

**shrg** 

SIKH HUMAN  
RIGHTS GROUP

# Autism Spectrum Disorder



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**Website:** [shrg.ngo](http://shrg.ngo)

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# Index

<b>Sikh Neurodiversity Network.....</b>	<b>Page 1</b>
<b>What is Autism?.....</b>	<b>Page 3</b>
<b>What causes Autism?.....</b>	<b>Page 5</b>
<b>Autism is not caused by.....</b>	<b>Page 7</b>
<b>Behavioural Characteristics.....</b>	<b>Page 8</b>
<b>Meltdowns &amp; Shutdowns.....</b>	<b>Page 12</b>
<b>Additional Facts.....</b>	<b>Page 13</b>
<b>Autism Myths.....</b>	<b>Page 14</b>
<b>Diagnosis.....</b>	<b>Page 16</b>
<b>Sikh Neurodiversity Network Ethos.....</b>	<b>Page 18</b>
<b>Achieving Our Aims and Objectives.....</b>	<b>Page 19</b>
<b>Helpful Resources.....</b>	<b>Page 22</b>
<b>Further Information.....</b>	<b>Page 23</b>



# **Sikh Neurodiversity Network**

The Sikh Human Rights Group (hereafter referred to as SHRG) is a Non-Governmental Organisation (NGO) with Special Consultative Status at the United Nations.

Mr Carlos Arbuthnott began his role as a Human Rights Officer & Project Coordinator for the SHRG in November 2020.

Amongst various other projects, he established and maintains the SHRGs Sikh Neurodiversity Network project. The aims and objectives of which are as follows:

- Address and raise awareness of the issues that neurodiverse individuals (as well as their families, friends, carers, etc...) face whilst accessing their local community and religious institutions.
- Host Special Educational Needs and Disabilities (hereafter referred to as SEND) engagement events at religious and community institutions, in the United Kingdom, for neurodiverse children and adults and those who are close to or care for them. The primary objective of these events is to listen to the concerns of the aforementioned parties and then to upskill the concerned organisation on what they could be doing to make their buildings and programmes more welcoming and nurturing environments for neurodiverse children and adults.
- Establish a nationwide support network for families with neurodiverse children and adults.
- Run medical practitioner-led SEND training days for those in positions of authority within their religious or community institutions.



# **Sikh Neurodiversity Network**

- Run medical practitioner-led SEND training days for UK police officers and support staff.
- After talking to the parents and carers engaged in our network we subsequently decided to begin coordinating 'neurotypical' and 'neurodiverse' youth engagement events. The primary objective is to forge genuine and subsisting relationships between neurotypical and neurodiverse youth.
- Finally, we also prepare informative literature and explanatory videos for parents and nonprofessional carers on but not limited to the following topics:

(i) Advice for parents and carers on how best to safeguard their child or themselves against negative interactions with the police or the criminal justice system in England and Wales.

(ii) Advice for police officers and support staff on what behaviours or personal characteristics might be indicators that an individual has a lifelong neurodivergent characteristic, what verbal and other communication techniques seem to work best with those with lifelong neurodivergent characteristics, and a myriad of other best practice suggestions...

(iii) We are also producing training programmes to enhance employment opportunities. Both for those with neurodivergent conditions and employers alike.

To find out more please click [here](#) or visit our website: [shrg.ngo](http://shrg.ngo)





# What is Autism?

The definition of autism has changed over time and continues to evolve as we understand more. Autism is a complex lifelong developmental disability that affects the way a child communicates, interacts and relates to the world around them. The underlying causes of autism are still uncertain. However, it appears likely from ongoing research that chemical imbalances in the brain, genetic factors and biomedical disturbances may be contributors.

There are other names for autism used by some people, such as:

- **Autism Spectrum Disorder (ASD).** That is the medical name for autism.
- **Asperger's Syndrome.** That is used by some people to describe autistic people with average or above-average intelligence (please see below for more information).

Autism is described as a spectrum disorder, which means that children and adults can be affected in different ways, some severely and others in more subtle ways. Hence why you may have heard the phrase that someone is 'on the spectrum'. All children and adults with ASD will be affected by a range of characteristics, which includes all or some of the following:

- Difficulties with social interaction (problems with social relationships, appearing inappropriate or paying little attention to others, often finding the actions and emotions of others confusing).
- Difficulty with developing imagination (problems in developing imaginative play or having a limited range of repetitive and rigid play, difficulties with planning and problem-solving).
- Difficulty with social communication (problems in developing speech or purposeful communication, difficulties using or understanding hand gestures or facial expressions).



# What is Autism?

In addition, children and adults with autism may (to a greater or lesser extent) have difficulties with:

- Self-help skills (such as washing, toileting, feeding, dressing, etc...).
- Physical skills (such as catching a ball, balancing, opening packets, holding a crayon, etc...).
- Language skills (such as using and understanding the various components of language. For instance, the distinction between 'he' or 'she', 'what' or 'where', 'on' or 'under' and so on... As well as following instructions).
- Academic skills (although this is often due to the aforementioned difficulties with the processing of language and issues with group learning).
- Attention.
- Inconsistent sensory input (such as being under or over-sensitive to touch, textures, sights, sounds, tastes and smells).
- Sleeping patterns.

There are around 700,000 autistic people in the UK - that's more than 1 in 100.

People with Autism come from all nationalities, cultures, religions and social backgrounds.

It is better for autistic individuals to receive help and support early on, rather than it being left until later in life.



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# What Causes Autism?

Nobody knows precisely what causes autism, or if it has a cause. Research suggests that autism develops from a combination of genetic and nongenetic influences.

These influences appear to increase the risk that a child will develop autism. However, it's important to bear in mind that increased risk is not the same as cause. For example, some gene changes associated with autism can also be found in people who do not possess an ASD diagnosis. Similarly, not everyone exposed to an environmental risk factor for autism will develop autism. In fact, most will not.

## Genetics

Research tells us that autism tends to run in families, so it can affect people in the same family. Changes in certain genes increase the risk that a child will develop autism. If a parent carries one or more of these gene changes then they may pass it on to their child (even if the parent does not have autism themselves).

Other times, these genetic changes arise spontaneously in an early embryo or the sperm and egg that combine to create the embryo. Again, the majority of these gene changes do not cause autism by themselves. They simply increase the risk of developing autism. Consequently, it may sometimes be passed on to a child by their parents, even if the parents do not have autism themselves.



# What Causes Autism?

## Environment

Research also shows that certain environmental influences may further increase (or reduce) the risk of individuals developing ASD. Particularly, in individuals who are genetically prone to the disorder. Importantly, the increase or decrease in risk appears to be small for any one of these risk factors:

## Increased Risk

- Advanced parent age (either parent).
- Pregnancy and birth complications (e.g. extreme prematurity [before 26 weeks], low birth weight, multiple pregnancies [twins, triplets, etc...]).
- Pregnancies spaced less than one year apart.

## Decreased Risk

- Prenatal vitamins containing folic acid, before and at conception and through pregnancy.

## Brain Biology

How do these genetic and non-genetic influences give rise to autism? Most appear to affect crucial aspects of early brain development. Some appear to affect how brain nerve cells, or neurons, communicate with each other. Others appear to affect how entire regions of the brain communicate with each other. Research continues to explore these differences with a focus on developing treatments and supports that can improve quality of life.



## Not Caused By

**Autism is NOT caused by:**

- Bad parenting.
- Vaccines, such as the MMR vaccine.
- Diet.
- Nor is it an infection that can be spread to other people.



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# Behavioural Characteristics

## Social Communication & Interaction Challenges

Often autistic people find it difficult to interpret both verbal and non-verbal language such as hand gestures or someone's tone of voice. Some autistic people are unable to speak or have limited speech, whilst others have very good language skills but struggle to understand things like sarcasm or someone's tone of voice.

Other social communication challenges include:

- Taking things literally or not understanding abstract concepts and ideas.
- Needing extra time to process information or to answer questions.
- Repeating what others say.

Autistic people often have difficulty 'reading' other people; recognising or understanding others' feelings and intentions – and expressing their own emotions. This can make it very hard for them to navigate the social world around them. Because of this, autistic people may:

- Appear to be insensitive - when they are not.
- Seek out time alone when overloaded by other people or by situations.
- Not seek comfort from other people.
- Appear to behave 'strangely' or in a way that is thought to be socially inappropriate or 'naughty' in children.
- Find it hard to form friendships.



# Behavioural Characteristics

## Repetitive & Limiting Behaviour

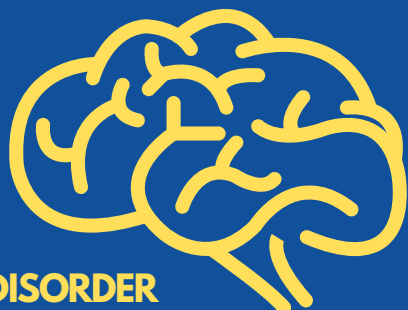
Autistic people often prefer to have routines, so that they know precisely what is going to happen rather than feeling like they are in the unknown. They may want to travel the same way to and from school or work, wear the same clothes or eat exactly the same food for breakfast.

You may notice that autistic people sometimes repeat movements such as hand flapping, rocking or the repetitive use of an object such as twirling a pen or opening and closing a door. This is known as 'stimming' and is in fact something that we all do to connect to the immediate environment around us. Furthermore, autistic people often engage in these behaviours to help calm themselves when they are stressed or anxious, but many autistic people do it because they find it enjoyable.

Routine changes can be highly distressing experiences for autistic people and make them very anxious. It could be a simple change like a bus detour or having to deal with a bigger change or event like Vaisakhi or changing schools, or facing uncertainty at work that can trigger their anxiety.

## Sensory Differences

Autistic people may experience over or under-sensitivity to sounds, touch, tastes, smells, light, colours, temperatures or pain. Essentially all or some of the senses. For example, they may find certain background sounds like music in a restaurant or a shop, unbearably loud or distracting. This can cause anxiety or even physical pain. Many autistic people prefer not to hug due to discomfort, which can be misinterpreted as being 'cold' or standoffish.



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## Behavioural Characteristics

Many autistic people avoid everyday situations because of their sensitivity issues. Schools, workplaces and shopping centres can be particularly overwhelming and cause sensory overload. This may manifest in autistic individuals covering their ears or clenching their fists when faced with such sensory overload - for example when there are loud noises. However, many simple adjustments can be made to make everyday environments more 'autism-friendly'.

### Intense Interests

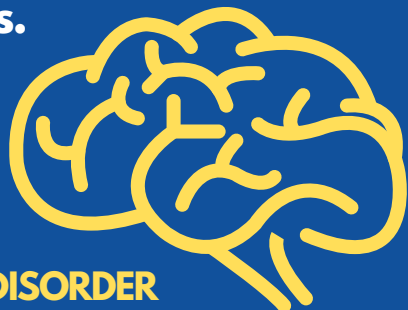
Many autistic people but by no means all have intense and highly focused interests, often from a fairly young age. These can change over time or be lifelong.

Autistic people can become experts in their special interests and often like to share their knowledge. For example, Greta Thunberg's intense interest in protecting the environment.

Like all people, autistic people gain huge amounts of pleasure from pursuing their interests and see them as fundamental to their well-being and happiness.

Being highly focused helps many autistic people do well academically or in the workplace. However, they can also become so engrossed in particular topics or activities that they neglect other aspects of their lives.

Whilst some autistic individuals might have intense interests, this isn't common with all autistic individuals. Some instead prefer variety in their day-to-day activities and work. So not all autistic individuals have the same preferences.



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# Behavioural Characteristics

## Extreme Anxiety

Anxiety is a real difficulty for many autistic people, particularly in social situations or when facing change. It can affect a person psychologically and physically and can impact the quality of life for autistic people and their families.

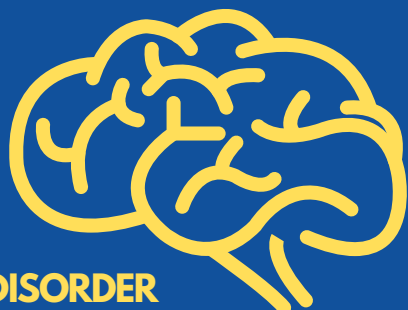
It is very important for autistic people to learn to recognise their 'triggers' and find coping mechanisms to help reduce their anxiety. However, 'neurotypical' individuals also need to be accommodating towards these coping mechanisms to help autistic individuals in situations that they find difficult. Particularly as many autistic people can have difficulty recognising and regulating their emotions.



**Accept.**

**Understand.**

**Love**



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# Meltdowns & Shutdowns

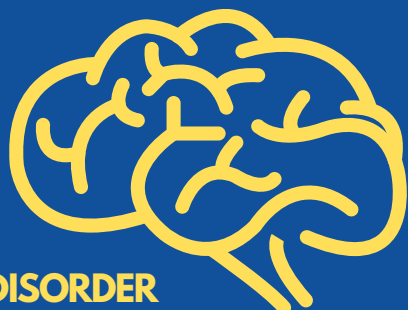
## Meltdowns & Shutdowns

When everything becomes too much and overwhelming for an autistic person, they can go into a 'meltdown' or 'shutdown'. These are very intense and exhausting experiences.

Meltdowns happen when someone becomes completely overwhelmed by their current situation and temporarily loses behavioural control. This loss of control can be verbal (e.g. shouting, screaming, crying, etc...) or physical (e.g. kicking, lashing out, biting, etc...) or both.

Meltdowns in children are often mistaken for temper tantrums. Parents and their autistic children often experience hurtful comments and judgmental stares from less understanding members of the public.

Shutdowns appear less intense to the outside world but can be equally debilitating. Shutdowns are also a response to being overwhelmed, but may appear more passive (e.g. an autistic person going quiet or 'switching off').



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## Additional Facts

**It is important to remember that autism can range from severe (low functioning Autism) to mild (high functioning Autism).**

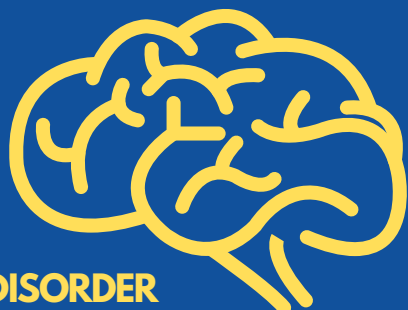
Therefore, although individuals with autism may share similarities, no two people with autism are the same, and their autism will inevitably affect them in different ways. For example, some individuals with autism:

Are unable to speak or have limited speech, whilst others have very good language skills but struggle to understand certain social interactions.

May do very well in school, whilst others may get overwhelmed and can't concentrate.

Find it relatively 'easy' to find, obtain and retain employment whilst others face many barriers and challenges along the way.

Can live independently whereas others may need full-time care.



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# Autism Myths



**Myth:** Autistic people either have very low intelligence or very high intelligence.

**Truth:** Autistic people can have any level of intelligence.

**Myth:** Individuals who possess autism, cannot have any other 'condition'.

**Truth:** Some autistic people also have learning disabilities or other conditions such as:

- Attention Deficit Hyperactivity Disorder (ADHD)
- Dyslexia
- Anxiety
- Depression
- Epilepsy

This means that they may find it hard to process information in the same way as others or to look after themselves and therefore may need a little bit of additional help in their daily lives.

**Myth:** Autism and Asperger's syndrome can be cured.

**Truth:** Autism or Asperger's syndrome is a lifelong condition; it is not an illness or a disease and therefore it cannot be 'cured'. However, with the right support, all autistic people can live fulfilling lives of their own choosing.



## Autism Myths

**Myth:** Individuals who possess autism are 'crazy' or 'mad'.

**Truth:** Individuals who possess autism are not 'crazy' or 'mad' and consequently they should not be labelled as such. They may have autism and a mental health condition, both of which can be managed or treated to help the individual live a fulfilling life, and contribute to society.

**Myth:** Adults and children who possess autism need strong discipline and to be 'kept in line', even shouted at, to fix the 'problem'.

**Truth:** Individuals who possess autism may have a few or a range of several difficulties. These difficulties should be identified and the individual should be supported in managing them and in finding appropriate coping mechanisms or approaches to deal with situations where the difficulties may occur. Shouting at the autistic person, taunting them, or telling them to 'fall in line', can cause the individual to have a meltdown or shutdown.

For example, if an autistic child requires a set routine for school, including the travel route, but the parent or carer is forced to take an alternative route due to traffic or roadworks - it is important to have an approach in place to help the child cope with that change.

**Myth:** Autism is gender specific.

**Truth:** Autism is not gender-specific. Males and females can both possess autism.



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## Diagnosis

Obtaining a diagnosis of autism has slightly different routes depending on the person's age.

### Children:

The first step is to speak to your child's General Practitioner (G.P.), or health visitor. However, as they are unlikely to be autism specialists, it is important to be clear on your reasons why you want them to refer your child for an autism diagnostic assessment.

The G.P. can request a paediatric assessment with a specialist, who will want to know your concerns along with your child's symptoms and developmental journey in depth. It can be useful to prepare for this assessment in advance by capturing the information in an observational diary. The paediatrician will then decide whether or not your child needs a formal autism diagnostic assessment.

Formal diagnostic assessments can take different forms, depending upon the area you live in and the approach your local authority takes. In addition, the steps taken after diagnosis are also dependent upon the local authority's pathway, and this can often be viewed on your local authorities' website.

The National Autism Plan for Children (NAPC) produced by the National Initiative for Autism Screening and Assessment provides clear guidance in relation to the identification, assessment and diagnosis of children with autism.



# Diagnosis

## Adults:

The first step is to speak to your General Practitioner (G.P.) explaining the reasons why you want a diagnosis. However, as they are unlikely to be a specialist in autism, it is important to be clear on your reasons why you want an autism diagnostic assessment.

If the G.P. agrees to refer you to a specialist for a review, they will likely make the referral to a diagnostic clinic in your local area. You can request a referral to a multidisciplinary autism specialist team, but unfortunately, there is no guarantee of this. The National Autistic Society has more information on its website.

Unfortunately, the waiting list for NHS diagnosis services is very long. The alternative is to pay for a private diagnosis by a specialist. However, this can be expensive.

The National Autistic Society can provide you with a list of diagnostic centres in your area, should you wish to enquire further.





# **Sikh Neurodiversity Network Ethos**

The doctrine of pluralism underpins the Sikh Neurodiversity Network. Pluralism is the recognition and affirmation of diversity, which is seen to permit the peaceful coexistence of different interests, convictions, and lifestyles.

According to GuruSikhi, every life is an expression of Waheguru, in a diversity of forms, abilities, temperaments and characters.

Therefore, in the Sikh Neurodiversity Networks' opinion, neurodiversity is simply another manifestation of mental pluralism in human life.

In other words, not all of us are the same, not all of us behave the same way and not all of us have the same mental approach towards life, education, learning new skills and social interactions. However, society often seeks uniformity and in some instances demands conformity.

However, with so much neurodiversity within our general society, this inevitably results in misunderstandings, tensions, and sometimes sadness when those who want conformity seek to change those who may be perceived as 'different'. This in turn further marginalises those who may not be perceived as 'neurotypical'.

Nevertheless, with a little bit of understanding these tensions can easily be overcome and society, groups and people can function extremely well as supportive and cohesive communities.



## Achieving Our Aims and Objectives

The greatest Sewa of those serving the Guru in Gurdwaras is to ensure that the doors of the Guru are always open, welcoming and accommodating for all people so that they feel embraced by the Guru.

Therefore, it is extremely important that no one feels marginalised or excluded simply because they think differently or behave differently or prefer silence or feel uncomfortable with strangers.

In our collective experience, Sikh religious and community leaders have consistently demonstrated vast amounts of empathy and sympathy towards those from diverse backgrounds including those who possess neurodiverse conditions.

However, Gurdwaras and other Sikh community institutions often lack the formal infrastructures (systems and policies) necessary to support those with lifelong neurodivergent characteristics such as Autism.

It is also extremely important to note that this issue is prevalent across our global societies and is by no means solely applicable to Gurdwaras and other Sikh community institutions.

Therefore, through the aims and objectives of our project, we are confident in our mission to overcome the difficulties faced by neurodiverse individuals both within Gurdwaras and the Sikh community, as well as within our wider UK communities, to ensure that everyone feels accepted and supported, irrespective of their backgrounds, beliefs and abilities.



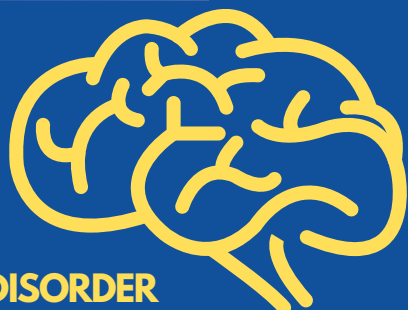
## Achieving Our Aims and Objectives

To fulfil our aims and objectives, the Sikh Neurodiversity Network is currently working with multiple Gurdwaras across the United Kingdom to make their buildings and programmes more welcoming and nurturing environments for neurodiverse children and adults.

This has included hosting regular SEND engagement events, parent and carer support groups and SEND after-school clubs. These events are also an opportunity for those with lifelong neurodivergent characteristics of any age and those who care for them to come together to discuss how the relevant institution can best support them and their families.

At these events, we have musical instruments, arts and crafts supplies, sensory toys, etc... for the children to play with.

This also provides our network volunteers with an opportunity to listen to the experiences of those with lifelong neurodivergent characteristics and those who are close to them. Specifically, regarding the problems and issues that they may have encountered and how these identified problems and issues can be redressed.



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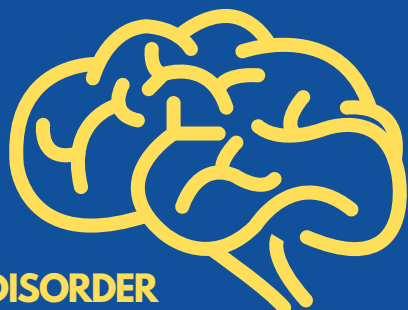
# Achieving Our Aims and Objectives

We are also seeking to establish a network of experts of all ages within the Gurdwaras who will be charged with increasing Sangat understanding, engagement and support for those with lifelong neurodivergent characteristics.

After their training, these neurodiversity ambassadors will go on to advise the Sangat about the different forms of emotional and related communications that seem to work best with neurodiverse children and adults.



We have also been working with local community leaders, representatives of local authorities, schools, etc... to ensure inclusivity for children and adults with lifelong neurodivergent conditions, such as Gurdwara Sri Guru Singh Sabha Southall (please see below).



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# Helpful Resources

**National Autistic Society:** [www.autism.org.uk](http://www.autism.org.uk)

**Child Autism UK:** [www.childautism.org.uk](http://www.childautism.org.uk)

**Autism Speaks:** [www.autismspeaks.org](http://www.autismspeaks.org)

**Autism Berkshire (Slough Based Support Services):**  
[www.autismberkshire.org.uk](http://www.autismberkshire.org.uk)

**Autism Links (Directory of Support Services and Groups):**  
[www.autismlinks.co.uk](http://www.autismlinks.co.uk)

**P.E.S.T.S. (Parents of Ealing Self-Help Training Scheme):**  
For more information please click [here](#)

**NHS Diagnosis Page:**  
For more information please click [here](#)

**Ambitious About Autism - Assessment & Diagnosis (Children) (Helpsheets and Parent Handbook):**  
For more information please click [here](#)

**National Autistic Society - Diagnosis Helpsheet (Children):**  
For more information please click [here](#)

**National Autistic Society - Pre-Diagnosis Support Guide (Adults) (Contains Useful Advice Re: Your Initial Discussions With Your G.P.):**  
For more information please click [here](#)

**National Autistic Society - Diagnosis Helpsheet (Adults):**  
For more information please click [here](#)





## Further Information

If you like the sound of this project and you would like to become involved or you simply want to find out a little bit more information then please contact:

**Mr Carlos Arbuthnott**

**Human Rights Officer & Project Coordinator  
Sikh Human Rights Group**

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