



**Inquiry into the identification and support for students with the significant challenges of dyslexia, dyspraxia, and autism spectrum disorders in primary and secondary schools.**

To the Education and Science Select Committee.

This submission is from the Board of Trustees of Salisbury School, Nelson.

We wish the following to appear in support of this submission:

Brenda Ellis, Principal, Salisbury School

Michelle Harman, Parent of a current Salisbury School student with autism

**About Salisbury School**

Salisbury School is a national residential school providing quality education and life skills programmes for female students with complex intellectual impairment, who had not achieved in their previous educational setting. Many of our students have also previously been disengaged from education through non-attendance.

Throughout our recent history, a large percentage of our students have been on the autism spectrum with intellectual disabilities, foetal alcohol syndrome, and other prevalent complex conditions such as dyspraxia.

As part of our normal practice, we implement best practice learning and living programmes for the exact cohort of students this inquiry aims to help. Our teachers are experienced specialists in their field. They have the specific knowledge to work with these students and develop programmes to cater for their individual needs on a 24/7 basis throughout the school term.

“Inclusion is not about placing all disabled students and students with special educational needs in either mainstream schools or special schools, ignoring differences and treating all students the same. It is about adequate provision to meet each pupil’s needs with the most appropriate provision, to enable each student to access fully education and the life of her school.” (Fullan, 2006)

## **SUBMISSION:**

### **Introduction**

This submission primarily focusses on students with autism spectrum disorder (ASD), as this population of children is growing rapidly every year. Teachers, principals, and parents say the increase in numbers is putting immense pressure on the New Zealand our education system. For example, in Nelson and Marlborough alone there are approximately 270 young people with ASD under the age of 18 registered with the Nelson/Marlborough branch of Autism NZ. Throughout the country it is estimated that ASD conditions touch the lives of over 40,000 people and their families (Source: Autism NZ).

Our submission also includes comments given to us from parents of young people with autism and dyspraxia, and from one former Salisbury student with dyslexia and aspergers. We have provided evidence relating to the following three Terms of Reference:

1. Identify best educational practice for dyslexic, dyspraxic, and autism spectrum students.
3. Investigate support available to and in schools for the transition through education for students with dyslexic, dyspraxic, and autism spectrum disorders, and the adaptations for their learning including Special Assessment Conditions.
4. Investigate whether teacher training and professional development prepare teachers to identify and support the education of dyslexic, dyspraxic, and autism spectrum students.

### **Salisbury's Recommendations**

We believe the mainstream education system in New Zealand is not currently meeting the needs of young people who have highly complex ASD, the diagnosis of which is increasing at an alarming rate worldwide. Our high level recommendations are:

1. Young people with complex ASD are provided with easier access to appropriate residential education facilities where the environment, staff to student ratios, specialist services, expertise and knowledge can cater effectively for the greatest level of need.
2. A consideration for clusters of mainstream schools within their communities to have a designated Transition Support Service, to set up programmes and assist each child's transition through school, and to and from their different schools as they move through education.
3. Teacher training providers include specific compulsory modules in pre-service training focussing on autism and intellectual disabilities to provide a basic grounding on best practice programmes.
4. Teachers continually undertake indepth PLD programmes specific to teaching children with autism and related disabilities.

## **Synopsis of Young People with ASD**

Young people with ASD often struggle in mainstream school settings and in their home environments, resulting in high levels of frustration and anxiety. This can often lead to incidences of challenging behaviour.

Their struggle is often linked to the inability to cope with unexpected change in structures and routines and to self-regulate their behaviour accordingly. Those with ASD also easily suffer from sensory overload due to crowded spaces and noisy and visually over-stimulating classrooms. They are challenged by 'normal' social situations and have an inherent lack of understanding of social rules, often exacerbated by difficulties to communicate.

Adding to this can be an over sensitivity to other's emotions and a difficulty reading body language and the feelings of others. Mounting frustration and anxiety with no abatement can result in anti-social, violent behaviour where others are targeted. Self-harming behaviour, along with ritualistic stereotypic behaviours present further difficulties and can be extremely challenging to manage.

As a result of being in such a high stress environment, young people with autism often choose not to participate in classroom programmes that require them to want to engage. Levels of anxiety and fear of failure can be overwhelming, leading to a loss of enjoyment of a positive learning experience.

See Appendix 1 for more detail on diagnostic criteria from Autism Speaks.

### **16 year old girl with aspergers**

"I didn't like it at college. People stare at you. You are judged. The girls made fun of me because I wasn't into the girly stuff they were into. If you are reading they think you are a geek, but I love to read about ancient history, and I love The Hobbit. I used to be threatened by girls and I never knew what I had done to them – I didn't even know them. Once they threw a water melon at my head and they pushed my friend down the stairs. They said they did it because my friend looked at them.

In the Learning Centre at college they baby you. They gave me the maths of a 7 year old –  $1 + 1 = 2$ . At Salisbury I had learnt much more than that but college never wanted to know about that. I learnt to do my maths in my head using the clock on the wall. I can do all the times tables in my head using the clock. My Mum has no idea how I do it.

At my last college they once locked me in a room to do some testing but I don't like to be in enclosed spaces. It scares me. They wouldn't let me out for ages and I didn't know why. If I understood why I might not have minded so much. Finally they let me out. They said to me they didn't want me there in mainstream, so I ran away to Mum's work and told her I don't want to go back.

I loved it when I went to Salisbury. I learnt to read, to do sign language, to ride a bike, and all went camping altogether as a group. I also did the St Johns' first aid training. I loved that.

Correspondence School is boring because there is no one to talk with, except my dog.

I want a job but no one will work with me. I would love to work with sign language. I learnt sign language at Salisbury because a friend of mine there was deaf. I would be a good worker. I would follow instructions."

## **Submission Relating to the Terms of Reference (ToR)**

**ToR One: Identify best educational practice for dyslexic, dyspraxic, and autism spectrum students.**

**Michelle Harman, mother of 14 year old Melissa who has autism and attends Salisbury:**

Having a **happy environment** and a **tailored programme for learning** is crucial for my daughter Melissa. If she is not happy in the morning then you get nothing out of her that day. Two years ago in her last mainstream school they used to frisk her to make sure she didn't have any toys with her. Her toys are her comfort and put her at ease. She is trapped in a three year old's mind so frisking her and taking her toys away from her is very upsetting for her. She would shut down and not learn anything.

**Routine** is also very important in order for Melissa to be happy and willing to learn.

**A high ratio of skilled staff are needed.** There are times when more than one person is needed to help Melissa through a task. Someone also needs to have her in their line of sight at all times – not on top of her, but always knowing where she is is important as she has no concept at all of safety, and if you call her she is unlikely to answer you. Her mainstream schooling couldn't give her the visual monitoring she needed for the full school day. Because she was not fully funded during school hours the children were piggy backed, meaning the teacher aide would be responsible for more children, and not necessarily able to provide Melissa with the support and assistance she required to engage with school and to provide for her needs.

**Mother of an 18 year old daughter with dyspraxia who attended Salisbury in recent years:**

To get the best out of my daughter in an educational setting, **small classrooms** and **learning programmes designed to be at her level** are necessary.

One of the problems with mainstream schooling for some children with intellectual disabilities is the need for the school to move through the curriculum. For my daughter to learn, you have to repeat things over and over again, and that is hard when a school has a programme to get through. What works are **individualised programmes to suit**.

**Holistic learning** also works best for children like my daughter – programmes that cover both typical subjects like maths and English, but also life skills. At Salisbury School they ran one-on-one programmes for her. She has a great memory of her time at Salisbury School and learnt a lot while she was there.

**Lynne, mother of a 16 year old with dyslexia and aspergers who attended Salisbury in recent years:**

Discrimination for children with learning difficulties starts early. Our earliest experience was at Kindy, as we didn't know what she had until a visit to Starship when our daughter was nearly eight, and we had originally been told it was foetal alcohol syndrome (her birth parents both had issues with drugs and alcohol). When we got a diagnosis it was a relief to have a name but with the name came the inability to meet MOE criteria to get the support we needed.

My daughter did best educationally when the school and its teachers **understood her disabilities and learning needs**. We got this from the teachers at Salisbury – we have never experienced such knowledge anywhere in the mainstream. Teachers need to be **highly qualified** – specialists in special education across the board, knowing all the learning difficulties associated with children with special needs

It is also important that teachers understand how she processes information through **cognitive assessments**. We had these assessments done for our daughter at a significant cost as they are extremely helpful for the education sector and families. They help everyone understand the best way to teach so we can all work to achieve the best possible outcomes for the child. Salisbury School used our daughter's cognitive assessments to design an individual programme for her education. However, no mainstream school was interested in looking at them to see how she processed information, so their programmes never worked for her. No point in using a teaching strategy that clearly will not work.

She had her best educational experience at Salisbury, where she was **with her peers** and they all understood each other, and the teachers understood all the girls' conditions and what was them just being teenagers! Putting her into mainstream school has never worked. She is not with her peers there.

**Consistency and routine** is key with a child with aspergers. The things we did at home were not the same as what the mainstream school did. With a residential placement at Salisbury there was consistency between school and the residential setting. It was the first time in her education that there had been consistency between school and home life.

My daughter is very sensitive to noise, so the **classes need to be quiet**. She has now left mainstream secondary school, again, and is doing Correspondence School at home with just myself and her dad, as she couldn't cope with the noise at school. She was also terribly bullied there and was too scared to go back. In fact she hardly leaves the house now because she is still scared she will see some of the bullies from her last school, which she left over a year ago. The school refused to deal with the bullying saying "the girls are just being silly". A child with aspergers doesn't understand this- they believe the threats are real, and it is terrifying, and for our daughter it ended up affecting her physically. She had chronic stomach pains, headaches, regular vomiting, but no underlying physical ailment – just stress. We removed her from mainstream as her educational needs were not being met and it was making her physically ill.

When she arrived at Salisbury at age 13 she had a reading age of a six year old. At Salisbury she quickly improved her reading and now she is reading at her age level. Eight years of mainstream schooling couldn't do what Salisbury did in two, nor could thousands of dollars a year in private tuition! She loves books and all she wants to do is read books. She would go back to Salisbury tomorrow if she could – if there was funding for her to go there.

## Salisbury School. New Zealand's only special residential school for female students:

In our experience educating children with ASD and its associated complexities, and based on a wide range of current literature (Attwood,T., Larkey,S., Alexander, B.), the recommended best educational practice for these students is as follows:

1. To achieve focus and to reduce anxiety levels, **low stimulus environments** help to manage sensory overload tendencies, as opposed to colourful or noisy classrooms.
2. **Knowledgeable and experienced staff** who understand autism are crucial for ensuring the student's needs are met every hour of the day.
3. **Fully individualised learning programmes** (adapted curriculum to meet specific needs) that place the student at the heart of the matter achieve the best educational outcomes.
4. The inclusion of **targeted social skills programmes** that focus on how to develop and maintain friendships and reduce anxiety improve the likelihood of a student with ASD being willing to take part in school and family-based activities. These programmes include how to cope in social settings, how to prepare for changes to routines and structures (such as changes that occur throughout the school day), and how to take turns. They also help students to self-regulate behaviour so they understand, for example, that participating in a less favoured activity will be followed by a favoured activity.
5. School wide **positive behaviour support** with a focus on managing emotions appropriately helps to reduce anti-social behaviour. This is particularly important as young people with ASD do not often understand the notion of consequence. Their behaviour often results from their lack of understanding of the world and is not because they are 'acting out.'
6. **A high staff to student ratio** is essential when working with ASD, for successful learning to take place.
7. **A cultural context** needs to be embedded in best practice programmes for young people with autism, just as it should for all young people. For example, a Maori world view in regard to young people with special education needs to focus on an holistic approach, along with adaptation and management of the environmental triggers, so as to encourage better engagement in learning.
8. **Consistency and collaboration** across all settings (home, school and other agencies) is crucial in helping the young person make sense of the world and to reduce anxiety and fear.
9. **Visual cues** are a critical best practice tool that must be used to allow for everyday learning and living tasks to be understood and completed. Young people with autism struggle to generalise these skills from one setting to the next so the importance of consistency in the use of visuals in the home and in the school environment is crucial to success.
10. The development of **relevant assessment tools** that accurately measure student progress enable programmes to be tailored to meet individual need. For example a young person with ASD will need to have a new skill broken down into a series of small steps in order to acquire that skill. The new skill then needs to be practised across a range of different settings so that the new learning is maintained. This can take a significant period of time.
11. **Robust evaluation processes** are integral to best practice within the school and in the wider education sector.
12. Provision of a **safe and secure learning environment** builds trust and reduces anxiety for the young person with ASD.

**ToR Three. Investigate support available to and in schools for the transition through education for students with dyslexic, dyspraxic, and autism spectrum disorders, and the adaptations for their learning including Special Assessment Conditions.**

**Michelle Harman, mother of 14 year old Melissa who has autism and attends Salisbury:**

Transition through school has been unbelievably stressful for Melissa and our family. We live in Pahiatua, so our schooling choices are limited. Since she was five years old until she was 12 we had to move her through three mainstream schools as they couldn't cope. We have tried to get her into many other schools, but we were either not successful because they didn't want her, or they weren't appropriate because they were too cramped, noisy, or had a transient student body. The only success we have found for her was at Salisbury School – her fourth school. Successful transition within the mainstream education system does not exist in my opinion. Even the transition from task to task is difficult for her. If she is not ready to move to the next activity then it just doesn't work, but mainstream systems, even in special education day units, aren't designed to work how she works.

**Mother of an 18 year old daughter with dyspraxia who attended Salisbury in recent years:**

My daughter is one of those with hidden disabilities. She looks normal and her disability is not severe enough for her to get ORS (Ongoing Resourcing Scheme) funding. Yet she couldn't talk as a toddler and communication and friendships have always been a struggle throughout her life. Anxiety is a big problem for her and that she forgets what she has learnt, so lessons need to be repeated again and again. Children with dyspraxia's brains are wired differently. These problems make transition through school difficult. There have been years of a lot of tears and a lot of frustration. There was some support in schools for my daughter from an educational point of view when moving from primary to secondary school, for example, but when we had to switch schools a few times to find the right school, then any friendships she did make were lost. She made a lot of friends at Salisbury as there were more kids like her, and she is still in touch with them, and she wouldn't have such great friends if that network wasn't there.

Now that she is 18 and has left college we are finding that there is absolutely nothing that is suitable for her now. Her life journey doesn't stop when she leaves school and yet services to help her seem to stop. She had a very good transition from Salisbury and earlier this year she was training at a technical institute in a community services and job employment skills course for students with special needs. But the course was hopeless. She was badly bullied by another student and so she has left. She wants to work in early childcare but the tertiary courses just don't suit her. She would be great working with younger children. There are a lot of empty promises of things the educational facilities will do, but they don't equate to anything. It is difficult for me as a parent, but I know it is even harder for some families who don't have the strength or ability I have to help my daughter.

**Lynne, mother of a 16 year old with dyslexia and aspergers who attended Salisbury in recent years:**

For my daughter there was no support for her transition through mainstream school at all. She moved through two primary schools as the first one didn't work for her, and intermediate school was a write-off. She didn't qualify for ORS funding or IDEA services, because despite her low IQ she wasn't quite low enough for their funding. In mainstream she is a square peg trying to fit in a round hole.

## Salisbury School. New Zealand's only special residential school for female students:

At Salisbury we strongly believe in working in partnership with families so that we can support them at the same time that we are working intensively with their child. We have a dedicated Transition Manager, who offers a service that is not time bound and begins when the application is accepted for a placement at Salisbury.

Salisbury's Transition Service follows the young person throughout their schooling at Salisbury and supports them and the family when it is time to transition back into the home community.

An important aspect of the transition role is the networking and connecting of local agencies who may be able to provide ASD support so that the family and the young person have educational, supported employment and recreational options in their lives at home.

Through the Transition Service, Salisbury can also link new families with existing Salisbury families if each family desires that contact. This offers another perspective; at the same time it also provides a support mechanism for parents who share similar challenges when living with a young person with ASD.

Our model for transition includes:

1. Diagnosis – what will be the greatest areas of need for the young person with autism and their family
2. Timely response to need for transition planning
3. Active engagement of the young person and family in the process, in an affirming and ongoing manner
4. Parent education, support and networking opportunities
5. Robust aftercare community based services
6. Strength-based approaches
7. Quality collaboration and teamwork between all parties
8. Well-developed social and community networks

#### **ToR 4: Investigate whether teacher training and professional development prepare teachers to identify and support the education of dyslexic, dyspraxic, and autism spectrum students.**

##### **Michelle Harman, mother of 14 year old Melissa who has autism and attends Salisbury:**

In mainstream schools teachers don't have the right training- they just don't have it. In my experience teachers who think they are special needs teachers aren't really. If our former mainstream school couldn't handle Melissa they would ring and say "come and pick her up." She would soon work out that if she kicked off she would get to go home. Or, if she did something 'wrong' they would send her to the time out room and leave her there on her own to scream. This could be for up to three hours. When I found out, I pulled her out of school and she stayed out for 28 weeks before I was able to get her into Salisbury, which was hard fought through an advocate. In our mainstream schools, containment or medication ended up being the ways of dealing with children with complex autism – this is not education. It should be a basic right for every New Zealander, including Melissa, to get an education. My daughter is allowed to be happy!

##### **Mother of an 18 year old daughter with dyspraxia who attended Salisbury in recent years:**

Throughout my daughter's education she has met some amazing teachers who have gone the extra mile for her, have been enthusiastic and had a real understanding of dyspraxia. This is not the case for all teachers though. It is a bit pot luck. At one mainstream school a principal said to me about the children in the special unit "They are never going to equate to much." That is appalling. Generally, I found that when my daughter was in primary school only a very few teachers had any knowledge about dyspraxia. In fact, I had to get specialists in from the Dyspraxia Support Group of NZ to help upskill the teachers. I believe specific training about dyspraxia needs to be included in teacher training.

##### **Lynne, mother of a 16 year old with dyslexia and aspergers who attended Salisbury in recent years:**

I feel the teachers in mainstream just don't have the training needed for kids with aspergers and autism. They need more than a day's worth in their teacher training, and they need to start listening to parents. Just because a book says a kid with aspergers does X, does not mean every kid with aspergers does the same thing. No two are the same but mainstream teachers don't understand this – they only get taught to teach the 'average' child.

One teacher once said to me after she went to a course about autism "I wish I had known about autism earlier. You have to teach them differently." Sadly, my daughter had already finished her course there, so that was a waste of money. Teacher ability is hit and miss both within the MOE and outside of it.

Attitudes still need to change in the mainstream. I was told at one primary school "we don't take special need students here!" I made an official complaint about this with the MOE. Needless to say we didn't attend that school. At her next school we were told after we left by a board member that the principal (who had been away on a mission) had said he would never have accepted her enrolment if he had been there at the time.

It is not easy to get into a school if you aren't average or above. Discrimination starts early when you have a special needs child.

### Salisbury School. New Zealand's only special residential school for female students:

In our experience working with mainstream schools, there is often a lack of experience and expertise to effectively manage an ASD student's complex needs in a mainstream classroom. Students with less complex ASD can often cope in mainstream schools with the level of expertise available, but for those students with more complex challenges the mainstream classroom setting can be a noisy, confusing, daunting, disordered and frightening place.

Teacher training establishments are not including specific compulsory modules in pre-service training that focus enough on autism and intellectual disabilities as a basic grounding. Autism, as well as intellectual disability resulting from premature birth and from foetal alcohol syndrome, is being diagnosed in higher numbers than ever, so it is important that our teachers are receiving training for today's children, and those coming through the system in the future. (Alexander, B., 2014).

As well as pre-service training, more in-depth professional learning and development (PLD) may help teachers manage autism more effectively in mainstream settings. Critical factors such as the importance and use of visual cues for learning, understanding conditions associated with autism like echolalia, knowing the reasons for stereotypic behaviour and how to manage this in a mainstream setting (hoarding behaviour, flapping, etc), as well as understanding obsessive behaviours and their management, would all be valuable PLD. We are aware that several tertiary providers have programmes already running and at Salisbury our teachers regularly undertake PLD such as that listed above and we share our knowledge with families and other schools. We carry out in-house PLD and we contract other providers as well.

Thank you for undertaking this inquiry and considering our submission.

John Kane  
Salisbury School Chair  
On behalf of the Board of Salisbury School

## APPENDIX 1

### DSM-5 Diagnostic Criteria

From: <https://www.autismspeaks.org/what-autism/diagnosis/dsm-5-diagnostic-criteria>

*Autism Speaks is pleased to provide the full-text of the diagnostic criteria for autism spectrum disorder (ASD) and the related diagnosis of social communication disorder (SCD), as they appear in the fifth edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-5). As of May 2013, psychologists and psychiatrists will be using these criteria when evaluating individuals for these developmental disorders.*

Social (Pragmatic) Communication Disorder 315.39 (F80.89)

#### Diagnostic Criteria

- A. Persistent difficulties in the social use of verbal and nonverbal communication as manifested by all of the following:
1. Deficits in using communication for social purposes, such as greeting and sharing information, in a manner that is appropriate for the social context.
  2. Impairment of the ability to change communication to match context or the needs of the listener, such as speaking differently in a classroom than on the playground, talking differently to a child than to an adult, and avoiding use of overly formal language.
  3. Difficulties following rules for conversation and storytelling, such as taking turns in conversation, rephrasing when misunderstood, and knowing how to use verbal and nonverbal signals to regulate interaction.
  4. Difficulties understanding what is not explicitly stated (e.g., making inferences) and nonliteral or ambiguous meanings of language (e.g., idioms, humor, metaphors, multiple meanings that depend on the context for interpretation).
- B. The deficits result in functional limitations in effective communication, social participation, social relationships, academic achievement, or occupational performance, individually or in combination.
- C. The onset of the symptoms is in the early developmental period (but deficits may not become fully manifest until social communication demands exceed limited capacities).

Submitted October 2, 2015

D. The symptoms are not attributable to another medical or neurological condition or to low abilities in the domains of word structure and grammar, and are not better explained by autism spectrum disorder, intellectual disability (intellectual developmental disorder), global developmental delay, or another mental disorder.

Autism Spectrum Disorder 299.00 (F84.0)

#### Diagnostic Criteria

A. Persistent deficits in social communication and social interaction across multiple contexts, as manifested by the following, currently or by history (examples are illustrative, not exhaustive, see text):

1. Deficits in social-emotional reciprocity, ranging, for example, from abnormal social approach and failure of normal back-and-forth conversation; to reduced sharing of interests, emotions, or affect; to failure to initiate or respond to social interactions.
2. Deficits in nonverbal communicative behaviors used for social interaction, ranging, for example, from poorly integrated verbal and nonverbal communication; to abnormalities in eye contact and body language or deficits in understanding and use of gestures; to a total lack of facial expressions and nonverbal communication.
3. Deficits in developing, maintaining, and understanding relationships, ranging, for example, from difficulties adjusting behavior to suit various social contexts; to difficulties in sharing imaginative play or in making friends; to absence of interest in peers.

*Specify current severity:*

**Severity is based on social communication impairments and restricted repetitive patterns of behavior** (see Table 2).

B. Restricted, repetitive patterns of behavior, interests, or activities, as manifested by at least two of the following, currently or by history (examples are illustrative, not exhaustive; see text):

1. Stereotyped or repetitive motor movements, use of objects, or speech (e.g., simple motor stereotypies, lining up toys or flipping objects, echolalia, idiosyncratic phrases).
2. Insistence on sameness, inflexible adherence to routines, or ritualized patterns or verbal nonverbal behavior (e.g., extreme distress at small changes, difficulties with transitions, rigid thinking patterns, greeting rituals, need to take same route or eat food every day).
3. Highly restricted, fixated interests that are abnormal in intensity or focus (e.g., strong attachment to or preoccupation with unusual objects, excessively circumscribed or perseverative interest).

Submitted October 2, 2015

4. Hyper- or hyporeactivity to sensory input or unusual interests in sensory aspects of the environment (e.g., apparent indifference to pain/temperature, adverse response to specific sounds or textures, excessive smelling or touching of objects, visual fascination with lights or movement).

*Specify* current severity:

**Severity is based on social communication impairments and restricted, repetitive patterns of behavior** (see Table 2).

- C. Symptoms must be present in the early developmental period (but may not become fully manifest until social demands exceed limited capacities, or may be masked by learned strategies in later life).
- D. Symptoms cause clinically significant impairment in social, occupational, or other important areas of current functioning.
- E. These disturbances are not better explained by intellectual disability (intellectual developmental disorder) or global developmental delay. Intellectual disability and autism spectrum disorder frequently co-occur; to make comorbid diagnoses of autism spectrum disorder and intellectual disability, social communication should be below that expected for general developmental level.

**Note:** Individuals with a well-established DSM-IV diagnosis of autistic disorder, Asperger's disorder, or pervasive developmental disorder not otherwise specified should be given the diagnosis of autism spectrum disorder. Individuals who have marked deficits in social communication, but whose symptoms do not otherwise meet criteria for autism spectrum disorder, should be evaluated for social (pragmatic) communication disorder.

*Specify* if:

**With or without accompanying intellectual impairment**

**With or without accompanying language impairment**

**Associated with a known medical or genetic condition or environmental factor**

(**Coding note:** Use additional code to identify the associated medical or genetic condition.)

Associated with another neurodevelopmental, mental, or behavioral disorder

(**Coding note:** Use additional code[s] to identify the associated neurodevelopmental, mental, or behavioral disorder[s].)

**With catatonia** (refer to the criteria for catatonia associated with another mental disorder, pp. 119-120, for definition) (**Coding note:** Use additional code 293.89 [F06.1] catatonia associated with autism spectrum disorder to indicate the presence of the comorbid catatonia.)

Table 2 Severity levels for autism spectrum disorder

<b>Severity level</b>	<b>Social communication</b>	<b>Restricted, repetitive behaviors</b>
Level 3 "Requiring very substantial support"	Severe deficits in verbal and nonverbal social communication skills cause severe impairments in functioning, very limited initiation of social interactions, and minimal response to social overtures from others. For example, a person with few words of intelligible speech who rarely initiates interaction and, when he or she does, makes unusual approaches to meet needs only and responds to only very direct social approaches	Inflexibility of behavior, extreme difficulty coping with change, or other restricted/repetitive behaviors markedly interfere with functioning in all spheres. Great distress/difficulty changing focus or action.
Level 2 "Requiring substantial support"	Marked deficits in verbal and nonverbal social communication skills; social impairments apparent even with supports in place; limited initiation of social interactions; and reduced or abnormal responses to social overtures from others. For example, a person who speaks simple sentences, whose interaction is limited to narrow special interests, and how has markedly odd nonverbal communication.	Inflexibility of behavior, difficulty coping with change, or other restricted/repetitive behaviors appear frequently enough to be obvious to the casual observer and interfere with functioning in a variety of contexts. Distress and/or difficulty changing focus or action.
Level 1 "Requiring support"	Without supports in place, deficits in social communication cause noticeable impairments. Difficulty initiating social interactions, and clear examples of atypical or unsuccessful response to social overtures of others. May appear to have decreased interest in social interactions. For example, a person who is able to speak in full sentences and engages in communication but whose to- and-fro conversation with others fails, and whose attempts to make friends are odd and typically unsuccessful.	

## APPENDIX 2



# Autism characteristics differ by gender, studies find

By Sarah DeWeerd  
27 March 2014

**Missed signs:** Underdiagnosis of autism in girls may contribute to the often-cited 4:1 ratio of boys to girls with the disorder.

Two studies published in the past month lend support to the notion that autism looks different in girls than it does in boys, making it harder to recognize and diagnose in girls. The studies reflect growing suspicion in the research community that the underlying biology and the experiences of girls with autism may both be distinct.

The first study, published in the March issue of the *Journal of the American Academy of Child and Adolescent Psychiatry*, is the largest yet to try to parse the differences between boys and girls with the disorder<sup>1</sup>.

The researchers report that autism characteristics in girls depend on their level of intelligence. “On the lower end, they tend to have more social communication impairment and lower cognitive ability” than boys who have the disorder, says study leader Thomas Frazier, director of the Center for Autism at the Cleveland Clinic in Ohio. “On the higher end, they have fewer restricted interests.”

These differences may make it tricky for parents, teachers and doctors to recognize the signs of autism in girls. This is especially true because autism has traditionally been thought of as a boy problem: Four times as many boys as girls are diagnosed with the disorder.

“For a long time the gender disparity has been talked about as if it’s a fact,” says Jane McGillivray, associate professor of psychology at Deakin University in Victoria, Australia. McGillivray led the second study, a pilot effort to investigate friendship skills in girls and boys with high-functioning autism, published 28 February in *Molecular Autism*<sup>2</sup>.

Researchers are now beginning to question the degree to which this gender disparity is real.

Some studies have found that girls may be genetically protected from developing autism. Others suggest that autism is underdiagnosed in girls — that is, clinicians often fail to recognize the disorder, especially in girls with normal intelligence.

Defining gender differences in the symptoms of autism may help researchers nail down how much each of these possibilities contributes to the skewed diagnostic ratio.

## High and low:

The first study draws on information from 304 girls and 2,114 boys with autism enrolled in the Simons Simplex Collection (SSC), a database of individuals with autism and their unaffected parents and siblings. (The SSC is funded by the Simons Foundation, SFARI.org's parent organization.)

Some of the findings echo those of previous studies of gender differences in autism, but this study is substantially larger, adding heft to the results.

Among individuals with autism who have an intelligence quotient (IQ) lower than 70, girls have greater social communication impairments than do boys, the researchers found. Girls in this group also have lower IQs on average than the boys do.

Those findings are consistent with previous studies showing that females diagnosed with autism tend to be more severely affected than males. They are also in line with the hypothesis that more mutations are required to produce autism in females. "Females may require extra hits, but once they get those extra hits they become severely affected," Frazier says.

Curiously, the researchers also found that regardless of IQ, girls with autism show more irritability and externalizing behaviors than boys who have the disorder. That's a surprise because externalizing behavior — that is, acting out — is typically thought of as a boy-like behavior.

Finally, for individuals with IQs above 70, the most striking difference between girls and boys with autism is a lower prevalence of restricted interests among girls.

Some researchers say this last finding doesn't jibe with clinical experience. "They do have restricted interests, but their restricted interests are more socially appropriate," says David Skuse, professor of behavioral and brain sciences at University College London, who was not involved in either study.

For example, a 10-year-old girl with autism might bombard a listener with facts about her favorite pop star whereas a boy might rattle off train timetables, and a teen girl with the disorder might obsessively collect makeup rather than old coins. Clinicians may be more alert to certain stereotypical restricted interests, such as trains, than they are to female topics.

"The problem is that the way we have defined autism, conventionally, is a male stereotype," Skuse says.

Frazier says that because the analysis found a large difference in the level of restricted interests between boys and girls, this gender difference is probably real. In addition, he notes that highly trained clinicians evaluated individuals enrolled in the SSC and would have picked up on restricted interests even in the girls.

Still, it's possible that the clinicians missed some subtle symptoms, Frazier says. The girls' "restricted interests may just be more female-specific presentations that we're not picking up in the data."

The results suggest that clinicians need to be extra diligent about looking for restricted interests in girls, Frazier says. Otherwise, high-functioning girls might be labeled as having social communication disorder — a new diagnostic category that involves social impairments but not the restricted interests and repetitive behaviors characteristic of autism.

It may also be easy to misdiagnose girls with low IQ as having intellectual disability alone. In both cases, these girls would miss out on behavioral interventions that could improve their social deficits.

## Female prism:

The second study also suggests that autism can be subtle and difficult to identify in girls. McGillivray and her colleagues administered the Friendship Questionnaire to 25 girls and 25 boys with autism, all aged 10 to 16 years. This questionnaire contains 35 multiple-choice questions to assess an individual's understanding of friendship and the quality of his or her social relationships<sup>3</sup>.

Not surprisingly, the researchers found that individuals with autism score lower on the Friendship Questionnaire than controls do.

Within the control group, boys score lower than girls do — consistent with the general sense that girls have better social skills. Among those with autism, too, scores differ by gender: Girls with autism have higher scores than boys with the disorder, but their scores are lower than those of girls in the control group.

“The interesting bit is that females with autism were similar to the typically developing males,” says McGillivray.

Together, Frazier says, the two new studies suggest that “maybe we need sex-specific norms for some of the instruments we use.” Instead of evaluating girls' restricted interests or social skills on an absolute scale, he says, researchers should compare their scores with those of unaffected girls of the same age.

It's possible that girls with subtle social deficits aren't diagnosed with autism because they don't actually have autism. Yet many clinicians insist that many of these girls have the disorder, though they have trouble explaining why. Conversation with these girls “just has that quality of not quite meshing,” McGillivray says. “It is very difficult to specify.”

Experts say that in order to understand gender differences in autism — and to improve diagnosis for girls — they will need to better define what is abnormal about these girls' behavior.

As a step in that direction, Frazier plans to look for questions about restricted interests and repetitive behavior on autism tests that garner similar answers for girls and boys. That subset of questions may do a better job of picking up the behaviors in girls, he says.

Researchers may also need to design studies that include girls with subtle social difficulties who are not diagnosed with autism. That's because the field currently has a chicken-and-egg problem: trying to characterize autism in girls by studying girls diagnosed according to boy-centric criteria.

“When you're looking at the female phenotype, if you look at it through the male prism you'll only see the male characteristics of autism,” Skuse says. “You only see what you expect to see.”

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