

Latrobe Health Advocate

# **Engagement inspiration.**



*The Latrobe Health Advocate respectfully acknowledges Aboriginal people as the Original Custodians of the land we walk on today – the land of the Braiakaulung people of the Gunaikurnai nation and passes on respect to their Elders past and present, future and emerging.* 



The Latrobe Health Advocate thanks all the people who shared their time, experience, wisdom and ideas with us. It is their lived experience that we share in this document so that we might all learn to better connect, communicate with and support one another.

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#### Our research...

Before undertaking this work we did some research to answer the following questions...

How do we engage the right people well and maximise the benefits to them?

How do we maximise our influence on government and others?

How do we think usefully about 'place' and communities within place?

To learn more about this research you can read our report: *Elevating the voices of Latrobe communities*.

#### Our model...

Through our research and community engagement, we have developed an engagement model and creative ways of working. Community engagement is our core business and underpins how we work with others in the Latrobe Health Innovation Zone and beyond. The *considerations for good engagement* highlighted in this report are now embedded into our engagement model to ensure we are acting on and continually reminded of what matters to people in the community.

#### Our partner...

We partnered with The Australian Centre for Social Innovation (TACSI) to engage with communities for this report. TACSI's expertise in collaborative engagement complimented our local knowledge and connection to community.



#### Letter from the Advocate

In my 2018-19 Statement of Intent I made a commitment to the Victorian Minister for Health and communities in Latrobe to undertake a codesign process to determine a way of working for my office. As the Latrobe Health Advocate, an essential part of my job is to listen to and understand the views and needs of people in Latrobe. For me, the only way to do this is to first understand how people in Latrobe want to have their voices heard and why this is important to them. In particular, people who may be experiencing disadvantage, people who may not usually have their voices heard, or people who may not recognise their voice which may be for a range of reasons.

To do this work, my office has partnered with The Australian Centre for Social Innovation (TACSI), an organisation with a proven ability to work together with communities, walking alongside and learning from people in their everyday lives to create change that is community-led. An organisation that shares the values of the Latrobe Health Innovation Zone and has demonstrated a commitment to creating community-led solutions.

We also partnered with local communities. People living or working in Latrobe that bring their own expertise to the discussions. Expertise in what matters to them, how they want to have their voices heard and expertise in how the decisions of governments and services impact them. This work would not be possible without involving communities from the very beginning.

Through working together with TACSI and local communities we have learned about a range of contemporary engagement techniques and methods. We have tested these locally and adapted them to suit the Latrobe context, engaging with local communities on their terms, not ours. We have learned that methodology is not a substitute for authenticity, and we have seen first-hand how engagement is good for people's health and wellbeing. We have established relationships that we intend to nurture into the future.

It is evident that people in Latrobe do want to engage. They have something to say and they want to be heard. People in Latrobe care about their health and wellbeing and they care about each other. They understand the core purpose of governments and services. They have expressed a desire for these services to demonstrate a culture. of empathy and openness and to show that they care. There are some outstanding examples in Latrobe where this is already happening and the benefits to communities, organisations and governments are clear. I have no doubt that listening and responding to the needs and aspirations of people in Latrobe can have a significant positive impact on their health and wellbeina.

Creating an environment where the feedback, ideas and experiences of local communities are valued equally alongside clinical and technical expertise will enable creativity and change within the Latrobe Health Innovation Zone.

It has been a privilege to hear the stories I have heard so far and to be able to share some of them in this report. I want to thank everyone who has contributed to this work and look forward to continuing to learn from local communities as my office implements the engagement model and ways of working that have been developed.



J. Budeno

Jane Anderson Latrobe Health Advocate

# Improving health outcomes by engaging with all communities in Latrobe.

While we all experience varying challenges and opportunities in our lives, some people are known to experience greater exclusion due to the way society, services and systems respond to their age, gender or sexuality, health, culture or race, economics, education or they may live in an area that is not easily accessible. In order to enable the inclusiveness of everyone in Latrobe, it is important we understand how to help people navigate their unique barriers.

All members of Latrobe communities are invited and supported to share their views and aspirations with the Latrobe Health Advocate and this engagement occurs in a variety of ways.

The overall purpose of this work is to design and develop a community engagement model with people that may be experiencing disadvantage through disability, financial stress, isolation, family violence, chronic disease, mental illness, sexuality, cultural diversity, and age. In year one, three focus areas were identified as a starting point:

- People living with a disability
- People living with chronic conditions
- People who are culturally and linguistically diverse

The Latrobe Health Advocate will continue to engage with these communities, as well as reaching out to other communities and hearing from them about how they want to have their voice and what matters to them. The engagement model will continue to develop as more communities are engaged.



# Who can learn from and respond to the voices of people in Latrobe and why?

This report captures some of the key barriers that people who are new to Australia and/or living with disability or multiple chronic conditions face in accessing the supports they need and having their voices heard, and the ways they would like these barriers to be overcome.

The Office of the Latrobe Health Advocate is using this report as a starting point for reflecting on how we engage with local communities. We would be happy for you to do the same.

#### What this report is not...

This report intends to provide guidance but it is not a fixed set of instructions about how to engage with people. We have learned that methodology is not a substitute for authenticity. Engagement needs to be authentic and meaningful, designed with purpose to fit people and place.

#### What this report is...

Instead, it is a story of what we've heard, which we hope will encourage greater community engagement, conversations and some change in how we all work together for the best health and wellbeing outcomes in our communities.

#### Who might find it helpful and how?

This report is intended as a helpful starting point for people who live in, visit or provide services to people in the Latrobe Valley. It also has relevance for governments and services beyond Latrobe that have a role and can benefit from listening and responding to the needs and aspirations of the public. Consider which approach might best suit you:

- If you are someone **making decisions** or delivering services that affect individuals, families and communities, you could use this report as a starting point before you engage with people directly (so that they can be brought into the decision making and service delivery process).
- If you are a **professional**, **family** member or **friend** you might be able to relate to the stories in this report and think about what it means for you in relation to how you support and engage with people in your community.
- If you are a **person with lived experience** you could use this report to help you to advocate for yourself, educate others, or find experiences you may relate to or learn from (while we know every experience is different).

#### **Our engagement process**

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Identified a need to better understand how to engage with and support people with distinct lived experience.



Named key questions to explore.

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Identified organisations, groups and individuals to engage with and learn from.

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Arranged to meet people at places where they felt comfortable.



Developed tailored activities to make conversations engaging.



Facilitated semistructured conversations.



Analysed each conversation and identified themes.



Identified actions for the Latrobe Health Advocate.



Summarised what we learned in this document.



Shared draft content with people in Latrobe to test for accuracy and hear their feedback.

Shared this document publicly to inspire others to build on their engagement, service and advocacy work.



Now we will continue having community conversations and learn as we go.

# What we heard across all the people we spoke to.

#### THEMES

#### **Considerations for good engagement**

We learned that people and communities are complex, all with different needs and circumstances. There is no single way to engage with communities.

Through our engagement we need to recognise and celebrate diversity. Diversity of people, culture, experience and opinion. We need to provide different ways and places for engagement to suit different needs (verbal, written, at community locations).

We heard that face-to-face conversations are effective and that if we want to build trusting relationships people need to be able to look us in the eye and read our facial expressions.

We learned that people in Latrobe do want to engage and that it is important to show them what we have heard.

#### Barriers and enablers of good wellbeing

We learned that the health system is complex, and that people need to develop skills and networks in order to access the supports they need when they need them. We heard about how this can be easier for some people than it is for others.

We heard that health professionals, particularly General Practitioners and specialists can be hard to access and build rapport with as they may be too far away, booked out, too expensive or only in the area temporarily.

We learned that a lot of people rely on public transport, which, within Latrobe is primarily buses and taxis. At times this can be difficult depending on schedules, location of services and the nature of a person's disability, chronic condition or understanding of Australian transport systems.

People talked openly with us about mental health and wellbeing. They shared their desire for easier access to more mental health supports and services in their communities.

We observed how valuable it is for people to be part of a group where they can connect with others, support each other and share experiences.

#### What really matters

Everyone that we spoke to talked about their connections to community, the importance of belonging, contributing to and being supported by the world around them.

The ideas and aspirations that people shared with us all came from a place of wanting to make a difference for themselves and others.

People showed us that it is important for them to be able to advocate for and look after themselves. They expressed a desire for everyone to be treated equally and without judgement.

People talked to us about the health benefits of animals and music and the positive impact they can have for communities and individuals.

The people we spoke to were aware of the things that create stress or tensions in their lives.

# Who has consultation fatigue? Not Latrobe Valley communities.

People in Latrobe have shown us that they do want to engage. They have something to say and they want to be heard. Yet we have heard concerns about over engaging and creating consultation fatigue. We find ourselves asking, who is experiencing consultation fatigue and where is it coming from?

In Latrobe, some of the best examples of engagement and connectivity are happening all the time. There are real conversations and connections, many that are organic or unplanned with little structure. However, there seems to be a gap between where communities are and the ways and places governments and services are trying to engage. Communities have expressed frustrations about 'engagement' but it's not because they don't want to contribute.

#### The Office of the Latrobe Health Advocate is reflecting on...

- How might we make engagement easily accessible to the people of Latrobe?
- How might we record and report on the depth and quality of conversations and community feedback?

What if...

- ... we made community engagement easier and relaxed the rules? Could staff in services be given permission to spend time with people, building relationships and understanding what matters most?
- ... governments and services could say 'we don't have all the answers, but we are here to listen to your questions and then to work together with you to find the answers'?
- ... services and governments treated every interaction with community as an opportunity to truly engage with and hear from people, recording and paying attention to needs and aspirations?

"Someone from the Government who can do something?"

Community member

"They all seem to promise everything and do nothing."

"Why bother?"

Community member

> "We want to know what is going on with us."

Community member

# Forget about procedures, paperwork, protocols and remember...PEOPLE.

Services and governments can get so consumed by their own paperwork and internal systems that it becomes less about the people that they exist to serve and more about ticking a box on a form.

#### The Office of the Latrobe Health Advocate is reflecting on...

• How can we ensure that we stay focused on people and communities and don't fall into the trap of 'paper over people'?

#### What if...

- ...staff in services and governments were supported to be creative about ways to make their day jobs more about people and less about paperwork?
- ... services and governments asked...do we need this paperwork and how does it benefit our consumers and the local community?
- ... Government performance measures were based on kindness and empathy with results and ratings informed by feedback from communities?

"I feel like a number."

Community member

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"You need to make people feel like they do matter."

Community member

"Keep it simple, regardless of your audience."

> Person from a community service organisation.

## "This group is a safe and happy place for me every Friday."

It make sense to engage with people where they are already engaging. They are more likely to feel safe and comfortable. They will have their peers there to support them. The place or territory of the engagement may not belong to government or services but to community - this shifts the balance of power.

People in existing groups were easier to engage with. We observed that when people were with their peers, they felt safe. They talked about things in front of each other that they may not have talked about in the past. The engagement was mutually beneficial.

#### The Office of the Latrobe Health Advocate is reflecting on...

• How might we get the balance right between creating a space for our engagement activities and going with the flow of the group's usual interactions and dynamic?

#### What if...

- ... through our engagement, existing groups and community relationships can be strengthened with people feeling more empowered and connected?
- ... staff from services were enabled to 'join in 'with community activities, get to know people and learn about their needs and aspirations?
- ... health and social services could be remodelled and delivered at locations and times convenient to communities, places where people are already gathering?

"This group is more like a family to me."

*Person living with disability* 

"Elderly people are quite interesting they have a great story to tell."

Community member

"We all seem to get along. We all have fun."

*Community member* 

# Active reflection.

#### Questions that might get you started...

If you are a **decision maker**, consider:

- Is your organisation experiencing engagement fatigue? What could be done differently to reinvigorate how your organisation engages with and responds to local communities? Could your staff work together, in partnership with local communities to create other ways of engaging?
- Does your organisation have formal / traditional engagement structures in place such as a Community Advisory Committee or Customer Focus Group? Are these structures enough to enable your organisation to truly hear from communities and remain responsive to their needs and aspirations?
- When you engage with communities how aware are you of power dynamics? Is your agenda open to community input or have your outcomes been predetermined?
- What is your appetite for engaging with communities with an open agenda? How confident are you about engaging before you have developed answers to potential community questions?
- How do you share and test what you have heard with communities? Are there ways you can demonstrate how your organisation is responding to the needs and aspirations of people in Latrobe?
- How do you currently create feedback loops with the people accessing your services or systems? How do you know what people like and don't like and how do you respond to this information?
- How do you include lived experience in your decision making? Is there value in your client base and communities that you're missing out on?

#### If you are a **staff** person, **family** member or **friend**, consider:

- How can you show people that you are listening to them? How could you be a role model within your team or network?
- What can you do to challenge the status quo, and help those around you to be open to creating new ways of listening to people in the community?
- What can you do to enable people, who may not recognise their voice, or may not usually have their voice heard to share their views?

#### If you are a **person living, working or studying in Latrobe**, consider:

- How do you like to have your say? Have you shared your engagement preferences with people and organisations that offer supports and services to you and your community?
- When you have a positive experiencing engaging with a service or organisation, how might you provide feedback to staff and decision makers to tell them they are doing a good job and to give them the energy to keep doing what they are doing?
- How might you support others in your community to share their views and participate in engagement activities?
- Having your voice and participating in community engagement activities to help you to enjoy good health and wellbeing.

# What we heard from people living with chronic conditions.

#### THEMES

# Considerations for good engagement

#### Keep it simple

The people we spoke to didn't ask for a lot. It was the simple things that matter to them. A cup of tea and some biscuits. Acknowledgment and feedback about their contribution. Communications via a local newspaper, on the radio or a letter in the post.

#### Keep it social

When we asked about how we could best plan our engagement activities, we received strong feedback about the benefits of social time. Combining engagement activities and consultation processes with a social activity such as a walk, or barbeque, or simply time in the agenda for people to connect with others.

#### Keep it real

The people we spoke with were clear in expressing their expectations that engagement needs to be honest and authentic. People told us to be open about why their feedback matters, what we have heard and the difference their feedback has made to the work that we are doing.



Hi Alister, just a big thank you to the both of you for coming to speak with & I, it's truly appreciate. As we get older we feel invisible & forgotten about in so my ways. With what you are doing gives us hope & made us feel good. I forgot to mention that after a sleep apnea test I was diagnosed with sleep apnea & given a letter to higher or buy a machine. Unfortunately I can not afford to do anything about it. This must happen to many & it is a dangerous condition. Just a heads up on how hard it is to do things for our health at times. Cheers

#### Wednesday 4:24 pm

Hi **A**, thanks for your kind feedback we are pleased to hear you both valued our chat. We did too it was great to hear from you both. I'll add some extra notes about the sleep apnea test - thanks for sharing that. We will be in

(A)

iMessage

#### Barriers and enablers of good wellbeing

#### Finding and keeping a good doctor

We learned about how important a 'good' doctor is for people living with chronic conditions. People told us that a good doctor listens, creates a good care plan and gives good referrals, helping patients to understand and navigate a complex system. However, it is not always easy to find a good doctor, and it can be disruptive and challenging when doctors move on. People living with chronic conditions want to know about staffing changes and want to be included with the 'handover' of their records, their story and their relationship.

#### Navigating a complex system

People that we spoke to shared their frustrations and concerns about accessing services and specialists. Some people have made the decision not to access services that they know they need due to barriers such as long waiting times, costs, travel distances or limited transport options. They said it was easier or cheaper to stay at home.

When thinking about times they have accessed a specialist or someone other than their doctor, people expressed a desire for health professionals to see 'all of them' and not treat them as a single issue, symptom or condition.

#### What really matters

#### Living life

The people we met with had a resilience about them, and despite their chronic conditions, they were finding ways to go about their business and live their day-to-day lives. Sometimes it was said out loud, other times it was not, there was an obvious desire from people in Latrobe to be able to enjoy their lives without being stopped by their chronic conditions.

#### Staying connected

All of the people we spoke to talked to us about the importance of connecting with others. We witnessed some strong friendships and heard about the powerful impact of knowing that someone is looking out for you and is there to help you to navigate the complexities of the health system and chronic conditions.

#### **Company of animals**

Interestingly, whenever we spoke to people living with chronic conditions, we heard stories about their pets and how valuable they are to them. People told us that pets can be good company, they make you feel good and can be easy to look after, even on a difficult day.

# <image>

#### **INSIGHT 1**

#### When patients and health professionals engage and navigate the system together as partners, the caring is real and the outcomes are strong.

When someone takes the time to show that they care it can positively affect a patient's experience with the health system, and give them the confidence to continue accessing services and professionals that can help them with their chronic conditions over the long term...

People with chronic conditions can require good medical support to live their best lives. In order for this to work well, people shared that having a doctor who knows them well, that they've built trust with and who cares about their social and emotional wellbeing beyond their blood test results was important. It helped people feel heard and feel they are equipped to navigate life and the complex systems that they often utilise to live well.

#### The Office of the Latrobe Health Advocate is reflecting on...

• How might we show that we care when we are talking to people and listening to their experiences. How do we partner with community?

#### What if...

- ... people with chronic conditions had a 'care manager' role who helped them navigate their whole wellbeing in complex health systems?
- ... General Practitioners (GPs) were afforded time to engage and get to know their patients as people?
- ... health services including GPs had stronger connections and referral pathways into community based activities and could support patients to navigate between health services and social supports?

"You get used to a doctor and then they leave. What am I going to do about a doctor now?"

Person with chronic conditions

"I've got a pretty good doctor who I've had for twelve years...she hears what I'm saying."

Person with chronic

"We have a good understanding of each other (my doctor and I)"

Person with chronic conditions



## It's better together.

We learnt that people living with chronic conditions can benefit when they have someone they can count on for practical and emotional support. This might be a life partner, brother, sister, neighbour or friend. Regardless, having someone to help navigate a complex system and be there to get you to and from appointments can make a big difference.

Multiple people told us about times when they were contacted by a neighbourhood house, community centre or sports club to check on them when they hadn't attended for a while. It was so special to them that they were missed.

#### The Office of the Latrobe Health Advocate is reflecting on...

 How might we create engagement opportunities where people can participate together and support each other?

#### What if...

- ... we designed engagement activities to hear the perspectives of people living with chronic disease alongside the people that they rely on to get through?
- ...we deliberately created time and space for people to connect with each other, and ways for them to stay connected beyond our engagement activities?
- ... we supported people in the community to engage directly with their peers and to share what they learn with us and others?

"I just like it (the neighbourhood house). We all seem to get along. We have fun."

Person living with chronic conditions

"We all got problems, we all help each other out."

Community member

"We just loved the friendships and made a whole lot of new friends."

Community member

#### "Getting out and about keeps me sane."

Person living with chronic conditions



## Pets are great for engagement and good for health. They offer cuddles, comfort and good company.

People living with chronic conditions in Latrobe talked to us about the healing power of pets. They showed us that being around their pets helped them with their sense of emotional connectedness and overall wellbeing.

All of the people with chronic conditions that we met with had pets. Having pets present and in the room, and often as the centre of attention made people (including ourselves) feel good - we felt more connected to our feelings and each other. This created a safe and open environment for engagement to occur.

#### The Office of the Latrobe Health Advocate is reflecting on:

 How could we involve pets and animals in our engagement activities?

#### What if...

- ... there were more pet friendly places in Latrobe? Would people feel more connected to each other and enjoy better health and wellbeing together?
- ... local services embraced the healing power and company of pets?

"I like my animals."

Person living with chronic conditions

"He's a life saver. I get home and he (my dog) is there to greet me."

Person living with chronic conditions

# **Active reflection.**

#### Questions that might get you started...

#### If you are a **decision maker**, consider:

- How can you assess your organisational culture and get feedback on how this impacts the experience for people living with chronic conditions?
- What can you do within your organisation to make things easier for people living with chronic conditions?
- What can you do to give greater flexibility to your staff to enable them to take a more holistic and relational approach when they are working with people living with chronic conditions?

#### If you are a **staff** person, **family** member or **friend**, consider:

- Are you more of a prescriber or a partner?
- How do you help others to navigate complex health and social systems?
- What could you do differently to help people with chronic disease achieve their goals and aspirations?

#### If you are a **person living with a chronic condition**, consider:

- What are your barriers to having your voice heard? What or who could help?
- Who helps you to access and navigate the local health system? Can you help others by sharing what you have learned about the local system?

# What we heard from people living with disability.

#### THEMES

#### **Considerations for good engagement**

#### One step ahead

People need to pre-empt the needs of people living with disability where possible, in order to increase the physical and emotional safety of the engagement. This might involve talking on the phone beforehand to better understand a person's needs, providing options and alternatives, finding an accessible venue or inviting people to bring a support person if they would like. But we found it is also the details such as providing an agenda, pre-reading and name tags so that engagement is as accessible as possible. It's also important to respond to unexpected needs, by checking in regularly during a conversation.

#### Hearing unheard voices

While some people are excellent and consistent advocates for themselves or their loved ones, others might not be comfortable speaking up. Engaging a mix of leading advocates and those who might not have a voice already is important to ensure diverse representation of the experience of living with a disability in Latrobe Valley.

#### Creating opportunities for peer support

Meeting with multiple people with a disability at the same time (while not expecting their experience to be the same) can help in some situations as people can give each other voice. We've found that many people could relate to each other's experience and the engagement itself was a validating experience. People also told us that they enjoy learning from others and hearing about how their experiences and preferences might be different.

#### Fitting into existing routines

For some people, their routine is very important and helps them to live well. When this is the case it's important that engagement fits into, rather than disrupts, this routine. For example, we visited people at work and shared a morning tea break and a chat. We also visited places that people are used to attending so they felt more comfortable on their home ground.

#### **Barriers and enablers of good wellbeing**

#### Getting support is hard

The people we met are all very skilled at navigating the complex systems around them to find and access the supports that they need. However, they have had to learn these skills the hard way and can still struggle to get what they need to live well because formal disability supports can be hard to understand, navigate, request and access.

#### Working together works

People seemed to really appreciate a collaborative approach, in one case an employer created teams that best suited the skills and personalities of their employees. In another case, a parent felt that their child's school wasn't willing to work together for their child's best interest.

#### People are diverse but systems are not

We heard that services struggled to be flexible and responsive to the diversity of people, their disabilities and their needs. People fell through the gaps if they didn't fit into the categories or eligibilities of the system and often had no alternative.

#### What really matters

#### Listen

The people we met living with disability in Latrobe Valley were clear on a common theme - that they know themselves and their needs best. It is important to them that their experience is valued and respected, and it guides the people and supports around them.

#### Nothing about me without me

Following on from this, people wanted to lead or at a minimum be included in the decisions that affect them, and have the information and accessibility they need to be able to fully participate in these decisions.

#### Celebration

We heard a few stories of people being recognised for their skills and talents! It was important for everyone we spoke to that they are seen for their strengths, successes and abilities rather than their challenges.



# "She listened, she let me cry, she let me laugh."

People want services to genuinely care and to work with them to creatively find the best supports, rather than having perfect solutions.

One person described different attitudes toward supporting the learning needs of their child. One school told her they weren't able to help, while another sat down and talked through the different possibilities.

#### The Office of the Latrobe Health Advocate is reflecting on...

• How might we build personal connection with and between the people of Latrobe Valley through our engagement?

"People need to be treated with regard."

Person living with disability

"He (the disability advocate) and I go way back."

Person living with disability

"I laughed, I begged, I cried."

Person living with disability

#### What if...

- ... health professionals and service staff were permitted to nurture their relationships with their clients and encouraged to build a culture of compassion within their organisation?
- ... staff were taught active listening skills through regular training sessions and activities that involved people with a disability?



#### Computer says no.

#### People are expected to fit into rigid and complex services, whereas services should fit the people they serve.

Disability services believe they are listening. They have 'systems and processes' in place to hear the voice of people with disability. However these systems can be impersonal and often prevent people from feeling heard. Feedback loops can be incomplete. We know that people feel heard when they have a genuine, power sharing relationship with someone who cares.

We met with services that had efficient complaints processes, but without a way of completing the loop of feedback and letting people know how their complaint had been responded to.

There were examples of projects that aimed to engage and collaborate with communities, but that could be improved by meeting people where they are and asking them to help frame the project itself.

#### The Office of the Latrobe Health Advocate is reflecting on...

How might we advocate for more flexible, human centred • systems?

#### What if...

... service managers regularly attended groups or activities led • by people living with disability?

"I needed to learn how to communicate with society. Should we be penalising people for not being able to communicate well?"

Person living with disability

"Treat us as humans as we are entitled to be heard, shown respect and offered dignity."

Person living with disability

"I learned how the system worked."

Person living with



# What can we learn from our neighbouring communities?

We can learn from each other to make sure decision making in Latrobe Valley is informed by the lived experience of people living with disability. Neighbouring communities might have some common challenges, but also unique experiences.

Some people living with disability compared their good experiences in East Gippsland to their experiences in Latrobe Valley. They have said that some people with disability in Latrobe Valley are struggling to be heard and to get what they need.

East Gippsland has a Disability Advisory Committee that consults to the council to bring consideration of access and other experiences of people living with disability into decision making.

Latrobe Valley decision makers have other ways of listening to people living with disability but some people thought it could be better.

#### The Office of the Latrobe Health Advocate is reflecting on...

• How might we make decisions in partnership with people living with disability?

#### What if...

- ... we could build on the existing ways for people living with a disability in Latrobe to share their views and reach a point where more people are heard and the response of governments and services is more coordinated?
- ... people living with disability in Latrobe Valley were connected to those in neighbouring regions, to exchange information and learn together?

"I didn't know you could do that (request library books) until they told me."

Person living with disability

"It really concerns me what's happening out there."

Person living with disability

"I'd rather die in a corner than go to the emergency room...it's horrible."

Person living with disability

# **Active reflection.**

#### Questions that might get you started...

#### If you are a **decision maker**, consider:

- How do you involve people living with disability in your decision making? Could you bring more lived experience to the table and benefit from the value this would add?
- How do you test the accessibility of your service, engagement and communications? How could you improve accessibility?
- How do you prevent people living with disability from needing to repeatedly educate your staff about their needs and preferences?
- How do you respect and protect the human rights of your clients?

#### If you are a **staff** person, **family** member or **friend**, consider:

- How do you listen? How do you facilitate choice and control?
- How do you communicate in ways that work best for people?
- How do you find solutions together?
- How do you distinguish between what you want for the person and what they want for themselves?

#### If you are a **person living with disability**, consider:

- What are your barriers to having your voice heard? What or who could help?
- Are there advocacy or advisory groups nearby you could join so that Latrobe Valley can learn from your experience?

# What we heard from people who are culturally and linguistically diverse.

#### THEMES

#### **Considerations for good engagement**

#### Meet face to face

People told us that they want to have a relationship, be connected with. They recognised us from previous engagements and connected more easily. It is important that the place of engagement and any associated activities are safe and neutral for the communities and cultures involved.

#### Allow time

We know from this engagement as well as previous work that relationships might take a little more time across different cultures in order to understand communication styles, build understanding and trust. Some cultures have certain considerations that require time, such as cooking a meal for a guest, or not sharing personal challenges with people you don't know well.

#### Take a leap of faith

There were a few instances in this engagement where one individual was the first to courageously be vulnerable and share something more personal. After one person took this leap of faith, others supported that person and shared their own fears, challenges and feelings.

#### Don't start from scratch - community are the experts

We found people were very happy to talk with us as we were building on the existing trusted relationships, with well-loved facilitators. The trust given to the facilitator was extended to us. It is important to pay attention to who is trusted and who isn't.

#### Have persistence

Group facilitators needed to gently push past fears of English not being good enough, or 'that's not for me'. Humour and energy from the facilitators broke the ice, as well as a confident person being vulnerable first, paving the way for others. It also helped to ask the same question in different ways and to be mindful of not making assumptions. This helped with language and cultural barriers, but also with a recurring unwillingness to criticise services that support you, often due to a fear of repercussions.

#### Barriers and enablers of good wellbeing

#### Employment

Many people told us that taking care of the family financially was often a huge stress on their mental wellbeing. People explained that they were struggling to find employment for themselves or their partners. They weren't sure how to get the right qualifications and were applying for jobs with no luck.

#### Social capital

It's challenging to lose the supports you have, especially when you don't have many because they are in a home country or are part of a small group in Latrobe Valley. A wider/larger support system helps connect to opportunities like employment, sharing resources like cars and child minding, learning new skills and making friends. When people have little social capital, it creates many barriers to wellbeing.

#### Connect in a variety of ways

Having different opportunities to connect to people means more people can engage. Some people are quiet, struggle with English or don't leave the house much, so supports need to allow for this.

#### What really matters

#### To love and be loved equally

Many people spoke to the universality of love - that it can break down barriers, unite and heal. It was a unifying factor in diverse cultural groups, including between majority and minority cultures.

#### A sense of belonging, a safe place to be vulnerable

It was clear from different group sessions we went to that being a part of a group was comforting, rewarding and also a great resource for people.

People felt safe to share the things that were really challenging for them in their lives. The stoic side of Australian culture was left outside the doors and people connected deeply and personally. "We all need love in our life. Love means a lot. We should not be racist, we should love everyone equally."

Person with a multicultural background

"We are all the same, we all smile the same."

*Person with a multicultural background.* 



## Flying trapeze with no safety net.

The people who love and care for us are a safety net that protects us from harm. When things get tough, we have a shoulder to cry on, a home away from home, people to help us answer hard questions. For those who've migrated to Australia, this safety net often disappears. It's hard to rebuild these networks in a new country, but not impossible.

We spoke to many women who had migrated to Australia for whom family was their source of strength. Most people had a small family in Australia - a partner and/or children.

However many people didn't have other supports, and were really struggling and feeling more vulnerable without extended family and best friends they could confide in.

The small connections that are made, such as someone attending a group because their husband liked to go, are great opportunities for new connections and supports. Some people at the groups went out of their way to bring new people to the group who they thought would benefit - even taking time off work to introduce them!

#### The Office of the Latrobe Health Advocate is reflecting on...

• How might we support new migrants to quickly connect and build networks that may lead to long lasting friendships?

What if...

- ... we had more friendship groups?
- ... we had more places and conversations that support connection through vulnerability?
- ... migrants who have lived in Australia longer were supported to mentor newer migrants?

"When I get stressed, I think of my family."

*Person with a multicultural background.* 

#### "My daughter helps me feel stronger. "

Person with a multicultural background.

#### "My mum and dad passed away."

*A person's response when asked who they go to for support.* 

#### "This group is more like a family to me."

Person with a multicultural background.



# Mindfulness doesn't put food on the table.

It's harder to enter the workforce when your skills might not be recognised, your English is less fluent and there is racial judgement. Employment can be a gateway to financial, social and emotional security and health, and the stress of unemployment can affect our mental wellbeing and more.

People at different events spoke about the stress of trying to find work, and financial stress of taking care of their families.

#### The Office of the Latrobe Health Advocate is reflecting on...

- How might we support employers and services to better understand the value people from different cultural backgrounds can bring?
- How might we better understand how employment and wellbeing are connected, and address underlying causes of mental stress as well as the symptoms?

#### What if...

- ... we told more stories about the amazing contributions culturally diverse Australians make to the Latrobe Valley community?
- ...there was more emphasis on all aspects of health and wellbeing in Latrobe Valley including physical, social, mental and spiritual?

"All I need is two days of work and I'll be happy."

Person accessing support services.

#### "We all have tensions. I have too many."

*Person with a multicultural background* 

# Active reflection.

#### Questions that might get you started...

If you are a **decision maker**, consider:

- What are the diverse cultural communities that you engage with? How could your organisation better understand these cultures?
- How might your services and staff create opportunities for connection and to support your clients to build social capital?
- How do you stay in tune with and responsive to the ever-changing dynamics and networks of culturally and linguistically diverse communities?

#### If you are a **staff** person, **family** member or **friend**, consider:

- How are you connecting with your neighbours and the people you meet?
- How might you make new migrants feel welcome, and connect them to your network of friends or family?

#### If you are a **culturally and linguistically diverse person** consider:

- Who are the people around you who could help with any challenges you are facing?
- How might you support others who are currently going through the same challenges you have in the past?
- What are the formal and informal ways you could hear about new job opportunities?

# Actions for the Latrobe Health Advocate.

Working together with local communities to develop an engagement model for the Office of the Latrobe Health Advocate has been an invaluable experience. We have heard directly from people about why engagement matters and how we can make it meaningful, from a community perspective, not ours.

It is now our job to honour the commitment we have made, to implement the community engagement model we have developed. We will elevate the voices of the people we have been listening to and work with governments and services towards a health system that has the capacity to continuously listen and respond to the needs and aspirations of local communities.

We will...

- Continue to implement our engagement model and update our engagement tools and ways of working based on the preferences people have shared with us
- Continue to engage with...
  - People living with disability
  - People living with chronic conditions
  - o People who are culturally and linguistically diverse
- And, also...
  - People experiencing financial stress
  - Aboriginal and Torres Strait Islander People
  - LGBTI people
  - o Communities in Latrobe
- Share our engagement model and what we have learned with....
  - Latrobe Valley communities
  - o The Latrobe Health Assembly
  - Services and businesses within the Latrobe Health Innovation Zone
  - The Victorian Government
- Include the voices of people we have spoken to in our priority projects. In 2019-20 these projects will focus on...
  - o Social inclusion and human connections in Latrobe
  - o Barriers and enablers to a healthy lifestyle in Latrobe
  - Access to services in Latrobe and in particular, GPs
- Invite feedback from others about this work and continue to learn about the value of listening and responding to the voice of local communities.

The Office of the Latrobe Health Advocate welcomes feedback on this work and invites people from Latrobe and beyond to share their own ideas, experiences and reflections about the importance of listening and responding to the voice of communities.



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