



MULTIPLE AND INTERSECTING FORMS OF DISCRIMINATION AGAINST AUTISTIC WOMEN

For the Attention of the
Special Rapporteur on Violence against Women

Autistic Women in Australia

Violence against women with disabilities goes beyond discrimination or the use of power in relationships. It is the use of systemic power to ignore, isolate, marginalize, stigmatize and vilify inconvenient people who may be viewed as using an unfair share of community resources.

In the case of Autistic women, violence is compounded by the denial of our existence. If our existence and specific circumstances are not acknowledged, we do not have the same protections as other women in society and the additional protections afforded to people with disabilities are denied us.

Autistic people without an associated learning disability have a life expectancy of 58 years old and are 9 times more likely to die, with it being their leading cause of death. Autistic women, often develop comorbid mental health conditions after a lifetime of unmet needs, systemic neglect and violence. Autistic women have double the risk of suicide as men.

This paper explores the causes and extent and negative outcomes against Autistic women in Australia.

"This is an important document that raises awareness of the reports by women with autism of being the victims of discrimination. This is an unacceptable situation and requires urgent investigation so that appropriate policies can be implemented to prevent this in the future"

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Contributing NGO's



Autism Asperger Advocacy Australia (A4), a non-government organisation, was launched in 2002 and is Australia's grassroots organisation representing the diverse views of autistic people, their parents, carers and professionals



The Autistic Self Advocacy Network of Australia and New Zealand (ASAN AUNZ) is run by Australian and New Zealander Autistic people, for Autistic people. We are associated with ASAN making us a part of an international Autism advocacy network.



The Autistic Women's Association, a non-government organisation, was the world's first group formed in 2008 addressing the needs of autistic women and girls. Our mission is to offer education and support to autistic women, children, and seniors, and parents/caregivers across the globe. We operate three online support groups with current membership of 3,000 women and girls with over 100,000 supporters.



The Sisterhood Society Australia, a non-government organisation, provides people with information about Autism with a focus on the gender differences in women and girls. Our website is an information hub for relevant supports, services, resources and networks. We operate two online support groups, 'Sisterhood of the Autistic Girl' and 'Sisterhood of the Autistic Woman'. The Sisterhood Society Australia has over 1,500 members.



Yellow Ladybugs, a non-government organisation 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. We are renowned for creating positive and inclusive experiences for autistic girls and women.

Autism Spectrum Conditions

Medical Perspective

Autism spectrum Condition (ASC) is a lifelong neurological difference defined by diagnostic criteria that include differences in social communication and social interaction and restricted, repetitive patterns of behaviour, interests, or activities. Many Autistics also experience differences in sensory perceptions, affecting the way in which an individual experiences and interprets the environment. About 1 in 68 children has been identified as being autistic (having an autism spectrum condition), according to estimates from CDC's Autism and Developmental Disabilities Monitoring (ADDM) Network. Research from Autism Asperger Advocacy Australia found that Medicare funds 53% of Australian diagnosis for children under 13 years of age. In Australia less than 50% of diagnosis for children are obtained when under 16 years of age. Early diagnosis is critical for promoting optimal life outcomes.

An Autistic Perspective

Asking someone what it's like to be Autistic is like them asking you what it's like to be non-Autistic. It's like asking what it's like to be human. It makes no sense. It's all we know, and everyone's experience is different. When you meet one person with autism, you know one person's manifestation of autism.

Being Autistic feels like being in a foreign country, not understanding the customs, culture or language of the people we live amongst and frequently finding ourselves in situations we don't have the tools to deal with. Ordinary everyday situations and life in general can leave us feeling violated and exhausted mentally, physically, emotionally and sensorily. For those of us not diagnosed or, as is commonly the case, misdiagnosed it can be totally confusing to work out the 'what' and 'why' of our experiences and happenings. It is also important to note that many Autistic women feel misunderstood, unheard and that their way of doing things is wrong because it looks different with parenting being one major area where we are commonly misunderstood.

Our autistic natures can mean we struggle to regulate our emotions, our body movements and sensory systems. Everything can require intensive effort and concentration to get through every day, particularly when we are out of our safe spaces which is usually our homes and families (but for many, even these spaces are not safe). Autism can mean feeling every emotion in our workplaces, offices, our children's classrooms, indeed, anywhere there are people. This overwhelm requires us to plan extensively to avoid the shutdown and meltdown we can experience from the assault to our sensory and communication systems. For many of us with executive functioning difficulties, planning is extremely hard. It requires skills that we don't instinctively have and can end up making us feel like failures. Society tells women we are great at organising our families and that we can emotionally support our families wonderfully and when this doesn't happen we are seen as less than, leading to poor mental health and inertia.

In amongst this, autistic women also talk about blissful experiences with their passions, whether they be science, the arts, animals, cosplay, advocacy, their families and relationships. For many of us, the ability to focus so intensely on our passions means that we get very good at doing what we love. It also leads to an insatiable thirst for knowledge, constantly questioning, redefining our identities and moving towards acceptance of difference and what it means to be an Autistic woman today.

Terminology

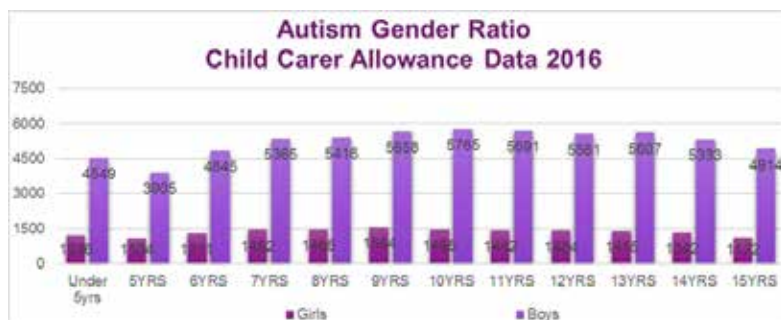
Language is a powerful tool enabling the expression of ideas, abstract and concrete, and the way in which words are used conveys meanings which influence and develop attitudes and community standards. Generally, person first language i.e. person with autism, is used in disability discourse. However, many members of the autism community believe that person first language does not reflect their relationship with autism. Autism is an integral part of the people we are, in the same way as, for example, gender. Therefore when we refer to an individual as an Autistic person or as many advocates identify, as Autistic, we are recognising the value of a person, for whom autism is an integral part of their humanity. We are also recognising the value of autism as a part of the human condition, different but integral to society and not something that needs to be marginalised and isolated. For this reason, this paper addresses the perspectives of Autistics or Autistic women and girls.

The Violence of Discrimination in Health Care

The Australian public health system provides a means for investigating, documenting and understanding the causes and consequences of violence. It develops policies and primary prevention programs with the goal of preventing violence and provides advocacy to support victims in reducing and redressing harm done by violence. When Autistic women and girls, with their unique needs and diagnostic characteristics, are not recognized in society, they are not protected by the supports afforded to others in society. They do not have the same protections against violence as their peers and in addition, are often abused by the health system that is intended to help them. In addition, the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) emphasises *“the need to incorporate a gender perspective in all efforts to promote the full enjoyment of human rights and fundamental freedoms by persons with disabilities.”* Both the public and private health sectors in Australia fail to incorporate gender perspectives in their understanding and support of Autistic people, a group already disadvantaged and often abused by a system that has a limited understanding of their needs.

Systemic Violence against Autistic Women Who Are Missed & Misdiagnosed

Historically, autism was thought to be more common in males than females. It is now known that the rates of autistic females, a ‘hidden’ disability group, is much higher, meaning many undiagnosed females exist in the population. In Australia, there is no register or database with firm statistics of prevalence. Women and girls are an almost invisible minority within a minority group, the disabled community. Autism Asperger Advocacy Australia obtained data through the Australian government of their Carer Allowance (Child) showing that at present, the gender ratio for diagnosis is 3.8 boys to 1 girl.



While the diagnostic criteria for autism are very clear, the feminine expression of autism is not recognised consistently for a number of reasons. These include:

- The social and communication difficulties experienced by girls and women may not be as obvious as those experienced by males. The presence of a second X chromosome is thought to

support the ability of girls in developing coping, masking and social echolalia as strategies to combat their communication difficulties. While they are often effective, these practices limit participation in society because they are exhausting and cannot be sustained for longer periods of time.

- There are few studies examining the presentation and true representation of girls and women on the autism spectrum. Many studies have low numbers and have not been peer reviewed. Additionally, diagnostic screening instruments and clinicians bias can view autism through a male phenotype, distorting results.
- This ‘feminine expression’ of autism is not restricted to females. It may be present in males who can experience similar challenges in having their autistic needs recognised through diagnosis.

How Does Misdiagnosis and Late Diagnosis Constitute Violence Against Women and Girls?

- Education – people with disabilities are entitled to modifications and supports which facilitate equitable outcomes. Without diagnosis, these cannot be accessed.
- Unemployment and underemployment – People with disabilities are entitled to access supports in seeking and maintaining employment. Without appropriate education and supports in finding work, many Autistic women cannot access the workforce at a level commensurate with their abilities or even at all.
- An unusual presentation, for example, lack of eye contact results in negative judgements by society. Stigma of their ability to parent is a common result.
- The impact on health and wellbeing is significant, with specific difficulties in identifying pain, poor access to dental and health care specific to the sensory needs of Autistic women and girls.

Why, When the Core Characteristics of Autism are Common to Males and Females, are Females Underdiagnosed?

The view of autism as primarily a condition affecting males, often predisposes health and education professionals to overlook the possibility of autism in girls. Teachers and health care professionals may not suggest the need for diagnosis to parents. Many diagnosticians are more familiar with the criteria as shown in males. For example:

- The DSM 5 states that, *“Severity is based on social communication impairments and restricted repetitive patterns of behaviour”*. This is often expressed when boys line up cars or spin wheels, significantly differing from typical play patterns. When girls are lining up Barbie dolls on a shelf or grouping clothing in her wardrobe, rather than observing a restricted and repetitive behaviour, girls are likely to be praised for neatness, traditionally highly desirable in girls.
- Deficits in social-emotional reciprocity, a core characteristic of autism, are often observed when children do not have friends. Female friendships rely heavily on talking and social communication, interactions that an autistic girl may struggle with. Autistic girls often relate to others in the same way as males, by “doing”. They may develop friendships with boys or interest based friendships with girls e.g. caring for a pony. Because the girl has friends, the quality of the friendship may not be questioned, resulting in misdiagnosis.
- Difficulties with executive functioning are also part of the profile of autistic people. In boys, this is more often recognized in an inability to care for belongings and a strong desire for sameness. Girls may also have a strong desire for sameness but are often likely to express their difficulty with executive functioning in rigidly neat behaviour. This is often not seen as a deficit, as neatness is traditionally considered to be desirable in girls.
- Girls can have better language skills than their male peers. Again, supported by the social strengths of the second X chromosome, girls are more likely to mimic, practice and try on the personas and language structures of those around them.
- Persistent deficits in social communication and social interaction across multiple contexts may manifest in both boys and girls as difficulty with emotional regulation. Boys generally act out. Throwing a table at the teacher is very likely to result in assessment and intervention. Girls, on the other hand, are more likely to internalise their emotions. They may appear to be passive, closed off or may cry frequently. They are often perceived as gentle, quiet and sensitive – traditional female virtues which do not attract the attention which would alert to the possibility of autism. A girl who behaves with aggression and/anger when distressed attracts extremely negative consequences, but not necessarily an opportunity for diagnosis.

Studies have shown that parents of autistic children notice a developmental problem before their child's first birthday and 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. Yellow Ladybugs research found, In Australia, 51% of girls are diagnosed within one year of their parent first raising concerns with their GP or paediatrician. 23% of girls wait between one and two years, 17% wait 2-5 years and 9% wait more than 5 years.

Yellow Ladybugs research found, In Australia, 10% of autistic girls receive a diagnosis before the age of 3, 37% aged 3-5yrs, 24% aged 6-8yrs, 16% aged 9-12yrs, 4% aged 13-18 yrs. with 9% 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!” and “Sharon, a mother of six children was able to demonstrate the fallacy of this to her GP. Her five older children were successful and developing typically. Her marriage was stable with both parents balancing home and work life in building a successful business. Her*

youngest child was different and this could not be attributed to maternal neurosis. The child was subsequently diagnosed with moderate autism and intellectual delay."

- **Misdiagnosis** *ADHD, bipolar, mild developmental delay, social anxiety.*
- **Treatment of co-occurring conditions** *"My daughter developed an eating disorder that we 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"*

Financial Barriers to Diagnosis

Women who seek a late diagnosis often have few options available. Women can seek a mental health plan referral to a clinical psychologist or psychiatrist for a diagnosis. The mental health plan enables a portion of the cost to be reimbursed by the government health provider, Medicare. Competing funding priorities are a barrier for autistic women who are parenting autistic children. In rural and isolated areas, diagnosticians are frequently not available. Rather than use costly private services, women usually prioritise the needs of their children above their own. Partners and family may deny and/or ridicule the pursuit of diagnosis. This is a layered vulnerability with tragic circumstances.

Access to diagnosis relies on accurate information from professionals. Cindy was told by her fourteen year old daughter's psychiatrist that diagnosis would cost \$2500. As a single parent, already paying privately for counselling for her child, this was beyond her means. Without diagnosis, the young girl could not access education supports. Failing and ashamed, she refused to go to school and as the department pursued her mother over attendance, she left home to protect her mother from prosecution. Some years later, her mother became aware that diagnosis was available free for children under 16.

The health system in Australia plainly violates the rights of Autistic women. Participation in society is limited by the most basic of rights, for without diagnosis, the capacity of an individual to seek access to enjoy the same rights, supports and functions accessed by the population in general. Without a diagnosis, or acceptance of diagnosis, Autistic women experience further violations in domains outside of healthcare.

Economic Discrimination and Violence

- **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** *"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** *"Means I cannot see my own psychologist"*

Emotional Discrimination and violence:

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"*

Harm Done by the Lack of Post Diagnosis Support

Australia has no formal support for autistic women diagnosed late in life. None of the groups and networks run by autistic people, for our autistic community are funded by the government. Online peer support is often the only support a woman receives but it can only address some issues experienced by autistic women.

When diagnosed late in life, women have already been subjected to years of distress from not having their needs met or understanding why they are so different. Learning that they are autistic and finding support from an autistic community can give women a huge sense of relief and the opportunity to work with their strengths to address their needs.

The lack of post diagnosis support for Autistic women would most likely not be tolerated for other disabilities. No person diagnosed with paraplegia would be sent home without access to mobility support. Importantly, in order to develop a positive self-image, after a lifetime of being held to non-autistic standards of what women are, Autistic women need to know it is ok to be disabled. They need to know and meet others like them: autistic people who were never a non-autistic child. They need to know that this is a legitimate way to be a person.

Life Expectancy, Autism and Health Conditions

It is important to recognize that severe mental health problems are not an inevitable adjunct to Autism and may be caused or exacerbated by the stress and anxiety caused by discrimination and being marginalized.

In 2016 a UK Charity, Autistic, released the report *'Personal Tragedies, Public Crisis'*, which revealed the shocking life expectancy of autistic people compared to the general population. Some of the worst affected autistic people are those with epilepsy, who have a life expectancy of only 39 years old. Epilepsy is 20 to 40 times more common in autistic people than non-autistic.

For those autistic adults who did not have an associated learning disability, the average age of death was 58 years old, compared to 70 for the general population. Autistic people are 9 times more likely to die from suicide with it being the leading cause of death for those autistic individuals without intellectual disabilities. The study found autistic women have double the risk of suicide as men.

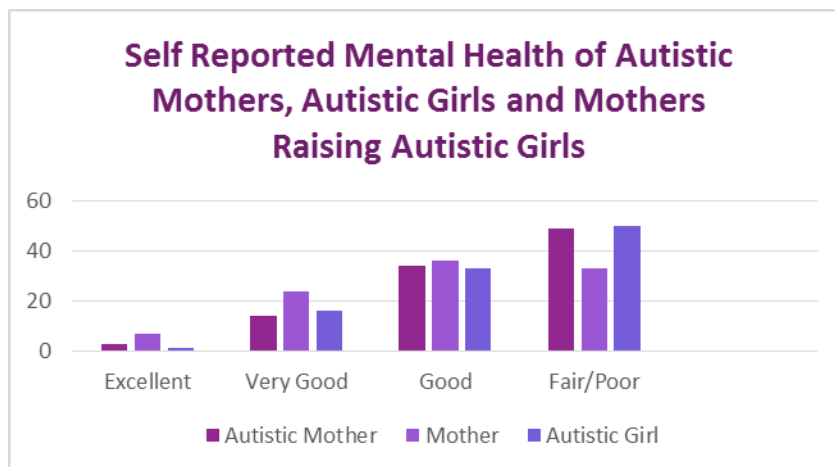
The current mental health of our autistic girls and women, and barriers to them obtaining timely and appropriate mental health support must be seen as a systemic violence against us resulting in harm and untimely mortality. Based on the available data on Australian autistic girls, there is no reason to believe that the life outcomes of the study from Autistica is not relevant to Australian women.

Mental Health

Autistic women and girls may be misdiagnosed with mental illness conditions such as anxiety, depression, OCD, eating and personality disorders. However it should be noted that autistic women can also experience mental health conditions in addition to autism, resulting in a complex mix of symptoms and characteristics. Public mental health services use an approach of medication and hospitalisation aimed at reducing symptoms of acute mental illness to a point that people can reenter the community and leave acute care settings. Long-Term follow up in public mental health care is often poor due to funding and other resourcing considerations. When Autistic women are misdiagnosed with mental illness conditions they do not have, hospitalisation and medication is usually not helpful at all. Although mental health co-morbidities are sometimes present, many autistic females have experienced inappropriate or no support due to a lack of knowledge about autism or an unwillingness to admit mistakes among professionals.

A key feature of autistic females is that they appear able to mask their difficulties much more effectively than males. There may be a complete disconnect between parts of the autistic person's life and relationships that others may not realize, as they may only see one aspect of the person. In fact, many autistic women report feelings of 'leading a double life', hiding their true selves from the world and having to 'act' to fit in, adapt and cope with the way they experience the world. Geraldine relates masking at work as similar to being on stage for 9 continuous hours, 5 days a week for years. Professional actors could not sustain this pressure which is necessary to avoid the negative attitudes towards autism expressed by other employees.

The presentation of autism in women can include issues with identity, belonging and self-injurious behavior. Partly as a result of this, a common misdiagnosis for autistic women is Borderline Personality Disorder. (The same symptoms can be experienced by those with a diagnosis of both Borderline Personality Disorder and Autism). A misdiagnosis of borderline personality disorder often carries stigma within health settings and can result in discrimination and invalidation. This can exacerbate anxiety and mood symptoms and do more harm than good for women who may already be vulnerable.



Yellow Ladybugs research found, the self-reported mental health of autistic parents, parenting an autistic girl, 49% report fair to poor mental health, 34% good, 14% very good and 3% have excellent mental health. For comparison, 33% of non-autistic parents, parenting an autistic girl, self-reported their mental health as being fair to poor. For autistic girls, 50% are suffering fair to poor mental health, 33% are good, 16% have very good and 1% have excellent mental health.

8% of autistic girls are receiving no mental health support while waiting for services, 32% require more mental health support than currently receiving, 39% are receiving adequate support and 21% require no support.

Factors involved in not accessing adequate mental health needs include:

- **Escalation to Suicide, Self-Harm and Severe Depression:** *"your child has to be deemed on the verge of killing themselves or someone else before you can even get an assessment", "if your child isn't trying to commit suicide you can't access mental health services", "She has been suicidal and self-harms, suffers from severe anxiety - I have to access private counselling which is expensive" and "It took my child trying to kill herself to access free supportive therapy"*
- **Discrimination Due To Autism Diagnosis:** *"My daughter was in the mental health service but as soon as she was diagnosed with ASD they discharged her" and "Long waiting lists also a diagnosis of ADHD seems almost to make MHI irrelevant... 'it's because she's autistic'" and "were not interested and insisted on discharging her from their services once we received her diagnosis despite still exhibiting auditory and visual hallucinations"*
- **Autism Diagnosis Delay Precludes Mental Health Support:** *"Can't access mental health services without a diagnosis" and "Without an official diagnosis seeking services she needs is impossible"*
- **Insufficient Public / Government Mental Health Services:** *"They left her unsupported for 3 whole years following an urgent referral for her mental health"*
- **Rural Access:** *"Any services we "have access to" means a 2 hour drive minimum", "I pay for a private practitioner 5 hours from our home", "In rural areas mental health can be frustrating because of lack of continuity and changing over of staff often" and "Our location is a huge limitation to what support we can access. Extensive travel is required. Travel is physically draining on my children"*
- **Lack of Female Autism Expertise:** *"finding a psychologist with female autism experience is like finding a needle in a hay stack", "Mental health professionals, in our experience, don't understand girls on the spectrum. My daughter has highly refined masking skills and performs in the clinical environment", "She is severely mentally ill as well as Autistic and her Autism wasn't taken into consideration at all in relation to her mental health issues"*
- **High Costs:** *"She needs higher frequency. And I have had to stop seeing my own psych to pay for hers", "I have accessed private mental health services in the past but the costs became too much"*

- **Previous Poor Provisioning Creates Barrier:** *“Due to past bad experiences my daughter thinks mental health providers are idiots”*
- **Gaps from Institutions to Community Support:** *“She has been in mental health unit for past 7 months, but when allowed to go home to our country town there are hardly any services that could help me at all”*
- **Not Knowing Where to Get Help:** *“I don't even know what is the right support for her”, “She shuts down often, but we're not sure what will help”, “I don't know of any services available for a 13-year-old, late diagnosed teen girl” and “My child experiences a great deal of anxiety but we get no support and I do not know where to get help for her”*
- **Ageing from Child to Adult Services:** *“She is now 18 so there are no services for her”*

Rather than providing support and improving life outcomes for Autistic women, the mental health system in Australia often violates women emotionally, financially, physically and systemically. If the same conditions of access to diagnosis and support were applied to other groups, for example, deaf and hearing impaired people, there would be an outcry at the injustice and infringement of basic human rights. Autistic women are invisible members of society. There is no outcry for us.

Physical Health

Autism affects the ability to communicate and manage interpersonal interactions. This can impair the ability to access help and support. Autistic women may experience difficulties in understanding that their health experiences require medical attention. Social isolation and lack of a peer group for comparison may lead them to believe that their experiences are normal. Prior to diagnosis, most Autistic women do not realise that others do not experience the same difficulties.

Sensory Processing Disorders (SPD) can impair the way Autistic women process and respond to sensory information. A woman may have an under sensitivity to pain and not display outward signs of pain to medical professionals. For example, some women have reported that their progression through childbirth was at the later stages of completion before being given assistance as they outwardly did not present in a way maternity staff could relate to. A woman's SPD may become a barrier to her being able to physically access medical help. Health care professionals may not realise that tactile defensiveness, noise, fluorescent lights, odours and many other environmental factors may cause pain and suffering, limiting access to medical premises. When women do try to self-advocate by describing their sensory needs and supports required, health care professionals frequently ridicule or dispute the diagnosis and refuse to consider accommodations. Geraldine reflected on the refusal to allow her to sit on her own clothing brought for the purpose rather than directly onto a plastic sheet. After being ridiculed, she was in tears and was unable to proceed with the examination.

Access to and communicating concerns for health care is problematic for Australian autistic girls. We know that accessing healthcare and communicating their health concerns is problematic. Medical professionals should ensure their offices have had an autism friendly sensory audit to be accessible for autistic patients. Yellow Ladybugs research found, 34% of girls are able to access their doctors without distress, 55% require loving support from a parent and carer to help them cope and manage with the environment, 10% 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. Yellow Ladybugs research found, 3% 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 53% of girls can communicate their needs to health professionals.

Eating Disorders

The Autism Research Centre at Cambridge University released findings relating autism to eating disorders including anorexia. In the study, teenagers scored higher for traits of Autistic Spectrum Disorder (ASD) compared with a large group of similarly aged adolescent girls without anorexia. Autistic girls have higher 'systemizing' skills. They therefore follow a strict system of behavior of day-to-day living that is a trait of both autism and Obsessive Compulsive Disorder. (OCD). The researchers suggest that clinicians should consider a crossover between the obsessive, systemizing and self-focused traits of autism with those of anorexia. They also suggest that this crossover is important when thinking about treatment and causes of anorexia. Without a diagnosis of Autism, Autistic females may not receive the appropriate treatment.

Polycystic Ovary Syndrome (PCOS)

The Autism Research Centre at Cambridge University released findings relating to Polycystic Ovary Syndrome (PCOS), which affects between 6 and 10% of women in the general population. Research showed women that are autistic or score high in autistic traits are more likely to have PCOS. However, those women are also under diagnosed, despite the health symptoms of the condition. It can be speculated, in the absence of further research that the difficulty in accessing healthcare, understanding 'normal' body functioning and the sensory elements to a menstrual cycle would account for the lower diagnostic rate for autistic women.

Violence against Autistic Women

Autistic experience and appearance to perpetrators can compound violence. Violence against women with disabilities is more than discrimination or the use of power in relationships. It is the use of systemic power to ignore, isolate, marginalise, stigmatise and vilify inconvenient people who may be viewed as using an unfair share of community resources. In the case of Autistic women, violence is compounded by the denial of our existence. Violence is about power, personal, communal and systemic. If our existence and specific circumstances are not acknowledged, we do not have the same protections as other women in society. Just as disability discrimination creates disadvantage for people with disabilities, the compounded difficulty of being denied information and recognition of your disability makes a safe environment much harder to achieve and often, it must be created in isolation. It also makes it easier for society to attribute blame to the Autistic victims of violence. If we are not recognised, society does not have to own a collective responsibility for the way in which we are treated. Furthermore, many individuals and systems who perpetuate violence against Autistic women, may perceive an advantage in continuing their behaviour. Social and societal privilege is built on sustaining an underclass. Autistic women and girls, who are unrecognised and ignored become one of the tools for sustaining privilege and power for others.

Abuse and Bullying at School

Abuse at school can take many forms with many perpetrators. Sometimes it is student peers, sometimes it is teachers, and sometimes it is environmental factors that impact on the child's autistic way of experiencing their world.



Yellow Ladybugs research found, only 30% of autistic girls have not experienced bullying at school. Yellow Ladybugs asked this as a multiple answer question. 47% of girls have been verbally abused, 20% have been physically abused, 12% have had their property damaged and 53% 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"

- **Exclusion by peers:** *"She has been excluded from parties and other events by children she considered to be her friend."*
- **Teacher's as the bullies:** *"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 "willfully 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"*
- **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", "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 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:** *"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 Punished 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", "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."*

Women and girls are often unable to identify when abuse is occurring, particularly when it has become normalized. Communication difficulties and a lack of access to advice from a support network or advocates who understand the interplay of autistic characteristics, Autistic women often do not know the safety mechanisms for reporting abuse.

According to Dr Emma Goodall (2016), difficulty with interoception, which she defines as *"an internal sensory system in which the internal physical and emotional states of the body are noticed, recognized/identified and responded to"* are common to many Autistic children. If these difficulties are not addressed, they continue to affect individual capacity to identify emotions and monitor body sensations which alert individuals to problems. This directly impacts on an individual's capacity to seek help.

Autistic women are often the victims of social predators and opportunists. 83% of women with disabilities will be sexually assaulted in their lifetime (Stimpson & Best, 1991). Only 3% of sexual abuse cases involving people with developmental disabilities are ever reported. There are no statistics about Autistic women. Morgan said, *"Before I had information about Asperger Syndrome, I thought if people smiled at me, they were nice and that they liked me. I could not and still cannot see the signals that help many women to avoid certain men. I let them get too close. I have been*

badly physically abused. I believed people who said they only did it because they loved me." It is likely that Autistic women are over represented in this group.

Social Isolation Risk Factor

It is well documented that social isolation increases the risk of violence within relationships and bullying at work, at school and in the community in general. Yellow Ladybugs research found, 55% of parents and/or their daughters have been unable to access their communities in the past month. The following factors show the extent of vulnerability for Autistic women and girls:

- **Judgement of general community** *"Behaviour and others judgment can make us feel unable or reluctant to access community activities".*
- **Limiting community 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"*
- **Restriction to 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".*
- **Restriction to social media platforms** *"there is always internet community" and "mum always has online support"*
- **Economic hardship** *"I dropped out of school because I was bullied. I couldn't get an education and I can't get a job."*

Signs of Abuse

Abuse of Autistics may be difficult to detect. As with the general population, abusers are usually someone known to their victims. Autistic women and girls may have high contact with service providers, may be placed in residential settings and are often socially isolated and under control of carers who are themselves in distress. While many may show signs of abuse such as emotional reactivity, self-harm, low self-esteem, eating disorders, repetitive stimulatory behaviours, elopement and faecal smearing, others become passive, to the point of catatonia. The victims may not receive help as many people believe that these behaviours are typical of autism rather than signs of distress. Similarly, the physical and behavioural signs of abuse common to the typically developing population may be overlooked as occurring as a result of perceived "typical" autistic behaviours or symptoms of co morbid conditions such as Ehlers Danlos Syndrome.

Dependence on others to communicate also increases vulnerability to abuse for Autistic women.

Stigmatisation & Discrimination of Mothers

Australian mothers are expected to raise children, manage family schedules and finances, maintain the home and provide a safe and secure environment for her children to grow, and, often, contribute financially. Australian mothers are expected to do this independently. In contrast, historically, and across many cultures, mothers have raised their children with the help of their families, friends and a range of other community supports. They have relied on their village. The notion that mothers should cope successfully alone penalises mothers with disabilities, including autistic mothers. When they reach out for support, society views them as inadequate in their ability to parent.

The implications for disabled mothers when seeking support can be catastrophic. Evidence (Carter, 2013) shows that in numerous cases that have appeared before the family courts, children have been removed from the care of their mothers for no other reason than their disability. A study by Autism Women Matter, Autism Research Centre and Cambridge University found that Autistic mothers were more likely to suffer pre and post-natal depression, greater difficulties in areas of parenting such as multitasking, coping with domestic responsibilities, and creating social opportunities for their child. Communicating with professionals about their child was stressful for Autistic mothers who are more likely to report feeling misunderstood by professionals, greater anxiety and selective mutism, and not

knowing which details were appropriate to share with professionals. Autistic mothers were more likely to find motherhood an isolating experience, worry about others judging their parenting, and feel unable to turn to others for support in parenting. Autistic mothers and mothers of children with autism were equally likely to have had contact with social services in the UK, with similar outcomes where 1 in 5 mothers of a child with autism, regardless of maternal diagnosis, were assessed by social services; of those, 1 in 6 had their child compulsorily placed for adoption. The research also found that allegations and investigations of suspected fabricated illness amongst children with autism and their siblings were two orders of magnitude higher than the known incidence the UK.

In Australia, fear of these outcomes, result in many Autistic women being afraid to seek help. This systemic violence against women with disabilities is hidden from the public eye. In addition, statistics on court outcomes involving parents with disability are not collected so the extent of this abuse is unknown.

Like Autistic women in Britain, Australian mothers might play or communicate differently. Autistic mothers might process the world differently and maybe learn in different ways. Autistic mothers might prioritise differently. Sadly, these differences that stem from being autistic are often seen as being less than, or not enough by mainstream Australian society. The resulting social ostracism at best, or systemic intervention at worst, is an abuse against autistic mothers that can place negative burden on a mother's mental health and family relationships.

This experience is a contradiction of the United Nations Convention on the Rights of Persons with Disabilities, Article 23. This Article commits States to ensuring that children are not separated from their parents based on a disability of either the child or one or both parents. Article 23 also commits States to taking measures to eliminate discrimination against persons with disabilities in matters relating to parenthood and to giving persons with disabilities assistance in the performance of their child-rearing responsibilities. Such assistance for autistic mothers, provided by services with expertise in autistic women does not exist in Australia.

Access to Justice

Autism is a significant barrier to seeking justice, compounding social, emotional and economic injuries done to many Autistic women. Professor Neil Brewer (2015) states that *"There are certain characteristics of individuals with ASD that might make them vulnerable to involvement in crime given certain situational disorders."*

Communication difficulties, including literal interpretation of language, combined with the difficulties in judging and reacting to social cues experienced as a characteristic of autism often lead to dire consequences.

"I couldn't afford a lawyer, but I wasn't eligible for legal aid. The community law advisor said it would be easy to take out a restraining order myself, so I tried. The magistrate told me not to step in the box. I looked around and could not see a box. I thought I might be standing on it already. I got up on a step to see if it had been under my feet. The magistrate went off at me for stepping in the box when he had told me not to. I looked around and realised that he was talking about the witness box. If he had said "Do not step in the witness box," I would have known what he meant. The whole court was laughing at me. I left straight away because I was so embarrassed I could not speak. I didn't get a restraining order. We lived with violence for many years."

Difficulties in reading the emotions and intentions of others result in some Autistic women being victims of opportunists, who profit from their social naivety.

Jeanette reported *"As a young woman I was very naive. I didn't yet have my Asperger's diagnosis and was desperate to be accepted. I was targeted by a criminal 'boyfriend and committed crimes to gain his approval. I went to prison I became a social chameleon in order to survive. I was such a convincing social 'actor' that I identified with being a criminal so spent the next few years in and out of prisons. More understanding about Autism, and a timely diagnosis, may have kept me out of prison and spared me and the victims of my crimes from a lot of misery. I'm doing well in life now but five years of my life were lost."*

If a woman does not have a diagnosis, it can be extremely difficult for her to receive understanding and justice. Autistic women may be victims of crime or may technically become perpetrators of crime without really wanting to while under the influence of a predator. An unusual demeanor, particularly lack of eye contact, may result in a prejudgment

of dishonesty by those involved in the justice system. Fear may lead to mutism or difficulty following instructions. Some plead guilty out of fear and fail to explain their circumstances.

Women involved in Family Court decisions may be disadvantaged for the same reasons. Many have difficulty sourcing information and processing advice. *"I believed my husband when he said his lawyer told him he would not have to pay child support because he could not afford that and maintain his status as a professional. It did not occur to me that someone would lie at the expense of his children"*

Autistic women in prison may be susceptible to a range of abuses when their unusual behaviours are not understood or are perceived as annoying by other inmates who often have emotional difficulties. In Australia prisons lack the resources for autism support, so some Autistics are in protective custody.

Difficulties in accessing the protection of the law are compounded by ethnicity, poverty, geographic isolation and for some Autistic women, intellectual delays. These are all groups that are disadvantaged in the general population but Autism is an additional factor that may lead to systemic abuse, not only for Autistic women, but for their families too.

Education: Perpetuating Systemic Violence

"The Disability Standards for Education 2005 sets out the obligations of education and training providers to ensure that students with disability can access and participate in education and training on the same basis as those without disability." (Australian Government, 2016). It is well known that educational attainment is an important predictor of positive life outcomes across all measures of wellbeing, including health, employment, and income prospects with completion of Year 12 resulting in a greater likelihood of being employed throughout adult life. What then are the implications for Autistic females?

This paper has already examined the negative impact of access to education supports through misdiagnosis or a lack of diagnosis. This is compounded by the attitudes and practices prevalent in many schools. Firstly, we acknowledge that there are many skilled and caring teachers who provide an excellent education for each student. While the Australian government provides disability funding and Autism specific training for teachers (Positive Partnerships), there is no formal measure of accountability which ensures that schools provide quality support for students with disabilities. The consequence is that many Autistic students, particularly girls who may be undiagnosed or whose diagnosis is questioned by people unfamiliar with female presentation, are not receiving the supports and accommodations to which they are entitled. In 2012, the Australian Bureau of Statistics reported that 86% of autistic children (no gender breakdown) reported 'having difficulty' at school, social inclusion, learning and communication as the main issues, despite many Autistic children being of above average intelligence. In addition, Campbell explains that Australia has created situations of lawful discrimination, for example, in the case of *Purvis v NSW*, the law determined that behaviour is not a part of disability. In the case of autism, behaviour is often a key to identifying autism and yet Australian children can be legally excluded from education by virtue of the expression of autism when distressed.

Frequent media articles, school exclusion records and family stories demonstrate that Autistic students are restrained, secluded and suspended at higher rates than other students. School refusal is common as children can no longer bear daily bullying, harassment and abuse by students and sometimes, staff. Girls who have been denied diagnosis are not represented in any data but their distress is evident. This is supported by the number, again, undocumented, of parents who choose distance education or home schooling because of the violence their children experience at the hands of those who have a duty to protect and educate.

Sadly, the bullying, harassment and denial of human rights in schools is not restricted to children. Mothers, particularly those on the spectrum who do not present as typical experience denial of human rights too, as can be seen in this statement from a mother who has a diagnosis of autism and a degree in education.

"I was really hurt and angry" An Autistic mother tells of the trauma endured when her son's paediatrician bullied and threatened her with the Department of Human Services after she spoke of her plans to not enroll her autistic son in a mainstream state school the following year and instead opt to homeschool.

This bullying was not just verbal but formalized in a letter. Written by her son's paediatrician, it was also sent to the family GP, Occupational Therapist and to the Queensland Education Department with a recommendation to refuse

her son a medical certificate excusing enrolment into mainstream school. *"I will not provide that [medical exemption] and recommend that other medical staff also do not provide such paperwork".*

The paediatrician was opposed to homeschool based on the mother's disclosure of her own autism diagnosis, disclosure of her own negative experience being bullied through school and the paediatricians doubted the mother's capabilities stating *"I believe it is more in his developmental interest to attend school, than to allow his mother to keep him home and try to educate him".*

Sadly, this is despite the fact that his mother has a Degree in teaching.

The letter became even more threatening when paediatrician said *"...and advise her [mother] of the breach to Queensland State law if she does not enroll him in a school program, which can become a child protection issue".*

The mother said *"I feel shaken and triggered by it. I have worked really hard to feel safe and feel I have control and autonomy over my life and how I parent educate my son. I feel that slipping away".*

ABS data (2012) suggests that the difficulties experienced in gaining an education continue after school. Of the Autistic students who finish school, 81% had not completed a post-school qualification in comparison to both students with disabilities and students without disabilities. Again, there is no breakdown of gender and undiagnosed girls are not represented.

What is the situation for Autistic students who do have opportunities for higher education and training?

These female students describe their experiences:

- *"I filled out the forms to apply for a university individual education plan but they did not get back to me. When I realised they weren't going to and found out who to ask, the date had passed so I could not have one".*
- *"I asked for supports but I could only get general ones like help in the library, which I did not need, and access to a quiet room during breaks. It is up to lecturers to decide what accommodations they will give. They did not want to compromise their courses by giving additional help. I needed to be able to talk about assignment briefs to be sure I understood".*
- *"The lecturer was excellent and gave me a dedicated work station so I did not have to compete for equipment because being bumped and general noise aggravated my sensory difficulties. Other students were angry that I had special treatment and said I played the "Autism card" so I dropped out because I was too ashamed to face the comments every day".*
- *"I failed an exam because the student in front of me was wearing a strong perfume. I am extremely sensitive to smell and so I explained to the supervisor and asked to be allowed to move, but the request was denied as ridiculous".*
- *"The student support unit did not understand autism in women. They prepared a plan that was more suited to a male expression of autism. I told them my mentor was an international speaker on Autism and she would be willing to provide free professional learning. They declined".*

The lack of accountability for inclusive practice in education institutions is a form of systemic abuse, denying Autistic women the right to learn and prepare for productive lives.

Employment

The failures of the education system are repeated in access to employment. In 2012, the labour force participation rate for Autistic people was 42%. This contrasts with a 53% employment rate for people with disabilities and 83% for the general population (ABS, 2012). Very few Autistic women are subsequently able to access further education and training, restricting their choices to casual or low paid jobs, often below their capacity to work. Most Autistic employees have proved to be loyal, task oriented, often fastidious in the completion of duties and generally excellent workers. They just need a chance to get a job. The Australian government funds specialist employment services for people with disabilities. They provide support by negotiating with employers, providing information about the disability and reasonable accommodations. However, those women who do not have a diagnosis are not able to access these specialist employment services.

Why is that a concern? Autism complicates the application process with women who cannot make eye contact, being considered dishonest or sly. Others need support in communicating, particularly in stressful situations. Specialist employment services can explain the difficulties so that employers do not interpret autistic behaviours according to social norms.

- *“They got me a job in a laundry but the noise was terrible and I got very stressed... My voice got louder and louder and I was sacked for shouting at people even though everyone told him I did nothing wrong”.*
- *“I was advised not to disclose autism because this could be used to discriminate against me. I was lucky that I did in my application because when I was harassed at work, Workers Comp tried to say I was not suited for the job because I was autistic and I would not have been employed if they had known”.*
- *“I tried to tell my employer about autism and the supports I needed. She said she didn’t want to know because she did not want to invade my privacy. Luckily, my co-workers were great and they helped work out some things that we could do when I was overwhelmed”.*

Once again, while employment services have a duty to pursue the best possible outcomes for their clients, they are generally geared towards support for people with intellectual, sensory and physical disabilities. Very few understand or provide adequate assistance for Autistic people and understanding of female presentation is rare. The consequences for unemployed Australians are dire. Financial and health outcomes are poor, but the damage done by the expectation of society that all citizens work and that those who do not are “leaners” is intolerable and unfair for those who do not get an opportunity to participate in employment. Autistic women, and undiagnosed are victims of this emotional and economic abuse.

National Disability Insurance Scheme

The National Disability Insurance Scheme (NDIS) is an initiative to reform disability funding in Australia through one independent statutory agency known as the NDIA. The reform is revolutionising disability funding creating a unified national system. The NDIS claims it *“will support a better life for hundreds of thousands of Australians with a significant and permanent disability and their families and carers”* as it replaces previous 'block' funding and offering a more individualised approach that is needs based.

- Designed to be an insurance model the NDIS works with participants to design capacity building goals and funded supports are allocated to achieve these goals providing they meet the 'reasonable and necessary' legislation.
- The rollout of the NDIS is changing the face of disability support fast. New funding models, rapid growth, complex administration processes and an unexpected demand for autism support have resulted in significant problems.
- Carers and other staff often lack autism specific training. Lack of autism specific training has a huge impact on effective service provision for autistics. Not only do NDIS staff not understand their clients, but mothers, including Autistic mothers are usually client advocates.
- Complex administration and funding changes which may negatively impact on an organisation’s capacity to operate have resulted in organisations expanding their services so that they can become a “one stop shop”.
- Clients and their advocates are often not told of services and community access opportunities not provided by their main provider, limiting choice. Clients are often not supported in self managing cases. *“I was talking to a staff member about people who want to self-manage. She said they had some people who wanted to do that and that she gave them their files. They bring them back within a few days because they did not understand the complexity of case management and they cannot do it. I asked about training, support or gradual handover and the response was that they did not have time for all that”.*
- Carers and other staff often lack autism specific training. Lack of autism specific training has a huge impact on effective service provision for autistics. Not only do NDIS staff not understand their clients, but mothers, including Autistic mothers are usually client advocates.

- Autistic communication is usually very literal. The following example is an experience common to many Autistic mothers trying to coordinate support for children. *“Support worker booked hours before shift service provider phoned to say the worker had called in sick and asked would you like us to try find a replacement. I said yes. They said if I do I will phone you back before 1pm. I received no phone call so made other arrangements by that time. At 3pm a support work from the service provider showed up. I sent them away as other arrangements had been made. Service provider then tried to charge that shift to my daughters plan because they emailed my support coordinator who emailed me which I didn't see. Regardless I was expecting a phone call as discussed directly from service provider who rang in the first place earlier that day”.*
- Late diagnosis, particularly for girls, often impacts on services which can be accessed and the way in which they are delivered. *“I have an issue with my middle daughters plan. She was accepted at 5yrs old, no planning meeting until 6mths later when she turned 6yrs old. She has not had her official diagnosis due to several barriers and the NDIS is meant to be needs based but told me I cannot self-manage because she has no proof of disability”.*

The lack of Autism specific training for NDIS staff can result in severe systemic abuse as Autistic women. For example, Federal Discrimination Law (2016) is very clear about the requirement for reasonable adjustments to be made for people with disabilities. Autistic mothers have had many experiences in which NDIS staff not only ignore their communication needs, but humiliate and disadvantage them for their autistic characteristics. The law states:

5.2.2 Direct discrimination under the DDA

Section 5 of the DDA defines 'direct' discrimination. It provides:

5 Direct disability discrimination

- (1) For the purposes of this Act, a person (the discriminator) discriminates against another person (the aggrieved person) on the ground of a disability of the aggrieved person if, because of the disability, the discriminator treats, or proposes to treat, the aggrieved person less favourably than the discriminator would treat a person without the disability in circumstances that are not materially different.
- (2) For the purposes of this Act, a person (the discriminator) also discriminates against another person (the aggrieved person) on the ground of a disability of the aggrieved person if:
 - (a) The discriminator does not make, or proposes not to make, reasonable adjustments for the person; and
 - (b) The failure to make the reasonable adjustments has, or would have, the effect that the aggrieved person is, because of the disability, treated less favourably than a person without the disability would be treated in circumstances that are not materially different.
- (3) For the purposes of this section, circumstances are not materially different because of the fact that, because of the disability, the aggrieved person requires adjustments.

Fair adjustments? An Autistic Mother Details Her Recent Meeting With a NDIS Planner

- *Planning meetings are conducted by phone now so participant must request for a face to face meeting with a reason for it. A longer wait for a face to face planning meeting is used as a way to pressure participants into agreeing to a phone meeting.*
- *No information was provided from the NDIS to me prior to my planning meeting*
- *NDIS planner was late due to being 'off site' forgetting our scheduled appointment*
- *Planner was did not do a clear formal introduction therefore misunderstanding the role of my disability advocate*
- *Planner was rude, aggressive, angry and talked over the top of both myself and my advocate*

- *Planner refused to look at my supporting documents which included a letter from my GP stating my disabilities, a summary of all the assessments and diagnosis from psychologist including valuable information about my functioning, a carers statement from my husband who couldn't attend due to work commitments and finally I had included an 'about me' page that I felt would help the planner understand me better as I lack verbal skills.*
- *Planner reacted angry when I was having trouble answering the WHODAS questions*
- *Planner was not trying to understand when I attempted to explain why I was having trouble and how I could be helped. Instead she talked over the top of me saying it was a standard questionnaire for all disabilities and I must answer.*
- *Planner then berated my disability advocate saying 'didn't you explain to her what happens in the first planning the meeting?!'*
- *Planner misunderstood advocates role mistaking her for a 'support coordinator' and not listening to advocate.*
- *When advocate said she was uncomfortable in this meeting the planner threatened to call of the meeting saying 'do you want to just end this now?!'*
- *Planner had no experience or training of Autism admitting her knowledge was 'very limited'*
- *Planner admitted she had no information about me other than my diagnosis of Autism Spectrum, despite the NDIS office having records of my original 'access forms' including psychologist report.*
- *Planning meeting went on for over 3 hours due to communication breakdowns*
- *Planner criticised my written 'goals' saying they weren't written in the 'NDIS language'*

Communication discrimination is not restricted to verbal interactions. NDIS participants are required to access information via the NDIS website. This is notoriously difficult to navigate. Autistic mothers who may have limited reading and/or comprehension skills are not able to access the information they require, compounding the abuse of human rights already experienced.

Many Autistic mothers report feeling powerless and intimidated by the rigors of communication with NDIS planners and carers. They are exhausted and humiliated by systemic discrimination and cannot face or cannot access the information required to address discrimination. This is compounded when they find out that the NDIS has an internal review process. The pain and suffering of the NDIS interactions experienced by many Autistic mothers cannot be quantified and certainly is not reflected in any data.

Trauma and Post-Traumatic Stress Disorder

Growing up with sensory difficulties, sensitive nervous systems, on top of a very different view of the world seems to also mean that we autistic women are very prone to trauma. Situations and environments that well-meaning professionals such as teachers, counsellors, early intervention therapists and even our parents, might not realise are causing us harm but actually are is cause for growing concern among advocates and activists. Compliance based therapies, authoritative parenting, forced medication, forced medical procedures such as blood tests and forced schooling are contributing to trauma, resulting in accumulative stress and at worst PTSD.

In forums and social media platforms all over the world, where autistic women have access to the internet, and also at in person support groups, many of us who are advocates and activists are seeing the results of years of trauma developed by years of accumulated exposure to distress and anxiety experienced through direct discrimination, harassment and denial of personal experience, an accumulation of extreme stress even in children. Most commonly, children who cannot cope within the rigid school education structure of mainstream schooling and/or kids who are misunderstood by their families. In extreme cases, of which there are many, women and daughters are displaying signs of PTSD or accumulative PTSD.

Many autistic women report abusive childhoods where they have been physically, emotionally or sexually abused (or all three); they have experienced homelessness either forced or simply to not have to live with the abuse. Women with communication difficulties and/or social challenges can be targeted by abusers and predators throughout their lives and if there is no one looking out for them or helping them to spot predators, all kinds of awful situations can arise.

For non-autistic women, who do not have the same sensory, communication and social challenges, going to a therapist and trying to get relief from symptoms that are debilitating and interfering with life, it might be relatively straightforward. For the autistic woman, this couldn't be further from the truth. Autistic women commonly report that their therapists do not believe they are autistic, resulting in the focus of therapy to be justifying their autism diagnosis or trying to convince their therapist that they really do have difficulties. For the autistic woman who experiences alexithymia, which is difficulty in recognising or getting in touch with emotions, trying to get treatment for PTSD can prove almost impossible.

Women in this situation are dismissed as having no issue because they did not seem overly emotional when talking about their trauma. If the therapist is not well read or educated on autistic ways of being, thinking or feeling then they will dismiss the woman based on their narrow diagnostic criteria and the woman misses much needed treatment and empathetic understanding. This scenario is common and there are many reasons for this. One being the one mentioned above, alexithymia. Another is that when you have been constantly let down and treated badly or even misunderstood, trust is at a low. We do not trust when the very people who are meant to help us hurt us. The autistic woman may have already been through a slew of professionals who have labelled them 'resistant' or 'diagnosis shopping'.

Historically, women's health and in particular mental health have not been taken seriously. If you add autism to the mix, then you have a recipe for disaster. As an autistic woman, you are lucky to come through it without mental scars or PTSD. As well as sensory issues, communication difficulties further alienate us, making it extremely hard for us to understand and be understood. This is another significant barrier to accessing appropriate supports and/or services. All professionals working with us need to understand this and be mindful that it is a disability, not us being difficult or resistant.

Autistic women are still finding that even when they have found the courage to advocate for themselves, that they are still, at best, not accommodated for and at worst, discriminated against. It is appalling that women put up with and live with symptoms of trauma for as long as they do, rather than risk more trauma from bad treatment. Many of the women contributing to this paper experience bad treatment on a weekly if not daily basis, be it in our interactions with NDIS planners, therapists, teachers, principals, doctors, psychologists, early intervention specialists and more.

For many women, it is our co-occurring conditions are what causes us the most grief. Whether it is a psychosocial disability, severe anxiety, depression or PTSD, we deserve to be treated like humans, with respect and understanding. Professionals have a duty of care and they should keep up to date with relevant autism research but they should also immerse themselves in the culture of the women they are trying to help, in the form of autistic writings, where they can truly get a glimpse of how our brains work.

Many aspects of activism and advocacy in the area of autism are essential is ensuring that our girls, our future women do not grow up undiagnosed, misdiagnosed, or without the accommodations and support that can mean the difference between well-adjusted or traumatised

Gender Differences

Autistic people and women have the same sorts of gender identities and sexualities as their non-autistic peers. Anecdotally autistic people are more likely to identify as Trans, Queer, gender Queer, Lesbian or Asexual. Autistic women with diverse gender identity or sexuality experience intersectional disadvantage as Autistics and due to their gender or sexuality. Transsexuals, Gender diverse and Queer people historically and presently experience a significant amount of discrimination from personal attacks to structural bias.

Gender identity and autism are usually researched as part of a general focus on sexuality. There is little information available about the impact of Gay, Bisexual, Lesbian and Transsexual (GBLT) on autistic experience by gender apart

from anecdotal evidence in online forums. Abuse and discrimination exist and are described by anguished personal experience.

- *"I don't want her coming to parent group. She looks ridiculous."*
- *"God does not make mistakes. Go back to being a man."*
- *"The guys do not want a woman looking at them in the toilet."*
- *"Women don't want men in their toilets. You don't know if they are faking transgender to spy."*
- *"Employing transnics would be bad for my business because religious people would not want to be served by you."*
- *"It's really important to dress your girl like a girl or these days they go transsexual."*

Biologically female to male transitions are also complicated by the fact that women are often carers. They may not have the financial means to transition as they would wish and attract negative attention, in addition to abuse experienced as an Autistic person. Some may be reluctant to attract additional negative attention by discussing their lives.

While broader society is aware of the alternative sexualities of GBLT people, few understand that sensory issues can also extend to alternative sexualities. For example, when a sensory sensation is very powerful, it can become sexually stimulating or alternatively sexual experiences can trigger sensory revulsion.

- *"My mum wears plastic bags by her skin and the kids laugh because they can hear her rustling".*
- *"I don't like sex. I like to feel the wind on my skin. I feel trapped in sex. I feel free in the wind".*

Therapists who would not think of eliminating typical sexual behaviours and who do not have a deep understanding of autism attempt to suppress harmless behaviour rather than managing it, for example, by wearing plastic that does not rustle.

Autistic people are often subject to stereotyped beliefs about sexuality and disability. Some Autistic people experience tactile defensiveness and sensory overload which makes sex unpleasant or threatening. These people may identify as asexual. There is often an assumption that all Autistic people are asexual. Asexuality is far from universal. These kinds of stereotypes are unhelpful and can lead to an Autistic woman's diagnosis or experience being questioned and gas lighted.

Vulnerable people, particularly girls, may also be denied their own sexuality by overprotective parents and residential care facilities. It is not unusual to find autistic girls and women who are isolated from sexual relationships because parents do not want their daughters to be exploited. They may tell them that they are not capable of marriage or that they are asexual, to prevent perceived exploitation. They may also not be provided with information about sexuality in order to discourage curiosity and their opportunities for social interactions are often highly controlled.

Jeanette says *"When I was a teenager my mum told me that women weren't supposed to enjoy sex. As we were in a strict Christian community I thought this must be true. Because I had been told it wasn't enjoyable for women I had little or no interest in sex as a teenager. When I was older I worked out my mum had probably said that to make me disinterested in sex, but had known herself it wasn't true which was odd because it turns out that I am asexual anyway!"*

Actions Required To Reduce Violence and Discrimination

The United Nations Convention on the Rights of Persons with Disabilities (CRPD) reminds us that societal concepts of disability are evolving. This paper clearly demonstrates that the harm and negative outcomes of disability result from the interaction between people, attitudes and environments. Strategies which aim to remove the barriers to full participation and to eliminate the violation of the human dignity of persons with disabilities, also requires the mainstreaming of disability issues, including the impact of gender, to bring about sustainable change. Why gender?

World-wide, we recognise that females with disabilities are often at greater risk, throughout society of violence, abuse, maltreatment and neglect. If data does not reflect the female experience, appropriate policies cannot be developed and female specific supports cannot be implemented when needed.

This paper reflects a concern that despite Australia being a signatory to the CRPD, systemic processes and attitudes still result in barriers to participation and human rights violations for persons with disabilities, even within organisations with a brief to provide support and equal opportunity. We note that these organisations rarely consult with, or ensure that persons with disabilities are involved in decision-making at the level of management, policy making and program delivery. Involvement by persons with disabilities is usually on a voluntary basis. Consultation with disabled persons is usually done as a kindness, rather than paid recognition of expertise, as is afforded to non-disabled staff and consultants. Persons with disabilities are rarely represented on management boards, with membership criteria often designed specifically to exclude based on the lack of prior experience. The gender bias of management teams is well documented in Australian society. There is no reason to believe that Autistic women do not face similar and more challenging barriers to participating in decision making.

We take this opportunity to remind Australians that under the CRPD, Article 4, General Obligations, Australians, as signatories have agreed to the following:

States Parties undertake to ensure and promote the full realization of all human rights and fundamental freedoms for all persons with disabilities without discrimination of any kind on the basis of disability. To this end, States Parties undertake:

- A. To adopt all appropriate legislative, administrative and other measures for the implementation of the rights recognized in the present Convention;
- B. To take all appropriate measures, including legislation, to modify or abolish existing laws, regulations, customs and practices that constitute discrimination against persons with disabilities;
- C. To take into account the protection and promotion of the human rights of persons with disabilities in all policies and programmes;

This collective of Autistic women respectfully request that the Special Rapporteur consider actions that they believe will change the experiences of Autistic women and girls whose invisible presence in disability discourse and practice results in multiple and intersecting forms of discrimination and violence. Legislation is required to recognize our presence in society and to prevent harm done to ourselves, our daughters and to future generations.

Steps required in developing a pathway for change:

- A. An agreed series of consultation and Government processes designed to inform legislative change are required to recognize our presence in society and to prevent harm done to ourselves, our daughters and to future generations.
- B. Consultations will be founded on an understanding and acceptance of the link between discrimination and violence
- C. Consultations will involve direct and genuine involvement of people with disabilities in decision making processes affecting their lives

Government departments including justice, education, NDIS and health services must be accountable for upholding the Disability standards:

- Provide equitable employment opportunities at all levels of organisations as a model for private organisations.
- Set targets for inclusion.
- People with disabilities which are highly represented in accessing the NDIS should be employed to provide professional learning and training at all levels and all areas of government services.
- Develop protocols for informing people with disabilities of their rights, of processes and of procedures

- Ensure that individual disability supports are in place when meeting with clients with disabilities.
- Clients should have the opportunity to evaluate the supports received and people with disabilities should be a part of the committee charged with developing standards of service to form a basis for evaluation.
 - 1) Researchers and disability services must examine their provisions for gender bias according to criteria developed by a panel which includes equal representation of people with disabilities.
 - 2) Clients of disability services need to be explicitly made aware of the grievance procedures, using accessible materials, including contact details for advocates who share that disability whenever possible or who have certified training in supporting that condition.
 - 3) In celebrating and provision of successful inclusive practice, organisations should be publicly rewarded for excellence in disability service provision, determined by client satisfaction and disability friendly audits.

References

- American Psychiatric Association. (2013). Diagnostic and statistical manual of mental disorders: DSM-5. Washington, D.C: American Psychiatric Association.
- Australian Bureau of Statistics. (2014). Autism in Australia, 2012.
<http://www.abs.gov.au/ausstats/abs@.nsf/mf/4428.0>
- Australian Government. (2005). Disability Standards for Education 2005. <https://www.education.gov.au/disability-standards-education-2005>
- Australian Government. (2016). Students With Disability, <https://www.education.gov.au/students-disability>
- Australian Human Rights Commission. (2016), Federal Discrimination Law, 2016. <https://www.humanrights.gov.au/our-work/legal/publications/federal-discrimination-law-2016>
- Baron-Cohen, S. (2013). Girls with anorexia have elevated autistic traits. <http://www.cam.ac.uk/research/news/girls-with-anorexia-have-elevated-autistic-traits>
- P. Bos, P. et al. (2016). Testosterone reduces functional connectivity during the 'Reading the Mind in the Eyes' Test. *Psychoneuroendocrinology* 68:194-201
- Blakemore, M. (2015). Human Right Violations Against Parents That Are Autistic, Have an Autism Spectrum Condition. www.autismwomenmatter.org.uk/featured/human-right-violations-against-parents-that-are-autistic/
- Brewer, N. and Young, R.L. (2015). Crime and Autism Spectrum Disorder, Myths and Mechanisms. Jessica Kingsley Publications
- Cambell, C. (2003), A HARD CASE MAKING BAD LAW: PURVIS V NEW SOUTH WALES AND THE ROLE OF THE COMPARATOR UNDER THE DISABILITY DISCRIMINATION ACT 1992. (CTH)
- Centres for Disease Control and Prevention. (2014). Autism Spectrum Disorder (ASD). <https://www.cdc.gov/ncbddd/autism/addm.html>
- Convenor, Autism Advocacy Asperger Australia. (2016). Autism diagnoses in Australia continue to grow in 2016. <https://www.a4.org.au/node/1340>
- Cusack, J. et al. (2016). Personal Tragedies, Public Crisis. <https://www.autistica.org.uk/wp-content/uploads/2016/03/Personal-tragedies-public-crisis.pdf>
- Dowse, L et al.. (2013). Stop the Violence: Addressing Violence Against Women and Girls with Disabilities in Australia. Background Paper. Hobart: Women with Disabilities Australia.
- Goodall, E. (2016). Interoception 101. <http://web.seru.sa.edu.au/pdfs/Interoception.pdf>

Meng-Chuan Lai et al. (2016) Quantifying and Exploring Camouflaging in Men and Women with Autism.
http://docs.autismresearchcentre.com/papers/2016_Lai_Quantifying-and-exploring-camouflaging.pdf

National Disability Insurance Scheme (NDIS). About Us. <https://www.ndis.gov.au/about-us>

Pohl, A. Baron-Cohen, Blakemore, M. Crockford and S. Allison, C. (2016). Positive & Negative Experiences of Autistic Mothers.
<http://www.autismwomenmatter.org.uk/research/positive-negative-experiences-of-325-autistic-mothers-vs-91-typical-mothers-online-survey-autism-and-motherhood/>

United Nations. (2006). Convention on the Rights of Persons with Disabilities and Optional Protocol.
<http://www.un.org/disabilities/documents/convention/convoptprot-e.pdf>

Yellow Ladybugs. Blakemore, M and K. Koulas (2016). Yellow Ladybugs Australia Specific Information.
info@yellowladybugs.com.au