

In response to the invitation by the United Nations Office of the High Commissioner for Human Rights (OHCHR), Yellow Ladybugs welcomes the opportunity to contribute to the report on the protection of the rights of the child in the implementation of the 2030 Agenda for Sustainable Development.

Yellow Ladybugs, a non-government organisation with strong bridges to the community, is dedicated to the happiness, success and celebration of autistic girls and women. Our mission is to protect their rights to experience a fulfilled life through the realisation of their full potential. Yellow Ladybugs do this by raising acceptance and awareness both in the autism community and the broader community of the female presentation of autism in the education, employment, medical sectors. Yellow Ladybugs are renown for creating positive and inclusive experiences for autistic girls and women and seek every opportunity to advocate for their rights.

In compiling this submission, Yellow Ladybugs obtained input from 1,974 autistic girls and, their parents from Australia, United States of America, Morocco, European Union, Canada, New Zealand, United Kingdom and Ukraine. The survey respondents were predominantly parents and carers with some input from girls. We provide direct quotes from our community to give them a voice after a history, and indeed present, of under representation against gross discrimination and stigmatisation. Responses from October 2006 through online survey.

Key highlights from our survey shows that 71% of girls are victims of sexual and physical assaults, verbal bullying, social exclusion and having their property damaged at school. Against bullying, only 20% of girls have had access to their autistic female peer group and 67% of parents are accessing a Yellow Ladybugs social event or wish their child to access our programs. 51% of girls have had no access to early intervention support with 48% of girls having repeated, and costly, re-assessments to find professionals that understand how autistic girls presents. 55% of girls, and their parents, have not had access to the community in the last month.

Discrimination and Inequality in Healthcare

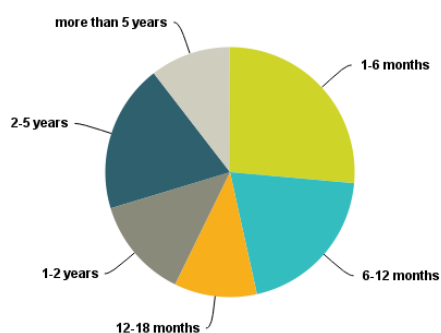


Figure 1 Length of Delay in Diagnosis for Girls

Studies have shown that parents of autistic children notice a developmental problem before their child's first birthday (reference <http://www.cdc.gov/ncbddd/autism/data.html>). 47% of girls are diagnosed within one year of their parent first raising concerns with their GP or pediatrician. 24% of girls wait between one and two years, 19% wait 2-5 years and 10% wait more than 5 years.

Research has shown that a diagnosis of autism at age 2 can be reliable, valid, and stable with the medium age of diagnosis of Autism Spectrum Condition being 3 years and 4 months and Asperger Syndrome of 6 years and 2 months (reference <http://www.cdc.gov/ncbddd/autism/data.html>). 10% of autistic girls receive a diagnosis before the age of 3, 34% aged 3-5yrs, 17% aged 9-12yrs, 6% aged

13-18 yrs. with 11% still waiting to have their disability recognized. Factors impacting on more timely diagnosis for autistic girls include:

- **Lack of professional training on feminine presentation of autism** *"No one felt that she was ASD because she didn't line things up, showed empathy & had eye contact"*
- **Delay to observe child development progress** *"Practitioners felt that she was so high functioning that there was a good chance she would 'grow out it'.", "Kept saying she's young she will catch up"*
- **Blaming parents** *"No one would listen. Blamed it on my mental health." And "The first paediatrician we saw thought there was nothing wrong. Neurotic mother syndrome!"*
- **Misdiagnosis**
- **Treatment of co-occurring conditions** *"My daughter developed an eating disorder that had to focus on for about 6 months before we could pursue the ASD diagnosis"*
- **Rural access to services** *"Waiting lists for speech pathology, occupational therapy and rural access to psychologist"*
- **Internalised, quieter presentation** *"Because she lacked problem behaviours"*

52% of girls are diagnosed correctly with one assessment. Lack of professional training has 22% of girls requiring a second assessment, 17% of girls had more than two assessments and 9% of girls are still waiting to be diagnosed. Late or no diagnosis impacts on girl's ability to access early intervention programs. 51% of girls had no access and 49% did have access. Families are incurring expenses in seeking appropriate diagnostic support for their child. 24% had no cost, 6% paid under \$250, 15% paid between \$250-\$500, 21% paid \$600-\$1,000, 19% paid over \$1,000 and 16% paid over \$2,000. The diagnostic process and cost implications has ramifications on autistic girls and their families. Impacts include:

- **Housing** *"ended up selling our house, almost lost our car", "our home is currently for sale to pay the debts that have accumulated.", "We have almost lost our home because of the money we've spent"*
- **Debt accumulation** *"all costs went onto the credit card and its just part of the monthly interest I pay to this day", "Extreme hardship but necessary. I took out a high interest loan and did not tell my husband"*
- **Planning for old age** *"Withdrew superannuation to cover the cost"*
- **Contribution to reduced mental health and access to services** *"Financial strain also mental & emotional stress", "Means I cannot see my own psychologist"*
- **Emotional stress on autistic girls** *"More impact on my daughter as she is fearful of being under constant analysis to such an extent that she screamed once as I was trying to drag her into an appointment "THERES NOTHING WRONG WITH ME!!!!", "I had to work extra days at work even though this affects my daughter who has separation anxiety but it had to be done."*
- **Future family planning** *"We delayed having additional children"*
- **Reduction in quality family time** *"No holidays for 4 years"*

Layered Vulnerabilities and Economic Disadvantage

Consideration of the degree of vulnerability experienced by autistic girls, by systemic and community failures to meet their autistic needs, on the family unit. 82% of Autistic children are growing up in two adult households where 33% of parents share the same neurology as their child, diagnosed or self-identifying as autistic. 37% of children are growing up with parents that report their own mental health to be fair to poor with physical health a difficulty for 29% of parents. As girls struggle in education, health systems and a sense of social belonging, at home they are prone to economic disadvantage. 50% of parents are not in full or part time employment with systemic failures proving a barrier. Factors in unemployment;

- **When a girl is failed in education:** *"I need to be available if the school needs me", "We are in deep financial debt. I had to give up work for the past 3 years to become a full-time carer to help see my daughter through school."*
- **When school is not accessible:** *"I gave up work to home school my daughter".*
- **When mental health support does not meet her needs** *"I am currently unemployed due to the emotional needs of my daughter and the emotional toll it takes on me".*
- **When employers are not flexible to the needs of her carers:** *"to start my own business with flexible hours to meet the needs of my autistic children".*
- **When a girl cannot access before and after school care:** *"I am not working by choice to manage therapies and appointments, getting her to school and caring for her as she would not cope well in out of school care."*

Economic disadvantage can be a barrier to girls accessing fee paying healthcare, reduces their ability to be diagnosed and receive appropriate levels of mental health support to manage co-occurring conditions including social anxiety, depression and eating disorders. Financial ramifications on the family unit are discussed in section 'discrimination and inequality in healthcare'.

Accessible Communities

55% of parents have been unable to access their communities in the past month. Factors of community participation;

- **Judgement of general community** *"Behaviour and others judgment can make us feel unable or reluctant to access community activities".*
- **Access to peer group** *"We automatically have community within our home, four of five of us are autistic. We have many autistic friends and families we spend time with".*
- **External carer support** *"I delay any shopping trips until my daughter is not with me as she can't cope"*
- **Autism friendly environments** *"We pace our outings and go to autism friendly places a lot".*

- **Service provision against life balance** *“my daughter is sick of going to see specialists in allied health. and this appointment fatigue contributes to my daughter's resistance to us engaging in asd social support”.*
- **Social media platforms** *“there is always internet community”* and *“mum always has online support”*
- **Economic hardship**

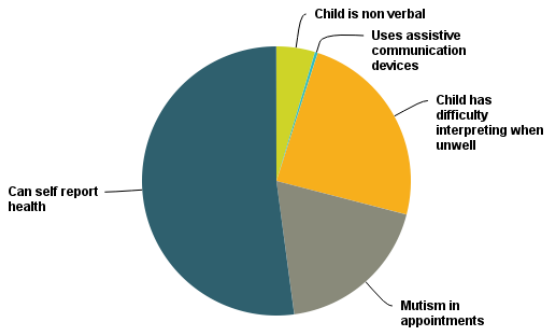


Figure 2 Girls Communicating Health Concerns

Medical professionals should ensure their offices have had an autism friendly sensory audit to be accessible for autistic patients. 31% of girls are able to access their doctors without distress, 56% require loving support from a parent and carer to help them cope and manage with the environment, 12% of girls experience an overwhelming assault to their senses resulting in a meltdown or shutdown and 1% of girls access a doctor home visiting service.

There is a need for medical professionals to be trained on how to engage with an autistic girl in her communication style and help her interpret her feelings of being unwell. 5% of girls are nonverbal, 1% use assistive communication devices, 24% of girls have their parents

communicate their health needs, 19% of girl’s experience mutism in doctors’ offices from being overwhelmed and 51% of girls can communicate their needs to health professionals.

Restricted Access to Education

18% of parents have been unable to access education for their daughter, due to suspension, exclusion or being sent home. 39% having to change schools, due to their daughter's needs not being met.

- **Safety concerns:** *“She is now homeschooled as they 'couldn't guarantee her safety' and would only allow her to attend an hour a day”.*
- **Home Schooling:** *“I was often called to pick her up from school. She is currently on homebound (home schooling) due to her anxiety. The school does nothing to help her.”*
- **School Refusal:** *My daughter has school refusal and the school has not helped build a connection. I'm not sure she'll go back to school”*
- **Absconding:** *“My daughter is only attending school for half days. This comes after a term of multiple calls each week to pick her up early due to her extreme distress, repeated absconding, physical attacks on teaching staff”*
- **Suspended for meltdowns:** *“There's been many suspensions, due to meltdowns or shutdowns”*

Education: Curriculum not modified

44% of parents believe that the current teaching styles did not match their daughter's learning style. This is compounded by 51% of parents feeling that their concerns were not listened to by the school. This supports the 52% rating, parents gave to schools, as to well their daughter's needs were being accommodated overall at school.

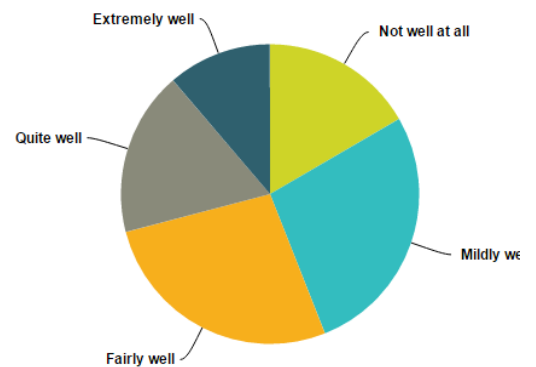


Figure 3 Teaching and Learning Styles

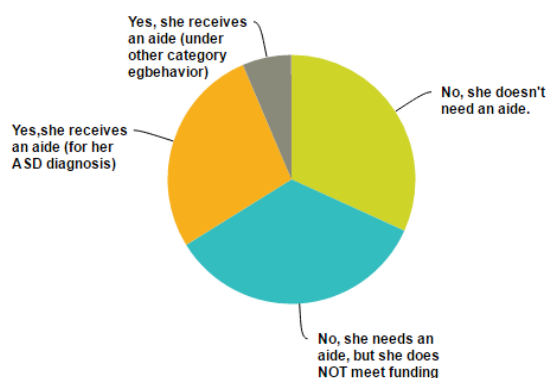
- **Schools minimalizing the extent of need:** *“Concerns are often dismissed due to my daughter "appearing" to function well (flying under the radar) She is very compliant and mimics other children so appears to be coping”.*
- **Lack of preventative support:** *“I feel that they don't listen enough, as my daughter is so quiet they just overlook her till she melts down, I feel that because she is also high functioning they don't seem to think her being autistic needs allot of their attention”*
- **Insufficient Staffing and Budgeting:** *“It has been difficult getting support, we've been told they are understaffed and a lot of IEPs in the classroom. We hope this year is better, in introducing different learning styles and providing opportunities for our daughter to LEARN”.*

Education: Lack of funded support

34% of respondents felt their daughter needed access to an aide, but were ineligible due to funding requirements, despite an autism diagnosis.

- **No funding:** *“My daughter has strong language skills, so missed out on funding. She didn’t get funding for behavior, because she is not outwardly disruptive to other students, but she is imploding internally, not performing to her potential, and I am concerned the real impact will not be seen until her teens and adult life.”*

In a study of autistic girls in mainstream primary schools, four key areas were identified as creating difficulties: class rules; working collaboratively; completing tasks; and other interactions with peers (Moyse R 2015). Furthermore, Attwood advises girls have issues such as executive functioning, difficulty in beginning and completing tasks on time, slower processing speeds, along with rigid and inflexible thinking (Attwood 2007; Garnett et al 2013 cited in Moyse R 2015). These factors are not taken into consideration, when applications are assessed for classroom aides in Victoria, Australia at mainstream schools.



fine
me”
Figure 4 Access to aide

- **Limited access to support:** *“The principal listens but they struggle because she needs an aide for organisation and she isn't eligible”*

- **Lack of Training:** *“Her school aide is NOT trained for girls with asd so I don't feel she really understands how to handle her”*

- **Not understanding the female presentation:** *“They pretend to listen. Being a female and presenting in a very different way to boys, a lot of her challenges are masked and hidden as she deals with this internally”.*

- **Girls and Parents Not Listened to:** *“They won't listen re anxiety at home, when I ask for more supports they say “but she's at school”. When I explain she's madly compensating they don't believe*

Autistic Girls Sense of Belonging, Friendship and Bullying

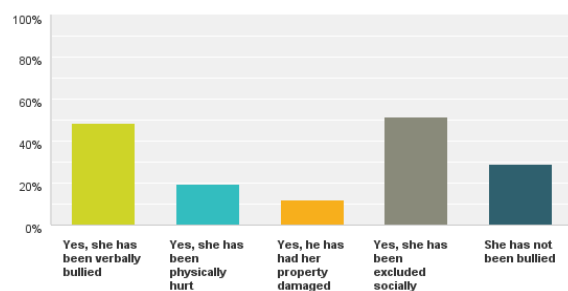


Figure 5 Autistic Girls Bullied at School

16% of girls have no sense of belonging at school, 31% have a bit, 26% have some, 21% have a lot and 76% have a tremendous sense of belonging. The tremendous amount of belonging must be viewed alongside both the rates of bullying and friendships of girls. 30% have no friends at school and 70% do have friends. However, only 29% of autistic girls have not experienced bullying. Yellow Ladybugs asked this as a multiple answer question. 48% of girls have been verbally abused, 20% have been physically abused, 12% have had their property damaged and 52% have been socially excluded.

- **Sexual abuse at school:** *“She has also been touched inappropriately by boys and has been unable to defend herself”, “Sexual harassment”, “Sexual abuse”, “Pants have been pulled down”, “sexually harassed.”*
- **Social Naivety Results in Abuse Not Recognised:** *“She would not correlate kids being mean to her - she just thinks that's how kids play.”, “Thankfully she doesn't yet recognise that the other children are talking inappropriately to her so she's not distressed”, “She can't tell when they are mean to her. They try to get her to do things and say ugly things to her.”, “Several children bully her. She is just beginning to understand that they aren't good friends”, “She will call children her friends even while they're shouting abuse at her. If she does realise they're bullying (usually when it gets physical) she will make up stories about the children's lives to excuse their behaviour”*

- **Social Exclusion:** *"She has been excluded from parties and other events by children she considered to be her friend."*
- **Teacher's as the bullies:** *"A teacher was removed after being witnessed harassing her in the hallway", "She has also been teased for her meltdowns being told that she was always over reacts and makes such a drama of the smallest things", "her previous teachers have said she has "wilfully refused" to do certain tasks, just because she couldn't understand and/or has never been able to do the tasks.", "Bullying from her teacher has been a major problem which has led to us removing her from the school and we are now home-schooling", "bullying from a certain teacher to continue to make fun of her in front of the class which is then continued by some of the kids out of class.", "The bullying was really from teachers. They dropped her on her head, sent her home on the bus with no pants on, lost her communication device, damaged or lost her iPads multiple times, ignored her in class, yelled at her, isolated her, etc."*
- **Discrimination based on disability:** *"Kids laughing at her for not speaking", "Other kids (mostly other girls) recognised and exploited my daughters naivety / gullibility, generosity.", "Making fun off her arm steaming, toe walking, other children thinking she is contagious", "she has been called dumb and stupid as she does not get the jokes or sarcasm", "On occasion, her need for sensory input has upset another child who did not appreciate her sensory seeking and has lashed out, bitten etc.", "She has been bullied about her anxiety (which often presents as mutism)."*
- **Physical Assaults:** *"Harassing, being choked, verbally abused.", "During a recent to session to explore the roots of new self-harming it was discovered that the harm had originated from a peer that pinched and twisted her skin (resulting in small sores) to stop her from talking when they sat together this then progressed into a self-harming habit to control behaviours", "Had stitches on her face from rocks being thrown at her"*
- **Verbal abuse:** *"Name calling... being accosted in the playground when she left a game because they weren't playing fairly. Told she can't play for whatever reason", "She had a magic necklace which was a talisman for the confidence she needed to get through the day. She was mocked by her classmates"*
- **Friends as bullies:** *"Not bullying, just excluded by a so called best friend", "Sometimes things happen to her from her friends that she doesn't understand."*
- **Social media bullying:** *"She has been bullied verbally and via social media", "the boys have posted sexual explicit comments on social media during school time which resulted in their suspension", "she was threatened online after complimenting another girl that she wanted to be friends with, the other girl mistook it for sarcasm and they started an online abuse campaign against her"*
- **Girls Victimised for being Victims:** *"I got suspended when I was the victim of bullying"*
- **Reporting Mechanism:** *"was targeted by bullies as she wouldn't tell anyone what happened", "school turn a blind eye"" The school did NOTHING to stop it.", "She has been a little bullied, but the schools have been on top of it.", "It was well tolerated by the staff.", "The response from the school varied according to the teacher. Mostly ineffectual."*

Girls must be able to identify when abuse is occurring, how to report the abuse and be able to escalate their concerns. 30% of parents are unsure if their child can report a problem, 15% of girls cannot, 43% of girls can tell a teacher and only 12% of girls know how to escalate their report of abuse if it is not listened to, actioned.

Girls Autistic Peer Community

80% of girls have not had access to their autistic female peer group. Yellow Ladybugs holds events for autistic girls, themed like birthday parties, for autistic girls to find their peer group and acceptance. 10% of respondents have accessed a Yellow Ladybugs event with 57% wishing to access our events, 9% of girls cannot access events and 24% have access to some support. Positive autistic female role models, 15% could name at least one, 51% do not know any and for 34% they would not understand what a role model is.

Our Recommendations for Investment, Accountability, Equality and Non Discrimination

- Access to before and after school provisions with staff trained in autism
- Increased carer provisions for employers
- Parents access to opportunities for their emotional resilience to increase workforce participation
- Diagnostic challenges to be addressed to alleviate the need for second, third and fourth costly assessments

- Professionals including teachers, medical staff and mental health workers to be trained on feminine expression of autism
- Medical offices to have an autism sensory audit to reduce barriers to access health services
- Doctors to have training on how to engage with autistic girls to help them be independent in self-reporting health concerns
- Nonverbal girls must be given access to communication assistive devices
- Girls to have access to opportunities to engage with other autistic girls
- Understanding training for student peers to accept diversity as a natural component of life
- No tolerance policy on bullying with recognition of all forms including physical, verbal, property damage and social exclusion
- Access to gender specific social groups
- Self-advocacy training
- Online safety training and online moderated platforms for connecting girls

Conclusion

Autistic girls are encountering discrimination, poverty, mental health distress, education failures and social exclusion against professional's lack of training to identify them in a timely manner. Their failures impact on girls by not accessing early intervention support alongside their autistic male peers. Children's comments, and within some parental description of their child's behaviours, is girls expressing "therapy fatigue" with one child referring to her therapy as "abusive".

Yellow Ladybugs does not advocate for a normalisation agenda for autistic girls, supports must be meaningful to the child and allow her space to follow her own trajectory. Autism is not to be eliminated or hidden, autism is what our girls will grow into as they age. The onus is on homes, schools, professionals and the community to allow her to grow into a confident woman, self-assured in her own identity, as an autistic female, without internalised self-oppression. Therapy sessions should not replace her right to be a child, and engage in her interests, indeed, those interests when nurtured may become her employment expertise.

The wider community must take inclusion from ideal ology to practice in both building design, communication and social engagement. Autistic girls have a low level sense of belonging, where bullying is their normal experience and accessing the community and health services leaves them 'coping and managing' or completely overwhelmed their voices are silenced in mutism, meltdowns and shutdowns.

Autistic girls must be given their voices to grow into empowered women who can self-advocate in their own health, report when a victim and have the capabilities to advocate within systems for their needs to be recognised. For far too many girls, this is not their current reality.

Autistic girls are having the stability of their home life compromised with higher levels of unemployment, higher levels of parents physical and mental difficulties and high levels of debt accumulated through parents fighting against systemic misunderstanding and poor provisioning for their children.

Gender based 2030 Sustainable Goals must include disability, to not do so is segregating autistic girls from programs they may be able to access where reasonable accommodation is built within.

Thank you for considering the needs of autistic girls in the development of the 2030 Agenda for Sustainable Development.

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