

# Youth led like minds like mine project

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# Introduction

The Youth Led Like Minds Like Mine project was commissioned by The Mental Health Foundation of New Zealand. The project is made up of three key components:

**Part One:** An investigation into stigma and discrimination experienced by young people with mental health issues.

**Part Two:** Young people who took part in the research will be invited to become part of a youth led group to help develop solutions to the issues identified. They will be supported by a project co-ordinator from The Mental Health Foundation. The Collaborative will then conduct an evaluation of this part of the project, evaluating the level of youth participation in the leadership and growth of the programme.

**Part Three:** After a period of time, determined by all those involved, The Collaborative will conduct an early outcomes review, evaluating the impact of any initiatives developed.

Part one of the project was carried out by The Collaborative for Research and Training in Youth Health and Development (The Collaborative). The findings of the research conducted for part one of the project, are outlined in this report.

**The purpose of the research was to explore young people's perceptions of:**

- stigma and discrimination faced by young people with mental health issues
- potential solutions to issues identified
- potential leaders/participants for a peer based group, which will explore the development of initiatives to reduce the problems identified

**The aim of the research was to benchmark young people's experiences and thoughts about stigma and discrimination in relation to:**

- the community
- family and friends
- school, recreational groups, cultural groups and workplaces
- accessing adequate mental health services and support
- strategies to counter stigma and discrimination

The researchers were Sarah McKay and Sue Bagshaw, with support from Ria Schroder from The Collaborative. The project coordinator from the Mental Health Foundation was Steve Carter.

# Methodology

The Youth Led Like Minds Like Mine research involved a qualitative methodology. A qualitative approach enables participants to self define problems and solutions, and recognises participants as 'experts' who have unique knowledge and insight into their own experiences (Patton, 2002).

## Ethics

Ethical approval for this study was obtained from the Upper South A Ethics Committee.

The Collaborative is committed to ethical research and evaluation practice. In line with its ethical guidelines the researchers undertook to ensure at all times that:

- all participation was voluntary
- informed consent was sought and gained from each participant
- the right to privacy and confidentiality was respected for each participant
- the dignity and worth of every individual and the integrity of families/ whānau and the diversity of cultures was respected

All names and identifying details of participants have been changed to preserve the anonymity of the participants.

## Recruitment

Recruitment of participants was from high schools, health organisations and support groups who work with young people with mental health issues.

## Focus Group and Interview Procedure

There were five focus groups and four individual interviews. The research team decided to include participants from different groups to explore a wide range of perspectives and experiences.

## Semi-Structured Question Guide

Each of the focus groups and interviews followed a similar question format that included questions about the participant's perceptions of:

- attitudes to young people with mental health issues
- effects of stigma and discrimination on seeking help
- effects of stigma and discrimination on accessing mental health services
- effects of stigma and discrimination on interactions with organisations, and on employment, recreation, and study
- possible solutions to the issues identified

These questions were framed as open-ended questions in order to encourage participants to share as many of their own ideas as possible, without being exposed to the preconceived ideas of the researcher.

# Terminology

'Youth consumers' – young people who have experienced mental health issues

'Participants' – young people involved the focus groups and individual interviews

'GLBT' - gay, lesbian, bisexual and transgender young people

'YSS' – Youth Speciality Service, a youth mental health service for 13 to 18 year olds.

'CAF' – Child Adolescent Family Mental Health Service

'GP' – General practitioner

'Stigma' - the negative responses and attitudes of others towards young people with mental health issues (Martin et al, 2008)

'Discrimination' – negative actions towards young people based on stigmatising beliefs and attitudes about mental health issues (Martin et al, 2008)

'Self stigma' - the young people's attitudes and behaviours towards themselves, which result from internalising the stigmatising attitudes of others (Peterson et al, 2008)

## Language Used in Research Report

Many of the themes of this report are often contested within broader society. This is reflected in the different perspectives, language and labels used by people to represent them.

Therefore the researchers recognise that the language used in the report, reflects that of the world view of the researchers and the young people and may not necessarily be congruent with other definitions.

The researchers valued the use of 'real language to tell real stories' from participants and believed discounting this would not support, but marginalise their perspectives. Subsequently, they were careful to use the language of the participants in the report. For example, during the research young people were more likely to respond to the questions about 'the negative attitudes of others towards mental health issues' than questions that used the terms stigma and discrimination. Therefore the words stigma and discrimination are often referred to in the main body of the report as the 'negative attitudes of others.' When used in discussions with young people this term reflected a broad definition of 'attitudes', encompassing the negative actions of others as well.

# Findings

This section provides an overview of the main findings of this report. These include:

**Attitudes towards young people with mental health issues**

**The impact of negative attitudes on how young people see themselves**

**The impact of negative attitudes on social life and relationships**

**Experiences with:**

**Organisations**

**Employment**

**School**

**The media**

**Seeking help and support from health services**

**Possible ideas for how to create change**

# Attitudes towards young people with mental illness

## MAIN THEMES:

- 1.1 negative attitudes towards young people with mental health issue
- 1.2 positive attitudes towards young people with mental health issue
- 1.3 participants ideas about where negative attitudes come from
- 1.4 how young people would like people to relate to them

## 1.1 Negative attitudes towards young people with mental health issues

### The main negative attitudes experienced were:

- people blaming the young person for mental health issues
- people blaming the young person's circumstances for mental health issues
- attitudes based on fear of mental health problems
- the idea that young people with mental health issues are different
- bullying, teasing and gossip

### → Blaming the young person for mental health issues

### Attitudes that blamed the young person for their mental health issues:

- it's a young persons choice to have mental health problems
- young people should be able to fix mental health problems for themselves
- young people with mental health issues are 'just trying to get attention'
- young people should have no problems because life was 'harder in our day'

"Or like you said, 'Just get over it'. You know, just like, go out with friends more. It's not just that, you know. If it was that easy, we wouldn't be here."

"People seem to think that, and treat you like it's a choice you've made and they seem to think that you've chosen to be it and it's your own stupid fault. ...'why would we care?'"

"...the younger you are the more older people just kind've brush you off and just think that they are acting out (and) don't actually have a mental health issues..."

## → Blaming the young person's circumstances for mental health issues

### Attitudes that blame mental health issues on the young person's circumstances saw mental health issues as the fault of:

- inherited family issues
- the young persons peers – such as friendships with other young people with mental illness
- family dysfunction
- the fault of the diagnosis or health professional

“...with my family they were like, ‘Oh, it’s genetic, it’s okay, you know, your granddad - it’s all family related so, yeah, it’s okay.’ But it wasn’t okay.”

“...(her mum) thought she was just trying to be like that friend (with mental illness), looking for attention, and trying to be more like the friend.”

“...my mums...like, ‘those counsellors they’re giving you all these ideas.’”

## → Fear based responses

### Attitudes based on fear of young people with mental health issues were:

- people with mental health issues are unpredictable, dangerous and violent
- fear of associating with young people with mental health issues
- wanting to know a person with mental health issues is ‘under some sought of control’

“...and (if you) are told that you are with someone who is psychotic... it is a pretty scary thing to hear...like they are an axe murderer or something...”

“...in the wider community it’s just like...They want to know that you’ve been on medication and that you’re under some sort of control.”

## → Mental health issues as ‘difference’

### Attitudes that see people with mental health issues as ‘different’ see them as:

- ‘not normal’/ ‘crazy’
- needing be in a psychiatric ward
- becoming a different person
- someone who you wouldn’t associate with
- particularly different if they are from a visible youth sub culture

“...and most of my family were just freaked out and treated me differently for ages and then they realized I was still the same person...”

“...if someone finds out that someone has got a problem... they are quite standoffish, they don't actually listen...”

### → Bullying, teasing and gossip

#### Bullying, teasing and gossip were:

- personally experienced by some young people
- observed happening to others
- related to the friendships a young person had before they became mentally ill

“...and then when I went back to school, everybody knew; they'd look at me strangely. There was a lot of gossip around it all...it was really hard...”

## 1.2 Positive attitudes towards young people with mental health issues

Participants gave examples of a number of positive attitudes and responses towards young people with mental health issues.

#### The main positive attitudes experienced were people:

- being supportive
- being willing to try and understand
- continuing to treat young people in the same way
- being willing to offer practical help and support

“Having people to support you, who understand, who are just there for you, (are) like stepping stones, you have the support to get through it.”

“...she filled in the areas (when) I couldn't think for myself, so she thought for me and she was telling me what to do and I would just have to follow that, because I just could not think for myself.”

## 1.3 Participants ideas about where negative attitudes come from

Participants talked about their ideas of where negative attitudes about mental health issues come from.

#### Two main ideas about what causes negative attitudes were discussed:

- a lack of understanding
- the effect of age, culture and class on people's attitudes

### → A lack of understanding

The most common explanation from participants of why people have negative attitudes towards mental health issues was a lack of understanding. A number of reasons for 'a lack of understanding' from others were discussed.

#### Reasons for peoples lack of understanding towards young people with mental health issues:

- a lack of information about and experience of mental health issues from others
- a lack of understanding leads to fear
- people not knowing 'how to react'
- people seeing mental health issues as a burden
- understanding is a process that is relational and often takes time

"That would be the main thing, understanding, if people would take the time to understand, you know, it would just make things so much...easier..."

"I think people don't like to relate to people with mental health issues because... they don't really know how (to) act and react around them."

"Some people do not know what to do, so they kind of either try and stay away from you or I guess turn against you sometimes..."

### → The effect of age, culture and class on people's responses to mental health issues

Participants also talked about the effect of age, culture and class on people's attitudes such as the way in which different family backgrounds and generational differences affect people's attitude towards mental health issues.

#### Demographics influence people's attitudes towards mental health issues including:

- age
- family background and social status

## 1.4 How young people would like people to relate to them

This section outlines participant's thoughts on unhelpful and helpful responses from people (such as friend's and family) when they find out about mental health issues and undertake to 'support' young people.

### 1.4.1 Unhelpful responses from others

#### Unhelpful responses were identified as:

- people wanting a 'quick fix' for their problems
- participants feeling that they came to 'represent mental health issues'
- people asking how they are, but not really wanting to know
- over reactions to their mental health issues such as constant monitoring
- being frequently asked about their mental health issues
- people only being willing to help if they think 'they are in crisis'
- pressure to talk about their mental health issues, when this may not be helpful
- unhelpful religious responses

"...they might be (supportive) for a while, but then they realise that there isn't a quick fix and they're actually going to have to be in it for the long haul..."

"I spent more time helping them and then, of course, I was getting worse because I was helping them..."

"Because its, 'oh, that's okay, they're not going to kill themselves, it doesn't actually matter, they don't need any help or support at all'."

"Sometimes if you're not religious...people praying for you... it's a nice thought, but it can be really invasive."

### 1.4.2 How young people would like people to relate to them

#### Participants said the most helpful responses to their mental health issues from others were:

- people being willing to 'just be there for them'
- people genuinely trying to understand
- people continuing to support them over the long term
- people continuing to interact with them and treat them like a 'normal' person
- firm but caring responses are helpful when appropriate
- people being willing to find out how young people would like to be supported

"They don't know how easy it actually is just to support someone with mental health issues. They think it's a really, really big thing. But just being with the person and hanging out with the person and talking and just being there and just doing stuff is actually all, most of the time that we need..."

# The impact of negative attitudes on how young people see themselves

This section explores the impact of negative attitudes on how participants see themselves and their mental health issues. This can also be called self stigma – when a person experiences negative messages and behaviours towards their mental health issues this can affect how they see themselves (self esteem) and their mental health issues.

Self stigma can also influence how people behave, such as someone hiding their mental health issues because of fear of how others might react if they find out about them. We have called this strategies young people develop to manage stigma and discrimination.

## 2.1 The impact of the attitudes of others on how young people see themselves

Young people discussed how negative attitudes such as people judging them, impacted how they viewed themselves and their mental health issues.

### Attitudes from others towards mental health issues affect young peoples:

- self esteem and emotions
- beliefs about their own mental health issues – such as positive reactions from others that challenged their belief that they would always be treated badly by others because of their mental health issues

“...it is a low judgement of themselves...I guess that they will always be judging themselves, like ‘why doesn’t anyone listen to me, why do I have to fight so hard just to get accepted or to be appreciated for who I am’, you know, it is like, ‘why, why, why, why’.”

“...it brings you down because...it just makes you feel like less of a person...because they’re not treating you as normal.”

“Even if you put on that rock hard front of ‘I don’t care’, deep down inside you are dying.”

“...and then actually I found the people who (I) didn’t think...were friends, had actually come forward to be your friend.”

## 2.2 Strategies used to manage negative attitudes from others

This section outlines the strategies young people use to deal with potentially negative attitudes from others toward their mental health issues. This includes hiding emotions and limiting activities and relationships because of fear of other people’s reactions to their mental health problems.

**Fear of people finding out about mental health issues was a significant barrier to:**

- joining groups
- asking for help with mental health problems
- social life and relationships

**The main strategies used by young people to limit negative responses from others were:**

- hiding emotions
- pretending everything was alright
- not asking for help
- picking the 'best day' to do things
- avoiding social situations

"...I almost felt I had to act a certain way and after a while I just stopped sharing my emotions...and bottled it up."

"Avoiding kind of having in-depth conversations with people..."

"My best friend refuses to accept my health issues....So if I'm really low...I can't text him and say, 'oh hey, can we go out for a coffee, I'm feeling real crap?' He doesn't want to know about it, I have to be up and bubbly and all of that."

### **2.3 The negative affect of some of these strategies**

Many participants remarked on how unhelpful some of the strategies they used to manage negative attitudes from others were.

**Young people discussed the negative affect of some of these strategies. This included:**

- 'bottling up' emotions worsens mental health issues
- the use of self destructive ways to express emotions when you 'bottle them up' such as getting angry with people and taking drugs and alcohol

"You bottle up and it gets worse and worse and then it explodes at the worst time.... and (your) saying very self-destructive (things) and using substances and stuff."

"And then it is real hard if you are like trying to medicate your emotions with alcohol, drugs to feel better."

“Well, it comes out eventually. You bottle it up...(then it will be) the slightest little thing and... ‘bang’ and you’ll take it out on that person and then you’re ...like - it was just nothing, but you had to just let it out eventually.”

## **2.4 Other issues that affect self and wellbeing**

The negative attitudes of others towards mental health issues were not the only issues that affected how young people viewed themselves and their experience of mental health issues.

**Participants acknowledged that other issues also affect self and wellbeing.  
This included:**

- the pressure to fit into wider youth culture
- developmental issues such as the stress of ‘managing teenage emotions’ and mental health issues

“...(we) don’t have previous experiences (of mental health issues) ...there is a lot of confusion... (and) we sort of make quick judgements of ourselves as teenagers...wanting to keep up with everyone...”

# The impact of negative attitudes on relationships and social life

Participants discussed the affect of stigma and discrimination towards young people with mental health issues on their relationships and social life.

## The main themes in this section are:

- 3.1 the impact of social isolation on wellbeing and recovery
- 3.2 family support is particularly important
- 3.3 the impact of the social isolation on joining groups
- 3.4 how people socially isolate young people with mental health issues
- 3.5 social isolation and young GLTB people with mental health issues

### 3.1 Wellbeing and recovery

Young people were emotive when talking about the impact of social isolation on their lives, saying that it significantly influenced their mental health and wellbeing. Social connections were identified as a significant source of support for recovery and lack of social support was connected with mental health issues becoming worse over time.

“I found...that if I was alone...you just feel alone and you slowly start to get worse, but when you find that person that you can connect with or people that you can connect with, you start opening up, you start healing and you start getting better.”

### 3.2 Family support

Many participants commented about the importance of social and emotional support from family members. This was identified as particularly important for accessing mental health services as for many participants it was through parents that they initially sought help.

“Whanau help, family help...friends help, you know, just being understood...when I was going through my ordeal friends (and) family meant the world to me...like they were the ones I could depend on...”

### 3.3 Joining cultural and recreational groups

Discussions revealed that some cultural and recreational groups are supportive and some are not for young people with mental health issues. Fear of people finding out about mental health issues is a significant barrier to joining groups.

### 3.4 How people socially isolate young people with mental health issues

When asked how people socially isolate young people with mental health issues participants gave examples such as people ignoring them, treating them differently and avoiding them.

### **3.5 The impact of lack of social support on young GLBT people**

Social and familial support toward their sexual orientation was seen as crucial to for mental and emotional wellbeing in young GLBT people. Of particular importance was support from family members in helping young GLBT people to cope with the negative attitudes of others towards their sexuality. In many instances it is unclear the extent to which underlying mental health issues were exacerbated by negative attitudes towards being GLBT or mental health issues were caused by this, or both. Either way, it is evident that the stigma of being GLBT and subsequent affects on social connections greatly influenced their mental health and wellbeing, particularly the stress associated with 'coming out' to others about their sexual orientation.

# Experiences with organisations, Employment, school and the media

Participants discussed the experiences of young people with mental health issues in various settings.

## These settings were:

- 4.1 Organisations
- 4.2 Employment
- 4.3 School
- 4.4 The media

## 4.1 Organisations

Most young people did not identify any organisations who they had significant experiences with, because of their mental health issues. Those who did talked about having both positive and negative experiences with a variety of organisations. Examples participants gave showed that their experiences were largely dependant on the type of interactions they had with people they saw in the organisation.

### → Positive experiences with organisations

Positive experiences were based on the type of interactions young people had with people in the organisation. These were based on the person in the organisation:

- having knowledge of mental health issues
- showing understanding
- having a positive attitude
- being helpful
- being friendly
- being non judgemental

What was particularly important was that the person they saw was able to communicate in an understanding way.

### → Negative experiences in organisations

Negative experiences were also based on the type of interactions young people had with people in the organisation, although some organisational issues were also identified. Organisational issues included processes that discriminated against young people with mental illness such as Work and Income New Zealand's eligibility criteria for a social welfare benefits

### Examples of negative experiences with organisations were:

- not being listened to
- not having mental health needs taken into account
- people trying too hard to identify with them and not respecting their privacy
- people with little knowledge of mental health issues, who were less likely to be understanding
- discriminatory organisational processes such as Work and Income New Zealand's eligibility criteria for a social welfare benefits

“...with a case manager...she had had mental health issues...before. I was in there for...two hours with her talking about it...and there were lots of people around and... I just got really nervous about it.”

“...if you are young, able bodied, mentally skilled... you are not 60 years old and...in retirement, you have got your whole working life ahead of you, (they think) you should be in the workforce and you should be earning your keep...”

## 4.2 Employment

Most participants had no comments about employment as they were still at school and/or had not participated in employment.

### The main employment related issues were:

- the effect of work conditions and relationships on employment
- worry about how mental health issues might affect ability to maintain employment
- not knowing whether mental health issues would get worse and how this might affect ability to work
- worry about being able to 'get up in the morning' and attend work every day
- a number of participants gave examples of strategies they used to address their concerns about employment such as not talking to employers about their mental health issues

“...should I tell my prospective employer that I've had a mental health issues or not? I tend not to tell them. I get really, really anxious about what they might think of me... (so I) just leave the whole subject out of it.”

**These were connected to stigma and discrimination as each was significantly affected by:**

- whether they were able to talk to prospective employers about their mental health issues
- whether they were able to have flexible working conditions, where their mental health issues could be taken into account
- the level of support and understanding available to them in the workplace
- the underlying attitudes within the organisation towards young people and mental health issues, which affected how they were treated and their wellbeing

Young people said that the biggest barrier to employment for them was not whether they could do the job involved, but the environmental and employment conditions associated with it. They said when employment conditions were flexible and employers and workmates understanding; it made a significant difference to their ability to sustain employment.

## **4.3 At school**

Stigma and discrimination towards young people with mental health issues at school was one of the most significant issues discussed. Whether the school had previous experience in dealing with mental health issues was one of the main influences identified on the schools ability to effectively address the needs of young people.

### **4.3.1 Issues for young people with mental health problems at school**

**The most significant issues for young people with mental health problems at school were:**

- study/ workload in school
- teasing and bullying in school
- being put in the 'too hard basket'
- being GLBT at school

#### **→ Study/ workload in school**

One of the most significant issues for participants was the affect of their mental health issues on their ability to maintain school work. Whether they were supported with this by the school had a significant impact on success at school for a number of young people. Participants discussed the development of a cycle in which their mental health issues negatively affected their study and the stress of not keeping up with work worsened their mental health.

“At school...you are still trying to still do your work but you just can't concentrate on it, so the emotions are running around in your head and you just can't stop thinking about (them), so you can't get your work done, so you fall behind, and you feel worse...”

### → **Teasing, bullying and gossip in school**

Issues such as teasing and bullying in school were also significant issues identified by young people. They also discussed ways in which they tried to mitigate against the negative effects of gossip such as 'trying to hide' their mental health issues.

'Rumors, and secrets in schools, you feel left out, ashamed of the fact, so you try to hide it.'

### → **Being put in the 'too hard basket'**

One participant talked about being put in the 'too hard basket' and feeling abandoned at school because of their mental health issues, affecting their ability to succeed at school.

### **4.3.2 Experiences seeking help at school**

For many school was the first place they sought help with mental health issues and/or mental health issues became apparent. A number of young people said they had negative experiences trying to seek support with their mental health problems at school.

#### **When talking about experiences of seeking help and support with mental health issues at school important issues were:**

- a lack of awareness in schools of youth mental health issues and services
- priority given to disruptive students, affecting support available to others
- beliefs that young people are 'just trying to get attention'
- a lack of processes to support young people with mental health issues
- confidentiality is a significant concern
- a lack of holistic support

"...they didn't really seem to know...about how to work with you or mental health issues, or don't really know about any of the things that are out there that can help (you)... which to me seems pretty stupid..."

"They (need) help but they (disruptive students) really suck up the resources and...they take up the counselling time."

"...and (they think) teenagers are doing it for attention...they need people who...aren't going to get annoyed and agitated at you..."

"...and you go and see this...counsellor... and he says, 'start problem solving', it is not really giving (you) any motivation to carry on with the day. There is no overall support to actually get through your schooling..."

## 4.4 The Media

The majority of depictions of mental health issues in the media discussed by participants were negative. The most common portrayals identified were 'extreme' depictions in which only a few stereotypical symptoms and types of mental health issues were emphasised, in movies and on television.

### 4.4.1 Negative portrayals of mental health issues in the media

#### Negative portrayals of mental health issues in the media were identified as:

- often depictions are of 'severe' mental health issues and symptoms
- derogatory depictions
- people are portrayed as 'defined' by their mental health issues
- limited and one dimensional portrayals
- mental health issues are frequently connected to drugs and violence
- people with mental health issues are sometimes depicted as socially isolated and impaired
- depictions reflect peoples perceptions of what they think mental health issues are like
- mental health issues in young people are portrayed as mainly a developmental issue such as 'just part of being a teenager'

### 4.4.2 Positive portrayals of mental health issues in the media

#### Positive portrayals discussed were:

- the Like Minds Like Mine adverts
- music and poetry with lyrics that participants could identify with

#### ➔ The Like Minds Like Mine adverts

Comments about the Like Minds Like Mine adverts were largely positive. Young people said the way that the adverts challenged people to know someone before they judge them was particularly effective. The positive effect of portraying people with mental health issues as 'normal' and 'just like everyone else' was also discussed.

#### ➔ Music and lyrics young people could identify with

A few participants also talked about the support they received from music, particularly when they could identify with lyrics that showed other people 'going though' what they were experiencing.

### 4.4.3 A lack of portrayal of mental health issues in the media

A number of participants could not think of any depictions at all. One young person remarked that a lack of portrayals of mental health problems in the media reflected the tendency of the media to 'hide' rather than acknowledge mental health issues.

# Help and support from health services

This section explores experiences of stigma and discrimination associated with health services and support. It also addresses other barriers that hinder adequate access to mental health services and support for young people. While some of these barriers are not directly linked to stigma and discrimination they are included as participants said that access to adequate mental health services for young people is very important for recovery and wellbeing.

## The main themes in this section are:

- 5.1 the importance of mental health services for young people
- 5.2 deciding to seek help
- 5.3 other barriers to seeking help from mental health services
- 5.4 barriers to ongoing support from mental health services
- 5.4 positive experiences with health practitioners

## 5.1 The importance of mental health services for young people

### Mental health services for young people are important because:

- mental health issues are prevalent (common) in young people
- early intervention is important
- it is not always helpful to rely solely on family or friends for support
- when help and support is delayed mental health problems worsen

## 5.2 Deciding to seek help

### Participants gave examples of how their own perceptions (ideas) about mental health issues (self stigma) and developmental issues affected when and how they decided to get help with mental health problems. These included:

- deciding to seek help can take time
- the challenge of recognising their mental health issues – ‘knowing that you need help’
- developmental issues
- fear of potential reactions from health practitioners

### ➔ The challenge of recognising mental health problems

A number of young people said a significant barrier to accessing health services was their initial difficulty in recognising that they were mentally unwell. One of the main

reasons given for this was they didn't want to accept that they might have a mental health issues, so they tried to ignore it.

"I just (thought), no I don't need it, I don't need it at all, it will pass (and) things will sort (themselves) out."

### → **Developmental issues**

Developmental issues were highlighted by participants as having a significant influence on young people's ability to ask for help with mental health issues.

#### **Developmental issues connected with seeking help included:**

- the affect of young people's emotional maturity and inexperience on asking for help, such as a greater tendency to worry about what people might think of them
- a lack of experience making it harder for young people to identify their mental health problems and seek help
- young people may believe that their mental health issues are not 'important enough' to access health services
- young people may not feel confident asking for help with mental health issues

"The big thing with people seeking help is they're afraid of someone turning around and saying 'no, you are just being stupid'."

'Sometimes you don't know you have a mental health issue so don't think about how to get out of it.'

"...at a younger age it is harder to ask for help...you (don't) realise it as being a mental health issue...you might just think well maybe everyone thinks the same way and I am just like... I am not just coping with it very well."

### **5.3 Other barriers to seeking help from mental health services**

#### **Other Issues that affected access to mental health services were:**

- family support is essential
- not knowing where to access help or being offered adequate options
- a lack of health practitioners and support people with knowledge of youth mental health issues
- a lack of youth services for specific mental health issues
- finding out about mental health services
- particular issues for Maori, GLBT and rural young people

## → Maori, GLTB and rural young people access to mental health services

### Issues accessing mental health services for Maori young people:

- health professionals that they could not culturally relate to or who did not make an effort to relate to them as Maori
- a lack of processes to refer them to someone who might be more appropriate
- the importance of recognising whanau and not seeing mental health services as the only significant sources of support and recovery for the young person

### Issues accessing mental health services for young GLTB people:

- GLBT participants also said they would have liked to have the option to be referred to a counsellor with experience in working with GLBT young people.

### Issues accessing mental health services for young rural people:

- it can be harder for young people from rural areas to ask for help
- in a small community where 'everyone knows everyone else' there is a greater risk of people finding out about mental health issues
- living in a rural community had benefits as well, such as young people potentially receiving more help and support from a community with close ties
- finding an appropriate service or person to talk to in a rural area was a significant issue
- the distance rural young people had to travel to access mental health services in Christchurch
- a reliance on adults such as parents who were not always supportive, for travel to Christchurch based services

## 5.4 Barriers to ongoing support from mental health services

Experiences of mental health services were largely dependant on the quality of interactions young people had with individual mental health practitioners. Although other issues such as waiting lists and multiple referrals were also significant issues.

“...It's not the health service, but the actual person you see.”

“Well, he laughed at me about my anxiety and kind of made a joke about it. And I'm not the only person, I actually know several other people who've been to see him and agreed specifically with me. Very harsh, especially for with working with teenagers...when I was there he was way too harsh...”

“ (I) just pretty much (got), 'oh you're a horrible person, get over it'. And... you cannot cope... because you're not choosing to do it...”

**Barriers to ongoing support once participants accessed mental health services were:**

- experiences are dependant on the quality of interaction with health practitioners
- uncaring and insensitive health practitioners
- communication issues with practitioners
- a lack of understanding about youth mental health issues by practitioners
- waiting lists
- multiple referrals
- a focus on efficiency and cost
- differences between adult and youth mental health services
- being offered too much help is also unhelpful sometimes
- interactions with health services are also influenced by the attitude of the young person

**→ Communication issues with practitioners**

**Communication issues with practitioners included:**

- a lack of information about their treatment from health practitioners
- not feeling that the practitioner had enough time to, or was unwilling to listen to their perspective on what was happening for them
- feeling frustrated by health practitioners who say that 'they understand', when they don't

"I was given a bad case manager; a very bad case manager at (a youth mental health service) - I didn't know what I'd done to get (into the service). He didn't tell me."

"...it is like having a voice taken from you, you feel like you can't talk to start with, (and) you feel so miserable and so unsure of yourself when you (end up)...talking to people questioning your legitimacy, (and being) a young person that is even further engrained..."

**→ A lack of understanding about youth mental health issues by practitioners**

**A lack of understanding was connected to:**

- feelings that health practitioners did not take mental health issues seriously, because they were a young person
- health practitioners treating them as though they were 'just trying to get attention', when they asked for help

“...because if you had the same sort of symptoms or thoughts and stuff in an adult, they would just look at you differently...They would look at you, (and think) okay, you are not acting.”

“It is not just a phase, you may really have some actual underlying issues...opposed to being a youth or a kid (who is) just trying to get attention.”

### ➔ **Waiting lists and multiple referrals**

#### **Issues connected with waiting lists and multiple referrals were:**

- frustration about constant referrals to other agencies
- continuously having to ‘retell their story’ to another health practitioner and cope with new systems
- distress associated with ‘reliving’ their stories each time they had to retell them to a new health practitioner
- the affect waiting for specialist mental health care had on people supporting young people with mental health issues
- young people were less likely to become mentally distressed if they were able to see a health practitioner without delay

‘They don’t tell you where to go. Psych services just have a phone number, and they have long waiting lists if you aren’t referred.’

“...and you’ve got to answer the same questions. You might go to one, one week and then they review you and you have to answer all the horrible hard questions again.”

“...you’d move from different agencies and they ask you (about it all again), and you have to re-live it. So... this is stuff that’s been going on five years and you’re still re-living it...”

### ➔ **The differences between adult and youth mental health services**

A number of participants said the level of support they received in youth mental health services was far greater than adult services. They said adult services were more impersonal and clinical, as they were more likely to treat clients as adults who needed to take responsibility for their own recovery. Participants said that this was not helpful as it was arbitrary to believe that they suddenly need less support ‘just because they turn 18’ or are older.

“...just the adult way they do things...everything was...more independent, like, you want support...but when you are in the adult world, it is like, ‘we are here to help you, but go and do your own thing’...”

## **5.5 Positive experiences with health practitioners**

Participants discussed how positive relationships with health professionals are more likely to empower young people to be able to take responsibility for their lives and led to recovery.

**Positive interactions are based on health practitioners who:**

- are caring, understanding and able to listen
- are able to make a genuine connection with the young person
- are able to relate to the young person as an individual rather than a clinical case
- helped young people 'feel at ease' by being 'down to earth and nice', rather than being entirely clinical and impersonal
- told young people they were doing well, without being patronised

'...she gives you a way to sort it out and gives you all the help you need. By what she says to you, she shows she cares...'

"...and they actually sound like they are trying to get a handle on what you are actually saying to them."

...they let you tell your story and try to understand...they listen to the whole story.'

"...continuing (to try)... to make that connection, like sometimes even when I wasn't having a great day, they would still try, even though you are not in your right frame of mind, you still feel that they are trying to really connect."

"(She) used to come and visit me and she was there the whole step of the way, she was so good...she helped me stand alone and would ring up, come around every so often, and that. She was really, really good."

## Ideas for how to create change

Participants identified a number of ideas for ways forward when asked about potential solutions to the issues discussed.

### The main themes in this section are:

- 6.1 more education about young people and mental health issues
- 6.2 more peer support and consumer groups
- 6.3 ideas for improving experiences at school
- 6.4 ideas for improving experiences with health services

### 6.1 Education about young people and mental health issues

Participants talked about the importance of education to increase understanding of mental health issues and young people in society.

#### Education campaigns should focus on:

- education aimed at employers
- education aimed at parents
- education within schools
- education aimed at young people
- education for the general public

#### → Why education about young people and mental health issues is important

Participants believed an increase in understanding of mental health issues for young people in society would help to decrease stigma and discrimination. In addition young people said when people are willing to understand and support people with mental health issues; it can be beneficial for them as well. This included the opportunity to learn more about them selves and grow and the self confidence that comes from helping others.

“...not well people (with mental health issues) are away over there and you don't have to see them or engage with them, (but when) everyone sees more and more (of them, then)... they are normal.”

#### → Education aimed at employers

Participants suggested more education for employers about youth mental health issues would be beneficial.

#### → Education aimed at parents

Education and information aimed towards parents was considered particularly important with some participants saying “changing parents thinking” should be a priority. This included teaching them skills to cope in a positive way.

### ➔ Education within schools

A lack of understanding about youth mental health issues in school by both staff and students was a significant issue commented on throughout the report. Participants also talked about the possible positive impacts of this type of education such as more understanding for young people with mental health issues from other students.

“And the people that have a mental health issues know that hopefully the other kids won’t treat them differently.”

### Ideas for education in schools:

- Posters and pamphlets in schools
- Sharing personal stories
  - opportunities for young people to share their personal story at school
  - the power of personal stories as young people are more likely to relate to other young people with similar experiences
  - this may be difficult for some young people as they would be publicly talking about personal issues so anonymous written stories could be displayed or read out in schools
- Include information on mental health issues in health classes
  - such as videos about mental health issues for young people
  - lessons that give more insight into the biological and environmental factors that influence mental health in young people to help them better understand their own issues from a developmental perspective
  - classes could start in intermediate school to give young people information before they develop possible mental health issues
- Education for teachers and guidance counsellors
  - a significant problem identified was the lack of knowledge of youth mental health issues by school guidance counsellors and teachers

### ➔ Education for young people about mental health issues and support services

#### For an education campaign towards young people to be effective it needs to include:

- good quality information which young people are able to relate their own experiences to
- youth appropriate language such as not too much jargon that they are unable to understand
- information showing young people that it is ‘ok to ask for help’
- support services are available
- information about supportive cultural and recreational groups
- less information about generic mental health issues and more about how they affect young people in particular

## → How this education and information might be delivered

### How education and information for young people about mental health issues could be delivered:

- adverts on the radio or on television - these could include well known people that young people can relate to
- information at youth events - such as a stall about youth mental health issues at youth festivals
- an information booklet about support services available
- information placed on youth appropriate notice boards
- websites

### 5.1.5 Increasing awareness of youth mental health issues within society

The main solution suggested to increase awareness of youth mental health issues in general society was through campaigns in the media. Such as adverts about the need to watch out for signs of mental health issues in young people.

“...there are stages before that which lead up to you actually having a mental health issues...showing those states as a kid would be...I guess beneficial, like getting people to watch out for the signs earlier.”

### → Like Minds Like Mine adverts that include young people

There was significant support from participants for the development of Like Minds Like Mine adverts with a focus on youth mental health issues.

### Suggestions were:

- adverts that show that young people experience mental health issues
- adverts that show the need to watch out for signs of mental health issues in young people
- the current adverts portray people with a lot of support, when some people with mental health issues did not necessarily have this
- it would also be good to have adverts that depicted different types of mental health issues

“...like when there's that guy on the ad and all his friends are like, 'oh, come out and surf' and that. He's got support, he's dealing with it, his boss is okay with it, you know, he's got a wife, kids, a good boss, he's got good friends. And, you know...not everybody has that...”

## 6.2 Peer support and consumer groups

### 5.2.1 The value of peer support groups

#### Peer support groups are valuable because:

- they are a place where young people can identify with others who had similar experiences and ‘share their feelings’
- peer mentoring is effective because it can be easier to make relationships with people who are the same age with similar experiences
- this type of relationship can also be more trustworthy
- the developmental opportunities for young people, which initiatives such as these offer

“I think it would be easier just to hear it from someone who is already experienced, like a non adult, someone who has recently gone through something like that.”

### 5.2.2 More opportunities for peer support

#### There was significant support in the focus groups for more opportunities for peer support. This included:

- creating more opportunities for young people with mental health issues to interact and meet each other informally
- the development of more formal groups and processes of support
- health practitioners could refer young people to peer support initiatives

“...setting up those processes for young people, like...(saying to others)...I have been through this...the information I have learnt about myself, (that) I can help others with... and breaking down those barriers, so that young people can say, ‘hey I have got a mental health issues – oh you have got a mental health issues too, let’s get together and do something and help people who are feeling isolated’...”

“It would help to have a place where I could share my emotions and not

## 5.3 Improving youth mental health services

Young people talked extensively about the importance of effective youth mental health services for young people. They also suggested many ways in which services can be improved this included how participants would like health practitioners to relate to them and more developmentally appropriate services.

## → How participants would like mental health practitioners to relate to them

### How young people would like health practitioners to relate to them:

- showing they genuinely care and want to help
- supportive and caring body language and tone of voice
- being welcoming
- listening and trying connect
- being helpful and friendly
- showing they are knowledgeable about the young persons situation
- showing they genuinely care and want to understand
- being supportive throughout the young persons journey
- treating young people with respect
- letting young people talk about how they feel when they need to
- not 'fussing over' the young person
- not making assumptions, but giving young people the opportunity to tell their whole story before making conclusions
- giving young people answers and solutions that they can relate back to themselves
- not 'just telling young people what to do' but giving young people helpful information about what they are experiencing
- giving young people meaningful options, including practical things that they can do
- giving young people information about other places they can get support from
- acknowledging young peoples way of expressing themselves
- not only talking in clinical language, but having 'normal' conversations with young people

## → The need for developmentally appropriate services

### Issues connected with the need for developmentally appropriate services are:

- practitioners need to be aware of developmental issues for young people
- it is ineffective using adult models of mental health practice with young people
- mental health issues in young people can be overlooked when they are assessed using adult models of diagnosis or analysis
- the importance of having practitioners who understand the interaction between the effects of puberty and mental health issues on young people
- participants acknowledged it can be hard to separate what are developmental issues for young people and when these become mental health issues, saying this line is sometimes unclear
- being able to communicate and work effectively with young people was is essential

“They’re not trained. They’re inexperienced and they don’t actually know what they’re doing...and you can’t do that (use an adult model). It does not work like that at all, I’ve come across a bit of that. They just don’t understand.”

“They’re looking for the extremes that adults get. They’re looking for the huge alcohol abuse and drug use and of course teenagers do that, but they don’t do it to the extreme because they don’t have the resources basically.”

“Because teenagers have the mood swings and everything else that’s going on and (are) still developing... (health practitioners) need to have a bit of experience with young people... (like knowing the difference) between teenage mood swings and mental health and (that) sometimes they overlap...”

## 5.4 Improving support and attitudes at school

**The need for better support and attitudes towards young people with mental health issues in school was a very significant issue for participants. Ways schools could be more supportive were identified as:**

- systems to ensure people with mental health issues are helped effectively
- constructive support from teachers
- good pastoral care for students with mental health issues
- access and referral to appropriate mental health services for young people in school
- practical support with school work
- peer support systems
- a willingness by teachers to positively engage with students as issues arose
- young people they may always not know how to support themselves and therefore sometimes need to be given support and advice from a caring adult
- confidentiality
- support needs to be easily accessible
- increasing the number of support people available at school such as counsellors and guidance counsellors who are able to work with and have knowledge about young people with mental health issues
- more options about who to see at school such as a male or female

“...I was really upset every single class, I wasn’t smiling and she (the teacher) kept me back from the class one day and said, ‘what’s up?’, and I actually told her. And even since I left school, I still keep in contact with her now and I wish there were more teachers like her, but there just aren’t...”

“I was really lucky... I had supportive teachers who would...fit in my teaching room with my (issues). Like I used to like to stand a lot, so they let me stand up to do my work....I mean, they were just always there to try and help me to get me through...”

“The main thing would (be) education - educated people in schools, there needs to be more counsellors, more social workers...”

## Conclusion

This study was undertaken to increase our knowledge of stigma and discrimination experienced by young people with mental health issues and to involve them in the development of solutions.

The importance of the perspectives of young people as mental health consumers can be summarised by Whal who said,

“to truly understand and appreciate what stigma is and how it affects people with mental health issues, we have to hear from the ones who face that stigma on a daily basis. They can best inform us—from their own personal experiences and in their own words—what stigma is, what it does, and how it is conveyed”... and contribute to the development of “important strategies of empowerment” (Whal, pg. 468, 1999).

Throughout the study young people reported many experiences of negative attitudes and actions towards their mental health issues. They gave examples of encountering these attitudes in a variety of settings throughout their lives such as in school, in health services, in the media, in sports groups, organisations and from friends and family.

Negative attitudes from those working with young people such as teachers, guidance counsellors and health professionals are also evident throughout the report. This challenges the assumption that people who work with young people with mental health issues are immune from attitudes of stigma and discrimination, because they are trained and mandated to help them. It also illustrates the need for those working with young people, to reflect on the way in which they work with the young people they are supporting.

In addition this report shows that we cannot assume that the needs of young people with mental health issues are the same as adults and therefore they may not be captured by the adult led consumer movement. While the information and stories collected in this report reflect many of the common themes found to be associated with mental health issues, stigma and discrimination, it also provides insight into the unique perspectives and particular needs of young people.

But the information discussed was not wholly negative; participants also reported having some positive experiences. They gave examples of people who were: caring, inspiring, supportive, respectful and understanding. Importantly this included examples of practical help given as well, such as teachers who found ways for students to participate in class and a health practitioner who encouraged a young person to apply for a consumer advocacy position. This illustrates a particularly significant theme identified; the need for a great deal of both informal and formal support at every stage of young people’s mental health issues/ recovery and the effect of stigma and discrimination on the support available to them.

In addition participants gave examples of how positive experiences with others challenged their assumption that they would always be treated negatively because of their mental health issues.

Some examples are:

- a participant who found out others had experience of mental health issues they did not know about
- people they didn't expect being supportive
- the positive impact of a supportive sports team for young person
- the positive impact of teachers who offered a young person practical support
- examples of family members learning over time that their young person was not a different person now they had a mental health issues
- a health professional who inspired a young person to follow her aspirations

While many negative experiences of stigma and discrimination were identified, these positive examples of people's attitudes and responses suggest opportunities for further change and provide hope for the future.

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