A teaching trust of Brighton and Sussex Medical School

Sussex Partnership NHS Foundation Trust

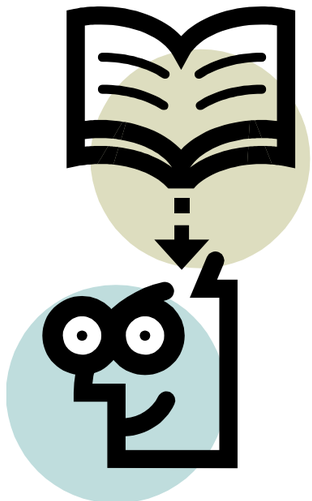
# An Introduction to Autism Spectrum Conditions within a CAMHS Context

Hampshire Child and Adolescent Mental Health Services

Autistic Spectrum Conditions Assessment Teams

# Overview

- What is an Autistic Spectrum Condition?
  - Talking, listening and communicating
  - Getting on with people and making/maintaining relationships
  - Thinking and behaving using imagination and flexibility
  - Sensory sensitivities
- Celebrating ASC
- ASC in the public eye
- CAMHS referral guidance for an ASC assessment
- Challenges of ASC assessments within CAMHS
- Mental health difficulties in ASC
- Strategies to support children with ASC
- Signposting



To find out more about ASC, have a look at the **National Autistic Society** website (www.nas.org.uk) or the **Autism Hampshire** website (www.autismhampshire.org.uk).

## Support for Parents

- The National Autistic Society runs a variety of parent and family support groups across Hampshire which parents may find useful. We recommend that parents check out their website (www.nas.org.uk) for more local information on all the groups and activities the society provides.
- Hampshire Gateway details activities for children with additional needs. Families can register for a Gateway Card that will provide access to activities, play schemes, and buddy schemes. Website- www.hampshiregateway.info
- Hampshire Carers Helpline can offer support and guidance on: 0845 722 1122
- Parent Voice offers support and advice for parents with children with additional needs. They can put families in contact with local support or activity groups. Website- www.hants.gov.uk/tc/edpp/pphome.html

## Educational Support

Children with ASC may be eligible for more support in school. Parents are advised to contact the school SENCo for advise. For advise regarding applying for an EHCP, parents should contact the school SENCO, Educational Psychologist or Local Education Authority.

The IPSEA Website, www.ipsea.org.uk can provide advise and support with regards to special education needs.

Parent Partnership Service offers impartial advice, information and support to parents/carers of children with special educational needs including advise on negotiating with schools (www.hants.gov.uk/parentpartnership)

# Where can I get support?

**Specialist CAMHS Consultation Line for children & young people already being seen by CAMHS**

*The Specialist CAMHS consultation lines provide an opportunity to talk with a mental health professional.* ***Available Mon-Fri between 12-1***

Fareham & Gosport– 01329822220

Winchester– 01962831044

Eastleigh– 02380673984

New Forest– 02380743030

Andover– 01264835356

**Aldershot– 01252335600**

Basingstoke– 01256392766

Havant– 02392224560

If you are unable to call during the allocated time slot, please call and leave a message detailing a suitable time for a clinician to call you back.

For new referrals please call the CAMHS Single Point of Access 03003040050 or E Mail Spnt@hantscamhsspa@nhs.net

SPA operates 9-5 Monday to Friday

**MindEd**

*MindEd is a portal that contains a wealth of information for anybody working with children and young people.*

*The bite-sized chunks of e-learning are designed to give you the confidence to identify a mental health issue and act swiftly, improving outcomes for the child or young person involved.*

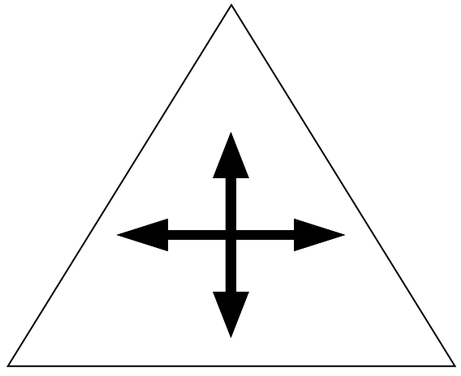
**Website-** www.minded.org.uk

# What is an Autistic Spectrum Condition?

Autistic Spectrum Condition (ASC) is a highly variable neurodevelopmental disorder affecting social communication and interaction *that impacts significantly on social, educational and occupational functioning*.

People with ASC have difficulty in three areas:

Talking, listening and communicating with others



Thinking and behaving using imagination and flexibility

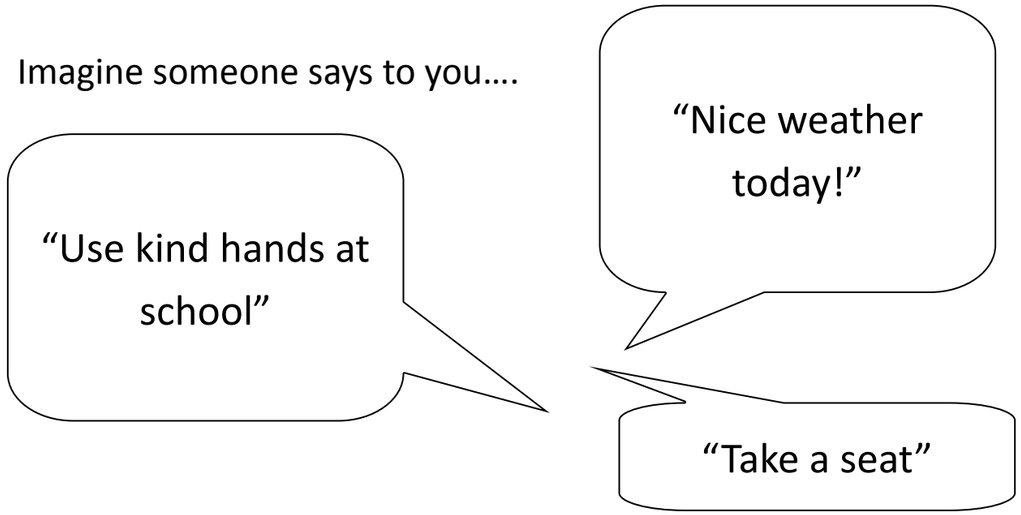
Getting on with people and making/maintaining relationships

Some people with ASC also experience sensory sensitivities

# Talking, Listening and Communicating

Communication is much more than just talking; it is a way people can express themselves, get their needs met and understand other people. This is made more difficult for someone with ASC (even those with an extensive vocabulary) as many of the things people say don't make sense!

Imagine someone says to you….




The common use of sarcasm, metaphors and colloquial sayings can be confusing for people with ASC as they can take things very literally.

*Why would someone say the weather is nice if it is raining?*

*Why is the doctor telling me to take a seat?*
*Where do they want me to take it?*

*Why does my teacher tell me to use kind hands? What are they?*

## Using Imagination and Flexible Thinking

- Children with ASC may find it difficult to be flexible in their thinking, which can cause misunderstandings, social difficulties and friendship breakdowns. Take time to talk to young people, possibly using social stories, to help them understand why their view might be different to other peoples'.
- For some children, the inclusion of a question mark on their visual timetable may help them to start to learn to tolerate some uncertainty and cope with unplanned events. Be sure to do this during a time of relative stability for the child.

- Keep changes factual, timely and where possible, provide an alternative time for the planned event to be rearranged and identify this on the visual timetable.
  For example, **"we cannot go swimming today, because the swimming pool is closed for repairs. We will go swimming on Saturday."**
- Where possible, provide warnings of change in classroom, teacher or lessons at school. If this in unavoidable, have an 'action plan' available to the child which details what is happening, what might be different and how they can cope. For example **"I am having a different teacher today. Her name is _____. I can ask her for help by _____".**
- Similarly, have a 'passport' for the child that can be provided to new members of staff that briefly details in what areas they struggle, and what strategies are in place to help them. This ensures that strategies are used consistently.
- Older children may need additional support in school during creative writing tasks or reading fictional stories, if this is an area of difficulty for them.

## Getting on with People

- Increase a child's opportunities to make friends by supporting them to access social activities. This could be after-school clubs, or small groups facilitated at school by an ELSA.
- Older children with ASC often find it easier to socialise over the internet. Encourage this, but ensure it is being done safely and under supervision. Practical advice and teaching activities on internet safety for ASC teenagers is available in the STAR SEN Toolkit, available from www.childnet.com/resources/star-toolkit
- Take time to talk through friendship disputes with a young person so that they can understand what has happened and start to problem solve how to resolve the issue.
- Educate those around young people with ASC. An increased understanding of ASC amongst relatives and peers can reduce arguments and disputes as people are more tolerant and understanding of how socialising might be hard for people with ASC. The National Autistic Society and Autism Hampshire have good resources for relatives, friends and partners regarding ASC.

Understanding what people mean can be made even more tricky when people's faces don't match what they are saying, for example when someone is crying but telling you that they are 'ok'.

And what about when people say things that aren't true? People with ASC can take things very literally, and may assume what you say is accurate. It can then be very upsetting when it turns out to be incorrect. Kind of like someone saying they will do something and then not doing it– annoying right?

**How can I help?**

- Say exactly what you mean.
- Try not to use metaphors or sarcasm
- Be honest when voicing your feelings.
- Use exaggerated facial expressions to help communicate emotions.
- Be prepared to repeat what you say, explaining in more detail.

**"I'll be back in one minute."**

People with ASC also find it hard to make themselves understood by others, which can cause them to not get the help they need or to shy away from talking to others all together.

# Strategies to support children with ASC

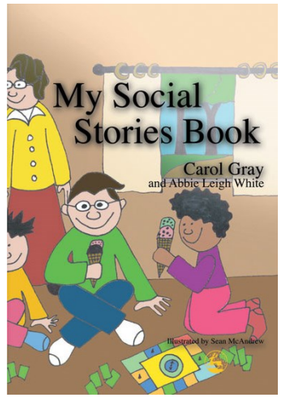
## If you think a strategy might be helpful– try it!

*You do not need to wait for a diagnosis of ASC to try out strategies. Strategies used with children with ASC; such as visual timetables, social stories and clear instructions, are helpful for many children even those without ASC.*

Throughout this booklet, we have suggested strategies you can use to help people with ASC with regards to some of the difficulties they experience as part of their diagnosis. Below we have briefly detailed some additional strategies that my be helpful...

### Talking, Listening and Communicating

- Provide other methods of communication other than verbal– picture cards, drawing, hand signals etc. At school, children of all ages can benefit from a card that they can show to staff to alert them that they are not coping and need to leave the room.
- Emotional Literacy Support at school can help children learn to identify how they are feeling and express this safely to others. All school will have an ESLA.
- Use social stories to teach children how to talk to and listen to others. The 'My Social Stories Book' by Carol Gray is a valuable resource with lots of social stories included. You can also easily create specific ones for children based on their individual difficulties.
- Praise good listening skills.



# Mental Health Difficulties in ASC

Around 65% of people with ASC also have a diagnosable mental health condition. Common comorbidities can include:

- Anxiety (in particular in social situations) at between 11-84%.
  (White, SW; Oswald, D; Ollendick, T; Scahill, L ; 2009)
- ADHD– *although prior to 2013 a diagnosis of ASC and ADHD was not permitted*.
- Obsessive Compulsive Disorder at around 30%. (Russell, et al; 2013)

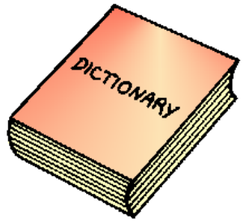
However, it can be difficult to diagnose these comorbid mental health conditions in ASC populations…

- It can be hard to diagnose ADHD alongside ASC due to the overlap of symptoms.
- Language and communication difficulties can make it tricky for people with ASC to verbally express their difficulties.
- People with ASC may express symptoms of social anxiety but this could actually be a reflection of their skill deficits in social interaction.
- A person with ASC may find it hard to recognise, understand and share their emotions with others, making it difficult for them to report feelings of low mood or anxiety.

## But….

There are some things about communication that people with ASC are very good at, such as:

Speaking clearly and directly




Usually telling the truth

Knowing lots of different words

Being accurate and factual in what they say

Sharing knowledge with others

# Getting on with people

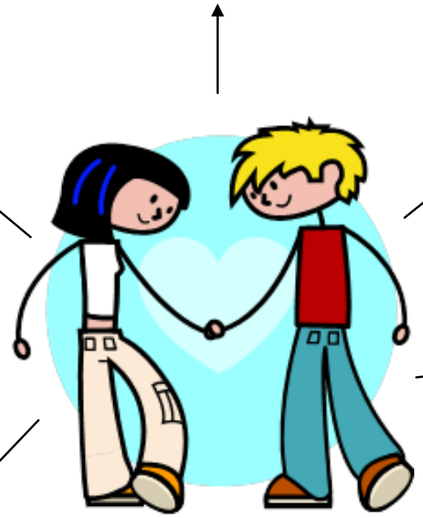
Making friends can be hard for people with ASC but this does not mean that cannot make friends at all.

It is a common misconception that people with ASC don't want friends but this is far from the truth .

Many desperately want to  socialise but just find it bit more difficult.

I often don't understand why or when people get angry. This makes it hard for me to know how to fix it.

How do I react to other people?



I don't know why people behave the way they do?

My interests aren't the same as other people's.

Sometimes I get overexcited when there are lots of people around and they get annoyed at me.

Sometimes people upset me but I cant explain to them why.

I prefer to be on my own. Doing things with other people is hard for me.

# What challenges might ASC assessments pose in CAMHS?

**Increased rate of referrals**

CAMHS are seeing an increase in both general referrals and ASC assessment referrals. This increase may be due to an increased awareness of ASC with communities as well as changes in commissioning which has meant that CAMHS now assess young people aged 5– 18 years.

**After care**

CAMHS are not commissioned to provide post-diagnostic support for children and young people with ASC, unless they have a comorbid mental health difficulty. For those who do require on-going CAMHS work, unfortunately the waiting lists are long and they require clinicians with skills in ASC.

# What challenges might ASC assessments pose in CAMHS?

**Long waiting lists and limited staffing/resources**
In recent years CAMHS have experienced cuts in funding, despite an increase in referral rates. This is impacting on the number of staff in teams and how quickly they can see young people for assessments.

**Differential diagnoses?**
It can be difficult to pick out whether symptoms are suggestive of ASC or whether they are better explained by other difficulties such as ADHD, Learning Disabilities/Difficulties, Attachment difficulties, anxiety or neurological conditions.

**Family investment in a diagnosis of ASC**
Families can come to CAMHS very invested in a diagnosis of ASC. Occasionally, when a child does not meet the diagnostic criteria at the time of assessment, families become distressed, request second opinions and sometimes make complaints. This adds additional waiting times for assessments.

**Clinician speciality in ASC**
Not everyone in CAMHS is a specialist in ASC which can cause some clinicians to feel less confident to conduct an initial ASC assessment. Teams have clinicians who are specifically trained to deliver specialist ASC assessments, as well as to support other clinicians to feel confident to be mindful of ASC in their work.

**Being compliant with NICE Guidelines**
CAMHS works hard to follow NICE guidelines with regards to ASC assessments, but teams are restricted by a lack of resources and staff. The pressure to deliver assessments in a timely manner also poses a risk of reducing quality in assessments.

It is important to remember that children with ASC have a number of fantastic qualities that make them good friends.

They take social rules seriously.

They are very fair and equal in their relationships.

They are loyal.

They like people to follow the rules so they encourage good behaviour.

**How can I help?**

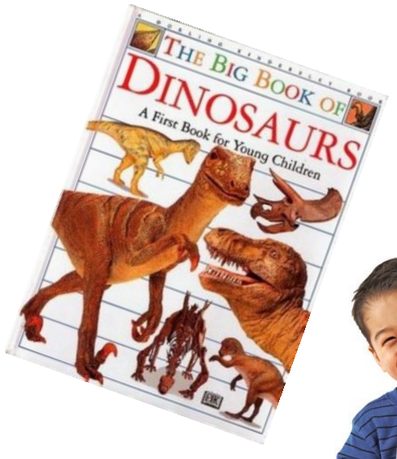
- Use social stories to teach children how to interact with others.
- Facilitate group activities and model appropriate responses.
- Try and encourage children to play together using their shared interests.
- Spend some time talking with older children about what relationships are and what they should and shouldn't be, especially with those who are socially vulnerable.
- Look out for bullying. Many young people with ASC are bullied by their peers.

# Using Imagination and Flexible Thinking

Imagination is much more than just a way children play when they are younger. We use imagination and our ability to think and behave flexibly every day. For someone with ASC, the inability to do this can make things difficult and impact on their ability to communicate and develop relationships.

Many people may first notice children with ASC as having a lack of imagination when they observe their play:-

- Lining up toys.
- Playing games or with toys repetitively .
- Not playing role play games or pretend play.
- Preferring to read factual books rather then fiction.
- Being unable to pretend that an item is something else (such as a shoe being a plane)- we call this symbolic play.



# CAMHS Referral for an ASC Assessment

ASC assessments for children aged 5– 18 years old are currently undertaken in CAMHS. If you are concerned that a young person in your care may have an ASC and feel that they should be assessed, you will need to make a referral to your local CAMHS team. This can be done via the child's GP, school or by parental referral.

Before sending a referral to CAMHS, try to collect as much information as possible. The more information CAMHS receives regarding the child and their current difficulties, the better. Brief referrals with limited information often require clinicians to gather more information, which can delay the referral being processed.

**Identify signs and symptoms of ASC**

*You should have been provided with a copy of the NICE guidelines for recognising ASC in both primary and secondary aged children. Further copies can be obtained for the NICE website.*

**Use the CAMHS processionals helpline if you wish to discuss further**

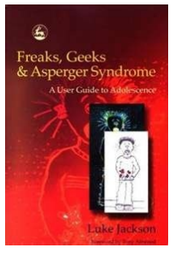
Compile all information into a referral letter, highlighting the current difficulties the child is having and what ASC-specific signs and symptoms they are presenting with.
Examples of these traits both at home and at school would also provide extra information regarding the pervasiveness of their difficulties.

Also include– what strategies have been tried/ are in place currently
- which services have been or are currently involved with the child

# ASC in the Public Eye

There are many famous people who have a diagnosis, or have traits associated with, ASC. Some of these individuals have become well-known specifically due to their diagnosis and their advocating awareness of the condition for example:

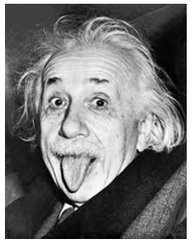
Temple Grandin is a professor of animal science, author and ASC activist. She has been influential in raising ASC awareness and has even been subject of a film.




Luke Jackson wrote his book as a teenager as a guide for other people diagnosed with ASC. Luke is now an adult and is running his own ASC consultancy firm.

Rosie King is an ambassador for the National Autistic Society. She has given talks and written articles about what it is like having ASC.

Others are known for their intelligence or for their specific skills in areas such as sport, music or art. You may not even have known they had ASC!



Albert Einstein had difficulty with social interactions and alt-hough he was very intelligent, he reportedly found it difficult to learn in school.

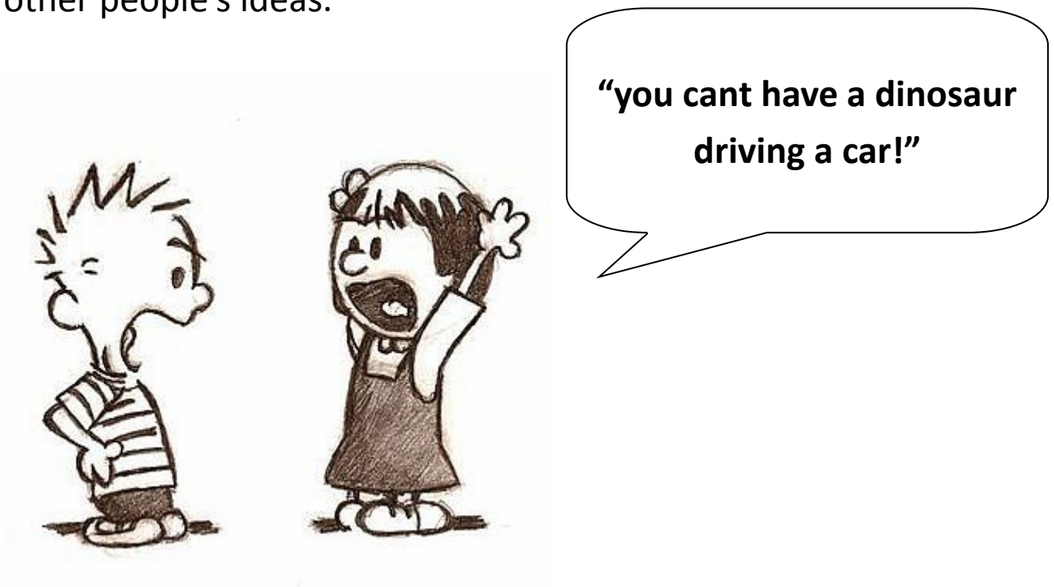
Actress, Daryl Hannah, famous for her roles in Kill Bill, Blade Runner and Splash, was diagnosed with ASC as a child.

James Hobley is a dancer and was a finalist on Britain Got Talent in 2011. He has since gone on to be awarded a place at the English National Ballet School.

Jessica-Jane Applegate MBE is a Paralympic swimmer, diagnosed with ASC, who won gold in the 2012 Summer Paralympics.

Adam Young AKA Owl City reports that he has Asperger's Syndrome (now re-ferred to as ASC).

As children become older, their inability to think imaginatively or flexibly may become apparent when they are asked to create stories in English class or when required to be accommodating to other people's ideas.




## However…

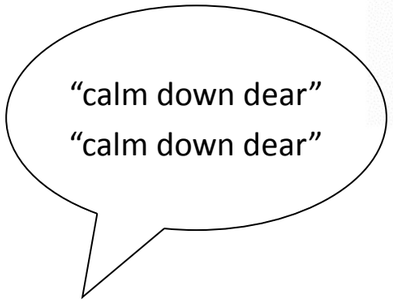
This is not to say that if someone has a good imagination, they cannot have ASC. Many girls with ASC actually have very good imaginations and often use this to escape into a comfortable and safe place when things are difficult.
Some girls (and boys) on the autistic spectrum can create detailed fantasy stories or concoct very realistic accounts of events that have never actually occurred!

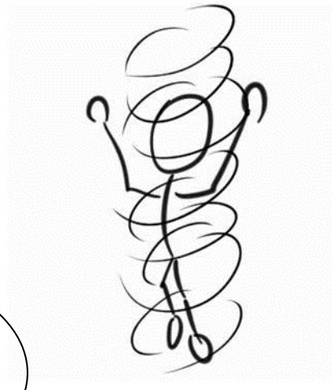
## What about flexible BEHAVIOUR?

To behave flexibly is the ability to do things differently occasionally or to be able to accommodate changes in routine, environment and even change they way he say or do things.

Examples of a child with ASC struggling to behave flexibly include:-

- Becoming distressed when a routine changes.
- Being distressed when a classroom or teacher is different.
- Needing to drink from the same cup at home or sit in the same seat at the dining table.
- Wanting to do the same thing over and over again– such as spinning in circles or flapping their hands.
- Needing to repeat certain words or phrases .



# Celebrating Autistic Spectrum Conditions!

Autistic Spectrum Conditions are often deemed as being an unfortunate condition to have that involves a lifetime of not understanding the world and struggling to fit in.

People very rarely take time to consider how wonderful ASC is and how perhaps, people without ASC are actually impaired…

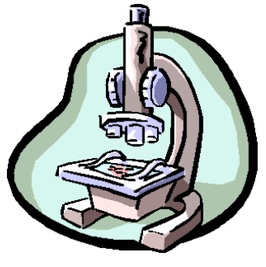
**Definition of Neuro-typical (non-ASC):**

***"Neurotypical individuals almost invariably show a triad of impairments, consisting of inability to think independently of the social group, marked impairment in the ability to think logically or critically, and inability to form special interests (other than in social activity)."***

ASC can create unique and fascinating minds. People with ASC have brains that are 'wired' differently to others' which can give them skills others may not have such as an eye for detail, good memory skills, retention of facts and the ability to see the world from a different perspective.

People with ASC are likely to be actively involved in the future of technology, computers, academics, research, design, construction and invention (just to name a few!).

So really, the world would be lost without people on the Autistic Spectrum!



**How can I help?**

- Ask the young person how they experience the world.
  - what do they find hard it to look at or hear?
  - what catches their eye in a room?
  - are there any smells, tastes, textures you don't like?
- Then adapt the environment based on their needs to help them.

- Try to keep noise to a minimum where possible but also provide a quiet space for people to go if being in a noisy room become too much. Be mindful of subtle noises such as people eating, tapping or the sound of electric items (laptops, electric lights).

- Be aware of how visually over stimulating and distracting many places are, such as classrooms. Where possible, try not to overfill walls with lots of different colours, patterns and pictures or have a 'cool down' space available with neutral colours that is less stimulating.

- Some people may benefit from having strip lights turned off.

- Try not to wear strong scented perfume or aftershave. Also be mindful when cooking or when out in the community that certain smells may be experienced differently by people with ASC.

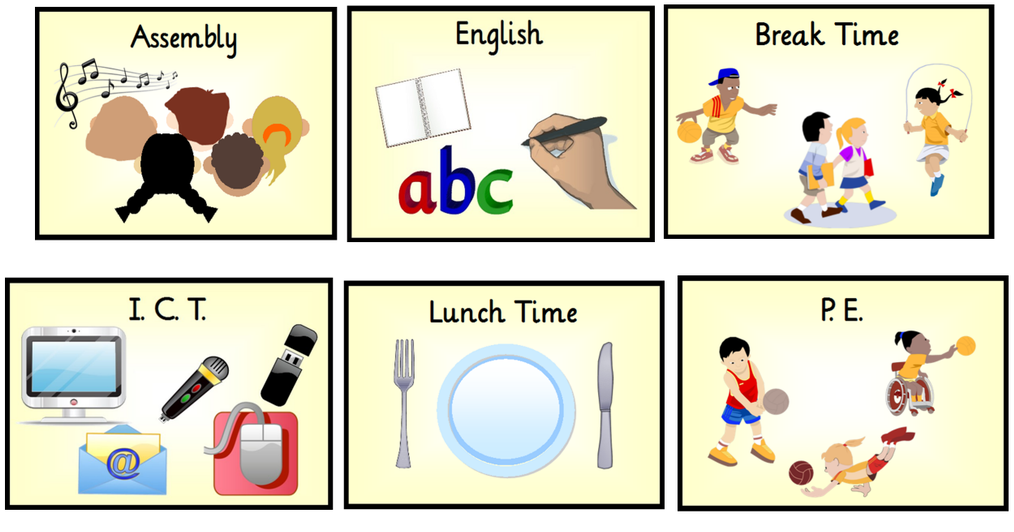
- Be mindful that not everyone with ASC will want to be hugged, even when they are upset or distressed.

- Try to remove things that cause discomfort, e.g. take labels out of clothing buy loose clothes if the individual finds tight clothing uncomfortable.

- Be aware that some people with ASC may need encouragement to consider the weather and support to dress accordingly.

**How can I help?**

- A child or young person with ASC should not be forced to play imaginatively. It is a skill that does not significantly impact their functioning, and therefor they should be allowed to play in a way that they find enjoyable and comforting.
- Use visual time tables, diary planners and calendars so that young people know what is going to be happening during the day/week.
- Establish "if I can't" rules to help manage incidences when the young person cannot do or use items the way they usually do, e.g. "If I can't wear my red jumper today, I can wear my blue one instead."
- Do NOT discourage stereotyped or repetitive ritualistic behaviours such as spinning, hand flapping, rocking or finger flicking. Children should be given appropriate time and space to engage in these behaviours, perhaps in their room after school or in a quiet space during break time,  as it helps them regulate themselves.
- Be patient when a young person is repeating words or phrases. They may be doing it to help process what you have said, or the sound might be helping them be calm.



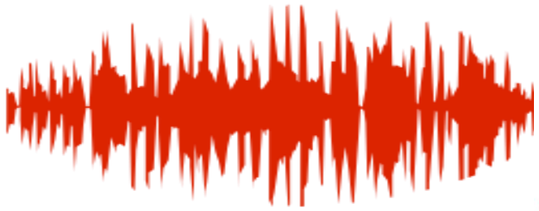
# Sensory Sensitivities

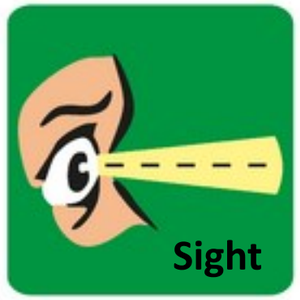
Some people on the autistic spectrum are highly sensitive to sensory stimuli around them, which can cause a great deal of distress.

*Imagine if you heard noises ten times louder than everyone else, or if wearing certain types of clothing caused you physical pain?*

*Might make every day life a bit unbearable sometimes?*

- Crowded places like supermarkets or parties.
- Unexpected sounds such as fireworks or sirens.
- The sound of hand driers, hair driers or vacuums.
- Babies crying or the sound of other people eating.
- People shouting, music lessons or school assemblies.

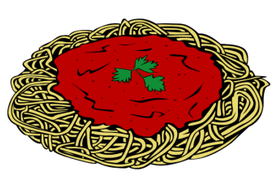





- Being overwhelmed by lots of colours and pictures in a room.
- Distracted by patterns on walls or upholstery.
- Seeing small details in images, which can be distracting!
- Sensitive to light.

- Smelling food to a much stronger intensity.
- Being more aware of people's body odour or perfume.
- Complaining that the smell of food cooking is horrible.
- Smelling smells in the environment that others cannot smell.

- Strong tasting foods such as curry or sweets.
- The texture of foods like juice or sauces with bits in, lumpy mashed potato or chewy meats.
- Foods that are mixed together, like a stew or a pasta.
- Tasting things differently to other people.



- Not liking hugs or being touched by others.
- Finding tight clothing, seams or labels uncomfortable.
- Disliking the feel of sitting on certain chairs, sofas or the floor.
- Being over or under sensitive to heat or the cold.
- Resistant to wearing coats, shoes, hats, gloves etc.