



St Giles Trust  
Breaking the Cycle of Offending

# Living and Working with Autism:

A guide to a better understanding of Women  
with Autism Spectrum Condition and accessing services.

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# 1. The Purpose of This Guide

## The St Giles Trust ASC Project

The ASC Project was commissioned by the National Offender Management Service and delivered for two years by St Giles Trust\* in Partnership with Cambian Group\*\*.

The focus was to provide Information and support to female offenders in HMP Holloway with high-functioning Autistic and or Schizoid Personality Disorder traits.

The aim of the project was to support women with extended experience of criminal justice, health and social services to break out of the cycle of offending and to improve outcomes for high risk, high harm ASC/PD (Autism Spectrum Condition/Personality Disorder) female offenders returning to the community from custody.

The Project also provided training and support to Peer Mentors and Prison Staff to support women accepted on to the service and raise awareness. The reason for focussing on both ASC and Schizoid PD female offenders is that both tend to present similar behavioural traits.

We have put together this resource Guide to collate all the information we have learnt regarding working with women and ASC over the course of the project. Please note that the purpose of this is not to diagnose, but to inform and guide both staff and service users through the process of diagnosis and to point people towards support services.

Although the ASC project focussed on females within the criminal justice system, the findings are not

gender-specific, and can also be applied to both prison and community settings.

However it is important to remember that this guide is based on the women supported by this project who displayed autistic traits which are likely to be more pronounced than the general population based on the fact that they were in prison during the time they were supported, which may have influenced their behaviour.

***\*St Giles Trust** is a UK-based charity aimed at breaking the cycle of prison, crime, disadvantage and creating safer communities by supporting people to change their lives. Our services put reformed ex-offenders at the heart of the solution, training them to use their skills and first-hand experience to help others through peer-led support.*

***\*\*Cambian Group** is a specialist healthcare provider working with people affected by personality disorder, complex mental health needs and challenging behaviours across health and justice services. Within the ASD Project they provided forensic psychological support to staff towards managing clients.*



## 2. What is ASC?

Autism or Autism Spectrum Condition (ASC) affects how someone communicates with and relates to other people, and the world around them. It is a developmental, lifelong condition that originates in childhood, and whilst there is no cure, with the right knowledge and skills someone with autism can live a successful and fulfilling life.

Autism is a spectrum condition, which means that although there might be some common difficulties, everyone will be affected differently and therefore supporting an individual's needs should be tailored. High-Functioning Autism (Asperger Syndrome) is a form of autism.

People with High-Functioning Autism are often of average or above average intelligence. They are less likely to have difficulties with speech but may struggle to understand and process language, which will effect their communication. 'Kanner' Autism is the name given to those at the opposite end of the spectrum who may only be able to speak a little, or not at all. Those with Kanner Autism tend to have much higher support needs.

A person with autism typically presents difficulties with **social interaction, social communication, and social imagination (flexibility of thought)**

Social Interaction	Social Communication	Social Imagination
Someone may find it more difficult to form relationships with others, and may struggle to understand both their own, and other people's emotions.	Someone may struggle to communicate both verbally and non-verbally with other people	Someone might display repetitive behaviours or be rigid in their thinking. They may also have a limited ability to predict a person's behaviour or motivations for doing something.

## Women and Autism – Wallpaper Women

Whilst it is believed that more men than women have autism, according to research the ratio between men and women receiving a diagnosis ranges from 2:1 to 16:1, it is also believed that women are better equipped to mask their autistic traits more than men in order to fit in with peers.

For instance, women with Asperger's have learnt to mimic with social skills though observing others behaviour and in some cases such as Lucy's (see case study) use their imaginations and creative play to escape into a world of fantasy, resulting in them 'fading' into the background or becoming what we called 'wallpaper' women. Generally speaking, there is also a greater expectation in society for women to be social. As a result of this,

women who have autism are often unrecognised as being autistic, and therefore remain undiagnosed for most of their life. We found this to be the case during our project with women as old as 38 having never been recognised as autistic. In addition to issues around recognition, the entire diagnostic criteria for Asperger's Syndrome were created on the basis of male behaviours, who tend to be more troublemaking than women with the same diagnosis.

## 3. Working with Autism

### The Do's and Don'ts

#### DO

- Respect their need for space
- Be patient
- Focus on goals or life difficulties directly related to offending behaviour
- Be precise in what you say
- Minimise background noise
- Break down information and instructions into small chunks
- Use graphics and flowcharts to explain things if possible

#### DON'T

- Touch the person
- Use emotionally complex questions
- Push the person in to social activities
- Use sarcasm or tell white lies
- Say 'maybe', 'perhaps', 'sometimes' or 'later'
- Be offended by direct honesty from the person

- Use figures of speech such as: 'pulling your leg' or 'pull yourself together'

### Creating an Autism-Friendly Support Service

When you are supporting someone with Autism, it is important to create an environment that enables them to flourish, and in order to achieve this, attention should be given to the following information.

#### Heightened sensitivities

Individuals with autism tend to be highly sensitive to their environment. As a result, sound and lighting can be highly distracting and even stressful. For instance, sitting in a noisy environment or in a room with florescent lighting would be extremely distracting for someone with ASC. In order to avoid this, try

to provide a quiet space with options for dimmer lighting and possibly some sort of 'escape room' where people can go and get some peace and quiet.

### Routine & Structure

People with Autism enjoy routine and structure, therefore avoiding interruptions or sudden changes to their routine is important. Try to give the individual advance warning if there is even potential for a change in schedule i.e. you are running late to meet them.

Obviously if this is unforeseen, warning cannot always be given, but allowing as much time as possible to process the change, as well as understanding how stressful this might be for someone with autism is very important for reducing the level of stress and anxiety it causes them.

### Visual Learning

Individuals with autism are likely to struggle with spoken discussion so it is important to create an environment where people can learn visually, through images and written word or discussions.

### Instruction

Many individuals with ASC have an incredible ability to focus on following directions; therefore providing clear instructions on how to do something will be extremely beneficial to the individual. Often people with autism prefer written instructions, such as a list, as this enables the individual to refer back to them.

## 4. Living with Autism

### In Prison

People in Prison who are autistic are likely to be at the more able end of the spectrum, with High-functioning Autism (Asperger Syndrome) as a result of having independence and an ability to commit the crime in the first place. In our experience, someone with Asperger's might appear very independent and capable when in fact their Asperger's is masking their vulnerability. As a result, the person might be very confused by a situation without being able to communicate this.

Someone with Autism in Prison may struggle in the following ways:

- Understanding the consequences of their actions
- Inability to learn from past experience
- Lack of understanding as to how others will perceive their actions

- Find unexpected situations extremely difficult to cope with
- Intimidated by dangerous situations, causing heightened anxiety
- Tendency to like rules and routine
- Inability to adapt learning from one situation to another
- Make clear to them the consequences of their actions
- Odd/eccentric behaviour makes them vulnerable to bullying
- The perfect victim

### In the Community

As we have mentioned already, Autism impacts how someone communicates and interacts with others and the world around them. When working closely with someone in the community it is important to be aware, and make others aware, of the ways in which their behaviour might differ. For

instance, they may exhibit the following 'unconventional behaviours':

- Lack of eye contact, or in some cases prolonged eye contact
- Lack of awareness of personal space
- Shouting loudly
- Unknowingly getting involved in dangerous or criminal activity under someone else's influence
- Isolation behaviour which appears eccentric/odd
- Sudden outbursts of extreme anger or happiness
- Obsessive interests
- Inability to recognise danger
- React to stressful/ unexpected situation with extreme anxiety

All of these behaviours might make the person vulnerable to manipulation, bullying, or even getting into trouble with the police.

We found it beneficial to inform staff and professionals about the affect of autism on the person's behaviour so that reasonable adjustments could be made to ensure a fair service was delivered.

## 5. Am I Autistic?

If you have noticed the traits we have described in yourself or have been feeling for a while that you might be autistic then you may want to consider having a formal diagnosis. This is completely an independent decision, as some people may just be happy to self-diagnose.

### Screening Tools

We have included in this guide two screening tools which were used during the project to identify women as possibly having autistic traits: the Autism Spectrum Quotient (AQ- 10) designed by the Autism Research Centre (ARC), and the ASC Observation Screening Tool designed by staff on the St Giles ASD project.

***Please remember that neither of the two tools are diagnostic, they are a means to identify autistic traits in an individual so that you are able to provide them with support but no score indicates that an individual has an Autism Spectrum Condition (ASC).***

*If after looking at this guide you think that you, a friend or relative, may have ASC, please speak to your GP for advice.*

## AQ-10 Autism Spectrum Quotient (AQ)

1.	I often notice small sounds when others do not	definitely agree	slightly agree	slightly disagree	definitely disagree
2.	I usually concentrate more on the whole picture, rather than the small details	definitely agree	slightly agree	slightly disagree	definitely disagree
3.	I find it easy to do more than one thing at once	definitely agree	slightly agree	slightly disagree	definitely disagree
4.	If there is an interruption, I can switch back to what I was doing very quickly	definitely agree	slightly agree	slightly disagree	definitely disagree
5.	I find it easy to 'read between the lines' when someone is talking to me	definitely agree	slightly agree	slightly disagree	definitely disagree
6.	I know how to tell if someone listening to me is getting bored	definitely agree	slightly agree	slightly disagree	definitely disagree
7.	When I'm reading a story I find it difficult to work out the characters' intentions	definitely agree	slightly agree	slightly disagree	definitely disagree
8.	I like to collect information about categories of things (e.g. types of car, types of bird, types of train, types of plant etc)	definitely agree	slightly agree	slightly disagree	definitely disagree
9.	I find it easy to work out what someone is thinking or feeling just by looking at their face	definitely agree	slightly agree	slightly disagree	definitely disagree
10.	I find it difficult to work out people's intentions	definitely agree	slightly agree	slightly disagree	definitely disagree

**Scoring:** Only 1 point can be scored for each question.

Score 1 point for Definitely or Slightly Agree on each of items 1, 7, 8, and 10.

Score 1 point for Definitely or Slightly Disagree on each of items 2, 3, 4, 5, 6, and 9.

If the individual scores **more than 6 out of 10**, consider referring them for a specialist diagnostic assessment.

## ASC Screening Tool

### Observations Yes/No

- *Does not appear to like or have close relationships, including family?*
- *Nearly always prefers solitary activities?*
- *Enjoys few activities if any?*
- *Other than close relatives, has no close friends or confidants?*
- *Does not appear to be affected by criticism or praise*
- *Presents as emotionally cold, detached or bland?*
- *Presents as withdrawn or shy?*
- *Reacts negatively to a change in their routine?*

## What's Next?

After reading this guide and using the screening tools, you will hopefully understand a bit more about Autism. For a lot of people, just simply understanding their behavior is enough, but for others, they may prefer to have a diagnosis so that they can access support.

Please bear in mind when you are making the decision whether to get a diagnosis or not, that Autism is not a mental health diagnosis and does not automatically mean that you are entitled to support.

If you are given a diagnosis of High-Functioning Autism, you will not be supported by your community mental health team on the above basis. Please refer to our further reading section which guides you towards other information about Autism. This guide also includes a section on Services (in London) and we have indicated which of these services require a diagnosis and which do not.

## 6. Diagnosis

Getting an autism diagnosis can be daunting; however it can also mean gaining access to the right support.

Most importantly, we found that it helped people to understand themselves and explained why they find some things particularly difficult or even why they are especially good at something.



## Getting a formal diagnosis

If you believe you might be autistic, and would like to have an assessment you will need speak with your GP. Your GP will ask you to explain your reasons for thinking you might have autism, and how a diagnosis would help you. If they are satisfied with you reasoning you can ask them to refer you for an assessment.

In our experience, people have waited up to two years for a diagnosis following a referral from a GP. We have found that a supporting letter from a professional agency outlining specific concerns and highlighting the need for a diagnosis has sped up the referral, though this is not always the case.

The assessment will usually be carried out by either a Psychiatrist or Clinical Psychologist. You can find out where your local diagnostic service is using the NAS website (<http://www.autism.org.uk/directory.aspx>). Most services will only accept a referral from a GP but some may accept self-referrals.

The assessment will usually involve a series of questions about your developmental history from when you were a child, focusing specifically on your use of language, play and thoughts. It is particularly important for parents (or siblings) to be involved at this stage if possible as they might have a clearer memory of your childhood.

In most cases, you will not receive your diagnosis on the day of assessment and will usually be sent a report in the post a few weeks after. Some diagnosticians may call you in advance to give the result and then send out their written report, others may ask you to come back into the service to talk through the report or what it is going to say.

You should be offered the chance to query anything written in the report, if for instance you don't think it is accurate, but ultimately this is at the diagnostician's discretion. If you do have a follow up appointment, we have found it useful to bring along either a support worker or family member as it may be a lot of information to take in.

At this stage you should ask any questions you have about the diagnosis, also ask for advice about services which are available to you now.

## **What happens next?**

It is important to mention that you are not automatically linked into support services once you have been given a diagnosis. However it does mean that you are more likely to be able to access services and claim any benefits you are entitled to. Please consider that some people may not feel that they need any more support, and are happy just to be diagnosed.

The National Autistic Society offers loads of amazing services for people with an Autism diagnosis such as; an Autism Helpline (0808 800 4104), an online community, Facebook or Twitter pages to join discussions, a free publication written by and for autistic people called Asperger United, and finally you can become a NAS member and receive a quarterly magazine called Your Autism.

Please note that membership to the NAS and Your Autism Magazine is aimed at anyone wishing to know more about autism including; parents, family members, careers, professionals and of course individuals with autism themselves.

## **Impact on Benefits**

Those with a formal diagnosis may be entitled to benefits such as:

- Disability Living Allowance/ Personal Independence Payment
- Employment and Support Allowance
- Housing/Council Tax Benefit
- Working Tax Credit
- Jobseekers Allowance

In addition, parents or carers may be able to claim:

- Income Support
- Carer's Allowance
- Child Tax Credit
- Housing/Council Tax Benefit

To find out more, contact the Department for Work and Pensions at [www.dwp.gov.uk/eservice](http://www.dwp.gov.uk/eservice) or alternatively you can call the Benefit Enquiry Line on 0800 882200

## **Housing**

In addition to being able to claim Housing Benefit or Council Tax Benefit, those with a diagnosis may also want to consider living in supported accommodation, which can vary depending on the level of support required.

The NAS provide residential services all over the UK. For more information call 0117 974 8430

## 7. Lucy's journey to a diagnosis

***“I was relieved to finally have an assessment, which I'd been after for years. Receiving my diagnosis was a weight off my mind; suddenly everything made sense. I read books on Asperger's, and I understood why I am the way I am, and I understood why I'd been bullied for so many decades. Before my diagnosis, it was like walking through a fog”***

Lucy was referred to the ASD Project by her Art Therapist about three months prior to her release from prison. Before we offer our support to a client, they need to first undergo an assessment using the Autism Quotient (AQ). Lucy certainly met our criteria, having scored highly on the AQ, which indicated higher than average autistic traits.

The caseworker explained that we do not offer any kind of diagnosis, but that the score could help us and others supporting Lucy to understand her better as well as giving her a better understanding of herself. The caseworker also provided Lucy with some information about Autism to read about in her own time. Immediately after starting to work with Lucy, we were able to identify some autistic traits in her behaviour.

For instance, Lucy liked the routine of the prison as she found rules easy to comply with. She was also meticulous about the timing of the meetings with her caseworker and would become noticeably anxious if the caseworker was late. In addition, Lucy would wait at the window every week at the same time, watching to see the

caseworker walking towards the building.

Finally, Lucy didn't appear to have formed any social relationships with others in the prison and told us that she was being bullied. As a consequence, she spent almost all of her time on the wing, and even stopped her Mum from visiting through fear of being bullied when she was in a different area of the prison, outside of her comfort zone.

Over the next three months the caseworker met with Lucy once a week to coordinate plans for her resettlement. The meetings with the support worker were an opportunity for Lucy to discuss how she was coping in prison and focus on plans for her release.

These weekly visits also enabled the caseworker to build a relationship with Lucy which would be beneficial in the community. During this time, a referral was

made for Lucy to have an Autism Assessment. This was something that she was very keen to have as she had always felt like she was different to other people, but had never known why.

On the day of her release Lucy was met at the gate by her caseworker and accompanied throughout the day to her appointments, and back to her mother's house where she would be living. Unfortunately, without any formal diagnosis, Lucy would not be considered to be in 'priority need' for housing. So despite needing some independence, Lucy would be staying at her Mum's house for the foreseeable future.

Now that Lucy was back in the community, she lacked confidence going out anywhere on her own, so the caseworker accompanied her to all of her appointments, including probation each week. During the remainder of her free time Lucy would almost always be at home, watching DVD's or using

the internet for hours on end. Lucy also has a very keen interest in fantasy novels and has even written a book herself.

After a couple of months, Lucy's caseworker chased the referral to the Autism Assessment Clinic, and was informed that it could take over a year for an assessment appointment to be given. Finally, over a year after the referral was made, Lucy was invited to an assessment appointment, which her caseworker attended with her.

Four weeks on, Lucy was diagnosed with High-Functioning Autism. Her support worker is now working with her to ensure that she gets the necessary support she needs around this. Since we have been working with Lucy, we have seen a huge improvement in terms of confidence.

Lucy now happily goes on her own into town after probation appointments to visit the shops. She still likes to be accompanied if she makes a new journey for the first time but after that she is happy to make the journey alone. She is also looking towards new opportunities in terms of employment and studying. We are hoping that in the future Lucy will be live independently, in supported accommodation.

***“I needed help and got it in spades! Nothing is too much trouble for these people. If I don't have the answer, they do. The support workers are friendly and extremely helpful. The world doesn't seem quite so scary. I'm increasing in confidence and feel more in control of my life”.***

## 8. Support services

### Useful websites:

**National Autistic Society –**

[www.autism.org.uk](http://www.autism.org.uk)

**The Autism London Asperger group (ALAG) -** [www.alag.org.uk](http://www.alag.org.uk)

**A2ndvoice -** [www.a2ndvoice.com](http://www.a2ndvoice.com)

**Ambitious about Autism -**

[www.ambitiousaboutautism.org.uk/talk-about-autism](http://www.ambitiousaboutautism.org.uk/talk-about-autism)

**Centre for ADHD & Autism Support -**

[www.adhdandautism.org](http://www.adhdandautism.org)

**Autism Unravelled -** [www.autism-](http://www.autism-unravelled.org)

[unravelled.org](http://www.autism-unravelled.org)

**Asperger's Syndrome Foundation -**

[www.aspergerfoundation.org.uk](http://www.aspergerfoundation.org.uk)

### Employment/Training services:

**Employ Ability -** [www.employ-ability.org.uk](http://www.employ-ability.org.uk)

**Larches Community -**

[www.larchescommunity.org.uk/](http://www.larchescommunity.org.uk/)

**Autism Outreach -** [www.autism-outreach.org.uk](http://www.autism-outreach.org.uk)

**Skills for Work – Autism London -**

[www.mcch.org.uk/](http://www.mcch.org.uk/)

For more information about services please visit the NAS website for their service directory

<http://www.autism.org.uk/directory.aspx>

### London social groups

**Barnet Asperger's Social Group -**

[www.barnetmencap.org.uk/Aspergers.htm](http://www.barnetmencap.org.uk/Aspergers.htm)

**NAS Greater London North – Outings**

**Group -** [www.autism.or.uk](http://www.autism.or.uk)

**NAS Greater London North - Social**

**Skills Group -** [www.autism.org.uk](http://www.autism.org.uk)

**NAS Greater London North – Social**

**Steps -** [www.autism.org.uk](http://www.autism.org.uk)

## Information Resources:

**Autism: a guide for criminal justice professionals**, by The National Autistic Society. This guide provides background information about autism and working in the criminal justice system (available to download online or order a hard copy for free on the NAS website)

**What next? Information for adults with autism before and after diagnosis**, by the National Autistic Society (order free on NAS website)

**The Complete Guide to Asperger's Syndrome**, by Tony Attwood, published by Jessica Kingsley Publishers, 2006. This book is essential reading to assist in understanding ASC.

**Build Your Own Life: A Self-Help Guide for Individuals with Asperger's Syndrome**, by Wendy Lawson, published by Jessica Kingsley Publishers, 2003. Wendy Lawson herself has Asperger's Syndrome.

**Congratulations! It's Asperger's Syndrome**, by J Birch, published by Copy Solutions, 2002. Written by a woman who found out she had been diagnosed with AS at 43 years of age.

**Appreciating Asperger Syndrome**, by Brenda Boyd is a useful book that individuals can read regarding the strengths associated with ASC.

## 9. Further reading

### Autism in Books

#### **The Curious Incident of the Dog in the Night-time by Mark Haddon**

A murder mystery novel like no other. The detective, and narrator, is Christopher Boone. Christopher is fifteen and has Asperger's Syndrome.

#### **The Rosie Project by Graeme Simsion**

Love isn't an exact science - but no one told Don Tillman. A thirty-nine-year-old geneticist, Don's never had a second date. So he devises the Wife Project, a scientific test to find the perfect partner.

#### **Look Me in the Eye by John Elder Robison**

The story of a boy growing up with Asperger's syndrome at a time when the diagnosis simply didn't exist.

#### **Mockingbird by Kathryn Erskine**

11-year-old Caitlin has Asperger's syndrome, and has always had her older brother, Devon, to explain the confusing things around her. But when Devon is killed in a tragic school shooting, Caitlin has to try and make sense of the world without him.

#### **Delightfully Different by D.S. Walker**

This captivating story provides invaluable insights into the childhood of a girl who has Asperger's syndrome. Fiction allows the

author to explore different perspectives and add poignancy to the experiences of sensory sensitivity and being bullied and teased of someone who has Asperger's syndrome.

### Autism in film

#### **Temple Grandin (2010) (Biopic)**

A biopic of Temple Grandin, an autistic woman who has become one of the top scientists in the humane livestock handling industry.

#### **The Boy Who Could Fly (1986)**

An autistic boy who dreams of flying touches everyone he meets, including a new family who has moved in after their father dies.

#### **My Name is Khan (2010)**

An Indian Muslim man with Asperger's syndrome takes a challenge to speak to the President seriously, and embarks on a cross-country journey.

#### **I am Sam (2001)**

A single Autistic father fights for custody of his 7-year-old daughter, and in the process teaches his cold hearted lawyer the value of love and family.

#### **Snow Cake (2006)**

A drama focused on the friendship between a high-functioning autistic woman and a man who is traumatized after a fatal car accident.

## 10. Contact details

For further information about this guide or advice on how to access support please contact a member of our team at:

### **St Giles Trust**

Georgian House  
64-68 Camberwell Church St  
London SE5 8JB  
020 7708 8000

Working in partnership:



*St Giles Trust is a registered charity No 801 355. We aim to break the cycle of offending, crime and disadvantage and create safer communities. St Giles Trust Head Office, 64-68 Camberwell Church St, London SE5 8JB. [www.stgilestrust.org.uk](http://www.stgilestrust.org.uk)*

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