



**PEOPLE WITH DISABILITY
AUSTRALIA**

**A voice
of our
own**

National Safety and Quality Health Service Standards: third edition

Submission to the Australian Commission on Safety and
Quality in Healthcare

SEPTEMBER
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Copyright information

National Safety and Quality Health Service Standards: third edition – Submission to the Australian Commission on Safety and Quality in Healthcare

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About PWDA

People with Disability Australia (PWDA) is a national disability rights and advocacy organisation made up of, and led by, people with disability.

We have a vision of a socially just, accessible and inclusive community in which the contribution, potential and diversity of people with disability are not only recognised and respected but also celebrated.

PWDA was established in 1981, during the International Year of Disabled Persons.

We are a peak, non-profit, non-government organisation that represents the interests of people with all kinds of disability.

We also represent people with disability at the United Nations, particularly in relation to the United Nations Convention on the Rights of Persons with Disabilities (CRPD).

Our work is grounded in a human rights framework that recognises the CRPD and related mechanisms as fundamental tools for advancing the rights of people with disability.

PWDA is a member of Disabled People's Organisations Australia (DPO Australia), along with the First People's Disability Network, National Ethnic Disability Alliance, and Women with Disabilities Australia.

DPOs collectively form a disability rights movement that places people with disability at the centre of decision-making in all aspects of our lives.

The work of PWDA embraces the 'Nothing About Us, Without Us' motto of the international disability community and Disabled Peoples' International, the international organisation representing national organisations of people with disability in over 130 countries.

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Introduction

PWDA welcomes the opportunity to provide a submission to the [National Safety and Quality Health Service \(NSQHS\) Standards](#) (third edition).

PWDA is Australia's peak cross-disability Disability Representative Organisation. Nationally 5.5 million Australians have a disability, around 21.4% of the population.ⁱ

When compared with people without disability, people with disability continue to experience discrimination and poorer life outcomes across all life domains.ⁱⁱ It is estimated that 22% of people aged over 15 with disability in Australia have experienced some form of discrimination compared with 15% of those without disability.ⁱⁱⁱ Disability discrimination is the largest ground of complaint to Anti-Discrimination NSW (ADNSW)^{iv} and the Australian Human Rights Commission (AHRC).^v Discrimination against people with disability appears deeply entrenched across systems.

Governments have an obligation to respect, protect and fulfil human rights.^{vi} Disability Rights are Human Rights.

The overarching theme of this submission is that greater consideration, understanding and resourcing of disability healthcare is needed to achieve quality, safe standards.

The third edition of the NSQHS needs to ensure that health system resourcing, health staff training, health service access and health facility accessibility are inclusive, equitable and support the rights and needs of people with disability to enjoy quality healthcare on an equitable basis with others.

Submission structure

The Australian Commission on Safety and Quality in Healthcare has asked for written feedback to address [7 questions](#). This response to the request is organised into two parts and a conclusion:

- Summary of Recommendations
- Part 1 Examines the research we conducted with people with disability to understand their concerns and recommendations.
- Part 2 Addresses each of the seven questions we were asked to address, informed by our research from Part 1
- Part 3 Conclusion

Executive Summary

This submission and its recommendations have been underpinned by survey research that PWDA conducted with people with disability. Respondents shared their lived experiences of skilled, kind, accessible, holistic healthcare where they felt listened to, respected, and their adjustment needs were met.

They also shared their experience of the many barriers to good healthcare, whether these were financial, a lack of knowledge on the part of healthcare staff about disability, poor communication, physical inaccessibility, a lack of communication or other adjustments, or poor integration with other health services or the care and support services the person needed.

We have provided recommendations to address the issues raised by respondents, as well as the questions asked of those preparing submissions. This is important because the second edition of the National Safety and Quality Healthcare Service (NSQHS) Standards did not address the needs or concerns of people with disability in a detailed or meaningful way.

People with disability face great disadvantage in health outcomes, compared with non-disabled people. PWDA wants to ensure that the NSQHS third edition includes requirements to change so that people with disability receive accessible, inclusive, equitable health care that meets their needs.

Summary of Recommendations

Part 1 Research with people with disability

Recommendation 1 Require all hospitals to enable patients or their carers to report, and if necessary, escalate, critical safety concerns.

Recommendation 2 Require all hospitals to appoint Disability Liaison Officers and empower them to plan for and authorize the adjustments people need.

Recommendation 3 Require all hospitals to gather patient feedback, outcomes, identify and act on issues to improve healthcare quality and safety for people with disability, and report on this annually.

Recommendation 4 Require all hospitals to appoint a co-design group that includes people with lived experience of different disabilities, to examine all aspects of patient care and recommend reforms.

Recommendation 5 Require all health staff to undergo disability awareness training appropriate to their roles, facilitated by a person with lived experience of disability

Recommendation 6 Require all hospitals to provide accessible communication formats for all patients.

Recommendation 7 In addition to requiring all General Practitioners to complete training recommended above, fund the development of a Continuing Professional Development (CPD) resource library and work with Disability Representative Organisations and people with disability to develop training resources on different health and accessibility topics.

Recommendation 8 Undertake mapping of places where healthcare is inaccessible or absent, require annual reporting against how these inequities are being addressed.

Recommendation 9 Work with health professionals and their associations to expand access to bulk billing, especially in rural, regional and lower income areas.

Recommendation 10 In addition to expanding bulk billing, similar to general practice, require the publication of waitlists and gap fees wherever these exist.

Recommendation 11 Require mental healthcare facilities to form an advisory board of people with lived experience of different disabilities and service use, to examine all aspects of patient care and recommend reforms.

Recommendation 12 Require mental health professionals to undertake the training at recommendation 5, and also training related to intersectional and disability specific issues with mental healthcare.

Part 2 Addressing submission questions

Recommendation 13 Require that a capacity audit be undertaken, and map created of under-served areas in terms of general practice, specialist care and hospital services

Recommendation 14 Require annual reporting of the actions taken to improve health services in areas identified under the capacity audit

Recommendation 15 Co-design disability awareness training for health professionals with disability and require rollout, the implementation of performance measures and reporting

Recommendation 16 Develop and implement communication tools and processes that promote service integration.

Recommendation 17 Co-design care with patients and create accountability for prompt and effective care

Recommendation 18 Follow nutrition research to provide high energy meals, appropriate diets and assistance to eat and drink for patients who need it

Recommendation 19 Establish an anonymous complaints line and web portal to avoid repercussions and enable photographs to be shared

Recommendation 20 Require all healthcare facilities and providers to meet quality standards

Recommendation 21 Avoid mixed wards and ensure the safety of patients especially people with disability, female and gender diverse people

Part 1- Research with people with disability

People with disability “experience large mortality inequalities” compared to non-disabled people,^{vii} with adults with intellectual disability facing the greatest levels of premature death.^{viii}

In order to understand the obstacles and barriers people with disability face when trying to access the healthcare that could prevent this, PWDA conducted research using a survey. We also provided the option to call our team to access assistance to complete the survey, for anyone who found the online survey inaccessible, and participants were able to skip questions they did not want to answer, or to stop at any time. We explained that answers would be anonymised to protect privacy.

We called for people with disability, or people who cared for or helped a person with disability to complete the survey, and we asked survey respondents to tell us about themselves, and their experience of:

- hospital care,
- general practice care,
- other healthcare- such as specialists, allied healthcare, health screening and diagnostic services,
- mental healthcare

Demographic and yes/no answers have been described numerically. We asked open-ended questions so that people could describe their experiences of care, what worked well, what did not, and how they think things should change. The responses were analyzed, grouped thematically, the numbers recorded, with some answers touching on more than one theme.

About survey participants

269 people completed the survey, and 89% identified that they have a disability. Across participants there was a representative demographic spread of genders, ethnicity, adults, rural and regional participants and older persons. Younger people under 25 were not well represented, but 39% of people completing the survey identified that they care for a person with disability or help them to access healthcare, and the answers clearly reflect that in cases these were the children of that person. The full survey report can be found at [Appendix A](#).

Hospital Care

Of the survey participants 71.6% had visited hospital within the last 12 months, 90% within the last 2 years, and over one third (36.68%) live in rural or regional areas.

We asked people to reflect on their hospital experience and tell us what went well.

Over half of participants gave positive examples. Good treatment outcomes, caring and knowledgeable doctors, the kindness, care, and good communication by hospital staff, were key themes. Whilst noted less often, specific disability accommodations were mentioned, as well as positive experiences with day surgery, transfers and paramedics.

Unfortunately, another key theme was respondents who identified that 'not much' or nothing went well, with a range of issues identified including:

- Long emergency department wait times.
- Poor staff understanding of disability needs.
- Instances of dismissal or lack of meaningful care.
- Accessibility challenges (physical environment, communication barriers).
- Issues with hospital transfer between facilities.

- Regional hospital delays, especially around surgery.
- Staff too overworked or stressed to provide care.
- Reliance on private care for better outcomes.

We then asked people whether they had any concerns about the care they received at the hospital.

Almost a quarter of people said they had no concerns or the care was good, but many specific issues were identified including:

- Long wait times – both in emergency and for call bells to be answered.
- Poor communication – between departments, with patients and in accessible formats.
- Accessibility and accommodations - denial of personal mobility aids, staff untrained in neurodiversity and disability support, discharge without handover or planning for disability support staff, inadequate adjustments for chronic illness and chemical sensitivities.
- Essential care and safety - Lack of help with feeding, drinking, toileting, personal hygiene or wound care, no suitable food for patients with dietary restrictions, medication error, loss or delayed dosage, inadequate pain management, safety issues from other patients on mixed wards.
- Infection control concerns – Lack of masks or protective measures for people with chronic illness.

We then asked people what they thought would make hospital care better. In addition to addressing the issues already raised, respondents called for:

- Staff training and awareness - Training in disability support, neurodiversity, sensory needs, and communication, and for staff to “listen, care, and understand” disability experiences.
- Staffing and resources - More nurses and trained staff to reduce strain, improve patient outcomes and reduce waiting times, better access to assistive equipment such as wheelchairs, mobility and transfer aids.
- Communication – To make communication more accessible by facing patients who lip-read when speaking, providing forms in accessible formats for patients who are blind, adjustments for people who use assistive communication devices or need a translator or other supporter to communicate; as well as improving the clarity and consistency of communication, and engaging more respectfully with patients.
- Accessibility and environment – Providing sensory friendly waiting areas, improved wayfinding, access to personal aids, carers and assistive devices if needed, and mask and fragrance free policies.
- Personalised care - Person-centered care, recognition of chronic illness and disability needs in treatment planning, care and discharge plans that integrate with NDIS and other supports.

Taken together this feedback shows that there are examples of good practice, care, kindness and hospital staff who make adjustments to ensure services are provided in an inclusive, accessible way. The safety issues raised related to abuse by other patients, neglect by staff, medication mismanagement, overworked staff, premature discharge and communication issues undermine the very premise of hospital care. It is also difficult to see how health outcomes can be achieved when nutritional, continence and pain relief needs are not met.

Respondent feedback clearly highlights the need for greater disability awareness training, better communication, the need to increase hospital resources and to better integrate NDIS or other supports into healthcare. Worryingly issues related to personal safety arose

related to inappropriate medication use, failure to account for dietary or nutrition needs that posed a life-threatening risk, and mixed wards where a threat was posed by other patients.

Recommendations

Recommendation 1 Require all hospitals to enable patients or their carers to report, and if necessary escalate, critical safety concerns

Recommendation 2 Require all hospitals to appoint Disability Liaison Officers and empower them to plan for and authorize the adjustments people need

Recommendation 3 Require all hospitals to gather patient feedback, outcomes, identify and act on issues to improve healthcare quality and safety for people with disability, and report on this annually

Recommendation 4 Require all hospitals to appoint a co-design group that includes people with lived experience of different disabilities, to examine all aspects of patient care and recommend reforms

Recommendation 5 Require all health staff to undergo disability awareness training appropriate to their roles, facilitated by a person with lived experience of disability

Recommendation 6 Require all hospitals to provide accessible communication formats for all patients

General Practice Care

PWDA acknowledges that general practitioners, specialists and allied healthcare providers run their own private businesses, independent of many government controls. However, government funding in the form of Medicare, the impact that these forms of healthcare (or a lack of them) has on the lives of patients, and the pressures on the healthcare system, speaks to the need for better planning and standards under the NSQHS third edition.

We asked people to reflect on the care they received from General Practitioners. Ninety per cent of respondents identified that they saw the same general practitioner at each visit.

We asked what makes it hard to visit the doctor, and the key themes that arose were:

- **Appointment access** - Difficulty getting appointments when needed, particularly in urgent or acute situations.
- **Cost and bulk billing** - Many cannot afford GP visits unless bulk billed, and availability of bulk billing is poor and shrinking.
- **Transport and mobility** - Long travel distances, no accessible public transport, unreliable wheelchair accessible taxis, dependence on others for transport.
- **Physical Inaccessibility** - inaccessible clinic spaces (e.g., narrow doors) create obstacles.
- **Continuity of care** - Not all patients have a regular GP available.
- **COVID safety** - Some raised concerns about a lack of masks and infection control in clinics.
- **Homebound patients** - People who are bedridden or housebound described a lack of suitable home visits or coordinated care.

We then asked survey participants what works well when you visit your doctor?

A range of positive experiences were shared including:

- **Doctor–patient relationship** - Experienced, caring, and understanding doctors, friendly and supportive clinic staff.
- **Continuity and trust** - Seeing the same GP consistently, doctors who know patient history and follow through with treatment.
- **Telehealth**- Telehealth and home visit options were appreciated, especially for people with limited mobility, chronic illness, or who are homebound.

- **Accessibility and accommodation** – it was appreciated when practices accommodated adjustments needed for specific disabilities.
- **Holistic support** – GPs who understand the complexity of conditions and provide more than “tick-box” or prescription-only care.

We then asked what would make the visit to the GP better, and the additional key theme related to the training of doctors and medical staff to improve their understanding of disability, cultural needs, functional medicine and chronic illness.

Recommendations

Recommendation 7 In addition to requiring all General Practitioners to complete training recommended above, fund the development of a Continuing Professional Development (CPD) resource library and work with Disability Representative Organisations and people with disability to develop training resources on different health and accessibility topics.

Recommendation 8 Undertake mapping of places where healthcare is inaccessible or absent, require annual reporting against how these inequities are being addressed.

Recommendation 9 Work with health professionals and their associations to expand bulk billing.

Other Healthcare

We asked people about their experiences with other types of healthcare including specialists, allied health, and diagnostic services. Some participants praised flexibility and telehealth access, and supportive attitudes or specific accommodations made. Others raised concerns about long waitlists, lack of access to care in rural and regional areas, lack of disability accommodations, and unsafe environments.

When asked what could make these types of healthcare better, similar themes arose to GP care, but affordability was emphasised due to the much higher costs of specialist and allied healthcare and the low or non-existent Medicare rebate. The complete lack of access in rural and regional areas, and long waitlists for specialists that were not disclosed were highlighted as barriers in need of addressing.

Recommendations

Recommendation 10 In addition to applying similar recommendations to general practice, require the publication of waitlists and gap fees wherever these exist.

Mental Healthcare

Sixty-five per cent of survey respondents reported that they had seen someone for mental health support, with nearly half (45%) reporting positive experiences of accessible, respectful communication and attitudes, genuine listening and trauma-informed care. 16% had negative or harmful experiences and the need for disability awareness training arose again as a theme.

When asked what could make mental healthcare better, responses included:

- **Treatment approaches** - requests for services tailored to chronic illness and disability literacy.
- **Access and affordability** - Need for more affordable services and longer appointments, and greater access to telehealth for those unable to attend in person.
- **Workforce training and conduct** - Calls for better training of professionals to avoid stigma, harmful behaviour, or dismissiveness, and monitoring of inappropriate behaviour in mental health settings.

- **Peer support** - Clear demand for peer workers in all mental health services, recognising the value of lived experience.
- **Environment and safety** - Need for safer, more supportive clinical environments.

Recommendations

Recommendation 11 Require mental healthcare facilities to form an advisory board of people with lived experience of different disabilities and service use, to examine all aspects of patient care and recommend reforms

Recommendation 12 Require mental health professionals to undertake the training at recommendation 5, and also training related to intersectional and disability specific issues with mental healthcare

Part 2 Addressing submission questions

Australians with disability are recognised in the [National Preventative Health Strategy](#) as a priority population that experiences a disproportionate burden of disease that is unfair, related to social disadvantage, and avoidable.^{ix} Access to preventive health care such as:

- vaccination,
- screening tests (e.g. for breast, bowel, skin, cervical and prostate cancer),
- protective measures (such as sunscreen, seatbelts and STI prevention), or to
- health-promoting activities (such as regular exercise, eating a healthy diet),

can substantially reduce the risk of poor or life-shortening health issues for individuals and the burden of chronic disease on the health system.^x Addressing the inequitable burden of preventable disease for people with disability is best done through co-designing approaches with communities to improve accessibility and inclusion.^{xi}

From the survey work with people with disability, we can see that a range of access barriers to general practice, screening and healthcare facilities remains an obstacle to receiving this care.

The NSQHS [second edition](#) does not contemplate or address the need for preventive healthcare to be accessible, and the 3rd edition must do so. People with disability have historically had poor access to preventative healthcare, but if access barriers were removed and the 21.4% of people with disability were enabled to access in line with the Australian Medical Association recommendation, then \$1.19B worth of health savings could be achieved per year^{xii}.

As part of this [consultation](#) on the focus areas for the NSQHS Standards (third edition) we have been asked to address [7 questions](#), and this follows below.

Submission questions

1. What existing and emerging safety and quality risks should the Commission be considering in the third edition?

As identified in our research, healthcare accessibility remains a key obstacle for people with disability. The barriers include:

Physical accessibility – spaces that are inaccessible to mobility devices, remotely located from public transport or unreachable to those without private transport, or too far for rural and regional patients.

Economic – Expensive/ unaffordable care, lack of bulk billing, cost of travel (taxis/ long journey to city/ cost of carer to take someone to health appointments) too great on top of healthcare cost.

Insufficient care – Hospitals or GPs too busy to see people or to get an appointment when needed, too rushed to provide care including essential health and personal care in hospitals, total lack of health/ mental health service in some areas.

Communication – not listening, not in accessible formats, no translation, too rushed, dismissive of people with disability, not allowing communication supports such as care or NDIS supports in hospitals, failure of handover communication between hospital and care team or GP, failure to read or listen to instructions about essential medications or supports needed for a person's disability in hospital.

Discrimination or abuse – Neglectful, dismissive, discriminatory or abusive communication or behaviour.

The second edition did not mention ways to screen for, stop, or sanction, these types of dangerous behaviours. No provision was made for reporting that protects patients and their carers from reprisals.

It is clearly unsafe when patients are unable to get appropriate medication doses, pain relief, basic feeding, toileting and hygiene assistance in hospitals. Undoubtedly this contributes to longer hospital stays and poorer health outcomes.

The shortage of accessible and affordable healthcare services of all types poses a quality and safety risk for everyone, but especially for people with disability. Barriers to accessing GP, mental health, and planned care, then raises the risk that people will end up in hospital who would not otherwise have needed to be there. Not only do these barriers contribute to poorer health outcomes for that individual, but also to the overall stressors on the hospital system, in turn reducing availability for those in crisis.

Recommendations

Recommendation 13 Require that a capacity audit be undertaken and map under-served areas in terms of general practice, specialist care and hospital services

Recommendation 14 Require annual reporting of the actions taken to improve health services in areas identified under the capacity audit

Recommendation 15 Co-design disability awareness training for health professionals with disability and require rollout, the implementation of performance measures and reporting

2. How can the third edition have a greater impact on driving high performance?

As already recommended, there is a need to co-design processes and training with people with disability, and this work must include people with a wide range of different disabilities, experiences and intersections with social, cultural and health systems. It is critical then that processes for measuring performance be developed, in order to track and drive performance improvement.

The second edition makes statements about performance, but rarely are they phrased in a way where performance against them is measurable. This needs to change, and annual, transparent reporting then needs to be required to drive quality.

This reflects a fundamental shift, and doubtless will require significant investment. However reshaping healthcare to become equitable, inclusive and high quality is likely to save not only lives but costs, as earlier and preventive care can reduce the need for expensive hospital beds.^{xiii}

3. How can the third edition support integration of services, within and across health services?

The Communication for Safety Standard under the NSQHS [second edition](#) requires structured clinical handover processes, but it clearly is not happening consistently. People with disability repeatedly raised in the survey issues that relate to a lack of integration with and communication between different hospital departments, hospitals and general practice, different health professionals, the healthcare providers and NDIS or other care teams.

The third edition of the NSQHS needs to require that processes be put in place to ensure this is achieved, as setting standards has not been effective. The NSQHS [second edition](#) does not mention handover with NDIS or other care providers, but this needs to be required in the third edition.

With the evolution of digital systems such as [My Medicare](#), [My Health Record](#) since publication in 2021, there are more opportunities to record and manage health information in ways that could improve health communication and patient care.

Recommendations

Recommendation 16 Develop and implement communication tools and processes that promote service integration.

4. How can the third edition support a continuous learning approach and minimise a compliance mindset?

The complaints and issues raised in our survey results reflect a lack of compliance with many of the standards in the NSQHS [second edition](#), and positive feedback often reflects compliance. It would be counter-productive to abandon compliance requirements in the NSQHS third edition. The nature of healthcare and its requirement for continuing professional development already requires a continuous learning approach, however the nature of what is learnt and from whom needs to change.

Requiring disability awareness education for all healthcare workers, developed and delivered by people with disability could greatly improve health outcomes. Similarly, gathering performance feedback at staffing, faciality and outcome levels, and then developing and delivering training to address the issues identified, offers the best opportunity to support meaningful and continuous improvement in the safety and quality of healthcare.

5. What needs to change in the current format and structure of the standards for the third edition to be easier to understand and act on?

The second edition of the guidelines^{xiv} identifies diversity and high risk groups, but does not really address the needs of people with disability. It does not require that clinicians listen to people with disability or their families or act on concerns raised. It creates no accountability for the consequences of failing to listen or act. This must change in the third edition.

The third edition also needs to make it easier for patients and family members to report concerns and have them recorded, included in the assessment of risk, and acted on in the moment – not left till a post event complaint, by which time further injury or death may have resulted.

6. Are there areas of duplication or redundancies that could be removed from the current standards?

PWDA has not identified duplication or redundancies in the current standard for removal, but rather a need for additions and a re-shaping to improve the accessibility, inclusion and equity of healthcare.

7. Please provide any additional comments you think will assist the Commission with the development of the third edition of the NSQHS Standards.

People in hospitals and closed settings such as aged care, who are too sick or unable to advocate for themselves, have a high risk of neglect. This ranges from a lack of help with toileting and regular bathing when needed, and no help with feeding^{xv} for those who need it in order to eat. This contributes to: frailty, urinary tract and skin infection, weight loss and nutritional deterioration,^{xvi} worsening symptoms, delayed recovery and increased mortality.

Our survey work confirmed that this is part of the lived experiences of respondents, and it needs to be corrected urgently.

In order to free up urgent hospital beds, people with disability and elderly patients can also face being relocated to sub-standard facilities with little-to-no rehabilitation services, poor-quality care, no handover information, and little infection control. This can promote deterioration and undermines the prospect of recovery from illness.

Patients and family members can be too afraid to report sub-standard treatment, or share details of sub-standard facilities, lest they or their relative be punished for doing so.

Women in closed settings such as group homes, psychiatric hospitals experience high rates of sexual assault by men,^{xvii} and our survey identified safety concerns on the part of female patients related to mixed wards in hospitals and mental healthcare settings.

Recommendations

Recommendation 17 Co-design care with patients and create accountability for prompt and effective care

Recommendation 18 Follow nutrition research to provide high energy meals, appropriate diets and assistance to eat and drink for patients who need it

Recommendation 19 Establish an anonymous complaints line and web portal to avoid repercussions and enable photographs to be shared

Recommendation 20 Require all healthcare facilities and providers to meet quality standards

Recommendation 21 Avoid mixed wards and ensure the safety of patients especially people with disability, female and gender diverse people

Part 3 Conclusion

Australians with disability are recognised in the [National Preventative Health Strategy](#) as a priority population that experiences a disproportionate burden of disease that is unfair, related to social disadvantage, and avoidable.^{xviii} This inequity contributes significantly to the lower life expectancy of people with disability compared with their non-disabled peers.^{xix}

This presents an excellent opportunity to require reform under the NSQHS. Access to preventive health care such as:

- vaccination,
- screening tests (e.g. for breast, bowel, skin, cervical and prostate cancer),
- protective measures (such as sunscreen, seatbelts and STI prevention), or to
- health-promoting activities (such as regular exercise, eating a healthy diet),

can substantially reduce the risk of poor or life-shortening health issues for individuals and the burden of chronic disease on the health system.^{xx} Addressing the inequitable burden of preventable disease for people with disability is best done through co-designing approaches with communities to improve accessibility and inclusion.^{xxi}

From the survey work with people with disability, we can see that a range of access barriers to general practice, screening and healthcare facilities remains an obstacle to receiving this care.

The NSQHS [second edition](#) does not contemplate or address the need for preventive healthcare to be accessible, and the 3rd edition must do so. People with disability have historically had poor access to preventative healthcare, but if access barriers were removed and the 21.4% of people with disability were enabled to access in line with the Australian Medical Association recommendation, then \$1.19B worth of health savings could be achieved per year^{xxii}.

Incorporating the recommendations contained within this submission into the third edition of the NSQHS Standards will improve the accessibility, inclusion, equity and effectiveness of Australian healthcare.

Appendices

Appendix A – PWDA Survey: National Safety and Quality Health Service (NSQHS) Standards

Introduction

People with Disability Australia (PWDA) has a national membership of people with disability.

In August 2025, PWDA launched a national survey to inform our submission for the review of the National Safety and Quality Health Service (NSQHS) Standards.

The survey was conducted from 7 August 2025 to 7 September 2025, closing at 5:00 pm AEST. A total of 269 responses were received.

Among respondents, 89.61% (207) identified as a person with a disability, and 39.56% (89) identified that they care for someone with a disability, or help them to access healthcare.

The survey explored experiences with hospitals, GPs, specialist and allied health, and mental healthcare. Respondents also provided demographic data, caring roles, identity and location.

A total of 20 questions were asked, combining multiple-choice and open-text.

Summary of key findings

Overall, the survey shows people with disability face significant barriers across the health care system, with challenges around accessibility, affordability, staff training, communication and environments. While there are examples of positive and supportive care, negative experiences were more common, particularly in hospital and mental health care.

- 89.61% (207) of respondents identify as a person with disability.
- 71.64% had been to hospital in the past year, and nearly 90% within two years.
- 77% of respondents had accessed mental health services.
- 90.98% see the same doctor when they visit the GP
- Women and girls with disability made up most respondents (63.81%)
- 23.33% of respondents identify as LGBTQIA+ and 5.71%% as trans and/or gender diverse.
- 11.90% as CALD and 3.81%First Nations.
- 3.81% of people identify as a young person with disability (under 25 years)
- Most respondents (58.52%) live in major cities
- Over one-third (36.68%) live in rural or regional areas

Common themes across all health care areas include

1. **Accessibility** – Barriers to physical access (doors, waiting rooms, wayfinding), inaccessible communication (including verbal, forms and online), lack of home visits and no sensory friendly spaces when needed.

2. **Affordability** – Costs of GP (including lack of bulk billing availability), cost of specialists, and diagnostic care are major obstacles.
3. **Staff Training and Attitudes** – Disability awareness training, cultural competency, and trauma-informed practice.
4. **Under Resourcing of Healthcare** – Overworked, stressed or rushed health staff, and appointment or practitioner shortages was seen as one of the most pressing issues compromising the timeliness and quality of care.
5. **Communication and Respect** – Positive experiences often came down to being listened to, respected and health staff taking the time needed; negatives came from poor or inaccessible communication, and being rushed or dismissed.
6. **Telehealth and Flexibility** – Telehealth, home visits, flexible hours, and preparedness to adjust care to improve accessibility were widely praised and seen as critical improvements.
7. **Infection Control** – COVID and airborne illness safety remain key concerns for people with chronic conditions.
8. **Peer Support** – Demand for inclusion of lived experience workers in mental health services.

Question 1: When was the last time you visited a hospital

Answered 268. Skipped: 1

Answer Choices	TOTAL	QTY
The last 12 months	71.64%	192
Last 2 years	16.42%	44
More than 5 years ago	6.72%	18
More than 10 years ago	1.49%	4
I am unsure	2.24%	6
I prefer not to say	1.49%	4

Comments:

- Most respondents (71.64%) had **visited** a hospitals within the last year.
- 16.42% respondents had visited a hospital within the past two years
- Almost all respondents had been to hospital in the last 24 months.
- Only a small minority had not been to hospital for over five years or could not recall.

Question 2: Why did you go to hospital?

Answered: 265: Skipped: 4.

Answer Choices	TOTAL	QTY
For your own care	79.25%	210
To support someone else	24.53%	65
I prefer not to say	1.89%	5

Comments:

- Most respondents (79.25%) had visited the hospital for their own care.
- 24.53% attended hospitals to support someone else.
- A very small number withheld their reason.

Questions 3: Thinking about your experiences at a hospital. What do you think went well?

Answered: 233. Skipped: 36

Respondents shared mixed experiences in hospitals, ranging from excellent care and positive staff interactions to negative accounts of poor communication, long waiting times, and lack of accessibility.

Key Themes

- 52.6% (123 responses) shared a positive experience
 - Good treatment outcomes
 - Caring and knowledgeable doctors and nurses.
 - Effective communication in some cases.

- Smooth provision of tests and medications.

“The doctor was knowledgeable and caring.”

- 9.4% (22 responses) shared a negative experience
 - Long emergency department wait times.
 - Poor staff understanding of disability needs.
 - Instances of dismissal or lack of meaningful care
 - Accessibility challenges (physical environment, communication barriers).

“Hospital staff struggled to understand the needs of disabled patients.”

“I had to wait a long time in emergency. I was left alone without assistance.”

- **Systemic barriers:**
 - Issues with hospital transfer between facilities.
 - Regional hospital delays, especially around surgery.
 - Staff too overworked or stressed to provide care.
 - Reliance on private care for better outcomes.

“Being a regional hospital the surgery waiting time was long, but once it happened it went well.”

Question 4: Did you have any concerns about the care that was given at the hospital?.

Answered: 241. Skipped: 28

Responses showed clear concern about hospital care. While a few had positive experiences, most concerns related to long waits, poor staff training, lack of accommodations, and safety risks.

Key Themes

- **Long waits and delays:** People described waiting excessive times in emergency and for call bells to be answered.

“There was a long wait in emergency. I almost left without being seen.”

- **Poor communication:** Lack of communication:
 - Between departments.
 - With patients about their care.
 - In accessible formats or with interpretation when needed was a recurring issue.
- **Accessibility and accommodations:**
 - Denial of personal mobility aids (e.g., wheelchairs).
 - Staff untrained in neurodiversity and disability support.
 - Discharge from hospital without handover or planning for disability support staff.
 - Inadequate adjustments for chronic illness and chemical sensitivities.

“I wasn’t allowed to bring my own wheelchair. Care was not adequate without it.”

Yes, staff were untrained in dealing with neurodiverse people and those with communication difficulties.

Imagine turning up with your guide dog... Then being asked if I was driving home. I mean, it was funny, but it sums up the robot style of some intake areas in these places.

Negative attitude and lack of understanding to FND (Functional Neurological Disease).

- **Essential care and safety:** Some patients and their carers raised:
 - Lack of help with feeding or drinking.
 - No food offered that patients with dietary restrictions could eat.
 - Lack of help, or very long delayed help with toileting and continence.
 - Issues with medication error, loss, delayed dosage.
 - No help with personal hygiene or wound care.
 - Inadequate pain management.
 - Safety issues from other patients on mixed wards.

No assistance for personal hygiene, had to have my husband take time off work to shower me every second day. Issues with timing of medication.

Regular and important medication was hardly ever ordered on time ... so every five days or so I went without for 1-2 doses. Medication was rarely administered on time

- **Infection control concerns:**

- Some were alarmed by the absence of masks or protective measures, especially important for people with chronic illness.

Question 5: What do you think needs to change to make hospital care better?

Answered: 244. Skipped: 25

Comments

Respondents provided suggestions for improving hospital care, with a strong focus on staff training, accessibility, communication, and resourcing. Many emphasised the need for hospitals to recognise and respond to disability-specific needs rather than relying on standardised, one-size-fits-all care.

Key Themes

- **Staff training and awareness:**

- Training in disability support, neurodiversity, sensory needs, and communication.
- Requests for staff to “listen, care, and understand” disability experiences.

- **Communication:**

- Accessible communication, including: facing patients who lip-read when speaking, providing forms in accessible formats for patients who are blind, adjustments for people who use assistive communication devices or need a translator or other supporter to communicate.
- More respectful engagement with patients.
- Clearer, consistent communication across departments.
- **Accessibility and environment:**
 - Quiet, darker waiting areas for people with sensory or environmental health needs.
 - Greater access to personal aids and assistive devices.
 - Access to carers in hospital who provide support in their daily lives.
 - Wayfinding help in hospitals for people who are blind or have low-vision, or for people who become lost.
 - Need for fragrance-free and mask policies to protect people with sensitivities.
- **Staffing and resources:**
 - More nurses and trained staff to reduce strain and improve patient outcomes.
 - Better access to assistive equipment such as wheelchairs, mobility and transfer aids.
 - Shorter waiting times.
- **Personalised care:**
 - Person-centered care.
 - Recognition of chronic illness and disability needs in treatment planning.

- Care and discharge plans that integrate with NDIS and other supports.
- Help with eating, drinking, toileting when needed.

Consideration for sensory challenges, MCS, trained staff for wheelchair transfers, including hoist.

All staff need training in how to support neurodiverse people and those with communication difficulties. Hospitals need to prioritise services based on health equity. I.e they should prioritise services to people with poorer health outcomes (i.e. neurodiverse people, people with autism, ADHD, AuDHD, communication difficulties, congenital conditions such as cerebral palsy, spina bifida, downs syndrome, fragile x syndrome.

There should be requirements to provide adjustments and to guarantee access to care for people with disability. The current NSQHS standards don't even mention disability or the NDIS (it's not even in the definition of 'diversity' in the glossary).

Question 6: Do you usually visit the same doctor when you go to the GP?

Answered: 255. Skipped: 14

Answer Choices	TOTAL	QTY
Yes	90.98%	232
No	6.27%	16
I am unsure	1.18%	3
I prefer not to say	1.57%	4

Comments:

- The majority of respondents (90.98%) see the same doctor consistently.
- Only 6.27% (16) respondents said they do not see the same doctor when they visit the GP.

Question 7: Is there anything that makes it hard for you to visit your doctor? (For example: it costs too much, hard to travel there, no appointments when you need one, or something else).

Answered: 238. Skipped: 31

Comments:

Respondents identified multiple barriers to accessing GP care, with the majority pointing to appointment availability, affordability, and physical or logistical challenges.

Key Themes

- **Appointment access:** Difficulty getting appointments when needed, particularly in urgent or acute situations.
- **Cost and bulk billing:** Many cannot afford GP visits unless bulk billed, and availability of bulk billing is poor and shrinking.
- **Transport and mobility:** Long travel distances, no accessible public transport, unreliable wheelchair accessible taxis, dependence on others for transport.
- **Physical Inaccessibility:** inaccessible clinic spaces (e.g., narrow doors) create obstacles.
- **Continuity of care:** Not all patients have a regular GP available.
- **COVID safety:** Some raised concerns about a lack of masks and infection control in clinics.

- **Homebound patients:** People who are bedridden or housebound described a lack of suitable home visits or coordinated care.

My son has very high anxiety, making it difficult for him to leave the car and enter a doctor's surgery. I need someone to take me. My GP moved from 5min drive each way to 20-30 min drive each way. It's the furthest I go and I have to go many times a year for in person administration of medication.

“Doors to rooms too small.”

I am homebound and mostly bedridden. Needs coordination of support during my functional hours to visit. Challenging project.

At the destination, I need to navigate harmful environments of large shopping centre (noise, light, fast moving people around me, smell and chemicals from stores).

Nobody can hear my weak voice, cannot communicate from wheelchair to receptionist, manoeuvre in powered wheelchair in cluttered space is challenging.

Question 8: What works well when you visit your doctor?

Answered: 231. Skipped: 38

Comments

Respondents highlighted what works well for them when visiting their doctors, with the strongest emphasis on continuity of care, telehealth, and supportive doctor–patient relationships.

A small number of negatives were noted, typically around costs to visit the doctor, rushed appointments, poor communication or “Nothing works well”.

Key Themes

- **Continuity and trust:**
 - Seeing the same GP consistently.
 - Doctors who know patient history and follow through with treatment.
- **Doctor–patient relationship:**
 - Experienced, caring, and understanding doctors.
 - Friendly and supportive clinic staff.
- **Telehealth:**
 - Strong praise for telehealth and home visit options, especially for people with limited mobility, chronic illness, or who are homebound.
- **Accessibility and accommodation:**
 - Practices that accommodate adjustments needed for specific disabilities or chemical sensitivities.
 - Ability to book appointments in comfortable environments.

- **Holistic support:**

- Doctors who understand the complexity of conditions and provide more than “tick-box” or prescription-only care.

home visit and tele-health options, flexible to needs

One specialist does zoom consults with me which is so helpful. Started post covid as I'm immuno-compromised and setting was open public outpatient area.

She was experienced and caring, great in building rapport. She takes my concerns seriously when I raise medical issues and explains what may be the cause and practical issues i.e. where to access healthy fresh produce, how to find a female informed clinic to do intimate CT scans that bulk bills.

Question 9: What would make your visit to the doctor better?

Answered: 221. Skipped: 48

Improving the affordability and availability of care were the two most common responses. Respondents identified practical improvements that would make visits to the doctor more accessible, inclusive, and supportive. Suggestions centred on telehealth expansion for people with disability, environmental accessibility, better staff training, and personalised care.

Key Themes

- **Telehealth and flexibility:**

- Many called for universal access to telehealth for people with disability.
- Requests for extended opening hours and flexible appointment scheduling.

*Longer opening hours, different location.
Telehealth with video, not by telephone.*

- **Accessibility and environment:**

- Bigger doorways and accessible physical environments.
- Transport that gets people to the doctor.
- Separate quiet waiting areas for people with sensory sensitivities.

Separate waiting room for kids with sensory issues, autism, ADHD

There is also minimal transport that is able to get participants within this area directly to the GP.

- **Staff training:**

- More awareness of disability and cultural needs.
- Training in functional medicine and chronic illness.

- **Safety and infection control:**

- Airborne disease prevention measures (e.g., masks, ventilation).

- **Personalised care:**

- Doctors taking time to understand individual needs and experiences.
- Consistent access to a regular GP.

My doctor knowing more of what I need and not me having to keep track of everything and figure out on my own.

Having a bigger pool of local doctors. Having more time. Not having to explain my story every time. Having doctors that are holistic and listen to me, and understand that I am the expert in my complex health conditions.

Question 10: Thinking about your experience with these types of other health care, what worked well for you?

Answered: 209. Skipped: 60

Responses reflected a mixed set of experiences with specialist, allied health, and diagnostic services. Some participants praised flexibility and telehealth access, while many others raised concerns about long waitlists, lack of disability accommodations, and unsafe environments.

Key Themes

- **Positive experiences:**
 - Specialists and allied health who offer telehealth, Zoom and home visits.
 - Psychologists and allied health workers often described as supportive and flexible.
 - When a health care provider takes the time to understand and listen to the patient.
 - Trauma-informed care.
- When people listen to me and give me time to explain things. Don't make assumptions about me based on what I look like.
- **Accessibility issues:**

- Diagnostic services not adapted for disability (e.g., breast scan access difficulties).
- Environments often not safe for people with chemical sensitivities or trauma histories.

I'm fortunate that the specialist I see most often is willing to mostly do telehealth (improved accessibility). All my allied health appointments have also been via telehealth or home visit, which is needed because of my limited mobility/limited capacity to leave the house.

Breast Screen Victoria is very accommodating for PWD; however, you need to mention that you may need assistance, and they will do their best to accommodate you.

Question 11: What do you think needs to change to make these types of other health care better?

Answered: 219. Skipped: 50

Respondents proposed a wide range of systemic and practical changes to improve specialist, allied health, screening, and diagnostic services. The strongest calls were for affordability, accessibility, inclusive practice, and transparency around service availability.

Key Themes

- **Affordability and Medicare access:**
 - Calls for more affordable private health insurance.
 - Greater access to Medicare-rebated allied health sessions.
 - Funding so it is affordable to get scans and health checks within recommended times.

Many are hard to access and expensive.

Make private health insurance more affordable!

*Specialist need to provide subsidised consults so low income people can
access care*

Access to affordable allied health for all, not just NDIS participants.

- **Training:**

- Better training for all practitioners in different disabilities, and the impacts on physical and mental health
- Disability and cultural awareness training

*Better education in the different disabilities and impacts of mental and
physical health.*

Better training in neurodivergent traits

*Far better training for allied health in regard to NDIS reporting
requirements.*

- **Accessibility and environment:**

- More availability in under-served areas.
- More home care and telehealth options.
- Fragrance-free and mask requirements to protect those with sensitivities.

- **Transparency and waitlists:**

- Public disclosure of waitlist times for services so patients can make informed choices.

Disclosure of waitlists for all health services otherwise we are waiting our time going on waitlists unnecessarily- we are even required to disclose health information without being given an appointment which is a waste of our time if it is unlikely to happen. Reorientation of health system and services to support people with more complex needs first. Some health providers seem to "cherry pick" easier clients and are paid the same for it as someone treating a complex client.

- **Disability inclusion and training:**

- Training for practitioners to ensure disability awareness and inclusive care.
- Recognition of the role of families and carers in ongoing treatment.

- **Patient-centred care:**

- Education for clinicians about specific conditions.
- Better health coordination, navigation and assistance for patients with disability who are users of many health services and require many specialist and allied health appointments.
- A stronger focus on holistic, tailored approaches instead of generic treatment pathways.

*Training ensure practitioners are disability aware and culturally aware.
Specialist need to provide subsidised consults so low income people can
access care*

*In time. Collaborative holistic approach to issues causing detrimental
health outcomes and link people to housing, healthy food, health and
support services in local area.*

*Funding so will be safe and subsidised to get scans and health checks
within recommended times.*

*I have 9 specialists, go to the physio twice a week and get several bloods
and scans often. It is difficult to give 1 answer for all of the above*

Question 12: Have you ever seen someone for mental health care or support?

Answered: 234. Skipped: 35

Answer Choices	TOTAL	QTY
Yes	76.92%	180
No	20.09%	47
I am unsure	0.85%	2
I prefer not to say	2.14%	5

Comments

1. 76.92% of respondents have accessed some form of mental health support.
2. About 1 in 5 (20.09%) have never accessed mental health services

Question 13: Thinking about your experience with these types of mental health care, what worked well for you?

Answered: 179. Skipped: 90

Access to care in terms of affordability, a lack of local appointments, and accessible transport were raised again as barriers. Respondents gave varied feedback about the mental health care provided.

3. Nearly half (45%) reported positive experiences, with supportive, respectful providers and telehealth working well.
4. Once again comments indicated that accessible, respectful communication and attitudes, genuine listening and trauma-informed care were essential.

Easy access, calm environment, understanding sensitivities (light, sound) and TFT EFT CBT were all helpful tools for disability related anxieties

Psychology - trauma informed, knowledgeable, availability (with extra support during crisis moment), pro bono client, takeaway gems, makes a huge difference with daily life/functioning.

Psychiatrist - public hospital DISCHARGE; community health Trauma informed, compassionate, I felt heard.

Mental Health Nurse - I wasn't able to visit hospital, due to post hospital discharge anxiety, so 2 nurses did a home visit.

- 16% reported negative experiences, describing care as useless, harmful, or disengaged.

Nothing about the public health system works. There are mistakes, negligence and privacy breaches.

Personally not a lot. I was sent for support with a chronic illness, the person who seen me had no clue off what I had, and really not a lot of compassion

I couldn't find anyone who could use and understand my communication through AAC. If I could that would be a game changer for my privacy, instead I take a support worker with me to appointments to "translate/assist with communication."

About one-third (38%) were either neutral or unclear, indicating limited or mixed experiences.

5. The need for disability awareness training came up again.

They start by telling you things like visual cues are important. Brilliant. I can't see them. Do they know what else I might do? No.

When they are neuro-affirming in practice and not just in theory

Question 14: What do you think needs to change to make these types of mental health care better?

Answered: 182. Skipped: 87

Key Themes

- **Treatment approaches:**
 - Requests for services tailored to **chronic illness and disability literacy**.
- **Access and affordability:**
 - Need for more affordable services and longer appointments (10–15-minute slots seen as inadequate).
 - Greater access to telehealth for those unable to attend in person.

time, time, time, 10 minute appointments don't work and only responding with medication is short-sighted.

Funding so that people can access inclusive clinical care by trained clinical psychologists and professionals who are disability aware, cultural and trauma aware.

It's prohibitively expensive. 6 sessions a year is woefully inadequate for most people, let alone those who are neurodivergent and have multiple other comorbidities. And realistically most people aren't going to get lucky and find the right therapist on the first try.

- **Workforce training and conduct:**

- Calls for better training of professionals to avoid stigma, harmful behaviour, or dismissiveness.
- Monitoring of inappropriate behaviour in mental health settings.

Reform so inappropriate behaviour monitored and action taken. How to do complain about mental health professional who can only berate you without understanding you. How do people know if a practitioner has a negative unsafe history of behaviour?

- **Peer support:**

- Clear demand for peer workers in all mental health services, recognising the value of lived experience.

- **Environment and safety:**

- Need for safer, more supportive clinical environments.
- Some respondents described current professionals as “not practical” or dismissive.

Question 15: Is there anything else you'd like to tell us about your experience with health care or ideas to make it better.

Answered: 178. Skipped: 91

Respondents used this space to raise broader systemic concerns and highlight gaps across the healthcare system. The responses emphasised the need for disability awareness, affordability, accessibility, and equity in healthcare.

Key Themes

- **Disability awareness and training:**
 - Calls for stronger training for medical professionals on disability rights and needs.
 - Emphasis on “time and patience” as critical qualities for clinicians.
 - Avoid linking all mental health issues to disability, other issues like stress or working long hours could be the problem.
 - Practitioners need to understand the difference between intellectual disability and mental health conditions, and what they look like when they are co-morbid.
 - Avoid incorrectly diagnosing disabilities or physical health issues as mental health conditions.
 - Better availability and accessibility for autism and ADHD assessments and more education for providers about the different ways they present in women, men.
 - More education for practitioners about how people present when they have co-morbid conditions (e.g. ADHD and Autism, Bipolar and Autism etc.)

I think it is basically about educating health professionals about disability and making sure they treat everyone with greater respect, especially if you don't have a carer.

There is a lack of knowledge about how to assess, treat and support people with dual disabilities (i.e. mental health issues and cognitive disability). A lot of traditional assessment and treatment modalities may not be appropriate.

Stop assuming conditions such as ME/CFS, FND & endometriosis are psychiatric disorders

- **Patient-centred care:**

Most of the problems I encountered have been due to a real lack of care. Unwillingness to be flexible, or to even think about what they are saying and doing. This comes from all levels of health care. I find registered nurses are generally the best and reception staff the worst by far. Followed in a close second by specialists. Let's face it, you don't go to a specialist unless there is a real issue. They need to do what they are paid very well to do and that is to provide a fix and to be caring and thoughtful in their manner and delivery.

The biggest issue in healthcare is the lack of patient-centered care that responds to the needs of the individual.

- **Access to NDIS supports:**

- Concern about how NDIS rules intersect with healthcare, creating barriers to access.

- **Affordability and cost:**

- Cost of essential tests and ongoing care was a major concern, leaving some unable to access what they need.
- High cost and lack of care for people living in rural and regional areas.

- **COVID and infection control:**

- Some respondents stressed the importance of maintaining mask requirements and strong safety standards in hospitals.

- **Accessibility:**

- The lack of appropriate or sufficient mental health care was raised, both crisis care and care by appointment.
- Premises and bathroom physical inaccessibility came up repeatedly
- Lack of accessible communication and Auslan were raised.

- **Equity and systemic barriers:**

- People described inequities across the health system, with barriers disproportionately affecting people with disability.
- The issue of discrimination and stigma, both disability-related and mental-health-related, was raised.
- Criticism of the public vs private healthcare model, particularly affordability and gaps in services.
- Improving written standards will not change anything without enforcing penalties for non-adherence.

My experience of healthcare services has been highly abusive, as has a lot of what I have witnessed happen to others in the same facilities and

hospitals. I am proud of how I have advocated for myself and my peers when I've been able. I hope one day it becomes unnecessary as our governments and other healthcare bureaucrats listen to their disabled patients and stop protecting staff acting in bad faith.

If you tell 000 that the person who is needing care has autism, they will not come. They keep calling you asking how they are going and saying they are extremely busy. This has happened on many occasions. However, when autism is not mentioned, they arrive in a timely manner.

I don't want to be talked down to because I have cerebral palsy. People think I'm thick but it doesn't affect my mental capacity and actually I'm super aware of how my body works.

People completing the survey

Question 16: Do you identify as a person with disability? (tick one)

Answered: 231. Skipped: 38

Yes	89.61%	207
No	8.66%	20
I prefer not to say	1.73%	4

Comments:

- 89.61% (207) of respondents identify as a person with disability.

Question 17: Do you care for or help someone with disability access health care: (tick all that apply)

Answered: 225. Skipped: 44

Yes	39.56%	89
No	58.67%	132
I prefer not to say	2.22%	5

Comments:

- A large proportion of respondents (39.56%) care for or help someone with disability access health care, reflecting the dual perspectives of people both living with disability and providing support to others.

- The majority (59%) stated they are not in a caring role or support someone with disability to access health care.
- A small proportion chose not to disclose.

Question 18: Do you identify as any of the following: (tick all that apply)

Answered: 210. Skipped: 59

Aboriginal and / or Torres Strait Islander	3.81%	8
From a culturally or linguistically diverse (CALD) background	11.90%	25
Member of the LGBTQIA+ community	23.33%	49
Woman or girl with disability	63.81%	134
Trans and / or gender diverse	5.71%	12
Young person with disability (under 25 years)	3.81%	8
Older person with disability (65+ years)	20.48%	43
A person living in a rural or remote area	19.52%	41
I prefer not to say	5.24%	11
Other (please describe):	13.33%	28

Comments:

- Women and girls with disability made up most respondents (63.81%)
- 23.33% of respondents identify as LGBTQIA+ and 5.71% as trans and/or gender diverse.

- 11.90% as CALD and 3.81% First Nations.
- 19.52% came from rural or remote areas.
- 3.81% of people identify as a young person with disability (under 25 years)

Question 19: Where do you live in Australia?

Answered: 229. Skipped: 40

Answer Choices	TOTAL	QTY
Major City	58.52%	134
Rural or regional area	36.68%	84
Remote area	0.44%	1
I prefer not to say	2.62%	6
Other (please describe):	1.75%	4

Comments:

- Most respondents (58.52%) live in major cities
- Over one-third (36.68%) live in rural or regional areas
- Only one person identified as living in a remote area.

Question 20: What is your age group? (tick one)

Answered: 230. Skipped: 39

	TOTAL	QTY
Under 18	0.00%	0
18 - 24	2.61%	6
25 - 34	4.78%	11
35 - 44	16.96%	39
45 - 54	28.70%	66
55 - 64	24.78%	57
65+	21.30%	49
I prefer not to say	0.87%	2

Comments:

- Most respondents are between 35 and 64 years old
- A significant 21.30% are 65+
- Very few respondents were under 25 (only 6 people total).

ⁱ Australian Bureau of Statistics (2022), [Disability, Ageing and Carers, Australia: Summary of Findings](#), ABS Website, accessed 22 September 2025..

ⁱⁱ Rosemary Kayess and Therese Sands, *Convention on the Rights of Persons with Disabilities: Shining a light on Social Transformation* (UNSW Social Policy Research Centre, 2020); Australian Bureau of Statistics (n1); Australian Institute of Health and Welfare (n 1);

Jeromey B Temple, Margaret Kelaher and Ruth Williams, 'Discrimination and avoidance due to disability in Australia: evidence from a National Cross-Sectional Survey' (2018) 18 *BMC Public Health* 1347.

ⁱⁱⁱ Australian Institute of Health and Welfare (n 1) 163.

^{iv} Anti-Discrimination NSW, *Annual Report 2021-22* (2022) 15 <https://antidiscrimination.nsw.gov.au/documents/annual-reports/anti-discrimination-annual-report-2021-22.pdf>

^v Australian Institute of Health and Welfare (n 1) 163.

^{vi} Committee on the Rights of Persons with Disabilities, *General comment No. 6 (2018) Equality and non-discrimination* CRPD/C/GC/6 (26 April 2018) [30]; Australian Human Rights Commission, *Free and Equal. A reform agenda for federal discrimination laws* (December 2021) 16; United Nations, *Convention on the Rights of Persons with Disabilities* (12 December 2006), article 5.

^{vii} Yang, Yi et al., All-cause and cause-specific mortality inequalities between people with and without disability: a nationwide data linkage study in Australia, *The Lancet Public Health*, Volume 10, Issue 1, e11 - e19 last accessed 2 Sep 2025, [https://www.thelancet.com/journals/lanpub/article/PIIS2468-2667\(24\)00266-4/fulltext](https://www.thelancet.com/journals/lanpub/article/PIIS2468-2667(24)00266-4/fulltext)

^{viii} Trollor J, Srasuebku P, Xu H, et al, Cause of death and potentially avoidable deaths in Australian adults with intellectual disability using retrospective linked data, *BMJ Open* 2017;7:e 013489. Last accessed 2 Sep 2025 <https://bmjopen.bmj.com/content/7/2/e013489>

^{ix} Australian Government, Department of Health, National Preventative Health Strategy 2021-2030; Valuing health before illness: Living well for longer, 2021, P21 last accessed 2 September 2025, https://www.health.gov.au/sites/default/files/documents/2021/12/national-preventive-health-strategy-2021-2030_1.pdf

^x Australian Government, Department of Health, National Preventative Health Strategy 2021-2030; Valuing health before illness: Living well for longer, 2021, P22-4 last accessed 2 September 2025, https://www.health.gov.au/sites/default/files/documents/2021/12/national-preventive-health-strategy-2021-2030_1.pdf

^{xi} Australian Government, Department of Health, National Preventative Health Strategy 2021-2030; Valuing health before illness: Living well for longer, 2021, P30 last accessed 2 September 2025, https://www.health.gov.au/sites/default/files/documents/2021/12/national-preventive-health-strategy-2021-2030_1.pdf

^{xii} Based on the ACE Prevention Study of 123 illness prevention measures to improve population health in Australia. T, Carter R, Barendregt J, Mihalopoulos C, Veerman L, Magnus A, et al. Assessing cost-effectiveness in prevention (ACE-Prevention): Final Report. Brisbane: University of Queensland & Melbourne: Deakin University; 2010. Last accessed 10 October 2023 https://public-health.uq.edu.au/files/571/ACE-Prevention_final_report.pdf

Investing in preventative healthcare for everyone could save the healthcare system \$140 billion over 20 years according to the Productivity Commission. Productivity Commission (2017). Shifting the dial: 5 year productivity review, last accessed 10 October 2023, <https://www.pc.gov.au/inquiries/completed/productivity-review/report/productivity-review.pdf> Australian Medical Association, Health is the best investment; shifting from a 'sickcare' system to a healthcare system, last accessed 10 October 2023, <https://www.ama.com.au/sites/default/files/2023-06/Health-is-the-best-investment-shifting-from-a-sickcare-system-to-a-healthcares-system.pdf> \$140B x 0.214 = =\$29.9B / 20 years = \$1.14B

^{xiii} As a guide, in NSW a hospital bed costs \$1075 per day NSW Government, Treasurer, Minister for Health, Health insurers rorting public hospital beds, Media release 30/9/2024, online as at 12/9/2025, <https://www.nsw.gov.au/media-releases/health-insurers-rorting-public-hospital-beds>

^{xiv} Australian Commission on Safety and Quality in Healthcare, National Safety and Quality Health Service (NSQHS) Standards: second edition, 1.15 P 13, last accessed 20/8/2025 https://www.safetyandquality.gov.au/sites/default/files/2021-05/national_safety_and_quality_health_service_nsqhs_standards_second_edition_-_updated_may_2021.pdf

^{xv} Barton AD, Beigg CL, Macdonald IA, Allison SP. High food wastage and low nutritional intakes in hospital patients. *Clin Nutr.* 2000 Dec;19(6):445-9. doi: 10.1054/clnu.2000.0150. PMID: 11104596. <https://pubmed.ncbi.nlm.nih.gov/11104596/> Allison S. Institutional feeding of the elderly. *Curr Opin Clin Nutr Metab Care.* 2002 Jan;5(1):31-4. doi: 10.1097/00075197-200201000-00006. PMID: 11790946. <https://pubmed.ncbi.nlm.nih.gov/11790946/>

^{xvi} Cansado P, Ravasco P, Camilo M. A longitudinal study of hospital undernutrition in the elderly: comparison of four validated methods. *J Nutr Health Aging.* 2009 Feb;13(2):159-64. doi: 10.1007/s12603-009-0024-y. PMID: 19214346. <https://pubmed.ncbi.nlm.nih.gov/19214346/>

^{xvii} Victorian Mental Illness Awareness Council, Zero Tolerance for Sexual Assault: a safe admission for women https://www.abc.net.au/reslib/201305/r1115028_13591277.pdf Jayashri Kulkarni, Sexual Assaults in psych wards show urgent need for reform, *The Conversation* 17/5/2013 <https://theconversation.com/sexual-assaults-in-psych-wards-show-urgent-need-for-reform-14265>

^{xviii} Australian Government, Department of Health, National Preventative Health Strategy 2021-2030; Valuing health before illness: Living well for longer, 2021, P21 last accessed 2 September 2025, https://www.health.gov.au/sites/default/files/documents/2021/12/national-preventive-health-strategy-2021-2030_1.pdf

^{xxix} People with disability generally have higher rates of some modifiable health risk factors and behaviours than people without disability. Australian Institute of Health and Welfare (2024) [Health of people with disability](https://www.aihw.gov.au/reports/australias-health/health-of-people-with-disability), AIHW, Australian Government, accessed 12 September 2025 <https://www.aihw.gov.au/reports/australias-health/health-of-people-with-disability>

^{xxx} Australian Government, Department of Health, National Preventative Health Strategy 2021-2030; Valuing health before illness: Living well for longer, 2021, P22-4 last accessed 2 September 2025, https://www.health.gov.au/sites/default/files/documents/2021/12/national-preventive-health-strategy-2021-2030_1.pdf

^{xxxi} Australian Government, Department of Health, National Preventative Health Strategy 2021-2030; Valuing health before illness: Living well for longer, 2021, P30 last accessed 2 September 2025, https://www.health.gov.au/sites/default/files/documents/2021/12/national-preventive-health-strategy-2021-2030_1.pdf

^{xxxii} Based on the ACE Prevention Study of 123 illness prevention measures to improve population health in Australia. T, Carter R, Barendregt J, Mihalopoulos C, Veerman L, Magnus A, et al. Assessing cost-effectiveness in prevention (ACE-Prevention): Final Report. Brisbane: University of Queensland & Melbourne: Deakin University; 2010. Last accessed 10 October 2023 https://public-health.uq.edu.au/files/571/ACE-Prevention_final_report.pdf

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PEOPLE WITH DISABILITY AUSTRALIA

People with Disability Australia (PWDA) is a national disability rights and advocacy organisation made up of, and led by, people with disability.

For individual advocacy support contact PWDA between 9 am and 5 pm (AEST/AEDT) Monday to Friday via phone (toll free) on **1800 843 929** or via email at pwd@pwd.org.au

Submission contact

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