

ASC POST DIAGNOSIS SUPPORT

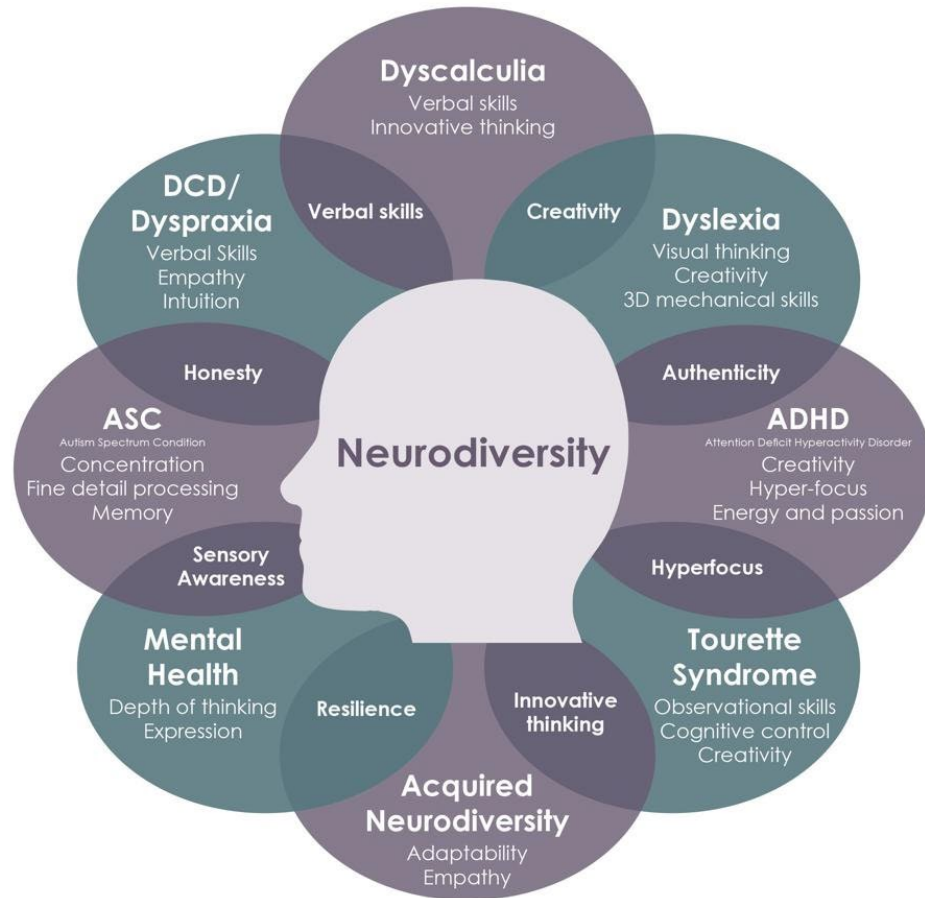
KAREN UPTON RESOURCE FOR PARENTS AND
CARERS 2022 September VERSION

SOME DEFINITIONS OF TERMS USED IN
NEURO-DEVELOPMENTAL CONDITIONS SUCH
AS “AUTISTIC SPECTRUM CONDITION”

FORM FILLING/INFORMATION REQUESTS

- AUTISM/ASD IS CLASSIFIED AS A DISABILITY
- AUTISM IS **NOT** A LEARNING DISABILITY IN UK DEFINITIONS
- AUTISM IS A LEARNING DIFFICULTY IN THE UK
- IF YOU READ ANYTHING WRITTEN IN THE USA, THEY DO CLASSIFY IT AS A LEARNING DISABILITY, WHICH CAN CAUSE CONFUSION.
- LEARNING DISABILITY = INTELLECTUAL IMPAIREMENT = GLOBAL DELAY WHICH PERSISTS INTO ADULthood.

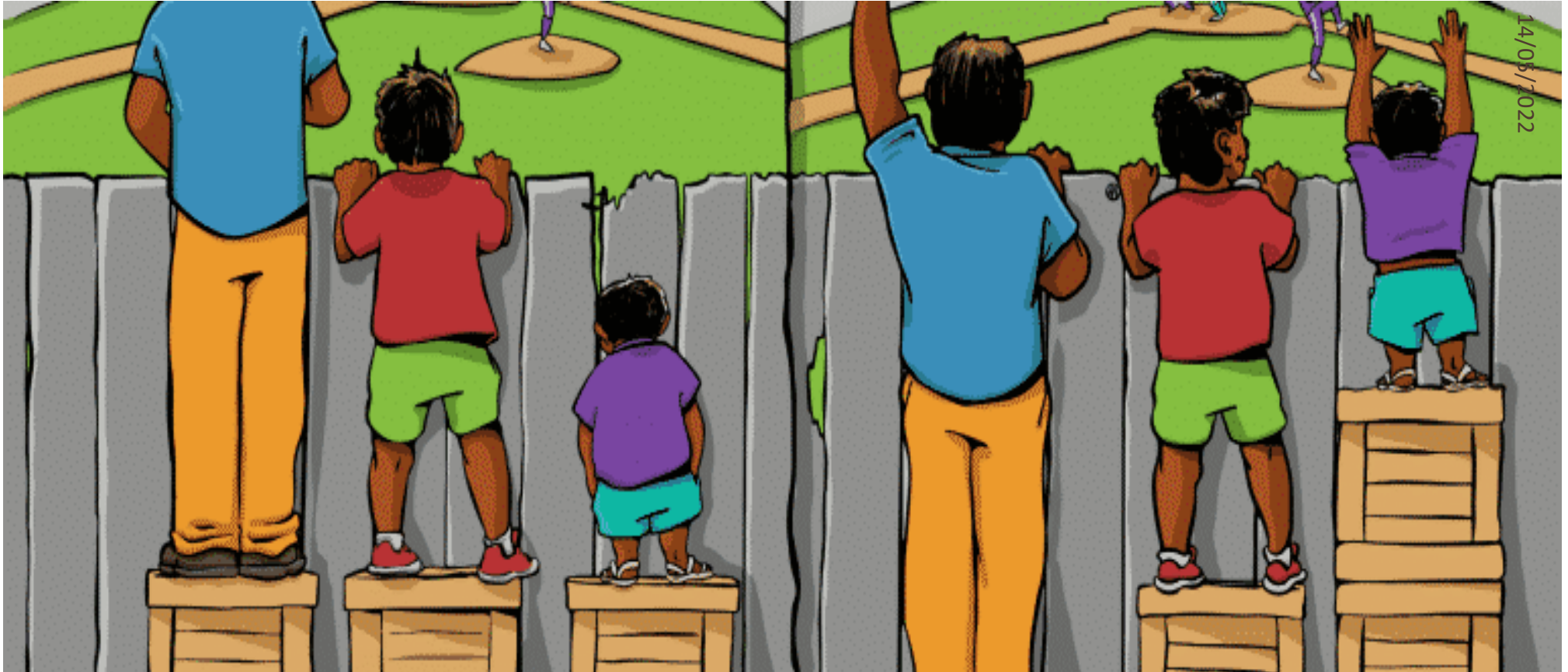
NEURODIVERSITY OR NEURODIVERGENCE



Created by Dr Nancy Doyle based on the work of Mary Colley

- DIFFERENTLY WIRED NERVOUS SYSTEM?
- DIFFERENCES IN ABILITY – STRENGTHS AND WEAKNESSES – AND NEEDS
- SOME CONDITIONS MAY BE MORE, OR LESS, ALIKE AND MAY CO-EXIST

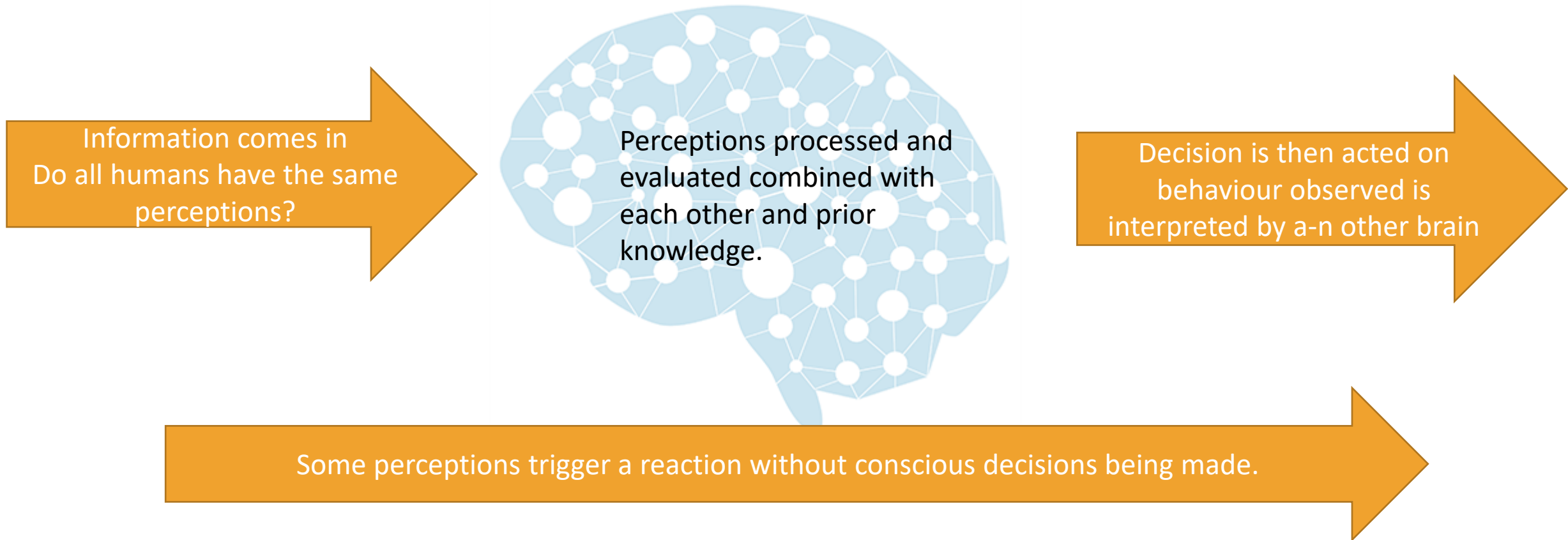
EQUALITY OR EQUITY? Not all people need the same adjustments.



[Autism: what's more important equality or equity? \(sidebysidetherapy.ca\)](https://sidebysidetherapy.ca)

Slides copied from other sources included with some original
slides from KEU

If an object is blue we can agree it is blue, but we cannot know what blue looks like to anyone else. We tend to assume that everyone has the same experience.



Why?

- Do different people choose different food in a restaurant?
- Do some people have a favourite colour?
- Do we make different choices of perfumes?
- Do we make different choices of music to listen too?
- Do some people like the feel of fur and others hate it?
- Do some people get sea sick and others not?
- Do some people tolerate pain better than others?

WHAT DOES AUTISM OR ASD MEAN?

Definition: (Medical Model only considers the deficiencies)

This is a life-long condition characterized by:

- “Persistent difficulties with social communication and social interaction”
- “Restricted and repetitive patterns of behaviour, activities or interests”
(this includes sensory behaviour), present since early childhood,
- to the extent that these “limit and impair everyday functioning”. (NAS 2020)[DISABILITY](#)

A diagnosis is made by an “expert” specialist who says we have deficiencies sufficiently to gain the label. This is needed in our society so that laws such as the “Equalities Act” and the “Care Act” and the Children Act 1989 are considered relevant to our needs. It does not say exactly what needs to be done to aid the person. The way in which it affects the person will develop and change with age and experience.

“If you know one autistic person, you know one autistic person”

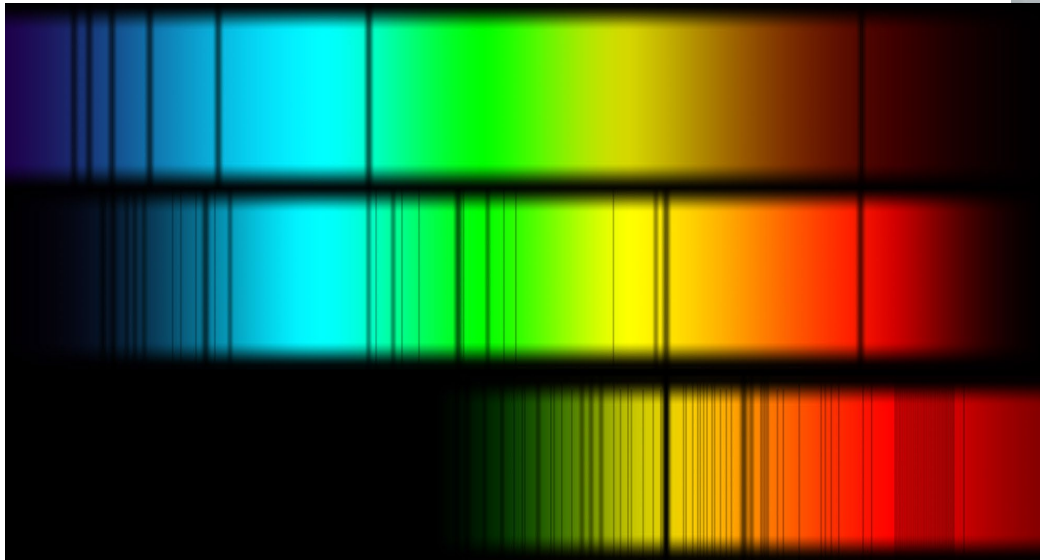
SPIKEY PROFILE OF ABILITIES

- None of us are as able in all fields.
- Autistic people tend to have more extreme variability between different skills
- Just because they may be gifted in their special subject, it cannot be assumed they will be able to work out how to tie shoelaces, or have a conversation with a stranger
- Most autistic children are NOT GIFTED, they are NORMAL but different.
- They also tend to have several more extreme sensory sensitivities than is usual.
- The behaviours they show are ways that they have developed to cope in a neurotypical world. They are not always useful or considered appropriate. Some things which work when they are 3 no longer give good results as a teenager.



A SPECTRUM CONDITION ?

Absorption spectra of 3 different stars, giving information about the differences between them. We can consider the different colours to be different neurological functions. Each strip representing a different person, with different level and ability in different skills





ASD IS A SYNDROME

- DEFINITION: A MEDICAL TERM for a group of symptoms or characteristics which are commonly seen together.
- THE NEURODIVERSE CONDITIONS are all syndromes which have been defined and redefined as we understand them more.
- THERE IS GREAT OVERLAP BETWEEN THE DIFFERENT CONDITIONS.
- THE SEVERITY OF THE DISABILITY DUE TO ANY CONDITION WILL VARY FROM PERSON TO PERSON. Some may be less severely disabled because they have greater ability to overcome the problems associated with their differences and may have greater abilities because of their differences. if we can make reasonable adjustments these people will not be disabled.
- To understand the evolution of definition and mis definition of autism, ASD, Asperger's syndrome see the book <https://www.bookdepository.com/NeuroTribes-Steve-Silberman/9781760113643>



WHO HAS A VISIBLE DISABILITY?

THE SOCIAL MODEL OF DISABILITY

- THERE ARE MANY VIEWS OF WHAT DISABILITY MEANS. If we have no personal experience of disability or autism, we will have a view, absorbing them from what we hear from family and friends, see in the media, or have been taught elsewhere.
- THE MEDICAL MODEL considers and defines what is wrong with some one/ So you went to a specialist to get a diagnosis for your child.
- THE SOCIAL MODEL SAYS THAT DISABILITY IS A SOCIAL RIGHTS ISSUE and involves disabled people being excluded from taking part in **NORMAL EVERYDAY ACTIVITIES**. It gives responsibility to the able to make reasonable adjustments to places and activities so that the less able are included. This is the root of why disability is one characteristic, protected under the Equalities Act. [MODELS OF DISABILITY](#)

COMMON CHALLENGES FOR AUTISTIC PEOPLE

Additional
diagnoses, ADHD
etc

Sleep (or lack of
it)

Masking WHICH OF THESE
TWO PORCUPINES IS LESS SPIKEY?

Tantrums and melt
downs

MELTDOWN OR TANTRUM?

SENSORY ISSUES
STATISTICS PRESENTED AT AN
OCCUPATIONAL THERAPISTS
CONFER...

School/ social

food

Toilet/Bathroom
problems

Stimming
STIMMING

COMMON CHALLENGES FOR FAMILIES

The system

Sleep (or lack of
it)

Mental health
support

Communication
and
understanding

PDA or extreme demand avoidance
syndrome COMMON CHALLENG...

Behaviour of the
person

CHALLENGING BEHAVIOUR

Isolation

Advocacy at
school or with
professionals

Keeping up with
development of
the child.

Acceptance

EXPLAINING AUTISM

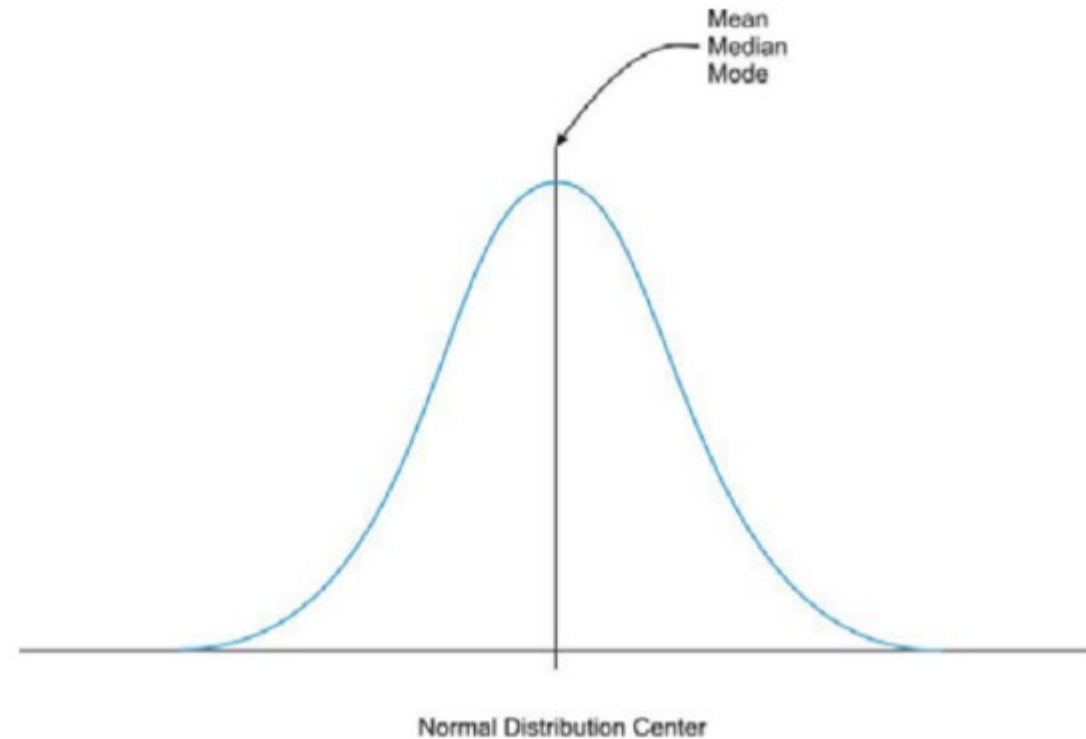
STATISTICS PRESENTED AT AN OCCUPATIONAL THERAPISTS CONFERENCE NOVEMBER 2021

[Approaches to Sensory Support Webinar 30/11/2021 - YouTube](#)

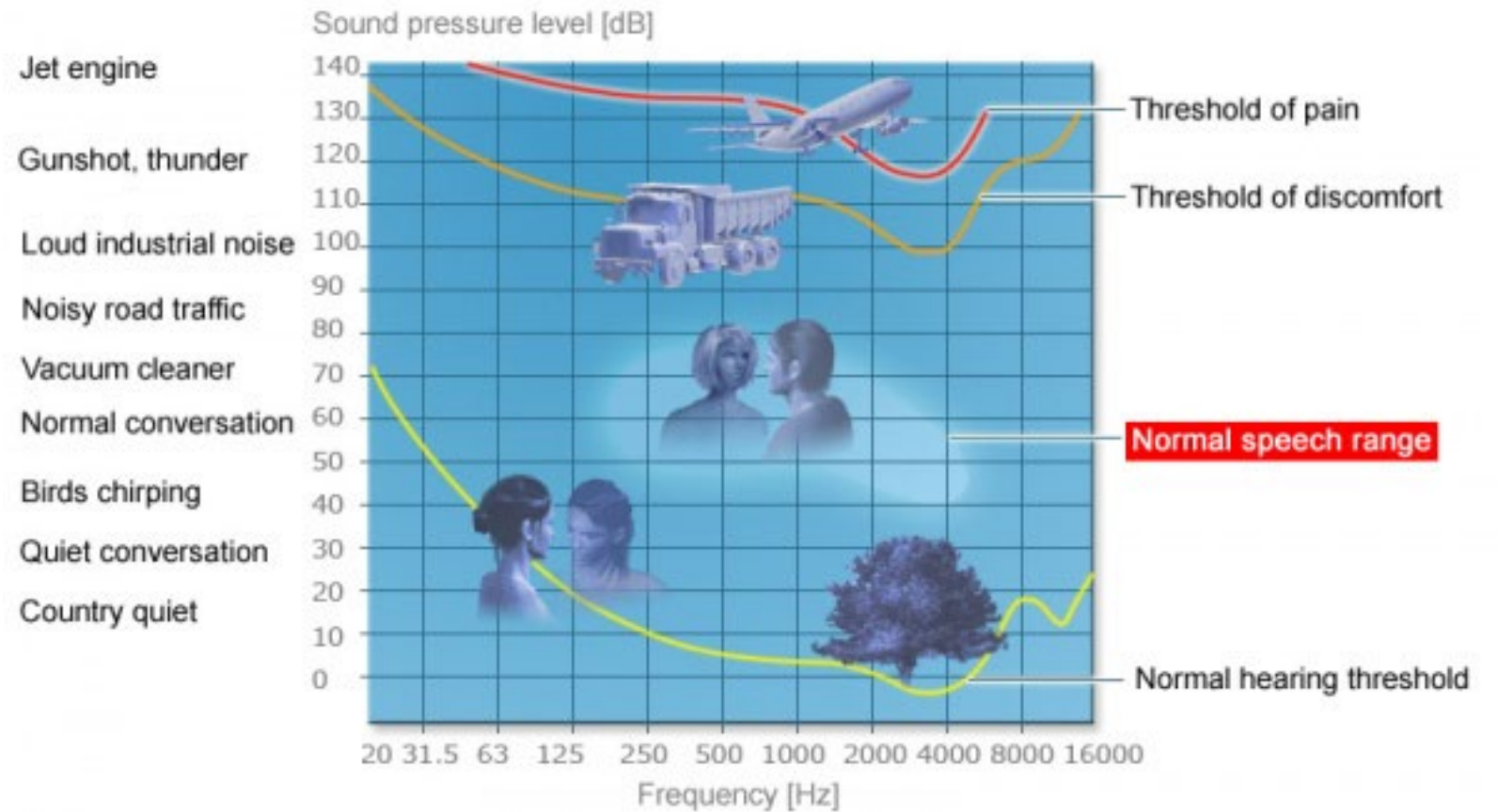
- 1 IN 7 PEOPLE ARE NEURODIVERGENT ESTIMATED
- Up to 96% of autistic people and 40% of children with adhd have sensory processing differences. The needs are not diagnosis dependent.
- NOT all need an occupational therapy assessment and with reasonable adjustments many will manage well.
- Sensory processing plays a core role in the development of
 - **motor skills,**
 - **emotional regulation,**
 - **sleep**
 - **learning.**
 - **I would add digestive problems to that list.**
- There is an increasing body of evidence that differences in sensory processing cause some of the core features of autism.
- More information about sensory processing. [Sensory Processing – Humber Sensory Processing Hub](#)

GRAPH TO SHOW DISTRIBUTION OF ANY CHARACTERISTIC WITHIN A POPULATION.

- Closer to the middle of the range the more typical and the larger the number of people with that characteristic.(consider measuring height)
- In society the further from the middle the less typical the person is.
- The range of sensory processing variation from
 - undersensitive (hyposensitive) to
 - over sensitive (hypersensitive)

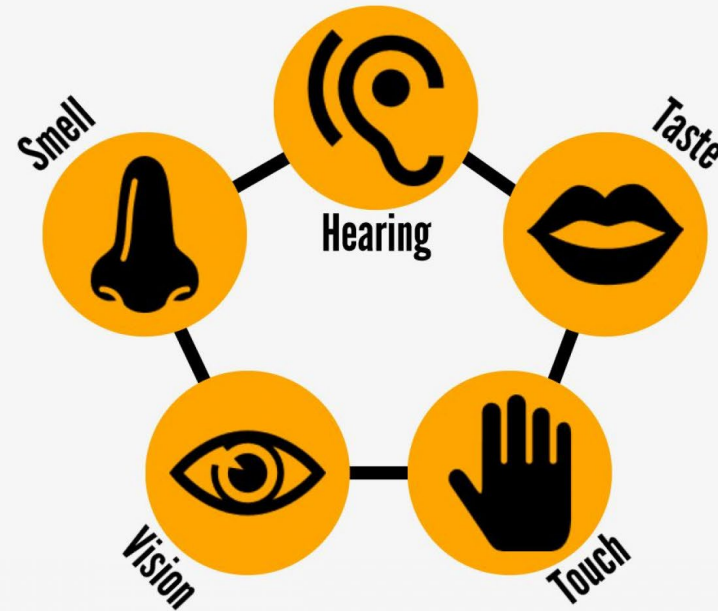


WHAT IS NORMAL SENSORY SENSITIVITY/ PROCESSING?



Sensory System

Commonly recognized sensory systems are those for:



Definitions

Hearing

The faculty of perceiving sounds.

Taste

The sensation of flavour perceived in the mouth and throat on contact with a substance.

Touch

Come into or be in contact with.

Vision

The faculty or state of being able to see.

Smell

The faculty or power of perceiving odours or scents

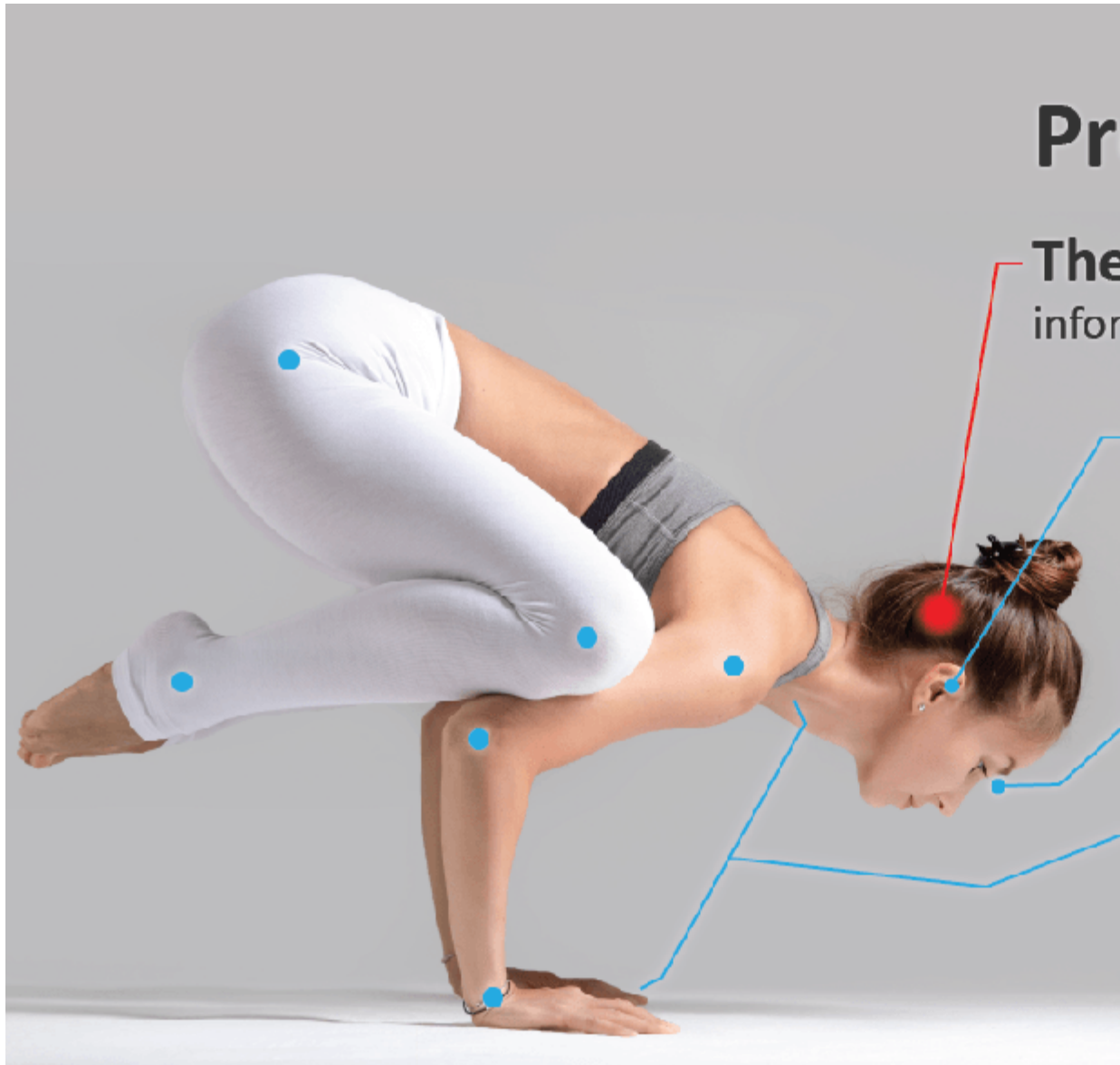
Proprioception

The Brain receives and interprets information from multiple inputs:

Vestibular organs in the inner ear send information about rotation, acceleration, and position.

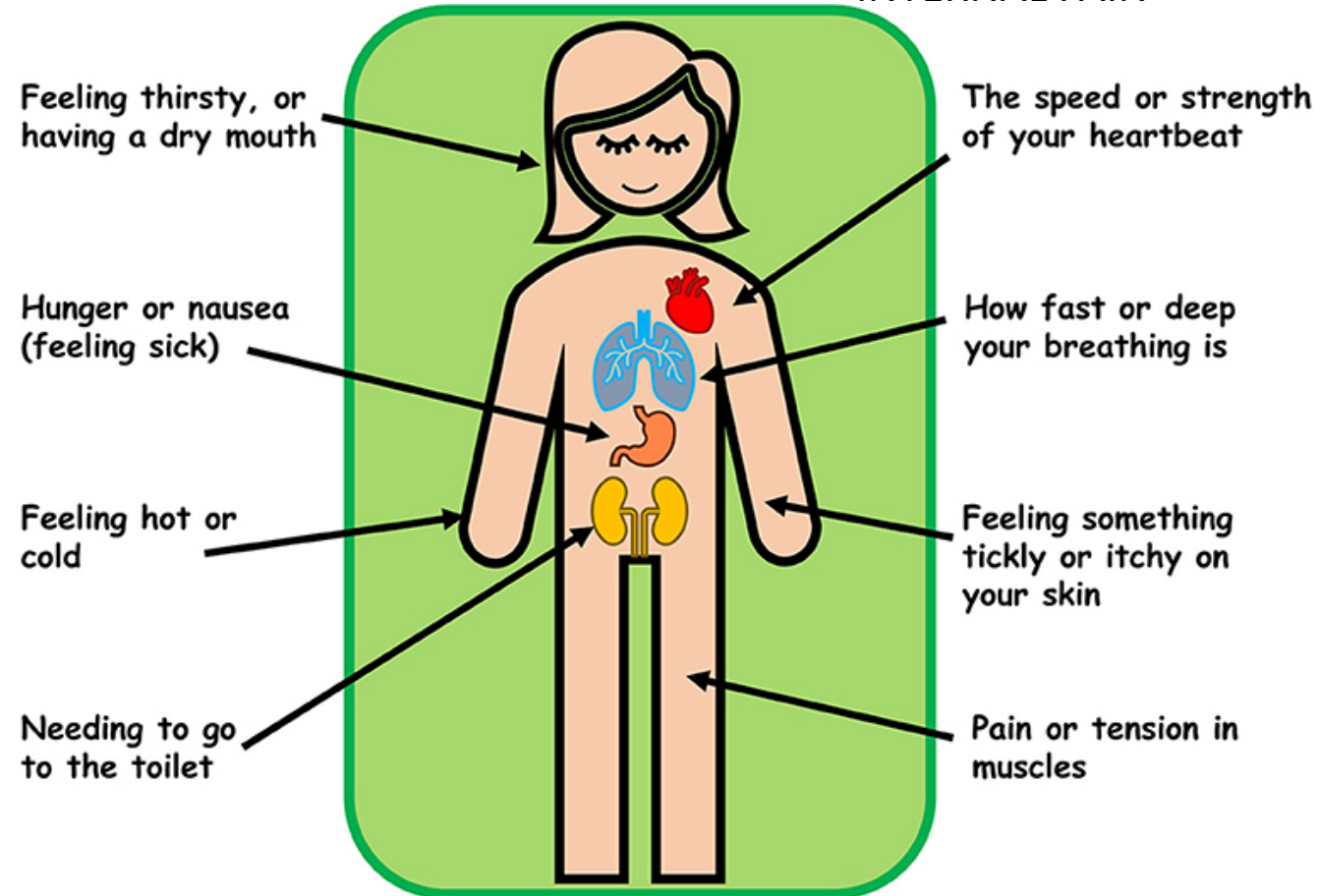
Eyes send visual information.

Stretch receptors in skin, muscles & joints send information about the position of body parts.



INTEROCEPTION

DON'T FORGET
EMOTIONS and
INTERNAL PAIN



Sensory Processing Red Flag Behaviors Checklist

THE AUDITORY SYSTEM

- ☐ Exhibits extreme reactions (crying, screaming, running away) or significant difficulty with tolerating sudden noises, specific noises, crowds, and/or loud noises
- ☐ Startles easily and becomes agitated in noisy environments
- ☐ Appears distracted by all sounds
- ☐ Covers ears even at the anticipation of a sound or in uncertain/unfamiliar environments
- ☐ Has difficulty responding to and following directions presented verbally
- ☐ Makes constant noises (singing, humming, clicking)
- ☐ Fails to respond when name is called
- ☐ Tends to use a loud speaking voice

THE ORAL SENSORY & OLFACTORY SYSTEMS

- ☐ Seems very reluctant to try new foods or is known as an extremely picky eater
- ☐ Exhibits extreme resistance to oral sensory experiences like brushing teeth
- ☐ Refuses to use utensils to eat
- ☐ Chokes or gags while eating or brushing teeth
- ☐ Seems to be constantly biting, chewing on, or mouthing hands, clothing, fingers, toys, and other objects
- ☐ Bites others
- ☐ Constantly makes mouth noises, such as clicking, buzzing, and/or humming
- ☐ Stuffs mouth with food at mealtimes
- ☐ Has difficulty with chewing or drinking from a cup or straw
- ☐ Displays constant movements of the mouth, such as moving tongue, tapping teeth, and/or rubbing lips
- ☐ Has strong aversions to certain smells (food or non-food)
- ☐ Seeks out specific smells regardless of safety (food or non-food)
- ☐ Frequently smells non-food objects

THE PROPRIOCEPTIVE SYSTEM

- ☐ Colors/writes with heavy pressure or not enough pressure
- ☐ Pushes others and/or plays aggressively
- ☐ Does everything with 100% force, not grading the force of movements adequately
- ☐ Crashes/falls on the floor constantly throughout the day
- ☐ Has difficulty with body awareness, such as running into objects or others
- ☐ Appears tired or sluggish, such as slumping and leaning



How Your Child's Sensory Processing Issues May Change Over Time

Kids don't outgrow sensory processing issues. But the signs change as kids get older. Here's what you might see.



Baby

- Feels limp or stiff when held
- Doesn't want to be cuddled
- Has problems eating or sleeping
- Can't calm self; is extremely fussy
- Constantly needs to touch people or objects

Grade-schooler

- May play too rough with others
- Appears awkward in social settings
- Has trouble with writing utensils, buttons, zippers, etc.
- Has a hard time making transitions between places or activities

High-schooler

- Feels anxious or depressed in social settings
- Is resistant to changes in routine or trying new things
- Has trouble staying focused
- Is slow to complete tasks
- Has difficulty understanding and responding to physical touch, which can cause trouble with dating

Preschooler

- Is fussy about how clothes and shoes feel
- Constantly moves around; can't seem to get comfortable
- Has frequent temper tantrums
- Is oversensitive to smells, lights and noise
- Finds the playground overwhelming

Middle-schooler

- Is afraid to try new things
- Acts impulsively
- Doesn't finish tasks; is easily distracted and fidgety
- Struggles to understand personal space
- Has clumsy, uncoordinated movements; has trouble playing sports

Understood

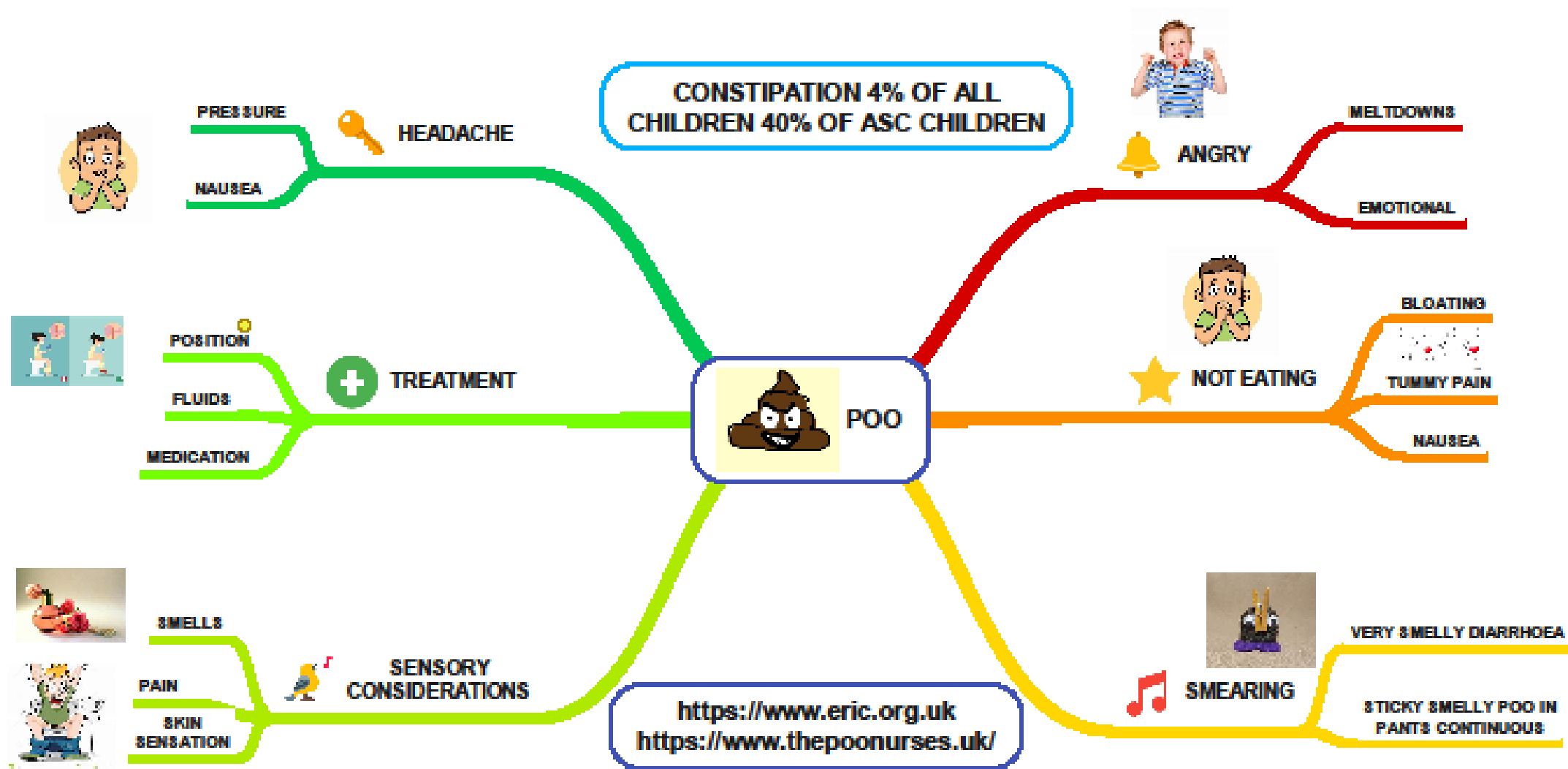
for learning & attention issues

For more tips and resources, go to
understood.org

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Develop Interoceptive awareness

- Good video
- <https://youtu.be/To39nUkk2IM>



BACK COMMON CHALLENGES FOR AUTISTIC PEOPLE .

CHALLENGING BEHAVIOUR

- Many of you will have been referred to the paediatrician because your child's behaviour has been considered challenging.
- Can be seen as children and young people expressing distress when they are not able to do so in words.
- Remember that challenging behaviour is not a pleasurable activity for your child (usually)
- Do we know what functional needs and/or performance difficulties might be contributing to their distress?

MELTDOWN OR TANTRUM?

- **MELTDOWN**

- INVOLUNTARY
- EMBARRASSING
- DUE TO SENSORY AND/OR SOCIAL OVERLOAD
- IS LIKE A STORM AND HAS TO RUN ITS COURSE
- USUALLY LEAVES THE CHILD EXHAUSTED

- **TANTRUM**

- VOLUNTARY
- THERE IS A GOAL FOR THE BEHAVIOUR
- CEASES AS SOON AS THE CHILD HAS GOT THEIR OWN WAY
- CHILD REMAINS ACTIVE AND ENGAGED AFTERWARDS.

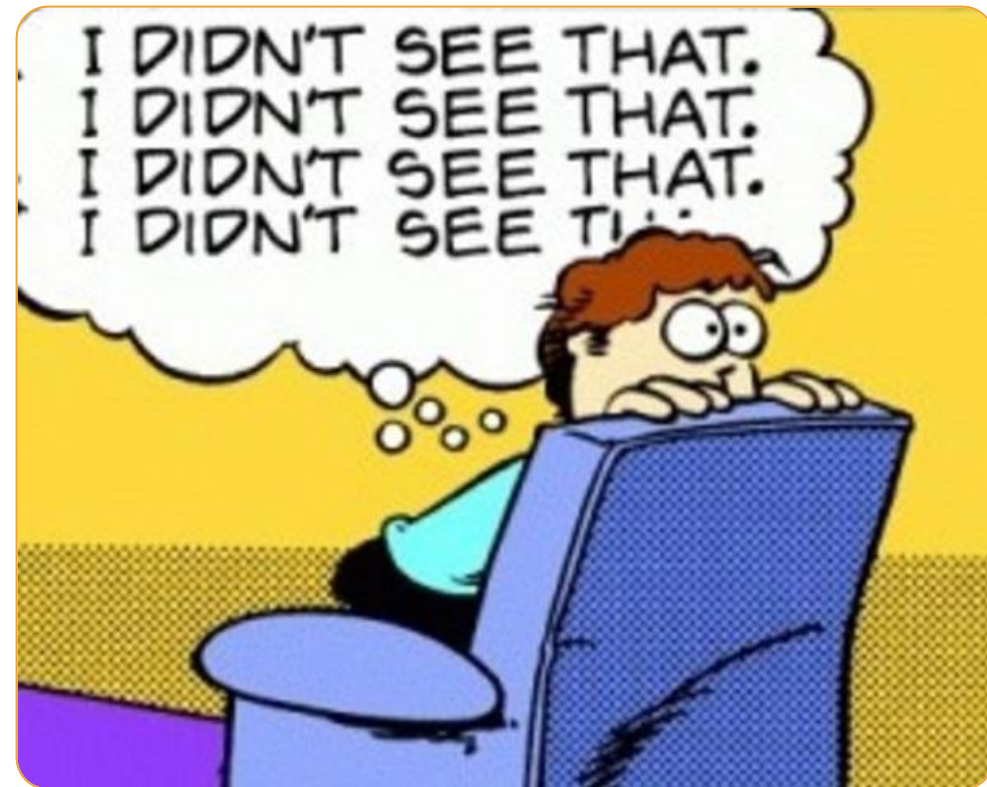
Is there a physical cause of distress? (Related to Interoception?)

ASD IS PRIMARILY A COMMUNICATION PROBLEM INDEPENDENT OF INTELLECTUAL ABILITY

- They may not be able to define, in words, what is wrong, even if it is just that they are hungry (decreased sensitivity in interoception?)
- They may have been told not to be silly when complaining in the past. (anxiety preventing speech or possibly a feeling that they are wrong to complain)
- Their threshold for pain and discomfort may be very different from yours.

Too little information, hyposensitivity. When they become aware, it is a sudden surprise or comes too late.

- CLASSICALLY TO WHAT IS GOING INSIDE THEMSELVES
 - HUNGER/ FULLNESS
 - NEED TO PASS URINE OR OPEN BOWELS
 - COLD/ HEAT
 - PAIN
 - OWN EMOTIONS (ALEXITHYMIA)
- FACIAL EXPRESSION
- OTHER PEOPLE'S POINT OF VIEW



TOO MUCH INFORMATION.

LEADS TO MELTDOWNS, SHUTDOWNS and in the longer term AVOIDANCE

TOO MUCH SOCIAL INTERACTION

Too Many People

Too Long With People

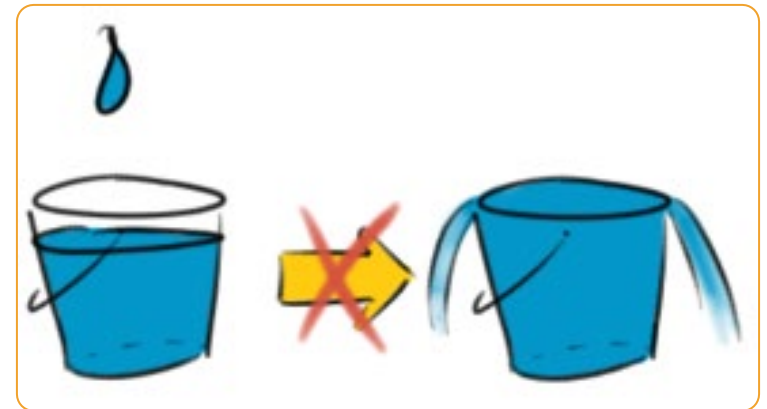
TOO MUCH SENSORY INFORMATION from the environment, light, sound, smells, touch.

TOO MUCH CHANGE Transitions from awake to sleep, from one lesson to another, or too many lessons in a short period of time with no processing time in between, supply teacher, school day to weekend or holiday.

UNCERTAINTY means too many potential choices to decide between.

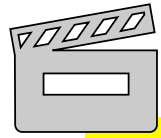
THE BUCKET HAS A SMALLER CAPACITY THAN usually EXPECTED.

THE AMOUNT REMAINING WILL VARY DEPENDING ON BACKGROUND ANXIETY and How much it was filled by previous events.



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Different emotions trigger the same surge of adrenaline, and all are perceived as **danger**. All add information so risk overload (TOO MUCH INFORMATION)



EMOTION

- SURPRISE(MAY INCLUDE ANY UNEXPECTED EVENT)
- EXCITEMENT
- IRRITATION
- ANXIETY
- FEAR
- PANIC



ADRENALINE

- RAISED HEART RATE
- RAISED BREATH RATE
- SWEAT
- DRY MOUTH
- NAUSEA
- BOWELS



DIFFICULT BEHAVIOUR?

- PANIC ATTACK
- MELT DOWN
- SHUTDOWN
- AVOIDANCE
- LOSS OF RATIONAL THOUGHT.
- MEMORY BLOCK

INFORMATION CANNOT
BE UNDERSTOOD OR
REMEMBERED

**DO NOT ADD
SENSORY OR
OTHER
INFORMATION**

**How can you
HELP ESCAPE?**

KEEP SAFE

MELT DOWN
SHUT DOWN

Triggers may be:
SURPRISE(ANY
UNEXPECTED EVENT)
EXCITEMENT
IRRITATION
ANXIETY
FEAR

ADRENALINE
RESPONSE CAUSING
PHYSICAL CHANGES

DANGER IS ALL THAT
IS PERCEIVED,
WHATEVER THE
TRIGGER.

**SELF-CALMING
TECHNIQUES
(require early
recognition)**

**TRIGGERS WHICH
COULD LEAD TO
STIMMING MAY BE A
RESPONSE TO STRESS,
AS A METHOD FOR
SELF-CALMING**

COMMON CHALLENGES
FOR AUTISTIC PEOPLE .

STIMMING

- SENSORY BEHAVIOUR
- IF NOT STIMULATED ENOUGH IT CAN BE A WAY TO SELF-STIMULATE
- IF BECOMING ANXIOUS IT CAN BE AN IMPORTANT SELF-CALMING ACTIVITY. CAN ULTIMATELY WIND UP ANXIETY AS WELL.
- SOMETIMES CAUSES PARENTAL EMBARRASSMENT? IS IT REALLY A PROBLEM OTHERWISE?
- <https://youtu.be/WexCWZPJE6A> VIDEO BY AMETHYST AT ASK AN AUTISTIC ON STIMMING FROM THE AUTISTIC PERSPECTIVE.

ARE WE MAKING REASONABLE DEMANDS?



When is a won't do a can't do?

- If in doubt, consider it to be a can't do.
- It is the difficult work of parents and advocates to learn to recognise the difference.
- Be open to finding out what unexpected thing your child finds difficult or cannot do.
- Don't expect it to be the same on every occasion.
- Don't expect understanding of words such as good, bad, rude, polite. be specific and give a reason.
- Don't expect your child to be able to tell you they can't do something or why they can't do it in words. They may not even be aware it is necessary in this particular situation.
- Trying to force your child to do a can't do will lead to a melt down, shutdown or escape.

PDA or extreme demand avoidance syndrome

COMMON CHALLENGES FOR AUTISTIC PEOPLE.

- Anxiety driven
 - Anxiety about being controlled by other people's demands or expectations.
 - This may be so extreme that even if it is a simple thing which the person does want to do or needs to do, they become unable to do it if it has been suggested by another person.
- Avoidance
- Hostage negotiation
 - Never promise (threat or reward will be a source of increased anxiety)
 - Never lie (including giving a tricky politicians answers)
 - Never say NO

GAP

EXPLAINING AUTISM

- Your child has been to a hospital and seen doctors and others for the diagnosis.
- They may be frightened that they have a serious illness.
- These are some resources which may help you to discuss this with them.
- <https://youtu.be/6fy7gUlp8Ms> Amazing things happen video explaining autism suitable for children. Watch it on your own first and then with your child if you think it is suitable.
- <https://youtu.be/dUbsyd8Fnyw> Good for parents and relatives and family and friends, explains behaviours. My be good for your child with a diagnosis, but does use the word weird so may not be so good?
- <https://www.ambitiousaboutautism.org.uk/information-about-autism/preparing-for-adulthood/making-sense-of-your-autism-diagnosis>
- Ambitious about autism have produced these videos made by young people to help others when they get a diagnosis. I think good for parents to watch and then they may think they are useful for their children to watch or at least will give them ideas for talking themselves.

GAP

ASSOCIATED CONDITIONS

COMMON CHALLENGES FOR AUTISTIC PEOPLE .

LEARNING DIFFICULTIES OR DISABILITY

DOWN'S SYNDROME

FRAGILE X

NEURO-DEVELOPMENTAL DIFFERENCES

- ADHD/ ADD
- DYSPRAXIA,
- DYSLEXIA
- DYSCALCULIA

• PHYSICAL HEALTH

- ALL CHRONIC CONDITIONS ARE MORE COMMON
- HYPERMOBILITY
- BOWEL PROBLEMS [Slide 23](#)
- EPILEPSY

• CHALLENGING BEHAVIOUR

- PATHOLOGICAL DEMAND AVOIDANCE
- OPPOSITIONAL DEFIANT DISORDER

• MENTAL HEALTH

- ANXIETY
- DEPRESSION
- EATING DISORDERS
- PSYCHOSIS
- OBSESSIVE COMPULSIVE
- GENDER DYSPHORIA

• TO FIND OUT MORE INCLUDING DEFINITIONS GO TO

- [Related conditions - a guide for all audiences \(autism.org.uk\)](https://www.autism.org.uk)

DISABILITY

DEFINITION UNDER THE EQUALITIES ACT (IT IS A “PROTECTED CHARACTERISTIC”)

- UNDER THIS ACT A DISABLED PERSON IS SOMEONE WHO HAS **“A PHYSICAL OR MENTAL IMPAIRMENT WHICH HAS A SUBSTANTIAL AND LONG-TERM ADVERSE EFFECT ON HIS OR HER ABILITY TO CARRY OUT NORMAL DAY-TO-DAY ACTIVITIES.”**
 - **SUBSTANTIAL = MORE THAN MINOR OR TRIVIAL**
 - **LONG-TERM = IT HAS LASTED OR IS LIKELY TO LAST MORE THAN A YEAR, OR IS EXPECTED TO RECUR OVER A LIFETIME IF IT FLUCTUATES IN SEVERITY.**
 - **NORMAL DAY TO DAY ACTIVITIES, GOING TO SCHOOL, SHOPS, TO SEE A DOCTOR**
- A DISABLED PERSON SHOULD EXPECT THAT COUNCILS, SCHOOLS AND OTHERS HAVE A RESPONSIBILITY TO IMPROVE AND PROVIDE SERVICES TO ENABLE A DISABLED PERSON TO HAVE ACCESS TO NORMAL DAY-TO-DAY ACTIVITIES SUCH AS EDUCATION. THIS COMES OUT OF THE “SOCIAL MODEL OF DISABILITY” WHICH HAS INFORMED VARIOUS ACTS OF PARLIAMENT. [WHAT DOES AUTISM OR ASD MEAN?](#)

MODELS OF DISABILITY

COMMON CHALLENGES FOR AUTISTIC PEOPLE .

- MEDICAL
- SOCIAL
- MORAL
- PHILANTHROPIC
- IDENTITY
- RESOURCE FOR FURTHER INFORMATION humorous talk given by comedian and disability rights activist Stella Young.
- Stellyoungtedtalk 10 minutes

What is normal?

- **NEUROTYPICAL:** NON AUTISTIC PERSON
- **NEURODIVERSITY :** We are all different neurologically and so have parts of our neurology which you may identify with which is seen as a part of a diagnosis of autistic behaviour. However, if we are not disabled, we are not counted as autistic.
- **NORMAL RANGE** If we can measure something people who fall in the middle 95% of the range from smallest to largest are counted as within normal range ie normal.
- **NORMAL DEVELOPMENT** A child is developing normally if s/he attains certain thinking and motor skills by a certain age.
- **When it comes to our nervous system very little can be measured. Normal is defined by societal norms.**

ADHD AND ADD

- ATTENTION DEFICIT AND HYPERACTIVITY DISORDER WITH OR WITHOUT HYPERACTIVITY
- DISORDERS OF ATTENTION ALONG WITH IMPULSIVENESS.
- 40% OF PEOPLE WITH ADD OR ADHD HAVE SENSORY PROCESSING DIFFERENCES

LEARNING DISABILITY

- A LEARNING DISABILITY AFFECTS THE WAY A PERSON UNDERSTANDS INFORMATION AND HOW THEY COMMUNICATE. THIS MEANS THEY CAN HAVE DIFFICULTY:
- UNDERSTANDING NEW OR COMPLEX INFORMATION
- LEARNING NEW SKILLS
- COPING INDEPENDENTLY

WHICH OF THESE TWO PORCUPINES IS LESS SPIKEY?

Porcupine showing his spikes.



Porcupine Masking spikes are concealed, but they are all there.



Grades of Autism (out dated terms)

The concepts of **HIGH FUNCTIONING AND LOW FUNCTIONING AUTISM** are out-dated and cause confusion.

DOES HIGH FUNCTIONING MEAN INTELLECTUALLY MORE ABLE OR LESS SEVERE DISABILITY DUE TO AUTISM? These two things are often unrelated, but to an observer may superficially seem to be the same.

DOES LOW FUNCTIONING DENOTE A PERSON WITH AN ADDITIONAL LEARNING DISABILITY OR A GREATER DISABILITY DUE TO THEIR AUTISM?