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YELLOW LADYBUGS SUBMISSION:

NATIONAL AUTISM STRATEGY - DISCUSSION PAPER

Yellow Ladybugs is grateful for the opportunity to share our expertise and experience in making a submission to the consultation process for the National Autism Strategy Discussion Paper. In sharing this information, Yellow Ladybugs intends to further its stated mission to improve the lives of autistic girls, women¹, and gender diverse individuals, by ensuring that we are seen, heard, supported and valued. As an autistic led organisation, and Australia's largest charity supporting autistic girls, women, girls and gender diverse individuals, our submission reflects both diverse lived experience and the professional expertise of the autistic community we represent.

Autistic girls and women have been overlooked historically, due to their presenting differently, the gender bias in screening tools and diagnostic criteria, existing stereotypes about how autism presents and the way girls are socialised, and a lack of clinician training and experience in recognising girls. The commonly quoted studies in recent years suggest that boys are four times more likely to receive an autism diagnosis than girls. Recent research is beginning to confirm what the autistic community has long suspected, however, which is that there are as many autistic females as there are males. A June 2022 study found that when the common clinical tools are adjusted for sex biases, roughly the same percentage of boys and girls are identified as autistic.² This same study also noted that research is yet to accurately account for the gender diverse autistic population, many of whom are being missed for the same reason women and girls are missed. Recent studies have also found that it takes two to three years longer on average for girls to be diagnosed, and that 80% of autistic females remain undiagnosed or misdiagnosed at the age of 18.³

These barriers to diagnosis and recognition all contribute to the layered vulnerabilities autistic girls, women, and gender diverse individuals face; including economic disadvantage and inequality in healthcare, restricted access to education, lack of support in the work place, and limited access to communities and their autistic peers. Autistic girls and women have a higher rate of mental health conditions including anxiety, depression and eating disorders. Many autistic girls and women are often misdiagnosed, misunderstood, and missed completely. ***Yellow Ladybugs welcomes the acknowledgement of these issues in the Discussion paper and supporting documents for the National Autism Strategy, and notes that it is critical that this acknowledgment, and the***

¹ We use identity first language based on our community's preference. We will also use the term 'girls and women' as our key focus but also support and represent gender diverse individuals.

² www.spectrumnews.org/news/autisms-sex-bias-disappears-after-tracking-trajectories/

³ McCrossin, R. (2022). Finding the True Numbers of Females with Autistic Spectrum Disorder by Estimating the Biases in Initial Recognition and Clinical Diagnosis. *Children*. 9(2), 272 <https://pubmed.ncbi.nlm.nih.gov/35204992/>

commitment to specifically address the needs of autistic girls, women and gender diverse people is embedded in the National Autism Strategy itself.

YELLOW LADYBUGS PRIORITIES - NATIONAL AUTISM STRATEGY

In providing this submission, we would like to highlight three over-arching priorities for the Yellow Ladybugs community:

1. Autistic-led – Nothing about us without us

As the content of the National Autism Strategy is developed, the full diversity of autistic voices and experiences must continue to be central to this process. This can only be achieved via deep engagement with autistic-led organisations and the wider autistic community. As Australia's largest advocacy organisation with a specific focus on supporting and advocating for autistic girls, women and gender diverse people, Yellow Ladybugs is well positioned to provide the level of engagement needed to ensure that the National Autism Strategy is able to fulfil its objective of delivering better support and life outcomes for all autistic people in Australia, including those cohorts (eg autistic girls, women and gender diverse people) who have typically been missed and misunderstood.

It is imperative that any Strategy priorities, programmes, outcomes and solutions are co-designed, implemented and led by the autistic community. This means investment in any recommendations that come from this Strategy, including any funding or grant opportunities should prioritise user-led organisations such as Yellow Ladybugs.

2. National investment in autistic-led peer connection programmes

The National Autism Strategy offers a unique opportunity prioritise the importance of peer connections in improving life outcomes for autistic people, and to make a strong national commitment to significant and ongoing investment in autistic-led programmes that deliver authentic and strength-based peer connection opportunities. Yellow Ladybugs' youth social events programme and online peer connection communities are examples of programmes that can be scaled nationally, and expanded in scope, with proper investment. Peer connection programmes are something that have historically been undervalued, and under-invested in by governments who have typically focused on a medicalised approach to supporting autistic people. The autistic community, including the Yellow Ladybugs community have spoken clearly, however on the powerful impact user-led peer programmes can have in fostering inclusive and supportive individual and community/cultural connections. Noting that lived experience is a critical component of evidence-based research, we can demonstrate how our events programmes and peer connection activities act as a protective factor against isolation and exclusion for our community of autistic girls, women and gender diverse people, and how they do this by fostering a sense of belonging and acceptance within the framework of neurodiversity and autistic/neurodivergent culture.

3. Commit to being genuinely neuro-affirming

The National Autism Strategy must be genuinely neuro-affirming. This will require a significant shift away from the pervasive medicalised and deficit-based model of how to support autistic people. A

Strategy that simultaneously claims to have centred autistic voices, but that also continues to promote approaches built around behaviourism, compliance-based training, and teaching autistic people how to meet neuro-normative expectations, is a Strategy that is not neuro-affirming. A Strategy that aspires to the outcome of autistic people being able to meet the goals of neurotypical culture is not neuro-affirming. There is no place for Applied Behaviour Analysis (ABA), Positive Behaviour Support (PBS) and other neuro-normative therapies and approaches in this Strategy. It is time to address the flaws, conflicts of interest and ethical limitations of the so-called evidence-base behind these programmes, and to meaningfully address the harms these approaches cause to the mental health and wellbeing of the autistic community, and to understand how they contribute to the misconceptions and attitudes of wider society that autistic people are broken and disordered and need to be 'fixed'.

YELLOW LADYBUGS FEEDBACK ON THE NATIONAL AUTISM STRATEGY DISCUSSION PAPER

1. Social Inclusion

Barriers to social inclusion:

As an autistic-led and user-led organisation, Yellow Ladybugs recognise the numerous and complex barriers that prohibit many autistic girls, women and gender diverse young people from living the lives they want and from participating fully within the community. These barriers include:

- Autistic females⁴ experience social exclusion due to gender bias, stereotypes and misconceptions – this exclusion comes from their neurotypical peers, the wider community, and professionals who are less familiar with the internalised presentation of autism.
- Barriers to diagnosis and autistic identity are also barriers to participating in the community – these barriers include cost, knowledge, and access and availability of neuro-affirming professionals familiar with internal autistic presentations. These barriers to accessing our own neurology and identity have a flow on negative impact in accessing autistic culture and finding our place in the wider community.
- Intersectional disadvantage, including being female, being disabled and for many in our community, being LGBTQIA+. This intersectional disadvantage has a negative impact on autistic girls, women and gender diverse people in all spheres of participating in the community.
- Greater risk of vulnerability. Autistic girls, women and gender diverse people are at higher risk of being victims of bullying, discrimination and exclusion, violence, abuse, neglect and exploitation.

Proposed solutions – social exclusion

Addressing social exclusion and improving community participation: We are advocating for the Strategy to remove barriers to community participation by committing to a significant national investment in peer connection programmes for the autistic community, including targeted

⁴ This includes cis-females, AFAB people, those who identify as female or socialised as female.

investment in peer programmes for priority cohorts including autistic girls, women and gender diverse individuals. Our recommendations and solutions are as follows:

- Increase peer connection opportunities by investing in autistic-led programs and services that support autistic girls and women to discover their community and improve participation in ways that interest and engage them. These programs must be neuro-affirming and strengths based.
- Ongoing commitment to the principle of *nothing about us without us*. Direct engagement with autistic women, girls and gender-diverse young people, and the organisations that support them, is vital to ensuring that the needs of the wider autistic community are adequately addressed. Lived experience needs to be at the centre of every discussion.
- Support programs need to be implemented for vulnerable autistic communities at greater risk of experiencing abuse. Improved supports are needed for proactive prevention for autistic girls and women who may be susceptible to abuse, bullying and discrimination.
- Funding commitments for autistic-led programs and initiatives that encourage a neuro affirming and strengths-based understanding of neurodiversity. These programmes are not only of direct benefit to the autistic community, but are also a critical factor in changing society attitudes towards autism and creating a community that embraces autistic culture and neurodiversity.

Improving community attitudes towards autistic individuals: A society that embraces neurodiversity and neurodivergent culture is a society that can start to unpack the ableism and pathologising medical-model narrative that still dominates any discussion about autism. A priority within this, is to actively break down the stereotypes and misconceptions around autism being ‘a boy thing’ and to improve community understanding of the internalised autistic experience often seen in women, girls and gender diverse individuals. Any work in this space needs to be neuro-affirming and created by autistic individuals and autistic led organisations. Improving community attitudes towards autistic individuals involves a multi-faceted approach. We encourage the Strategy to take into consideration the following.

- Listen to autistic voices and use those voices to educate the wider community on neurodiversity. As described by the *Changing Community Attitudes to Improve Inclusion of People with Disability* report for the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with a Disability, this strategy works best when education campaigns are paired with reinforcement of legislation laws, in particular anti-discrimination laws.
- Implement neuro-affirming educational programs in schools that promote and encourage neurodiversity and acceptance, thereby reducing stigma and discrimination.
- Educate and encourage neuro-affirming media representation to help overcome stereotypes and misconceptions about autism found within the wider community.
- Implement a national community education campaign that breaks down stereotypes and misconceptions by increasing understanding of the internalised autistic experience often seen in women, girls and gender diverse individuals. Ensure that it is neuro-affirming and created by autistic individuals, and autistic-led organisations.

2. Economic Inclusion

Barriers to economic inclusion

Late diagnosis of autistic girls, women and gender diverse individuals, and poor understanding of the internalised autistic presentation both have significant impacts on their life outcomes in relation to education and employment. This results in many autistic girls and women facing additional barriers to their education, higher unemployment rates, increased mental health disorders and a loss of identity.

Education: We are advocating for the Strategy to address the specific barriers autistic girls and gender diverse students experience in the Australian school system, so they are no longer overlooked and miss out on the support they are entitled to. The National Autism Strategy must commit to the creation of a society where autistic young people are able to participate in an education experience that is built upon a neuro-affirming and inclusive school setting.

- **Autistic girls often have hidden needs and miss out on support at school.** Autistic girls and gender diverse students often have an internalised autistic presentation. With more cognitive resources to hide their autism, including better language or imitation skills and the ability to mask their autism, the needs of autistic girls are more hidden. This creates specific barriers and disadvantages when accessing supports. Education around supporting students with an internalised autistic presentation needs to be embedded into the education and training of all current and future teachers.
- Many autistic girls do not meet the criteria for school-based funding because they exhibit lower levels of disruptive behaviour and may have developmentally appropriate language skills. Exclusion from funded disability supports means that many autistic girls go through their schools years with a risk of poor education outcomes, increased mental health challenges, are more susceptible to exploitation and predators, and are at an increased risk of school refusal/school can't.
- Autistic girls are more vulnerable to bullying and abuse at school. A 2016 Yellow Ladybugs survey found that 71 percent of autistic girls reported experiencing some form of bullying, including verbal abuse, social exclusion, physical and sexual assaults, and property damage while at school. The long-term emotional impact of bullying and extended periods of feeling excluded can detrimentally impact on outcomes for autistic girls and gender diverse people, and contribute to low self-esteem, anxiety, and depression.
- School-based mental health wellbeing programmes are currently primarily based on the PBS model, which is based on behaviourism, and an off-shoot of ABA. The PBS model places neurotypical behavioural expectations on autistic young people and is focused on changing the external behaviour of students through a system of rewards (for desired behaviour) and disincentives (for undesired behaviour). PBS is widely criticised in the autistic-led/allied research and professional community for not being neuro-affirming, and for frequently causing harm to the mental health and wellbeing of autistic young people. It is time for this approach to go, and

to be replaced by behaviour and wellbeing programmes which are trauma-informed and founded on the basis of neuroception and a modern understanding of neuroscience.

Employment: While there has been some improved understanding of supporting the sensory needs of autistic people in the workplace (although this still can be deeply improved), autistic women and gender diverse individuals face some unique barriers when it comes to employment. Two key challenges they face that are frequently overlooked include their experiences of rejection sensitivity dysphoria and executive dysfunction.

- Rejection sensitivity refers to the heightened sensitivity to criticism or rejection, which can make it difficult for many of us to navigate workplace dynamics and process feedback from employers and peers.
- Executive dysfunction refers to difficulties in planning, organizing, and multitasking, which can impact our ability to perform certain job tasks without proper guidance and support.

Proposed solutions – economic inclusion

Education

- Neurodiversity to be embedded in the school curriculum – this includes a commitment to invest in the creation and implementation of programmes that teach schools about creating a genuinely neuro-affirming classroom environment for autistic students including including access to safe spaces, the availability of neuroaffirming communication pathways that students can access, greater awareness by staff and students of covert bullying techniques, and development of a school culture of inclusivity.
- Invest in school-based disability and inclusion policies that specifically address the support needs of autistic girls and gender-diverse students who typically fly under the radar, and who may not be visibly disruptive and who appear to be coping or 'fine' in the classroom. Disability-based supports need to be available to all autistic students, not just those who exhibit external behavioural challenges, or those with an intellectual disability or language delay.
- Commit to an overhaul of the PBS model that is currently the dominant behavioural-wellbeing model in Australian schools. Explore the neuro-affirming and evidence-based alternatives such as Dr Ross Greene's Collaborative and Proactive Solutions (CPS) model, and the PACE model.

Employment:

- To address the barriers autistic women and gender diverse individuals experience in the workplace, it is crucial for employers to foster an inclusive and supportive work environment. This can be achieved by promoting awareness and providing training to workplaces to understand the specific needs of the autistic community. Autistic-led organisations can support this initiative by creating campaigns that tackle workplaces to foster a culture of acceptance and understanding. As an example, Yellow Ladybugs can provide guidance on best practices for supporting autistic individuals in the workplace and assist in developing tailored strategies for overcoming specific barriers faced by autistic women.

- By addressing barriers such as rejection sensitivity and executive dysfunction needs, employers can create a more inclusive and accessible work environment where autistic women and gender diverse individuals can thrive and contribute our valuable skills and talents.

3. Diagnosis, services and supports

Barriers to diagnosis, services and supports

Autistic girls, women and gender diverse individuals face a number of barriers to diagnosis and ongoing support that are multifaceted and complex. They include:

- Barriers to accessing diagnostic services remain a huge factor to obtaining a diagnosis for autistic girls, women and gender diverse people. Affordability of the assessment process, long wait times, and the scarce availability of professionals able to diagnosis and assist with ongoing support, means that less women and girls are able or willing to access a diagnosis.
- Clinician bias around autism, particularly how it presents in girls, remains common in the medical community and the allied health sector. Key professionals are not equipped with adequate knowledge about autism, and are less likely to identify autistic traits in women and girls due to the belief that autism is primarily a male condition.
- Misconceptions that autism is a “boys disorder” often means that the internalised autistic presentation, more commonly associated with girls, gets overlooked by parents, schools, and health care professionals. Ongoing community misinformation and stigma around autism have resulted in some parents of autistic girls unable or unwilling to recognise autistic traits in their child, or in themselves.
- Masking, and less disruptive behaviours. Reduced behavioural issues often seen in autistic girls, combined with increased communication abilities, masking and other compensating behaviours, mean that autistic girls are not getting recognised, this are getting diagnosed later, if at all.
- Diagnosis of co-occurring conditions such as anxiety and depression are often given to autistic girls and women a diagnosis before autism is considered. Misdiagnosis is also a common experience for autistic women – for example bipolar disorder and borderline personality disorder.
- Compliance-based and neuro-normative support services continue to be promoted as the gold standard for therapy for autistic children. Compliance therapies, including ABA, are deficit-based approaches which focus on “fixing” neurodivergence, by behavioural modification and enforcing neurotypical communication styles and behaviours. The majority of the autistic community is strongly opposed compliance-based therapies, and research is now revealing the ineffectiveness of these therapy approaches, the problems behind their so-called evidence base, and the significant harm they have caused, including their link to PTSD and poor mental health and wellbeing outcomes, and heightened risk of being vulnerable to abuse, for the autistic people subjected to them.

Proposed solutions – diagnostic, services and supports

The barriers autistic girls, women and gender diverse individuals experience in accessing diagnosis and support structures can be reduced by a commitment to the creation and implementation of neuro-affirming services, which aim to understand the uniqueness and strengths of each autistic person. This includes providing training and resources to healthcare and education professionals around how autistic girls, women and gender diverse individuals may present, making the diagnosis process easier to access, improving affordability and access to diagnosis. This includes:

- A strong national commitment to make diagnosis accessible, affordable, and available for all autistic women, girls and gender diverse people, so that they can access diagnosis services and tailored supports that are neuro-affirming and autistic approved. This should include prioritising timely assessments, reducing the number of medical professionals required for a diagnosis, and an overhaul of the costs associated with obtaining a diagnosis, especially when multiple health care practitioners are required.
- Prioritise the importance of neuro-affirming peer connection programmes as an important support service for the autistic community. Peer support groups help to reduce isolation, improve mental health outcomes, and provide peer support by helping autistic people to find their peers and be welcomed into the autistic community.
- Provide more access to neuroaffirming training and educational opportunities that aim to reduce clinical bias within the medical field. Many key professionals are not equipped with adequate knowledge about autism and are less likely to identify autistic traits in women and girls due to a belief that autism is primarily a male condition.
- Commit to a National Autism Strategy that is genuinely neuro-affirming and that states unequivocally that there is no place for compliance-based therapies such as ABA, other intensive behavioural ‘interventions’ or programmes that aspire to neuro-normative standards or expectations in the way we support autistic people in Australia. The Strategy provides a unique opportunity for Australia to become a world leader in undoing the harms that have been (and continue to be) done to the autistic population via an adherence to the medicalised deficit-based model, and to forging a new approach in how we support autistic people that is founded on the principles of neurodiversity.

4. Health and Mental Health

Barriers to health and mental health

Autistic girls, women and gender diverse people experience significant barriers in the health and mental health sectors. Statistically, autistic women and girls have higher rates of mental health challenges, suicidality, self-harm and other complex interrelated issues. They may also experience co-occurring physical health conditions which are poorly understood. Medical misogyny is pervasive in the health sector, which leads to autistic women being gaslit and invalidated in the health system. Key barriers include:

- Autistic girls, women and gender diverse people experience various co-occurring conditions which can have a significant impact on their wellbeing. This can be exacerbated by late or delayed diagnosis.
- Late diagnosis has significant impacts on life outcomes in relation to health and access to support.
- There is a strong correlation between autistic masking and poor mental health outcomes, including autistic burnout, anxiety/depression, eating disorders, trauma, and loss of identity.
- There is a lack of neuro-affirming mental health services, combined with a lack of practitioner understanding surrounding autistic patients, and in particular, autistic patients experiencing mental health issues.
- There is a lack of understanding regarding the difference in presentations around mental health crisis experience by autistic girls, women and gender diverse people.
- There is a desperate need for more crisis services to be available for children under 12 experiencing mental health issues. These crisis services need to be neuroaffirming and practitioners must recognise the many and varied autistic presentations displayed by young people.

Proposed solutions – health and mental health

Yellow Ladybugs encourages the National Roadmap to address the challenges surrounding the health and wellbeing of autistic people, with particular consideration to the complex physical and mental health issues experienced by autistic girls, women, and gender diverse individuals. We recommend that that National Autism Strategy prioritises the development of properly funded programmes, education and training for providers, and services to ensure that the health and mental health needs of autistic girls and women are met, and specifically the impacts of inadequate healthcare for autistic girls and women in the following areas:

- Escalation to suicide, self-harm and severe depression
- Lack of knowledge about common co-occurring health conditions including POTS, Ehlers Danhlos, PMDD.
- Discrimination due to autism diagnosis
- Insufficient public mental health services and knowledge
- Rural access to mental health services and community support
- Lack of expertise in autistic girls and women and gender diverse individuals and cross intersectional groups such as LGBTQIA
- High costs associated with mental healthcare services
- Lack of knowledge on where to get help
- Lack of support for autistic mothers

About Yellow Ladybugs

Yellow Ladybugs is an autistic-led non-government organisation with strong bridges to the community. We are dedicated to the happiness, success and celebration of autistic girls and women. We believe all autistic individuals of all genders deserve to be recognised, valued, accepted and supported in order to live life on their terms. We are committed to shining a light on autistic girls and women through the creation of positive and inclusive experiences for our members, and through advocating for the rights of all autistic individuals and celebrating their neurodiversity.

Yellow Ladybugs runs regular informal social events that offer peer-to-peer connections for autistic girls⁵, generally between the ages of five and sixteen. Our events bring our members together in an inclusive, fun and sensory-friendly setting. Underpinning every Yellow Ladybugs event, our mission is to foster a sense of belonging for all our autistic girls, to help them connect with their peers, and to instil a sense of autistic pride within our community.

We are also committed to changing the common misconceptions about autism, ensuring autistic girls and women are properly supported according to their needs, and building a society that values and empowers all autistic individuals. We actively seek to address the many challenges the community of autistic girls and women face, including barriers to diagnosis, lack of inclusion in school and employment and access to support services.

Yellow Ladybugs is an inclusive organisation, and while we have a particular focus on autistic girls and women, we recognise all genders, and we welcome trans and gender diverse autistic individuals into our community. As an organisation, we do not support the idea of gendered autism, or a that there is a 'female presentation', which is a counter to the stereotypical male presentation of autism. We seek to dismantle all stereotypes which are harmful to the autistic community. We know that autistic girls and women, and particularly those with hidden needs, continue to be significantly disadvantaged, however, and we remain committed to our mission to reduce these issues.

⁵ Yellow Ladybugs also welcomes gender diverse autistic individuals to our events