Appendix

Key concepts

We have heard from autistic people that a fundamental part of conceptualising autism is about understanding key areas being discussed by autistic researchers, scholars, academics and autism organisations to raise autism awareness.

This appendix contains some key concepts to increase your knowledge of autism.

Some of these concepts are listed below and have weblinks to where more information can be accessed (including some weblinks to video explanations):

Neurodiversity and neurodivergence

Autistica explain that "neurodiversity describes the idea that people experience and interact with the world around them in many different ways. Whilst we all see the world differently, research suggests that 1 in 7 of the population is neurodivergent. This includes people who are autistic, and those with dyslexia, dyspraxia, dyscalculia, and Tourette's syndrome. Many neurodivergent people have more than one diagnosis" (Autistica).

The neurodiversity movement

The National Autistic Society says that "the 'neurodiversity movement' is a social justice movement that seeks civil rights, equality, respect and inclusion for all neurodivergent people... The main aim of the movement is to end the discrimination neurodivergent people face in society. This includes fighting against

the 'pathologisation' of neurodivergence, including autism, which means changing views in medical science and society more widely so that people understand neurodivergence as a difference, not a 'deficit' or 'disorder'" (National Autistic Society's webpage on theneurodiversity-movement).

Double empathy problem

The double empathy problem was coined by Dr Damian Milton and suggests that autistic and non-autistic people struggle to empathise with each other due to different experiences of the world and communication styles (National Autistic Society's webpage about the double empathy problem by Dr Damian Milton).

To learn more, here is a weblink to **National Autism Trainer Programme Double Empathy Problem Video** which gives a full explanation.
This video also features in the National Autism

Trainer Programme (NAPT). To learn more about NAPT, here is a webpage to <u>National</u> <u>Autism Trainer Programme project leads on importance and key outcomes video</u>

Social model of disability:

The Social Model of Disability was developed by Disabled people and describes people as being disabled by barriers in society, not by our impairment or difference. If modern life was set up in a way that was accessible for Disabled people, then we would not be excluded or restricted.

The social model of disability helps us recognise barriers that make life harder for Disabled people. These barriers are identified as being the physical environment, people's attitudes, the way people communicate, how institutions and organisations are run, and how society discriminates against those of us who

are perceived as 'different'. Removing these barriers creates equality and offers Disabled people more independence, choice, and control. (Social Model of Disability: Language Disability Rights UK)

Monotropism

Monotropism is a theory which was first developed by Dinah Murray and Wenn Lawson. Monotropism is an individual's tendency to focus their attention on a small or singular number of interests at any time.

The National Autism Trainer Programme video explains that "the theory of monotropism describes the way which autistic people's neurology processes sensory information, engages with something in order to give it our full focused attention, works to move our attention from one thing to another and validates autistic experience in a non-pathological way".

To learn more, here is a weblink to <u>National Autism Trainer Programme Introduction</u> to <u>Monotropism video</u> which gives a full explanation. This video also features in the National Autism Trainer Programme (NAPT).

Interests and hyperfocus

Pete Wharmby is an autistic author, advocate and ex-English teacher. Here he discusses interests and how they should be embraced: "the vast majority of autistic people will have 'special interests' - topics they are capable of exploring in huge detail for long periods of time. Often misunderstood as 'hobbies' or 'pastimes', they are in fact much more than that. The complete absorption into a topic or activity (or "hyperfixations") can be both lifeaffirming and life-allowing: they give depth and meaning to our lives but also enable us to enjoy our lives, by acting as a kind of mood regulator, keeping our stress levels down and helping us get through the events of the day" (National **Autistic Society webpage).**

SPELL stands for: Structure; Positive (approaches and expectations); Empathy; Low arousal; Links:

SPELL is the National Autistic Society's framework for understanding and responding to the needs of autistic children and adults. It focuses on five principles that have been identified as vital elements of good practice when working with autistic people, and emphasises ways to change the environment

and our approaches to meet the specific needs of each person. The SPELL framework recognises the individual and unique needs of each child and adult and emphasises that planning and intervention be organised on this basis. The SPELL framework can be used with all autistic people, regardless of age or level of support needs (The SPELL framework).

REAL stands for: Reliable, Empathic, Anticipatory and Logical

REAL is an autism-informed approach. "Enacting the REAL principle amounts to doing what you say you are going to do **reliably**, **empathising** with the world view of the individual, **anticipating** potential difficulties and addressing them before they arise, and communicating clearly and **logically** to avoid ambiguity." (**University through the eyes of autistic students and staff** Martin, N. & Milton, D. (Editor), Sept 2020, Neurodiversity Reader.)

Masking

"To 'mask' or to 'camouflage' means to hide or disguise parts of oneself in order to better fit in with those around you. It is an unconscious strategy all humans develop whilst growing up in order to connect with those around us.

However, for us autistic folk the strategy is often much more ingrained and harmful to our wellbeing and health. Because our social norms are different to others around us, we often experience greater pressure to hide our true selves and to fit into that non-autistic culture. More often than not, we have to spend our entire lives hiding our traits and trying to fit in" (Dr Hannah Belcher on the National Autistic Society website).

Autistic burnout

Autistic people often talk about autistic burnout as a source of distress, but it's only just starting to be recognised in wider conversations. At the National Autistic Society website, Dr Dora Raymaker, Research Assistant Professor discusses research exploring autistic people's experiences of autistic burnout. "Autistic burnout is a state of physical and mental fatigue, heightened stress, and diminished capacity to manage life skills, sensory input, and/or social interactions, which comes from years of being severely overtaxed by the strain of trying to live up to demands that are out of sync with our needs."

(National Autistic Society's webpage on understanding autistic burnout).

Meltdowns and shutdowns

Autistica describe meltdowns and shutdowns as "reactions to extreme distress. Meltdowns involve a range of behaviours which may include self-injury, crying, shouting, rocking and other outward signs of distress. Shutdowns are similar to a 'freeze' response, where someone may struggle to communicate or move. Meltdowns and shutdowns can happen from stressors such as sensory overload, social overwhelm, uncertainty and unexpected changes" (Autistica Public Transport Report).

Sensory differences

The National Autistic Society explain that "processing everyday sensory information can be difficult for autistic people. Any of their senses may be over- or under-sensitive, or both, at different times. These sensory differences can affect how they feel and act, and can have a profound effect on a person's life" (National Autistic Society).

To learn more, here is a weblink to the <u>National</u> <u>Autistic Society guide for all audiences about sensory differences, NDTi's supporting autistic people flourishing at home and beyond: considering and meeting the sensory needs of autistic people in housing and <u>Miguel Jiron's Sensory Overload video.</u></u>

Alexithymia

Autistica explain that "around a half of autistic people have difficulties understanding and describing their own emotions. This is known as Alexithymia. Alexithymia can make anxiety feel worse for autistic people" (Alexithymia | Autistica).

To learn more, here is a weblink to <u>Autistica's</u> <u>video anxiety in autism explained</u>. This video talks about stimming and alexithymia too.

Anxiety

Anyone can experience anxiety. It is common to feel anxious when in a stressful or challenging situation. However, some autistic people may feel anxious in their day-to-day lives due to navigating social and sensory environments that might be difficult or challenging. Research suggests autistic people are more prone to experiencing anxiety and estimates that up to half of all autistic people experience high levels of anxiety on a regular basis. If you or someone you know is struggling with high levels of anxiety, there is support and help available.

Co-occurring conditions

The National Autistic Society explain that "autism is often diagnosed alongside other conditions. It's important to support people with more than one condition in a way that meets all their needs, while understanding that the needs that arise from being autistic are distinct" (National Autistic Society).

To learn more about different co-occurring conditions, here is a weblink to the National Autistic Society where this is discussed in more detail.

Diagnostic overshadowing

The Local Government Association suggest "Diagnostic overshadowing occurs when clinicians or caregivers attribute a person's symptoms or behaviours to their autism and / or learning disability diagnosis without considering other potential causes, such as medical conditions, mental health issues, or other neurodevelopmental conditions" (Local Government Association).

To learn more, here is a webpage to <u>Local</u> <u>Government Association's report on diagnostic overshadowing</u>.

Stimming

The National Autistic Society describe stimming as: "Stimming or self-stimulating behaviour includes arm or hand-flapping, finger-flicking. rocking, jumping, spinning or twirling, headbanging and complex body movements. It includes the repetitive use of an object, such as flicking a rubber band or twirling a piece of string, or repetitive activities involving the senses (such as repeatedly feeling a particular texture). Many non-autistic people stim. Although stimming varies from person to person, the reasons behind it may be the same: for enjoyment an attempt to gain sensory input, e.g. rocking may be a way to stimulate the balance (vestibular) system; hand-flapping may provide visual stimulation an attempt to reduce sensory input, e.g. focusing on one particular sound may reduce the impact of a loud, distressing environment; this may particularly be seen in social situations to deal with stress and anxiety and to block out uncertainty" (National Autistic Society's webpage about stimming).

To learn more, here is a webpage to the National Autistic Society's information about stimming.

Identity and intersectionality

In a video from the National Autistic Society Embrace Autism Series, the National Autistic Society talks about intersectionality being anything "that is a part of your identity and that is a part of who you are, that might impact how you navigate the world and also, how the world might perceive you. Intersectionality is the acknowledgment that everyone has their own unique experience of discrimination and oppression, and we should consider everything and anything that can marginalise people - gender, race, class, sexual orientation, physical ability etc. To help you with this, we've got resource documents on the National Autistic Society's Embrace Autism web page that you can access and be sign posted to various organisations that cover a range of intersectionalities" (National Autistic Society).

To learn more, here is a weblink to the <u>National</u> <u>Autistic Society's identity and intersectionality</u> <u>video: Embrace Autism Series</u>.



Camden All-Age Autism Strategy 2025 – 2030

