

OUTER EAST
PRIMARY CARE **PARTNERSHIP**

MENTAL HEALTH
ACCESS AND
PATHWAYS PROJECT

NOV 2019



DISCLAIMER & CONFIDENTIALITY

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This report has been developed for service providers, their staff and partners within the MH sector in the Eastern region of Melbourne. The personas and journey maps may be shared and adapted as necessary to assist the local MH service system.

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EXECUTIVE SUMMARY

INTRODUCTION

The Department of Health and Human Services (DHHS) Inner and Outer Eastern Melbourne Areas- sponsored the Outer East Primary Care Partnership (OEPCP) to explore implications to the local mental health system as a result of the introduction of the National Disability Insurance Scheme (NDIS).

PROJECT OBJECTIVE

To define and understand the experience of clients accessing, entering and using the mental health system in Eastern Melbourne, with a focus on:

- Exploring the different pathways used by clients to gain access to services;
- Understanding the engagement and role of organisations involved in the delivery of services;
- Identifying the changes and gaps in the introduction of the NDIS has created;
- Understanding the factors that improve a client's journey;
- Identifying opportunities for strengthening local service supports and the client experience.

METHODOLOGY

Understanding of the lived client experience was seen as fundamental to comprehending the impacts of a rapidly changing mental health system. This project employed Human Centred Design (HDC) methodologies to ensure the lived experience was central to the whole process.

Four client journey maps were developed which provide visual representation of client behaviour, feelings, motivations and attitudes at each stage of their journey. They highlight a series of key touch points between the client and the service system.

Two core group were involved in the development of the journey maps:

MH Stakeholders

(system providers) – staff from various services in the region came together in several workshop settings to map the operational aspects of the client experience. Using the

personas and a client journey mapping process the group created a step by step of the client lifecycle and hypothesised about the emotional experience of that person. There journey were then overlaid with the 'lived experience' captured in the system user phase.

MH clients

(system users) – Clients were invited to participate in an interview to shared their experiences of the local MH system. Flyers were distributed via contacts at local service providers including client participation committees.

Interviews were 1-2 hours long and held in a location that the client nominated as most comfortable including their home, or a local café. Clients were provided with a client participation information sheet and were required to complete a participation consent form.

Interviews consisted of a series of semi-structured questions focused on people's experience of finding out about, accessing, receiving and using services. The interviews were transcribed for the purposes of analysis and identifying themes. The insights gathered are rich and have been used to inform key content on the four journey maps including the emotional experiences and moments that matter.

PERSONALITY
 extroverted, confident, changeable, loyal, curious, active

TECH USAGE
 low, medium & high

PREFERRED CHANNELS
 online, social media, phone, in-person

INCOME LEVEL
 low

BIO
 Today, Rex, 38, is 48 years old and currently lives in an SMI. He has been there since it's built, but a lot of staff goes down and he has to get out of there at some point.

KEY FINDINGS FOR REX
SERVICE NEEDS
 • Need housing, support to access the system and get services
 • Consistency of staff and services
 • To be heard and understood - and to feel like he has some power
 • Staff who are experienced, flexible and personable
 • Services that are local and easy to access

GOALS
 • Reduce isolation
 • Reconnect with his kids
 • Support with managing other services
 • Gain a sense of purpose and independence

FEARS & FRUSTRATIONS
 • Constant change services, staff, rooms and
 • Too many systems, processes and overload of information
 • Lack of awareness/proximity

TRUST
 I NEED PEOPLE WHO TAKE THE TIME TO LISTEN TO ME AND HELP ME WORK THINGS OUT
 I NEED STAFF WHO WON'T GIVE UP ON ME EVEN WHEN I'M BEING HYPERTACT

HOPE & CONTROL
 I NEED A GOOD TEAM OF PEOPLE WHO CAN HELP ME AND SHOW THE SYSTEM WORKS FOR ME
 I WANT TO BE INVOLVED IN THE DECISIONS THAT AFFECT MY LIFE
 I WANT TO HAVE SOME CHOICE & CONTROL

COMMUNICATION
 KEEP ME IN THE LOOP, I GET EACH WHEN I DON'T KNOW WHAT'S GOING ON
 GIVE IT TO ME IN PLAIN ENGLISH - HELP ME UNDERSTAND
 I NEED HELP GETTING MY HEAD AROUND THIS WHOLE NDIS THING

REX'S JOURNEY SCENARIO

REX has an extensive history of mental illness which is exacerbated by his substance use (alcohol). Rex's drinking has at times made his housing situation extremely tenuous. His use of alcohol and chronic smoking means the often has little money left for anything else. At times this leads to him presenting other residents for violence.

REX has recently been discharged after a hospital admission. While in hospital, he underwent a change in medication which has assisted in reducing his hallucinations. Rex requires assistance with a range of needs, including accessing the NDIS. Rex says he would like to get out more and connect with the community and would also like to have contact with his estranged children.

STAGE	1	2	3	4	9	11	14	15	20	21	23	25	26	28	30	32	34	36	40	42		
FINDING OUT ABOUT SERVICES	REX is contacted by a support worker from the hospital who asks if he would like to see a counsellor. REX is unsure what to do and asks for help. The counsellor explains the NDIS and how it works. REX is interested but needs more information. The counsellor provides a list of services and contact details. REX is overwhelmed by the amount of information and needs to take time to process it.	REX is contacted by a support worker from the hospital who asks if he would like to see a counsellor. REX is unsure what to do and asks for help. The counsellor explains the NDIS and how it works. REX is interested but needs more information. The counsellor provides a list of services and contact details. REX is overwhelmed by the amount of information and needs to take time to process it.	REX is contacted by a support worker from the hospital who asks if he would like to see a counsellor. REX is unsure what to do and asks for help. 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PEOPLE & PLACES	SMI Case Manager	SMI Case Manager	SMI Case Manager	SMI Case Manager	SMI Case Manager	SMI Case Manager	SMI Case Manager	SMI Case Manager	SMI Case Manager	SMI Case Manager	SMI Case Manager	SMI Case Manager	SMI Case Manager	SMI Case Manager	SMI Case Manager	SMI Case Manager	SMI Case Manager	SMI Case Manager	SMI Case Manager	SMI Case Manager	SMI Case Manager	
REFERRAL PATHWAYS	FROM Hospital TO Case Manager	FROM Case Manager TO Community MH Service	FROM Case Manager TO SMI	FROM Case Manager TO SMI	FROM Case Manager TO SMI	FROM Case Manager TO SMI	FROM Case Manager TO SMI	FROM Case Manager TO SMI	FROM Case Manager TO SMI	FROM Case Manager TO SMI	FROM Case Manager TO SMI	FROM Case Manager TO SMI	FROM Case Manager TO SMI	FROM Case Manager TO SMI	FROM Case Manager TO SMI	FROM Case Manager TO SMI	FROM Case Manager TO SMI	FROM Case Manager TO SMI	FROM Case Manager TO SMI	FROM Case Manager TO SMI	FROM Case Manager TO SMI	
SYSTEM ACTIVITIES	Information sent to NDIS database	Information sent to NDIS database	Information sent to NDIS database	Information sent to NDIS database	Information sent to NDIS database	Information sent to NDIS database	Information sent to NDIS database	Information sent to NDIS database	Information sent to NDIS database	Information sent to NDIS database	Information sent to NDIS database	Information sent to NDIS database	Information sent to NDIS database	Information sent to NDIS database	Information sent to NDIS database	Information sent to NDIS database	Information sent to NDIS database	Information sent to NDIS database	Information sent to NDIS database	Information sent to NDIS database	Information sent to NDIS database	

KEY THEMES

Three themes were identified as being critical to the lived experience:



TRUST

People accessing MH services must feel respected, cared for and supported as they navigate the system and use services. This primarily focuses on the workers and supporters they encounter, but extends to how the system is structured and the support approaches and therapeutic models used in different stages of care.



CHOICE AND CONTROL

People need to feel empowered and in control when using MH support services. This means clarity about how to access the care they require; flexible services that are responsive to the individual's needs and circumstance; and, a clear understanding of service availability.



COMMUNICATION

People accessing the MH system require information that is easy to understand, readily available and accessible in ways that suit them. Clear information for all parts of their journey is important. This includes: how the system works; how to access funding and services; service availability, wait times and waitlist progress; roles and responsibilities of each service provider and workers.

RECOMMENDATIONS

The following recommendations aim to give your organisation support with how to strengthen elements of trust, choice and control and communication. A checklist version has been developed and can be found in the appendix section of this report.

TRUST

- 1 Ensure your organisation's mission and value statements are client-centric and clearly defined. A care model that reflects these values is provided using a welcoming, hopeful and empathetic approach.
- 2 Implement ways to capture, review and action client needs from frontline staff.
- 3 Ensure staff feel empowered to modify their practice to deliver better client experience outcomes.
- 4 Clearly defined and client-centric processes exist for providing care across multiple internal services and for partnering with other agencies.
- 5 Ensure staff have the expertise to respond to complex and multiple diagnoses.

CHOICE & CONTROL

- 6 Clients are asked what they need and value most. Use this insight to design services, and wherever possible co-create services with clients.
- 7 Seek regular feedback from clients in relation to service performance, delivery and discharge processes.
- 8 Empower the client to choose services that suit their needs by providing easy to understand service and availability information.
- 9 Offer flexible models of care that can be adapted to meet the needs of the individual client.
- 10 Engage clients in the planning and coordination process and facilitate referrals when required.

COMMUNICATION

- 11 Use a clear client communications model, which provides regular and useful information about your services. Check delivery is tailored to individual need.
- 12 Have an effective staff communications model, which reinforces the organisation's mission and values and shares client feedback.
- 13 Proactively communicate delivery times and progress to clients.
- 14 Ensure staff are informed about new services and policy changes and that training is provided when necessary.
- 15 Regularly review processes for communicating with other services/providers to ensure seamless integrated care.

BACKGROUND

In November 2017, the National Disability Insurance Scheme (NDIS) commenced in Inner Eastern Melbourne (Boroondara, Manningham, Monash and Whitehorse Councils) and Outer Eastern Melbourne (Knox, Maroondah and Yarra Ranges Councils). The introduction of the NDIS resulted in a major transformation in the delivery of Mental Health Community Support Services (MHCSS). Simultaneously, the recommissioning of federally funded mental health programs saw the introduction of several new services in the area.

The Department of Health and Human Services (DHHS) Inner and Outer Eastern Melbourne Areas sponsored the Outer East Primary Care Partnership (OEPCP) to coordinate a project that would explore the implications of these changes. An understanding of the lived client experience was identified as a fundamental mechanism to comprehend the impacts of a rapidly changing mental health system.

The OEPCP is one of Victoria's 28 Primary Care Partnerships. Its partnership consists of health and community support agencies who provide services to the community of the Outer East metropolitan area of Melbourne¹. The OEPCP provides a platform through which agencies can work together in a more collaborative and coordinated way.

THE ROYAL COMMISSION

The Royal Commission into Victoria's Mental Health System commenced in 2019. The Royal Commission has been tasked with providing a comprehensive set of recommendations on how to best support Victorians with a mental illness, including those at risk of suicide. It will also play a role in raising public awareness about mental health². The Victorian Government has already committed to implementing every recommendation from the Royal Commission.

While the Royal Commission is an influencer for change across Victoria, this report focuses on the local MH service system and how the lived experience of local people can highlight opportunities for change and improvement within the Eastern metropolitan areas.

OBJECTIVES

To define and understand the experience of clients accessing, entering and using the mental health system in Eastern Melbourne, with a focus on:

- Exploring the different pathways used by clients to gain access to services;
- Understanding the engagement and role of organisations involved in the delivery of services;
- Identifying the changes and gaps the introduction of the NDIS has created;
- Understanding the factors that improve a client's journey;
- Identifying opportunities for strengthening local service supports and the client experience.

AUDIENCE & INTENDED USE

This report has been developed as an evidence based storytelling tool for service providers, their staff and partners within the MH sector across Inner and Outer Eastern Melbourne. The journey maps and findings may be shared and adapted as necessary to assist the local MH service system.

¹ OEPCP website

² State Government of Victoria (Department of Premier and Cabinet) 2016

PRESENTING THE CLIENT PERSPECTIVE

Human-Centred Design (HCD) is a creative approach to problem solving that puts the user at the centre of the process. This project employed HCD methodologies throughout.

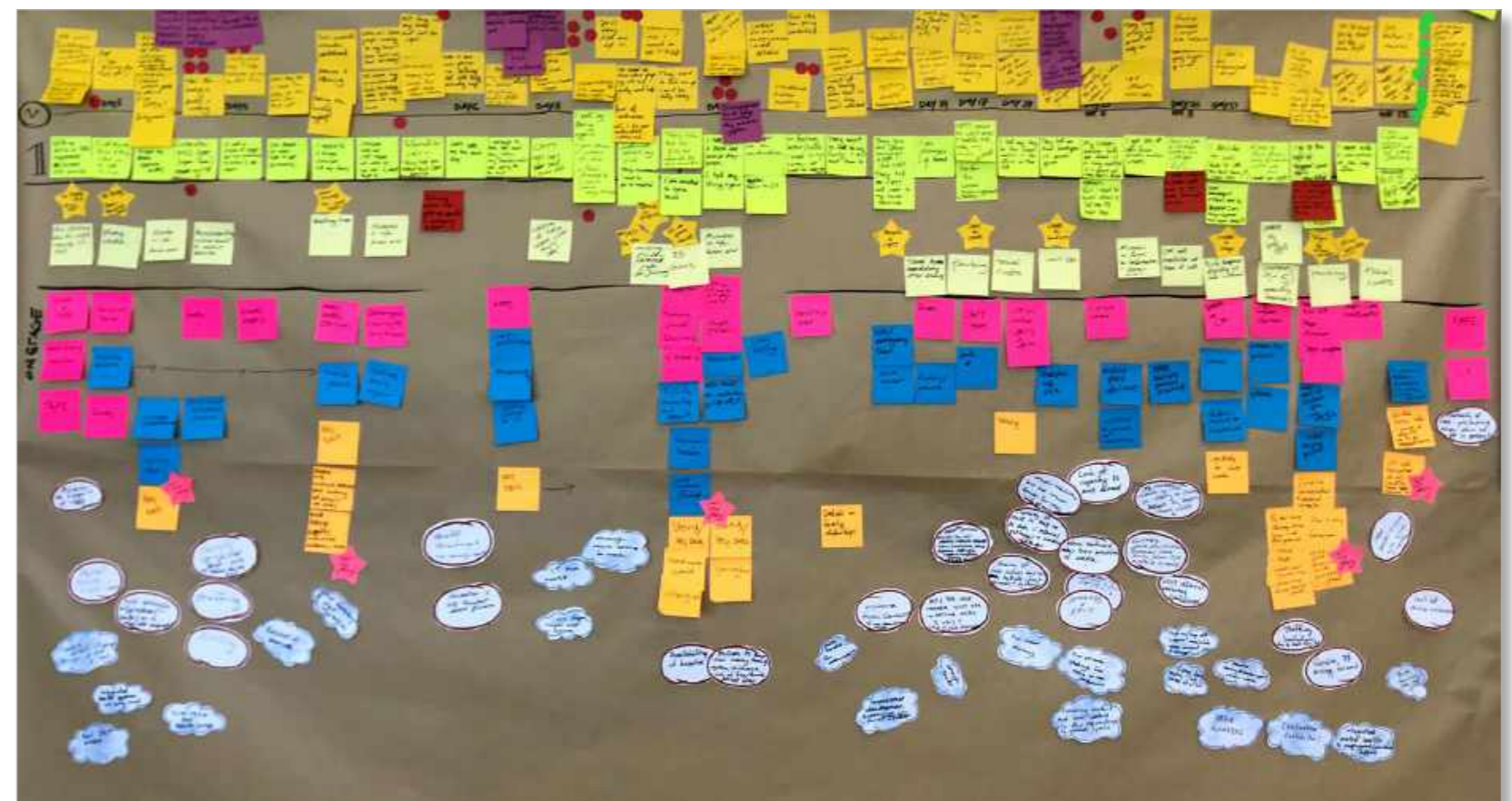
WHAT IS JOURNEY MAPPING?

Client journey mapping is an approach used to illustrate a service from the perspective of the client. Journey maps are based on mapping a series of 'touch points' between the client and the service. For the purposes of this project, mapping was undertaken to illustrate the service system, rather than individual services. A visual tool was produced incorporating both the physical (functional aspect of client experience) and the emotional (rational aspect of client experience) journey. The overall aim of journey mapping is to capture client behaviour, feelings, motivations and attitudes at each stage of their journey to build empathy for clients and to inform stakeholders about how they can improve the client experience.

The sector representatives at the journey mapping workshops were from both clinical and operational management roles.

Journey maps were developed using fictional client personas and a 10-stage mapping process.

- 1 Steps in their journey
- 2 Referral pathways
- 3 People, systems and processes they engage directly with
- 4 Referral pathway challenges
- 5 Emotional responses at each stage of the journey
- 6 Needs
- 7 Decision making motivators
- 8 Moments that matter
- 9 Backstage challenges and flows
- 10 Ideas and Innovations



METHODOLOGY

WHAT ARE PERSONAS?

To personify the mapping process, and ensure attention remained focused on the client experience, four personas were developed – Peter, Chrissy, Rex and Mel. Personas are fictional, yet believable prototypes that are developed to represent a client group. They have individual names and stories that reflect personal attributes and behavioural characteristics such as needs, motivations, attitudes and pain points. While the chosen personas don't perfectly reflect all clients, they do assist in bringing clients "to life" and provide the context required to make decisions eg. "What would happen to Chrissy if organisation A was no longer available to provide her a service."

THESE PERSONAS CATEGORISED CLIENTS USING THE FOUR MAJOR ACCESS POINTS TO THE SERVICE SYSTEM ACROSS INNER AND OUTER EASTERN MELBOURNE AREAS:

Person feeling anxious/depressed/not quite right

Person feeling anxious, depressed or other mental health issue and seeking mental health support in primary care, and not otherwise able to access/afford services

OEPCP would like to acknowledge EACH for assistance in developing this persona.

PETER

"I'VE JUST GOT TO GET THROUGH THIS ROUGH PATCH. THIS IS NOT ME!"

Age: 58
Occupation: Retired school teacher
Education: University
Location: Hawthorn
Family Status: Married, 3 adult children & 4 grandchildren
Nationality: British
Health: Active lifestyle
 Pain management – required as a result of recent double knee op.

PERSONALITY
 Introvert — extrovert
 changeable — loyal
 passive — active

TECH USAGE
 low internet & email — high
 social media —
 mobile apps —

PREFERRED CHANNELS
 online —
 social media —
 phone —
 speaking to family/friends —
 other services/referrals —

INCOME LEVEL
 low — high

BIO
 Hello, I'm Peter. I'm 58-years old and retired a couple of years ago after teaching for 35 years. I live with my wife, Sal. We have three kids and 4 grandkids. Our family is everything to us. In my younger days, I was an elite athlete and was a keen mountaineer throughout my 30s and 40s. I've pushed myself hard over the years and as a result, recently had to have a double knee replacement. It was on the cards for a while, but was still a bit of shock when it happened. I just wasn't prepared for the downtime. I've had some complications with my recovery, so progress has been slow. Really slow. And it's been a whole lot more painful than I anticipated. I'm usually a really active and outgoing person but recently I've begun to feel 'flat' and unmotivated. I'm worried about my recovery and feel like I'm becoming a burden on Sal.

KEY FINDINGS FOR PETER
SERVICE NEEDS
 Experienced staff who listen and respect me
 Confidentiality is critical – "I don't want anyone knowing about this"
 Wants a 'quick fix'
GOALS
 Get back to the active life and mental state I had before surgery
 Be able to manage all my physio and outpatient appointments
 Walk on a daily basis
 Feel strong and independent
 Stay fit and healthy as long as possible
FEARS & FRUSTRATIONS
 Privacy and confidentiality
 Finding the 'right' help
 Inexperienced staff
 Being kept waiting for appointments
 Not feeling in control with decision making

FRUSTRATED
FRIENDLY
INSIGHTFUL
PERCEPTIVE

I WANT AN EXPERIENCED CLINICIAN WHO I RESPECT AND CAN CONNECT WITH. (CONFIDENTIALITY IS CRITICAL)
TRUST

I WANT TO FIND SOMEONE WHO GETS WHAT'S IMPORTANT TO ME AND CAN DELIVER SERVICES IN A STYLE AND IN AN ENVIRONMENT I AM COMFORTABLE IN.
CHOICE & CONTROL

I WANT A SERVICE DIRECTORY OF PSYCHOLOGISTS WITH THEIR CREDENTIALS AND EXPERIENCE SO I CAN EASILY SEARCH FOR A PROVIDER THAT FITS MY NEEDS.
COMMUNICATION

Refer to page 22 for Peter's detailed persona and journey map.

CHRISSY

"I WANT TO HAVE A BETTER LIFE AND BE A GOOD MUM"

Age: 28
Occupation: Unemployed
Education: Secondary (Completed Year 10)
Location: Ferrtree Gully
Family Status: Single mum, living with her two children
Nationality: Anglo Australian
Health: Childhood trauma
 Substance use (alcohol)
 Overweight – feels like it is due to her medication

PERSONALITY
 introvert — extrovert
 analytical — creative
 changeable — loyal
 passive — active

TECH USAGE
 low internet & email — high
 social media —
 mobile apps —

PREFERRED CHANNELS
 online —
 social media —
 phone —
 speaking to family/friends —
 other services/referrals —

INCOME LEVEL
 low — high

BIO
 Hi, I'm Chrissy. I'm a single mum living in Ferrtree Gully with my two kids who are 5 and 7 years old. I'm currently unemployed and have been in and out of jobs for the last 10 years. I have had mental health issues since I was in my late teens. In the past, I've had support from a number of different places, but no one is helping me at the moment. My mum lives nearby but we had a big fight recently, so I'm not talking to her much at the moment. She is always trying to tell me how to parent my kids. I was seeing a guy for a while but we broke up a couple of months ago. My friends are too busy with their own issues. I feel really alone.

KEY FINDINGS FOR CHRISSY
SERVICE NEEDS
 Experienced staff (must be female)
 Very high flexibility – "I need services that can fit around my lifestyle"
 Family-centred – "Parenting is hard and I don't want to lose my kids"
FEARS & FRUSTRATIONS
 Have stability and security in my life
 Have ongoing support (emotional, financial)
 Have a better life (now)
 Inconsistent staff
 Being challenged or questioned
 Strict boundaries
 Emotional vulnerability during therapy
 I want to see a psychologist for as long as I want
 Lack of flexibility in services

CONFRONTING
IMPULSIVE
LACK OF INSIGHT
IMPATIENT

PROVE YOURSELF TO ME – I'VE BEEN IN THIS SYSTEM A LONG TIME!
 RECOGNISE THAT I'M A GOOD MUM – PROTECT MY KIDS AND ME, AND KEEP US TOGETHER.
TRUST

I ONLY WANT FEMALE WORKERS
 I NEED SERVICES THAT ARE FLEXIBLE AND FAMILY FRIENDLY
 I WANT TO BE ABLE TO SEE MY PSYCH AS OFTEN AS I WANT.
CHOICE & CONTROL

DON'T OVERLOAD ME WITH INFORMATION I DON'T NEED – I WON'T READ IT!
 MAKE SURE THE INFO I NEED IS THERE WHEN I NEED IT, IS EASY TO UNDERSTAND, AND SIMPLE TO ACCESS.
COMMUNICATION

Refer to page 18 for Chrissy's detailed persona and journey map.

Person has a permanent psychosocial disability and needs more support eg. Difficulties with activities of daily living, communication, socialisation etc.

OEPCP would like to acknowledge EACH for assistance in developing this persona.

REX

“ I’VE JUST GOT TO KEEP IT TOGETHER. I WANT TO SEE MY KIDS AGAIN ”

Age: 48
Occupation: Unemployed
Education: Secondary & Apprenticeship
Location: Millgrove
Family status: Separated, two adult children, living in an SRS
Nationality: Anglo Australian
Health: Substance use (alcohol), Heavy smoker, Poor nutrition and low physical exercise

PERSONALITY

introvert extrovert
analytical creative
changeable loyal
passive active

TECH USAGE

low internet & email high
social media
mobile apps

PREFERRED CHANNELS

online
social media
phone
speaking to family/friends
other services/referrals

INCOME LEVEL

low high



LOW SELF-ESTEEM
DEPENDENT
IMPRESSIONABLE
VULNERABLE

KEY FINDINGS FOR REX

SERVICE NEEDS

- “Hand holding” support to access the system and get services
- Consistency of staff and services
- To be heard and understood – and to feel like he has some power
- Staff who are experienced, flexible and persevering
- Services that are local and easy to access

GOALS

- Reduce isolation
- Reconnect with my kids
- Support with managing other services I am accessing
- Gain a sense of purpose and independence

FEARS & FRUSTRATIONS

- Constant change (services, staff, rosters etc)
- Too many options provided and overload of information
- Lack of assertiveness/ proactivity

BIO

G’day, I’m Rex. I’m 48 years old and I currently live in an SRS. I’ve been there a while. It’s alright, but a lot of stuff goes down and I’d like to get out of there at some point.

I’ve got two kids, but they’ve grown up and don’t speak to me anymore. My marriage ended about 10 years ago and they gave up on me a few years later.

I am on a disability pension. After I pay for rent I barely have enough money left to buy smokes let alone anything else. Some of the other residents whinge about my drinking and smoking... but what am I going to do? I can’t afford anywhere else to live.

I have been told I am entitled to services through something called the NDIS because I have a mental illness. I want to find out more about it, but have no idea where to start. I’d really like to spend less time sitting around the SRS and do some other stuff. It’d be really nice to talk to my kids again.

TRUST

I NEED PEOPLE WHO TAKE THE TIME TO LISTEN TO ME AND HELP ME WORK THINGS OUT.

I NEED STAFF WHO DON’T GIVE UP ON ME EVEN WHEN I’M BEING DIFFICULT.

CHOICE & CONTROL

I NEED A GOOD TEAM OF PEOPLE LOOKING OUT FOR ME. I NEED TO KNOW ‘WHO’S WHO’ AND HOW THE SYSTEM WORKS FOR ME. I WANT TO DO STUFF I ENJOY THAT GETS ME OUT AND ABOUT.

COMMUNICATION

KEEP ME IN THE LOOP. I GET ENGY WHEN I DON’T KNOW WHAT’S GOING ON. GIVE IT TO ME IN PLAIN ENGLISH – HELP ME UNDERSTAND.

I NEED HELP GETTING MY HEAD AROUND THIS WHOLE NDIS THING!

Refer to page 10 for Rex’s detailed persona and journey map.

Person is experiencing mental health crisis

MEL

“ I DON’T KNOW WHAT TO DO... I CAN’T COPE WITH THIS ANYMORE ”

Age: 22
Occupation: Student
Education: Secondary. Enrolled in TAFE course.
Location: Box Hill
Family Status: Single. Youngest of 4 children.
Nationality: Vietnamese (second generation)
Health: Substance use (marijuana), Increasing paranoia and depression, Agoraphobia, Poor diet, Isolation

PERSONALITY

introvert extrovert
changeable loyal
passive active

TECH USAGE

low internet & email high
social media
mobile apps

PREFERRED CHANNELS

online
social media
phone
speaking to family/friends
other services/referrals

INCOME LEVEL

low high



ANXIOUS
OVERWHELMED
DEPENDENT
VULNERABLE

KEY FINDINGS FOR MEL

SERVICE NEEDS

- Feeling safe and that there are people who I can contact who will care about me
- Confidentiality and discreteness. “My family cannot know about this”
- That they will help me get better – “I feel like I’m starting to lose my mind”

GOALS

- Get through this without my family finding out
- Develop better ways of coping
- Stop smoking and cutting
- Feel confident to leave the house
- Get back to attending TAFE and finishing studies

FEARS & FRUSTRATIONS

- Being judged on her self harming behaviour
- Feeling like she might get lost in the system – sent from one place to another
- Feeling pressured to “just get better”

BIO

Hi I’m Mel, I’m a 22-year-old student and the youngest of four children. I am close with my family but I recently made the decision to move out of home to live with two friends.

My parents were not happy with my decision to move out. They have very high expectations of me and I was struggling to cope with the pressure.

I am enrolled in a hospitality course at TAFE but have not been going. I just don’t like leaving the house at the moment. I feel like someone is watching me. I’ve been smoking pot to help take the edge off but I know it’s probably doing more harm than good. I feel like I’m losing my mind.

TRUST

DON’T TELL ANYONE MY PARENTS CAN’T FIND OUT & I DON’T WANT MY ROOMMATES TO THINK I’M CRAZY.

DO PEOPLE REALLY KNOW WHAT TO DO AND DO THEY WANT TO HELP ME? DON’T LEAVE ME ALONE IN THIS.

CHOICE & CONTROL

TELL ME WHAT MY OPTIONS ARE AND HELP ME TO WORK THINGS OUT. I CAN’T MAKE PHONE CALLS OR GO TO NEW PLACES ALONE.

COMMUNICATION

I WILL SHUT DOWN IF I FEEL OVERWHELMED.

I NEED TO UNDERSTAND WHAT’S HAPPENING TO ME AND HOW THE SYSTEM WORKS.

EXPLAIN EACH STEP TO ME CLEARLY, TELL ME WHO’S WHO, WHAT’S GOING TO HAPPEN NEXT AND WHAT MY OPTIONS ARE.

Refer to page 14 for Mel’s detailed persona and journey map.

PROCESS USED

Two core groups were consulted as part of the project:

1. MH Stakeholders (system providers)

Staff from various service providers in the regions came together in a workshop setting to map the operational aspects of the client experience. Using the personas and a client journey mapping process the group created a step-by-step of the client lifecycle and hypothesized about the emotional experience of that person. These journeys were then overlaid with the 'lived experience' captured in the system user phase.

Two full day and one two-hour workshops were conducted in February and March 2019 with providers from the following organisations represented:

- EACH
- Eastern Health
- Eastern Primary Health Network
- Latrobe Community Health
- Mentis Assist
- Neami
- Private psychologist
- Wellways

2. MH clients (system users)

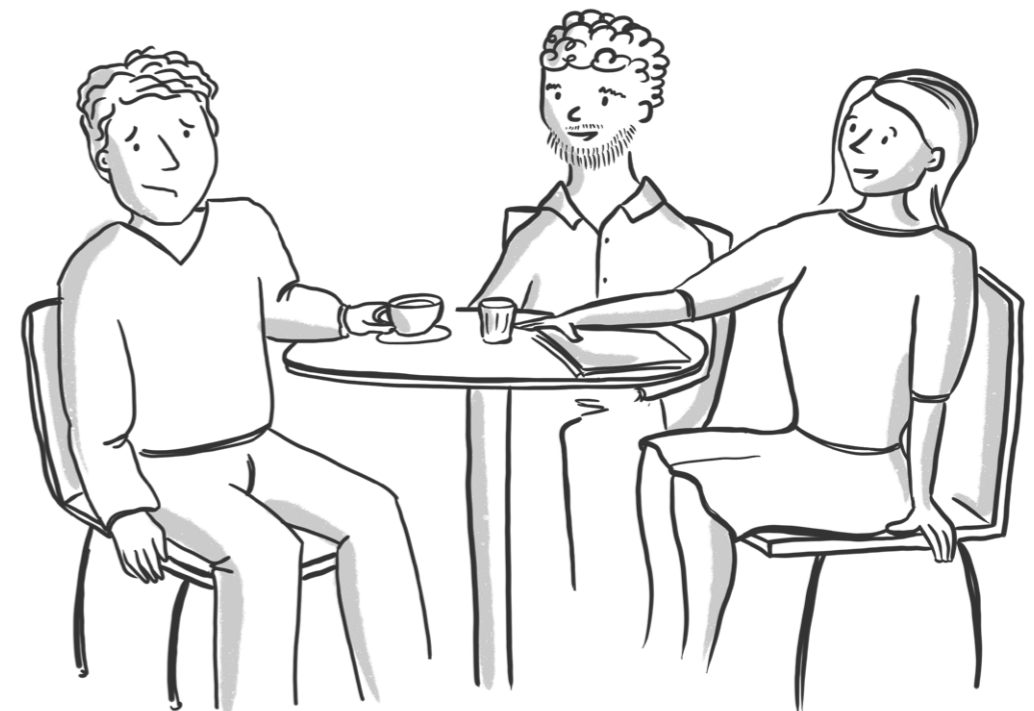
The HCD approach to gathering user input is detailed. It looks beyond the surface level 'client experience' and aims to understand their motivations, needs and values, in addition to their experience of 'the system'.

Clients were invited to participate in an interview to shared their experiences of the local MH system. Flyers were distributed via contacts at local service providers including client participation committees. Interviews were 1-2 hours long and held in a location that the client nominated as most comfortable including their home, or a local café. Clients were provided with a client participation information sheet and were required to complete a participation consent form.

Interviews consisted of a series of semi-structured questions focused on people's experience of finding out about, accessing, receiving and using services.

The interviews were transcribed for the purposes of analysis and identifying themes. The insights gathered are rich and have been used to inform key content on the four journey maps including the emotional experiences and moments that matter.

Refer to appendix for a detailed summary of the Client/Carer Interviews .



(LIENT JOURNEY MAPS

The following pages present the four client persona stories. Each journey map presents:

- The persona and their situation.
- The translation of key themes (Trust, Choice & Control, Communication) for the persona.
- A summary of the key 'Moments that matter' for the persona and the associated impact.
- A detailed analysis of the client journey as they engage with and use the MH system.



REX

“ I’VE JUST GOT TO KEEP IT TOGETHER. I WANT TO SEE MY KIDS AGAIN ”

Age: 48

Occupation: Unemployed

Education: Secondary & Apprenticeship

Location: Millgrove

Family status: Separated, two adult children, living in an SRS

Nationality: Anglo Australian

Health:

- Substance use (alcohol)
- Heavy smoker
- Poor nutrition and low physical exercise



LOW SELF-ESTEEM
DEPENDENT
IMPRESSIONABLE
VULNERABLE

KEY FINDINGS FOR REX

SERVICE NEEDS

- ‘Hand-holding’ support to access the system and get services
- Consistency of staff and services
- To be heard and understood – and to feel like he has some power
- Staff who are experienced, flexible and persevering
- Services that are local and easy to access

GOALS

- Reduce isolation
- Reconnect with my kids
- Support with managing other services I am accessing
- Gain a sense of purpose and independence

FEARS & FRUSTRATIONS

- Constant change (services, staff, rosters etc)
- Too many options provided and overload of information
- Lack of assertiveness/ proactivity

I NEED PEOPLE WHO TAKE THE TIME TO LISTEN TO ME AND HELP ME WORK THINGS OUT.

I NEED STAFF WHO DON’T GIVE UP ON ME EVEN WHEN I’M BEING DIFFICULT.

TRUST

I NEED A GOOD TEAM OF PEOPLE LOOKING OUT FOR ME.

I NEED TO KNOW ‘WHO’S WHO’ AND HOW THE SYSTEM WORKS FOR ME.

I WANT TO DO STUFF I ENJOY THAT GETS ME OUT AND ABOUT.

(CHOICE & CONTROL)

KEEP ME IN THE LOOP. I GET EDGY WHEN I DON’T KNOW WHAT’S GOING ON.

GIVE IT TO ME IN PLAIN ENGLISH – HELP ME UNDERSTAND.

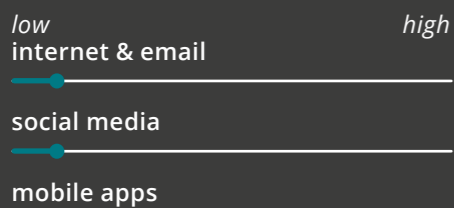
I NEED HELP GETTING MY HEAD AROUND THIS WHOLE NDIS THING!

COMMUNICATION

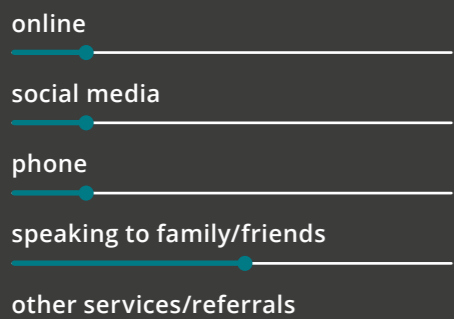
PERSONALITY



TECH USAGE



PREFERRED CHANNELS



INCOME LEVEL



BIO

G’day, I’m Rex. I’m 48-years old and I currently live in an SRS. I’ve been there a while. It’s alright, but a lot of stuff goes down and I’d like to get out of there at some point.

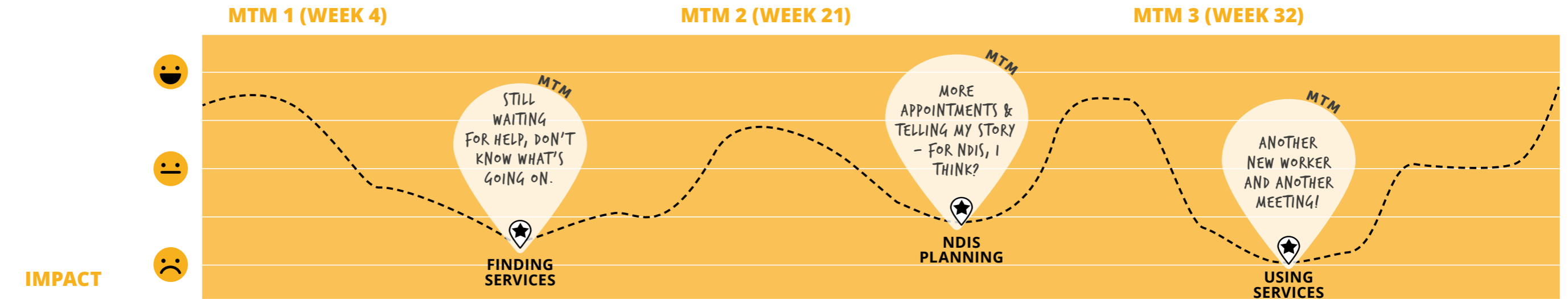
I’ve got two kids, but they’re grown up and don’t speak to me anymore. My marriage ended about 10 years ago and they gave up on me a few years later.

I am on a disability pension. After I pay for rent I barely have enough money left to buy smokes let alone anything else. Some of the other residents whinge about my drinking and smoking... but what am I going to do? I can’t afford anywhere else to live.

I have been told I am entitled to services through something called the NDIS because I have a mental illness. I want to find out more about it, but have no idea where to start. I’d really like to spend less time sitting around the SRS and do some other stuff. It’d be really nice to talk to my kids again.



SUMMARY OF MOMENTS THAT MATTER (MTM) FOR REX



Individual



- Increased risk of disengaging.
- Increased alcohol use which could lead to eviction/homelessness & police involvement.
- Reduced trust in system and all involved.

- Confusion about what all the different appointments are for.
- Concerned about having to pay for appointments/reports.
- Frustrated about having to retell his story.

- Increased chaos in Rex's life due to his confusion about who is who and who does what.
- Risk of Rex declining NDIS – it is not meeting his expectations. He thought he would have more control (over finances).

Support Network



- Additional management required of Rex.
- Additional administrative time.
- Dealing with personal stress caused by working with Rex or monitoring his behaviour.

- Workers require a strong knowledge of the NDIS and its processes in order to keep Rex adequately informed and supported.
- Additional administrative time.
- Lack of support due to absence of 'care team'.

- Confusion amongst workers if not working as a team.

System



- Reduced quality of care due to system pressures and inefficiencies.
- Increased use of additional services including MH hospitalisation.
- Affects of alcohol use on physical health resulting in use of PH services.
- Increased risk of homelessness.

- Use of additional services required to develop an NDIS application and plan.
- Impact on MH services and resources when a client who is eligible for NDIS is not accessing services through NDIS.
- Duplication of information – multiple client records and system.

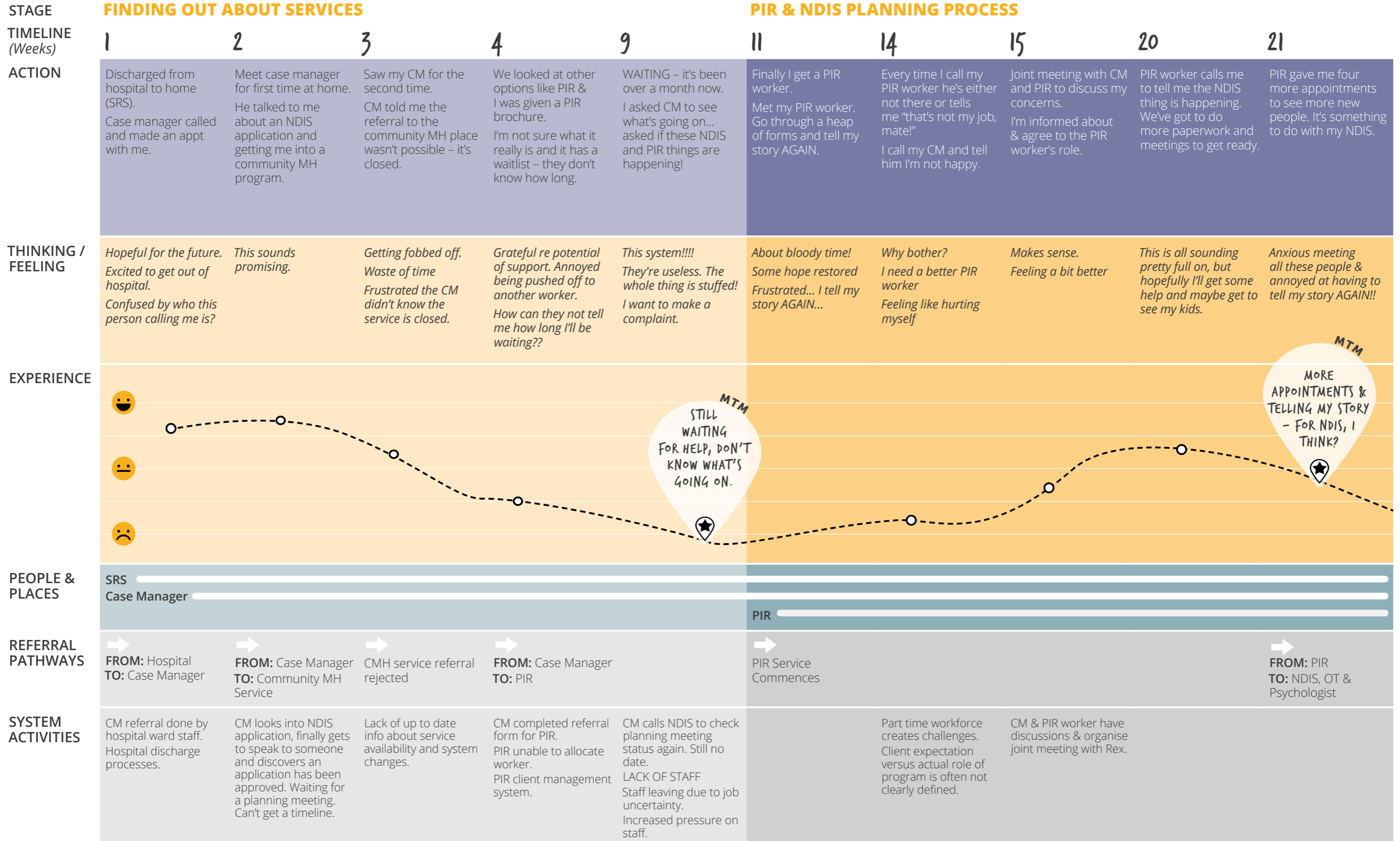
- Duplication of resources and information.

REX'S JOURNEY

SCENARIO

Rex has an extensive history of mental illness which is exacerbated by his substance use (alcohol). Rex's drinking has at times made his housing situation extremely tenuous. His use of alcohol and chronic smoking mean he often has little money left for anything else. At times this leads to him pestering other residents for smokes.

Rex has recently been discharged after a hospital admission. While in hospital, he underwent a change in medication which has assisted in reducing his hallucinations. Rex requires assistance with a range of needs including accessing the NDIS. Rex says he would like to get out more and connect with the community, and would also like to have contact with his estranged children.





STAGE	PIR & NDIS PLANNING PROCESS (CONTINUED)			USING THE PLAN & SERVICES								
TIMELINE (Weeks)	23	25	26	28	30	32	34	38	40	42		
ACTION	Appt with psychologist Psych gave me a letter. Gave it to PIR.	A lady (OT) turned up to do cooking with me @ home. Something to do with NDIS. PIR says I have a planning meeting – whatever that is!??!	PIR worker picks me up & takes me to planning meeting (3 hrs) He takes in a suitcase of info – all about me! NDIS said they will pay for everything.	PIR says plan has come in. I get a bit of paper. I'm told I still can't access services or money.	My PIR contacts me and tells me we're finished – he can't help me anymore. Apparently they're finding me a new person (support co-ord) and they'll be taking over. And there's still no news on my NDIS money!	I meet my new Support Coordinator. She tells me we are having ANOTHER meeting to work out how to use my NDIS money.	We go to a meeting with the NDIS. They tell me what I can get for the money I have. We fill out a heap more paperwork. I'm told I still have to wait.	I call the SC lady to see what's going on. She tells me she is getting all the service quotes together.	We have another meeting and she tells me what she has come up with, and gets me to sign a heap of forms.	I'm starting to attend the community MH place. I'm doing the music. This is all I wanted a year ago when I got out of hospital.		
THINKING / FEELING	Nervous – what will they be like? Will they tell me what to do? So overwhelmed with all these assessments. Why do they make everything so hard?	Enjoyed the cooking. Would do that again. Anxious. What questions do they ask? How long will the meeting be??	The meeting was so exhausting! She was nice, but said she used to be a physio and doesn't know much about MH. Awesome – what can I buy??	This is pretty good – I might get to actually do some stuff. I can see all the money in the plan and I want to spend it right now!	What a waste of time! The system is stuffed! It's my money & my life.	What?? What did I do?? I don't want to meet a new worker!	Annoyed at having to wait AGAIN for support. So many bloody forms!	She sounds on to it at least, but this is taking forever! How hard can it be? Better bloody be worth it!	I feel like I just signed my life away with all those forms. It sounds ok though – some stuff to get me out of the house.	Happy with the music group. Back to where I started before NDIS.		
EXPERIENCE												
PEOPLE & PLACES	SRS Case Manager PIR			NDIS Planner							SC	NDIS Services
REFERRAL PATHWAYS							FROM: PIR TO: Support Coordinator				TO: Other supports (cleaners, gardeners)	
SYSTEM ACTIVITIES	Information sent to NDIS NDIS database			PIR worker sends referrals, makes several calls re: waitlists		System changes – PIR service closes down		Lack of visibility of NDIS processes and waitlists.		NDIS services Client Management Systems / Database		

MEL

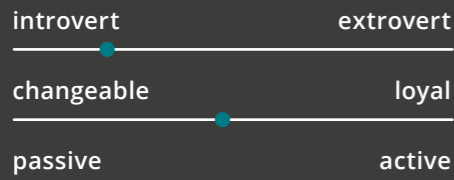
“ I DON'T KNOW WHAT TO DO... I CAN'T COPE WITH THIS ANYMORE ”

- Age:** 22
- Occupation:** Student
- Education:** Secondary. Enrolled in TAFE course.
- Location:** Box Hill
- Family Status:** Single. Youngest of 4 children.
- Nationality:** Vietnamese (second generation)
- Health:**
 - Substance use (marijuana)
 - Increasing paranoia and depression
 - Agoraphobia
 - Poor diet
 - Isolation

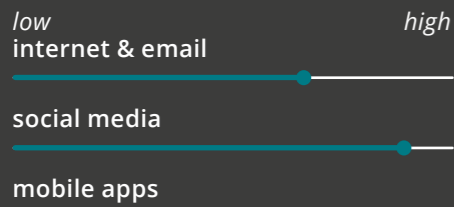
ANXIOUS
OVERWHELMED
DEPENDENT
VULNERABLE



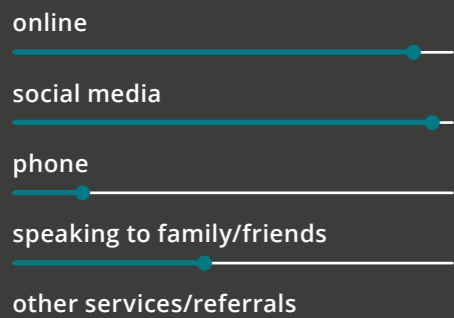
PERSONALITY



TECH USAGE



PREFERRED CHANNELS



INCOME LEVEL



BIO

Hi I'm Mel, I'm a 22-year-old student and the youngest of four children. I am close with my family but I recently made the decision to move out of home to live with two friends.

My parents were not happy with my decision to move out. They have very high expectations of me and I was struggling to cope with the pressure.

I am enrolled in a hospitality course at TAFE but have not been going. I just don't like leaving the house at the moment. I feel like someone is watching me. I've been smoking pot to help take the edge off but I know it's probably doing more harm than good. I feel like I'm losing my mind.

KEY FINDINGS FOR MEL

SERVICE NEEDS

- Feeling safe and that there are people who I can contact who will care about me
- Confidentiality and discreetness – “My family cannot know about this”
- That they will help me get better – “I feel like I'm starting to lose my mind”

GOALS

- Get through this without my family finding out
- Develop better ways of coping
- Stop smoking and cutting
- Feel confident to leave the house
- Get back to attending TAFE and finishing studies

FEARS & FRUSTRATIONS

- Being judged on her self harming behaviour
- Feeling like she might get lost in the system – sent from one place to another
- Feeling pressured to “just get better”

DON'T TELL ANYONE. MY PARENTS CAN'T FIND OUT & I DON'T WANT MY HOUSEMATES TO THINK I'M CRAZY.

DO PEOPLE REALLY KNOW WHAT TO DO AND DO THEY WANT TO HELP ME?

DON'T LEAVE ME ALONE IN THIS.

TRUST

TELL ME WHAT MY OPTIONS ARE AND HELP ME TO WORK THINGS OUT.

I CAN'T MAKE PHONE CALLS OR GO TO NEW PLACES ALONE.

CHOICE & CONTROL

I WILL SHUT DOWN IF I FEEL OVERWHELMED.

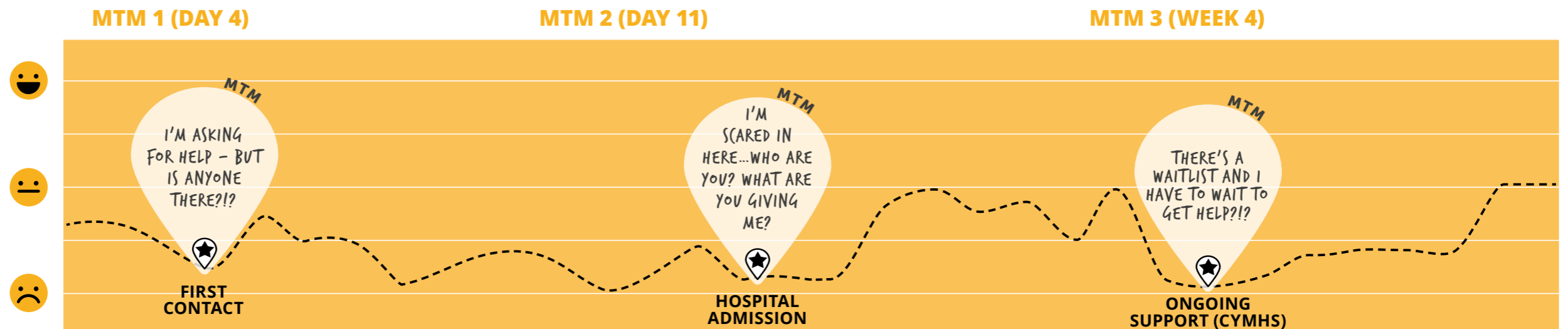
I NEED TO UNDERSTAND WHAT'S HAPPENING TO ME AND HOW THE SYSTEM WORKS.

EXPLAIN EACH STEP TO ME CLEARLY, TELL ME WHO'S WHO, WHAT'S GOING TO HAPPEN NEXT AND WHAT MY OPTIONS ARE.

COMMUNICATION



SUMMARY OF MOMENTS THAT MATTER (MTM) FOR MEL



IMPACT

Individual



- Increased risk of self harm.
 - Increased use of substances.
 - Reduced trust in system.
 - Risk of withdrawing further.
- Overwhelmed by the environment and constant change in staff.
 - Confronted by seeing other patients who are so unwell.
 - Unclear about the medication she is being given.
 - Fearful of her family finding out.
 - Concerned about having to pay for services.
 - May minimise her symptoms in order to leave hospital.
- Disengages and starts to give up on getting better.
 - Loss of trust in system.
 - Blames herself and withdraws, is alone again.
 - Reverts to using her coping mechanisms (substances and self harm).

Support Network



- Family and housemates feel disconnected from Mel.
- Housemates are concerned about where Mel is and what is going on.
- Breakdown in relationship with family.
 - Housemates feeling confused/afraid about Mel's behaviour.
 - Disengages from professional support channels.
 - Becomes non-responsive/cooperative to MH workers.

System



- Limited hours of phone support and opportunities for early intervention may lead to unnecessary or increased hospitalisations.
- Service limitations due to restrictions placed by client on the sharing of their information with other services/family members.
- No continuity of care to prevent relapse when no GP is present and no consent to include family in care team has been given.
 - Case manager needs to account for safety of client – limiting capacity to take on new clients.
 - Treatment becomes involuntary.
 - Housing is at risk.

MEL'S JOURNEY

SCENARIO

Mel has contacted the local mental health triage service saying she is feeling suicidal. She is tearful, agitated and distracted but oriented to place and time. She states people are watching her and that she is

too scared to leave the house because "they will get me". Mel does not want to contact her family as she says that they don't understand what she is going through.

STAGE	FINDING OUT ABOUT SERVICES			TRIAGE				CATT			HOSPITAL ADMISSION					
	DAY 1	DAY 3	DAY 4	DAY 4	DAY 4	DAY 4	DAY 4	DAY 6	DAY 8	DAY 8	DAY 8	DAY 10	DAY 10			
TIMELINE																
ACTION	Contacted by one of my teachers at TAFE. I could fail, because I haven't been there enough. I'm told to contact the Wellbeing team.	I call the Wellbeing team and chat to a nice woman. She suggests I come in for an appointment. I tell her that's not possible. She gives me some numbers to contact if I need.	I decide to call Beyond Blue and they insist I call Triage.	I contact Triage by phone. Called AH @ 11pm. I hang up. (open 7am-10pm)	I have barely left my room or eaten in 2 days. I decide to call Triage again.	I'm placed on hold - have to wait 30 minutes...	I speak to a lady at the Triage - I tell my story.	Triage lady tells me the CATT team will come & see me. Explains the CATT team to me	CATT team calls me the next day.	I arrange a time for them to come over in 2 days time when my housemates are going to be out.	The CATT team arrives 15 minutes after they said they would be there.	I tell my story again. I tell them I want to die. I feel scared & can't leave my house.	They are worried about my cuts. They recommend I need to go to hospital.	They take me to the ED to attend to my wounds.	I am admitted to psychiatric unit.	I talk to a psych, I talk to a social worker, I talk to nurses. I don't even know who is who. I tell my story again and again and AGAIN.
THINKING / FEELING	<i>Oh my god! If I fail, my parents will find out everything!</i>	<i>She won't understand. I can barely leave the house. I'm scared though, I think I need some help.</i>	<i>Ok! I'm going to do it! Someone else to call? I'll think about it for a bit.</i>	<i>Scared of judgment. Anxiety & fear of the unknown, will they be able to understand & help me. I don't want people to think I'm crazy!</i>	<i>Feel like having a smoke. Cutting myself. I really need help. I hope someone picks up this time.</i>	<i>How long do I have to listen to this music??!! PICK UP!!!</i>	<i>Raw, exposed, vulnerable & overwhelmed. Someone is listening. Feeling like hurting myself.</i>	<i>Does this mean I'm crazy? I'm scared what my housemates will think when these people come to our house. What will this cost me? My health cover is under my family - they CANNOT know!</i>	<i>Who is this new person I'm talking to? Will they actually help? Will they see my weed and call the cops?</i>	<i>No one can know anything about this! My family would disown me. Don't like the idea of strangers coming to my house</i>	<i>Anxious - they are late. Are they coming? Will the car have a mental health logo?? Overwhelmed. 3 people from the CATT team arrive!</i>	<i>Will they lock me up? I'm scared to show other people my cuts. But I really want help. Will I be over medicated? Restrained?</i>	<i>How long do I need to be in hospital?</i>	<i>They want to lock me up! I must be crazy! Maybe they'll fix me</i>	<i>I'm scared in here. It's a bit nuts. There are so many people who are REALLY unwell.</i>	<i>So many meetings! Who the hell are you??</i>
EXPERIENCE	😊	😊	😊	😞	😞	😞	😞	😞	😞	😞	😞	😞	😞	😞	😞	😞
PEOPLE & PLACES	Staff @ TAFE Wellbeing worker TAFE	Beyond Blue Home				Triage clinician		CATT team		Home		ED Nurses & Doctors	Other clients	Hospital		
REFERRAL PATHWAYS		→ FROM: TAFE TO: Beyond Blue	→ FROM: Beyond Blue TO: Triage				→ FROM: Triage TO: CATT					→ From: CATT To: ED	→ From: ED To: MH Ward			
SYSTEM ACTIVITIES	Access to support at TAFE Mental Health Royal Commission	Not enough information re: available supports.		Limited service hours due to funding and staffing.			Staff shortages. Not enough staff Info is lost throughout the referral process.					Availability of hospital Pressure to keep client moving through the system.	Discharge out of their hosp/service. Patient flow.			

MTM
I'M ASKING FOR HELP - BUT IS ANYONE THERE?!?

MTM
I'M SCARED IN HERE...WHO ARE YOU? WHAT ARE YOU GIVING ME?



STAGE	HOSPITAL ADMISSION					CYMHS				STEPPED CARE								
TIMELINE						DAY 14	DAY 17	DAY 24	WK 4		WK 8		WK 12					
ACTION	They put me on medication. No idea what it is.	I'm not feeling as paranoid. I guess I'm feeling a bit better. They say I can go home soon.	They want to talk to my family – I don't want them to!!	They give me some numbers & people I can call. Tell me the CATT team will come to my house tomorrow	I am discharged. I go home.	CATT comes to visit me and watch me take my meds. (X 3 days) I tell them I've got no food, but all they do is just check to see I'm not going to hurt myself.	They refer me to case management (CYMHS)	I tell my story to the CYMHS worker at her office. They tell me about Headspace – it sounds ok.	My CYMHS worker calls me. Tells me there is a big waitlist for Headspace. Tells me there are other options. I'm not sure. I need to think about it. I tell her I will text her.	I get lots of calls from private numbers and texts.	I get a letter telling me I'm going to be discharged. If I don't respond, I'll have to go back through Triage.	I decide to call. Chat to CM – she had some new ideas. She refers me to 'Stepped Care'	The next day the Stepped Care people call me. I make an appt.	I go to the appointment at their office.	I meet with a new person at the Steps Office. I tell my story again.	I am referred on to a whole lot of other services. <ul style="list-style-type: none"> • AOD • Psycho Ed groups • Youth Groups 	I start using services and seeing a GP and psychologist regularly.	
THINKING / FEELING	Feel like I'm being controlled. No one seems to care about how I really feel or what's actually going on for me.	I'm feeling really sleepy. What is this medication? I want to get out of this nut house, but what will it be like at home.	Haven't they been listening to anything?? I've told them 20 times my family can't know about this!!	What are these numbers for? Why do I have to call? Couldn't someone do it for me? What will my housemates think about this?	Where will I tell my housemates I've been? My room is chaos, I don't have any food and I think I owe money for a heap of bills.	Do they actually want to help me? I'm sitting here in my room and the place is a disgrace, but they don't seem to care.	Well that's something at least – maybe they are trying to help.	Wow she was different. I like her. She could see how I was doing instantly, and really listened. She gets that my family can't know about this.	Annoyed. Seriously? No one can help. What's the point?	They keep calling. I'm over this. Surely there's other options she could try.	Feeling panicked – these people are going to give up on me. I can't go back to hospital. That place is horrific!	I feel a bit	Another new person to talk to	Is it another long waitlist? I wish they could see me at home. I'm finding it hard to leave the house still.	I'm so over going over all the same stuff Nervous. "Will they judge me?" "What do I have to say?"	It's taken 3 months Hopeful. "Maybe I can get help" "Maybe I can have a different life"	So many people to see. I want to enjoy my life again. I hope I'll be able to stay with this clinician and not be moved on again.	
EXPERIENCE																		
PEOPLE & PLACES	Hospital					Housemates		Discharge team		CATT team		CYMHS worker			Steps intake		Steps Office	TAFE GP
REFERRAL PATHWAYS						➔ From: MH Ward To: Home		➔ From: CATT To: CYMHS					➔ From: CYMHS To: Stepped care		➔ From: Stepped care To: Services			
SYSTEM ACTIVITIES	Income from Centrelink of not attending TAFE.	NDIS for general disability not mental health clients.	Agencies looking to support similar clients. Multiple client records and systems.	Capacity of staff to keep up to date with referral pathways and service changes.	Unwell mentally but not unwell enough for NDIS.	Lack of capacity to meet demand. Demands & KPIs	Extensive wait lists for services.	Clunky data collection systems take away from time with clients.	Case manager needs to account for safety of client.	Staffing limitations due to short term \$\$	Service \$\$ moving forward.	Out of date resources. New model of care with Triage + CATT	Continuity of care – preventing relapse where no GP is present.					

CHRISSY

“ I WANT TO HAVE A BETTER LIFE AND BE A GOOD MUM ”

Age: 28

Occupation: Unemployed

Education: Secondary (Completed Year 10)

Location: Ferntree Gully

Family Status: Single mum, living with her two children

Nationality: Anglo Australian

Health:

- Childhood trauma
- Substance use (alcohol)
- Overweight – feels like it is due to her medication

CONFRONTING
IMPULSIVE
LACK OF INSIGHT
IMPATIENT



KEY FINDINGS FOR CHRISSY

SERVICE NEEDS

- Experienced staff (must be female)
- Very high flexibility – “ I need services that can fit around my lifestyle”
- Family-centred – “Parenting is hard and I don’t want to lose my kids”

- Have stability and security in my life
- Have ongoing support (emotional, financial)
- Have a better life (now)

FEARS & FRUSTRATIONS

- Inconsistent staff
- Being challenged or questioned
- Strict boundaries
- Emotional vulnerability during therapy
- I want to see a psychologist for as long as I want
- Lack of flexibility in services

PROVE YOURSELF TO ME – I’VE BEEN IN THIS SYSTEM A LONG TIME!

RECOGNISE THAT I’M A GOOD MUM – PROTECT MY KIDS AND ME, AND KEEP US TOGETHER.

TRUST

I ONLY WANT FEMALE WORKERS.

I NEED SERVICES THAT ARE FLEXIBLE AND FAMILY FRIENDLY.

I WANT TO BE ABLE TO SEE MY PSYCH AS OFTEN AS I WANT.

(CHOICE & CONTROL)

DON’T OVERLOAD ME WITH INFORMATION I DON’T NEED – I WON’T READ IT!

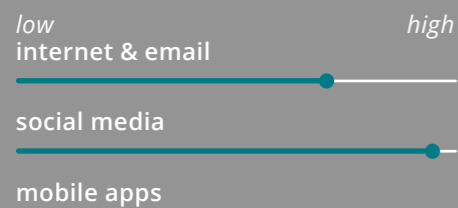
MAKE SURE THE INFO I NEED IS THERE WHEN I NEED IT, IS EASY TO UNDERSTAND, AND SIMPLE TO ACCESS.

COMMUNICATION

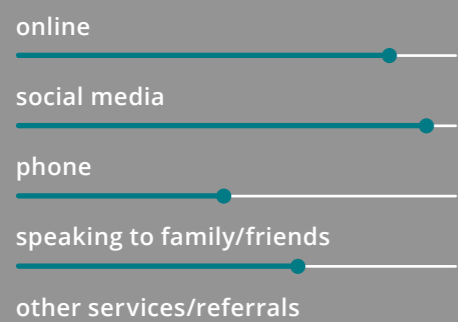
PERSONALITY



TECH USAGE



PREFERRED CHANNELS



INCOME LEVEL



BIO

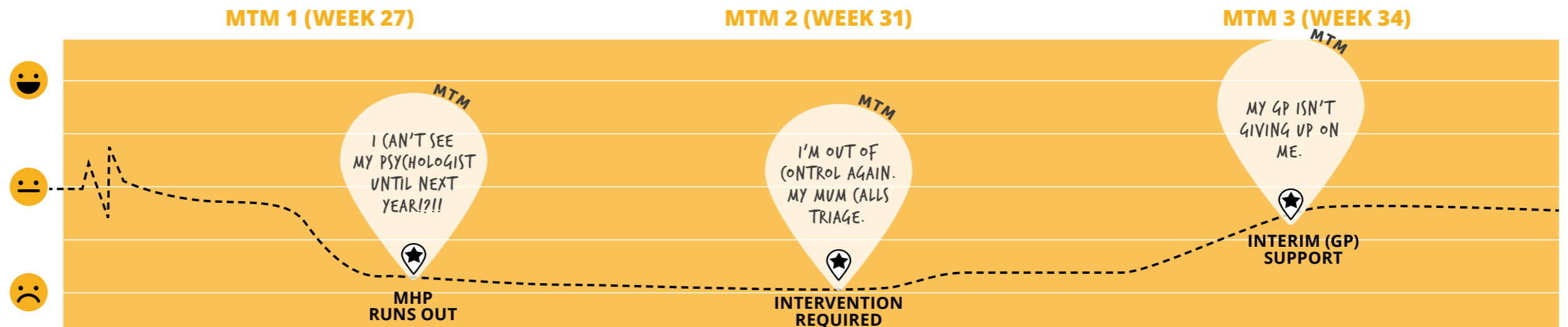
Hi, I’m Chrissy. I’m a single mum living in Ferntree Gully with my two kids who are 5 and 7 years old. I’m currently unemployed and have been in and out of jobs for the last 10 years.

I have had mental health issues since I was in my late teens. In the past, I’ve had support from a number of different places, but no one is helping me at the moment.

My mum lives nearby but we had a big fight recently, so I’m not talking to her much at the moment. She is always trying to tell me how to parent my kids. I was seeing a guy for a while but we broke up a couple of months ago. My friends are too busy with their own issues. I feel really alone.



SUMMARY OF MOMENTS THAT MATTER (MTM) FOR CHRISSEY



IMPACT

Individual



- MH declines as no clinical support in place.
- Financial stress/inability to pay out of pocket for psychology sessions – lack of control.
- Impact on parenting of two children.
- Impact of increased drinking on Chrissy and her children.
- Lack of trust – disengages with support network as a result.
- Lack of control and choice – fear of hospitalisation and losing kids.
- Some hope is restored.
- Feeling like someone cares.
- Increased stability.

Support Network



- Mum – Stress associated with Chrissy's behaviour and mental health.
- GP – Additional management (emotional and clinical) required for Chrissy.
- GP – Additional administrative time spent finding appropriate support options.
- GP – Personal stress associated with providing support.
- Mum – knowing who and when to call for help.
- Duty of care for grandchildren versus loss of trust from daughter.
- Lack of support for GP as no 'care team' in place.
- Mum and GP can work with Chrissy as a team to put supports in place.

System



- GP availability for other patients.
- Availability of resources that provide information on new MH referral pathways.
- Quality of care provided due to stress on system.
- Unnecessary contact with the acute system (triage).
- Potential avoidable hospital admission.
- Use of carer support services.
- Potential involvement of services such as Child First/Child Protection.
- Sharing of information/consent requirements.
- Capacity of system required to accommodate Chrissy's needs (eg. preference for female, family centred, etc).
- Positive outcomes of this support model will reduce the load on other clinical services.

CHRISSEY'S JOURNEY

SCENARIO

Chrissy visits her GP stating that she is feeling completely overwhelmed by everything at the moment. Chrissy states she is struggling to keep her house tidy, get the kids to school on time and is drinking more. She expresses concern that her current medication is causing an increase in weight gain. She wants to stop taking it.

Chrissy has tendencies to search for conflict and is not sure what support she needs to address the issues in her life. She is highly resourceful and has trialled a number of providers but is not yet satisfied.

STAGE	GP – MHP & PSYCHOLOGIST REFERRAL					10 SESSIONS WITH PSYCHOLOGIST					GP ONLY SUPPORT		
TIMELINE (Weeks)	1					2	16	22	22	26	27		
ACTION	I call and make an appt with my GP. I tell them it's urgent.	I see my GP the next day. I tell her about all the stuff that is going on in my family.	We talk about my meds – I tell her I'm taking them regularly, even though I'm not.	She writes me a MHP and refers me to a new psychologist.	I call and make an appt. I tell them it's urgent.	I meet the new psychologist (Jen) 3 days later. Jen is good – we get along really well.	I see Jen every 2 weeks and see my GP every other week.	On my 8th session with Jen she tells me we only have 2 more sessions to go.	After 10th session I'm discharged	Feeling so good... I'm going to drop back on my meds.	Family stuff is starting to go a bit haywire – I'm not feeling so great.	I call to make an appt with the GP to get another MHP	I go back to the GP. I want to see Jen again.
THINKING / FEELING	Everything is a bit out of control. I can't keep going like this. I need some help.	My family are all useless! They rely on me for stuff when I'm hardly holding it together.	I hate these meds – they're making me so fat!	Here we go... another new psychologist, how useless will this one be?	I've got to amp it up or I'll be waiting for weeks to see her!	Wow – she actually knows her stuff and seems to care.	I'm feeling positive. Things are improving. This is a good team of women I've got helping me.	This is rubbish! Am I supposed to be magically 'fixed' after 10 sessions?	I'm actually feeling pretty good... it's been a productive few months working with her. I think I'll be ok.	I'm sick of looking this way – the only way to fix it is to kick the meds.	Feel like I'm going backwards. There's got to be a way to get more sessions with Jen.	I want to see Jen again – she really gets me and I made great progress with her.	There's got to be a way to get around the 10 session rule
EXPERIENCE													
PEOPLE & PLACES	Home		GP/ Medical Clinic			Psych							
REFERRAL PATHWAYS	From: Self To: GP		From: GP To: Psych								From: Self To: GP		
SYSTEM ACTIVITIES			A lot of Information is required to complete MHP.			Having to wait several days for appointment					Making time to get another MHP		



STAGE TIMELINE (Weeks)	GP ONLY SUPPORT			TRIAGE		GP ONLY SUPPORT			STEPPEd CARE			
ACTION	30			31		32			34		35	
ACTION	GP tells me it's not possible until next year.	GP tries to discuss other options, but I'm not interested.	Things are getting worse. The house and kids are out of control. I'm drinking too much. I'm falling back into depression.	My Mum steps in – she calls Triage. I'm so angry with her for doing this – I DON'T WANT TO GO TO HOSPITAL	Triage does an assessment. They tell me if I want to stay out of hospital. I must see my GP.	I go back to see my GP.	GP tells me she needs to do some research into available services. She wants to see me twice a week until we get something in place.	GP starts to look into other service options – she has a lot to learn. She insists I start taking my meds again. I agree.	I see her every few days. She tells me about a lot of new services. I'm not that keen to try other things.	She tells me about some counseling options available through a new program called Stepped Care. I reluctantly agree to try it out.	GP tells me she's still looking at what other support I can access until the next MHP next year.	
THINKING / FEELING	<i>Stupid GP! She can't organise anything. I know what I need!!</i>	<i>This is ridiculous! I'm asking for help. I need help!</i>	<i>I've got to get it together. They'll take my kids away.</i>	<i>I can't go to hospital – they'll take my kids away. I don't want DHHS involved again. I wouldn't send my dog to a MH ward</i>	<i>What's my GP going to do? She couldn't help me before! This system is crazy.</i>	<i>I'm a bit embarrassed – I was pretty rude to her last time I saw her.</i>	<i>I want to see Jen! Don't talk to me about all this 10 sessions rubbish!</i>	<i>She actually does care about me. She is really trying to help.</i>	<i>I know what works for me. All these new groups and things are not my scene.</i>	<i>Here we go again!</i> • Have to tell my story again • How many sessions this time? • Is this actually going to help?	<i>Thank god she is helping. I've got no idea where I'd even begin.</i>	
EXPERIENCE												
PEOPLE & PLACES	GP			Triage		GP						
REFERRAL PATHWAYS				From: Family member To: Triage		From: Triage To: GP			From: GP To: Stepped Care			
SYSTEM ACTIVITIES	MHP only allows 10 sessions in a calendar year!	Other options cost money; are too far away. Needs to see a female.		Privacy and information sharing schemes need to be considered here	Feeling lack of control over situation		GP having the time and knowledge to research other service options			Will service be able to accommodate Chrissy's needs location, time, preference for female?		

PETER

“ I’VE JUST GOT TO GET THROUGH THIS ROUGH PATCH. THIS IS NOT ME! ”

Age: 58

Occupation: Retired school teacher

Education: University

Location: Hawthorn

Family Status: Married, 3 adult children & 4 grandchildren

Nationality: British

Health:

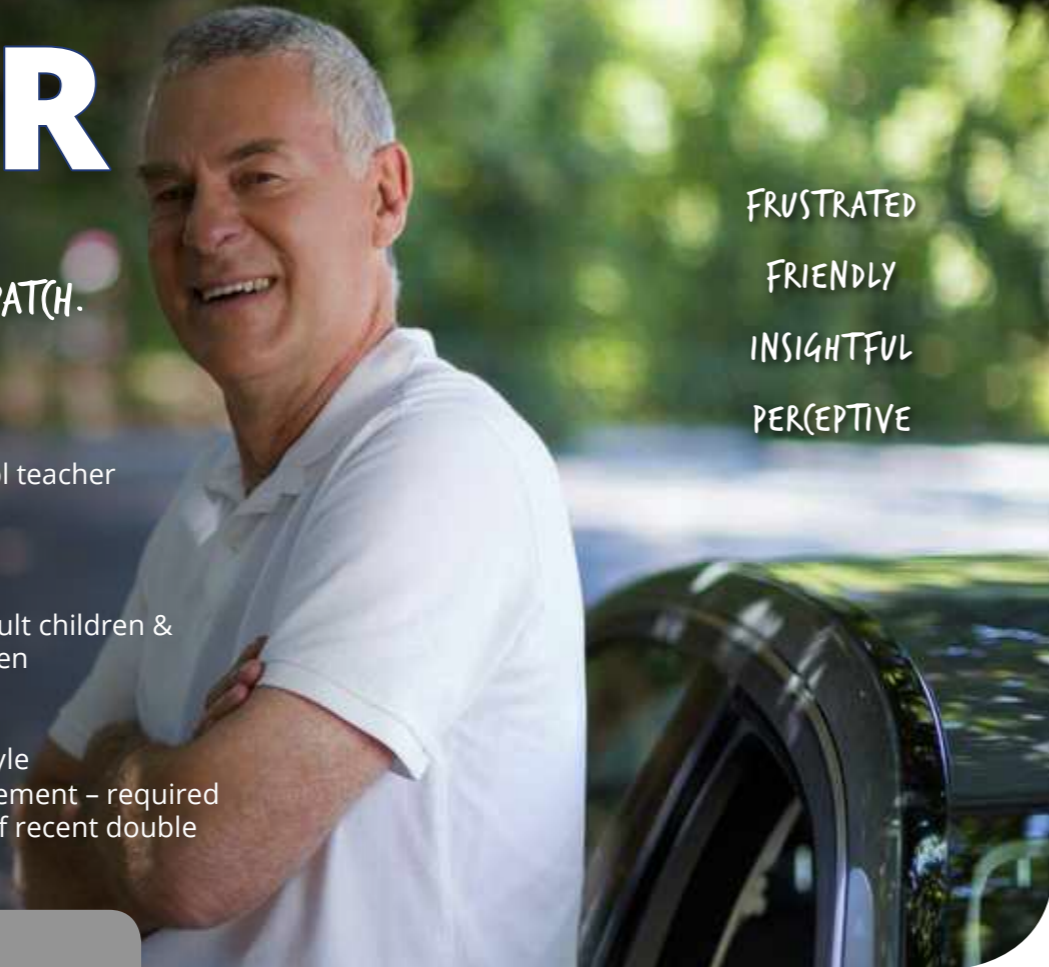
- Active lifestyle
- Pain management – required as a result of recent double knee op

FRUSTRATED

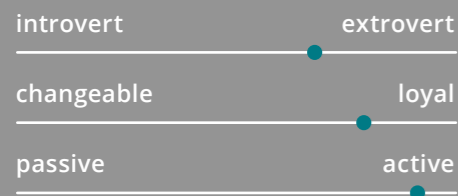
FRIENDLY

INSIGHTFUL

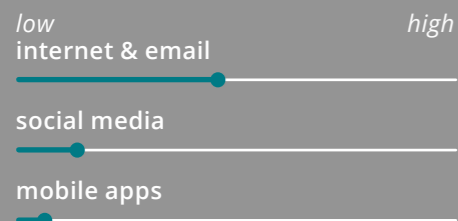
PERCEPTIVE



PERSONALITY



TECH USAGE



PREFERRED CHANNELS



INCOME LEVEL



BIO

Hello, I’m Peter. I’m 58-years old and retired a couple of years ago after teaching for 35 years. I live with my wife, Sal. We have three kids and 4 grandkids. Our family is everything to us.

In my younger days, I was an elite athlete and was a keen mountaineer throughout my 30s and 40s. I’ve pushed myself hard over the years and as a result, recently had to have a double knee replacement. It was on the cards for a while, but was still a bit of shock when it happened. I just wasn’t prepared for the downtime. I’ve had some complications with my recovery, so progress has been slow. Really slow. And it’s been a whole lot more painful than I anticipated.

I’m usually a really active and outgoing person but recently I’ve begun to feel ‘flat’ and unmotivated. I’m worried about my recovery and feel like I’m becoming a burden on Sal.

KEY FINDINGS FOR PETER

SERVICE NEEDS

- Experienced staff who listen to and respect me
- Confidentiality is critical – “I don’t want anyone knowing about this”
- Wants a ‘quick fix’

GOALS

- Get back to the active life and mental state I had before surgery
- Be able to manage all my physio and outpatient appointments
- Walk on a daily basis
- Feel strong and independent
- Stay fit and healthy as long as possible

FEARS & FRUSTRATIONS

- Privacy and confidentiality
- Finding the ‘right’ help
- Inexperienced staff
- Being kept waiting for appointments
- Not feeling in control with decision making

I WANT AN EXPERIENCED CLINICIAN WHO I RESPECT AND CAN CONNECT WITH. CONFIDENTIALITY IS CRITICAL!

TRUST

I WANT TO FIND SOMEONE WHO GETS WHAT’S IMPORTANT TO ME AND CAN DELIVER SERVICES IN A STYLE AND IN AN ENVIRONMENT I AM COMFORTABLE IN.

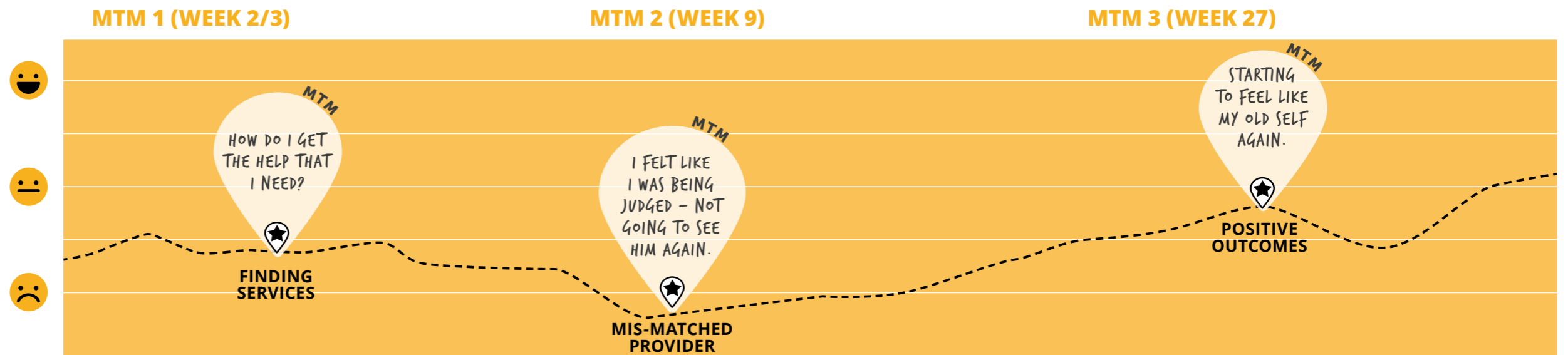
CHOICE & CONTROL

I WANT A SERVICE DIRECTORY OF PSYCHOLOGISTS WITH THEIR CREDENTIALS AND EXPERIENCE SO I CAN EASILY SEARCH FOR A PROVIDER THAT SUITS MY NEEDS.

COMMUNICATION



SUMMARY OF MOMENTS THAT MATTER (MTM) FOR PETER



IMPACT

Individual



- Overwhelmed with where to start.
- Risk of not seeking help at all.
- Disengages with GP as not knowledgeable on MH.

- Disengages again.
- Decreased motivation to get better leading to increased isolation
- Gives up on getting help

- Improved mental and physical health
- Feeling empowered (decision to change psychologist was a good one).
- Increased knowledge about mental health and available support.

Support Network



- Wife – stress associated with supporting Peter.

- Wife – stress associated with supporting Peter.

- Decreased stress.
- Improvement in relationship.
- Increased independence (Peter not relying on her).

System



- Health of individuals deteriorates while trying to navigate the complexity of accessing the system. Potentially leading to increased service use.
- Use of carer support services should Peter require ongoing support from wife.
- Use of primary/allied health services if not attending post op appointments.

- Pressure on system due to administrative requirements of MHP.
- Continued decline of Peter's health could lead to increased use of services (medication etc).

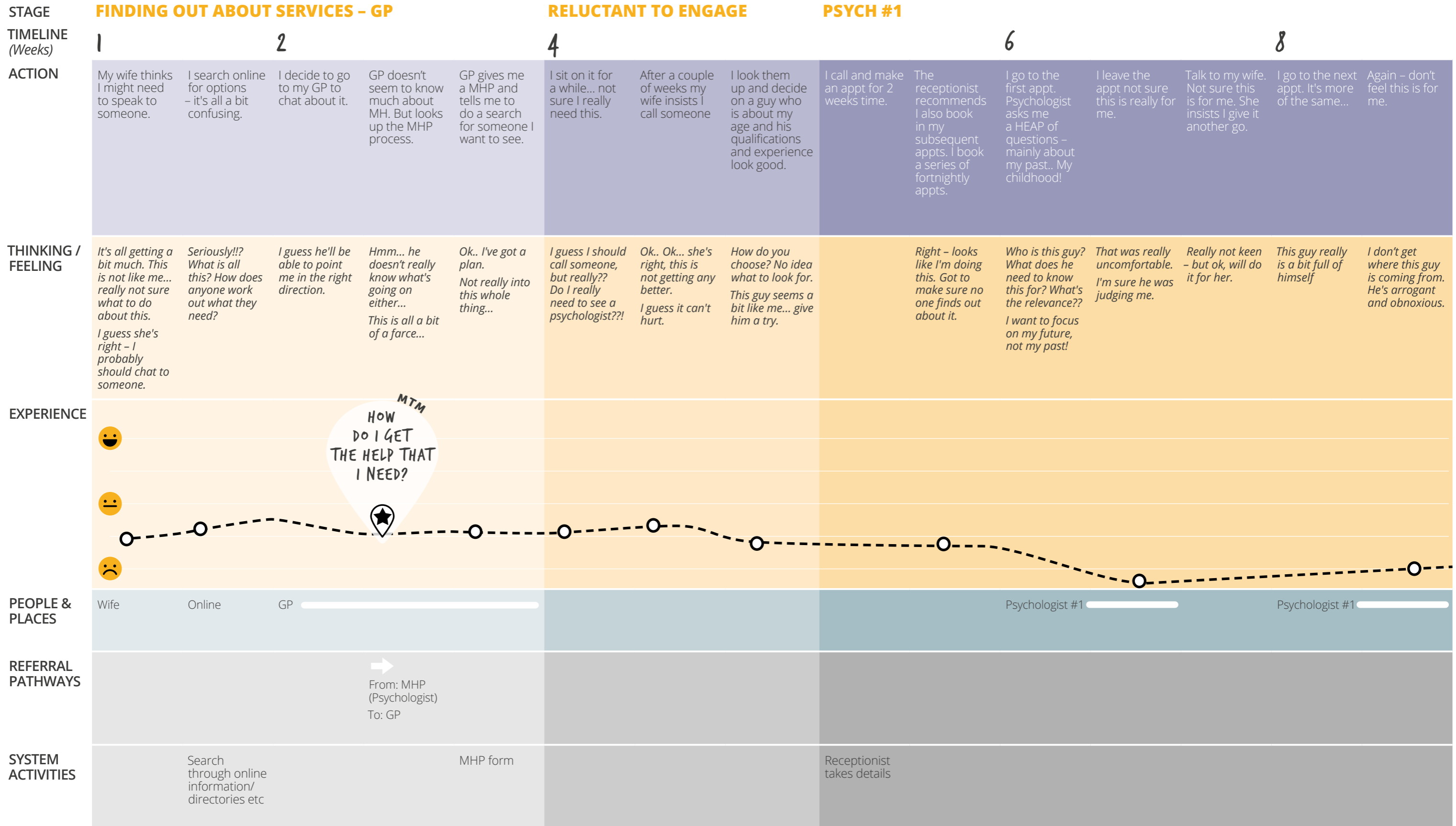
- Limited mental health services and support required resulting in more capacity for those with need.

PETER'S JOURNEY

SCENARIO

Peter has presented to his GP with his wife Sal. Peter describes feeling increasingly unmotivated with low mood after a prolonged recovery from a double knee operation. Sal reports Peter becoming increasingly quiet and

withdrawn. She states that he appears to be overwhelmed by relatively simple things such as getting out of the house and going to appointments. Peter states he feels helpless and a burden on his wife.



MTM
HOW DO I GET THE HELP THAT I NEED?



STAGE	RELUCTANT TO ENGAGE				PSYCH #2 & ONLINE RESOURCES											
TIMELINE (Weeks)	9	13		15	21	23	24	27	29							
ACTION	A week before my next session I cancel my appointment.	A month goes by... my wife is on my case to find someone else.	I go back to my list of possible people and choose another psych. A slightly younger, woman who started her career as a teacher.	I call and chat to her briefly on the phone. I have a good feeling... I make an appt.	I go to my first appt with new psych.	It's great! She asked a bit about my past, but also focused on what I want to achieve for the future.	She gives me some info for other things that may help me: Apps Info sheets	I see her again every fortnight for the next 6 weeks.	I'm feeling good about the progress. I'm surprised at the stuff we talk about – a lot of my past and history comes into it, but I can see how this is helping.	After our 4th session, she tells me I'll need to get an extension of the MHP to keep seeing her.	I call my GP to make and appt.	I see my GP – he writes up another 4 sessions on the MHP.	I call the psych and rebook another 4 sessions.	I see her again for another two sessions.	At the end of the 8th session, we both agree I'm in a pretty good place. I decide to cancel the next sessions for now.	I keep using the apps and online resources she has connected me to. This is enough to keep me focused and optimistic about the future.
THINKING / FEELING	<i>I'm not going to spend another hour with that fool. I feel worse when I leave than I do when I go in! That's not the idea.</i>	<i>She's right. Things really are not improving.</i>	<i>Let's try a different tack. I might feel better talking to a woman. She was a teacher once too – we might have a bit more in common.</i>	<i>She seemed good – professional but relaxed and easy to talk to.</i>	<i>This could be good. Definitely found it easier to talk to her.</i>	<i>Ok, great! If I can do this myself – all the better.</i>	<i>Things are going well. She really listens and has some great ideas. I'm definitely feeling like the cloud is lifting.</i>	<i>What? That seems like a waste of energy – what a stupid system!</i>	<i>This is crazy... they make you jump through some hoops for this stuff!</i>	<i>Starting to feel like my old self again. I'm getting on top of things and feeling positive more often than not.</i>	<i>Things are good. My physical and mental health are miles from where I was 3 months ago. I'm exercising each day and my wife and I are in a much better place.</i>					
EXPERIENCE																
PEOPLE & PLACES			Psychologist #2				GP			Psych #2						
REFERRAL PATHWAYS		➔ From: Psych #1 To: Psych #2					➔ From: Psych #2 To: GP			➔ From: GP To: Psych						
SYSTEM ACTIVITIES			Psychologist takes details							Need to provide info for MHP again						

SUMMARY OF CLIENT / CARER INTERVIEWS

NDIS

The general consensus from the research is that once the NDIS is in place it offers great benefits. Many participants spoke of major changes in their circumstance and lifestyle advantages as a direct result of the NDIS. Unfortunately, this significant upside was often overshadowed by the challenges experienced during the application, planning and review phases, as well as the ongoing administrative processes.

The introduction of the NDIS has been a huge learning curve for all concerned, including those working in the sector. Many participants spoke of educating their GPs and other practitioners about the system, including how difficult it was to find providers willing to support them with the complex documentation required for the application process.

ACCESSING THE MENTAL HEALTH SYSTEM

The complexity of the system, the number of service providers and the changing landscape of the Mental Health environment, is overwhelming for consumers and their supporters. Those who had good personal connections (family or other) or professional support networks were most successful in finding and accessing services. While those with no support were struggling to work out next steps.

Online research, peer connections and service referrals were cited as the most common ways people found out about services. The lack of informed or facilitated referral pathways was a common theme across participants. Many felt they had been left on their own to reach out and make contact with potential service providers, even when they were in an acute phase of illness and were struggling to communicate at all. In contrast, the most successful approach to people engaging with services and accessing what was needed, was through supported referrals with a continuity of care and a managed hand-over process.

USING THE MENTAL HEALTH SYSTEM

Overall, participants expressed a number of challenges associated with their experience of the MH system. These challenges fell into four key areas:

- 1. Service availability** – these factors included finding support that recognised and respected the individual's circumstance. Finding the 'right' people to support them. This included finding someone with expertise of a particular diagnosis from a particular group or with an appropriate cultural sensitivity. It also included having the option to choose how they received support eg. in a 1:1 and/or group setting.
- 2. Workforce** – GPs with no MH experience, staff who lacked empathy or support workers with a poor understanding of the diagnoses they were managing were cited as some of the challenges. The high turnover of staff in the sector was seen as particularly disruptive to continuity of care. Research participants spoke highly of peer support as a concept but that the system should not be over reliant on it and these workers also required high levels of support and training.
- 3. System culture** – When describing their experiences, particularly in the context of the public hospital system, the terms impersonal, disempowered and lack of empathy were used by participants. The system was described as one focused on managing symptoms and medication, with little consideration of the underlying stressors. There is also a significant lack of collaboration within the system between services, creating more challenges.
- 4. Financial** – Financial barriers have prevented some participants in accessing their preferred model of care. Those accessing subsidised psychological services, and those with enduring mental health conditions, they were often left to pay significant out of pocket expenses.

Three themes were identified as being critical to the lived experience.

TRUST

Trust in the MH system has been compromised on many levels. The complexity of understanding and navigating the system; the challenge of finding suitable workers and supports; the care that many individuals have experienced; and the constantly changing service landscape, has created a sense of uncertainty and scepticism. The effect is that people trying to use the system face an uphill battle to get the support they need and often feel defeated by the system that is supposed to be helping them.

The research shows that to build trust in the system people need to feel respected, cared for and supported as they navigate and use services. Enabling this across Inner and Outer Eastern Melbourne at a system-wide scale will require committed collaboration between service providers and funding bodies. Client engagement in the co-creation of services that promote and build trust is an integral part of this process.

However, to create a foundation for system-wide success, individual service providers must ensure they have a client-centric culture and operational practices in place to support broader development activities.

It's unknown, it can be scary and it's really difficult to work out.

There are individuals [workers] that 'get it.' But one of the problems is the inconsistency.

I felt so supported by her, I decided to follow her. That was two or three years ago, and I still travel to see her.

(CHOICE & CONTROL)

The core principles of the NDIS, 'Choice and Control' are powerful concepts and notions those using the MH system want. However today, clients find the system impersonal and rigid, and often feel constrained and disempowered.

This is driven by a combination of factors including: the complexity of the system and working out how to get the care they need; a shortage of services and staff; inflexible delivery models; a lack of services that suit the individual's circumstance; and care models which are perceived as compliance, rather than recovery focused.

To enable 'Choice and Control' the sector and individual service providers have a responsibility to better understand what clients want, need and value most. These insights must be used as a foundation for the design and development of services and delivery models. This is achieved by implementing regular and consistent client feedback processes that can be used to influence service design.

It's all luck of the draw as to who you get.

I was just sick of getting someone new all the time.

We'd been working on a 12-week format. I'd been really committed to it. By the end of the year, I had no sessions left. I had no money. She gave me two free sessions.

I wanted to find a psychologist who preferably was gay or lesbian. I didn't want to have to explain the complexities of a female female relationship.

(COMMUNICATION)

Poor communication creates challenges for clients across many aspects of the MH system. These include: a lack of clear information about how the system works and how to access services; challenges in searching for information about service providers and service availability; no visibility of waitlist or wait time progress for services; and, understanding 'who's who' and 'who does what' when engaging with and using multiple services.

When navigating the system, clients are at times challenged by all these factors concurrently, causing frustration and additional stress to people who are already in a vulnerable state.

Effective communication is the leading principal for delivering positive client experience outcomes. It underpins 'Trust' and is critical for enabling 'Choice and Control.' To improve communication across the sector, a multi-faceted approach is required.

Collaboration between service providers to define and implement communication standards and processes for client engagement will be the ultimate goal. However, individual organisations can optimise their own communication capability to provide a foundation for best practice communication across the sector.

I was told to phone them every week to see if there's any progress.

They don't always communicate and the messages just don't get through. I've been left stranded.

I'm a good communicator. For those that can't communicate, I hate to think what happens to them.

SERVICE PROVIDER REQUIREMENTS

- A client-centric culture.
- Care models which are welcoming, hopeful and empathetic.
- Systems to capture, understand and respond to 'the voice of the client'.
- Qualified and experienced staff who can support the complex needs of clients.

- Regular and consistent client research and feedback processes.
- Codesign practices for service design and development.
- Clear and up-to-date information about services and service availability.
- Client-driven planning and coordination processes.

- Proactive client communications model.
- Proactive service availability and delivery communication.
- Regular staff information forums and training.
- Best practice communication processes for partner engagement and information sharing.

SERVICE PROVIDER CHECKLIST

This checklist has been designed to assist Service Providers to assess their current Client Experience operational capability. The framework outlines key requirements to deliver on the client value points identified through this research. It is recommended that Service Providers implement internal development projects to establish this capability.



TRUST

	YES	PARTIAL	NO
1 Our organisations mission and values are client-centric and clearly defined. Our care model reflects our values and is provided using a welcoming, hopeful and empathetic approach.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
2 We actively use a system to capture, review and action client needs from frontline staff	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
3 Our staff feel empowered to modify their practice to deliver better client experience outcomes.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
4 We have clearly defined and client-centric processes for providing care across multiple internal services and for partnering with other agencies.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
5 Our staff have the expertise to respond to complex and multiple diagnoses.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
	<hr/>		
	SUBTOTAL		
	<hr/>		



(CHOICE & CONTROL

	YES	PARTIAL	NO
6 We regularly ask our clients what they need and value most. We use this insight to design our services, and wherever possible we co-create our services with them.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
7 We seek regular feedback from clients in relation to service performance, delivery and discharge processes.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
8 We empower the client to choose services that suit their needs by providing easy to understand service and availability information.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
9 We offer flexible models of care that can be adapted to meet the needs of the individual client.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
10 We engage clients in the planning and coordination process and facilitate referrals when required.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
	<hr/>		
	SUBTOTAL		
	<hr/>		



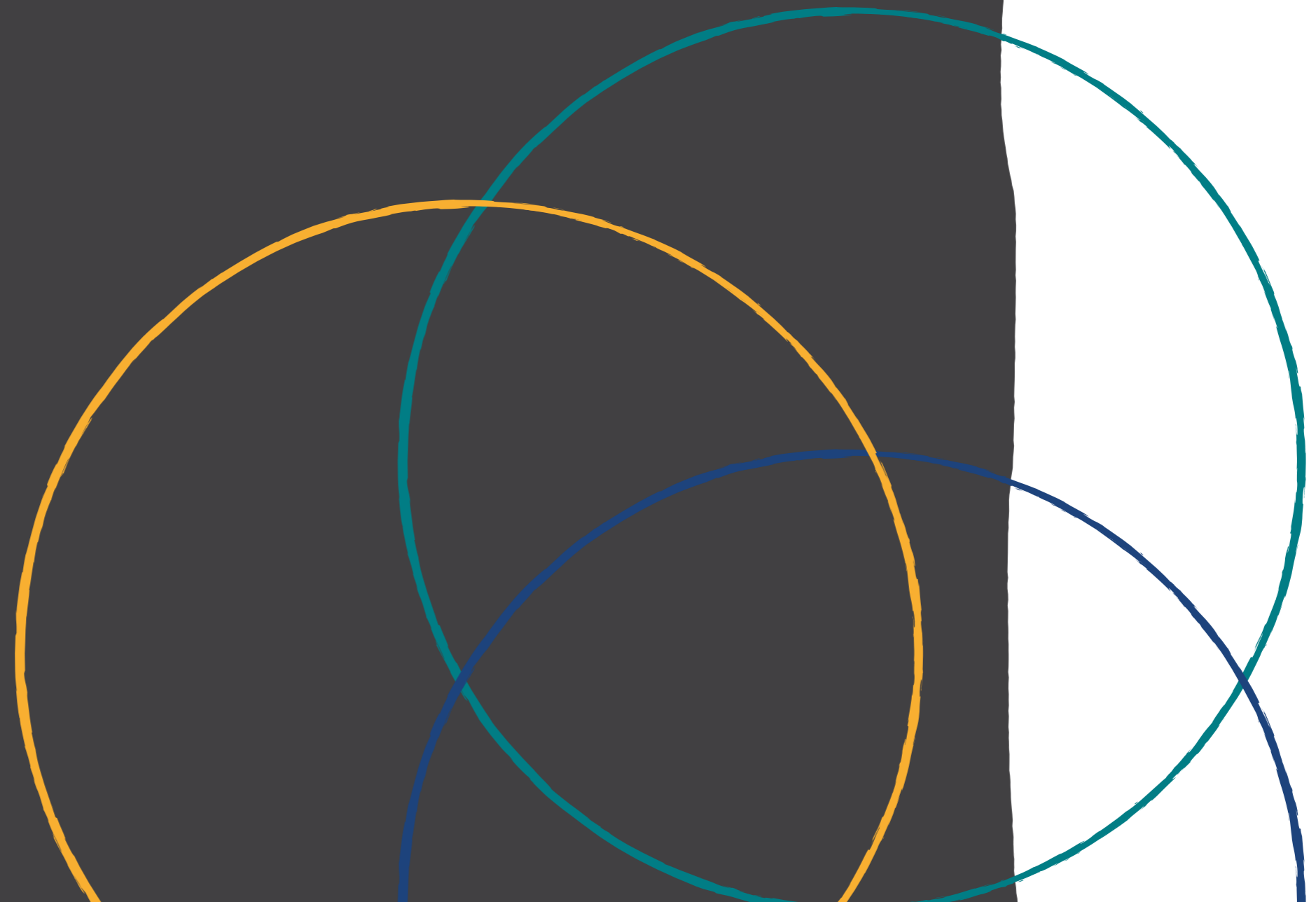
(COMMUNICATION

	YES	PARTIAL	NO
11 We have a clear client communications model, which provides regular and useful information about our service, service changes and sector information. Multiple delivery methods are offered to suit client needs.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
12 We proactively communicate service availability, delivery times and waitlist progress to our clients.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
13 We have an effective staff communications model, which reinforces our mission and values, and client stories/feedback.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
14 Our staff are kept up-to-date with new service offerings, policy changes and sector information and training is provided when necessary.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
15 We regularly review our processes for communicating with other services/providers to ensure seamless integrated care	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
	<hr/>		
	SUBTOTAL		
	<hr/>		

ABBREVIATIONS

BPD	Borderline Personality Disorder
CATT	Crisis Assessment and Treatment Team
CJM	Client Journey Mapping
CM	Case Manager
CYMHS	Child and Youth Mental Health Service
DBT	Dialectical Behaviour Therapy
DHHS	Department of Health and Human Services
ED	Emergency Department
GP	General Practitioner
LGBTQI	Lesbian, Gay, Bisexual, Transgender, Queer or Questioning and Intersex
MH	Mental Health
MHP	Mental Health Plan
MP	Member of Parliament
NDIA	National Disability Insurance Agency
NDIS	National Disability Insurance Scheme
OEPCP	Outer East Primary Care Partnership
PIR	Partners in Recovery
SC	Support Coordinator
SRS	Supported Residential Service

APPENDIX:
CLIENT/CARER
INTERVIEWS



CLIENT/CARER INTERVIEWS

The following quotes and commentary have been collated from conversations with local people who are using or caring for people using MH services in the East. It highlights key points in their journey where they have experienced difficulties and points of opportunity for system improvements. Information from these conversations has been used to inform key content on the four journey maps including the emotional experience and moments that matter.

ACCESSING NDIS

THE APPLICATION PROCESS

The NDIS application and planning process is demanding, protracted, time consuming and at times traumatic for applicants and their supporters. Two-thirds of the interviewees had been through the process and all of them spoke about the difficulty of navigating the system, the huge amounts of information (personal history data) and multiple meetings required to secure a plan.

In addition to the administrative overhead, the deficit-based focus of the NDIA assessment framework was stressful for MH clients. Being asked to focus on their limitations and inabilities was counter-therapeutic and created significant anxiety around the whole process.

Applicants who were at the time using 'undefined' MH services all started their NDIS journey with an application rejection. No rejection explanation was given. Those who went on to secure NDIS funding spoke of building their NDIS knowledge and support networks, making connections with community partners and embarking on tireless appeals processes which often took a year or more.

NDIS applicants who were coming off defined MH services, were automatically approved but this only eliminated the challenges of the first stage. Participants in this category still had great difficulty navigating the system, working out what they were eligible for and getting to the planning stage. The time from notification of approval to planning was often over one year.

Successful navigation of the system meant connecting with people 'in the know'. PIR Support Coordinators, Council NDIS Transition Coordinators and local MPs were critical in supporting successful NDIS appeals.

THE PLANNING PROCESS

Once at the planning stage, applicants were faced with another set of challenges depending on who their planner was. Some people met with planners who had no experience of MH. This meant the applicant and their supporters were at times educating the planner on MH diagnoses and needs in order to justify their application.

CONTACTING THE NDIS

Contacting the NDIS to get an update on application, appeals or planning information was impossible, with many people saying they were calling weekly for months on end for information and being told there was no progress.

I've been to info sessions, I'm very well connected and I've found it impossible to navigate... it's almost pushed me over the edge.

It's report after report of everything I can't cope with. It's thoroughly depressing.

It terrifies and infuriates me the amount of support you need to navigate the NDIS for psycho-social support

The planner was a physio. She actually said she knows nothing about MH.

8 months, weekly calls - 'sorry we can't tell you, it's in the appeals process.'

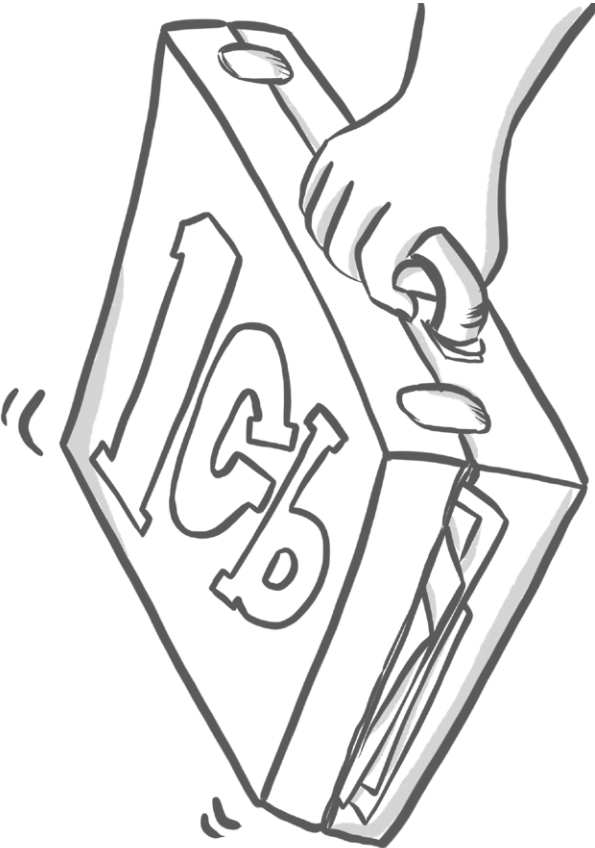
THE REVIEW PROCESS

The first NDIS plan review typically occurs 12 months after the plan has started. The focus is on assessing the funding amounts and the achievement of participant goals. This is another stressful process for participants, due to several contributing factors.

1. Many people were fearful of losing funding due to a lack of service providers to action a plan. "The services I need, don't exist."
2. The funding is tied to the 'achievement of goals', a philosophy which is contradictory to the therapeutic approach used by many within the MH system.
3. People were again forced to focus on the deficits in their ability and behaviour, rather than their strengths.

LIMITED UNDERSTANDING OF NDIS BY GPs AND OTHER PROVIDERS

The introduction of the NDIS has been a huge learning curve for all concerned, including those working in the sector. Many respondents spoke of educating their GPs and other practitioners about the system, including how difficult it was to find providers willing to support them with the complex documentation required for the application process.



I've got this great plan but I'm up for my nine-month review and there's this fear that I'll lose funding. There's a lot I haven't used because I haven't been able to get workers. I've got quite a generous plan, but I'm scared it will be cut back. I'm scared if every year I have to go through this, it's really stressful.

A lot of professionals have no idea about it

My psych had my partner explain the NDIS to him

RECOVERY ORIENTED PRACTICE UNDER THE NDIS

There is a lack of clarity around how NDIS-defined capacity building aligns with recovery-oriented practice. The application assessment and planning processes of the NDIS creates some conflict with the recovery oriented model used in the MH system. For eligibility assessment, the NDIS has a focus on disability and uses deficit-based language which relies on proof that a person's ability to participate in ordinary life is significantly reduced and that their condition is 'permanent'. This means individuals are forced to focus on the things 'they can't do' and are required to gather diagnostic evidence – often from practitioners with limited MH or NDIS experience – to prove it. This focus is contrary with the recovery approach.

The NDIS planning and funding process further alienates many MH participants, as it ties funding to the 'achievement of goals'. Participant choice and control is compromised by the rigidity of plans and scheduling.

My goal is just that I want to stay alive, I want to stay healthy. I want to try and get out of bed in the morning. Apparently you're occasionally meant to wash. Apparently you're meant to eat.

One of my therapeutic things is just to be in the moment.

THE NDIS IN ACTION

One of my goals for my plan this year was to start volunteering. With the Transport funding they've provided, I have started volunteering. So that's one of the big goals ticked.

If you weren't checking, they'd be ripping you off left, right and centre.

I'm now getting services into the house, because service providers had to change the way they do things.

The general consensus is that once the NDIS is in place it offers great benefits. Participants spoke about being able to access the services they needed and having peace of mind that they have the funding to do so. Many people spoke of major changes in their circumstance and lifestyle advantages as a direct result of the NDIS.

Unfortunately, this significant upside was often overshadowed by the challenges experienced during the application and planning phases, as well as the ongoing administrative processes. Those who self-managed their NDIS plans said it gave them greater flexibility and control. However, it was noted that at times it was a challenging and time consuming undertaking and one that required close monitoring.

Interviewees also spoke about the immaturity of the NDIS sector – noting that (especially in the early days) services they wanted and had funding to pay for - were not available. Services not existing at all, or not being available in their area were cited as limitations. These challenges were exacerbated by the fear of not using all their available funding and as a result losing it during the review process.

The physical health needs for people with mental illness was highlighted as a major issue. While it has been recognised for some time that people with severe mental illness are likely to die earlier, lifestyle interventions that encourage people to be more active are not being covered within their NDIS plans.

The NDIS has created significant changes in the delivery models for Support Workers and Support Coordination. Under the new model, an allocation of support hours is given (eg. Av. 100 hours per year for Support Coordination) and is billed in 15 minute increments. A worker will have designated times they can provide such support (e.g. Thursday 1-2pm) and the support is almost always provided over the phone. Previously, someone needing help could contact their worker in an ad-hoc manner and request near-immediate support. The care given was therapeutic and generally provided face to face.

Part of the reason I'm asking for gym is that my medication makes me put on weight. It's part of my disability. So, what she did give me was 10 hours with a personal trainer. 10 hours is nothing. I'd like to be able to go swimming everyday.

**I HAVE
HOPE FOR
THE FUTURE...**



ACCESSING THE MENTAL HEALTH SYSTEM

They've thought the system through in an intellectual sense, but haven't worked it through in a practical sense.

Getting involved in the system has been like stepping into a maze, I have no clear path.

THE BETTER CONNECTED, INFORMED AND ACTIVE IN THE MENTAL HEALTH COMMUNITY PEOPLE ARE, THE BETTER THEIR SUCCESS AT ACCESSING SERVICES THAT MAKE A DIFFERENCE IN THEIR LIVES.

The complexity of the system, the number of service providers and the changing landscape of the MH environment, is overwhelming for clients and their supporters. Excluding the carers, all participants showed some level of confusion about who they were dealing with and where they were from.

Similar to navigating the NDIS, the MH system takes effort and determination to understand and engage with. The respondents who had good personal connections (family or other) or professional support networks were most successful in finding and accessing services. While those with no support were floundering and struggling to work out what steps to take next.

FINDING OUT ABOUT SERVICES

Online research, peer connections and service referrals were cited as the most common ways people found out about services. Online forums were used by a number of people for both receiving and giving peer support and those involved in this activity found sharing their experiences with others with lived experience beneficial for their own wellbeing.

Finding specialist services for particular or complex diagnoses, or certain cultural sensitivities – for example, LGBTQI – is difficult. The lack of a MH service directory or up to date information that is readily available creates challenges for individuals and referring practitioners/services.

FACILITATED REFERRALS

The lack of informed or facilitated referral pathways was a common theme across respondents. Many people felt they had been left on their own to reach out and make contact with potential service providers, even when they were in an acute phase of illness and were struggling to communicate at all. In contrast, the most successful approach cited to engaging with services and accessing what they needed, was through supported referrals with a continuity of care and a managed hand-over process.

THE ROLE OF THE GP & PSYCHOLOGIST

A number of people stated that a strong relationship with their GP and/or psychologist provides a solid foundation of support. However, finding GPs with MH understanding and experience can be challenging. All interviewees had at some stage experienced GPs with no MH skill or awareness. Similarly, people spoke of the difficulty in finding psychologists who they could relate to and that had appropriate experience.

It was not uncommon for clients to follow and travel extended distances to see GPs and/or psychologists/psychiatrists they have established positive and strong relationships with.

I'm a good communicator, I hate to think what happens to those that aren't.

My GP literally left me sinking, watching my decline. You could physically see my decline. When I looked in the mirror, I was horrified by my beard – I used to be clean shaven. My teeth are crumbling. My decline has been major.

My GP plays the MH support role, and I can see her for free.

Because she'd listened to everything I'd said, and clearly acknowledged that she knew it would be difficult for me, I decided to follow her.

CLIENT/CARER INTERVIEWS

CRISIS SUPPORT

For those entering the system for the first time in a state of crisis, there is a sense that treatment is focused on managing the presenting symptoms and medication, before discharge. One interviewee spoke of his experience calling for help when he was in a suicidal state. He was instructed to contact his local hospital, which he did. A team was sent to see him the following day and then visited every 2-3 days for two weeks. In his own words "I wasn't any better. I wasn't eating, shaving, or showering." The focus of the visits was to check he wasn't harming himself and establish if he needed to be admitted. He had no food in the house during this time and was barely leaving his chair, and yet services were ceased.

After 2 weeks of home visits, I was discharged. They told me to call (community mental health service), but they didn't do it themselves. They told me to do it.

This highlights a significant gap between emergency care (triple 000 / CATT teams/ ED) and GP support. The gap is especially apparent for people who are feeling desperate and/or suicidal and are not already engaged with the system and have no other supports. The assessments made by CATT teams are focused on whether the individual has met minimum thresholds for compulsory treatment. Those that don't meet the assessment criteria, can be left with intermittent support which is focused on managing their current state rather than facilitating referrals for greater support and finding pathways to recovery.



USING THE MENTAL HEALTH SYSTEM

Overall, participants expressed a number of challenges associated with their experience of the MH system. These challenges fell into four key areas:

- Service availability
- Workforce
- System culture
- Finances

SERVICE AVAILABILITY

Specialist treatment

A common theme was the need to find support that recognised and respected the individual's circumstance. Whether it was expertise with a particular diagnosis, demographic group or cultural sensitivity, a number of participants said they'd had challenges finding the 'right' people to support them.

One mother spoke of searching for a psychologist specialising in young women with Autism. Ultimately, she found one but has to travel an hour each way for her daughter's appointments, which means a day off school once a week.

Another participant who identified as a gay woman, and was experiencing significant challenges in her relationship spoke of her lengthy search for a lesbian therapist.

I wanted to find a psychologist who was lesbian. I didn't want to have to try and explain the complexities of a female female relationship. She managed to refer me to a psychologist, the only one she knew of that was openly gay. When I contacted her there was a six month wait list.

Public vs private

The majority of the participants have at some stage experienced hospitalisation in the public MH system. All of them insisted it is something they do not ever want to experience again. "Horrorific" was a term used regularly when describing the experiences. Some respondents had put in place contingency plans to avoid the need to go to a public hospital in a time of crisis. Others said they would travel to a hospital outside of their region to receive treatment.

Public Hospital & CATT

Some participants who had contacted the public MH hospital system in times of crisis spoke of being turned away and told that the services were not available. Reasons given were being 'too busy', 'under resourced', 'no beds', and 'no funding'.

Group work isn't for everyone

Only two of the participants were currently accessing group based psychosocial supports. The others all said group based work was not for them and they would prefer other models for engaging with the community and connecting with people. A number of the participants were fearful of group settings and being surrounded by 'very unwell' people. Their concerns were, it would either confirm to them 'where they are at', or it could degrade their optimism for the future, by illustrating where they could potentially be heading.

Other participants with multiple diagnosis said the group environment conflicted with the recommended therapy for their diagnoses.

My emergency plan is fill me up with Benzos until I can get a referral to a private hospital. I would rather die than end up in the public MH system. I don't say that lightly.

I was told 'We don't have the resources; we don't have the money.' Well that's not really my problem is it? But it is my problem, because I'm asking for services and they're not available.

I'm scared of seeing people very mentally sick and visualising where I'm at now.

I have BPD, so I should do DBT. But I also have autism and that means I don't like strange situations with crowds.

CLIENT/CARER INTERVIEWS

I have got 10 sessions, it's not even one a month. How does that work when you've got complex needs and you're in dire straits?

MHP 10 Sessions is not enough

The subsidised psychology sessions offered through the Federal Government's Mental Health Plan (MHP) initiative were generally viewed as useful and all research participants had accessed the plan. However, for those with complex challenges it fell well short of what they required.

The one-size-fits-all approach of the ten sessions per annum and lack of flexibility to scale up or down as needed was a major hindrance. Some participants noted that in a difficult time, they may need to see a therapist once a week, while at other times a monthly visit may suffice.

With the ten sessions equating to less than one per month, continuity of care was also affected. Some participants ran out of sessions part way through the year and were left with no support as they were unable to fund their care themselves. By the time they were able to access a new MHP considerable time had lapsed and the wait times to see their preferred therapist could be extensive.

Wait times

During the service mapping stage of the project, conducted with service providers – 'wait times' for psycho-social support was raised as a major concern.

However, excluding appointments with in demand psychologists/psychiatrists or the NDIS application and planning process, participants barely mentioned wait times.



WORKFORCE

He was only dealing with me from the perception of whatever experience he had, but he wasn't qualified. So if I said something he didn't like, he'd tell me, "I'm not qualified to deal with this," and I'm thinking, "For God's sake, that's just what I need to hear."

They've got some dangerously under-trained people doing the work.

I was just sick of getting someone new all the time.

At some stage, all participants had experienced challenges with people they had encountered within the MH system. This included GPs with no MH experience; hospital staff who lacked empathy; or support workers with no understanding of the diagnoses they were managing. For those on the receiving end, this often caused additional stress while already in a very vulnerable state.

Participants said many workers in the sector are inexperienced and out of their depth and that more training was required to ensure quality care is provided. This is especially important when dealing with complex diagnoses and cultural diversity factors.

The high-turnover of staff and casual nature of the MH workforce creates many challenges, particularly for continuity of care. A number of participants expressed frustration about the lack of consistency in the workers they engaged and constantly having to re-establish relationships with those supporting them. Participants also discussed not being able to reach their workers in times of need because it was their day off. Services do not appear to have things in place to provide alternatives in these scenarios, meaning the person is left without support until their worker returns.

In an environment where staff shortages and access to qualified workers is a challenge, peer support is often used to 'fill the gaps'. The participants spoke highly of peer support as a concept and many had been involved in both providing and receiving support in this way. However, there is a risk that too much reliance is being put on these services and inadequate support is being delivered. While those providing the support have lived MH experience, they do not always have appropriate training or experience for the scenarios they find themselves managing, which could be detrimental for both parties.

I'm certainly not against peer work, I'm against it being used as this kind of stop gap measure.

CLIENT/CARER INTERVIEWS

SYSTEM CULTURE

The focus is for public hospitals is getting people to take their medication and getting them to appointments.

In the public system there's just this turnover of registrars and staff. There's no continuity. People are constantly retelling their story again and again. And it's counter-therapeutic.

I walked into her room and she had stuff, a mini trampoline for de-sensory modulation, some teddy bears, rugs, art stuff. I think, "Wow this feels like you could do healing in here."

The Public hospital experience

The biggest complaint about the public system was the lack of respect felt by the patients. Participants said that once they were 'in the system' they felt disempowered and were treated in accordance with impersonal, rigid and compliance driven processes. With a focus on managing symptoms and medication, these processes offered no consideration of the underlying factors causing the person's crisis or episode.

Participants reported experiencing a lack of empathy and a regimented approach when in the public hospital system. Some participants spoke of occasionally experiencing a staff member who they could 'connect with' and who they felt considered their circumstance rather than presenting symptoms.

By comparison, those that had experienced the private hospital system described it as a 'place for healing'. An environment set up to support the individual in their crisis and recovery and not focused simply on the risk assessment and management of the immediate presentation of symptoms.

Outpatient care

Several participants also spoke about a 'compliance focused' system, similar to the hospital experience, for clinical care provided in an outpatient setting.

One participant received in home visits every second or third day for two weeks. By his own account, his mental state did not improve over the period and the care given by the service was compliance oriented only. At the end of the two weeks he was discharged and told to call a local service provider.

Another participant who was engaged with a number of agencies spoke of the disconnect between the various groups and the challenges of using multiple services. The perception each worker had of her and the connection she had with them greatly impacted the support she received.

At times in care meetings she felt the process became directed with an overly pragmatic approach being taken to assess the services she was receiving. She felt it became a tick the box process to confirm she was getting the support they deemed necessary and to move on. They were focused on making sure I wasn't double dipping with multiple service providers. There was no sense that the overall approach had any kind of recovery focus.

Retelling their story

A recurring challenge faced by those in the MH system, was the need to be continually retelling their story and 'reliving their trauma' over and over again. This was caused by constant changes in services, high staff turnover and a lack of information recording and sharing within organisations and across the system.

Every second and third day they'd come in and ask me how I was. You could see how I was, the place was a disgrace and I'm sitting in a chair looking at them. And then two weeks later they discharged me.

I'm fatigued at having to recite the same info again and retelling my trauma. I'm just so sick of it. I want to focus on the future not the past.



FINANCIAL BARRIERS

Each person consulted expressed some kind of financial challenge when it came to accessing or using MH services. The scope of the financial implications was vast, from one respondent, who was ineligible for a Disability Support Pension, prioritising food for pets over food and care for himself; to people feeling guilty about the amount of NDIS funding they had access to.

For those not on an NDIS plan, financial barriers often prevented them being able to access enough care. The ten subsidised psychology sessions provided by the Mental Health Plan were viewed as piecemeal for those with enduring MH conditions. This meant people who required further treatment were out of pocket or had to negotiate creative solutions with service providers to get the help they needed.

People who have some financial means can also experience difficulties getting the support they need. Some spoke of being turned away from Triage and not being able to access public hospital based mental health services due to having private health insurance. One respondent who had been unwell for over twelve months, was unable to access a disability support pension, due to having a property portfolio, even though he had not earned an income for over a year and was in significant financial stress.

In a time of crisis, another respondent who was adamant about staying out of the public system, spoke of being able to supplement her therapy due to bonuses she received from a part time job. While her income was directed to support her mental health to keep her fit for work, a lack of communication between authorities saw her receive a large Centrelink debt.

The NDIS application and planning process requires enormous amounts of personal data and evidence to be collected. The appointments required with GPs, psychologists, psychiatrist to gather this as well as obtaining past medical history, created a financial challenge for a number of applicants.

I have access to a good psychiatrist and I have a decent NDIS plan and I feel guilty about that. I'm embarrassed to tell people because it's not common. And I have private health insurance. So that's privilege, and I find that really sad.

I'm lucky enough that my psychologist bulk bills me. She doesn't charge me any on top. For most people, there's a gap.

Last year I was back to being suicidal. It was only that I had money from bonuses I was able to afford to see my psych more regularly, which kept me in a fit state to work.

They got me to apply for my hospital records and all the records from my old GP. It cost \$30 to get my old medical records from him.

