

AMAZE SUBMISSION

Submission to the Australian
Building Codes Board Accessible
Housing Options Paper

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About Amaze

Amaze is the peak body in Victoria for autistic people and their supporters. Amaze is a not-for-profit organisation established in 1967 that represents around 55,000 autistic Victorians.

In 2015 Amaze launched its Strategic Directions to 2040 – a 25 year plan to achieve social impact where society respects every autistic person and they have real opportunities to participate and contribute. To achieve this, our three main goals are to:

- Increase community awareness and understanding of autism;
- Improve attitudes and behaviours towards people on the autism spectrum;
- Create more opportunities for people on the autism spectrum to participate and contribute to society in meaningful ways.

Amaze operates under a number of principles that guide our work and underpin our decision making. They are:

1. **Autistic People at the Centre** – We embody the motto “nothing about us without us”. We act as a facilitator to ensure the voices and needs of autistic people and their families/supporters are heard in the wider world. We actively engage with autistic people and their supporters to inform our priorities, how our organisation is governed and operates, and how we design and deliver our activities. We actively work to improve attitudes and behaviours towards autistic people and their families/supporters.
2. **Collaboration and Partnership.** We recognise that we cannot achieve our social impact goals alone and so we actively seek out like-minded people and organisations as partners.
3. **Courage and Independence** – We condemn any discrimination and ableism used to stigmatise or invalidate the life experience of autistic people. Whilst we adopt a practice of partnership, the needs of autistic people and their families will always come first, and we will speak out and challenge any government or organisation’s policy or practice that compromises autistic people.
4. **Evidence based** – We seek data and evidence to underpin decision making and we measure the outcomes of our work wherever possible. We advocate for greater collection of and accessibility to, data from public institutions that measure and track outcomes for autistic people and result in greater accountability.

1. Key points

Amaze welcomes the opportunity to provide a submission into the Australian Building Codes Board (ABCB) Accessible Housing Options Paper.

We are pleased that the Building Ministers' Forum agreed that a national regulation impact assessment (RIA) be undertaken by the ABCB, in consultation with Disability Ministers through the Disability Reform Council (DRC), on the costs and benefits of applying a minimum accessibility standard to all new residential dwellings in Australia.

The key points that Amaze would like to make are:

- That any minimum accessibility standard should consider the needs of all people with a disability, including autistic people.
- The RIA should consider the cost benefits of specific inclusions in a minimum accessibility standard to cater for autistic people. If the view is taken that minimum accessibility standards are not cost effective to meet the needs of autistic people, consideration should be given to whether Livable Housing Design Guidelines could better meet these needs (ideally linking guidelines to any minimum accessibility standard as a mandatory consideration).
- That the ABCB directly consult with the elderly and people with a disability (including autistic people), who tend to be more isolated to contribute to such processes.
- That there is a market failure in providing accessible residential dwellings and a minimum accessibility standard would make the market more efficient, whilst contributing to social aims of greater accessibility.
- That certain cost benefit analysis should be included in the RIA to ensure it encompasses the societal benefits of a minimum accessibility standard, including:
 - The costs of social isolation, as it could be argued that lack of access to residential dwellings would be a contributing factor to social isolation i.e. inability to access friends or families houses.
 - The benefits of enabling policies to reduce demand and cost of the health system. For example, minimum accessibility standards could help assist greater roll out of hospital in the home, due to greater accessibility of residential dwellings.

2. What is autism?

Autism is a neurodevelopmental condition which affects the brain's growth and development. It is a lifelong condition, with symptoms that appear in early childhood.

No two autistic people are alike as they will experience autism in different ways. All people on the autism spectrum are different and will experience autism in different ways. Every autistic individual is different and will experience autism in different ways, however these features are always present in some form:

Challenges in communicating and interacting with other people:

- Sharing interests and emotions. This can range from a lack of interaction to wanting to interact, but not knowing how to do it in an appropriate way.
- Using and understanding non-verbal communication, such as body language, eye contact or facial expressions.
- Making friends, maintaining friendships and adjusting behaviour to different social situations.

Sensory processing difficulties

- Being either over- or under-sensitive to sensory stimuli, including to sounds, smells, tastes, textures or visual stimuli. Often the same person will be over-sensitive to some things and under sensitive to others.

Repetitive routines in behaviour interests or activities:

- Repetitive speech, movements or use of objects.
- Routines, rituals or resistance to change.
- Interests that are very intense or narrow in focus.

Autism Spectrum facts:

- Autism affects around 1 in every 100-110 people, with around 164,000 Australians with autism (2015).¹
- 85 per cent of Australians have personal contact with a person with autism.²
- Autism is the largest NDIS diagnostic group with 29% of total plans.³

3. The proposed definition of accessibility

The Options paper defines accessible housing as “any housing that includes features to enable use by people either with a disability or through their life stages”.

Amaze supports this definition, noting that such a definition would be inclusive of the needs of autistic people.

¹ ABS, 4430.0 - Disability, Ageing and Carers, Australia: Summary of Findings, 2015.

² Amaze, Strategic Directions to 2040 and Strategic Plan 2018-2021, 2018.

³ NDIS National Dashboard as at 30 June 2018. <https://www.ndis.gov.au/medias/documents/national-dashboard-aug18/National-Dashboard.pdf>

4. The barriers faced by autistic people in accessing built and natural environments

Given the varied characteristics and needs of autistic people, the barriers to accessible housing will also be varied and experienced differently. However, there is evidence that common barriers experienced by autistic people when seeking to find accessible housing can commonly relate to structural or physical features of housing, including lighting, acoustics, smells, colours, spatial features and flow, flooring and other design elements.

We emphasise again that all autistic people will experience these barriers differently. For example, an autistic person that experiences hyper-sensory sensitivity to noise or lighting may experience sensory overload, anxiety and/or be unable to interact, participate or remain in an environment. A person that experiences hypo-sensory sensitivity may respond similarly if the environment does not meet their sensory needs, i.e. relating to touch or visual stimuli.

Of note, researched commissioned by Amaze found that 67.8% of survey respondents avoided community spaces due to the level of light or noise.

This study also asked whether in certain settings (educational institutions and employment), adjustments to lighting and/or sound levels and/or other sensory (smells, textures) were made to support autistic people. Based on survey respondents it found that the following percentages made such adjustments for autistic people to support their sensory needs:

- 9.4% of employers;
- 3% of post-secondary education; and
- 19.4% of schools.⁴

As illustrated above, these barriers impact the ability of autistic people to access public buildings, places and events. For further information regarding these and further barriers to accessing public places, please refer to *Amaze's Position Statement: Accessible environments for autistic people*.⁵

Housing design with the characteristics of autism in mind can reduce anxiety and increase independence and social participation of autistic people, it can also be cost saving and benefit to the wider community.⁶

An online poll of 1,012 Australians, conducted by Essential Research (commissioned by Amaze) in July 2016 found that 64% of respondents were aware that people on the autism spectrum can be over or under sensitive to stimuli like light and noise. Yet only 29% of respondents reported having a good understanding of how to support autistic people.⁷

It is noted that the options outlined in the discussion paper do not include any standards related to light and noise.

⁴ Jones S et al. 2017, Experiences of Autistic People and their Families, Centre for Health and Social Research, Australian Catholic University.

⁵ Available at <http://www.amaze.org.au/uploads/2018/03/Amaze-Accessible-environments-March-20181.pdf>

⁶ Boyle C (2016). Autism and the built environment – using design to improve outcomes. Autism Housing Pathways. Available at <http://autismhousingpathways.org/wp-content/uploads/2016/04/Autism-and-the-built-environment-%E2%80%93-using-design-1.pdf>; Shell, S (2016). Why buildings for autistic people are better for everyone. Forte Building Science.

⁷ Essential Research 2016. The Essential Report – Autism questions, 19 July 2016.

5. Is the market failing to provide accessible housing?

The definition of market failure is where the allocation of goods and resources by a free market is not efficient.

The main points to illustrate that the lack of accessible housing is a market failure are:

- 1) The National Disability Strategy set an aspirational target that all new homes will be of agreed universal design standards by 2020. This has not been met as it is estimated that only five per cent of housing stock will meet a standard by 2020.
- 2) The ABCB discussion paper highlighted in its preliminary costings that the cost impact in putting minimum design standards far outweighs the costs of retrofitting at a later date.

These points make clear that the free market is currently choosing an inefficient option of not designing new accessible housing, which gets more costly over time to retrofit. It also does not support achieving the social aims of accessibility for people with a disability.

Recent reports highlighting the lack of suitable housing for autistic people include:

- Victorian Parliament (2016). Inquiry into services for people with autism.⁸
- Victorian Ombudsman (2018) Investigation into the imprisonment of a woman found unfit to stand trial.⁹

These reports highlight the comprehensive approach required to provide accessible housing to autistic people, including affordability, appropriate supports and safeguards. The Victorian Parliament (2016) recommended that the Victorian Government update its State Autism Plan and include strategies to address the housing needs of autistic adults. The Victorian Ombudsman's report explores the lack of accessible housing for autistic people leaving prison, highlighting the needs for safe and secure housing capable of protecting these vulnerable people from harm.

Amaze considers the biggest barrier to minimum accessibility standards is the additional up front cost that is required, especially considering that housing affordability is a significant issue in cities such as Melbourne and Sydney. This barrier should be considered in its full context, noting that through taxation, all Australians currently pay for retrofits of residential dwellings through government home modification schemes related to disability services (including the NDIS) and aged care services.

Amaze notes that the NDIS is forecasted to spend around \$137 million in home modifications in 2019-20 (full rollout of the NDIS).¹⁰ It is assumed that with a growing ageing population that the overall cost of home modifications will increase with the ageing demographic. Some of these home modification costs borne by government could be prevented if a minimum accessibility standard was introduced, reducing the overall costs of such programs.

These costs are an important consideration noting that minimum accessibility standards are likely to reduce the costs of the NDIS and aged care services into the future. Amaze

⁸ Victorian Parliament (2016) *Inquiry into services for people with ASD – Final Report*. Family and Community Development Committee. Available at <https://www.parliament.vic.gov.au/fcdc/inquiries/article/2588>

⁹ Victorian Ombudsman (2018) Investigation into the imprisonment of a woman found unfit to stand trial. 16 October 2018. Available at <https://www.ombudsman.vic.gov.au/Publications/Parliamentary-Reports/Investigation-into-the-imprisonment-of-a-woman-fou>

¹⁰ NDIS, Assistive Technology Strategy, 2015. p. 7.

recommends that the ABCB undertakes research to understand what governments pay towards home modification schemes.

It is important to note that minimum accessibility standards would not prevent all home modifications being required for people with a disability or the elderly. However, such minimum accessibility standards should aim to minimise the costs of retrofitting and home modifications, which the ABCB has done by analysing which requirements would be the most difficult to incorporate retrospectively.

Amaze also emphasises that 29% of participants in the NDIS identify autism as their primary diagnosis. If the insurance principles of the NDIS are to be met for this group – reducing social costs and maximising this groups social and economic independence - accessible housing for autistic people will be essential.

6. Minimum accessibility standards to support the needs of autistic people?

Consistent evidence is available regarding best practice in housing design for autistic people.¹¹ Best practice recognises that the needs of autistic people when accessing housing can vary significantly and that it may be difficult to identify concrete minimum requirements for all housing. However, the evidence does find that common measures to achieve accessibility may include:

- Involving potential occupants (and/or family/carers) in the design process as early as possible;
- sound proofing, limiting external noise to a prescribed level indoors;
- neutral flooring and coloring; and
- lighting prescriptions, including no fluorescent lighting and mandatory dimmer switches.

For further evidence regarding best practice in housing design for autistic people, we would encourage you to review the following papers:

- Brand A (2010). Living in the Community – Housing Design for Adults with Autism. Helen Hamlyn Centre.
- Braddock and Rowell (2011), Making Houses that work: A resource Guide for families living with ASD and Co-occurring behaviours. Creative Housing Solutions and Rowell Brokaw Architects.
- Ahrentzen and Stelle (2009). Advancing Full spectrum Housing: Designing for Adults with Autism Spectrum Disorders. Phoenix, Arizona.¹²

In particular, the paper by Ahrentzen and Stelle (2009) outlines the following 10 design guidelines to meet some common needs of autistic people.

¹¹ Brand A (2010). Living in the Community – Housing Design for Adults with Autism. Helen Hamlyn Centre. Available at https://www.rca.ac.uk/documents/390/Living_in_the_Community.pdf; Braddock and Rowell (2011), Making Houses that work: A resource Guide for families living with ASD and Co-occurring behaviours. Creative Housing Solutions and Rowell Brokaw Architects. Available at [http://parenttoparentnys.org/images/uploads/pdfs/Making_Homes_That_Work_A_Resource_Guide_\(2\).pdf](http://parenttoparentnys.org/images/uploads/pdfs/Making_Homes_That_Work_A_Resource_Guide_(2).pdf); Ahrentzen and Stelle (2009). Advancing Full Spectrum Housing: Designing for Adults with Autism Spectrum Disorders. Phoenix, Arizona.

¹² Ibid.

1. Ensure safety and security
2. Maximize familiarity, stability and clarity
3. Minimize sensory overload
4. Allow opportunities for controlling social interaction and privacy
5. Provide adequate choice and independence
6. Foster health and wellness
7. Enhance one's dignity
8. Ensure durability
9. Achieve affordability
10. Ensure accessibility and support in the surrounding neighbourhood.

Options

Minimum accessibility standards to support autistic people may include sound proofing, lighting and flooring/colouring. At the very least, these standards should be considered for common areas of apartment blocks to ensure that the apartment block is accessible for all.

If the view is taken that minimum accessibility standards are not capable of providing for the needs of autistic people (due to different characteristics and/or needs across the spectrum or due to current levels of evidence), consideration should be given to whether Livable Housing Design Guidelines could better articulate best practice in housing design to meet the needs of autistic people. If the latter approach is taken, Amaze submits that any minimum accessibility standards should require building professionals to have regard to these guidelines. These guidelines should be developed in partnership with autistic people, their carers and autism organisations.

Accordingly, we recommend that consideration be given to the RIA assessing the cost-benefit of:

- incorporating into any minimum accessibility standards, minimum requirements in relation to sound proofing, lighting and flooring/colouring. At the very least, it should review the cost-benefit of these minimum requirements for common areas of apartment blocks; and/or
- requiring builders/professionals involved in home design to have regard to best practice guidelines (i.e. Liveable Housing design guidelines) for accessible housing design for autistic people (and people with other cognitive disabilities, and/or with intellectual disabilities or mental health conditions).
- The RIS should also consider the costs benefits of any minimum accessibility standards requiring building professionals to involve people with disability, including autistic people, and their families/carers in the design process as early as possible (to the extent possible).
- Given the evidence regarding the characteristics of accessible housing for autistic people is continually emerging, any minimum accessibility standards should include a requirement that the standards be reviewed every five years. This would enable the minimum accessibility standards to keep up to date with innovative practice and evidence.

7. “Nothing about us without us”

Amaze notes that at the consultation session it attended in Melbourne that the ABCB informed that it is unlikely to engage directly with the cohorts most likely to benefit from minimum accessibility standards, outside of current processes. Amaze understands the

premise that minimum accessibility standards would affect everyone who purchases a new dwelling, however the impact of improved accessibility of new residential dwellings will provide benefits for specific cohorts, namely people with a disability and the elderly.

Amaze embodies the motto “nothing about us, without us” and considers it critical that the ABCB finds avenues to directly engage with these groups as part of this consultation process. Suggestions include:

- Engage directly with the National Disability and Carers Advisory Council
- Provide options papers in more accessible and easy read formats
- Directly engage with peak bodies and other organisations to support getting the message out more broadly to target groups.

Simple measures such as these will ensure that these cohorts are properly engaged throughout the process.

8. Suggestions of research to be included in the RIA

At the ABCB consultation in Melbourne, the representative made clear that a focus would be on the cost benefits of a minimum accessibility standard.

As discussed above, Amaze would encourage the ABCB to review the literature regarding the benefits of accessible housing for autistic people.

Amaze has also found some evidence of the cost or savings that could be made by government as a by-product of a minimum accessibility standard, which is provided below:

8a. Social Isolation

Accessibility is a significant factor in supporting inclusion of people, avoiding the impact of social isolation and loneliness. The 2009 report, *SHUT OUT: The experience of people with a disability and their families in Australia* highlighted that more than 27 per cent of submissions said that lack of access to buildings and facilities is a barrier to full participation in the community. This was not specific about whether this applied to public or residential buildings. However, it is known that accessible housing, and a choice in housing that enables people with disabilities to live as independently as possible, is essential to wellbeing, health, quality of life and prosperity. It is also conceivable that a lack of accessibility to residential dwellings could be a contributing factor to social isolation as it would prevent individuals that have inaccessible housing from visiting friends and family.

Evidence shows that high levels of autistic people are socially isolated. Researched commissioned by Amaze found that:

- 51.6% agreed or strongly agreed that they feel socially isolated;
- 40.6% that they have lost friends because of the way those friends have responded to their or their family member’s autism;
- 39.3% that they sometimes feel unable to leave the house because they are worried about people behaving negatively towards them because of their or their family member’s autism.¹³

¹³ Jones S et al. 2017, Experiences of Autistic People and their Families, Centre for Health and Social Research, Australian Catholic University.

Another study in 2013 found that almost 40% of autistic youth never got together with friends. Similarly, almost 50% of autistic young adults never received phone calls from friends and were never invited to activities by friends. Overall, almost one-third of autistic young adults were socially isolated, with no contact with friends, no phone calls, and no invitations to activities.¹⁴ Amaze is not aware of any evidence that quantifies the impact of the built environment in contributing to social isolation for autistic people, however, it is likely to be a contributing factor given that autistic people can be sensitive to their surrounding environment.

In the UK, it has been reported that a leading cause of early death among autistic people is suicide.¹⁵ A recent Swedish study found that adults with autism (and no additional learning disability) are over 9 times more likely, relative to the general population, to commit suicide.¹⁶

Social isolation is costly for the community as well. A US study in 2017 that examined US Medicare spending data found that the program spent \$1,608 more annually for each socially isolated older adult than it did for those in the connected category who had more typical levels of social contacts. This additional spending is comparable to what US Medicare pays for certain chronic conditions, such as high blood pressure and arthritis. Overall, a lack of social contacts among older adults is associated with an estimated \$6.7 billion in additional federal spending annually.¹⁷

Reducing barriers to inclusion through the built environment, such as minimum accessibility standards for residential dwellings would help support greater inclusion of people with a disability and reduce costs for the community as well.

8b. The cost benefit of hospital in the home (HITH)

Amaze considers that a potential by-product benefit of minimum accessibility standards would be the reduction in demand for our hospital services, as greater accessibility would enable people to have their health needs supported through programs like HITH. Amaze notes a meta-analysis study, which concluded that the cost for HITH care was 73.5% compared to hospital based care.¹⁸ This would be of greater importance in future years due to Australia's increasingly ageing population.

9. Closing

We thank you again for the opportunity to provide this submission. We look forward to reviewing the RIA once it is released.

If you have any questions or we can provide further information, please contact Braedan Hogan, Amaze's Manager, Public Affairs and NDIS Transition on (03) 9657 1650 or via email at braedan.hogan@amaze.org.au.

¹⁴ Orsmond G et al. 2013 Social Participation Among Young Adults with an Autism Spectrum Disorder, published in: J Autism Dev Disord. 2013 Nov; 43(11): 2710–2719. Found at: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3795788/>

¹⁵ Cusack J et al 2017. Personal tragedies, public crisis – The urgent need for a national response to early death in autism. Autistica, supported by Deutsche Bank. UK.

¹⁶ Hirvikoski T et al 2015. Premature mortality in autism spectrum disorder. The British Journal of psychiatry, 207(5), cited in Cusack J et al 2017. Personal tragedies, public crisis – The urgent need for a national response to early death in autism. Autistica, supported by Deutsche Bank. UK.

¹⁷ Flowers L et al. 2017 Medicare Spends More on Socially Isolated Older Adults. Found at: <https://www.aarp.org/content/dam/aarp/ppi/2017/10/medicare-spends-more-on-socially-isolated-older-adults.pdf>

¹⁸ Caplan G et al. A meta-analysis of "hospital in the home" Med J Aust 2012; 197 (9): 512-519. 2012. Found at: <https://www.mja.com.au/journal/2012/197/9/meta-analysis-hospital-home>

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