

Mobile Community Connectors (MCC)
Program Customer Journey Mapping
Project: Access to Health Services for
Social Housing Residents

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Executive Summary

This project was commissioned by Ballarat Community Health, and funded by Department of Families, Fairness and Housing.

The purpose of this research project was to develop a deeper understanding of the barriers and enabling factors that residents of social housing in the Ballarat area (including rooming houses, public housing and supported residential services -SRS) face when they attempt to access health services. The experience of three groups was explored: (1) older person with chronic health issues; (2) parent with child/ren; (3) rooming house residents. Research participants were recruited through the Ballarat Community Health Mobile Community Connectors (MCC) program, which has been funded by the Department of Families, Fairness and Housing (DFFH) to support the social, health and well-being needs of social housing residents.

A human-centred design framework was used. Human-centred design actively involves the 'users' of services/products (social housing residents using the service of health care) to help understand how users typically experience that service/product, and how to improve their experiences.

A total of 12 participants attended six workshops. Participants constructed the 'typical' experience of three diverse resident experiences (older person with chronic health issues, parent seeking specialist diagnosis for child, rooming house resident with acute dental pain) trying to access and engage meaningfully with a health service. Participants took part in two focus group workshops, where the group worked together by talking and taking part in interactive activities to develop **personas** (a fictional but realistic archetype representing a 'typical' resident) and **journey maps** (a visual representation of the journey). They then described what the 'ideal user experience' could look like and made recommendations for key local service providers.

This report presents the three personas and journey maps representing the experiences of 'typical' service users. Each persona highlights this typical service user's profile* (name, age, gender, family details, living situation, presenting medical issues, supports) and encapsulates their actual experience, barriers, and ideal experience. Each customer journey map visually depicts the different phases of the service user's journey including: actions, touchpoints of interaction, thoughts, feelings and emotions, needs, pain/gain points, and solutions.

Emerging from participants insights are a range of means to both address barriers and facilitate enabling factors. Recommendations emerging from this process are detailed herein.

Ideally, relevant service providers will take on board the recommendations, and make changes to service design based on the contributions of the research participants.

*Following human-centred design frameworks, all details relating to the service profile are fictitious, and have been informed by relevant research and existing service provider knowledge based on consultation and engagement with social housing residents. Research participants chose the resident name and selected a photo from a creative commons image archive.



Project Background

Policy and Practice Context

In 2020-2021, more than 1900 people in the Ballarat region experienced/were at risk of homelessness, which is nearly twice the national average (Kirkham, 2021). The relationship between homelessness and poor health, and barriers faced by homeless people who attempt to access health care, are strongly acknowledged within research literature (Bennet-Daly et al., 2022). Poor health outcomes and barriers to accessing health care are also prevalent for those in precarious housing (Elmer, Osborne, Cheng, & Nadarajah, 2022).

In September 2020, during the first year of the COVID-19 pandemic, the Victorian government (through the Department of Families, Fairness and Housing) funded the High-Risk-Accommodation Response (HRAR) program in locations where transmission of and vulnerability to COVID-19 were considered to be relatively high. The HRAR program aimed to prevent, prepare for, and respond early to coronavirus (COVID-19) infection within public housing and other high-risk accommodation settings with shared facilities. The HRAR program finished in June 2022 and a new initiative (the Mobile Community Connectors (MCC) program) was funded for the 2022-23 financial year. The MCC aims to continue to support residents in high risk settings, through the provision of service navigation and a range of health promotion interventions to improve social connection and health supports.

To inform program planning, BCH MCC conducted focus groups, surveys, and workshops with stakeholders (with a focus on social housing residents). Through this process, the following priority health, well-being and social needs within these settings were identified: (1) mental health services access and responsiveness; (2) securing time sensitive medical (bulk-billed), dental and allied health appointments; (3) knowledge and capability to understand and access health support; (4) navigating the health system. As a result of the consultation process, a model was designed to focus on health literacy responsiveness (Community Connectors: Delivery Model Plan 2022).

Project Purpose

This research project was designed with the objective "to improve health literacy responsiveness and access to medical, dental and mental health services," as identified in the Community Connectors: Delivery Model Plan (2022). Service user consultation identified significant barriers to securing and attending a medical appointment. And furthermore, that there are barriers to receiving a service response that involves a clear plan for addressing the identified health issue/s in a way which meets service users' needs. Ballarat Community Health received approval from DFFH to contract Federation University to undertake a research project, which involved resident/lived experience workers in the development.

The research findings are intended to inform the development of strategies to better understand client needs and recommendations for future service design and delivery – and ultimately improve health outcomes. The findings could also inform the development of a pilot program that engages various health service hubs - with co-located service disciplines, including mental health, alcohol and other drugs (AOD) - to develop and implement action plans to address barriers and enabling factors.

Given BCH's current strong engagement with residents and health service provider stakeholders, it is envisaged that the insights developed from the project and emergent recommendations will be farreaching. Intended impacts and benefits will not be limited to people participating in the research, but also the broader Ballarat community. Further, the research has the capacity to benefit to local Ballarat community members, but also to inform service improvements at state, national and international levels through industry reports, peer-reviewed publications, and conference presentations.

Project Design and Delivery

Project Design

Within the context outlined above, this research aimed to develop a detailed understanding of the barriers and enabling factors residents experience when accessing health services through documentation and visualisation, in a way that effectively conveys lived experiences to service providers. The Principal



Researcher met weekly with key personnel relating to the MCC throughout the duration of the project, to support the design and delivery. Planning meetings were held with relevant BCH staff, to inform the Human Research Ethics Approval application and study design (particularly, workshop formats; participant recruitment; risk management procedures; meeting logistics such as catering, transport, arrangement of reimbursement; design of persona and customer journey mapping templates and workshop activity assets). Additional meetings were held with two MCC Peer Workers to inform the design of the workshop format and data collection tools, and to ensure relevance/appropriateness for participants.

Ethics approval and considerations

The project received ethics approval from the Federation University Human Research Ethics Committee (2023-025).

Healthcare settings internationally face pressures to respond more effectively to their patients' needs through the model of person-centred care (PCC), whilst also integrating resources (Malmberg et al., 2019). The goals of PCC (focus on inclusive, resource-effective, and adaptive healthcare systems which see the 'patient' as a 'person') are often incompatible with contemporary healthcare practices (Malmberg et al., 2019). As such, there is increasing emphasis on human-centred design approaches which privilege the knowledge of those with 'lived experience' of a particular issue. It is, of course, important to acknowledge that any research which involves talking about sensitive issues such as access to health care may cause distress to participants.

The research was designed with the National Statement Section 2.1 (Risk and Benefit) in mind. Key also was ensuring that people with lived experience of a particular issue were able to contribute to service design – given the acknowledgement of the current incompatibility between person-centred care and contemporary healthcare practices.

Specifically, the study was designed to ensure that no personal details were shared in a way which could identify any research participant. The design was such that the data collection involved the development of 'fictitious' personas and the journey map of this persona, rather than details/experiences of any one participant in the group. Participants were encouraged to speak about their general knowledge of access to health care for the particular group based on their collective knowledge of being social housing residents navigating local health care systems.

The Plain Language Information Statement (PLIS) identified the potential benefits (contribution to local service design/delivery, opportunity to share expertise) and risks (feeling distressed – in which case clear protocols were outlined) associated with the research project. As the research was undertaken at a Ballarat Community Health site, there was easily accessible information available about support services on-site. Participants were recruited through the MCC program advisory group, and thus had established relationships with MCC staff and an understanding of additional supports if required,. Generic information about additional support services (e.g. Lifeline) were provided on flyers available to all participants at the workshops. MCC workers were available during workshops to provide support as required.

Methodology

This research project was undertaken to develop an understanding of how social housing residents currently experience access to meaningful health care, within increasingly complex bureaucratic healthcare environments. Human-centred design was selected as the most relevant methodology, as it actively involves the 'users' of services/products (social housing residents using the service of health care) to help understand how users typically experience that service/product, and how to improve their experiences (Alsaadie & Alahmadi, 2021). In particular, data was collected to inform the development of a **persona** and **journey map** representing the characteristics and journey of a 'typical' customer accessing health care, representing each of the three groups (older person with chronic health issues; parent with child/ren; rooming house resident).

Research participants took part in two two-hour focus group workshops, with separate workshops for each of the three groups The workshops were designed to draw upon participants' collective knowledge and



expertise relating to the lived experience of being a resident in social housing, with data about the typical user journey collected through an informal, ethnographic approach using open-ended questions(Woods et al, 2017). They engaged in interactive and collaborative activities (using materials including post-it notes, whiteboards and markers) that are reflective of the human-centred design principles of designing *with* rather than *for* people (Szebeko & Tan, 2010) and in ways that were exploratory, future-focused and creative (Sriraman et al., 2011).

In the first workshop, participants were asked to collectively develop a **persona** (a fictional user representing requirements and characteristics of a specific user group) (Alsaadi & Alahmadi, 2021), which identified needs, insights, behaviours, and frustrations of potential users (Woods et al., 2021). Personas offer a way for service providers to identify and connect with their clients, and become more attuned to their needs (LeRouge et al., 2013). Participants also collectively developed a **journey map** (a visual representation of the 'typical' user journey, providing holistic perspectives of the markers of the patient experience with health service encounters) (Ly et al., 2021). The visual tool integrates the physical, functional aspects with the emotional, rational aspects of the journey in a way that captures behaviours, feelings, motivations, and attitudes across a care episode (McCarthy et al., 2016). Journey maps are acknowledged as visual vehicles for highlighting issues, enabling service providers to allocate resources or mitigate risks identified, and draw attention to complex situations previously unnoticed (Joseph et al., 2022). For both the persona and journey map, collective data collection and analysis techniques including the idea matrix and solution sketch (commonly used in human-centred design projects) (Woods et al., 2017) were used. The researchers synthesised the data collected and collectively analysed by participants at the workshop through further thematic analysis (Braun and Clarke, 2005).

In the second workshop, participants were shown the preliminary persona and journey maps developed through the synthesised thematic analysis. They engaged in "member checking," to verify that the persona and journey map constructed by the researchers were true representations of their experiences as conveyed in the first workshop (Guba and Lincoln, 1989). Participants then engaged in additional interactive and collaborative activities to generate ideas about an ideal situation for atypical user if there were no barriers in place, and to identify potential ways for health services to take on board the information and embed strategies to improve service responsiveness.

Participant Recruitment

Project participants were recruited from the Ballarat Community Health Mobile Community Connector (MCC) program). The initiative was funded for the 2022-23 financial year, to support residents in high-risk accommodation settings through provision of service navigation and a range of health promotion interventions to improve social connection and health supports for residents. The MCC team is comprised of specialist workers (health promotion officer/s, engagement/service navigator/s, and peer workers with lived experience in social housing), with background/expertise in health promotion, prevention, and protection programs. To inform program planning in 2022, BCH MCC conducted focus groups, surveys, and workshops with stakeholders (with a focus on social housing residents). As such, there is a culture of participation in stakeholder consultation/research within the MCC and broader BCH networks. Through this strong engagement, a Resident Advisory Group was developed, which meets every month to provide input and feedback relating to current issues/initiatives.

Participants were recruited through flyers distributed by MCC workers to clients in the MCC program. This distribution occurred both at Resident Advisory Group meetings and other MCCP health promotion activities. Participants were provided with a Plain Language Information Statement (PLIS) and Informed Consent, which provided clear information that participation in research is voluntary and choosing not to participate will not impact on any services they receive now or in the future.

The inclusion criteria for participant recruitment included:

- Over 18 years of age
- Social housing resident (public housing, supported residential service (SRS) rooming house) in the Ballarat area



Participant Reimbursement

It has become the norm in areas such as mental health, homelessness, cancer treatment and family violence to remunerate people with lived experience for their participation in research projects and service user consultation processes. Indeed, there is emerging consensus within these areas that it is unethical, and socially unjust, to **not** provide financial reimbursement to participants for their lived experience expertise, and the time and emotional labour that is expended to participate in research. The Victorian Royal Commission into Family Violence (2016) Recommendation 201 related to ensuring the centrality of victim survivor voices and responding to the needs and experiences of clients from different communities and client groups. Informed by this knowledge, BCH has made a commitment to ensuring that participants in focus groups/research relating to their lived experience expertise will be provided with \$50 gift cards as a reimbursement for their time/emotional labour, without remuneration that would be seen as an undue inducement for participation.

As such, participants were provided with \$50 gift voucher ecards (in plain envelopes) at the end of each session that they participated in. Participants were also provided with refreshments (tea, coffee, snacks) during each workshop.

Participant Details

A total of 12 participants were involved in the research, in the following groups:

- Four in the "older resident with chronic health issues" group;
- Five in the "rooming house resident with acute dental issues" group (with 3 residents participating in both workshops, and 1 resident participating in workshop 1 only, and another 1 resident participating in workshop 2 only).
- Three in the "parent seeking specialist diagnosis for child" group.

Participants self-selected to participate in groups where they felt they had the strongest sense of collective knowledge relating to the demographic and service issues.

MCC workers with knowledge of each group attended the workshops to provide support as required.



Project Findings

Project findings are presented as follows, as an Appendix at the end of this report:

- (1) Mavis*
 - Persona**
 - Customer Journey Map**
- (2) Shane*
 - Persona**
 - Customer Journey Map**
- (3) Kyra*
 - Persona**
 - Customer Journey Map**

*Following human-centred design frameworks, all details relating to the service profile are fictitious, and have been informed by relevant research and existing service provider knowledge based on consultation and engagement with social housing residents. Research participants chose the resident name, and selected a photo from a creative commons image archive

**Within each of the three Personas, barriers and ideal experiences are presented. Solutions are presented in the Customer Journey Maps.



Proposed Solutions

The 'visual products' that have been produced within the human-centred design context, and presented in the preceding section, offer valuable insights relating to social housing residents' experiences accessing healthcare. In and of themselves, each of the personas and customer journey maps enable service providers and policy makers to "step inside the shoes" of three different 'types' of social housing residents, attempting to access health care for different issues:

- (1) Mavis an older resident with an acute infected leg wound, and a range of underlying complex chronic medical conditions.
- (2) Shane a man who has just been released from Corrections, and experiences acute tooth pain, a cough, and anxiety.
- (3) Kyra a single parent with a child who is experiencing challenging behaviours during their first term of Prep and requires a paediatrician diagnosis, and psychology/counselling support.

Proposed solutions relating to identified areas of concern are identified below:

Area of concern	Proposed Solutions	Who could be involved?
Making appointments	Replace automated telephone systems with person who answers phone promptly, is friendly and knowledgeable about service system	GP clinics Medical centres Community Health Centres All areas of service provision (AOD, mental health, specialist clinics)
Referral processes	Requirement for service providers to be transparent about wait list times; closed waiting lists Obligation for service providers to return messages (rather than not returning calls; and not calling on a silent number and not leaving a message) Transparency about referral processes (automatic txt or letter to say referral has been received; indication of waiting time)	Relevant service providers
Ability to have all issues addressed in medical appointment by a doctor familiar with the patient and their history	Return to a 'traditional family doctor' model Doctors have adequate time to read your file thoroughly before your appointment (especially if a locum/new doctor) Longer appointments readily available	GP Clinics Medical centres Community Health Centres
Transport	Safe, reliable transport available (that doesn't' require using automated telephone services/apps for booking)	Relevant service providers
Transparency of costs	Requirement for costings to be provided up-front (in a way which explains what rebates available; how much customer will be out of pocket)	Clinical services



Service navigation support	Peer support models – co-designed with relevant service users with lived experience, to ensure relevance Advocacy/support worker models – co-designed with relevant service users with lived experience, to ensure relevance Workers kept up to date about key services/initiatives – better systems for workers to know what is out there	Relevant service provision areas (i.e. Corrections; housing services; Aged Care) Care Finder service
Negative treatment by service providers	Service providers made aware of the importance of their attitudes/interactions with residents – particularly those with issues which are stereotyped/stigmatised (such as AOD, mental health, legal issues, single parents, children with challenging behaviours) Management to ensure that front-line service providers trained/supported to show "affirmation and positive support" with every encounter Positive feedback to Ballarat police – to let them know that they have been making a difference through their positive interactions with residents	Relevant service provision areas Education providers providing qualifications for workers (such as Community Services, health, social work, education)
Carers of children with challenging behaviours and their families overwhelmed (particularly while waiting for diagnoses/treatment plans)	Support for the support people: respite programs; schools made aware of challenges for siblings and respond appropriately; support groups for parents/siblings (could be a peer support model)	Relevant service provision areas
Having to go to different locations for related services	Co-located service models	Relevant service provision areas
Outreach services to housing facilities	Outreach services to housing facilities (Dental Clinic, AOD, mental health, well-being, etc.)	Relevant service provision areas
Long waits in Emergency Department	Social worker 'on the floor' in Emergency Department – to provide support and information to people who are likely to become agitated/distressed during the long wait	Hospital Emergency Departments
Becoming your own advocate (accessing information and support from internet and social media support groups – Facebook)	Information about designated Facebook groups that have responsible administration processes Tips on how to navigate groups with potential misinformation/differing opinions Tips on how to access reliable information on the internet	Relevant service provision areas Social work student projects



Concluding Thoughts

While there were some barriers that were specific to one (or two) of the customer journeys, overwhelmingly, most barriers were prominent across all three journeys. Striking across all customer journeys was the **difficulty of navigating complex**, **disjointed**, **service systems**. In each of the journeys, participants identified the need for service navigation support as well as proposed solutions that would be most effective, of meeting their needs. Residents who constructed Kyra's user journey used evocative metaphors of puzzles and games to illustrate frustrations: "It's not a puzzle where you need to fill in a missing piece, but a game of Tetris. One wrong move and it all falls down – you go right back to the start."

Overall, barriers relate to macro-level, systemic, structural issues – mainly **relating to the way services are funded and structured.** Significant policy change, including shifts in resource allocation, would be required to adequately address these issues. Ideally, the findings and insights from this research project will contribute to research evidence relating to systems and structures that prevent people from accessing affordable, responsive primary health care in a timely manner. Participants in this study reflected on service system structures, which from their perspective require service users to "manipulate the system to get what you need."

These thought-provoking insights, distilled through the use of human-centred design, highlight the necessity of ensuring that people with lived experience are meaningfully involved in service design and evaluation. Participants spoke of the need to become 'professional doctor shoppers', on a seemingly never-ending quest to find service providers that treated them with respect and met their needs. We can assume that systems such as automated telephone services, use of apps to make appointments, and the "My AgedCare" have been implemented with the intention of improving access, consumer choice/experience – and ultimately reducing costs. However, the 'service end users' tell a very different story and tell us loudly and clearly that current systems simply do not meet the needs of those they have been purportedly designed for.

In a climate of cost reduction, it seems that the inability to readily access services described within each customer journey would most likely result in **increased costs to health and social services systems**. For example, the social, emotional, and financial costs of a child who is unable to attend school full-time and needs to wait 18 months to access a paediatrician are undoubtedly extreme. The residents who constructed Shane's customer journey highlighted how, in the absence of appropriate support, Shane would likely re-engage with harmful AOD use. They spoke eloquently of the 'domino effect' when preventative supports (such as peer support workers, or accessible social workers in Emergency Departments) are not readily available.

Participants acknowledged, at times they found it upsetting to reflect on the barriers and challenges that they, and many other people face, in their attempt to access timely, responsive health services. However, they all spoke poignantly about their desire to contribute to improving service responses and the health care system. A common sentiment expressed in all three groups was "*I want to do something to make changes, so other people don't have to go through what I've experienced.*" It is imperative that the knowledge and expertise of people with lived experience is seen not as an after-thought, or a tokenistic publicity exercise – but rather as an instrumental and fundamental component of practice/policy reform, service design, implementation, and evaluation.

Post-note:

Residents spoke passionately about the Resident Advisory Group, and the broader activities of the Mobile Community Connectors (MCC) program. They reflected on what a difference it has made for them to be seen as part of the solution, rather than part of the problem – and to have their voices heard and respected, and be involved in discussions about service design, delivery and improvement. Many participants took notes during the focus groups, so that they could share information about services that they did not previously know were available with their peers. Their expertise and knowledge, and passion for contributing to service improvement and making other people's lives better, was striking. Ironically, at the time that this final report was being prepared, there was no new funding for the initiative announced in the Victorian State budget 2023-24, and so the program's operations will cease at its planned completion date of 30 November 2023.



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Name: Mavis Gender: Female (she/her)

Age: 70

Family details: Husband (Joe), in Aged Care for 3 years; 2 adult

children, living in Queensland; 5 grandchildren

Living situation: Public housing, one-bedroom unit with dog (Bella)

Medical background: Osteoarthritis, high blood pressure, cataracts.

Presenting medical issues: Ulcer on leg (starting to weep and smell); swollen ingrown toenail; difficulty walking; requires medication – blood pressure, pain

relief/anti-inflammatory, eye drops, dressing for wounds.

Supports: Sister (Shirley), lives in the next Suburb (15 minutes away); Friendly

neighbour (Gwenda).

Experience

Arranging appointment:

- Reluctant to ring GP (trusted GP moved; finds phone system frustrating; doesn't want to be a bother).
- Stressed about transport (mobility issues with bus; cost issues of taxis; Gwenda able to drive her there (but not back).

Initial appointment:

- Doesn't wait long to see GP; GP polite and addresses leg wound and toe.
- Nurse at clinic is helpful and able to bandage leg and toe, provides information sheets, referrals, pathology slip and swabs wound and sends to pathology. Prescription for antibiotics and painkillers sent to Chemist for home delivery.
- Short appointment (only immediate health issues addressed; feels uncomfortable opening up to new doctor; everyone seems rushed; forgets to ask for blood pressure prescription).
- Leaves clinic feeling overwhelmed and confused about all the paper flustered about what to do next.
- Starts to fret about future costs; what to do if her toe gets worse; blood test (how to make appointment?)

Follow-up:

- No one to turn to about questions increases anxiety.
- Trouble with taxi phone system to get to pathology. Long queue advised to come back after GP appointment.
- Nurse at clinic recognises distress & arranges appointment to do care plan, contacting MyAgedCare.
- Relieved but long waits for assessment, and delay in services possible.
- Hopes she can receive the support she needs but feels anxious and worried.

Ideal Experience

- A "traditional family doctor" who knows her, doesn't rush her out and tells her "exactly what she is in for". Explains steps, writes down a clear plan, and can be contacted if she has a question/things don't go according to plan ("ring the desk and they'll put you through to me right away").
- Receptionist to offer empathy/make her feel listened to, knowledgeable of services, doesn't try to "fob her off" or act condescendingly.
- One-stop-shop with services in the same place.

- Full, up-front transparency so she doesn't feel nervous worrying about how much things will cost.
- **Key contact worker** who is "knowledgeable, empathic, a friendly ear" who can "help her with what to do step by step." More than a website or list of numbers to ring. Not everyone has helpful friends/family members.
- Reliable, affordable transport where she feels safe, and that's readily available, arranged by contact worker.



Barriers



Transport

- Taxis unreliable/expensive.
- Public transport difficult to use/can't always get her where she needs to go.



Health care access:

- Confused by automated telephone response.
- No regular GP local GPs leaving often.
- Short appointments only.
- Reluctance will she have to pay?
- Lack of clarity how much will it cost?
- So many services, processes and agencies.
- Lack of follow-up support; service navigation.



Other challenges:

• System reinforces that Mavis is taking up people's valuable time.



I just want someone to say,
'now we'll sort this out,
Mavis, one step at a time. Tell
me what you need and we'll go
through it together'.



Persona: Mavis



Awareness

Consideration

Accessing health services

Treatment

Follow up

- Leg and toenail pain worsens.
- Needs ongoing medication/scripts.
- Knows she needs to contact GP unsure of what will happen.

Reluctant to ring GP clinic (regular GP moved away: finds automated telephone system frustrating; doesn't want to be a bother).

- Only able to book appt. for one health issue.
- Trouble organising transport (Taxi expensive; bus inaccessible and not nearby).
- Takes referrals home to book follow up appts. confused by next steps.
- Scripts are delivered to her home.
- Calls sister and grandchildren for help.
- Calls other clinics to make additional appt. but confused by telephone systems.
- GP addresses leg and toe only.
- GP clinic refers blood tests & podiatrist, arranges next GP appt.
- Nurse (2nd visit) senses distress, advises about MyAgedCare plan.
- Tends to next steps (blood test, podiatry referral, wound treatment, next GP appointment, aged care assessment).
- Ongoing health care management.

Thinking

"I don't want to be a bother."

"I hope they don't have to cut my leg off."

"I wonder WHICH doctor - and will the new doctor understand me?"

"Will they be able to help me? They don't know me."

Disheartened &

Anxious

"How will I get home?"

"What was it they said I need to do first?" "I just can't figure out these machines. Why can't I just talk to a real person?"

"How am I going to make all these appoint-

"I just want to cry. I don't know what to do."

Worried

Scared &

Overwhelmed

"The doctor was really a

"They are ordering all these tests, do they think it's serious?"

"I hope someone can help me through this. I can't do it on my own."

Feeling

Uncertain & Frightened

- nice man."

Hopeful

Worried

Overwhelmed &



- Feeling scale: 8 = most negative 0 = most positive

 - Self

- Automated telephone system
 - Receptionist.
- Friend
- Receptionist

Relieved

- GP/Nurse
- Taxi company
- Family supports.

- GΡ
- Nurse
- Pathology nurse
- Pathology.

Multiple touchpoints as journey continues.

- Ongoing health support for chronic/acute health issues.
- Speak to a real person who understands her medical issues
- A quick appt. that meets all her needs.
- Timely GP appt.
- Get to the appointment safely and affordably.
- Reassurance and advice about what's next.
- Someone to explain everything clearly and answer question.
- Help with making and getting to appts.

- Reassurance
- Direct attention
- Active listening
- Clear explanations
- Immediate/ongoing health issues treated.

Long term: a clear plan in place, with a support person/service available to answer questions, help with appts. and follow up.

Unsure about what will happen, what she'll need to do.

Not able to speak to real person right away.

Call gets disconnected.

No regular GP.

Gets appointment, but only for a short time.

Transport from friend, but only one-way.

Script arrives at home.

Confusion about what to do - who to ask questions as family can only help so much.

Wound and toe (immediate issues) treated.

Lots of next steps.

Could be a delay in getting Aged Care assessment, and further delays for services. No support person who knows her entire history.

Told about new 'Care Finder service' – very new and no one knows how it will work. Mavis hopes the service can help her.

Someone to check in regardless of known health issues.

Replace automated telephone systems with actual person who answers phone promptly, is friendly and knowledgeable about service/systems. More flexibility with appointment length times. Short appointments only used when appropriate.

Increased access to reliable, affordable, easy to arrange transport.

Full, up-front transparency about costs so she doesn't feel nervous worrying about how much things will cost.

A support system for people with limited support, complex issues and multiple chronic health conditions – casework model.

GP has time to engage in relationship building.

Each touchpoint recognises importance of their interaction, and takes time to explain things carefully and clearly.

"One stop shop" where all services in one place, and someone can help with making all necessary appointments/plans before the person leaves. Case worker/advocate to be available for any support related to multiple complex needs – preferably available 24/7 and knows health history.







Name: Shane Gender: Male (he/him)

Age: 35

Family details: 2 children, no current access but wanting to arrange access **Living situation:** Just released from Corrections, chose to live in a regional city near children, wanting a fresh start away from associates, Corrections

arranged 2-week paid accommodation at a guest/rooming house.

Medical background: History of AOD issues, recurring chest infections, mental health issues (anxiety & depression).

Presenting medical issues: Tooth pain, cough (suspects another chest

infection), heightened anxiety.

Supports: None – assigned a case manager and appt in four days.



Monday: First night post-release, Shane wakes with intense tooth pain, a cough and heightened anxiety. Unsure which residents to trust and trying to stay away from "users." He stays in his room, hopes pain disappears. Pain and anxiety worsen. Tuesday: He turns to familiar coping mechanism (alcohol and cannabis), "just once until pain goes away." Police visit him at rooming house for post-release check. They're polite but are unsettling and anxiety-provoking.

Thursday: Shane attends Corrections appointment and mentions tooth pain to case worker. Worker contacts dental clinic, first urgent appointment in $3^{1/2}$ weeks. Shane is told about walk-in appointment option – advised to arrive early. Does not want case worker to notice he's been using and doesn't mention anxiety.

Friday: Shane finds bus route and arrives at the dental clinic at 7.30am – 11th in queue and staff advise "no guarantee he'll get in today." He waits three hours and not seen but pain/anxiety escalate – he buys alcohol on the way home. Other residents tell him to go to Emergency Department – standing room only θ long wait. Triage nurse says "take Panadol, make dental appointment or visit Urgent Care (UC) and 'no pain medication, as you've been drinking." He is fidgety, distressed and heads home after 2 hours and uses alcohol/cannabis to cope.

Saturday: He visits UC, seen after 1 hour & prescribed Panadeine Forte until Monday. Chest hurts but he does not tell doctor. **Monday**: He arrives at dentist by 7.00am – first in queue. Tooth pulled and given antibiotics & Panadeine Forte. Staff are respectful towards him.

Wednesday: Diagnosed with dry socket – returns to Dental Clinic (seen as priority) & told to gargle daily. Continues to self-medicate and money become limited.

Moving forward. Shanes' Anxiety worsens. He wants access to children but is distracted, alcohol use all-consuming and draining. He'll worry about the chest infection when it gets unbearable or he coughs up blood and is disappointed in himself for not staying clean. Tries to reduce alcohol/cannabis use, but is worried about next crisis and how he'll deal with it.

Ideal Experience

- "Affirmation and positive support" from police, staff, health & welfare professionals. "Feeling supported and treated in a positive way goes a long way and can turn your day around."
- Case worker based at housing: friendly, knowledgeable of services/systems, able to follow things up, honest/transparent. "There if you want them, but not knocking at your door."
- Ideal housing environment: Staff invested in care/well-being, really want to help and provide positive reassurance.
- Corrections peer support worker who develops rapport while 'inside." Able to "help get what you need" post-release and "not treat you with suspicion or judgment."
- Housing peer support worker that's knowledgeable about services, understands what you're going through.
- Outreach services at rooming house: Need to "feel really supported for that first step, in your natural environment." Ideally extend beyond dental to a range of services (AOD, mental health).



Barrier

COM

Limited support networks:

- No one who "understands the ropes" to support the transition from Corrections to community and connection to health and social services.
- Not sure who to trust; attitude/perception toward help-seeking.



Health care access:

- Delays in access to immediate dental services.
- Only being able to address most urgent health issue and dealing with 'crisis' situations.



Other challenges:

- Concerns about judgmental attitudes of health & welfare professionals/police/housing staff.
- Lack of access to adequate pain relief (concerns about people selling pain medication).
- Concern about disclosing AOD issues.
- Turning to self-medication to cope.



Health [is] always on the back burner – I'm only able to deal with 'crisis' situations.



Persona: Shane



Awareness

Consideration

Accessing health services

Treatment

Follow up

- Tries to ignore issue/avoids health services.
- Self-medication (Buvs alcohol & cannabis with crisis payments)
- Attends scheduled corrections appt.
- Tells caseworker about tooth pain hopes she can help.
- Unsure how to get to clinic on PT asks other resident to help.
- Resident unreliable, misses bus, arrives 'late' to
- Doesn't get seen & leaves > self-medication.
- Goes to ED later that night.
- ED refer to Urgent Care Clinic.
- Urgent Care refer to dental clinic on Monday.
- Urgent Care Dr prescribes Panadol > go to ED if worsens.
- Arrives early at dental clinic (6 am) and is seen.
- Tooth treated, pain relief given & told to revisit if any issues.
- Diagnosed with 'dry socket' - has to deal with that.
- Mental health/AOD issues become a priority.

Thinking

"I'm not gonna turn into a full time pisshead. I'm gonna have one big pissup, and two days later I'll get clean. I'll work on it then."

"Gotta get out of here quick so she doesn't see I've been drinking."

"I hope she can sort out my tooth."

Warv &

Nervous

"I'm never gonna get there on time."

"Why do you have to be there at 7 when it opens at 8.30?"

"She's gonna tell I've been drinking – now they'll keep me at the bottom of the list."

"Everyone's handballing me around."

"Got this tooth out. Now I can focus on other things."

"I'm finally gonna get a good night's sleep."

"What am I going to do about this?"

"I'm not gonna use...it's not doing me any good."

"I want to turn my life around. But how?"

Feeling



Numb



Feeling scale: 8 = most negative 1 = most positive

Disappointed Anxious Tired & Hungover Нарру & Relieved



Self - no where to turn for support

Caseworker

- Other residents
- Rooming house staff
- Receptionist Dental Clinic, Urgent Care
- Triage nurse ED
- Urgent Care staff.

- Urgent Care Dr
- Dentist
- Dental Clinic

Self – no where to turn for support

- Coping mechanism
- Treatment.
- Supportive case manager.
- Support navigating system where to start.
- Timely access to services treatment for tooth
- Pain relief
- Reassurance
- Support medical and mental health
- Positive affirmations and interactions
- Service navigation support.

- Treatment for tooth.
- Info about follow up and after care.
- Non-judgemental care.
- A good night's sleep.
- Safe and clean accommodation to care for tooth.
- Support from other organisations.

Not knowing how to deal with pain/anxiety – turning to alcohol. to helps him escape.

Not having any support people – outside corrections system.

Case worker supports with info and dental clinic booking.

3^{1/2} week wait for appt.

Told about emergency appt. with no booking – but no guarantee.

Misses bus (support person sleeps in).

Doesn't get seen at dental clinic.

Doesn't get pain relief > needing to self-medicate.

Senses judgement for drinking.

Pain & self-medication intensify with no treatment.

His tooth has been dealt with.

Told to come back if any problems.

Can now focus on other needs – mental health has improved.

On the way to recovery for tooth.

"Always playing catch up with everything."

"Dealing with crisis, not the underlying issue."

Someone to talk to: A support/ peer worker that supports his transition from corrections back into community.

Contact person showing vested interest. Asking "how's your day been."

Having an option to chat/have support outside visit times.

Knowing where to go for help for health issues.

Someone to talk to: A support/ peer worker that supports his transition from corrections back into community.

Outreach clinics (dental; doctors; podiatrist; AOD – just walk in and talk to them).

Drop-in peer worker at rooming house: someone who's good at navigating θ had similar experiences and situations. (And support for support workers).

Social/peer worker at ED – supporting people as they wait.

More urgent care locations and more awareness in community

Emergency access to affordable dental care.

More urgent care locations and more awareness in community.

Emergency access to affordable dental clinic.

Easy access to follow-up care for dental issues.

Support at housing, delivered through outreach where you can "feel really supported for that first step, in your natural environment."

Accessible case worker and peer workers at Rooming House.







Name: Kyra Gender: Female (she/her)

Age: 33

Family details: Five children (aged 14, 12, 10, 6 and 3); no contact

with ex-partner due to family violence concerns.

Living situation: Public housing.

Medical background: Eldest three children have no major health issues; Thomas (6) having trouble at Prep; Maisie (3) chronic cough (asthma TBC).

Presenting medical issues: Thomas requires paediatrician assessment due to challenging behaviours and psychologist (for support strategies); Maisie has recurring chronic cough.

Supports: Mother who lives nearby and works part-time; friends in housing complex.



Awareness: Kyra is concerned about Thomas' behaviours (tantrums, can't stay still/focused) since early childhood. Kyra has left a family violence situation & Thomas didn't regularly attend kinder. Prep teacher expresses concern about behaviours, advises assessment by paediatrician, psychologist support for outbursts, parenting classes. She feels jusdged, guilty and 'crushed' ("is it my fault?"); worried about how to pay for services, but relieved Thomas will get help.

Arranging diagnosis, dealing with behaviours: Krya feels hopeful and trusting of the 'system.' She goes to GP clinic, but doctor is rushed and says he will send referral to paediatrician and to come back to get mental health plan. Kyra revisits for mental health plan and receives list of psychologists; calls 5 on list *θ* leaves messages. Thomas' behaviour intensifies, school calls meeting to advise half days might be needed. Kyra feels desperate *θ* rings psychologists back but gets no response. She rings paediatrician who says no referral ever received – next appointment is in 18 months. Kyra can't focus on her needs or other children (Maisie's respiratory issues; her own dental issues) and she can't work. Lots of time/energy is spent trying to secure appointments and very lengthy waits (12-18 months) while still managing Thomas' behaviours.

Diagnosis: After 18 months attends paediatrician. Feels judged/belittled but doesn't want to "waste more time" on wait lists. Receives initial ADHD diagnosis after several months (and much paperwork).

Treatment trials: Trials medications. Long wait between paediatrician appointments; has to monitor progress/side effects at home/school; 8 months passes with many ups and downs; she feels overwhelmed and unsupported.

Re-diagnosis and ongoing management: Re-diagnosis for ASD recommended. Kyra feels exhausted/beaten down, judged and blamed by professionals as single mum. Constant stress/uncertainty about fees and how to pay them. Thomas' behaviour is increasingly challenging. She feels adrift, "at the mercy of the currents."

Ideal Experience

- Coordination/Advocacy team: Not having to navigate a complex, disjointed system alone. A specialised, multi-disciplinary team exists "that schools can approach to be an advocate" so parents can "learn what to ask."
- Transparency: Wait times; referral processes; infomation about what she (the parent) needs to do and what service providers are responsible for; costs (Medicare rebate covers).
- Easier access and responsiveness: "Shouldn't need 20 different phone calls to find what you need".

- Parenting support/respite for other children: During this waiting period, She gets as much support as possible to keep things stable and keep a brave face on for all her kids.
- Reliable social media/peer support groups: Designated Facebook groups that have responsible administration processes, and she is supported to navigate or access groups.
- Accountability: system works as advertised.



Barriers



Health care access:

- Excessively long waiting times for specialist diagnosis and treatment (public & private).
- Appointment and referral systems (time consuming, mentally exhausting).
- Lack of clarity how much will it cost? Who is responsible for what?
- Excessively high costs for specialists.
- Concerns about Child Protection.



Other challenges:

- Dealing with escalating challenging behaviours with minimal support.
- Judgemental attitudes assumptions about "poor parenting" lead to guilt and self-doubt.
- Lack of time for other children, own well-being; Life and all its challenges do not take a break.



"It's not a puzzle where you need to fill in a missing piece, but a game of Tetris. One wrong move and it all falls down –you go right back to the start."



Persona: Kyra



Awareness

Recognises son's

Consideration

Accessing health services

Treatment

Follow up

behaviour is an issue

- Managing ongoing effects of family violence (FV).
- School raises issue of behaviour.

School/teachers advise assessment by paediatrician and psychologist regarding behaviour; suggest parenting classes.

- Gets GP appt. for paediatrician referral.
- Securing appt, with paediatrician called many clinics (18-month wait).
- Securing appt. with psychologist/counsellor.
- Managing behaviour issues at home/school while waiting for treatment options.
- Tries reaching out to previous support connections.

- GP in a hurry.
- Paediatrician lots of paperwork.
- Treatment: medication: mental health sessions, behaviour modification trials. waiting for additional appts.
- Ongoing diagnosis management.
- Support for other children.
- Finding support for herself – info and support groups.
- Understands system better.

Thinking

"Is it something I have done?"

"Is it my fault?... as I didn't leave FV earlier "

"Other people can see there is a problem, not just me."

Guilty

"This is bigger than I initially thought."

"They seem to think it's because I am a crap parent."

"I've done what I needed to do... it's now up to the professionals?"

"How much is it gonna cost, how long will it take?"

"18-month wait? What am I supposed to do... what about my other kids, my work and me?"

Frustrated &

Angry

"I waited 18 months for THIS? I've been working my ass off for months."

"This is where the really hard stuff starts."

"Where's the light at the end of the tunnel?"

Grief

Relieved

'How am I meant to do this long-term?"

"One wrong move and it all falls down "

Ongoing

emotional roller-coaster

"I wish I knew some of this at the beginning."

Feeling

6 2

Feeling scale: 8 = most negative 1 = most positive



- Self School (Teachers - classroom and Social Emotional Learning - SEL).
- Self

Uncertain

School (Teachers - classroom and SFL).

Relieved

Defeated

- Specialist clinic intake staff/receptionists
- School staff (behaviour management).

- GP
- Paediatrician
- Psychologist
- School staff
- Pharmacist
- Self

Self

Exhausted

(physically

& emotionally)

- Support groups
- Various health professionals ongoing.

- Non-judgmental early intervention supports for challenging behaviours.
- School to be empathetic and supportive.
- To get a quick appt. for further referrals.
- Transparency or information about process ahead.
- Trauma-informed responses.
- Transparency about all steps in the process.
- Timely appts.
- Information about interim supports to manage children's needs.
- One professional she can trust who can help her find the support she needs and what services to access.
- Understanding who does what in process.
- Specialists she knows and trusts.
- Someone to call for support.
- Support implementing treatments.
- To be seen as a real person.
- Reliable support and information
- Credible social media support groups.
- 24/7 support line.

Tries to deal with it on her own; hopes behaviour will settle.

Avoids situations where behaviour might escalate (e.g. playgroups).

Others recognise issue.

Relieved she may get support, but uncertain of process ahead.

Gets GP appt. relatively quickly and paediatrician referral.

18th-month wait for paediatrician.

Unaware of support available in the interim.

Uses phone data to call clinics - loses a coping mechanism for son. "I just have to do whatever it takes to keep him from having tantrums."

Not the end of the journey - will have to go to multiple other health professionals and medications.

Medication can take 8 weeks to kick in, but system interactions improve with medication (support).

Finally has some handle on the system.

"Something happens and you're back to the start".

Early intervention supports readily available/accessible and trauma informed. Constructive and supportive school response.

Someone at school trained to understand complexities of family violence and trauma, in order to support parents.

Consistent approach across schools.

Advocate / case worker to support parents to access interim services and supports - based on individual needs.

Supporting parents to know what questions to ask and request the correct information prior to specialists appts, how to accurately document appt. outcomes, and understand what follow up is required.

Advocate / case worker to support parent to self-advocate and understand how the system works (i.e. pathways, diagnosis).

Ability to access other services if not 'the right fit' without long wait times.

Respite support for other children while dealing with crisis.

Self-care opportunities.

Service navigation support, based on need, and across services and organisations.

Designated peer or social media support groups; support to navigate misinformation.

