# Submission to National Autism Strategy

Submitted by Helen Said

CONTENTS	PAGE
About me	3
What does a National Autism Strategy need to achieve?	5
How can the Strategy support the rights, autonomy, and diversity of Autistic people?	5
What needs to improve so Autistic people are better supported for their whole life?	6
What can we do to better support Autistic people from different population groups?	8
What might help to improve people's understanding of Autism?	12
Are there any areas missing from this discussion paper that should be a priority in the Strategy?	18

### About me:

I am proudly Autistic, a migrant, and a 65 year old single mother. I was diagnosed with 'Aspergers' ten years ago. I have two adult neurodiverse children who are both leading happy, active lives. I am moderately 2e (twice exceptional), having both strong analytical / mathematical abilities and an Autism diagnosis. I am self-employed in various tutoring roles as well as sitting on advisory boards of CALD Autism research projects.

I am also politically inclined, having found out about global warming whilst at university in the 1970s, and being vocal about various social and equity issues throughout most of my life. I founded the group Neurodivergent Labor (formerly Spectrum Labor) six years ago. Please note that this is my individual submission and I am not writing this for or on behalf of any group.

I enjoy and prefer my lifestyle and Autistic attributes, despite having faced numerous obstacles and prejudices because of intersectional issues. As an immigrant child and as a girl who excelled in maths, growing up during the bad old racist, sexist days, other people's prejudices cast a long shadow over my younger life which clouded and complicated my inborn Autistic differences. Although there has been a long journey to finding my voice and identity, I enjoy good mental health and a positive outlook on life. I haven't always been content with life, but I've always believed that whenever there's a problem there's always a solution, even if it's not immediately obvious.

I was fortunate to grow up in a migrant family that valued our differences and actively dispelled the prejudices of our day. My parents were both from a mixed ethnic background and identified as Greeks from Egypt. Most unusually for migrants in the early 1960s, my parents were well educated and did white collar jobs. My parents instilled into me that we were different from our neighbours but worthy people who descended from ancient advanced civilisations.

My father frequently talked about his promotions at work (but didn't share much about the resistance he faced from Anglo Australian colleagues until much later in life). He read self-help books which I often borrowed. He also got involved in early multicultural reforms when I was a teenager, which impressed upon me that disadvantage came from an unequal society, not from personal shortcomings. I later went to university and engaged in student activism, including socialist politics and feminism, which further reinforced my conviction that poor life outcomes were the product of social inequality; society has its shortcomings and society can be changed. These realisations vastly improved my self-esteem and optimistic outlook on life. Despite knowing nothing about Autism until middle age, I did learn earlier on that there are many different ways of being and that a person can thrive without conforming; difference didn't mean that a person was flawed.

I have continued to read many self-help and self-improvement books and articles which contain good guidance about positive thinking, assertiveness and social strategies. I've also read a lot about society and Autism, including attending Reframing Autism's Autistic Welfare course, all of which helped put things into perspective.

I believe that most Autistics, regardless of measurable IQ or communication methods, possess strong abilities and interests that should be enriching our own lives and society. It is a tragedy, for Autistics, their families and society, that bullying, misunderstandings and mental health pressures prevent many Autistics fully utilising their abilities.

A recent study by researchers at the University of Iowa found that "autistic children are almost six times more likely to have thoughts of suicide if they have an IQ of 120 or higher than if they have average IQ."

Further, "The study shows that in non-autistic youth, high IQ was a protective factor against thoughts of suicide. Strikingly, the trend was the opposite in autistic youth, where those with exceptional cognitive ability were at increased risk for suicidal ideation."

https://medicine.uiowa.edu/content/autism-combined-high-iq-increases-risk-suicidal-thoughts#:~:text=The%20study%20shows%20that%20in,increased%20risk%20for%20suicidal%20ideation.

As a moderately 2e Autistic, I do not believe that mental health problems are our destiny, in fact I believe that, with self-acceptance, social acceptance, an outlet for our passions, non-judgemental support and the right environment, almost all Autistics can enjoy good mental health, develop our abilities and make significant contributions. Autistics like former Australian of the Year Grace Tame and climate activist Greta Thunberg show just what is possible, and there are many other examples of diagnosed and presumed Autistics including Temple Grandin, Elon Musk, Sir Isaac Newton and Albert Einstein.

I will now address the key discussion questions from the National Autism Strategy discussion paper:

## What does a National Autism Strategy need to achieve?

The National Autism Strategy needs to achieve good life outcomes for all people regardless of inborn brain type. Good life outcomes are not just the absence of mental health issues and socioeconomic problems, the absence of things we don't want, but should include the presence of things we do want - a long and healthy life, a joyful life, choice and control, feeling accepted and respected while maintaining our innate differences, the unhindered ability to develop and utilise our talents.

There is a reason why we have different brain types in the world; we all have something to contribute to the diversity of our world and to human advancement. We need to achieve a society which is committed to unlocking Autistic potential, not just to be fair to us, but to allow us to lead and contribute according to our abilities, to allow society to benefit from what we have to offer.

# How can the Strategy support the rights, autonomy, and diversity of Autistic people?

The strategy needs to examine every aspect of society and life and ask, "Is this enjoyable, accessible, safe and meaningful for all Autistic people?" eg Shopping centres – is the lighting, noise, clutter, direction finding, staffing levels and staff training, car parking and public transport, quiet areas, toilet facilities and available services and merchandise equally appropriate for Autistics and non-Autistics alike, including Autistics who face intersectional issues? Similar questions need to be asked about every other aspect of society, be it hospitals, education, employment, libraries, the justice system, housing, research projects, the goods we buy or the services we use.

Once we ask these questions, we, as a society - governments, service providers and boards of management in particular - need to start addressing the shortfalls. We need to adopt goals and plans to address the shortfalls and provide the funding to get the job done. It's not somebody else's job. It's not too expensive to properly accommodate the many Autistics who presently depend on welfare, NDIS, mental health services or get ensnared in the justice system – indeed, it's too expensive for society to continue alienating Autistics and wasting our potential.

The strategy needs to strive to eliminate ableist discrimination with the same clarity and determination with which we confront racism and sexism, with the same consequences for vilification and discrimination of all kinds.

## What needs to improve so Autistic people are better supported for their whole life?

We need to get away from this idea that Autism always means Autistic kids, which means abandoning the puzzle piece and kiddyish primary colour schemes as symbols of Autism. Organisations which speak on behalf of Autistics and the Autism community must have majority Autistic control. This can be legislated and achieved in stages, similar to the way in which some organisations have adopted and achieved gender balance (eg the success of Emily's List in changing parliamentary representation). The voice of parents and experts should always be respected but should never over-ride that of Autistic adults in matters that affect Autistic adults' lives.

Ultimately, choice and control rests with changing culture, public perceptions and fundamentally changing society's leadership, including parliamentary representation, so that parliament and all levels of leadership are as diverse as the societies they lead. Again, think Emily's List and affirmative action targets. I am the founder of Neurodivergent Labor (formerly Spectrum Labor), the first political party-based Autism advocacy group in Australia, which supports and advocates for Autistics and other neurodivergents on their political journey. Similar organisations are needed in all political organisations and throughout society to support Autistics in all walks of life.

Neurodivergent Labor aims to provide a safe space for Autistics and other neurodivergents within the political sphere and help develop policy. Autistic influence in Australia's leadership and decision making is sadly lacking, with the exception of the late former Deputy Prime Minister, National Party MP Tim Fischer, once Australia's best known rail enthusiast, who led Australia's successful gun control measures. In 1999, after retiring, Tim Fischer spoke to ABC Radio about his Autism self-diagnosis and explained how Autism helped him scale the political heights.

(Fischer, Tim (13 December 1999). "Tim Fischer tells of life with autism". <u>AM</u> (Interview). Interviewed by Kieran McLeonard. Australia: <u>ABC Radio National.</u>)

To date, no Australian politician has ever disclosed an Autism diagnosis or self-diagnosis while in office or prior to being successfully elected. This can and should change: several openly declared Autistics have been elected to public office in the United States in recent years, including Jessica Benham (Democrats), Yuh-Line Niou (Democrats) and Briscoe Cain (Republican). Australian Autistics need representation as much as anybody else.

Choice and control are needed at every step of our lives. Schools, workplaces, recreational facilities, community organisations and aged care services should all be prepared to accommodate Autistics. While the NDIS is helpful, the rest of society should be making room for differences. Recreational facilities that allow and encourage people to get together around typically Autistic passions eg computer nerds, animal lovers, train enthusiasts, dinosaur fans, should be nurtured and encouraged in all areas. Work and study arrangements that allow down-time, bi-phasic sleep cycles and accommodate different learning and social styles and sensory needs should be developed wherever possible.

More research needs to be done to support Autistics in all phases of life. All such research needs to be done either by Autistic researchers or using research co-design where Autistics guide and monitor research at all stages. Statistics gathering regarding Autism needs to be done through the National Census.

The following organisations have called for a question about Autism to be added to the 2026 National Census:

- Australian Autism Alliance submission to NDIS Review <a href="https://australianautismalliance.org.au/national-disability-insurance-scheme-ndis/">https://australianautismalliance.org.au/national-disability-insurance-scheme-ndis/</a>
  - Illawara Shoalhaven Local Health District submission to ABS Census review
- Neurodivergent Labor submission to ABS Census review
   <a href="https://consult.abs.gov.au/census/2026-census-topic-consultation/consultation/published\_select\_respondent?show\_all\_questions=0&sort=submitted&order=ascending&q\_text=autism</a>

- What can we do to better support Autistic people from different population groups? This Includes:
  - First Nations Autistic people
  - Autistic people from culturally and linguistically diverse communities – including those from multicultural, immigrant, and refugee backgrounds?
  - Autistic women and girls
  - Autistic people that identify as LGBTQIA+
  - o Autistic infants, children, and young adults
  - o older Autistic people
  - Autistic people who also have an intellectual disability.

I will deal primarily with CALD Autistics since this is where I have the most personal experience. Since receiving an Autism diagnosis ten years ago, I have become one of very few Autistic migrant self-advocates in Australia. Ten years ago, I couldn't find anything on the internet about CALD Autistics in Australia. I did find some comments from Black Americans, bemoaning the fact that people told them, "I thought only white folks got Autism", while Asian Americans commented that people said, "But why do you think you're Autistic? Asians are supposed to be nerdy anyway."

I also noticed that many websites that published information about Autistic traits seemed geared towards identifying the social differences of Autistics within the Anglo-Australian culture. Irritable Bowel Syndrome was said to be a common complaint amongst Autistics, but most food exclusion and inclusion lists to help people with IBS only mention typically Anglo-Australian foods.

It is acknowledged that the medical establishment less readily recognises the signs of Autism amongst women and girls because of the different female presentation of Autism, however ethnic biases don't seem to rate a mention in this discourse. Yet as pointed out in the report on Chinese families' experiences (website given below), "Whilst children from immigrant backgrounds living in Australia are more likely to gain an autism diagnosis (Abdullahi et al., 2017, Gao et al., 2022), they often receive diagnoses much later than White counterparts and present with more significant autism characteristics (Mandell et al., 2009). Further, these children and families appear to be less well supported following diagnosis. Autism is the most common primary diagnosis for participants of the Australian National Disability Insurance Scheme<sup>1</sup> (NDIS; National Disability Insurance Agency, 2022), but the share of CALD participants receiving NDIS support for autism is proportionally lower (19 %) than for non-CALD participants (26 %) (National Disability Insurance Agency, 2019). Moreover, poorer outcomes for CALD autistic children have been reported across areas including social connection, meaningful decision-making and attending mainstream schooling (Happe and Frith, 2020, National Disability Insurance Agency, 2019, Royal Commission into Violence Abuse Neglect and Exploitation of People with a Disability, 2021)."

Information about Autism isn't targeted towards ethnic communities (it's not just a matter of google-translating a brochure) and there is a lack of peer support for migrant Autistics and Autism parents, including educating and supporting extended families, since extended families play a bigger role in the lives of Autistics from CALD backgrounds. Because many newer migrants come from poorer countries which have

directly or indirectly been impoverished by white colonialism, old fashioned attitudes towards disability and Autism still hold sway with many migrants. Stigma plays a part in delayed diagnosis, isolation of families and hiding Autistic or disabled family members. More details will come out of the Disability Royal Commission.

I cannot find any research at all about Autistic adult migrants and rarely meet or hear of non-Anglo Australian Autistics my age. Yet Autism is a lifelong social, sensory and thinking difference and a steady 2-3% of all populations has always been Autistic (no, we are not a modern epidemic). The Autistic rights movement is heavily Anglodominated, and this is only now beginning to change. The Anglo domination of the Autistic rights movement is not a reflection of the practices or desires of Autistic advocates, who are by and large very aware and egalitarian, but rather a reflection of the ethnic biases of the medical world and the burden of disadvantage faced by CALD Autistics.

\*

# TRIGGER WARNING Discussion of negative Autism stereotypes

There are examples of intersectional issues of race and Autism being pursued in Australia. For example, in 2019, local Autism dad Binoy Zacharia successfully campaigned to stop Father Dominic Valanmanal of the Syro Malabar Catholic Church based in Kerala, India, visiting Australia to conduct a five-day long "residential retreat" for parents of Autistic children in Phillip Island Victoria, after Malayalam language videos surfaced in which the priest linked children's Autism to parents' "sins" such as "alcohol, cigarette, beedi (Indian cigarette) drugs, adultery, masturbation, homosexuality and porn films" and called Autistic children "animals." The issue was widely reported in ABC and SBS news. It is clear from this example that a National Autism Strategy must protect Autistics from the reintroduction of any Religious Discrimination Bill that would enshrine this type of pseudo-religious hate speech.

\*

This begs the question, how was Father Valanmanal granted a visa to come to Australia in the first place? Under Section 501 of the Migration Act, subsection 501(6)(d) provides that a person does not pass the character test to get a visa if there is a significant risk that, while in Australia, the person would "vilify a segment of the Australian community, incite discord in the Australian community or in a segment of the community or represent a danger to the Australian community or to a segment of the community, whether by way of being liable to become involved in activities that are disruptive to, or in violence threatening harm to, that community or segment, or in any other way."

Clearly Father Valanmanal vilifies a section of the community – Autistics and their parents. If the migration character test had been applied to him, he would have been refused a visa and his visit would have automatically been cancelled. Instead, CALD Autism parents had to campaign in the media and run a petition to stop the kind of hate speech which isn't tolerated towards any other section of our community. Clearly Autistics need the protection of Section 501 of the Migration Act and strong anti-vilification legislation (to be further dealt with later in this submission.)

As I cannot find any Australian research about CALD adults on the Autism spectrum, I began volunteering as an Autistic research subject so that I could directly confront researchers about their ethnic biases during my research interviews. The strategy paid off. In 2021, an Autism researcher connected me to Positive Partnerships – Macquarie University ground-breaking research into the Home-School Partnerships of migrant parents with Autistic children and I was offered a position on their Middle Eastern/Refugee research advisory board. The research report "Culture and Connection" has since been published on the Positive Partnerships website and I have been acknowledged for my contribution to the research on page vii of the report.

### chrome-

extension://efaidnbmnnnibpcajpcglclefindmkaj/https://www.positivepartnerships.com.au/uploads/MACQ-60532-Culture-Connection\_FINAL.pdf

It proved very difficult to recruit Middle Eastern/Refugee parents as interviewees, despite having interpreters and being granted a free advertisement in "El Telegraph". The "El Telegraph" ad yielded no response, although I feel it was valuable in helping to normalise discourse around the subject of Autism within Arabic speaking communities. It seems some migrant parents distrust the confidentiality provisions of research, are fearful of immigration authorities and find disability difficult to accept and discuss.

I have since been involved in a 2022 research project about Chinese parents' experiences with early intervention services and have been acknowledged as an author of the research report. ("What Is Early Intervention? I Had No Idea": Chinese Parents' Experiences of Early Supports for Their Autistic Children in Australia is available on ScienceDirect.)

I am concerned that Middle Eastern families may be bypassed in future research due to recruitment difficulties, yet there are many issues facing Middle Eastern Autism families that need to be addressed – the recruitment difficulties are in fact a sign that Autism is less acknowledged and understood within this community and that the research is thus more urgent.

Nothing is being done to make it easier for older immigrants to get a diagnosis. Autism is assessed through looking at social differences, but migrants are made to feel "othered", that our differences are because we are non-Anglo. This especially applies to migrant women - if we are stressed, we are made to feel like hysterical foreigners (think Mediterranean stereotypes). If we are shy, we must be repressed by traditional families (think Muslim stereotypes). If we have trouble communicating people assume we can't speak the language or have cultural differences. These assumptions are prevalent and seem to explain away differences, so make it harder for an adult migrant to gain a diagnosis. No research has been done on the barriers facing CALD Autistic adults and I have complained directly to Autism researchers when I have volunteered as a research subject. One researcher has promised to contact me later this year with a view to starting Australia's first ever research project specifically into the needs of CALD Autistic adults. It sounds great, but the lack of Australian CALD adult Autism research to date is nothing to celebrate.

The impact of lack of diagnoses on migrant women is profound – if a migrant woman must walk a tightrope to gain social acceptance, the Autistic migrant woman will be the first one to fall off. As Autistics we lack the ability to achieve this social balancing act to deal with other people's prejudices towards us.

My Autism diagnosis has given me the ability to let people know that I am socially, ideologically and intellectually different so we may not like the same things or do things the same way. I disclose my Autism diagnosis as I get to know people. I feel reassured when people can anticipate that, while I might at times appear different, they have some reasonable explanation for my differences without feeling suspicious towards me. There is otherwise some suspicion towards me as a very logical, forthright migrant woman. As a migrant woman, I don't offer the stereotypical ice breaking conversation starters, like sharing exotic recipes, since my special interests are campaigning and policy development. Some people find this confusing and threatening. My concern is that the ethnic biases in Autism research and advocacy mean most adult CALD Autistics remain undiagnosed and lack the information to make sense of their social differences or to self-advocate, with detrimental consequences.

A National Autism Strategy should highlight the need for social and medical researchers to overcome ethnic biases, so that research can investigate the needs of multiply marginalised and previously ignored sections of the population, such as Autistic migrants. In addition to interpreters and regular Autism research coproduction, researchers need both the funding and the motivation to establish CALD and Indigenous advisory groups to ensure all research questions and recruitment strategies are respectful and targeted towards recruiting CALD and Indigenous subjects for research, and that research findings are relevant to all ethnic groups and interpreted and presented through an Indigenous and CALD lens. Funding should be available to assist researchers to partner with ethnic and Indigenous organisations to incentivise such research amongst the diverse communities. This should be seen as an investment, not an expense, since research outcomes will help strengthen communities and improve life outcomes for the most marginalised Autistics, ultimately improving their productivity.

Additionally, Centrelink needs to be told that Indigenous and CALD Autism research advisory work is an important job, so that Indigenous and CALD Autistics and Autism parents, who face intersectional issues and are often short of time and energy, can devote themselves to this type of advocacy, for the good of the most vulnerable in our community, without being harassed into dropping such part time positions and accepting meaningless Centrelink job search activities.

## What might help to improve people's understanding of Autism?

The main improvement will come when people meet Autistics, get used to us and think, well they're OK. It was like this with Mediterranean migrants – we used to be disliked and mistrusted by many Anglo Australians in the 1950s and 60s, but during the 1970s and 80s, people started saying they knew some Greeks and Italians and they're OK.

Many people knew nothing about Autism until the 1990s or 2000s, and Autism is not a single easily defined condition, so it is not surprising that many people still do not understand much about us. Over the years, I have seen attitudes towards migrants and women change and I am confident we can change Autism understanding and acceptance, but it doesn't happen automatically.

The biggest single factor that helped change perceptions of migrants was sharing food and culture. Autistics have a lot to share and we can put ourselves out there, get known and participate in community life. I spoke on the topic "Flourishing in the Community" at Reframing Autism's 2021 Autistic Flourishing Symposium and my speech was summarised as a tip sheet which is available on the RA website. https://reframingautism.org.au/flourishing-in-the-community/

In this tip sheet, I argue that community groups can be varied in their membership yet specific in their interests and provide an outlet for Autistic passions. Perhaps the best example of Autistic passions which can win admiration and respect are the volunteers who run miniature rail ventures and model train exhibitions which delight children and attract tourism to country towns. But for such ventures to promote Autistics, not just train spotting passions, the public need to know that these ventures are run by Autistics; thus more Autistics need to feel comfortable disclosing their diagnosis.

In the last Autism research project I worked on, I was part of the Autistic adults' advisory group. I was listed as an author, the Autistic adults' advisory group was mentioned, my background in education was cited but nothing was said about who was in the Autistic adults' advisory group. I would have thought that my Autism status was just as relevant to the research as my background in education, but it seems inappropriate to say you're Autistic – even in Autism research! In all future Autism research projects I work on, I will ask if I can disclose as an Autistic parent with Autistic offspring in the final report.

Disclosure should become much more common to enhance Autism acceptance and understanding. Leading the way in celebrity Autism disclosure are people like former Australian of the Year Grace Tame, teenage climate activist Greta Thunberg, scientist Temple Grandin, billionaire Elon Musk and actors Daryl Hannah and Dan Ackroyd. This trend needs to continue and we need to celebrate the achievements of Autistics of all abilities.

I believe we need Autistic Pride events which promote our abilities rather than being dominated by helping professions. An Autistic pride event could be a display of inventions, collections and artworks by Autistic people, some talks by Autistics about their special interests, performances by Autistic musicians and comedians, some recordings or photos of Autistic people who are unable to be physically present at large gatherings and free Autistic-led computer classes throughout the day. Specialist

Autism schools could contribute children's artworks and recordings of their school productions; every Autistic person in Australia should be invited to send items, photos or recordings or be present and speak at such an event. I could envisage an Autism Pride event becoming an Autism festival or part of a wider Disability Pride week.

Accompanying the increased acceptance of all minority groups has been the development and implementation of anti-discrimination and anti-vilification measures. Autistics need anti-vilification laws on a par with racial groups, to make people think twice about spreading misinformation or bullying, and to give Autistic victims redress.

### TRIGGER WARNING

### Discussion of negative Autism stereotypes, murder, sexual violence

In recent years, numerous public figures have contributed to negative public perceptions of Autistics, which need to be actively debunked to improve people's understanding of Autism.

- Former US President Donald Trump linked vaccines to Autism, a view echoed by Pauline Hanson
  - https://www.seattletimes.com/opinion/trumps-reckless-linkage-of-vaccines-and-autism/ and
  - https://www.abc.net.au/news/2017-03-06/health-groups-appalled-by-hanson-vaccination-remarks/8328714
- One Nation Senator Pauline Hanson called for Autistic students to be removed from regular classrooms <a href="https://www.abc.net.au/news/2017-06-21/pauline-hanson-under-fire-repulsive-bigoted-comments-autism/8640328">https://www.abc.net.au/news/2017-06-21/pauline-hanson-under-fire-repulsive-bigoted-comments-autism/8640328</a>
- Newscorp journalist Andrew Bolt criticised climate activist Greta Thunberg, calling her "deeply disturbed" due to her Autism and "freakishly influential", which breached Australian Press Council standards
   https://www.theguardian.com/media/2020/jun/04/andrew-bolts-column-mocking-greta-thunberg-breached-standards-press-watchdog-finds
- National Party Senator Barry O'Sullivan claimed that the banks have shown an "almost autistic disregard" for the law <a href="https://www.abc.net.au/news/2017-11-27/barry-osullivan-urged-to-apologise-over-autistic-jibe-at-banks/9197614">https://www.abc.net.au/news/2017-11-27/barry-osullivan-urged-to-apologise-over-autistic-jibe-at-banks/9197614</a>
- Professor Jeremy Nicholson, head of the Australian National Phenome Centre, described Autism as "a silently growing monster" and "the most expensive disease in the Western world."
   <a href="https://www.perthnow.com.au/news/public-health/autism-community-hit-back-at-comments-from-professor-jeremy-nicholson-ng-b881057316z">https://www.perthnow.com.au/news/public-health/autism-community-hit-back-at-comments-from-professor-jeremy-nicholson-ng-b881057316z</a>
- Celebrity gardener Don Burke cited "Aspergers" as his excuse for bullying staff and sexually inappropriate behaviour

https://theconversation.com/no-don-burke-there-is-no-link-between-autism-and-harassing-behaviour-88237

It's not hard to see, from the examples cited above, that some of our society's leaders, and sections of the commercial mass media, are harming the public's perception of Autistics. To improve people's understanding of Autism, these negative depictions must stop.

Often these negative remarks are countered by leaders of Autism organisations which are not Autistic-led and where the spokesperson is likely non-Autistic. While community support is vital, the media's default position seems to be to choose non-Autistic or non-disabled spokespeople to defend Autistics. This is quite different to the way in which other disadvantaged groups are treated by the media – eg Indigenous groups have Indigenous spokespeople and women's groups have female spokespeople. When others are chosen as our spokespeople, no matter how well-informed and sincere they are, this can make Autistics look like we cannot stick up for ourselves and marks us as an easy target for further abuse.

Tougher anti-vilification laws could help discourage these sour depictions of Autistics and let us define who we are, but we are a long way from achieving this. As described in the June 4 2020 Guardian article quoted above, the Australian Press Council admirably ruled that Andrew Bolt's criticism of Greta Thunberg, on the basis of her Autism, "breached standards and was likely to cause substantial distress, offence and prejudice." However, the Press Council did not have the power to stop Bolt from continuing to make distressing, offensive and prejudicial media statements about Thunberg on the basis of her Autism.

Disappointingly, the Press Council defended Bolt's right to continue his remarks about "Thunberg's disorders", and her "symptom of autism and forms of Asperger's," with Bolt calling her a "freakishly influential goddess of global warming" and a "holy fool". The Press Council stated, "The objects of the Press Council are to promote freedom of speech through responsible and independent media and adherence to high journalistic and editorial standards. Consistent with that object, Press Council member publications [ie Newscorp, which publishes Bolt's columns] are at liberty to comment on the Press Council's adjudications." Clearly, Bolt's rebuttal of the Press Council's adjudications, which the Press Council itself condoned, caused further hurt to the Autism community. The Australian Press Council has shown that it is ultimately an ineffective weapon against those who vilify us. This demonstrates the need for Autistics to be protected by anti-vilification legislation.

As a step in the right direction, the National Autism Strategy could promote guidelines for respectful reporting and discourse about Autism. As a university student, the publication of the MacGraw-Hill Guidelines for non-sexist language, in the 1970s, had a profound impact on me. For example, the impersonal "he" was to be replaced by "he/she" (now being further replaced by the non-binary "they").

### https://www.jstor.org/stable/41592601?typeAccessWorkflow=login

The changes in language helped revolutionise women's place in society, and I am confident respectful language about Autism could have a similar impact on Autistics.

While there are guidelines around non-pathologising language to describe Autism and Autistics, these have yet to be adopted by sections of the medical profession, teaching profession and media. The National Autism Strategy should prioritise promoting and enforcing language change as a pathway to attitudinal change, while pursuing options to enforce attitudinal standards through anti-vilification legislation nationally and in all states and territories.

Stereotyped depictions of Autism need to be challenged. Sadly, negative stereotypes of minorities will threaten for as long as we have a commercial mass media driven by profits and a public hungry for sensationalism. Public education combined with enforceable media standards and articulate, actually Autistic spokespeople will undercut negative stereotypes and help change public perceptions.

Well-meaning stereotypes, that Autistics have more simple or natural minds, that we think like a cow for instance, can quickly morph into mistaken views that Autistics think or react like animals and lack self-control, and are thus more prone to violence. Repeated sensationalised media portrayals of distressed Autistic children, interspersed with spine chilling reporting of horrific lone wolf crimes committed by Autistics, creates the knee-jerk reaction that these people need to be shut away, that they are a puzzle piece, a danger, that they need to be spoken for by experts, that they are damaged... they need a cure.... we had better avoid vaccines just in case our kids turn out like them.....

Take for example Don Burke's bogus claim that "Aspergers" caused him to harass and sexually assault women (see The Conversation article of November 28 2017 quoted above) – an impression is immediately created that Autistic men are dangerous. How many Autistic men could have been denied jobs, rejected as dates or masked their diagnoses because of this news item? How many more men avoided seeking an Autism diagnosis to disassociate themselves from such behaviour? For every irresponsible media statement suggesting women are unsafe around Autistic men, a public education campaign is needed to undo the damage done to Autistics.

The National Autism Strategy cannot afford to politely sidestep negative media messages surrounding Autism; it should empower advocates to loudly and bravely debunk these falsehoods and re-educate the public. We can look to the ongoing successes of the Muslim community in dismantling Islamophobia for inspiration and a way forward.

Media reports of gun violence which repeatedly refer to the danger posed by "lone wolves", be they Autistic or not, can lead to suspicion of many Autistics' preference for spending time alone. Lone wolves who spend time alone are no more dangerous than violent gangs who spend time together — lone wolves evoke suspicion about how Autistics like to spend time alone, yet violent gangs don't evoke suspicion about how non-Autistics like to spend time together.

Advocates frequently remind the public that Autistics are more likely to be the victims rather than the perpetrators of violence. However, from time to time, we have to confront the fact that some Autistics have committed unthinkably brutal crimes while continuing to defend the Autistic community as a whole.

Tragically, in 2012, Adam Lanza, a young Autistic, killed 20 children and six staff at Sandy Hook Elementary School in the US, as well as his mother, before killing himself. According to the Independent 25<sup>th</sup> October 2017 Autism was not the cause of this massacre – "...Adam Lanza never accepted he had Asperger's syndrome, a condition on the autism spectrum, and never took medication he was prescribed. A report by the Connecticut child advocate in 2014 concluded Lanza's autism spectrum disorder and other psychiatric problems didn't cause or lead directly to the massacre. The report said Nancy Lanza rejected psychologists' recommendations her son be medicated and undergo rigorous treatment as a child for anxiety and other conditions. It said Adam Lanza, his parents and his educators contributed to his social isolation by not confronting his problems..... Lanza shot the children and educators with an AR-15-style rifle legally purchased by his mother, who took him to shooting ranges, authorities have said."

Apart from the obvious need to control guns in the US, I believe that better community attitudes towards Autism and mental health, and more positive media portrayals of Autism could have helped Adam and Nancy Lanza accept the Autism diagnosis and psychologists' recommendations, and helped avert this whole tragedy.

Much loved Melbourne comedienne Eurydice Dixon was shockingly raped and murdered in 2018 by Jaymes Todd, who had "a sexual sadism disorder, and had watched violent pornography before and after he attacked Ms Dixon as she walked home after performing comedy in the city on June 12 last year," according to ABC News 2<sup>nd</sup> Sept 2019.... "The court also heard that at the time of the offence, Todd lived with his parents in Broadmeadows in a home of 'rotting refuse' and 'squalor' which would have affected his emotional state."

While Todd is on the Autism Spectrum, this wasn't mentioned by the ABC News outlet as this clearly wasn't cited by the judge as the reason for the crime or Todd's high chance of re-offending. Disappointingly, The Guardian on 15 August 2019, usually a progressive news source, stated, "The court was told Todd, who has autism, spotted Dixon at Flinders Street Station after he had spent the afternoon drinking alcohol and smoking cannabis." The Guardian chose to highlight Autism despite the fact that Todd's Autism was clearly not the cause of the crime. In so doing, The Guardian bought into Autism "Bewareness", contributing to the false portrayal of Autism as a rape/murder risk factor and this is disappointing.

According to the New York Times, Aug 10 2019, "A Common Trait Among Mass Killers: Hatred Toward Women - The motivations of men who commit mass shootings are often muddled, complex or unknown. But one common thread that connects many of them — other than access to powerful firearms — is a history of hating women, assaulting wives, girlfriends and female family members, or sharing misogynistic views online, researchers say."

According to these researchers it's misogyny, not Autism (and not Islam) that should be highlighted in mass murders. Some violent crimes are committed by criminals who are clearly non-Autistic, as they use devious charms and lies to entrap their victims – yet these crimes are not thought to be an indication of how the non-Autistic mind works. Negative stereotyping is applied to the misunderstood minority group only.

In summary, we can improve public understanding of Autism by encouraging Autistics to put ourselves out there in the community, share our passions and publicly display our pride in who we are. Anti-discrimination and anti-vilification measures are needed to counter negative treatments and portrayals. Respectful language needs to replace pathologizing treatment. The National Autism Strategy needs to empower actually Autistic spokespeople to debunk negative stereotypes and myths about Autism.

 Are there any areas missing from this discussion paper that should be a priority in the Strategy?

### YES

### **Support 2e Autistics**

As a moderately 2e Autistic, I am most concerned about the level of prejudice and distress experienced by Autistics with high IQ, which contributes to high levels of suicidal ideation. While the whole world is allowed to see the bulging muscles of athletes and discuss every statistic associated with their prowess, if an intelligent Autistic, especially a woman, dares to reveal her maths skills or IQ she is considered an arrogant sexless snob – it's one rule for athletes and another rule for intellectuals. Is it any wonder that some high IQ Autistics become so miserable that they want to kill themselves? High IQ Autistics are idolised for their skills one minute and bullied for them the next. We never know what sort of treatment is around the corner since we cannot predict this fickleness. High IQ non-Autistics probably have a better chance of sorting through this ambivalence.

# Migration health tests label Autistics as a burden

Migration health tests insult all Autistics by labelling us as a burden on Australian society. Because of costs to the taxpayer, Australian born CALD Autistic babies and their families are regularly threatened with deportation to countries where Autistic children can be denied education, therapies and health services and where they and their mothers are virtual prisoners in their homes because of lack of social acceptance. Non-permanent resident families may avoid having their Autistic children diagnosed and accessing early intervention services for fear of being deported. Then when they finally gain Permanent Residence, these Autistic children are already a long way behind. Protecting Australian born CALD Autistic children, regardless of their visa status, should be a priority of this strategy. For more information, please refer to <a href="https://www.welcomingdisability.com/">https://www.welcomingdisability.com/</a>

### **Dyspraxia and Physical Education**

Dyspraxia, difficulties in sport, in our sport driven culture is a big one for us and more common amongst Autistics. Not enough research is done to help Autistics who struggle with Phys Ed and fitness. It is genetic, we are not just couch potatoes. My older daughter (self diagnosed Autistic ADHD) just got her ancestry genetic test back which gave her ethnic make-up. It also says, based on her genes, she is more likely to be introverted, a picky eater and her muscles tire more easily after exercise, all of which is true and is part of Autism. So where is the Integration support at schools for kids who struggle with sport? The issue is lost in the noise about an obesity epidemic and difficulty with sport is seen to have a moral cause.

As an Autistic I excel in maths and tutor students (I don't teach in a regular school because of my issues with hierarchy and the social and sensory environment, especially chit chat and power politics). I have never called a kid who struggles in maths a couch potato or made them feel responsible for their issues - when will there be a similar level of understanding for kids who struggle with sport? My younger (diagnosed Autistic) daughter couldn't walk until she was two and a half, but was constantly bullied in sport at school and I was always complaining to the school, but

sporting culture and Phys Ed is so competitive that the bullying always returned. I sent my kids to several specialised fitness programs after hours but these weren't subsidised and were closed down when they failed to make a profit. Clearly fitness is a health issue affecting the life span and quality of life for Autistics. The National Autism Strategy needs to adopt plans for keeping Autistics fit and healthy throughout our lives.

## Frame Autism Positively

I believe our National Autism Strategy should frame Autism positively, without shying away from the various challenges and inequities that Autistics face. The National Autism Strategy should call for the identification and nurturing of Autistic strengths in each Autistic individual and point out how this will benefit society. This is not just because our talents can be monetised, but because the National Autism Strategy can only achieve its objectives if it inspires positivity.

To give an example, I went to an allied health professional for my arthritis pain and she repeatedly implored me to do these mediocre exercises to "slow the decline" of my aging joints. The exercises lasted a fortnight and I could not face them after that as the negative messaging dragged me down. Eventually I attended a local Senior's exercise program where I was told that "we lose muscle mass as we age", but that the exercises would "increase core strength" and "build new neural pathways". It is now inspiring to do these exercises because, although I know old age comes with disadvantages, this is counter-balanced by a mental image of positive progress.

The 2015 research conducted by the Asylum Seeker Resource Centre "Words that Work" advises supporters how to advocate for misunderstood people (in their case, refugees): "Provide aspirational calls to create something good: effective messages are two parts solution to one part problem."

In advocating for Autistics, the National Autism Strategy also seeks to overcome misconceptions and inspire positive change about a misunderstood group; I think the "Words that Work" message is relevant to the way this Strategy should be framed. Highlighting Autistic strengths and contributions, rather than purely focusing on overcoming problems, can help inspire educationalists, employers, families, service providers and Autistics themselves to work towards a brighter future.