

# Autism in the Commonwealth



# *Jonathan Andrews*

*is a future trainee solicitor at Reed Smith.*



When considering future career paths as a student, Jonathan attended several networking events at law firms. Even at events focused on disability he found nobody willing to speak openly about being autistic in law, and a sense among others that there was nobody autistic in the profession. Jonathan knew this was unlikely to be the case, and instead that many in the profession were likely afraid to be open about it – and resolved to change this. After working with disability consultancy companies to explain to firms why it was smart business for them to seek to employ talented autistic people, emphasising the positive traits and dedication they could offer, he secured a training contract with Reed Smith.

Jonathan is passionate about raising awareness of autism, specifically to increase autism acceptance. He is the chair of UK charity Ambitious about Autism's youth council, a supporter of the National Autistic Society and Autistica; sits on the UK Parliament's Westminster Autism Commission; and has worked with employers, government organisations and schools across the country articulating a positive vision for autism.

He is a supporter of initiatives to support people with other disabilities, particularly into employment. He serves on the UK government's Work and Health expert advisory board, helping to deliver reforms to ensure more disabled people can access quality work, and is a supporter of the civil service's Autism Exchange which offers paid, quality work experience and internships to talented people with autism.

He has been recognised nationally and internationally for his advocacy; having reached out to over 10,000 people, he has been named European Campaigner of the Year, a Queen's Young Leader, and the joint first UK citizen to be a finalist for the Commonwealth Youth Awards.

Jonathan is a firm believer in the importance of the Commonwealth, and similar institutions, in the modern era. The Commonwealth provides stability and unity, organised around shared history, law and values, in an increasingly diverse and disparate world; and through this unity, it is best placed to allow its sovereign member states to respond collectively to the global issues facing the world today.

Autism inclusion is one such global issue – autistic people exist in every country in the world, Commonwealth and non-Commonwealth, whether they are recognised or not. And every one, whatever their nationality, should have the opportunity to be included in civic life and mainstream culture, to live their life to the full, and to reach as far as their talents and dedication allow. When autism is stigmatised, routine low-cost adjustments are not made, and the talents of people who happen to experience the world differently is denied, everyone loses out.

Ultimately, Jonathan wants to live in a world – and Commonwealth – where autism is recognised as not being a barrier to achievement, where those with talent are able to utilise this to contribute to society, and those who cannot work are properly supported. He recognises the forward-thinking nature of several Commonwealth countries in dealing with autism acceptance, particularly the UK and New Zealand, and is confident the body will be a key institution in the fight to ensure autistic people are accepted and valued for who they are.



'As Chair of the All Party Parliamentary Group on Autism in the UK Parliament, I welcome this autism toolkit for Commonwealth members, as I believe that it is vital to raise awareness of autism and the potential of autistic people in all parts of the globe. The Group is currently working with a range of organisations and the UK Government to bring about real change in the areas of education, health, employment, diagnosis, the criminal justice system, mental health and many more. World Autism Awareness Day is a wonderful opportunity to promote improvements across the board for people with autism and their families, and I am looking forward to seeing what more progress can be achieved in the coming year.'

*- Cheryl Gillan MP, chair of the (UK) All Party Parliamentary Group on Autism*

"As the founder of the UK's Westminster Autism Commission, I recognise the importance autism acceptance in society. This Commonwealth initiative will go to great lengths to build awareness of the autism spectrum internationally, across diverse and disparate countries and cultures; I firmly support its mission to dispel myths about the condition, and to inform others about what autism is, and the positive aspects autistic people can bring to society."



*- Barry Sheerman MP, founder and chair of the Westminster Autism Commission*

# What is AUTISM?



*"A mental condition, present from early childhood, characterised by great difficulty in communicating and forming relationships with other people and in using language and abstract concepts"*

- DSM IV (DIAGNOSTIC MANUAL FOR PSYCHIATRISTS)

*"A lifelong developmental disability that affects how people perceive the world and interact with others... autism is not an illness or disease, and cannot be 'cured'. Often people feel being autistic is a fundamental aspect of their identity"*

- NATIONAL AUTISTIC SOCIETY, UK




*"My world's not yours. I spy what you cannot,  
And yet am blind to what you clearly see.  
We're different, yes. But don't infer from that  
That my brain lacks your creativity."*

- CREATIVITY, 2014

Broadly autism is a condition which affects social development and behaviour, as well as sensory processing.

It is common for autistic people<sup>1</sup> to be socially 'different' to others – this can take many forms such as being withdrawn, or being social but in a noticeably different way.<sup>2</sup> People experiencing more profound autism might simply not communicate, do so in ways others don't recognise (e.g. not through speech, sign or body language).<sup>3</sup>

Many autistic people are hyposensitive (under-sensitive) or hypersensitive (over-sensitive) to different senses (e.g. touch, taste, sound, sight, sound, balance).<sup>4</sup> The same person can be over-sensitive to one sense but under-sensitive to others, and be affected by different levels of intensity for different senses. This can cause further social difficulty, especially if not recognised.<sup>5</sup>



Autism is a spectrum condition and everyone with autism will be different. There's a popular saying that "When you've met one autistic person, you've met one autistic person you've met on autistic person" - you can't draw any conclusions from it because everyone will experience autism differently. Some people will be very severely and noticeably affected, whereas in others autism is less obvious and 'invisible'.

But this doesn't necessarily mean it's more 'mild' in these people just because it's hard to spot - and it being less obvious can be less helpful sometimes, as people are less likely to recognise they are experiencing situations differently from others, and many burn up energy trying to disguise traits to appear 'normal'.

Autism is more common than many realise - currently, 1 in 88 people in the UK are believed to have autism/be autistic, while some figures suggest 1 in 50 people in the US and 1 in 33 men in South Korea are. 1 in 100 is the conservative estimate, but even this is a large amount. It means at least 24 million Commonwealth citizens are likely to be autistic and at least 14.4 million young Commonwealth citizens under 30.


## **MYTH - "AUTISTIC PEOPLE LACK EMPATHY"**

This is a common belief, because the behaviours of autistic people can often be seen as "inconsiderate" or "inappropriate" from non-autistic eyes.

But neuroscience has found "empathy" is actually made up of cognitive empathy - the ability to understand others and predict their behaviour, from your instinct, their words and body language etc. - and emotional empathy - the urge to care for others - and both are controlled by different parts of the brain.

Autistic people tend to have difficulty with cognitive empathy, also called "theory of mind", which involves putting themselves in others' shoes and interpreting their verbal and non-verbal signs. But some can learn how to do this, to different extents. And autistic people tend to have average to above-average emotional empathy, and can care very deeply about others.

Often this causes the person difficulty, as they can misread communication and offend without meaning to do so - and don't then know how to solve the issue, so withdraw from the conversation, giving the appearance of being cold, aloof and un-empathetic when the opposite is true.



## MYTH - “THE ‘EMPATHY DEFICIT’ IS ONE-SIDED”

Often it's thought only autistic people have difficulty understanding others, not vice-versa. But the influential “double-blind empathy” theory argues instead that both sides have trouble understanding each other, because both communicate in ways the other doesn't understand.

For example, non-autistic people may read into autistic body language something that isn't actually there, and misinterpret them. So understanding requires efforts on both sides.<sup>14</sup>

## MYTH - EVERYONE ON THE AUTISTIC SPECTRUM EITHER HAS ASPERGER SYNDROME OR ‘CLASSIC AUTISM’

People often think the spectrum is neatly split between the ‘high functioning’ Asperger end and ‘classic autism’, including people with learning disabilities and lower IQs. However, there are other diagnoses on the spectrum too; including Pervasive Developmental Disorder Not Otherwise Specified (PDD-NOS), which covers people who score high enough to be considered ‘autistic’ but don't fit into the specific Asperger or autism categories; or Pathological Demand Avoidance (PDA) which can involve an inability to carry out requests and person-centred obsessive behaviour.

While the ICD-10 diagnostic manual uses the above categories, the DSM-V has replaced them with one ‘Autism Spectrum Disorder’ (ASD);<sup>15</sup> and the ICD-11, due out in 2018, is expected to do the same.<sup>16</sup> So while people will keep their Asperger and PDD-NOS diagnoses, people in future won't be diagnosed with them, only ASD.

## MYTH - “STIMMING” AND “SCRIPTING” IS BAD

Autistic people often “stim” – where they perform a repetitive body movement, such as kicking the floor, waving/flapping hands, or grabbing/stroking an object – and “script” (also called echolalia), where they may repeat a phrase many times which has no relevance to conversation.<sup>17</sup> Naturally, this often makes people uncomfortable, and stimming and scripting are often looked on as bad.

However, these are the ways autistic people both calm and stimulate themselves, necessary because of their sensory differences. If people are not allowed to do so, this can cause great stress and damage their mental and emotional wellbeing, as the tension is not released.<sup>18</sup>

It is far better to let autistic people do so – or, if necessary in certain environments, to teach them how to do so without attracting attention.

## MYTH - AUTISTIC PEOPLE CAN'T BE IMAGINATIVE AND CREATIVE

This is a less common myth with younger people due to the media presence of autistic artists like Stephen Wiltshire MBE, but still common. It exists because a famous diagnostic tool for autism in the 80s, the 'triad of impairments', listed impaired imagination as a trait.<sup>19</sup>

But this actually refers to social imagination - the ability to predict others behaviour accurately - not ordinary imagination. Sometimes, autistic people can have difficulty with social imagination precisely because they have great abstract imagination, and can't "steamline" their creativity to fit how most conversations go - which often follow a set formula.<sup>20</sup>

And more and more creative industries have begun hiring autistic people in greater numbers in recent years. Autistic people are great authors, painters, architects, poets; many are very creative.<sup>21</sup>

## MYTH - AUTISTIC PEOPLE ARE ONLY SUITED FOR JOBS IN IT / DATA

Many autistic people are interested and skilled at IT and data roles, and many firms in this area now seek out autistic workers.<sup>22</sup> But not all autistic people are interested and/or skilled in this area.

There are autistic teachers, doctors, academics (in humanities as well as sciences); there are autistic lawyers (barristers and solicitors), bankers, consultants,<sup>23</sup> and Commonwealth politicians (such as former Australian Deputy Prime Minister Tim Fischer, who has high functioning autism).<sup>24</sup> There are also autistic librarians, cashiers, supermarket workers and many more.

Yet despite the vast majority of autistic people wanting to work, too many are unemployed - stats suggest only 15-35% of autistic adults are in full time employment. Many have skills to benefit employers on the job, but are held back because of difficulty with interviews and knowing how to express themselves.<sup>26</sup>

## MYTH - AUTISM IS A MENTAL HEALTH CONDITION

Autism is not a form of mental health problem - it's a developmental condition (also called neurological or neuro-divergent conditions / differences) which is present from birth and an integral part of how the brain works, not an illness.<sup>27</sup> It does not have 'bouts' of activity like mental illness - people are either autistic or not - and while some need and use therapy, others don't. The vast majority of autistic people do not want to be "cured" even if this were possible, and often feel the real barriers to their success come from how society views autism, not their autism itself.<sup>28</sup>

## **MYTH - AUTISTIC PEOPLE CAN'T HAVE MENTAL HEALTH CONDITIONS**

However, it is true that because of negative social treatment, autistic people are more likely to develop mental health conditions like depression and anxiety. 70% of autistic children meet the criteria for one condition and 40% for two, but are often undiagnosed because professionals wrongly assume these are part of their autism, or don't want to give them too many "labels".<sup>29</sup> This means many go without help for mental health problems.

The risks of poor mental health for autistic people is something the mental health charity Mind have tackled in the UK, with an autism toolkit launched in 2015 sharing best practice,<sup>30</sup> and is collaborating with autism organisations such as Ambitious about Autism to ensure that autistic people have better access to mental health services. As Equality Improvement Champion for Mind, I am also working to improve this.

## **MYTH - AUTISM IS JUST A SOCIAL CONDITION**

Autism also affects how people process the world through their sensory. It can make them either hypersensitive (oversensitive) or hyposensitive (under-sensitive) to different senses such as sound, touch, smell, taste, hearing, temperature, pain or balance; and the same person can be over-sensitive to one sense while under-sensitive to others (and often is).

This can cause added social difficulties because they're simply experiencing situations differently to others – what might feel fine for one person may be far too loud, bright, hot etc. for an autistic person, making them stressed for reasons others are less likely to understand, and so making their behaviour seem odd or rude when others might also act the same way in that situation.<sup>31</sup>

## **MYTH - AUTISTIC PEOPLE ARE ALL SAVANTS WITH A 'SPECIAL GIFT'**

It's true autistic people tend to have special interests, which they devote study to and therefore know a lot about. But this isn't the same as being a savant, especially because lots of autistic people don't just have one special interest, but a handful. Estimates are only 0.05% of autistic people are true savants – they're two very different conditions.<sup>32</sup>

That doesn't mean, however, that autistic people don't have special talents – like being very loyal to friends and employers, strong attention to detail, punctuality, dedication to work and a unique way of looking at issues.

## **MYTH - GIRLS AND WOMEN CAN'T HAVE AUTISM, OR ONLY A TINY NUMBER DO**

It was once believed girls could'nt be autistic, and the autism spectrum was a male condition. Then girls and women started being diagnosed, but at lower rates than men (and those diagnosed tended to be more severely affected).<sup>33</sup> It was suggested



this was because autism was a form of an “extreme male brain”.<sup>34</sup>

Now, though, more and more women and girls are being diagnosed, and there are many women open about being autistic – including successful academics, journalists and civil servants. It’s believed the male-centric nature of autism diagnosis, where psychologists are taught to look for behaviours observed in young boys, not girls or adult women (or adult men), means autistic women and girls are overlooked.<sup>35</sup>

Autistic women also tend to be better at disguising traits at an earlier age to “blend in”, especially those whose autism is mild or less obvious, so aren’t diagnosed until later on, when the strain of constantly masking their true identity becomes too much.<sup>36</sup>

On the subject of diversity, autistic people can also be LGBT (a large number are transgender),<sup>37</sup> and any race or age – though less ethnic minorities and older people are diagnosed with autism, this is more likely due to lack of awareness in communities than an actual difference in rate.<sup>38</sup> And autistic people can have other disabilities too, such as using wheelchairs or having dyspraxia or dyslexia.

## **MYTH - AUTISTIC PEOPLE CAN'T HAVE ACCESS ADJUSTMENTS IN THE WORKPLACE**

In the UK, autism is considered a disability for the purposes of the Equality Act, which means employers have an anticipatory duty to make reasonable adjustments for people on the spectrum to allow them to work to their full potential.<sup>39</sup>

This may include headphones if they are over-sensitive to sound, a quiet desk, having instructions explained clearly to them, changes to online tests when applying, and ‘job carving’ where roles from different jobs are “mixed up” and handed to various employees, so the person ends up in a job which utilises all their talents while avoiding weaknesses.<sup>40</sup> Many firms also now run autism awareness sessions to create understanding workplace cultures and “soft adjustments”.<sup>41</sup>

But it’s true that many employers are unaware of their duty to offer adjustments, and outside the UK, many autistic people will face difficulty if their country has no disability legislation helping them achieve adjustments and support.

## **AUTISM AND UNDERREPRESENTED GROUPS**

Autistic women and girls, discussed above, are the most notable group where identification/diagnosis and support is lacking, but there are other communities where awareness is also lower.

For example, in developed Commonwealth countries (Australia, Canada, New Zealand

and the UK), autism diagnosis rates among ethnic minority communities are lower than average. There is not suggestion this is due to any innate difference, however, but rather due to lower awareness among communities, often due to barriers to education about autism.

Many studies have found the same is true of lower socio-economic communities, whose autism diagnosis rates are also lower because many cannot afford private diagnoses and have to deal with long waiting times from public health providers. Faced with this, many simply give up, or if they do persevere, receive the diagnosis for themselves or their children much later.

Understanding of autism has developed over time, particularly over the last thirty years. Older people (particularly those over 50) in developed countries grew up at a time when autism awareness and diagnosis was nowhere near as prevalent, and only very noticeable cases were diagnosed. As such, many older people who would now meet the criteria for autism will not have been diagnosed and may not identify as autistic – but will still have the difficulties caused by autism, and often these will be more obvious than those diagnosed young because of a lack of interventions.<sup>42</sup>

## **MYTH - AUTISM WILL BE TREATED THE SAME ACROSS CULTURE**

Different traits/behaviours have different effects in different cultures. For example, in Japan and many African countries, it is considered polite to avoid eye contact when speaking to social superiors; in the Western World this would be considered disrespectful and a trait strongly associated with autism.<sup>43</sup>

In many cultures with less understanding of/education around autism, there exists a strong stigma around diagnoses – it can be incorrectly viewed as an illness or mental health issue, or as a sign of moral failing. In these cultures, people will be more hesitant to seek a diagnosis or to be open about it, if they can conceal it.<sup>44</sup>

And since the Commonwealth is made up of nations with very differing cultures, it's important to remember there won't be one pan-Commonwealth view of autism.

### **There are many practical differences:**

- In developed Commonwealth countries, there are a relatively high proportion of autism diagnoses, and a relatively high number of autistic people enter higher education, although workplace employment stats are low (around 15-30% in full time paid employment).
- Even within the countries there are differences, however – Canada and the UK recognise PDD-NOS as an autism spectrum condition, while Australia and New Zealand do not
- In developing commonwealth countries, there are the same number of autistic

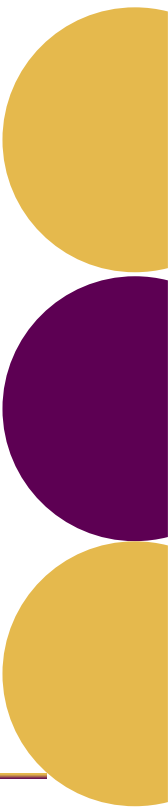


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people but diagnoses for autism are harder to obtain, and fewer autistic people tend to achieve higher education

- Autism can also be more misunderstood here – more likely to be confused as a learning disability or mental health issue or illness.<sup>45</sup>

However, it would be wrong to think things can progress by developed Commonwealth countries lecturing others on autism – there needs to be a full and inclusive dialogue, understanding the differences in how autism is viewed across Commonwealth cultures.



# Personal views from autistic people across the Commonwealth



**Dilshan Jayasinghe, CANADA**

*"The trend in Canada has been positive. As always, demand for services outweighs the supply. But more visibility of what persons with autism can do as meaningful persons in our society, in any capacity, is needed.*

*Society as a whole would benefit from that. Otherwise, a perception of dependency will continue; but while it's true people with autism should be supported, they should also be recognised as contributors to the wellbeing of self and society.*

*Personally being a full time student coupled with extra curricular activities keeps me fully engaged"*

**Garry Burge, AUSTRALIA**

*"My name is Garry Burge and I am 44 years old and live in Brisbane, Australia. I work at the University of Queensland Social Sciences & Humanities Library as a Service Support Assistant. Finding a job has been difficult, for even though I was doubted in terms of my academic ability, going to university became a reality in 1994 when*

*I was granted admission into the University of New England in Armidale, Australia. University life was a struggle as I find it difficult to make friends. My difficulty in school caused me to fail the first year of university in 1994 causing me to be excluded for one year. I never gave up in my determination in getting through and after completing a tertiary preparation course at the recommendation of the University of New England, I was granted re-admission in 1996*

*after showing cause that I met the requirements of the university's standing committee. After working hard, and only failing a couple of units, I was able to graduate in 1999 with the degree of Bachelor of Arts.*

*In my spare time I advocate as an adult on the autism spectrum and have my own website at <http://www.garryburge.com>. I have also assisted in setting up a support group for adults on the autism spectrum in Brisbane and know of adults who also advocate for autism on a worldwide scale. This is how I met Jonathan Andrews who advocates in the United Kingdom and Chris Mitchell who works for Autism Works (<http://www.autismworks.co.uk>) in the United Kingdom. I also know some other adults in New Zealand, some parts of Europe and in North America. My advocacy work connects me to more and more adults on a worldwide stage".*



**Fern Adams, UGANDA**

*Having spent a year living and working in Uganda with Project Trust, it became apparent that in other cultures it can be the case that autistic traits are not given such a negative stereotype as in the UK but are viewed as skills and talents. In Uganda, autism awareness is fairly non-existent; however traits such as determination, hard work and the ability to remember and collect knowledge is valued more than in the UK. During my time in Uganda I started off teaching a few subjects in a primary school but by the end of the year was head of two departments and school first aider. I also worked in a medical clinic where I started off by cleaning equipment but by being keen to pick up skills and knowledge by the end of my time I was dispensing medication, looking for malarial parasites under microscopes and assisting in basic operations. The skills I have that are directly related to my autism allowed this to become possible”.*



**Craig, UNITED KINGDOM**

*“Like many people who register high on the spectrum I often find that I view the world slightly differently to other people, often much more simplistically, but sometimes I’m aware of far more detail than others.*

*In my role as a software developer this has been quite a useful tool. On the down-side, I frequently find it really hard to understand new programming concepts.*

*However, when it comes to building an interface for people to use I’m much more capable than most of recognising what’s confusing and what feels natural to an end-user.*

*I only received my diagnosis a year and a half ago so understanding how autism affects me in the workplace is still an on-going process for me. From my late teensto early twenties I’ve been treated and medicated for extreme anxiety and depression. Having a diagnosis of autism has made such a wonderful difference to how I view my mental health and my outlook on the world.*

*One of the most tangible benefits I’ve felt is in the workplace. I no longer feel so angry at myself for being able to pick one thing up far quicker than others, and yet finding something apparently similar being permanently out of my reach. This has really helped me focus my efforts in my career towards more attainable goals”.*

# Notable Commonwealth Figures

## **Tim Fischer AC**

Deputy Prime Minister of Australia 1996-1999. Fischer's son is autistic, and he identifies as having 'mild autism' based on recollections of his childhood. He believes the intensity and determination these traits gave him helped him become Deputy Prime Minister

## **Chris Packham**

AUK AUK wildlife presenter. 'Came out' as having Asperger Syndrome in 2016

## **Michelle Dawson**

Autism researcher and self-advocate from Montreal, Canada. She is known for her strong opposition to Applied Behavioural Analysis (ABA) being used for autistic children.

## **Lisa Llorens OAM**

Australian Paralympian

## **Jessica-Jane Applegate MBE**



British Paralympian

## **Roshan Roy**

Autism World Ambassador and Naturally Autistic Award Winner from India



## Barriers to pan-Commonwealth Integration

- Having autism, or having a dependent who has been diagnosed as autistic, can be barriers to successfully obtaining a visa to live and work in Australia and New Zealand.<sup>46</sup> However, this depends on each individual case, and people diagnosed with PDD-NOS are not considered to be autistic for these purposes.
  - Different countries across the Commonwealth use a different diagnostic manuals to identify autism – either the DSM or ICD (differences discussed above).
  - Many Commonwealth countries, particularly those in the developing world, have a lack of knowledge around autism which can make receiving services and understanding difficult. This is particularly true in communities across countries which view autism as a mental health issue, or as an illness or spiritual disease of some kind.
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# R E F E R E N C E

- <sup>1</sup> This term is preferred to 'people with autism' by the UK Parliamentary Commission on Autism, the National Autistic Society, Autistica, and other leading autism organisations. Numerous opinion polls have also found it the preferred choice of autistic people themselves; as such, it is the term I will be using predominately throughout.
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# Creativity

I've heard it said I'm some quaint, programmed husk  
Who cannot think beyond a rigid box.  
Cold facts, harsh figures, dance at my fingertips  
While sweet imagination slips me by.  
But I can spot the spondee in a verse  
And signpost trochees, dactyls, and iambs;  
Uproot acrostics in a pyrrhic rush,  
Uncover the choree and the dibrach.  
The anapaest and amphibrach are clear  
As colors in a painting, to my mind.  
The cog-wheels of each line keep churning 'round  
As dative clauses latch onto the vine.  
And I can spot grand theories spinning 'round  
And sit back as they crash, crumble, and die.  
And then I pick the pieces up, and form  
Afresh, new truths from old malignant lies.  
And what about the beauty of the box?  
Why ever would I want to think outside?  
When I can grasp its roots and functions, and  
Gain a creative angle you're denied?  
My world's not yours. I spy what you cannot  
And yet am blind to what you clearly see.  
We're different, yes. But don't infer from that  
That my brain lacks your creativity.

*Jonathan Andrews*





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Designed by Shafira Charlette

*Simple Creativity*

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