about all these things that have been troubling you" (Dinh, 16).

"Like, just generally too anxious to even thinking about making the first step. Yeah Even us making a phone call, getting to the appointment and then you know that once you've made the appointment you have to get to it and then if you miss it they're going to ring you, and it's just, like, all too scary" (Emily, 19).

Stigma and judgement

"I guess sort of the fear of being judged, the negative associations that come from having a mental illness or mental health issues, or if you go see someone, is often portrayed by friends, media, lots of different places, as a very negative thing. And so that often puts especially younger people off, for fear of being judged, and those issues adding more issues to what they are already feeling" (Carissa, 18).

"Some of the things, actually, I think that stop people…they don't want to share it, because, like, some of the things are actually quite embarrassing to, you know, share and, they don't want other people to know… most of the people in my country.. From India or Pakistan or most of, I think Asian countries.. This kind of, getting help from that kind of service is, kind of, considered – it's terrible, you know. Like, you don't admit, even if you go there and, ah, people will say don't ever say anything that that's a problem" (Saja, 24).

Fear of unknown

"It's, like, just a fear of the unknown. Often you feel more comfortable, even if you're really uncomfortable in a situation, it's what you know so you don't want to change" (Emily, 19).

Parent issues

"You should be out partying or whatever, whatever they say, being a stereotypical teenager, not this person who just sits in their room all the time" (Katrina, 14).

"I just didn't want my family to think that anything was wrong, because it was already a very rough time. So I didn't want to put that pressure on top of everything else" (Lucy, 18).

Not wanting to go

"Well, it's kind of different for me, because I absolutely did not want to go. And my mum would actually drag me out of the house kicking and screaming, and lock me in the car, and then take me. So – and I'd be, like, crying and kicking the windows and stuff like that. And she wouldn't let me out. And then she would have to drag me inside of the place where I went to. And then when I did get in there, I'd just sit there

and look at the ground. Or I wouldn't make contact or anything. I wouldn't even talk to them. So I was very difficult at the start" (Isaac, 18).

Didn't want family/ siblings to look down on me

"The biggest reason why I didn't want to admit that there was things wrong with me was because of my family…. Like, my mum, she had always suffered from it but my sisters and brothers and everything, were all confident people. So I didn't want to admit that there were things wrong with me and them to look down on me, and think that I was – things were weird and stuff like that"(Issac, 18).

Disappointing our parents

"It's always the standard that we have to live up to, I think. So basically we reflect our parents and they don't want to be looked down on" (Khadija, 15).

Fears of being classified as mentally ill

"Yeah. I remember feeling trepidation about firstly being classified as being mentally ill as though that was something that was going to come back to bite me later, if that makes sense, and secondly, you hear scary stories about medication and you think, oh no, I don't want to go down that road, but you don't have to take it" (Charlotte, 24).

Our analysis of these themes is that there are many subtle and often unexpected reasons that influence help-seeking behaviour in young people in distress. The social environment – responses from parents, siblings, friends, students and teachers can be inconsistent, unsupportive or ignorant of the complexity of distress in the lives of young people.

Existing relationships and stereotypes about mental illness and treatment come together to influence expectations of what might happen in going to seek help. Many participants called for improvements in promoting consistent information in schools and wider communities, and also information about 'what it's like going to a service'.

4.4 When you went to get help for the first time, can you remember any things that put you off, or made you feel you wouldn't go back?

The following perspectives show many insights into what it is like to experience a support or therapy service. Young people talk about difficulties associated with engagement, assessment, sharing, planning work, whether advice or interventions work, and whether clinicians are committed or knowledgeable. Gender was raised. These themes further our understanding of the vulnerability felt by many consumers in accessing services.

Not providing information

> "When I went there, they didn't – some people didn't actually explain to me about the things that they were going on, they explained to – what things to do to help me, such as like breathing techniques and stuff like that. But I never understood why I needed to do these things. Just – they just told me that I need – I should do these things and they will make me feel better, and stuff like that, but they never actually explained to me why I should be doing this and why I actually felt like that" (Isaac, 18).

Wrong person to connect with

Many participants spoke about sensing a lack of connection with the therapist or not being understood.

> "I think another problem is if you get stuck with the wrong person for your first session, like that one person who assumes they know way more about you than you just because they have a degree or something and they've looked at you for five seconds, and that really puts you off because that is what happened to me with the whole counsellor thing; you get stuck with one bad person, you automatically assume everyone is like that because it's annoying" (Sara, 14).

Gender

> Maybe it's not the best support or what you expected. You thought 'this is going to be good, I'll get a lot of support' and maybe it wasn't what you wanted before, and like (name) said, that whole gender thing: it must have been really hard because she – I think when you talk to girls they understand because you go through things (together), like personal things. I think it's good to have the same gender (Sophie, 16).

Not being understood

> "Just, like, feeling they didn't understand a lot of the time as it was, or just finding it extremely unhelpful…..yeah, just having, like, almost traumatic experiences with psychiatrists when they're just unhelpful I guess and you get traumatised..(Emily, 19).

> "…if you feel that that person is going to – they're just doing their job, like, they're there doing their job for the money, they're not – I don't know. You maybe kind of feel like they have no idea what you're actually going through" (Rosie, 24).

The following five themes are about the experience of assessment and sharing personal information. Young people spoke about the need for a trusting relationship and the difficulty of expressing distress, or being asked very personal questions. Sessions can be intense and overwhelming.

I don't want to talk about it

> "When they start questioning you about things that you really - you've barely just come to accept within yourself and they want to know all the details, even when it's clearly making you upset and you say, "I don't really want to talk about it," they're like, "No, but talking is good" (Samantha, 14).

Interrogation

> "I didn't like it at all. They feel like they're interrogating you to find out if you're a danger to yourself and all this and it's like, that's not why I'm calling, to be interrogated" (Emily, 19).

Fear, uncertainty, distrust

> "Like, fear and just not being in control anymore. Someone might – an authority figure just being like, you're sick, just take...Them not understanding. There's not a lot of trust. Like, you can't just trust this stranger, especially when you're a young person and you're an adult" (Emily, 19).

You've worked hard not to tell anyone

> "Especially on the first time. You may have only recently decided a week ago, all right, I may need to actually seek out some help. If it's been going on for a couple of years and you've never spoken about it to anyone you're not going to want to go down and sit with a complete stranger and just tell everything you've worked so hard to not tell anyone…… I remember when I first did go it was so confronting for.. then to just speak about it like that when I've never spoken to it about anyone and they're just like - it's just intense"(Alice, 17).

Really clinical

> "Some psychiatrist appointments feel, like, really clinical. It's like, it's not that you're actually talking about some really emotional stuff, because it's a doctor. Like, I've cried in a psychiatrist's appointment and they just sort of like, didn't even offer me a tissue… Like – damn" (Emily, 19).

There were also perspectives about young people's sense of the knowledge and effectiveness of what the counsellor or therapist was saying or advising.

Don't know enough

> "I tend to find that more - in my experience I've found that more with (student) counsellors because they tend to know a bit about mental health but not enough really because they know a bit about anxiety and depression, but I feel like a lot of them basically just read through the pamphlets here, which I know they didn't but that's what it feels like sometimes" (Sara, 14).

Doesn't work for me

> "And the other thing is, if they have a technique that they tried the sort of things, but that doesn't work for me, but that's sort of the only thing they tried to teach me, I guess. Like, mindfulness just doesn't work for me. I hate the word now. It's just definitely not a technique for me. And that has put me off a couple of psychologists, that being their main method, like, within CBT therapy" (Carissa, 18).

> "It just didn't help. Sometimes it just doesn't help and you're just like – you look back and you're just like I went there and nothing happened so why should I go back again"(Dinh, 16).

This section highlights many important aspects of the way services are delivered to young people, as well as the engagement qualities and skills of staff in helping roles. Four areas of care stand out. First, the need to have information available (and explained) so as to promote trust and clarity of expectations. Second, for therapists to have high quality and youth focused engagement skills and an awareness that gender is important for some consumers. Third, to ensure there is a good match between the knowledge and skills of the therapist and the issues being experienced. Finally, interventions need to be personalised to suit the preferences and needs of the consumer.

4.5 What would help make it easy for a young person to visit a service and see a worker?

We asked this question to hear about ways of promoting positive help-seeking experiences and reducing the barriers or issues to help-seeking raised earlier. Young people provided responses about community information, visiting services, building relationships with therapists and the consumer journey of care. Quality of engagement and confidentiality were central topics. There was also a significant emphasis on being flexible in delivering services to young people when they need it, rather than experiencing eligibility criteria or service boundaries.

Engagement

In terms of engagement, participants highlighted two important aspects, including the need for non-judgemental approaches (especially in the context of seeing school counsellors) and the positive aspects of working with a therapist when they are relatively young and are of the same gender.

Clarity about limits of confidentiality

Participants talked of experiences where confidentiality limits and information sharing practices hadn't been clear to them. They suggested that there should be clear information presented to them about the limits of privacy and duty of care. If counsellors feel the need to contact parents after a session then they should let the young person know this and say why they are concerned about safety issues.

Flexible service design – easy access

The broad theme of flexible service design emerged from different experiences of the ways services were offered or delivered. Individual suggestions offered by participants included:

- Flexible and easy appointments, rather than waiting times, where young people walking in to a service could get some face-to-face help on the same day (drop in model);
- Having more sessions on mental health care plans. Participants talked about the negative impact of running out of appointments and having to wait for a new year;
- Having online contact and support – so that young people can maintain some anonymity, or have a less intense conversation than in a face-to-face session;
- Working with parents to help them understand the nature of the experience and mental health more broadly – this was important for a number of young people from CALD backgrounds;

  > "I think parent support, family support is very important as well and sometimes cultural families will have very strong beliefs and are religious, and everything. Sometimes they might feel that mental health is not an okay thing to have, and I think while speaking to the young person, I think if the family are talked to as well and told that that young person is getting help and she's going to be okay, I think the family pressure decreases a bit because I think for the family, and it's a disappointment, is always a big thing" (Aisha, 14).

- Delivering sessions at the young person's family home, if appropriate, to help reduce barriers of going to a service.

  > "Well, one of the best things were actually – well, the main thing and the reason why I'm here today is actually, they came to see me, instead of – because I had a really,

really, really big problem with going places. I did not like the outside world at all. And when I was at (name of service), I didn't have a choice in going or not, because they'd come just randomly. My mum would know when their visit was, but she wouldn't tell me. And then they would randomly show up. And then you're just – like, you wouldn't have a chance to, like, let yourself escape… And that actually worked the best for me, because I never felt worried, I never felt concerned or anything like that. It was – and I'd actually talk to them because I felt comfortable and I wasn't worried about how I was going to get home, or what was going to happen on the way, or people looking at me, and that kind of stuff.… So I opened up a lot more" (Isaac, 18).

Community information and supports

A number of conversations pointed to ways of strengthening community information to enable consumers, families and school communities to better understand how services work and also how to support young peoples' decision making and service use. Perspectives expressed included:

- The need for descriptive information about what is going to happen at the psychologist's appointment. How does it work? What is it like?
- The benefit of young people with faith having access to cultural, religious leaders to give them spiritual perspectives about emotional wellbeing;
- The need to help school communities understand the different experiences of mental illness or distress, so that there is a shared understanding to support young consumers, rather than stigma, or the unknown;

  "if you experience any of this it's okay to seek help and this is what they do to help you', so it's not just such a mystery and it doesn't feel like such a massive step of courage… (Katrina, 14)".

- Community information should encourage young people to get help at an early stage rather than when signs and symptoms become worse;
- Teachers need to be supportive and develop the knowledge and skills to recognise that student behaviour is often the result of distress, rather than simply trying to avoid school work.

Interestingly, the focus groups generated many valuable points which correspond with principles of high quality consumer-centred youth mental health care. These were further built on by exploring what helped young people to stay connected to services.

4.6 Can you remember any key moments, or things that made you commit to keep attending appointments?

There were a variety of responses to this question that mostly reflected the value of engaging and effective helping relationships. These included feeling comfortable, being cared for, having explanations that make sense, learning new practices or skills and being inspired by peer stories.

Feeling comfortable in the therapeutic relationship

This was a theme expressed in all focus groups:

> "Very much the personal relationship with the person I'm seeing… (Which is) open for sharing things for me. A major thing is – humour is a very, like, not so much a coping mechanism, but how I relate to people all the time. Like, my current psychologist that I see, we have a lot of banter that goes on, which makes it easier for me to talk about some things. And I guess it is just a matter of feeling comfortable, and not feeling like you're being interrogated all the time."(Carissa, 18).

Being there for me

On a deeper level, participants talked about the value of feeling genuine care from their counsellor or therapist.

> "I remember I was out living by myself, doing all right, but still feeling really anxious and really ill at ease everywhere I went, and I remember I've gone to do my shopping, I'm in the car park freaking out a bit and I remember calling my psychologist and just saying, "I'm in the supermarket car park and I can't deal,"…. I remember that what she said calmed me down and we had an appointment the next week and I thought, all right. I think I'll make it until then" (Charlotte, 24).
>
> "And they (name of service) wanted to help. They just didn't feel like they were just there to get paid, they actually wanted to help you make sure – they'd give you a call once a week, see how you're going- 'call them whenever you want'" (Ashley, 23).
>
> "Something that made me keep going back is I was seeing a gender therapist for a while, and while he was helping me with the gender dysphoria and that kind of stuff, he genuinely cared about my wellbeing and he'd say, "Okay, we're going to put this aside for now, let's focus on you," and he really helped me for the few times I got to see him" (Shannon, 19).

Explanations making sense

Participants also talked about the importance of receiving explanations of their situation, including diagnosis, which made sense and matched their experience.

> "When I went to (name of service) at first – I kind of always start of being, like, is this going to be all right, it's like, not going to really do anything. When I was at (name of service) I started off like that and then the counsellor kind of gave – pretty much gave me an explanation for why I was – it clicked and that was like the first time that I realised why I acted the way I did. Yeah. So I kind of, like, continued seeing her"(Rosie, 24).

Learning skills that work for me

Participants talked about how learning skills or practices that made an impact on their mental health was a key factor in them staying with a service.

> "With my psychologist once again I was like, probably not going to do anything and then I think about halfway through, so maybe like the third or fourth session, she did like a technique with me and it just, like – just sat really well with me and I still use that. Like, yeah, I'll come back" (Rosie, 24).

Inspired by peer stories

> "..Just talking with people and just seeing the changes they've made – the workers – they've said that they've been smoking for the same amount of years and they gave it up and just like, yeah, I can do this too" (Ashley, 23).

4.7 What types of services, activities or people have helped you the most?

This question was designed to encourage overall reflections on effective care and interventions. Some young people felt this was a difficult question to respond to, others were able to highlight key turning points for their mental health. There was a significant diversity of responses. Some participants talked about messages of hope and encouragement, or therapists helping young people take small steps to recovery. Accurate diagnosis and medication was raised specifically by 2 consumers. Others talked about specific practices and insights they had learned. A number of participants described how visual arts – drawing and painting- had helped them the most. Some participants also talked generally about support over a period of time, such as community mental health, or the cumulative impact of a range of services.

Hope and encouragement

> "I was in the (name of hospital)….and this lady said to me about small – accepting small victories for what they are instead of a bad thing, and she said it to me as – because I had a fear of the outside world at the time, and she had a very bad past with social anxiety, and she told me, instead of looking at it as, oh, I made it to the letterbox, I didn't make it very far, it's like, it was a failure, she said to think about, I made it to the letterbox today. It was like, I've never made it that far before, it was

very good…. And then the other one was, I actually was in a very, very, very bad way, and I had just told myself that I was going to give the next thing I came along 110%". …"a dude named (worker) …….. and I necessarily did not like (him), I did not like him at all. But he was necessary for what I needed. He gave me the push and the drive that I actually needed. He taught me to use my anxiety as – not as a thing to stop doing things, but to look at as a – if I felt anxious, I'd do it to make myself know that I can do it…. I wouldn't be here today without him" (Isaac, 18).

"I was really moved by even people doing things like I had told a friend that I was struggling at work and I'm look, "I don't even know if I can do this job," and "It's pretty awful," and they sent me home with my lunch for the next day, which, I guess, for me I thought that was really symbolic because people want you to live, people want you to prosper, and that really made me want to get through it and then you've got doctors and psychologists on the other end who – you find the will go get through it and they help you find the way" (Charlotte, 24).

Different help at different times

"For me it would switch between one extreme and the other. Whether it be, a very intense one-on-one session would sometimes just be really, really helpful, and then other times it definitely wouldn't, and just a more casual, social, relaxed environment would be a lot better, say, a youth centre or a youth group that I was still able to talk about those issues, but not in such a forced environment, an intense, enclosed environment…I definitely think that a lot of the talking therapies need to be combined with physical therapies, whether that be just creating something while you're talking, something to distract yourself, I guess, at the same time as talking about issues, but also, yeah, as (participant) had mentioned, like breathing exercises.. rather than just talk, talk, talk, talk, because that doesn't always work for people. So I reckon a good combination of both needs to be addressed" (Carissa, 18).

Medications

"Oh, yes. I wouldn't be here without them. Not to, like pill push or anything like that. But it just, it changed my life. Like, it's the only reason I'm about to finish Year 12. It – seriously, I wouldn't be here today if I had not been put on them at such a bad point last year. It just wouldn't – I wouldn't be here. So that was definitely a big thing for me……Out of all the therapy and therapists I'd seen, and lots of things that worked and coping mechanisms, and didn't – medication was definitely the thing that worked for me (Carissa, 18)".

Muscle relaxation for anxiety

> "Well, I was in the hospital once….. (the worker came) ..to see me with this note thing about muscle relaxation. I'd never heard of it before. I had no like psychiatrists or therapists or anything that had mentioned it to me before. And (he) actually mentioned it to me, and that muscle relaxation got me through, like, so many hard nights, just … like, got me through so, so much, with bad patches, just that one little thing.…It had a big impact on me" (Isaac, 18).

Problem solving – acceptance

> So, (the therapist/counsellor) pointing out that, just sometimes you cannot change the past, so don't let that past get in your way…things that might happen, you know, I know that – do you have the control over that? If you don't have any control over that then what's the point of, you know? So it's just, focus on short-term and that actually help me a lot to, I mean, getting to that, kind of mental detail. So, one of the things he was actually pointing out, like, there's nothing you can do. There's no point of, you know, getting all knocked out and, so, if you cannot change that, if there any way you can impact that decision and just try to get on with your study" (Saja, 24).

Right diagnosis

> "Getting the right diagnosis, like, really – especially when you've got all convoluted stuff, it's really easy to get diagnosed with the wrong thing, and then it's just a symptom and it's not the actual underlying issue" (Emily, 19).

Mindfulness that works

> "I would say that learning meditation and mindfulness and things like that can often be really helpful…and just realising that the way that I'm thinking is what's causing a lot of my distress a lot of the time. It's actually my thoughts and I can change them. That's what clicked with me….. My psych read me this paragraph from (a book), and that was, like the moment when I realised I could actually, like, separate my thoughts from – yeah – what was actually going on and how I felt".....Because that first one I was like, I'm, like, over this happy breathing shit. I'm like, I don't want to close my eyes and, like, I find that stressful and then she reads this paragraph to me" (Rosie, 24).

Community mental health team

> "The community mental health team has been the best for me. I mean, I only started seeing them…but I gave them the phone call, it was like 2 am and I said, "Look, I'm suicidal, I'm going to do it now." Two people came over within about 10 minutes and then they gave me a phone call every day and they had someone who visited me every

couple of days. And the one person I've been seeing from the – is still seeing me now and he even came and saw me in the hospital" (Shannon, 19).

"And the other one would be – that one's got a huge name – community mental health, where they – every time I needed support they were there for me. And, like, I had terrible, terrible, terrible night times. And at night times I'd always have panic attacks and felt so, so bad. And I'd just come out of my room and then I would go and sit on the couch, and one of them would be there, and they'd sit there and talk to me and calm me down, and stuff like that. …I am very, very, like, happy with the way I am at the moment compared to what I used to be. And that would be, I'd say a lot of it is from myself, and a lot of it is from the support that I got from the community mental health" (Isaac, 18).

Art therapy

"Well, it's just one little thing, that is just when I get nervous, or when I feel – start to feel depressed or anything, that I would just start scribbling on a piece of paper…..The other major thing is music, basically. Singing along to favourite songs would just – whether it's the calming or upbeat, music really usually helps….I discovered (drawing and music) them myself a long time ago, before I even knew I had issues, basically" (Lucy, 18).

"Yeah, I pretty much paint from when I get home to when I go to sleep…... I love it, it's like my life" (Katrina, 14).

"Some teachers don't understand. Sometimes drawing, you need to do it when you're feeling upset." (Samantha, 14).

Pets

"I actually found that my cat helped a lot because I would lie there with my favourite blanket and she loves the blanket too and she would lie on top of me. I would sit there and pet her and listen to her purr and tell her all my problems. She's a cat so she can't tell anyone, yet…" (Sara, 14).

4.8 If you had to recommend a service for another young person, who was in a similar situation to you, where would you tell them to go?

In terms of recommending services, participants generally spoke positively about the range of services they had identified in question 2. The list included:

- Under a mental health care plan
- Youth Health Services
- CAMHS if under 18 then Youth Mental Health Services

- Women's and Children's Hospital psychology services
- Beyond Blue New Access
- Shine SA
- Mental Illness Fellowship of SA
- Headspace
- Streetlink Youth Health Service
- Eastern Mental Health Triage
- Beyond Blue
- Some individual psychology practice websites that had articles on mental health topics (e.g. anxiety)

These discussions included a range of practical suggestions from participants on choosing services. Some participants expressed reservations about recommending a specific service and others talked more about the importance of the skill base and reputation of the professional/ service. Here are some perspectives:

Someone highly skilled

> "I go to (name of psychologist) and she is actually tailored for support in that area and it is a lot better because she is specifically (trained) - she's worked with a lot of people and she knows a million different ways to do everything" (Sara, 14).

Youth services

> "I would tell them to go to my local youth centre, because I believe that's a good one, even though it's about to be shut down" (Carissa, 18).

Mental health NGOs

> **"**Everyone, like, from admin to people that – like, because it's such a – they actually do so much there. Every single person you meet is understanding, like, lovely. A lot of the people that work there have lived experience as well which is awesome. Yeah and they do, like – a lot of people there stay there because of how comfortable they feel there, and I don't think you get that from a lot of places" (Rosie, 24).

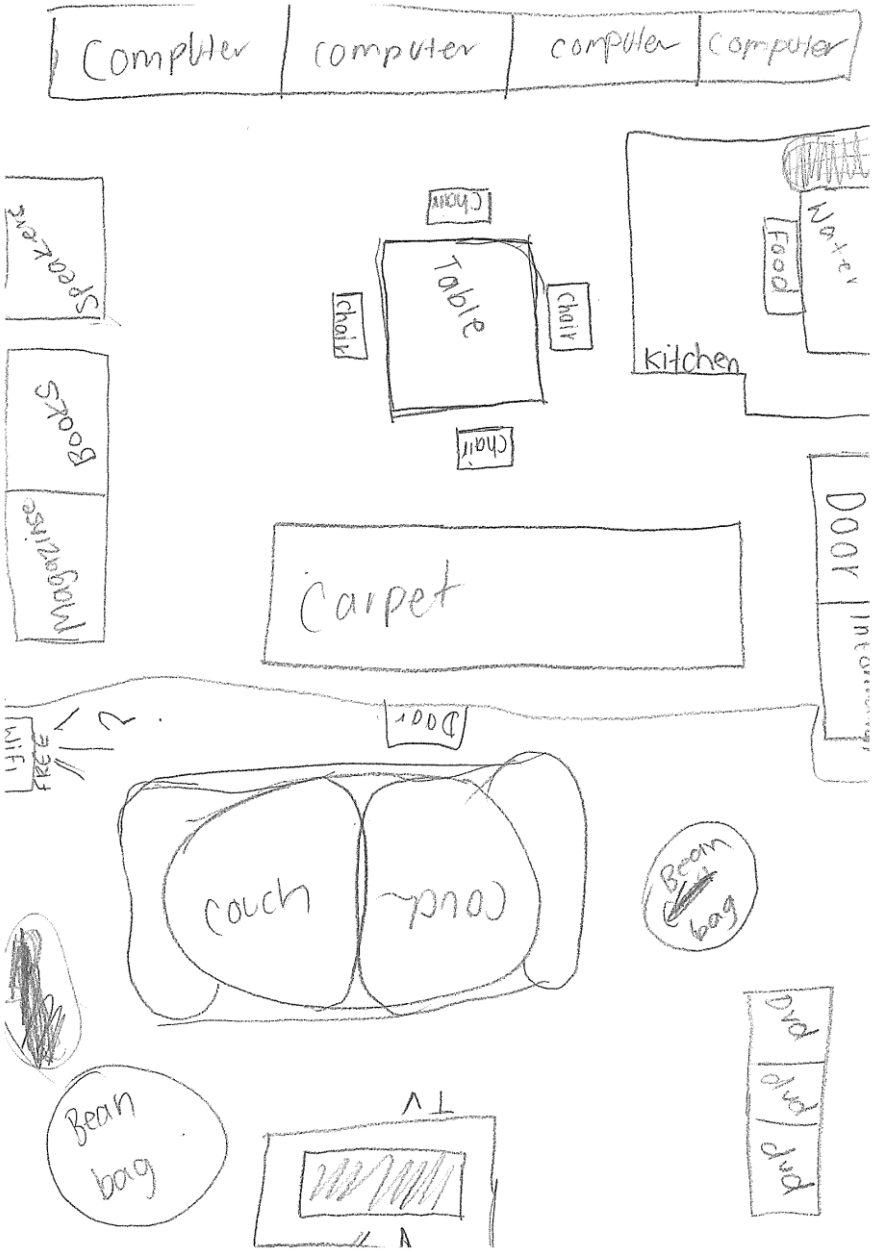
Headspace

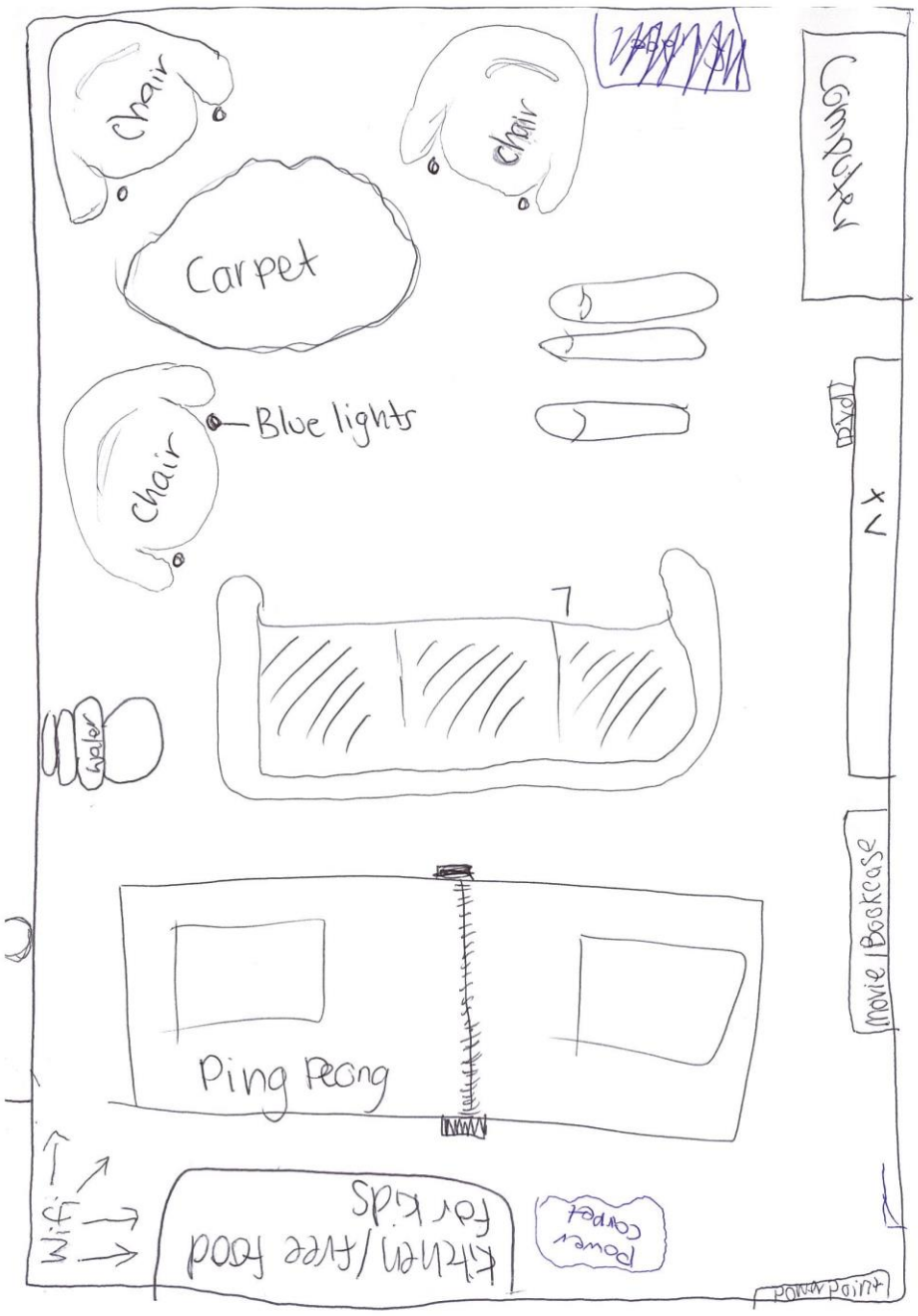
> "I think Headspace is more about realising that you're not alone and that there are many more people like you out there and it's not – because when you develop a mental health problem you feel like it's not right but I think at Headspace you realise that it's okay to have a problem like this and you can get help" (Aisha, 14).

4.9 *Youth-friendly services* – What would you change in order to make mental health services more youth-friendly and effective?

The last question provided a general opportunity for participants to connect their experiences or thoughts to how services might be better designed. These discussions acknowledged the points already made by participants, but at times identified new ideas. Some participants provided a drawing of what an engaging youth space may look like (Figure 1 below).

Figure 1 – The ideal support room/ space




Chair
Chair
Carpet
Computer
Chair
Blue lights
TV
Movie / Bookcase
Ping Pong
Kitchen / free food for kids
Power Carpet
wifi
PowerPoint

The following is a dot point summary of the suggested ways services could be better designed:

- More promotion in schools and connection of services to schools, like Doctors on Campus.
- Being able to book appointments online and have phone or skype based appointments.
- No waiting lists and more drop in models for getting help when you need it.
- Have male or female, and Aboriginal staff available on request.
- Flexible hours – be open after school or Saturday afternoon.
- Have computer and internet facilities, free wifi too, phone to use – easy to find information.
- Making appointments in less clinical settings - more ordinary and homely spaces, a place to chill.
- Encourage access and activities – have free food, or movies, TV, games, pool table, table tennis.
- Have group programs such as music, dance, art and cooking.
- Have 9pm-3am-drop offs from city (like some Youth Services) with follow up support during the week.
- Provide bus tickets to assist with transport home.
- Locate services in easy to reach locations, regional centres and the city.
- Locate services on the main street but have a side street opening for people who are sensitive to internalised stigma.
- Be clear about privacy, information sharing, and limits of confidentiality. Seek permission or advise when involving parents.
- Use less stigmatising and negative language such as ‘personality disorder’.
- Have understanding and kind administration staff.
- Ensure both doctors and nurses spend time engaging with us during hospital care.
- Don’t make us feel guilty for missing appointments.
- Have more sessions available on the Mental health care plans – private fees are too high and a barrier to attendance.

- Provide better follow up following hospital admissions, including supports in place and GP involvement.
- Provide continuity of care by minimising having to change therapists when therapy is going well. It is important to have someone who know you and is a key contact.
- Consider multi service models, like the Shine SA model, which can attend to physical and mental health needs and has spaces designed for young people.
- Have the option of home visits – if home is a comfortable place for a service.
- Make communication between appointments – phone calls, emails or texts.
- Provide short term safe houses for young people when there is stress at home.
- School communities need to be consistent in understanding and supporting us – not just during mental health week.
- Use the web, or other means to provide public feedback on good clinicians and what their special skills are – 'Rate your Psychologist', 'who's the best person to speak with'
- Provide more information on what the service is about, what will happen when we go there and who is going to be there.
- Provide information the right way – explain in person not just give you a pamphlet.
- Provide activities and support groups at school – not just talking groups but ones integrated with activities.

5. Translation

The findings of this research project indicate a number of key directions for the design and provision of youth mental health services. Funding bodies and service managers wishing to translate these findings into practice would:

1. Develop (or continue) regional networks which define referral relationships and care pathways for young people in need. These would involve schools, tertiary educators, primary health care, youth services and mental health services. Pathways would recognise the various ways young people seek help – self, family, friends and counsellors. They would also be clearly defined across primary, acute and specialist care services. Pathways would be well coordinated and easily experienced by young people and families needing to move between them or receive care by multiple providers.
2. Assist student counsellors and teachers to receive professional development in identifying mental health issues amongst student populations, supporting young people to access care and understanding the impact on their educational experience.

Prevention would also be a key focus. Training and policy on confidentiality and privacy would be enhanced.

3. Prioritise service designs and workforce competencies which are based on successful youth health engagement models and staff skill sets. Cultural safety and accessibility for diverse groups would be demonstrated. Stigmatised language and signage would be avoided and services would strongly consider co location with other health programs. Preferred services would demonstrate flexible access, delivery and communication options for young people and carers. Young people would receive assistance with transport to services.
4. Establish meaningful engagement and co design opportunities for young consumers regarding service design. These opportunities would have a focus on regional care pathways as well as specific services and programs.
5. Produce information about what it is like to visit a service for the first time, which informs young people about the role and expectations of receiving effective help
6. Promote a range of effective therapeutic and educational interventions based on the different preferences and needs of young people. Individual and group based activities, including peer work approaches, would be available.
7. Seek to extend mental health care plans to more than 12 sessions to avoid disruptions to care experienced by young people. This would recognise the time it often takes to find a suitable therapist and develop a recovery program which works.

6. Conclusion

This analysis of focus group discussions suggests a range of themes, experiences and preferences which can inform the ways mental health services are designed, promoted and available for young people. The perspectives provided by young consumers also highlighted the importance of areas such as community information and parental/family and teacher support in enabling easier pathways to help. Seeking help is influenced by availability of good quality information, confidential and supportive helpers. These can be friends, parents, student counsellors, teachers or work mates. Young people encouraged school communities to improve their capacity in these roles.

There are many influences which can affect young people's decision to arrange or attend initial appointments. Some of these are about stigma, uncertainty and fear about what will happen at a service, or what being diagnosed will mean, whether they will be negatively judged by clinicians or by parents, friends, family or the wider community. The cultural context of the family and community plays a significant role in decision making.

Participants in the groups have accessed a wide range of services. Student counsellors, GPs and psychologists were mostly used by participants. About 25% of young people had used public mental health services including inpatient and community service.

Once accessing a therapeutic service, the quality of the engagement and the impact of the service/intervention appear to be the two key themes which encourage young people to either stay connected or drop the service. Engagement includes communication by reception, admin and therapeutic staff. There are many subtle ways young people are put off. Sometimes they don't feel they are understood, or don't connect with the therapist. Gender may play a part. Sometimes, therapists go too fast with questions, or produce an overwhelming work plan, or 'go through the motions'. Diagnostic language can negatively impact on them.

Young consumers stay with providers when they can relate to them, when therapeutic explanations make sense and fit their experience, and when interventions work (or when clinicians provide another tool or strategy when one isn't working). Young consumers also need to feel confident in the knowledge and skills of the therapist. They pick up on genuine care, appreciating follow up calls, emails and texts between appointments, being able to call when needed, or home visits.

Collectively, participants indicated that different interventions are useful for different people. Young people reported positive and negative views about medication, mindfulness and cognitive behavioural therapy. Numerous participants suggested that groups, activities and arts-based practices should be offered. Care needs to be personalised.

A common discussion point was the time needed to get results for significant mental health issues. Young people want more than 10/12 sessions within a mental health care plan. This limit becomes a continuity of care issue for them.

There were many interesting suggestions made about design aspects of services. Engaging young people in the design of service facilities and service models will ensure that services will attract young people and best meet their needs. Some key features young people indicated are important include:

- flexibility – through drop-in service models, longer appointment times, home care, communication between appointments
- integrated services – through co-location and follow up care after hospital discharge
- appropriate staffing – friendly, skilled, gender mix and representing local languages and cultures.

7. Recommendations

Recommendation 1: HCA to promote the project's findings with the following health funders and service managers:

- Local Health Networks (LHNs) including the Women's and Children's Health Network, which operates Child and Adolescent Mental Health Services and Youth Health Services (My Health), and other LHN's delivering Youth Mental Health Services (Country Health SA, Central Adelaide Health Network and Southern Adelaide Health Network).
- Adelaide and SA Country Primary Health Networks, including key advisory and decision making bodies in the areas of mental health and young people's health
- Primary and specialist mental health providers including headspace and membership of the Mental Health Coalition of SA.

Recommendation 2: HCA to brief key health leaders in South Australia including:

- The Hon Leesa Vlahos, Minister for Disabilities, Mental Health and Substance Abuse.
- Mr Chris Burns, SA Commissioner for Mental Health
- Vickie Kaminski, Acting Chief Executive Officer, SA Health
- Amanda Shaw, Guardian for Children and Young People

Recommendation 3: Health Economics and Social Policy Group to ensure findings inform the planning and modelling associated with the Mental Health Service and Workforce Project. HCA and HESPG should also aim to publish the projects findings within the health research literature.

Recommendation 4: HCA to promote the project with peak bodies including:

- Youth Affairs Council of SA
- Mental Health Coalition of SA
- Royal College of General Practitioners
- Australian Clinical Psychology Association
- Consumers Health Forum of Australia

Recommendation 5: HCA to integrate findings into ongoing functions including advocacy and person centred training programs.

8. References

Australian Institute of Health and Welfare (2011) Young Australians: their health and wellbeing 2011. Cat. no. PHE 140 Canberra: AIHW.

Cranwell, K., McCann, T. V. & Polacsek, M. (2015) Join the conversation: Evaluating the effectiveness of experience-based co-design in improving the client experience of mental health transition across health sector interfaces. APHCRI.

Fildes, J., Robbins, A., Cave, L., Perrens, B. and Wearring, A. 2014, Mission Australia's 2014 Youth Survey Report, Mission Australia.

Lawrence D, Johnson S, Hafekost J, Boterhoven De Haan K, Sawyer M, Ainley J,

Zubrick SR (2015) The Mental Health of Children and Adolescents. Report on the second Australian Child and Adolescent Survey of Mental Health and Wellbeing. Department of Health, Canberra.

Slade, T., Johnston, A., Oakley Browne, M. a, Andrews, G., & Whiteford, H. (2009). 2007 National Survey of Mental Health and Wellbeing: methods and key findings. *The Australian and New Zealand Journal of Psychiatry*, *43*, 594–605.

Wolf, J., Niederhauser, V., Marshburn, D. & LaVela, S. (2014) Defining patient experience. Patient Experience Journal, Vol 1.

Appendix one – Focus Group Questions

1. How do young people work out that they need to get some help?

2. What are the services or people that you have visited to get help?

3. When young people have decided they want or need to see a doctor or psychologist, what might be some things which stop them from going?

4. When you went to get help for the first time, can you remember any things that put you off, or made you feel you wouldn't go back?

5. What would help make it easy for a young person to visit a service and see a worker?

6. Can you remember any key moments, or things that made you commit to keep attending appointments?

7. What types of services, activities or people have helped you the most?

8. If you had to recommend a service for another young person, who was in a similar situation to you, where would you tell them to go?

9. *Youth-friendly services* – What would you change in order to make mental health services more youth-friendly and effective?