



**BEING AUTISTIC:
INFORMATION FOR
PARENTS AND YOUNG
PEOPLE**

WHAT IS THIS BOOKLET?

This booklet was made by Aishling Dempsey, Senior Assistant Psychologist with the psychology team at Community Paediatrics, East Sussex Healthcare Trust, with input from the Allied Health Professionals, Nurse Teams and Clinical Psychologist Anita Marsden.

It provides information from evidence-based research and the autistic community that might be useful to you after your child is identified as autistic. Further reading, resources and organisations that can support you are sign-posted at the end.

You may have heard the term Autism Spectrum Disorder (ASD) being used. ASD is the diagnostic term used in the DSM-5 (medical diagnostic manual). In this booklet, we use identity-first language (e.g. *autistic person* rather than *person with autism/ASD*). This is the preferred language of the autistic community, and removes stigmatising words like 'disorder' from the everyday words we use to talk about autistic people.

TAKE A MOMENT....

It is important to take a moment and hold a space of compassion for your family. For some, it will be difficult and confusing news. For others, it will come with feelings of relief and validation. It may be a mix of both. Everyone reading this will be at different stages of their journey to understanding and supporting their child.

You are already supporting and accommodating your child. This booklet aims to provide you with some guidance, language and frameworks to continue supporting your child after learning that they are autistic. We hope that this booklet can validate your experiences, and perhaps invite you to think differently about autism and further your understanding of autistic experiences.



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WHAT IS AUTISM?



Autism is brain functioning style or 'neurotype' which is part of natural neurological variation. It includes a diverse range of experiences, strengths and challenges.

Autistic people have distinct ways of communicating, processing information and experiencing their senses.

Autism is an important part of someone's identity, and cannot be separated from how someone experiences the world. Autistic ways of being offer valuable insights and perspectives to society.

To identify autism, consistent differences must be observed in: social communication and interaction preferences, attitude towards structure, predictability and sensory processing. Here are some examples of autistic characteristics:

Social Communication Style

- Echolalia (repeating words)
- Finding it difficult to adjust behaviour to suit social contexts (e.g. talking to head teacher the same way as friends)
- Enjoying being alone or experiencing friendships differently to the 'societal norm' (e.g. being friends with older/younger children)
- Needing extra time to process information (especially spoken information)
- Mature, formal or unique language
- Preferring not to make eye-contact, or using fixed eye-contact or a mixture
- Preferring to talk about own interests/topics
- Non-speaking communication

Attitude Towards Structure, Routine and Sensory Preferences

- Preferring/needing routine and structure
- Repeating movements like hand flapping, rocking and fidgeting
- Need for sameness e.g. same food, clothes, games, movies, routines or behaviour patterns
- Differences in sensory processing like hypersensitivity (e.g. food, clothes, noise), sensory seeking (e.g. stimming), sensory aversions (e.g. certain smells, textures)
- Focused areas of interest, expertise and passions, ability to hyperfocus
- Preferring to organise/line up toys or play in repetitive ways
- Losing self in fantasy

Autism is often thought about in a negative way, and a lot of the time the assessment process contributes to this by highlighting difficulties. There are many wonderful strengths that can come with being autistic:

- **Creativity**
- **Expertise**
- **Ability to self-sooth**
- **Ability to hyper-focus**
- **Experiencing deep joy**
- **Enhanced memory skills**
- **Character strengths like loyalty, resilience and honesty**
- **Being more accepting of difference and less judgemental**

This is not to say that being autistic is not challenging, it can be disabling to be autistic. Often, autistic people can struggle with sensory overwhelm, bullying or difficulty regulating emotions. Many of the challenges that autistic people experience is because the world around us was not built with autistic people in mind.

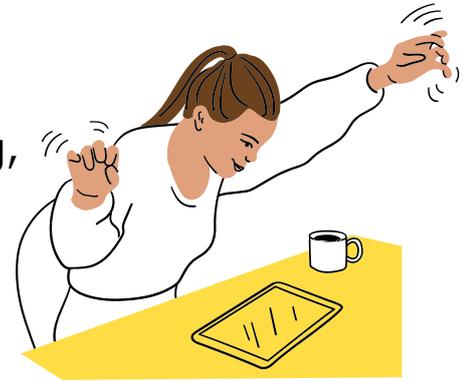
The 'social model of disability' is an idea which suggests that lots of the challenges and distress that autistic people experience are because the places we live, work and learn were not designed to suit autistic ways of being.

For example, most learning and work places expect everyone to communicate in the same way, mostly through speaking. Some autistic people are non-speaking, and some communicate better through typing or drawing.



Another example of the social model of disability is when the environment stops an autistic person from 'stimming'. Stimming means to move your body in a repetitive way which feels good, like rocking or hand flapping. Lots of autistic people stim to self-regulate to express themselves.

When autistic people are prevented from stimming, for example because of school rules around movement, or because they feel judged, this can be very upsetting and causes harm to autistic people.



There is nothing wrong with autistic ways of being, and autistic people thrive when they are able to be themselves. With the right changes and accommodations, some of the challenges experienced by autistic people can be minimised.

For example, wearing ear defenders or allowing for different ways of communicating. These types of changes help to create a safe environment where autistic people can be comfortable and content.

Everybody has different needs. It is important to recognise this, and find ways to best understand your child's needs, and empower them to ask for accommodations and support.

Scan the QR code or find 'Social model of disability - Autism by Differing Minds on YouTube.



Here are some common strengths and difficulties autistic people might experience. This table might be helpful to share with your child to help them understand their experiences.

Common Strengths	Common Difficulties
Deep and passionate interests	Finding friends you can connect with
Knowledgeable and observant	Knowing what to do when things change or are unpredictable
Truthful and trustworthy	Senses get overwhelmed
A strong sense of fairness and justice	Focusing on things you are not interested in
Ability to hyper-focus	Expressing your needs and feelings in a way that others understand
Feeling deeply and strongly	Knowing whether your friends are joking or not
Thriving on routine and consistency	Hard to notice when you are annoyed, sad or even hungry
Enjoying movement and other sensory experiences	Your body might react quickly before you have decided about what you want to do
Communicating in a way that is comfortable for you	Making eye-contact or doing small-talk

WHAT AUTISM ISN'T....

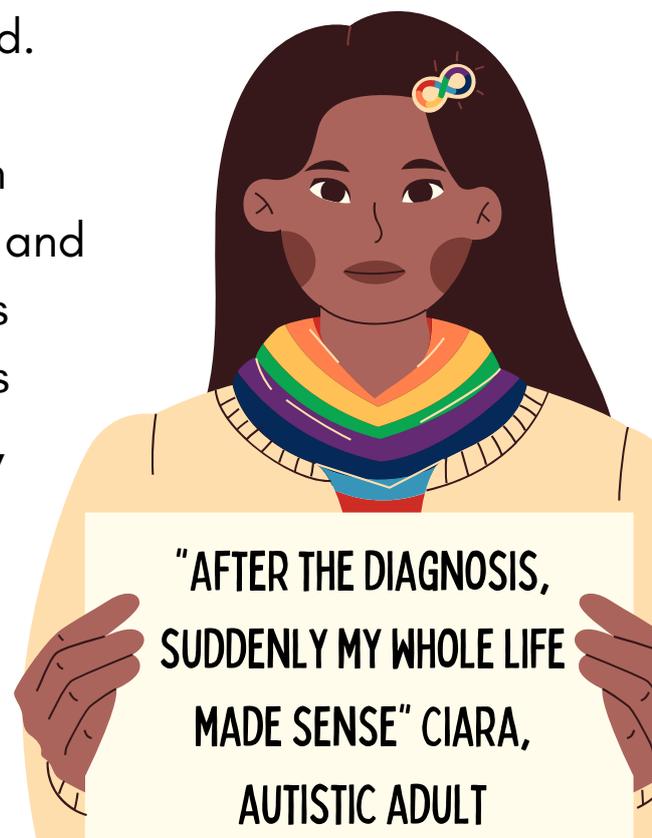
Autism is not a medical condition or a mental illness with treatments or a cure. This means that receiving an autism diagnosis is not the same as receiving a diagnosis of an illness or disease.

It might be helpful to think of diagnosis as *identifying* that someone is autistic. Being identified as autistic is helpful, as it provides you with the right language and information you need to understand and support yourself better.

It also provides a common language to explain your child's experiences and needs to others. Some autistic people describe the diagnosis as a *tool* to understand and communicate their experiences, differences and needs to others.

There might be a part of you that feels like your child has just 'gotten autism' because the process of being identified as autistic is in the form of a medical diagnosis. However, receiving a diagnosis is just being given a new word to describe how your child relates to the world.

There is no known 'cause' of autism, though research has explored the role of genetics and environment. Finding the cause of autism is not a priority of the autistic community. It is best to focus on understanding, accepting, supporting, and empowering the autistic people in your life.



AUTISM MYTHS

There are a lot of misunderstandings about autism. This can make the diagnosis process scary and confusing.

Being autistic does not mean that you don't have empathy or don't like to socialise. Many autistic people say they feel overwhelmed with empathy for others. Autistic people may express empathy or form friendships in ways that are different to societal norms (e.g. playing side by side with friends, rather than chatting).

Autistic people can have any level of intelligence. Some Autistic and people can experience challenges which impact their learning such as processing differences, sensory sensitivities or specific learning difficulties. Around 4 in 10 autistic people also have a learning disability.

Being autistic does not mean that you can't have friends, relationships, a job, or go to university or college. Lots of parents ask about what they can expect for their child to achieve. Each child's path is different, but being autistic doesn't mean that you won't continue to change, learn, develop and grow.



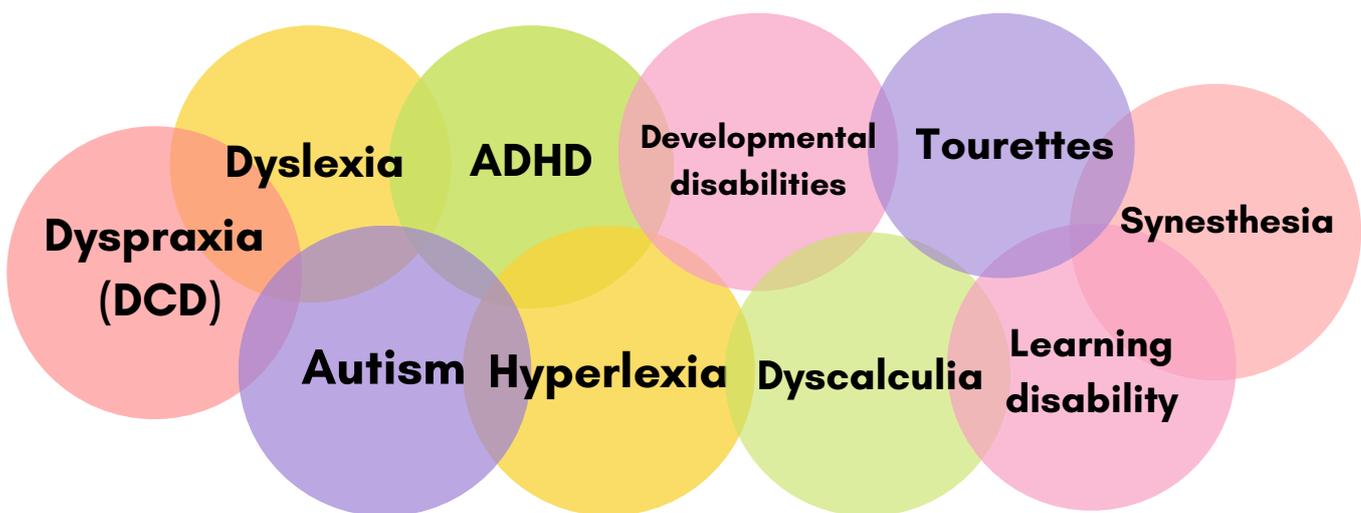
WHAT IS NEURODIVERSITY?

Neurodiversity is the biological fact that there are different types of human brains, in the same way there are different eye-colours and heights.

We live in a neurodiverse world- everybody's brain functioning style or 'neurotype' is different. In the same way there is no 'right' height, culture, race or gender, there is no 'right' type of brain.

There are brain functioning styles or neurotypes which are more common than others. Autistic people are *neurodivergent*. This means that autistic brains work differently or *diverge* from the most common type of brain functioning style.

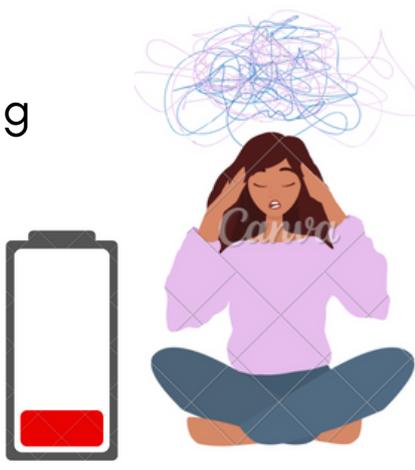
There are a number of ways of being neurodivergent. They often overlap, meaning many people experience more than one type of neurodivergence. Here are some examples of neurodivergence:



Neurodiverse is a word that describes a group of people with different brain functioning styles. There is no such thing as a neurodiverse person, as this term describes a range of neurotypes in a group. For example, an autistic person, an ADHDer, and a person with a learning disability are a neurodiverse group. A group of autistic people is not a neurodiverse group, as multiple different brain types are not represented.



'Neuronormative' is a word that describes how the world favours certain ways of thinking and behaving, like being good at writing, dealing with changes, sitting still or talking on the phone. This can make life harder for neurodivergent people. Everyone has preferences and needs, but for neurodivergent people, 'neuronormative' expectations and demands can be draining and distressing.



Being neurodiversity affirming means to value, respect and celebrate differences in brain types. This means thinking about autistic characteristics as differences, preferences and strengths rather than 'problems'.

In adopting this mindset, you can validate your child's way of being, and encourage others to do the same. This will allow them to feel safe and understood.

Here are ways to champion neurodiversity-affirmative thinking by leading autistic and allied advocates, psychologists and researchers at Thriving Autistic and The Adult Autism Practice:

- Support autistic people with their challenges, NOT autistic ways of being (e.g. ensuring there is time to focus on special interests, don't stop autistic people from stimming)
- Reject behaviour-based compliance and social skills 'training', which discourage autistic ways of being
- Respect and allow space for individual preferences for communication and interaction
- Advocate for systems and environmental changes to support autistic people (e.g. school)
- Recognise neurodivergent developmental trajectories
- Recognise co-occurring conditions and the impact of trauma
- Prioritise fostering a positive autistic identity
- Value diversity and disability
- Understand autism as a neurotype rather than a 'disorder' or 'condition'



THINKING DIFFERENTLY ABOUT DIFFERENCES

Often, autism is talked about in behavioural terms and focuses on problems. It is important to move away from behavioural and problem-based understandings of autism.

To do this, we need to think differently about autistic ways of being. Doing this will help you to look at autistic behaviour and thinking through a neurodiversity-affirming lens.

A good way to do this is to look at what autistic experiences feel like *inside*. This will help you to understand autistic characteristics in terms of needs, strengths and feelings which are positive or neutral, rather than 'deficits' or 'odd behaviours' that need to be changed.

The next few pages will look at some of common autistic characteristics and will.....

- 1) Consider what these experiences feel like for autistic people, rather than focusing just on behaviour
- 2) Re-frame autistic characteristics that are commonly talked about in deficit terms in a neurodiversity-affirming way



SOCIAL COMMUNICATION STYLES

When thinking about autistic communication styles it is useful to understand the double-empathy problem.

The double-empathy problem is an idea from autistic academic, Damien Milton which describes a mutual misunderstanding that can occur between autistic and non-autistic people.

We often hear about autistic people 'not understanding others'. However, autistic people express that non-autistic people do not understand them.

Social interactions are bi-directional. This means that how both autistic and non-autistic people communicate impacts the interaction. Often, autistic and non-autistic people communicate *differently to each other*, rather than autistic people having 'deficits' in social skills.

For more information on this, and some brilliant resources please visit 'differingminds.scot'



**"IT'S LIKE WE HAVE TO BE
BILINGUAL IN OUR OWN
LANGUAGE" FRANKIE,
AUTISTIC ADULT**

THE DOUBLE-EMPATHY PROBLEM

AUTISTIC PERSON

May:

- Like being alone
- Have enjoyable social interactions with other autistic people
- Need extra processing time
- Like to speak about topics they know about
- Use assistive technology
- Not use words to communicate
- Find eye-contact painful

May struggle to:

- Communicate with and understand non-autistic people
- 'Read between the lines'
- Overcome other people's misconceptions about autism
- Manage sensory distractions
- Understand non-autistic people's sense of humour



NON-AUTISTIC PERSON

May:

- Misinterpret autistic people
- Assume that autistic people lack social skills
- Communicate as expected within social hierarchies and group situations
- Enjoy using small talk or figurative speech (e.g. sayings, non-literal)
- Value eye-contact

May struggle to:

- Form positive first impressions of autistic people
- Recognise and understand autism
- Imagine autistic sensory difficulties
- Understand autistic people's sense of humour
- Communicate with non-speaking autistic people



Adapted
from
Frontiers for
Young Minds

- Some autistic people might need more time to process information. This means that if there is too much information, too many people talking or not enough time to process and reply before the conversation moves on, autistic people can be left behind in social situations.
- Some autistic people might feel overwhelmed or distracted by sensory input, like music playing or strong smells. This might make it difficult to keep track of their thoughts or what other people are saying.
- Some autistic people find eye-contact painful or distracting, while others don't mind it at all.
- Some autistic people might want to engage with others, but lack confidence due to past negative experiences or not understanding social conventions (expected behaviours) that seem intuitive to others.
- Some autistic people might prefer being alone, or might feel unwelcome by non-autistic people.
- Some autistic people might prefer to only talk about things or experiences that they are interested in.
- Some autistic people communicate at a slower pace

Experiencing one or a combination of these things can make social interactions very overwhelming and stressful. Autistic people may seek out time alone when overloaded by other people. It is important to respect this alone time.



Sometimes, autistic communication styles can be misunderstood as not wanting to interact with others, or not understanding social reciprocity (the back and forth of communication). This can make autistic people feel isolated.

By empathising and trying to understand what social interactions might feel like for autistic people, you can better understand different ways of communicating.

There are lots of things you can do to improve the experience of social interaction for your child. Most importantly, be patient and curious about your child's communication style and needs.



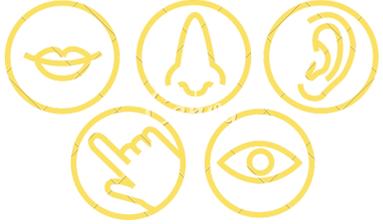
Speak clearly using straight forward language



Be direct and specific



Allow processing time



Reduce/increase sensory input



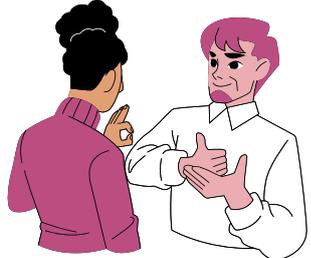
Be adaptive and flexible!



Don't judge



Use assistive technology



Be inclusive of all communication styles!



Be creative!



Provide small chunks of information



Use visual aids



Use their interests to communicate!

SENSORY EXPERIENCES

Depending on the person, context, time or sensory processing style, autistic people experience the sensory world in different ways. Sometimes, an autistic person might be hyper-sensitive to sensory input, and other times may seek sensory input.

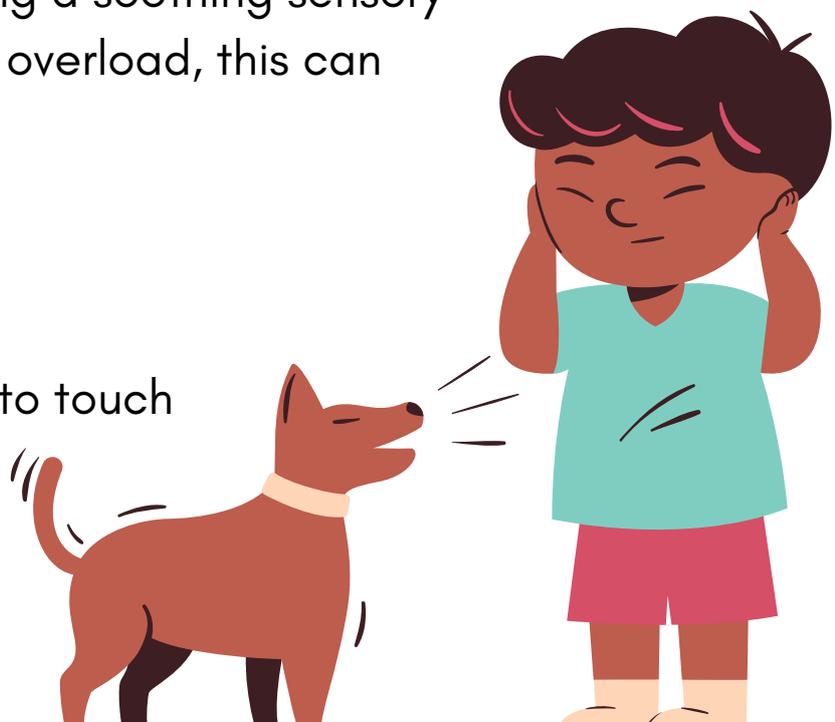
Feeling over-sensitive to sensory stimuli can be extremely overwhelming and sometimes debilitating. It can feel like a headache or a fuzzy brain. Recent research shows that processing more than one sensory stimuli (i.e. someone talking to you while watching the TV and eating) can be difficult for autistic young people.

Imagine someone trying to have a conversation with you while shining a torch into your eyes and blaring loud music- this is what sensory overload can feel like. This can make it hard to listen, talk or control feelings.

It is important to be mindful for when your child might be in sensory overload, for example straight after school or after having a long conversation. This might be a good time for some down time.

Reducing sensory stimuli, or creating a soothing sensory environment can help with sensory overload, this can be done by:

- having gentle lights
- using weighted blankets
- providing things that feel nice to touch
- having a quiet room
- ear plugs



STIMMING

Lots of autistic people seek sensory stimulation when they are under-stimulated, to regulate their emotions or to express themselves. This can look like rocking, hand-flapping, spinning, twisting, jumping, grimacing, licking lips, chewing on sleeves, rubbing fabrics, using sensory toys like poppets and fidget spinners, or sensory play like kinetic sand, playing with rice and water play.

This is called 'stimming'. Stimming feels incredibly soothing, and allows autistic people to relax and feel good. It is a natural thing to do.

Everybody stims! Many stims are more accepted by society like cracking your knuckles, tapping your feet or rubbing your hands on your thighs. Many autistic people are discouraged from stimming as movements like hand-flapping and rocking are less accepted by society.

As long as your child's stimming is not injuring themselves or others, this is something to be encouraged and celebrated as a self-soothing behaviour!



THRIVING ON ROUTINE AND SAMENESS

Most people have a favourite food they eat a lot, or a favourite song they listen to over and over. For some autistic people navigating the world can be overwhelming and uncertain, so having routines and familiarity provide comfort and safety beyond how non-autistic people experience them.

Why are routines and sameness supportive?

- Focusing on one thing at a time is comforting and provides a sense of satisfaction
- They reduce anxiety and promote an internal sense of safety in an uncertain world
- They reduce cognitive overload (like decisions and uncertainty)
- They support meeting needs for repetition
- They provide a sense of security, agency and autonomy, build trust and reduce power struggles



How best to make routines and structure...

- Makes schedules together with your child
- Allow their interests to guide the way they spend their time
- Encourage schedule building which includes flexibility and adaptability
- Experiment to find out what works best!
- Allow for preferences for sameness e.g. watching the same movie every week
- Visual schedules and social stories
- Creativity

INTERESTS, PASSIONS AND AREAS OF EXPERTISE

Many autistic people have strong passions, interests and areas of expertise. It might be hard for non-autistic people to understand why someone would want to spend hours being hyper-focused on learning about one thing.

For many autistic people, having a highly-focused interest plays a crucial role in their lives and wellbeing.

It is important to recognise your child's interests as a passion. This is a positive thing, rather than a negative 'obsession'.

Here are some quotes from autistic people from research and a blog from the iCAN Network talking about how their special interests make them feel inside:

"My special interest makes me feel like I can do anything" Ben

"I feel in power. I feel at home with my special interest" Frances

"Special interests are as important to us as the air we breath" Niamh

"Usually the world is exhausting and scary, but when I am absorbed in my interests, I feel inspired and energised" Cathy

"It makes me feel excited, natural and comfortable" Michael

"I doubt myself less when talking about my interests, I am more confident and less likely to experience issues with my speech" Kyal

MASKING



Masking is a word to describe a coping strategy used by autistic people where they suppress or 'mask' autistic ways of being to 'fit in' with societal norms. Research has found that 70% of autistic people mask. Masking is more common among autistic girls and women. Masking is a result of society not accommodating or accepting autistic people for who they are.

Autistic people mask for many reasons, including:

- To feel safe and avoid stigma
- Avoid bullying or discrimination
- To succeed in school or at work
- To make friends
- To fit in or feel a sense of belonging

Research surrounding masking has found that it has significant impact on mental health. Masking requires a lot of cognitive effort. This can lead to overload, difficulty speaking, memory loss and reduced ability to cope with sensory or social input.

By suppressing autistic characteristics, autistic people experience increased levels of exhaustion, anxiety, depression and stress. For autistic children, masking in school all day can be exhausting. This can lead to difficulty regulating emotions at home.

Autistic children can be supported to reduce masking by developing a positive sense of self and understanding of autism, being provided with flexible, non-judgemental spaces and relationships and being encouraged and accommodated to be themselves.

MASKING BEHAVIOURS



Hiding behaviours that are viewed as 'odd' e.g. stimming



Mimicking behaviour and language from other people/TV



Forcing smiles and facial expressions



Imitating and forcing eye contact



Quiet, polite, 'good behaviour' in school



Pretending to be like non-autistic people



Preparing and practicing topics, conversations or jokes



Hiding your feelings and mood



Talking to people even if you don't want to



Not talking about something you are really interested in

IMPACT OF MASKING



Missed/misdiagnosis, particularly for women and girls



Mental health difficulties like anxiety and depression



Low self-esteem and self-worth



Immense cognitive effort leading to overload



Avoiding social interactions, increased loneliness



Exhaustion and 'shutdown'



Confusion and lack of coherent identity



High levels of stress



Loss of skills and learning due to exhaustion

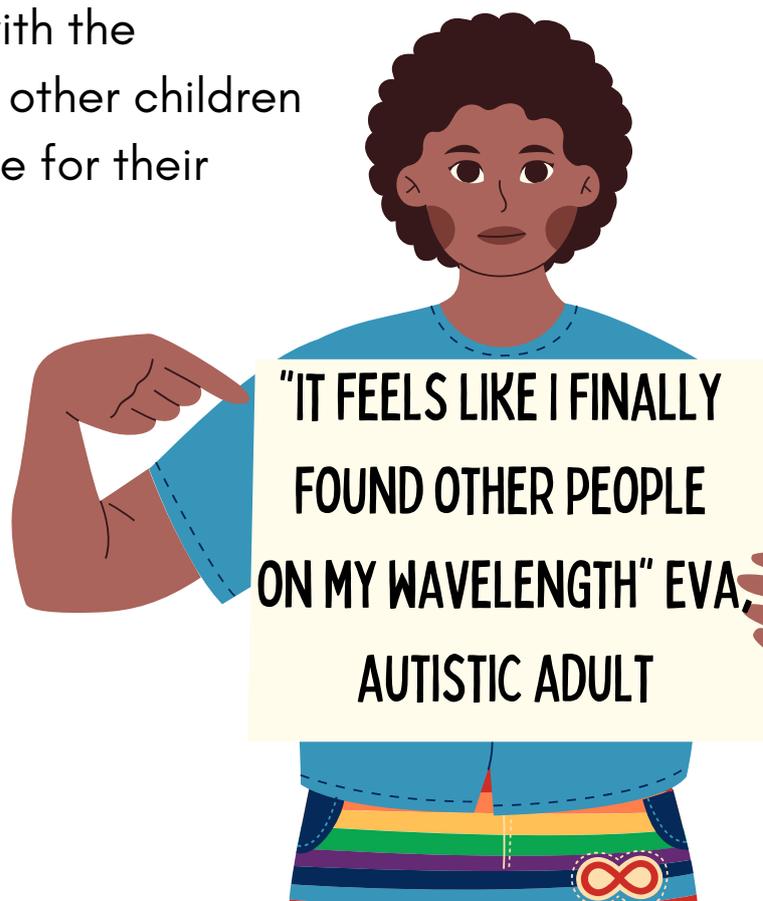
AUTISTIC PEERS: COMMUNITY AND FRIENDSHIP

There is lots of research which shows that being part of the autistic community leads to increased confidence, self-esteem, positive identity as well as reduced feelings of loneliness for autistic people.

Autistic people often describe feelings of validation, comfort, joy and ease when around other autistic people who just 'get' them. Finding other people that think, communicate and relate to the world similarly to you is comforting. It give you a safe space to be yourself without judgement.

You might find that your child already has autistic or neurodivergent friends who think and form friendships in a similar way to them. This can look like spending hours on a swing not speaking, or spending all of break-time talking about interests or playing video games and watching YouTube.

Encouraging your child to foster friendships with other autistic children might provide them with the opportunity to find their **neurokin**, i.e. other children who think like them. This will be positive for their self-esteem, development and wellbeing.



PDA

Pathological Demand Avoidance (PDA) is a profile which involves a high level of anxiety related to a need for agency and autonomy resulting in anxiety-driven avoidance of everyday demands and expectations.

These might include things like teeth brushing, going to school, doing tasks, answering questions, taking part in activities. Many PDA'ers use strategies like distraction, role-play and ignoring to avoid demands and expectations. This can be very stressful and can often result in emotional dysregulation.

If your child experiences fits this profile, they may benefit from strategies laid out by the PDA society to ease their anxiety, and reduce their experiences of demand and expectations.

PDA SOCIETY

Helpful approaches for a PDA profile of autism

Conventional support strategies, including those often recommended for ASD, are often ineffective and counter-productive with a PDA profile. In place of structure, routine, firm boundaries, praise, rewards/consequences, is a person-centred approach based on negotiation, collaboration and flexibility.

The PDA PANDA symbolises the need to tailor the environment to meet needs and our P A N D A mnemonic is a simple reminder of helpful approaches.

For more information please visit www.pdasociety.org.uk

Pick battles

- Minimise rules
- Enable some choice & control
- Explain reasons
- Accept that some things can't be done

Anxiety management

- Reduce uncertainty
- Recognise underlying anxiety & social/sensory challenges
- Think ahead
- Treat meltdowns as panic attacks: support throughout & move on

Negotiation & collaboration

- Keep calm
- Proactively collaborate & negotiate to solve challenges
- Fairness & trust are central

Disguise & manage demands

- Word & position requests indirectly
- Constantly monitor tolerance for demands & match demands accordingly
- Doing things together helps

Adaptation

- Try humour, distraction, novelty & roleplay
- Be flexible
- Have a Plan B
- Allow plenty of time

Pick battles
Anxiety management
Negotiation & collaboration
Disguise & manage demands
Adaptation

P
See the person

A
Explore interests

N
Engage positively

D

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UNDERSTANDING AUTISTIC PROFILES

Although there are common characteristics that autistic people may share, every autistic person is different. You may have heard of the term 'autism spectrum'. This term tries to capture the wide range of ways in which autism can present.

Parents often ask where their child is on the spectrum or if they are 'high or low functioning'. These terms are no longer considered to be useful in describing the experiences and abilities of autistic people.

In those terms, the autism spectrum looks like this:

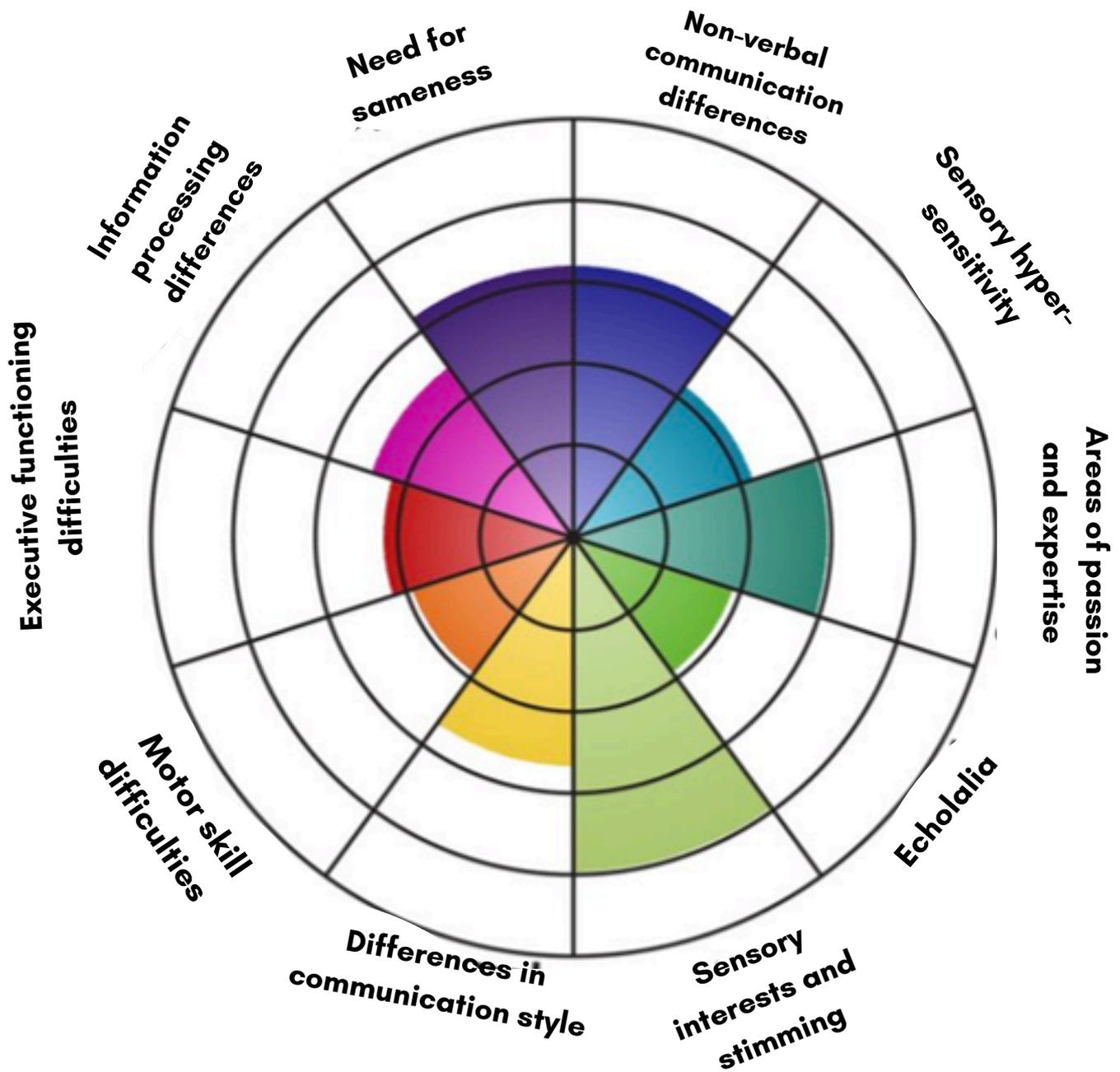


Autism is not binary or linear. There are infinite ways of being autistic. Your child will have their own unique strengths and needs which will be constantly changing depending on many internal and external factors (e.g feelings, age, environment, demands). This is not captured by this gradient (i.e. mild to severe) understanding of the autism spectrum.

It might be useful to think of the spectrum in terms autistic characteristics, and how relevant these characteristics are for your child.

The next page shows tool to explore your child's unique profile, and what being autistic means to them.

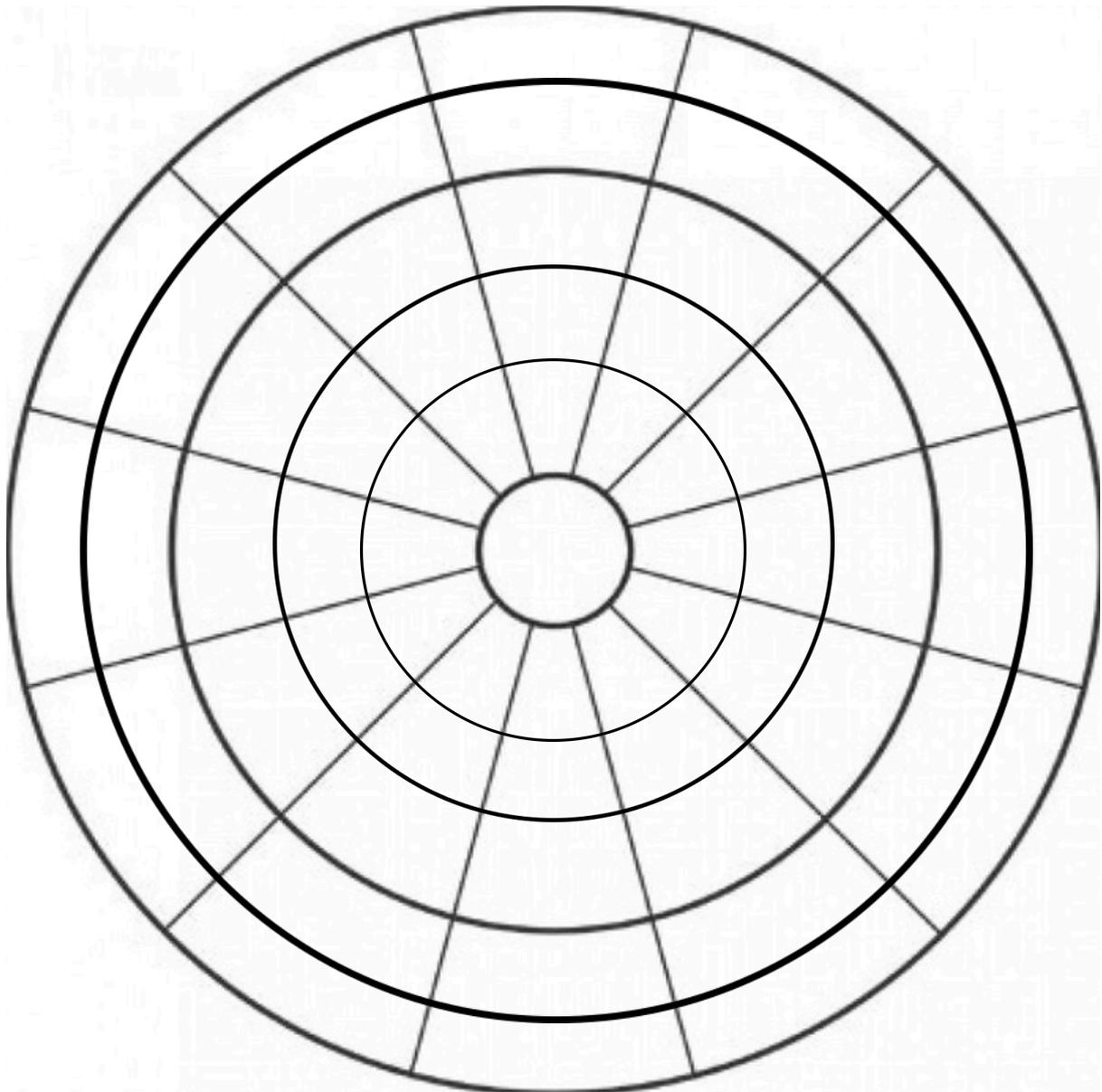
This is a wheel representing the autism spectrum made by autistic advocate Laura McConnell. Around the edge of each section, there is an autistic characteristic. The coloured in pieces represent how relevant each characteristic is in this person's profile; the more coloured in pieces, the more relevant that characteristic is.



For a person with this profile, all of these characteristics are relevant to their experiences of being autistic. In particular, sensory interests, areas of passion and expertise, need for sameness and non-verbal communication differences are important parts of their experience of being autistic.

The next page has a blank profile which you and your child can work on together to map their profile.

- Around the edge of each section, write an autistic characteristic. These can be one's named in the example, and/or any characteristics you and your child feel are part of what being autistic means for them.
- Choose a colour for each section, and colour in the pieces based on how important/relevant you feel that characteristic is. The more pieces coloured in a section, the more important/relevant that characteristic is for your child.



It might be useful to explore which parts of your child's profile they would like/need support with.

For example, preferring to spend time alone or spending a lot of time on passionate interests might be a big part of what being autistic means for your child, but not something they need/want support with, it is just their preference.



Whereas sensory sensitives and executive functioning difficulties may make life more tricky, and things like ear plugs and timetables can be supportive.

Ultimately, the best way to support an autistic child is to give them unconditional acceptance and space to be themselves. This can mean creating sensory soothing environments, appreciating their passionate interests and ways of communicating and supporting them to feel regulated and safe.



EXPLAINING AUTISM TO YOUR CHILD

Now that your child has been identified as autistic, it is really important to share this with them, and explore what it means for them as soon as possible.

Many autistic people describe having a sense that they are different from a young age. For many autistic people, their diagnosis explains this sense of difference. Research consistently finds that autistic people can feel relief, joy and validation after receiving their autism diagnosis. It reduces the anxiety of not knowing *why* things like sensory stimuli, socialising or communicating might feel difficult.

With the knowledge that they are autistic, your child can equip themselves with the tools and self-understanding they need to navigate the world.

Research finds that knowing that you are autistic increases self-esteem, confidence, efficacy and helps to develop a coherent sense of self. To achieve this, it is important to support your child to develop a positive autistic identity.

If your child is aware of autism or is a little bit older, learning that they are autistic might be challenging to their sense of identity. They might have a negative view of autism. It will be important to work with, and support your child to understand what it means for them to be autistic, as every autistic person is different.

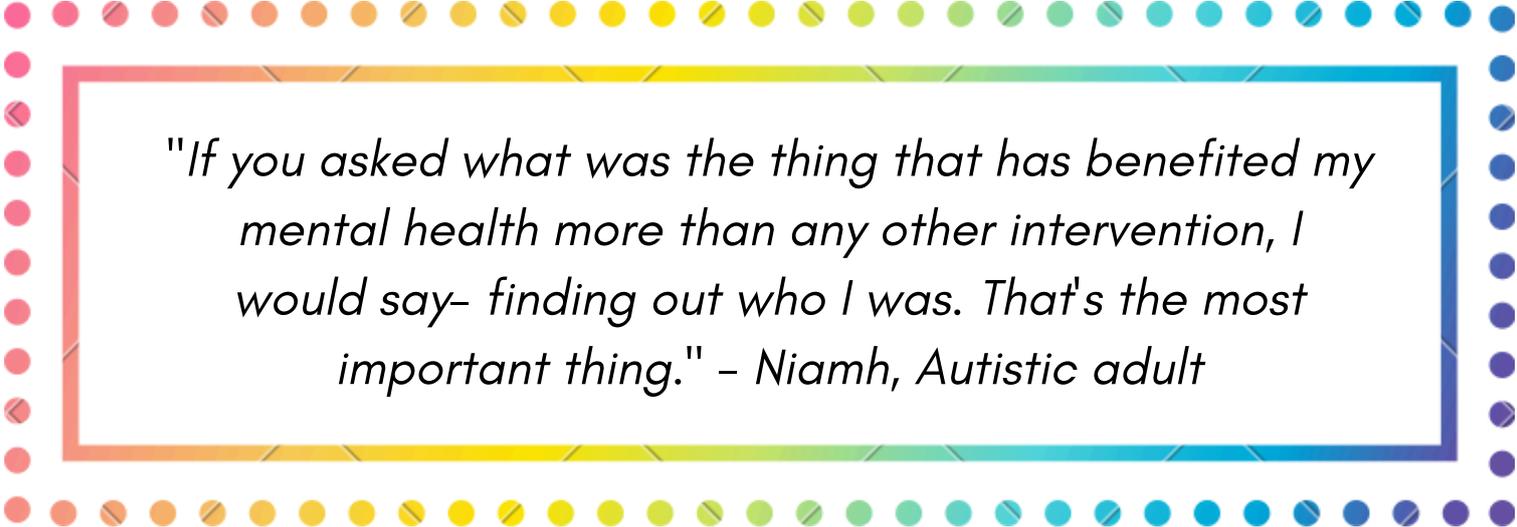


Having a positive autistic identity will allow your child to understand that there is nothing wrong with them. They are not 'disordered', they are autistic. Having a positive autistic identity does not mean believing you have 'superpowers'– lots of autistic people find this term harmful and not right– it is about knowing, accepting and loving yourself as an autistic person.

Empowering your child to form a positive autistic identity may help to reduce the stigma they may feel from others and will allow them to grow self-esteem and confidence in who they are.

It is likely that your child will have lots of questions. This might be straight away, or over time as they process, grow and learn. It is okay to say that you don't have the answers. Think of it as a collaborative approach where you and your child explore together what being autistic means to them.

Explaining what the autism diagnosis means to your child may seem like a daunting task. Do it at your own pace and lean on resources such as videos like Amazing Things Happen, and advice from autistic people or other parents of autistic children.



"If you asked what was the thing that has benefited my mental health more than any other intervention, I would say– finding out who I was. That's the most important thing." – Niamh, Autistic adult

Here is an example of what the conversation might go like, adapted from Dr. Liz Angoff's template for explaining autism to your child, and the following pages have worksheets and visuals to help you and your child learn about their autistic profile.

From the games and puzzles we did with the doctors, we learned that you are autistic. This means that your brain works a little differently to others.

It means that...*(strengths, e.g; communicating in a way that is comfortable for you like not making eye-contact, being super focused on comics and being able to remember lots of interesting things about them)*....come easy to you....

And other things like.....*(challenges, e.g; thinking and answering questions really fast, meeting new people, your routine changing)*.....are a little bit tricky.

There are loads of autistic people in the world! *(e.g. Greta Thunberg)*. You probably know some autistic people. Getting to know other autistic people can feel really good, you might feel like they 'get you'!

You are still the same person you were before we learned that you are autistic, now we just have a new word to describe what it is like to be you!

Let's make a plan together to learn about autism and what it means to be you.



BEING AUTISTIC: MY PROFILE

We learned lots about you over the past little while. We learned that your strengths, challenges and experience of the world align with the autistic experience.

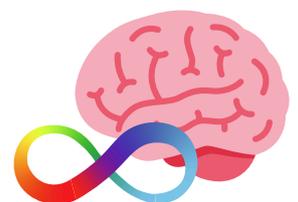
This means you are autistic, and you have a new word to help you and other people understand you better!

There are lots of autistic people in the world. Being around other people who's brain works in a similar way to yours can feel really good, it might be nice to hang out with/talk to some other autistic people.

It is good to think about how your brain works, and what being autistic means to you.

When you understand your preferences and differences, you and other people can support you to feel safe and comfortable.

Everybody is different. These pages will help you think about and write out what being autistic looks like for you.



Social Communication Style and Preferences

 Is texting more comfortable for you?

 Are you happier in your own company?

 Do you like to use words/phrases you learned on TV or from others?

 What are your eye-contact preferences?

 Do you like direct questions, or are they tricky?

 Do you need time to process and think about what has been said before responding?

 Do you find it easier to get along with other autistic people?

 Do you prefer talking about your interests?

 Do you find other people don't see how you are feeling when you are communicating with them?

 Do you other people not 'get you'?

 Does back and forth conversation confuse you?

Sensory Experiences and Preferences

 Are loud noises frustrating or painful?

 Do you notice smells, textures or sounds that others don't?

 Are you more aware of food textures than others?

 Do you feel and think better when some sensory input is filtered out?

 Do you move your body a certain way to feel good or to calm down? (e.g. jumping, dancing)

 Do nice lights or weighted blankets help you relax?

 Is it overwhelming when a lot is going on at once? Can this make you have big emotions?

 Does stimming make you feel good, or less stressed? (e.g. rocking, tapping, rubbing, using fidget toys?)

 Does it feel good to make certain noises?

Attitude Towards Routine and Repetition

 Do you have a need do to the same things everyday? (e.g. same walk, bedtime routine)

 Is it better to know about changes before so that you have time to adjust?

 What are your preferences for routines and structure?

 Does repeating certain movements or behaviours feel good or necessary?

 What are your preferences for sameness? (e.g. wearing the same type of clothes everyday)

 Is it easy or hard for you to adjust to something changing once you have an idea in your head?

 Does listening to the same song, or watching the same video or movie over and over again feel good?

 Does sameness like eating the same thing everyday feel easier because you know what to expect?

Other Autistic Experiences

What other experiences, preferences and differences are unique to you as an autistic person?

 Is it sometimes difficult to tell what you are feeling?

 Do you sometimes feel overwhelmed with your feelings, or overwhelmed with empathy for other people?

 Do you feel like you can't be yourself around others? Do you 'mask' or hide autistic traits to feel safe?

 Are you able to hyperfocus on one thing for a long time? Does it feel like you can't or don't want to stop?

 Do you have a strong sense of what is right or wrong, or what is fair?

 Do you have any areas or hobbies of expertise, passion or special interest that you love?

Let's make a plan!

How can we....



Help others understand my communication style?



Encourage, develop and nurture my positive autistic identity?



Make the sensory world more comfortable and enjoyable for me?



Find autistic role models and peers?



Meet my needs for routine, sameness and interests while easing my anxiety and resilience to change and flexibility ?

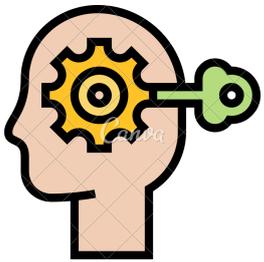


Help me to communicate my feelings, needs and experiences to others?

SUPPORTING YOUR AUTISTIC CHILD

Taking a neurodiversity-affirmative approach to parenting promotes a peaceful and accepting way of being. It will benefit your autistic child's development and wellbeing, as well as the wellbeing of everyone else in your home.

The next few pages will describe practical ways to support your autistic child by:



Growing and challenging your thinking and mindset about behaviour and parenting



Embracing your child's autistic ways of being and encouraging others to do the same

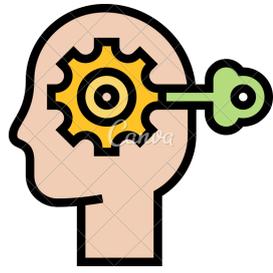


Adapting your home environment to meet your child's needs



Supporting your child to understand and regulate their emotions

BEHAVIOUR IS COMMUNICATION



The brain does not finish maturing until someone is in their mid-20s. For children recognising, regulating and communicating emotions and needs can be challenging. Most children do not have the emotional literacy to express themselves clearly all of the time, especially when they are experiencing 'big emotions'. Often, children will express themselves through behaviour.

For autistic children, there may be additional challenges which create big feelings more often:

- Environmental stressors like tight clothes, loud noises, changes to routines
- Increased difficulty recognising and labelling emotions (alexithymia)
- Difficulty with interoceptive skills (recognising bodily cues like hunger or tiredness)
- Not being understood by non-autistic people

As well that, differences in communication style may make it harder for autistic children to express big feelings:

- Being non-speaking
- Feeling too anxious to tell someone about their feelings/needs
- Preferring not to initiate conversations
- Being selectively-mute

Understanding that behaviour is often how children communicate their needs and big feelings will support you to feel compassion towards your child when they dysregulated. This will also help you to recognise the behaviours your child uses to communicate their needs and feelings.

WHAT WE SEE/THINK WE SEE

Tantrums

Crying

Deliberate actions

Not paying attention

Angry
outbursts

Looking for attention

Being naughty

Rigidity

Being manipulative

Panic attacks

Biting, kicking

Anxiety

Physical safety

Thoughts

Feeling out of
control

Sensory needs

Communication
style

Developmental
level

Hunger/thirst

Need for
connection

Misunderstood

Loss of executive
functioning

Lack of
knowledge
(e.g. when it is
hometime)

Frustration

Not knowing
what they are
feeling

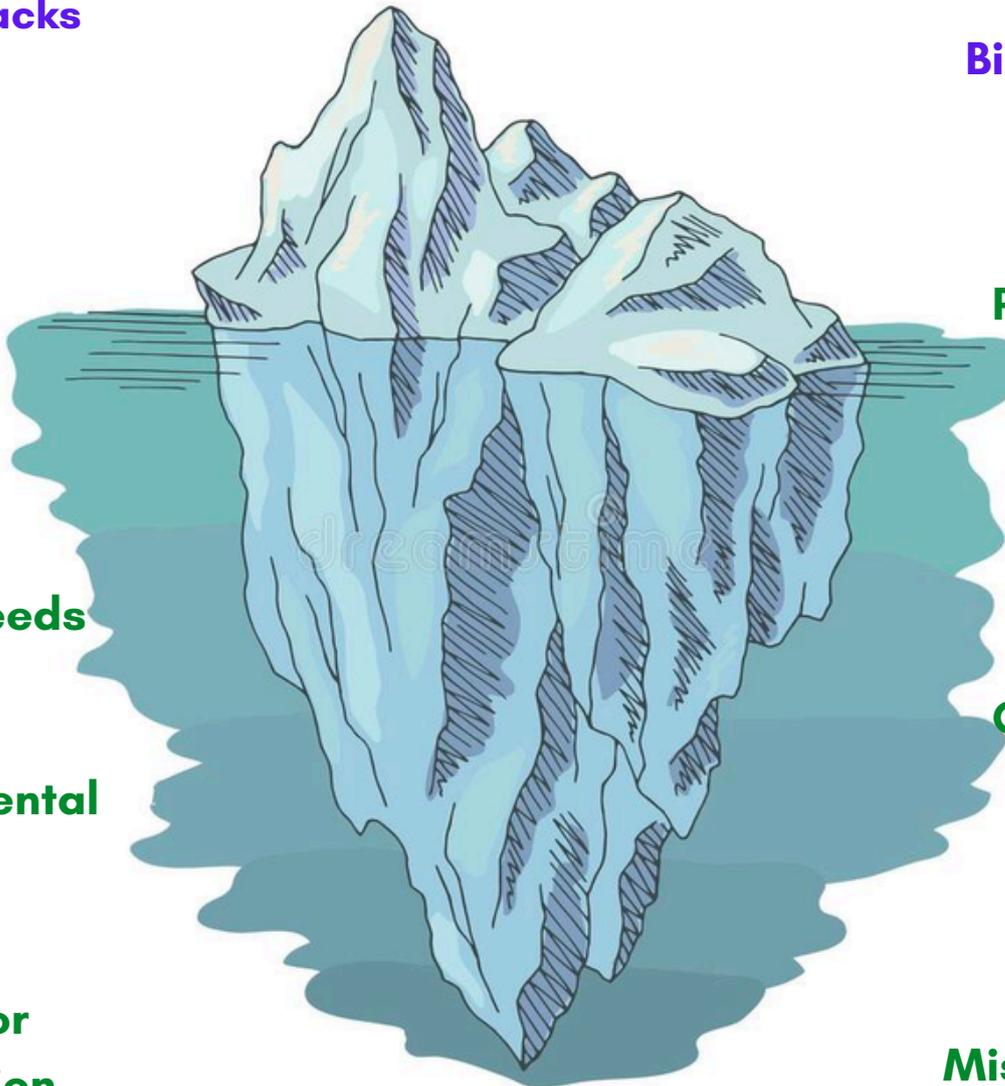
Literal
interpretation

Basic needs

People too close

Sensory issues

WHAT IS INSIDE



REFRAME THE BEHAVIOUR

"KIDS DO WELL IF THEY CAN"

~ROSS GREENE

WON'T



CAN'T

• JUDGMENTAL



- WILLFUL
- DEFIANT

HE'S LAZY
SHE JUST WANTS
ATTENTION
...RUDE!



• REWARDS &
PUNISHMENTS

- FRUSTRATION
- GUILT / SHAME



ADULT'S
MINDSET

VIEW
OF
CHILD

THOUGHTS

RESPONSE

CHILD'S
EXPERIENCE

• CURIOUS



- TOO MANY
STRESSORS
- SKILLS DEFICITS

WHAT'S GETTING IN
THEIR WAY?
HOW CAN I HELP?



• FIND & REMOVE
BARRIERS



- SUPPORTED
- STRENGTHENED



"SEE A CHILD DIFFERENTLY, YOU SEE A DIFFERENT CHILD"
~Dr. Stuart Shanker

When kids exhibit challenging behaviour we can be
"STRESS DETECTIVES"...finding and removing barriers.

- FIND STRESSORS → REDUCE THEM
- FIND UNMET NEEDS → MEET THEM
- FIND SKILLS DEFICITS → TEACH THEM

@kwiens62

EMBRACING AUTISTIC WAYS OF BEING

Embracing your child as an autistic person may mean shifting and growing your expectations of parenting, or how a child is 'supposed' to learn and play.



This is an open, accepting mindset that allows all children to express themselves and connect with others in their own way.

There are many ways of embracing autistic ways of being, which you may already be doing for your child. This might involve allowing and encouraging stimming, not forcing them to change how they play or encouraging siblings to embrace their sibling's way of being.

Here are some suggestions from Terra Vance, an autistic adult on how you can adjust your interactions with your child to embrace autistic ways of being:

- Find contentment in not worrying, fixing and controlling how they play and interact with others
- If your child likes to line up toys, or do something repetitive, bring your own toys and play happily and silently near them
- Be okay with them not joining you, you are interacting in a way that they feel safe and connected
- Play with sensory toys yourself, quiet your mind, try to feel the peace that they are feeling
- Show interest, but try not to ask too many questions or direct their play



ENVIRONMENTAL ADAPTIONS

There are many ways to make your home a safe, comfortable space for your autistic child.

By creating neurodiversity-affirming spaces and practices in your home, you can support your child in feeling emotionally regulated, safe, and able to explore being autistic without judgement or barriers.

Creating a neurodiversity-friendly environment will be a constantly evolving process. Ask and observe your child to understand their needs and preferences. Simple things like embracing sensory preferences can make a difference.

Here are some suggestions to creating a safe space for autistic children:

- A space to stim safely like a carpeted area free of furniture
- Sensory corners or rooms (e.g. a corner with lights, weighted blankets, toys, breathing exercises, books)
- A quiet space where your child will not be interrupted (e.g. a sign on their door for when they need space)
- Ways to facilitate their communication style (e.g. time to 'info dump', visuals, whiteboards to write on, emotion charts)
- Dimmer lights
- Reducing background noises (e.g. TV, radio, wearing noise-reducing headphones)
- Adaptive cutlery
- Decorating their room with their favourite characters and interests



EMOTIONAL REGULATION



For many children, recognising, regulating and communicating emotions is very challenging. For autistic children- especially in environments which do not support their needs- there can be additional challenges which impact emotional regulation.

For many autistic people, masking, being overwhelmed and misunderstood can be exhausting and can lead to difficulty regulating emotions. This can lead to autistic burnout:

"If I'm masking and everything, and I can't stim, my brain gets tighter and tighter and tighter. So what happens is that the elastic band starts stretching....and and if you stim, the elastic band starts going back to its normal shape. If you don't then the elastic band keeps stretching. And at some point, the elastic band is gonna just ping off your fingers and that's when you hit meltdown or shut down" - Frankie, autistic adult describing autistic burnout

When a child is experiencing autistic burnout, this can look like having 'meltdowns' and being overwhelmed by even small things. They may also go into 'shutdown' which can look like being passive or low in energy.

A good way to understand how autistic burnout happens and what it looks like is through a model called The Window of Tolerance, which is visually described on the next page.

The following resources are to support you and your child in emotional regulation, mindfulness and communicating distress.



THE WINDOW OF TOLERANCE

HYPER-AROUSAL: EMOTIONAL DYSREGULATION: RED ZONE

When you are in the red-zone, you are in 'fight or flight' mode. Your reactions take over and you lose control. You feel anxious and overwhelmed. **For autistic people, this can look like an autistic 'meltdown'.**

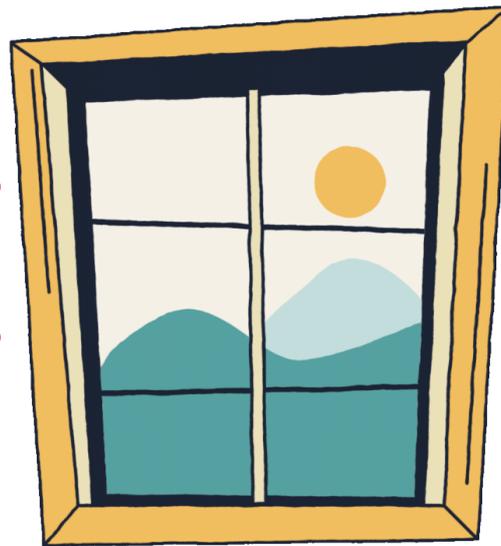
Signs you are here:

- Tension, shaking
- Emotionally reactive
- Defensive
- Racing and intrusive thoughts
- Feeling overwhelmed and unsafe
- Impulsivity
- Anger and rage

SHRINK YOUR WINDOW OF TOLERANCE

Stress, trauma, anxiety, sensory overwhelm, demands (internal and external), executive functioning difficulties, sleep issues

When your window of tolerance is shrunk, it doesn't take much to make you 'lose it' and feel really distressed



EXPAND YOUR WINDOW OF TOLERANCE

Meditating, stimming, listening to music, engaging in hobbies, being with neurodivergent people, breathing, resting, support for executive functioning

When your window of tolerance is expanded, you are more able to cope with challenges

OPTIMAL ZONE: EMOTIONAL REGULATION: GREEN ZONE

When you are in your window of tolerance, you feel like you can deal with the stress and pressures of life. This is the ideal place to be. We should aim to be here as often as possible.

Signs you are here:

- Feel and think simultaneously
- Awareness of boundaries
- Feelings are tolerable
- Reactions are appropriate to the situation
- Feel open and curious

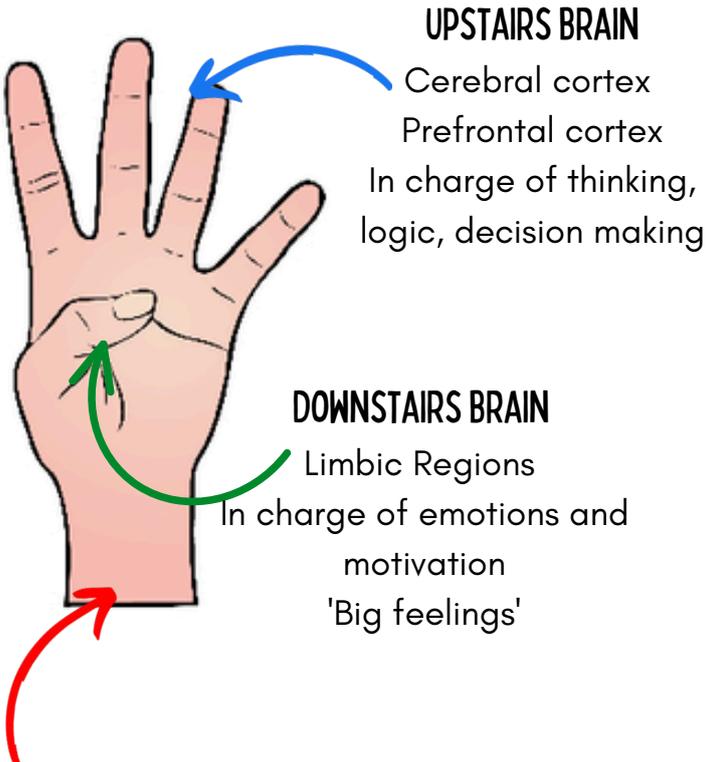
HYPO-AROUSAL: EMOTIONAL DYSREGULATION: BLUE ZONE

When you are in the blue-zone, you are in 'freeze' mode. Your body might start to shut down. You may feel numb, exhausted and depressed. **For autistic people, this can look like autistic 'shutdown'.**

Signs you are here:

- Feeling 'dead' or flat
- No energy
- Passive and disconnected
- Can't think

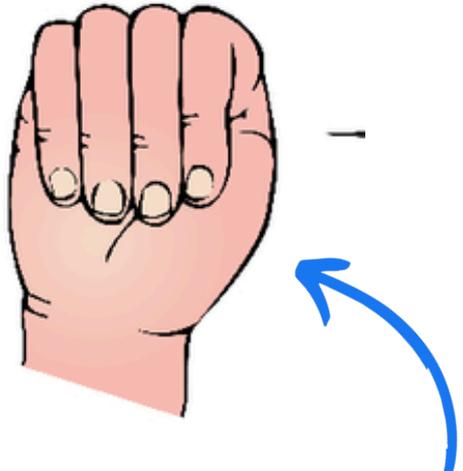
DAN SIEGAL'S HAND MODEL OF THE BRAIN AND FLIPPING YOUR LID



UPSTAIRS BRAIN
Cerebral cortex
Prefrontal cortex
In charge of thinking, logic, decision making

DOWNSTAIRS BRAIN
Limbic Regions
In charge of emotions and motivation
'Big feelings'

REPTILIAN BRAIN
Brain stem
Basic functions



When your brain is working well, your upstairs 'thinking' brain and downstairs 'emotional' brain are communicating effectively. This means your thinking brain can be accessed for logic and reasoning. Your upstairs brain is hugging your emotional downstairs brain, making it feel safe.



When you have big emotions, or too much information coming in to the upstairs brain your upstairs brain flips up and disconnects! This means you 'flip your lid' and your emotional brain is in charge. This means that you can no longer use your thinking and reasoning skills from your upstairs brain to make your emotional, downstairs brain feel safe and calm.

When you flip your lid, getting your upstairs and downstairs brain talking to each other again can help you to calm down. You need your upstairs brain to hug your downstairs brain again!

This can be done by:

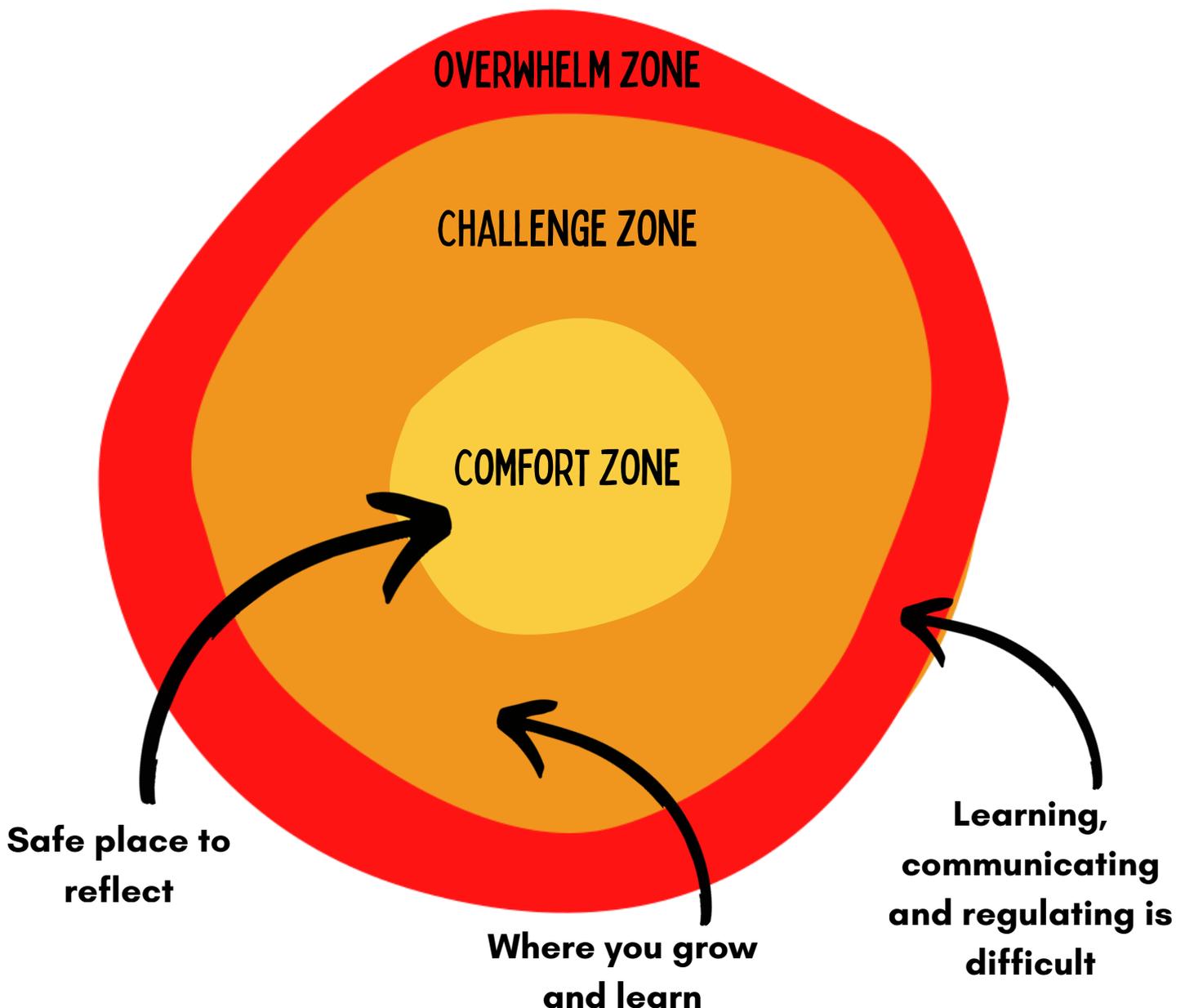
- Co-regulation (parents speaking calmly with compassion, patience and love)
- Self-soothing strategies (rocking, listening to music, breathing)
- Environmental soothing (lots of space, fresh air, sensory experiences)

COMFORT ZONE, CHALLENGE ZONE

The 'Comfort Zone, Challenge Zone' is a similar idea to The Window of Tolerance, presented in a different visual. The Zones of Regulation were created by Occupational Therapist, Leah M. Kuypers.

Having this visual drawn or printed out might support your child to identify when they are feeling calm and regulated (comfort zone), if they are in a place to learn, do tasks, practice wellbeing (challenge zone) or if they are feeling too overwhelmed.

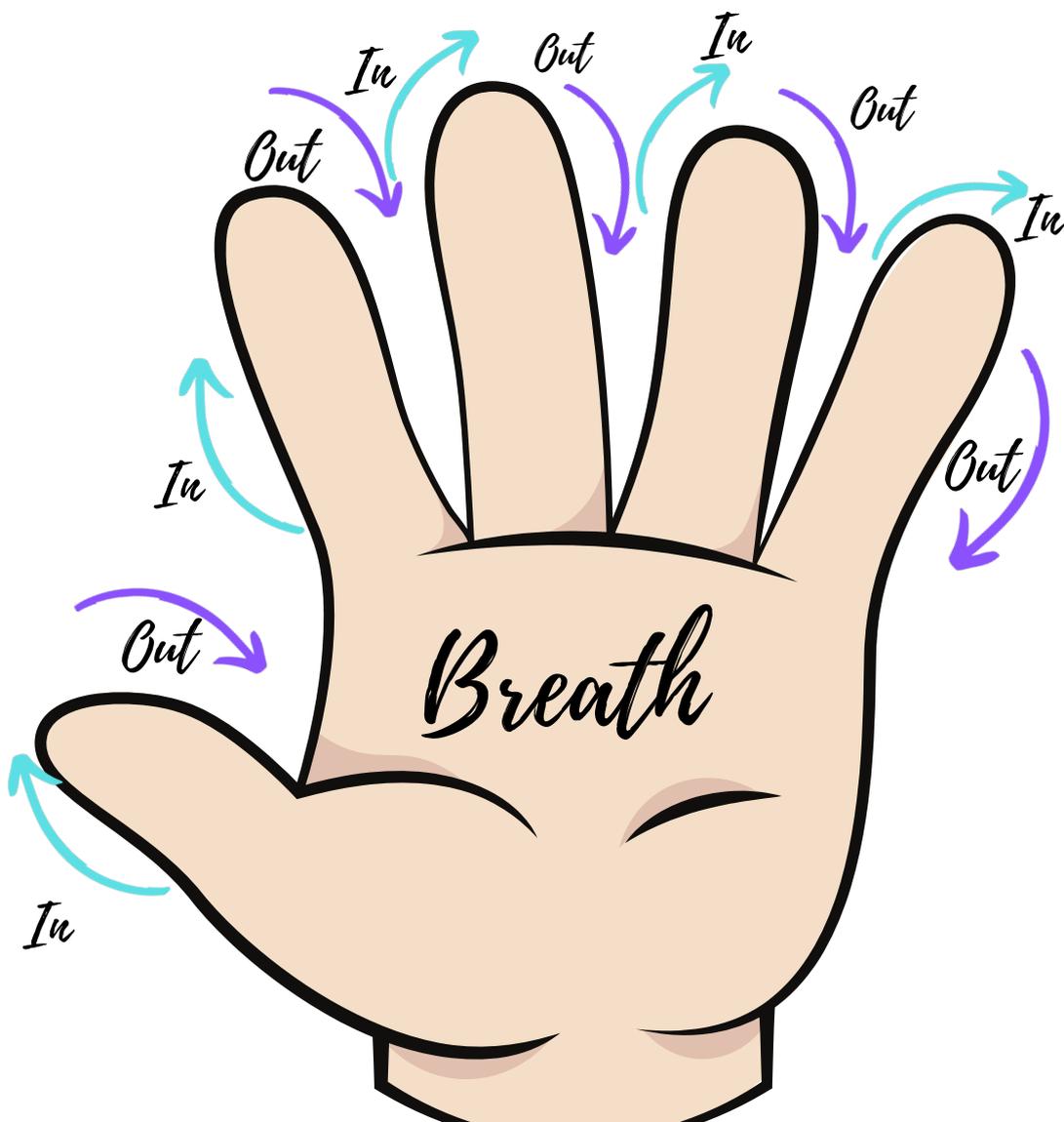
It can also support them to understand that working on their wellbeing and mental health is not always comfortable, but that they have the agency to let others know when they are feeling too overwhelmed.



HAND BREATHING

Taking deep breaths is one thing you can do to calm your mind, your body and bring you into the present to reduce any anxiety or big feelings. Lots of children struggle to see the point of taking breaths, it is useful to explain to them why taking breaths helps. Taking breaths stimulates the vagus nerve. This is in charge of turning off your 'fight or flight' survival mechanism/ This will reduce anxiety and bring you back more control. It is best to practice this as often as possible, not just when you are feeling overwhelmed and dysregulated.

Taking deep breaths is something that is always accessible. Many people benefit from having something tactile to focus on to help them take breaths. This is what hand breathing is for. Simply run one finger along your thumb and fingers on the other hand. Breathe in while your finger runs up the outside, and breathe out as it runs down the inside.



SIGN-POSTING AND RESOURCES

Here are some books to support you and your child to learn more about autism, what it means to be autistic and how to best support wellbeing.

Books for your child to understand themselves and support their wellbeing:

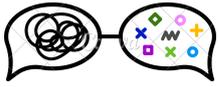
- The Neurodivergent Friendly Workbook of DBT Skills by Sonny Jane Wise*** This book is *highly* recommended by the psychology team.
- Wonderfully Wired Brains: An Introduction to the World of Neurodiversity by Louise Godding and Ruth Burrows
- The Secret Life of Rosie by Rose Smitten
- A Different Sort of Normal by Abigail Balfe
- Libby Scott book series (fiction series written by an autistic teenager)
- The Spectrum Girl's Survival Guide: How to Grow Up Awesome and Autistic by Siena Castellon
- Different, not less by Chloe Hayden
- Autism, identity and me by Rebecca Duffus

Parenting books that support neurodiversity-affirming practice:

- The Whole-Brain Child: 12 Proven Strategies to Nurture Your Child's Developing Mind by Daniel J. Siegal
- No-Drama Discipline: The bestselling parenting guide to nurturing your child's developing mind by Daniel J. Siegal
- Yes Brain: How to Cultivate Resilience, Encourage Curiosity, and Inspire Passion and Purpose in Your Child's Life by Daniel J. Siegal
- Avoiding Anxiety in Autistic Children: A Guide for Autistic Wellbeing by Luke Beardon
- Your child is not broken: Parent your neurodivergent child without losing your marbles by Heidi Mavir



YOUTUBE VIDEOS FOR YOU AND YOUR CHILD



To explain autism and neurodiversity:

- Amazing Things Happen, *National Autistic Society*
- Talking to Children About Autism, Accessible Version, *Reframing Autism*
- Neurodiversity Explained, *Kickstart Learning* (using Lego)
- Autism Acceptance Neurobears

Positive autistic identity and community:

These videos are clear and helpful to begin with, continuing to get involved with the autistic community, and following and watching some of the content from the social media autistic advocates and influencers suggested above is a great way to develop a positive sense of identity and community.

- Fast Facts About Autism (World Autism Awareness Day), *Autism From The Inside*
- Welcome to the Autistic Community, *Autistic Self-Advocacy Network*
- Teach Me Stock Motion Documentary, *Anna Contrill*
- What's in my bag? Autism survival edition, *Chloe Hayden*



Explaining emotions, psychological concepts and wellbeing tools:

- Upstairs Brain Downstairs Brain, *SEL Sketches*
- Practical Tips for Dealing with Anxiety, *Anxiety UK*
- Dan Siegal's Hand Model of the Brain, *Mo Mindful*
- Why Do We Lose Control of Our Emotions?, *Kids Want To Know*
- Brain Jump With Ned the Neuron: Challenges Grow Your Brain, *Kizoom*
- Window of Tolerance, *Sussex Partnership NHS Foundation Trust*
- Neurodivergent Lives, *The Autistic Girls Network*

WEBSITES FOR INFORMATION AND RESOURCES

Here are some brilliant websites that are full of resources, including ones used in this booklet.

- **neuroclastic.com**- blogs, articles, information, visuals, activism and stories about all things autism run by autistic writers, psychologists and parents.
- My Brain is Autistic- Neuroclastic a, a neuroinclusive story
- **authenticallyemily.uk**- A wonderful website full of resources for neurodivergent people and families
- **littlepuddins.ie**- visual supports, courses and blogs run by an autistic self-advocate and consultant
- **neurodiversitylibrary.org**- wonderful visuals for parents and children surrounding autistic identity, acceptance and advocacy
- **autism.org.uk**- National Autistic Society website
- **brightandquirky.com**- webinars, videos and information for parents
- **spectrumgaming.net**- gaming website for autistic young people to connect
- **differentminds.scot**- great information on social communication differences
- **thrivingautistic.org**- support and advocacy information and webinars run by autistic people
- **uniquelyhuman.com**- a fantastic podcast website surrounding autistic experiences
- **theautisticadvocate.com**- a collective of stories from autistic people about their lived experiences, and courses for autistic kids and parents
- **pdasociety.org.uk**- Pathological Demand Avoidance Society website with information and strategies for parenting a PDA kid
- **understood.org**- 'Through Your Child's Eyes' series looking at how experiencing various challenges feels for children with additional needs

LOCAL ORGANISATIONS

Please see our PIFU leaflet for more information about sign-posting and local support.

iSEND

Inclusion, Special Educational Needs and Disabilities (ISEND) is the name for the services provided by East Sussex County Council to support children and young people with SEND, with equality of access to education.

<https://localoffer.eastsussex.gov.uk/contact>

Amaze

A Sussex charity that works with parents of/children with disabilities and special education needs. You do not need a formal diagnosis to access Amaze services. *www.amazesussex.org.uk*.

ASPENS

Sussex based charity providing care and support to autistic children and young people from the age of 8 through to 25 and their families.

<https://www.aspens.org.uk/>

Spectrum

Free, county-wide service that helps Autistic children and young people 'aged 5-18' to join in activities in their local community, develop their independence and build confidence in developing key life skills.

www.eastsussex.gov.uk/spectrum

i-go Card

Free cardholder scheme for children and young people aged 0-25 with SEND across East Sussex to improve access to leisure activities.

www.eastsussex.gov.uk/igo

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Dr. Dan Siegel. <https://drdansiegel.com/resources/>

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