

5 July 2019

# Yellow Ladybugs Submission: Royal Commission into Mental Health

### Introduction

Yellow Ladybugs is grateful for the opportunity to make a submission to the Royal Commission into Mental Health. In making this submission, Yellow Ladybugs intends to further its stated mission to improve the lives of autistic girls and women, in particular by highlighting the specific challenges autistic girls and women experience with respect to their mental health and wellbeing.

We hope to draw your attention to these issues and we would welcome the opportunity to participate in the hearings process scheduled for July. Given our status as an autistic-led organisation, our members can offer both lived experience and in many cases professional expertise specifically on the intersection of autistic girls and women and mental health.

# Recommendations

- 1. Yellow Ladybugs recommends that the hearings process for this Royal Commission includes a targeted hearing for the disability community.
- Yellow Ladybugs would welcome the opportunity to be invited to speak at the hearings, to ensure that the mental health needs of autistic girls and women are given the appropriate level of consideration, and specifically the impacts of inadequate mental healthcare for autistic girls and women in the following areas:
  - Escalation to suicide, self-harm and severe depression
  - Discrimination due to autism diagnosis
  - Insufficient public mental health services
  - Rural access to mental health services and community support
  - Lack of expertise in autistic girls and women
  - High costs associated with mental healthcare services
  - Lack of knowledge on where to get help
  - Lack of support for autistic mothers.

# **About Yellow Ladybugs**

3. Yellow Ladybugs is an autistic-led non-government organisation dedicated to the happiness, success and celebration of autistic girls and women. Yellow Ladybugs runs regular social events which bring autistic girls together in an inclusive and sensory-friendly setting. These events help foster a sense of connection, belonging and pride for autistic girls.



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4. Yellow Ladybugs is committed to changing the common misconceptions about autism, ensuring that autistic girls and women are supported according to their needs, and building a society that values and empowers all autistic individuals. Yellow Ladybugs has a strong advocacy role in highlighting the many challenges autistic girls and women face, including barriers to diagnosis, exclusion in school and employment, and access to services.

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- 5. In 2016, Yellow Ladybugs was invited by the United Nations Office of the High Commissioner for Human Rights (OHCHR) to contribute to the report on Mental Health and Human Rights. On 25 October 2016, Yellow Ladybugs provided its submission (Attachment A). In compiling this submission, Yellow Ladybugs obtained input from 1,474 autistic girls and their parents from Australia, United States of America, Morocco, European Union, Canada, New Zealand, United Kingdom and Ukraine.
- 6. In preparing our submission to the Royal Commission into Mental Health, Yellow Ladybugs has drawn on its contribution to the OHCHR report on Mental Health and Human Rights, and the detailed survey which informed this submission. Yellow Ladybugs welcomes the opportunity to participate in the Royal Commission and is committed to ensuring that the mental health-care needs of autistic girls and women are specifically addressed as part of this inquiry.

# Discussion

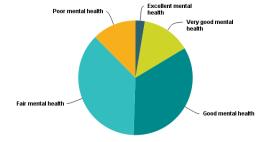
- 7. Autistic girls and women are impacted by their membership of other groups which also experience intersectional disadvantage. Autistic women with mental illness are experiencing three intersectional disadvantages - being autistic, being female and having a mental illness. Some of the areas in which intersectional disadvantage is particularly apparent include employment, education, housing, parenting, access to justice and/or legal services and access to healthcare, including mental healthcare.
- 8. Autistic women and girls currently comprise around one in four autism diagnoses in Australia. Strong anecdotal evidence suggests the actual prevalence of autism amongst women and girls to be considerably higher. Understanding around autistic women and girls forms a relatively new discipline and as recently as the mid-1990s, women and girls were thought to comprise only one in 25 diagnosed autistic people. Autistic girls and women can be misdiagnosed with co-occurring mental health conditions, have greater verbal and social imitation ability, are screened through male phenotype diagnostic instruments and are missing or underrepresented in research.

"My daughter developed an eating disorder that we had to focus on for about 6 months before we could pursue the ASD diagnosis" (Yellow Ladybug community member, 2016)



## Autistic Women and Girls Accessing Mental Health Services (2016 Survey Results)

- 9. In the self-reported mental health of autistic parents who are parenting an autistic girl:
  - 49% report fair to poor mental health
  - 34% good mental health
  - 14% very good mental health and
  - 3% have excellent mental health.



- 10. 37% of non-autistic parents who are parenting an autistic girl self-reported their mental health as being fair to poor.
- 11. For **autistic girls**, 51% have fair to poor mental health, 32% report having good mental health, 15% have very good mental health and 2% have excellent mental health.
- 12. 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 mentally unwell.
  - 5% of autistic girls are non-verbal
  - 1% use assistive communication devices
  - 24% of autistic girls have their parents communicate their health needs
  - 19% of autistic girls experience mutism in the doctor's office from being overwhelmed, and
  - 51% of girls can communicate their needs to health professionals.
- 13. It is important to ensure psychiatrists and mental health service providers have a better understanding of female autism to ensure services are timely, appropriate and meaningful.
  - 8% of autistic girls were receiving no mental health support whilst waiting for health services
  - 32% require more mental health support than they were currently receiving
  - 39% were receiving adequate support, and
  - 21% require no support.

### Impacts of Inadequate Mental Healthcare for Autistic Girls and Women

14. Verbatim comments from the 2016 Yellow Ladybugs Survey are provided below to illustrate some of the serious and distressing impacts of inadequate mental healthcare for autistic girls and women experiencing mental health illness (for more detail on these impacts, refer to **Attachment A**).

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## 15. 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."

"It took my child trying to kill herself to access free supportive therapy."

### 16. 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."

"Long waiting lists also a diagnosis of ADHD seems almost to make MHI (mental health issues) irrelevant...'it's because she's autistic.""

"...were not interested and insisted on discharging her from their services once we received her diagnosis despite still exhibiting auditory and visual hallucinations."

## 17. Insufficient public/government mental health services

"They left her unsupported for 3 whole years following an urgent referral for her mental health."

### 18. Rural access to mental health services and community support

"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."

"Our location is a huge limitation to what support we can access. Extensive travel is required. Travel is physically draining on my children."

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"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."

## 19. Lack of expertise in female autism

"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."

## 20. High costs associated with mental healthcare services

"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."

### 21. 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."

"My child experiences a great deal of anxiety but we get no support and I do not know where to get help for her."

- 22. Autistic women and girls experience the same mental health conditions as non-autistic people. Some are more prevalent among autistic people generally such as anxiety disorders, depression and post-traumatic stress disorder. There is increasing evidence that autistic girls and young women have a higher prevalence of eating disorders such as anorexia nervosa and bulimia nervosa than the general population. There is also evidence that within the population of people with eating disorders, there is a high prevalence of autistic girls and women. It should be noted that research into autism and mental health is an area which could benefit from more interest and resources.
- 23. Misdiagnosis of mental health conditions can occur for autistic women. A common misdiagnosis for autistic women is one of borderline personality disorder. The presentation of autism in women can include issues with identity and belonging and self-injurious behavior. These symptoms can be experienced by



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people with a diagnosis of borderline personality disorder as well as 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.

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- 24. Some legacy practices which still exist within institutions responding to mental illness/conditions can be abusive or discriminatory (e.g. use of seclusion and/or restraint). Mental health consumers who may be at risk of violence to others of self-injurious behaviour are kept in an often locked room within the high dependency unit of the hospital. For autistic women, seclusion can be particularly traumatic. Physical intervention is often used to get a patient into the seclusion room are and they may be forcibly medicated. Such methods can trigger meltdowns in autistic people or trigger post-traumatic stress responses. This in turn will likely escalate the situation.
- 25. Autistic people can experience meltdown or shutdown when overloaded. This can happen through sensory, emotional or information overload. Meltdowns are different for each individual but can look quite confronting or frightening for those witnessing them. A meltdown is not done deliberately or consciously; it does not come from a position of the autistic person trying to gain something and it is not based in anger. In a mental health setting, where people may be self-injurious or violent, a meltdown may be misinterpreted. If the consumer is not diagnosed as autistic, then meltdowns are likely to be misunderstood. This can result in escalation of force from hospital staff and the consumer and can even result in the person being transferred to a criminal justice setting.
- 26. Autistic people and people with mental illness experience stigma and discrimination in Australia. There are many unhelpful attitudes around mental illness and autism which are prevalent through society. These include that autistic women should not raise children.
- 27. A collaborative research project, '*Positive & negative experiences of 325 autistic mothers vs 91 typical mothers*' between Cambridge University, Autism Women Matter and Autism Research Centre shows autistic mothers are more likely to experience (compared to non-autistic women):
  - rates of 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
  - pre-or postnatal depression
  - stress from communicating with professionals about their child
  - more likely to report feeling misunderstood by professionals
  - greater anxiety, selective mutism and not knowing which details were appropriate to share with professionals
  - autistic women 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
- 28. Yellow Ladybugs is aware that Australian autistic mothers are encountering stigma and discrimination. Autistic women require targeted support to combat mental health distress in pre-and post-natal support,



promotion of parenting capabilities and reducing of professional stigmatisation and discrimination in their roles as mothers. Professionals require targeted training, by autistic people, to help them to provide meaningful support to families.

- 29. It is vital to promote all the various independent life domains (school/study, work, home ownership etc.) as an option for autistic women and girls. This means social inclusion and participation needs to be promoted, to women and particularly young women and teens.
- 30. From the 2016 Yellow Ladybugs survey, female autistic student respondents indicated that 71% had experienced some form of bullying.
  - 48% of autistic girls have been verbally abused
  - 20% have been physically abused
  - 12% have had their property damaged, and
  - 52% have been socially excluded.
- 31. Experiences of bullying can lead to mental health issues for autistic and non-autistic girls, but we know that autistic children are more likely to experience bullying.

### Identifying Systemic Failures in Mental Health Service Provisioning

- 32. In this submission we have highlighted some of the mental health challenges autistic girls and women experience including:
  - Service and access gaps in the public healthcare system that impact on autistic women and girls.
  - Mental health clinicians with a varied (and often low or non-existent) level of understanding autism in general and autism in women and girls specifically.
  - Stigma within society, both structural and casual, that limits the capacity and ability of autistic women with mental illness to work, study or participate in society in other ways.
  - Private mental health practitioners, particularly psychiatrists and clinical psychologists who lack understanding of autism and mental illness in women. This can lead to autistic women paying fees for services which are unhelpful or even counterproductive.
  - In many cases, the assessment for autism is costly. There are less diagnosticians in rural and remote areas which can also mean women are unable to access an autism assessment.
  - Mental health crisis services may have limited knowledge of autism and mental illness. This can result in a range of issues including dismissive responses to an autistic woman who is in crisis.
  - Autistic women may lack family or social support. This can mean they have nobody to advocate for them when accessing mental health services.
- 33. It is because of the particular challenges faced by autistic girls and women in the area of mental health that Yellow Ladybugs recommends that the Royal Commission into Mental Health specifically addresses



the topic mental health within the disability community, including the autistic community and specifically autistic girls and women.

34. Thank you for considering the needs of autistic women and girls in the Royal Commission into Mental Health. As a next step Yellow Ladybugs would welcome the opportunity to participate in the Hearing process.

Kind regards

## **Katie Koullas**

Founder, Yellow Ladybugs

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## ATTACHMENT A

#### 25<sup>th</sup> October 2016, Australia

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 Mental Health and Human Rights.



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 1,474 autistic girls and, their parents from Australia, United States of America, Morocco, European Union, Canada, New Zealand, United Kingdom and Ukraine.

#### Intersectional disadvantage

Autistic women are impacted by their membership of other groups which experience disadvantage, intersectionality. Autistic women who mental illness are experiencing three intersectional disadvantages - being autistic, being a woman and having a mental illness.

Other groups which face disadvantage, that autistic people are also included within, in Australia include:

- People with low socio-economic status
- Aboriginal and /or Torres Strait Islander peoples
- People who identify as Lesbian, Gay, Bisexual, Trans, Intersex or asexual and /or as gender divergent / Genderqueer
  - People with physical or other co-morbid disability.

Some areas in which intersectional disadvantage is particularly apparent include employment, education, housing, parenting, access to justice / legal services, and access to healthcare.

#### Access to Autism Diagnosis

Autistic women and girls currently comprise around one in four Autism diagnoses in Australia. Strong anecdotal evidence suggests the actual prevalence of Autism among women and girls to be considerably higher and perhaps gender equal in prevalence to men. Understanding around Autistic women and girls forms a relatively new discipline and as recently as the mid-1990s, women and girls were thought to comprise only one in 25 diagnosed autistic people. Females can be misdiagnosed with co-occurring mental health conditions, have greater verbal and social imitation ability, are screened through a male phenotype diagnostic instruments and are missing or underrepresented in research.

A timely and accurate diagnosis of autism is critical in accessing services and supports and often means the difference between isolation and belonging for autistic women and girls. Key finding from our research, 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. Factors impacting on more timely diagnosis for autistic girls include:

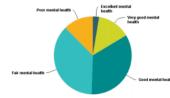
- Lack of professional training on feminine presentation of autism "No one felt that she was ASD because she didn't line things up, showed empathy & had eye contact"
- Delay to observe child development progress "Practitioners felt that she was so high functioning that there was a good chance she would '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"

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- Rural access to services "Waiting lists for speech pathology, occupational therapy and rural access to
  psychologist"
- Internalised, quieter presentation "Because she lacked problem behaviours"

#### Autistic Women and Girls Accessing Mental Health Services



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, 37% of non-autistic parents, parenting an autistic girl, self-reported their mental health as being fair to poor. For autistic girls, 51% are suffering fair to poor mental health, 32% are good, 15% have very good and 2% have excellent mental health.

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.

It is important to ensure psychiatrists and mental health service providers have a better understanding of female Autism to ensure services are appropriate and meaningful. Medical professionals should also ensure their offices have had an autism friendly sensory audit to be accessible for autistic patients. 31% of girls can 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.

8% of autistic girls are receiving no mental health support 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" and "After diagnosis CAMHS told us they do not usually do anything for a child diagnosed with autism but because of her extreme anxiety they will work with her but still waiting to hear (diagnosed 3 months ago) what they can do for her"
- 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"



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- 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" and "she is receiving CAMHS but it is unsuccessful due to their complete lack
  of autism expertise"
- 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"

Autistic women and girls experience the same mental health conditions as non-autistic people. Some are more prevalent among Autistic people generally - such as anxiety disorders, depression and post-traumatic stress disorder. There is increasing evidence that Autistic girls and young women have a higher prevalence of eating disorders such as anorexia nervosa and bulimia nervosa than the general population. There is also evidence that within the population of people with eating disorders, there is a high prevalence of Autistic girls and women. It should be noted that research into autism and mental health is an area which could benefit from more interest and resources.

Misdiagnosis of mental health conditions can occur for autistic women. A common misdiagnosis for autistic women is one of borderline personality disorder. The presentation of autism in women can include issues with identity and belonging and self-injurious behavior. These symptoms can be experienced by people with a diagnosis of borderline personality disorder as well as 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.

#### History of mental health services generally

Mental health services in Australia and the Western world more generally have come through an evolution over the past fifty years. These changes have been influenced by state Government policies and community expectations. Mental health care has moved from a predominantly institutional setting where people were housed 'out of sight' for long periods to a more community-based model of care today. While there are psychiatric hospitals and wards these tend to be for short term care while people are in acute stages of mental illness.

Another change in mental health services has been the attitudes towards illnesses and conditions within the community. Starting from a punitive, paternalistic attitude where patients had few rights or avenues of complaint and mental illness conditions were severely stigmatized to the attitudes more prevalent today around destigmatising illnesses, particularly anxiety and depression. However, attitudes are quite a 'patchwork', with stigma remaining around certain illnesses, particularly psychotic illnesses. Public health and awareness campaigns are delivered by both Government and community organisations but consciousness and attitudes among the community vary. Within mental health acute care, there has recently been more emphasis on empowerment and accountability, with such methods as 'advance agreements' promoted for consumers. This is an agreement made between consumer and their support worker and details their needs and preferences when in mental halest care settings.

While there have been several positive steps towards change, there are some legacy practices which still exist but which be abusive or discriminatory. These include the use of seclusion. Seclusion is a practice used in many psychiatric institutions around the country. Mental health consumers who may be at risk of violence to others of self-injurious behavior are kept in an often locked room within the high dependency unit if the hospital. These sorts



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of practices are largely unhelpful and foster a hospital environment which mirrors some of the practices within the criminal justice system. For Autistic women, seclusion can be particularly traumatic. Physical intervention is often used to get a patient into the seclusion room are and they may be forcibly medicated. Such methods can trigger meltdowns in autistic people or trigger post-traumatic stress responses. This in turn will likely escalate the situation.

#### **Meltdowns and Mental Illness**

Autistic people can experience meltdown or shutdown when overloaded. This can happen through sensory, emotional or information overload. Meltdowns are different for each individual but can look quite confronting or frightening for those witnessing them. A meltdown is not done deliberately or consciously; it does not come from a position of the autistic person trying to gain something and it is not based in anger. In a mental health setting, where people may be self-injurious or violent and staff are attuned to these issues, a meltdown may be misinterpreted. If the consumer is not diagnosed as Autistic, then meltdowns are likely to be misunderstood. This can result in escalation of force from hospital staff and consumer and can even result in the person being transferred to a criminal justice setting.

#### Stigma, Discrimination and Motherhood

Autistic people and people with mental illness both experience stigma and discrimination in Australia and across the globe. People who are both autistic and have a mental illness often experience a double dose of stigma. There are many unhelpful attitudes around mental illness and autism which are prevalent through society. These include that autistic women should not raise children.

Children have the right to be protected from all forms of abuse, neglect and violence and children are also violated by unwarranted removal from their families without their consent creating extreme mental health distress for parent and child. The United Kingdom remains one of the few European Union countries to practice 'forced adoption', the practice of removing children permanently from their parents and the subsequent adoption of those children. Disturbingly, approximately 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. Further, children are removed from their families as a predictor of 'future emotional harm' where no current or past abuse, neglect or violence has occurred and frequently alongside allegations of Munchausen by Proxy (Fabricated Illness).

A collaborative research project, 'Positive & negative experiences of 325 autistic mothers vs 91 typical mothers' between Cambridge University, Autism Women Matter and Autism Research Centre shows autistic mothers are more likely to experience, more so than non-autistic women:

- Rates of 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.
- Pre-or postnatal depression.
- Stress from communicating with professionals about their child
- More likely to report feeling misunderstood by professionals
- Greater anxiety, selective mutism and not knowing which details were appropriate to share with
  professionals
- Autistic women 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

Yellow Ladybugs is aware that Australian autistic mothers are encountering stigma and discrimination. Autistic women require targeted support to combat mental health distress in pre-and post-natal support, promotion of parenting capabilities and reducing of professional stigmatization and discrimination in their roles as mothers. Professionals require targeted training, by autistic people, to help them to provide meaningful support to families.

#### Social Inclusion

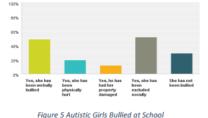
In Australia inclusion, could be improved through existing services, such as employment service providers, education providers, mental health and other health services, community disability and mental health support services, family support services and among business and employers. It is vital to promote all the various independent life domains (work, study, home ownership etc.) as an option for autistic women and girls. 'If you can't see it you can't be it'. This means social inclusion and participation needs to be promoted, both to women and particularly young women and teens.

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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. 80% of girls have not had access to their autistic female peer group. Yellow Ladybugs holds events for

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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.

Deficits thinking and focus can rob autistic women of their future. There is a social cost to exclusion - both monetary and in terms of the community, it translates that there will be a social benefit when autistic women and girls are included.

#### Identifying Systemic Failures in Mental Health Service Provisioning

- There are service gaps in the public healthcare system which impact on autistic women and girls. Hospitals and area mental health services are overstretched in some regional areas and remote areas meaning that not everyone who needs assistance can access it.
- Mental health clinicians vary in their level of understanding autism in general and autism in women and girls. This can lead to a variety of issues including misdiagnosis, inappropriate treatment or an inability for autistic women to be heard and respected by services.
- Stigma within society both structural and casual can limit the capacity and ability of autistic women
  with mental illness to work, study or participate in society in other ways. It can also have an impact on
  judicial and child welfare issues with a lack of understanding of female autism resulting in prejudicial
  treatment.
- Private mental health practitioners, particularly psychiatrists and clinical psychologists may also lack understanding of autism and mental illness in women. This can lead to autistic women paying fees for services which are unhelpful or even counterproductive.
- In many cases, the assessment for autism spectrum conditions is costly. There are less diagnosticians in rural and remote areas which can also mean women are unable to access an autism assessment.
- Mental health crisis services may have limited knowledge of autism and mental illness. This can result in
  a range of issues including dismissive responses to an autistic woman who is in crisis but presents
  differently to others. At its most extreme state, this lack of understanding can result in autistic women
  feeling powerless and even acting on suicidal thoughts or thoughts of self-injury after their contact with
  the crisis service which they expected to help them in fact left them feeling alone and ignored.
- Autistic women can experience bullying and violence in mental health inpatient settings, including sexual violence.
- Autistic women may lack family or social support. This can mean they have nobody to advocate for the in inpatient settings. It can also exacerbate the issue of transitioning back from a mental health inpatient setting to their home in the community. This can result in long hospital stays or frequent readmissions due to living at home post-discharge being unmanageable.



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#### **Recommendations for Systemic Support in Mental Health**

A world which has solved the issues outlined in this paper would be one in which:

- Autistic women are diagnosed at rates reflecting the actual prevalence off autism
- Mental health and other clinicians understand autism well. This could be achieved through education campaigns involving autistic self-advocates and as part of training programs and degree / doctoral courses for clinicians
- Practices such a seclusion are no longer practiced in mental health clinical settings
- Autistic women are included in policy making areas around mental health
- The level of stigma around autism and mental health decreases dramatically across the board
- Ableist slurs and insulting language around mental illness is seen as offensive in the same way racial slurs are today
- There are more services and supports around mental health and autism
- More services both around autism assessment and mental health treatment are available in regional and remote areas. This could be achieved remotely using video conferencing.

Thank you for considering the needs of autistic women and girls in the development of the report on the 'integration of a human rights perspective in mental health and the realization of the human rights and fundamental freedoms of persons with mental health conditions or psychosocial disabilities, including persons using mental health and community services; for the Human Rights Council at its thirty-fourth session.

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