

Your Health, Your Way

In 2025, we brought autistic and neurodivergent people together to co-design better health literacy and healthcare experiences.



Why this matters?

Autistic and neurodivergent people can experience significant barriers when navigating healthcare systems. Rather than simply identifying problems, the *Your Health, Your Way* project focused on **solutions and creating practical opportunities** for inclusive and accessible change in these systems.

*“Universal design
and inclusive
design **benefits
everyone.**”*

Autistic mother

Who participated?

 61 participants identified as:

- ▶ **70%** Women
- ▶ **20%** Men
- ▶ **3%** Non-binary
- ▶ **7%** Did not say
- ▶ **36%** LGBTQIA+
- ▶ **2%** Aboriginal and/or Torres Strait Islander
- ▶ **5%** Culturally and/or linguistically diverse

Participants and families shared experiences across the whole patient journey – from searching for healthcare information online and assessing whether it could be trusted, through to accessing services, attending appointments, communicating with professionals, making decisions, and engaging in follow-up care.

For many, this was the first time they felt **genuinely heard, validated, and empowered** to contribute their lived experience toward improving healthcare.

This project was supported by funding from the Australian Government through Brisbane South PHN.

4 key themes emerged:

1 Listen, validate, & believed

Being heard matters. Participants highlighted the importance of being heard and taken seriously by healthcare professionals. Many described having symptoms dismissed as anxiety and needing to repeatedly explain their needs.

94% Not taken seriously by health professionals.

85% Felt health professionals did not understand their neurodivergence.

*"I delay seeking healthcare because of **how I am treated.**"*

Autistic participant

2 Create welcoming & inclusive environments

The environment matters. Healthcare settings can be overwhelming to navigate. Participants highlighted the need for sensory-aware, predictable, and safe spaces that support different preferences and make accessing care easier.

3 Make information clear, accessible, & relevant

Accessible information matters. Participants reported finding and understanding healthcare information was a significant barrier, valuing personalised, practical, and easy to navigate information for their circumstance/s.

84% Reported confusing & conflicting information as a healthcare barrier.

65% Experienced difficulty navigating websites to access healthcare information.

91% Find specific examples easier to understand and apply healthcare advice.

4 Take a holistic, person-centred approach

Seeing the whole person matters. Participants highlighted the need for healthcare professionals to look beyond their diagnosis and understand their personal circumstances and experience. Additionally, they found navigating multiple services and repeatedly explaining their needs was a common challenge.

"Humanise the interaction."

Autistic mother

Better access. Better experiences. Better for everyone.

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Additional experiences of autistic parents

- **Burnout and advocacy fatigue** (constantly explaining autism, neurodivergence, and their child's needs to different professionals).
- **Hypervigilance** (feeling they need to remain constantly alert and ready to advocate/intervene).
- **Economic and financial impacts** (including taking time away from work to manage appointments and care responsibilities).
- **Stress and guilt** (particularly when appointments were cancelled or difficult to attend due to healthcare environments that did not support or understand their child's anxiety or needs).

*"Wouldn't it be great if there was a care coordinator, **so it didn't all fall on mum?**"*

Autistic mother

From lived experience to **action**: A foundation for healthcare inclusion:

L Listen to lived experience and create opportunity to influence service design.

I Include accessibility and inclusion planning from the beginning.

S Support information that works for autistic and neurodivergent people.

T Think beyond diagnosis; see the whole person and consider the individual.

E Embed co-design in decision-making to ensure changes reflect experience.

N Notice individual needs and strengths and avoid a one-size-fits-all approach.

By embedding lived experience into healthcare design and decision-making, we can move towards systems where people feel welcomed, understood, listened to, and empowered to participate in their own healthcare: **Your Health, Your Way**.

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