VALiD

Driving Change

A Call to Action for Intellectual Disability Health

Victoria

2026

Background to this paper

Introduction

Who are we?

VALID is the Victorian peak advocacy organization for adults with intellectual disability.

Since 1989, we have helped empower people with intellectual disability and their families to exercise their rights.

What is this paper?

This is a list of recommendations made by our community for the Victorian Government, on how we can improve the health of people with intellectual disability.

To develop this paper, we consulted with people with intellectual disability, parents, carers, and professionals (see 'Talking to our community' for more details). We received funding to do this work from The National Centre of Excellence in Intellectual Disability Health.

What is the problem?

People with intellectual disability are **dying preventable deaths at twice the rate** of the general population. In other words, up to **2 in 5 deaths** of people with intellectual disability are potentially avoidable.

People with intellectual disability make up roughly 1.8-2% of Australia's population – this means that **the number of Victorians with intellectual disability may exceed 120,000 people**. When discussing their health, it is important to remember that **this is not a small group**.

Healthcare is a human right. Under the *Convention on the Rights of Persons with Disabilities* (CRPD) – to which Australia is a party – people with intellectual disability have the right to 'the enjoyment of the highest attainable standard of health without discrimination on the basis of disability'.

Despite this, people with intellectual disability are **routinely mistreated and discriminated against** within the Victorian healthcare system. They face substantial barriers to accessing and utilizing health services, and the care they receive is often disjointed, inappropriate, or insufficient. Beyond the impact this has on health, interacting with the healthcare system itself has led to experiences of distress and trauma for many, as well as re-traumatization for those with prior negative experiences.

As a result of this discrimination – what the Royal Commission called "systemic neglect" – the health of people with intellectual disability is impacted at every step of the healthcare journey.

People with intellectual disability:

- access preventative healthcare at far lower rates.
- have much higher rates of physical and mental health conditions.
- experience twice the rate of emergency department and hospital admissions.
- endure significantly higher rates of preventable complications and death.

What do we want the Victorian Government to do?

The following recommendations are a renewed call to action for us all.

They do not ask the Victorian Government to start from scratch, nor do they ignore the work already being undertaken to improve the healthcare system's capacity to respond to the needs of people with intellectual disability.

These recommendations:

- **Reiterate the concerns and priorities outlined** in the *National Roadmap for Improving the Health of People with Intellectual Disability* (2021), the *Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability: Final Report* (2023), the *Inclusive Victoria: State Disability Plan* (2022–2026), and other state and federal frameworks, roadmaps, programs, and research reports.
- **Point to existing models and exemplars of best practice** taking place within Primary Health Networks, hospitals and consultation services, general practice clinics, and more.

Victoria is undergoing a significant period of transition, including the National Health Reform Agreement, changes to the National Disability Insurance Scheme, the emerging role of states in funding and implementing Foundational Supports, and the upcoming state elections.

It is vital that – as services and systems are being reshuffled and re-oriented to support these new realities – the health needs of people with intellectual disability are considered at every step of the process. **This is a rare opportunity to reshape the healthcare system to support and uplift the health of this neglected population** and will pre-empt any need for the Victorian Government to modify or retrofit an established system down the road.

There is a **long-established economic case** for investing in preventative healthcare; however, we also want to reiterate the **human cost** of a healthcare system that does not anticipate and accommodate the needs of people with intellectual disability. The following story was shared with us by a health professional working in the disability sector:

> *"We had a client who was saying that they were in pain for a long time…The approach the GP took was just to medicate…The GP disregarded all of [the client's support workers'] comments…[The client] didn't want to be transferred from bed to a wheelchair. No one could work out why. No one investigated why. And the reason was just because they had a massive tumor that was sort of protruding at the end of their colon and every time they sat, [it put] pressure on that area and it was very, very painful. By the time this was detected, the person is essentially palliative, it was so advanced that there really wasn't any recourse for this person."*

The inequity experienced by people with intellectual disability is preventable and has very real consequences.

Talking to our community

To create a snapshot of what our community considers most important right now, we talked to 32 people: 25 people with intellectual disability, 4 parents and carers, and 3 health professionals.

Our conversations captured a range of perspectives and experiences, including metropolitan versus regional, health system versus disability service, and community versus supported accommodation.

Recommendations

Our community recommends that the Victorian Government take the following actions to improve the health of people with intellectual disability:

1. Introduce mandatory disability training for hospital workers

Nurses, doctors, and other staff need regular and ongoing training on how to:

- listen and communicate in accessible and respectful ways.
- identify support needs and act on them (including the use of necessary equipment).
- follow existing care plans.

This training should be co-designed and should cover both attitudes and skills.

Our participants shared many stories of hospital staff who – through lack of adequate training or discriminatory attitudes – failed to provide inclusive and high-quality care.

> *"People in the hospital probably think they're patient and tolerant, but I think when push comes to shove, I've seen it. They're not. They're not."* – Parent

In a busy and overwhelming hospital environment, communication can be especially difficult. Hospital staff are rarely trained on clear, accessible communication for people with intellectual disability, and may hold biases and assumptions about the importance of this communication.

> *"I said to the doctor, "what are we going to do?" He goes, "I don't know how to explain it". [Another doctor] explained to me, and the [first] guy said to him, "Thank you. I did not know how to say all that". So, the doctors don't know how to explain things. Or don't want to, one or the other."* – Person with intellectual disability

We heard that people with intellectual disability are often overlooked or ignored by hospital staff, who assume that there is no way, or else no benefit, to communicating with individuals, explaining procedures, or gaining informed consent.

> *"I just get so annoyed...they think you're a drain... They should have more training on people like me, people who don't have a voice. Normal people, [staff will] go in and talk to them and all that...They don't give people like me the time of the day."* – Person with intellectual disability

We heard many examples of health professionals who would talk to an individual's support person but would not address the person with intellectual disability directly.

Participants also shared stories of hospital staff who could not use assistive equipment or did not understand its importance (e.g., hospital staff separating a patient from their communication board, leaving them unable to express their needs or concerns with staff).

> *"Sometimes...[patients] try and provide some advice and guidance to the hospital staff around how to use equipment for them because of their particular needs and they're ignored. And then that leads to, you know, either pain, discomfort, injury."* – Health professional

Most participants suggested that hospital staff should receive more training on how to work with people with disability, and on how to tailor their approach to the needs of the individual, rather than implementing a one-size-fits-all approach to inclusion. This included training on attitudes and mindset (e.g., avoiding assumptions, understanding disability rights) and on verbal and written communication skills.

> *"I think what would make it easier for me...is having more hospitals and more doctors doing Easy Read documents for us instead of just like seeing us and then, "OK, you've got this and that and everything", and then you have to try and figure out what it is and all that."* – Person with intellectual disability

Several participants also mentioned how important it was for staff to be trained on mental health indictors for people with intellectual disability, to avoid the over-diagnosis of mental illness – and so their mistreatment – based on behaviours that were actually rooted in discomfort or communication barriers.

Example: West Gippsland Healthcare Group	We heard two examples of "in-house" practices that could be adopted by hospitals across Victoria: • A committee responsible for assessing the accessibility of patient-facing written materials. • A team that provides training for emergency staff, including at orientation sessions.

For more details on how this can be done, see:

- National Roadmap: B1, C
- DRC: Recommendations 6.25, 6.28, 6.29, 6.32
- Inclusive Victoria: Priorities 2.1.7, 2.1.10

Another related suggestion was to develop quiet spaces: These would be situated near or within emergency departments to reduce overwhelm and make the environment more accessible.

2. Develop an outpatient model for hospitals

GPs are often not well-placed to coordinate care for people with intellectual disability. Developing an outpatient care model will:

- allow better continuity of care (e.g., to monitor the impact of medications).
- serve as a referral and transition pathway for GPs and paediatric services.
- provide care that requires specialised skills and knowledge (e.g., providing sedation if a patient needs it to have a blood test or scan).
- support effective and accessible referral to other services if needed.

Being able to receive check-ups and take care of their health was considered important for many of our participants; however, they also described feeling rushed by 15-minute GP appointments and not being able to fully express their concerns.

> *"Often it's so rushed in within a consult that people leave the consult and have no idea what the GP said, forget half of it, are too embarrassed to ask them to repeat. And it becomes a very sort of fractured process that doesn't add any value."* – Health professional

Several participants felt that GPs did not have sufficient skills and knowledge to provide appropriate care for people with intellectual disability.

> *"[GP] consultations, they're very generic. They're quite limited [to] addressing whatever the issue is [rather than on prevention]. Like you need a prescription, they'll give that to you. You need a blood test, they'll send you off with that...maybe it's just that time constraint...There are stereotypes that probably health professionals have in relation to people with an intellectual disability and very few GPs probably do a bit of extra training."* – Carer

In particular, our health professional participants reflected that there was a gap in health service provision for people with intellectual disability who required more extensive support than a GP could provide (e.g., sedation support).

> *"So things like blood tests, immunizations, you know, physical health checks, those sorts of things that [are] sort of entry level preventative health care, they should just be able to be accessed by people in whichever way they need to be able to access it, like the least restrictive method, but whatever works for them, because you could say to someone with a disability, "you can just go to the GP". Well, they can't."* – Health professional

These professionals recounted stories of patients who had been disengaged from healthcare for over a decade, or who otherwise were not receiving preventative healthcare and were only being diagnosed with a health condition once it was advanced, or during an emergency visit, rather than being diagnosed and treated early.

Due to the nature of their role, GPs were not always thought to be well-positioned to coordinate and oversee the care of people with intellectual disability.

> *"A lot of the GPs will just be like, "go to [the emergency department]". So then that's the worst possible place to put someone with escalated behaviours is in ED because you've now got a really bright, noisy environment where they have to wait for 8 hours and then they end up being shackled to a bed and sedated to be able to take a blood test."* – Health professional

This also makes transition out of the paediatric healthcare space challenging.

> *"The paediatric space is so lovely...but then they transition into what? Nothing. Back to the GP is the plan. And so then...what we do is if they [need] a neurologist...we then refer them into the epilepsy clinic. They might have a respiratory need. So we refer them into the respiratory clinic. And then the GP is to manage the rest. So, but then the respiratory clinic and the neurology clinic don't speak to each other...and the GP is supposed to hold all this information, but they actually have held none of it."* – Health professional

Having a specialised outpatient role would provide GPs and paediatric services with a referral pathway, to make sure that there is a continuity of care for their patients and that they can continue to access healthcare regularly regardless of their individual health and support needs.

Example: Centre for Development and Disability Health (CDDH)	This is a secondary consultation service within Monash Health that supports medical, disability sector, and allied health professionals to provide healthcare to patients with intellectual disability. They provide assessments and management strategies for complex presentations. This service could be replicated or adapted across different health settings in Victoria.

For more details on how this can be done, see:

- National Roadmap: B1
- DRC: Recommendations 6.29, 6.32, 6.33
- Inclusive Victoria: Priority 2.1.4

Another related suggestion was to create a GP specialisation pathway: We need GPs with knowledge of intellectual disability health. GPs should be able to upskill and specialise in disability health just as they can with other health topics like skin or mental health.

3. Expand the Disability Liaison Officer (DLO) workforce

Every barrier delays access to care. With more DLOs on-call, people with intellectual disability (and their supports) would:

- not need the emergency department as often.
- get support before and during their hospital stay, and for post-hospital follow-up.
- have someone to advocate alongside them for their needs.
- have someone to bridge the gap between disability services and healthcare.

We heard many stories of people with intellectual disability struggling to access healthcare and experiencing discrimination and neglect within the system.

> *"[When people are] a little tiny cog in the big machine of healthcare, I think that they get lost and they become vulnerable."* – Health professional

When individuals are not prepared for what they will experience during a hospital admission, and hospitals are not prepared to meet their access needs and support their entry into the system, then patients cannot access care or do not receive the care they need. This preparation should start as soon as possible and should involve communication between the health service, the person, and their supports (including their service provider if they live in supported accommodation and have complex handover requirements).

> *"What everyone needs to remember is, we're working as a team [to prepare for a procedure] and that starts at home, but also in the doctor's rooms or in the hospitals. It's teamwork."* – Parent

In practice, this coordinated support is often inadequate or not provided, and many participants felt that there was a gap that needed to be bridged.

Once within the system, participants shared that they were often neglected and did not receive basic care, let alone explanations about their condition and treatment options. Hospital staff were frequently unaware of their access needs, which led to poor care and avoidable health complications (e.g., pressure sores).

> *"I don't get a shower, I don't get on the [toilet]... I've actually heard a nurse say that it's too time-consuming and she left my bedroom."* – Person with intellectual disability

Several participants expressed the need for an advocate or companion who could support them during their hospital stay, and how precarious their situation could become when they did not have the resources to bridge this gap themselves (e.g., no funding for support workers, no family).

> *"When you get sick, when you go to hospital, they just put you in a room and forget about you."* – Person with intellectual disability

However, when these support people were present, there was also a risk that hospital staff would defer responsibility for care and treatment tasks back onto these external supports.

> *“People expect, “oh, mum's there, she's doing it”, so nobody comes and helps."* – Parent

Several participants also expressed concern for an individual’s transition out of hospital in a safe and timely manner, particularly for people with intellectual disability who lived in supported accommodation.

> *“[I know these two men in a group home, and] when they come home, they come home to a rotating staff. There's nobody consistent [to oversee their care].”* – Parent

People with intellectual disability need access to support as they navigate the health system. We suggest that the existing DLO role be maintained and expanded, for example with at least one fulltime equivalent in every hospital or health network.

Further training and community awareness-raising is also needed to support these professionals in performing their role.

For more details on how this can be done, see:

- National Roadmap: A, B4
- DRC: Recommendations 6.32, 6.34
- Inclusive Victoria: Priorities 2.1.1, 2.1.4, 2.1.8

Another related suggestion was to develop a peer support network: A volunteer peer support program – drawing inspiration, for example, from Victoria’s mental health peer support workforce – could enable people with lived experience to act as advocates and companions for individuals and their supports as they navigate the health system.

Further advice from our community

Our community provided many insights that the Victorian Government – while not directly responsible for – could influence through its health and disability policies and strategies.

Training for General Practitioners

Our participants shared that there are many factors that influence how they choose their GP (e.g., skills and attitudes, gender, a shared cultural or linguistic background, limited options in regional areas). For this reason, we need every GP in Victoria to be ready and able to treat someone with intellectual disability.

We found that existing university curricula for health professionals do not provide adequate training on disability. Disability training and professional development should not be one-off or tokenistic and should include:

- attitudes (e.g., human rights and the social model of disability);
- skills (e.g., using specific health tools, making reasonable adjustments, verbal and written communication for patients *and* their supports, including scripts and referrals in Easy Read); and
- person-centred approaches (e.g., communicating with and gaining meaningful consent from the patient, not just their supports).

Training was also suggested for allied health professionals and helpline workers (e.g., Lifeline, Nurse-On-Call) on how to provide individualised and inclusive care.

Example: Western Victoria Primary Health Network (WVPHN)	The Western Victoria PHN was chosen by the Federal Government to take part in their Primary Care Enhancement Program. Part of this program involved developing training materials and resources for GPs and other health professionals on how to meet the needs of people with intellectual disability. The Victorian Government can encourage other PHNs to follow this example and adopt GP training strategies for their own networks.

For more details on how this can be done, see:

- National Roadmap: B2, C, D
- DRC: Recommendations 6.25, 6.28, 6.29
- Inclusive Victoria: Priorities 2.1.7, 2.1.9, 2.1.10, 2.2.3

Medicare

Many of our participants made practical suggestions that could improve their health, but which required changes to Medicare:

- **Fund longer GP appointments** – People with intellectual disability often need more time to communicate their health needs and to undergo annual health checks using the Comprehensive Health Assessment Program (CHAP) tool. We suggest a change to Medicare that incentivises GPs to offer these longer appointments and make them affordable to our community.
- **Increase allied health allowance** – Access to allied health is crucial to staying as healthy as possible and preventing worsening health. The 5 subsidised sessions per year provided by a GP Chronic Condition Management Plan are not enough for people with intellectual disability, who often need ongoing care and multiple services. Access to psychology services was highlighted as a particular priority.

For more details on how this can be done, see:

- National Roadmap: B2

Supporting the support people

People with intellectual disability often require support to navigate the healthcare system, whether this be from a family member, carer, or support worker.

Many of our participants highlighted how important it was to have their support person attend appointments with them to make sure they were understood and to explain the doctor's medical jargon.

These support people take on advocacy and administrative roles but do not always have good health literacy themselves. Our participants suggested that:

- **For family and carers** – Health services should run workshops to increase carer health and disability literacy; A relevant body should develop a one-stop-shop hub of resources and disability service guidance (including resources in community languages).
- **For support workers** – Disability service providers and other bodies should provide training on advocacy and health literacy.

For more details on how this can be done, see:

- National Roadmap: A
- DRC: Recommendations 6.25, 6.28, 6.29
- Inclusive Victoria: Priorities 2.1.7, 2.1.9, 2.1.10, 2.2.3

Availability of services

Several participants living in regional and remote areas expressed concern that people with intellectual disability face additional barriers due to the low density of health and specialist services in their area. Individuals are often required to travel long distances to access care, are placed on waitlists, and otherwise cannot not access timely and high-quality healthcare.

This is a well-known phenomenon, and it is important for the Victorian Government to continue their work in augmenting regional and rural healthcare provision through workforce incentivisation and alternative care models, such as telehealth and home visiting services.

For more details on how this can be done, see:

- National Roadmap: B3
- DRC: Recommendation 6.32

NDIS and emerging gaps

Access to the NDIS is crucial to support an individual's access to healthcare.

We heard that:

- Support hours are essential so people can go to appointments, understand doctors' instructions, and do activities that will help their health (e.g., take medication, learn about healthy food choices and cooking).
- When there is not enough support – when hours are too low or cut, or people are not given access the NDIS – it becomes difficult or impossible to navigate the health system. This means that health issues go untreated. This is especially true for new migrants who do not always get a fair chance to access the NDIS.

Reducing people's NDIS plans or removing them from the scheme will increase the pressure placed on other systems; namely the hospital system, which is already unequipped to provide adequate care to its existing patients with intellectual disability.

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