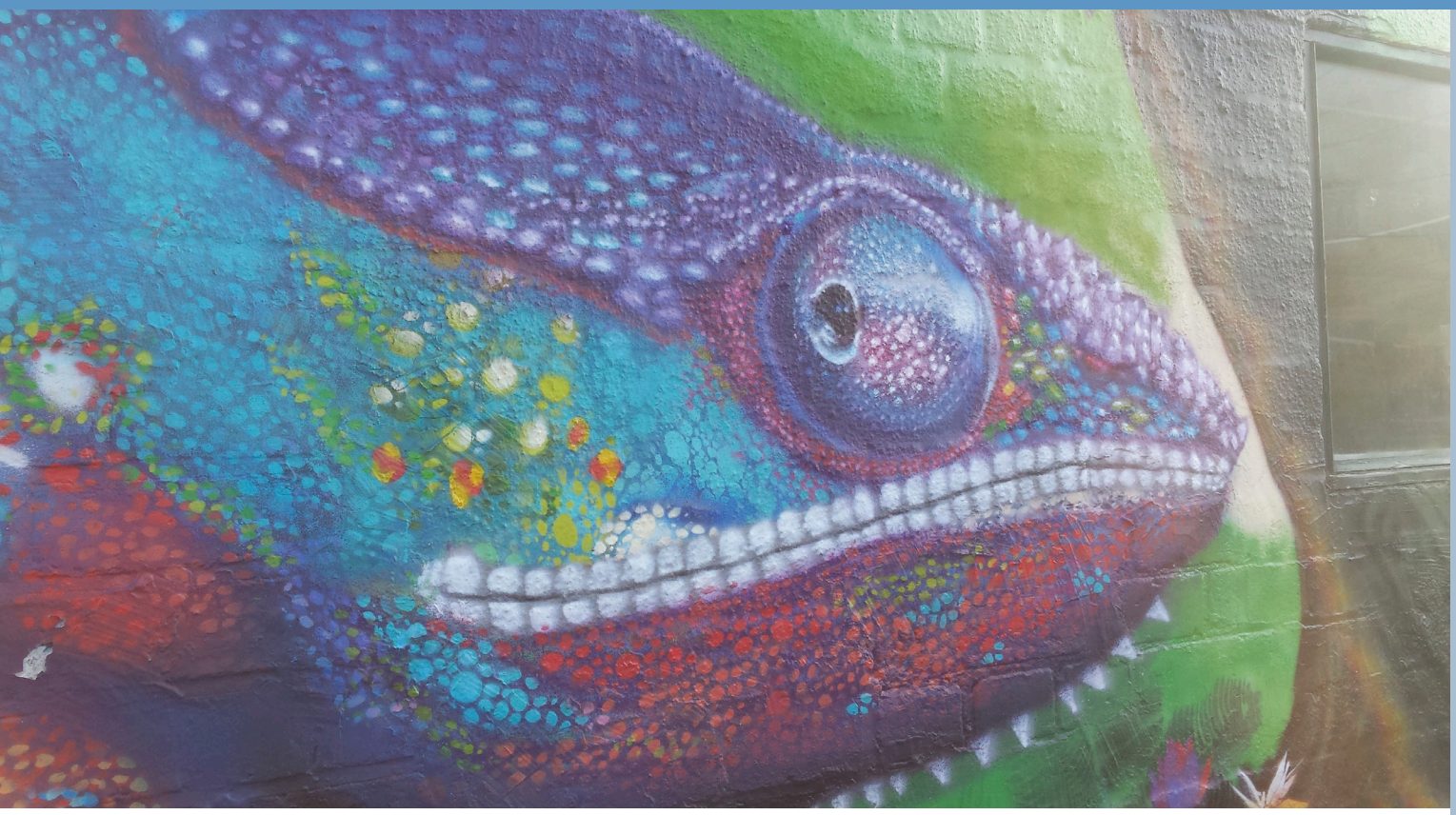
research in practice

Frontline Briefing



Autism inclusive practice

Dartington

www.researchinpractice.org.uk

1 Introduction

This Frontline Briefing offers a way forward to those who wish to make their practice more inclusive of autistic people and their families. Autistic people can feel excluded and invalidated by health and social care practices and the briefing aims to support practitioners in recognising and addressing these issues, while working towards an inclusive and strength-based approach.

The legislative focus of the *Autism Act 2009* is on adults. However, the revised *National Strategy* due to be issued in 2020 will (for the first time) include under 18s. Since autism is a lifelong condition, the principles in this briefing should also apply in most children and young people's circumstances.

A note on language

In any sphere, it is important to use language that is acceptable to the people we are working with. This can help dispel myths, support person-centred practice, and promote positive views. The descriptors used here are those accepted as current usage **but it is important to be aware** that not every autistic person prefers the same descriptive terms, and terminology in any field will develop over time.

Throughout the briefing autistic person is used, rather than person with autism. Although not universal, this is felt to be most acceptable to self-advocates and groups of autistic people. Such usage reflects wider identify-first language. Supporting consultation and research on identity-first language in autism can be found on the National Autistic Society website: **www.autism.org.uk/describingautism**

The term *Autistic Spectrum Condition* (ASC) is preferred, rather than the clinical term Autistic Spectrum Disorder (ASD). This is to avoid the stigmatisation that can accompany the term 'disorder' (although quotes from organisations and authors using the term disorder have been left in their original form). Thinking of difference, instead of deviance or disorder, is crucial to inclusive practice with autistic people.

Wherever possible, this briefing doesn't use terminology such as 'deficits', *complex needs* and *high functioning*. This is to challenge negative assumptions, that only some autistic people have 'complex' needs; that those with 'complex' needs can't function at 'high levels'; and that people labelled as 'high functioning' are not in need of care and support.

Neurodivergence is a more recent inclusive term that places autistic people alongside others with processing differences – people whose brains do not function in 'neurotypical' ways, and often in ways that differ from societal norms. The briefing also assumes the social model of disability whereby it's the society that a person lives within that can be disabling, not necessarily their individual differences.

Reflective questions

> What other uses of 'deficit' language can you think of that you have come across in your everyday practice?

> What sort of impact do you think hearing such language on a constant basis may have on an autistic person's view of themselves and their capacity to participate and contribute?

2 Background

What is autism?

Autism, as defined by the National Autistic Society (www.autism.org.uk/about/what-is.aspx) is a 'lifelong developmental disability' that affects how a person communicates with and relates to other people, and how they experience the world around them'.

The clinical definition is derived from the American Psychiatric Association's DSM-5 (2013) which primarily refers to:

- Persistent deficits in social communication and interaction across multiple contexts.
- Restricted, repetitive patterns of behaviour, interests or activities.

There were substantial increases in rates of autism diagnoses in the 1990s in the UK. This is thought to stem, at least in part, from changing and broadening diagnostic criteria alongside greater professional and public awareness (Taylor et al., 2013; Murphy et al., 2016). However, access to autism diagnosis is highly variable across the UK and the assessment tools used differ from locality to locality (Hayes et al., 2018). Nevertheless, there is some evidence that assessment and diagnosis tools are becoming more sophisticated and inclusive (Galanopoulos, Robertson & Woodhouse, 2016).

Prevalence

The current accepted rate of autism in the general population is approximately one in a hundred people, or 1.1 per cent. The National Autistic Society (www.autism.org.uk/about/what-is/myths-facts-stats.aspx) estimates that there are around 700,000 autistic people in the UK.

More males than females are diagnosed with autism, with the rate in the last decade thought to be four male to one female; recent research suggests the ratio is close to three males for every one female (Loomes et al., 2017). The male to female diagnostic ratio has been challenged, with some research suggesting that girls and women are more likely to have their autism overlooked.

Reasons for this may include autistic girls and women being more likely to 'mask' their autistic traits, as well as bias from practitioners who assume autism is primarily a male condition (Loomes et al., 2017) or in the way that assessment criteria have been developed as a result of research predominantly based on groups of males. Research also suggests that children and adults from black, Asian and minority ethnic (BAME) groups can experience difficulties and delays with obtaining an autism diagnosis (Slade, 2014; Begeer, 2008).

Older people often do not receive an autism diagnosis (Mukaetova-Ladinska et al., 2012), and autism and aging has been recognised as an area that needs to be researched, since current knowledge is limited (Murphy et al., 2016). The impact of under-diagnosis in older adults may be difficulties with social isolation at home or in residential care, possibly with physical and mental health difficulties; while family, carers, and health and social care practitioners may not realise the person may be autistic (Roestorf et al., 2019).

Taken together, this suggests that diagnostic rates should be higher. In response, the Department of Health and Social Care (DHSC) is putting measures in place to improve diagnostic data collection and analysis (www.digital.nhs.uk/data-and-information/publications/statistical/autism-statistics/autism-statistics/data-quality), which should support better knowledge in the future.

‘Treatments’ for autism

While some of the physical, emotional and psychological impacts of living with autism can be mitigated by timely health and social care assessment and support, autism is a lifelong condition that cannot be cured. NICE has issued guidelines and quality standards: **www.nice.org.uk/guidance/qs51** on the management of autism in adults: **www.nice.org.uk/guidance/cg142** and under 19s: **www.nice.org.uk/guidance/cg128**.

These guidelines recommend psychosocial interventions (Quality Statement 5), but do not recommend medication (Quality Statement 6) due to no evidence of effectiveness, and potential risks.

The Westminster Commission (**www.westminsterautismcommission.wordpress.com**) on autism, an independent cross-party group working alongside leaders from the autism sector, has identified a growth in ‘fake cures’ for autism. These are pseudo-scientific therapies, treatments and interventions with no evidence base. These can range from treatments with no effect (such as chelation therapy, which supposedly removes mercury from the body), to the administration of diluted bleach, which can be harmful and a potential safeguarding issue. The NHS has issued guidance **(www.nhs.uk/conditions/autism/autism-and-everyday-life/fake-and-harmful-treatments)** on these fake and harmful treatments.

Many autistic people are critical of ABA (Applied Behaviour Analysis), a common treatment for autism (see: **www.spectrumnews.org/features/deep-dive/controversy-autisms-common-therapy**). A core criticism is that it that it seeks to ‘normalise’ autistic children and adults, rather than understand and work with their strengths and differences and allow them to be who they are.

Reflective questions

- What might the impact be on autistic people of hearing about or experiencing fake or non-evidence-based therapies?
- Why might fake treatments for autism be attractive in the first place?
- What considerations may arise for practitioners?

Legislation and guidance

Autism is unique - it is the only long-term condition with its own statutory framework. The *Autism Act 2009* (**www.legislation.gov.uk/ukpga/2009/15/contents**) applies to adults aged 18 and over in England (Scotland and Wales have separate strategy and guidance). The *Autism Act* was followed by the 2010 implementation guidance, Fulfilling and Rewarding Lives: **https:/webarchive.nationalarchives.gov.uk/20130104203954/http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_113369**.

As a result of a review of the 2010 strategy, and following widespread consultation, *Think Autism* (**www.gov.uk/government/publications/think-autism-an-update-to-the-government-adult-autism-strategy**) was issued by the Government in 2014 and updated the vision outlined in Fulfilling and Rewarding Lives. *Think Autism* set fifteen challenges for action, primarily for adults aged 18 and over, within three main areas:

1. An equal part of my local community.
2. The right support at the right time during my lifetime.
3. Developing my skills and independence, and working to the best of my ability.

Reflective question

> Looking at the 15 'I' *Think Autism* statements (Appendix One on page 18), how far do you think we have come in achieving these for autistic people since 2014?

Think Autism was reinforced in 2015 by the publication of Statutory Guidance (**www.gov.uk/government/publications/adult-autism-strategy-statutory-guidance**), which sets out the requirements placed upon local authorities, NHS bodies and NHS Foundation Trusts across nine areas:

1. Training
2. Identification and diagnosis
3. Transitions (from children to adults)
4. Planning of local services
5. Preventative support
6. Reasonable adjustments
7. Complex needs
8. Employment
9. Criminal Justice

An Autism Executive Board co-chaired at high level within the DHSC with an autistic self advocate currently monitors progress (**https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/492641/Think_Autism_CONTRAST.pdf**) against *Think Autism*, drawing from evidence derived from the Autism Self-Assessment Framework (SAF) (**www.gov.uk/government/publications/autism-self-assessment-framework-exercise**). The House of Commons library published a briefing in 2019 summarising UK autism policies and services (**https://researchbriefings.parliament.uk/ResearchBriefing/Summary/CBP-7172**).

As set out in the *Autism Act 2009* and the supporting guidance, someone with an autism diagnosis should receive a Community Care (now *Care Act 2014*) assessment. The *Care Act* requires that agencies assess for health and wellbeing and take a preventative approach and, in theory, made it easier for assessors to assess the holistic needs of autistic individuals.

Where someone does not have, or is on the waiting list for an autism diagnosis, it is good practice to assess against presenting needs rather than wait for a clinical label to trigger assessment and support. The National Autistic Society has produced a guide for local authorities on good practice in assessing autistic adults under the *Care Act*, as have the Autism Alliance: **www.autism-alliance.org.uk/wp-content/uploads/2019/09/Assessment-checklist-guidance-v2.pdf**

Alongside the statutory guidance is a set of advisory guidelines for children's and adults' practitioners from the NICE National Institute for Health and Care Excellence: **www.nice.org.uk/guidance/qs51**

Reflective questions

> How familiar are you with the legislation and guidance around autism?

> Do you know who your local authority, CCG or NHS Trust autism lead is?

Evidence from the 2016 and 2018 Autism Self-Assessment Framework returns (**www.gov.uk/government/publications/autism-self-assessment-framework-exercise**) indicate that, whilst some progress was made after the introduction of the *Autism Act*, it had slowed or regressed by the 2018 SAF and by the time of the 2019 All Party Parliamentary Group Report on Autism that 'not enough has been done locally and nationally to make sure that the Act is being enforced' (**www.pearsfoundation.org.uk/news/rachel-franklin/the-autism-act-10-years-on**). The *Autism Strategy in England* will be renewed in 2020.

3 Autism and everyday life

The phrase 'Once you've met one person with autism...you've met one person with autism' makes it clear that autistic people's experiences can be very different. What may work with one autistic person may not work with another – it might not even work with the same autistic person on a different day.

Autism impacts on the lives of autistic people in many ways. While a basic guide to the 'signs' or 'symptoms' of autism can be found on the NHS website (**www.nhs.uk/conditions/autism/signs/adults**), a core principle is for practitioners to be aware of *difference* – how autistic people may experience the world differently both from non-autistic people and from other autistic people.

Not recognising these differences can place an autistic person at a disadvantage. For example, underpinning instances of so-called 'shutdowns' (where a person partially or completely shuts themselves off from the outside world) or 'meltdowns' (often expressed in supposed 'challenging behaviour') is often an autistic person's reaction to sensory triggers. Only seeing the behaviour of a 'shutdown' or 'meltdown' rather than the stimuli that caused it can, along with pre-existing stereotypes, contribute to stigma and labelling (Hurley-Hanson et al., 2019).

Some research suggests that where social workers tend to hold positive, strengths-based attitudes to autistic people (Haney & Cullen, 2018) they will have a foundation for inclusive practice. Person-centred working is as important here as with any other individuals. Getting to know the person, understanding that person's needs and strengths, likes and dislikes, and building knowledge about their triggers is central to autism inclusive practice.

Reflective question

> What do you need to know about an autistic person's strengths and differences, particularly sensory, that may impact on their behaviours?

Sensory differences

Autistic people can have different ways of sensory processing and be hyper or hypo sensitive to noise, light, touch, taste and smell. Sometimes, people may be hyper in one aspect, but hypo in another. This can mean that autistic people may have a highly variable range of sensory experiences (DuBois et al., 2017; Tavassoli et al., 2018), which can lead to difficulties across a range of contexts.

The looks and smells of everyday items may be unbearable to some autistic people yet hardly noticed by others. Some autistic people may display a liking for, or be strongly averse to, particular visual shapes or patterns like those found on carpets or wallpaper, or everyday smells like cleaning chemicals and perfumes. Autistic people may have a strong preference for or aversion to the feel of certain clothing, leading to refusals to wear confining and/or discomforting uniforms, or the desire to always wear one particular item of clothing. There may be an attraction to textiles or shapes, which can lead to perceptions of inappropriate touching of other people's clothes or hair. The National Autistic Society has further information and examples (**www.autism.org.uk/about/behaviour/sensory-world.aspx**) of sensory differences that may be experienced by autistic people.

Sensory difference can cause distress in public places (Marco et al., 2011). For example, someone who may be hyper sensitive to noise and light could find the input in a busy shopping centre overwhelming. Low level buzzing made by electric lights, or a fridge, may not be picked up by other people - but can sound loud and invasive to an autistic person.

Sensory difference may also affect how autistic people react to health and social care practitioners. Some autistic people may be hypertensive to touch, experiencing extreme anxiety during clinical assessments or appointments such as those at dentists (Thomas et al., 2017). Sensory difference can also lead to misunderstandings by professionals – such as interpreting a preference for strong or bland-tasting foods as eating disorders (Cermak et al., 2010).

Autistic people may also have differences with the sixth and seventh senses, vestibular (relating to movement and balance) and proprioceptive (relating to body position and muscle control) (Imperatore Blanche et al., 2012; Kern et al., 2007).

With vestibular difference, some autistic people will avoid movement, for instance in cars or at funfairs, and others will actively seek out movement, such as on swings and trampolines. If an autistic person experiences proprioceptive difference, the person may appear to be rigid and uncoordinated, possibly avoiding physical movement; on the other hand, another autistic person may be fidgety, or actively seeking out physical activity and contact with objects or people, or perhaps becoming more alert after exercise.

Stimming, or self-stimulative behaviours, such as playing with a paper clip under a desk, or repeated actions with a favoured object, or flapping, or continued rocking on an axis – are thought to be ways of imposing control, calming, and communicating intense emotions (Kapp et al., 2019). Stimming can also be present alongside the need for calming colours, lights or sounds. Appreciating how an autistic person may experience an environment, for example by attending a sensory workshop, can support practitioner confidence and sensitivity around stimming.

Such sensory differences can combine with a need to *focus* on particular topics or aspects of a conversation, or a need for tasks to be done in an expected sequence at expected times of the day (Planche, 2002). An autistic person may also have difficulties in *self-organisation*, being unable to deconstruct tasks such as homework or the fact that crossing two shoelaces is supposed to come before the tying of two shoe laces. Some can find it extremely hard to organise essential everyday activities within the available time; and the perception of time itself might also be difficult for an autistic person to process (Casassus et al., 2019).

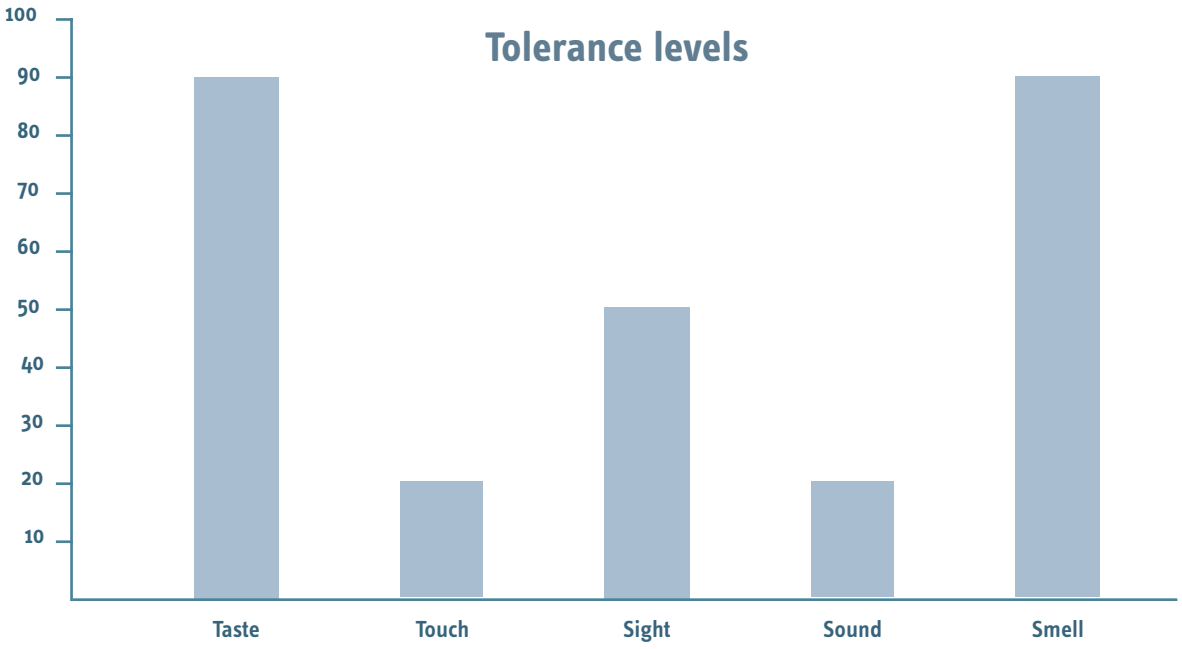
The National Autistic Society's 2017 campaign and film, Too Much Information, demonstrates the impact of 'sensory overload' on one individual. Details, and the accompanying video, can be found here: **www.youtube.com/watch?v=Lr4_dOorquQ&safe=active**

Reflective questions

> In the chart highlighting tolerance levels, the individual can tolerate and has a preference for high levels of taste and smell, but has an aversion to anything but low levels of touch or sound.

> What might be the issues to consider when assessing and planning day opportunities with them? What do you think the impact of consistently high anxiety levels could be for an autistic person?

Example - Individual sensory profile across the five senses: Person A



Communication and social interactions

Eye contact can be difficult or feel painful for autistic people (Rajiv Madipakkam et al., 2017). This can be made to feel worse by social expectations around communication. *Masking*, where autistic individuals attempt to display behaviours that are expected of them in order to avoid stigma and conflict and gain acceptance – in class, social group or the workplace, is common (Hull et al., 2017). However, there is also some research that suggests autistic people are aware of their strengths, and can be critical of the social norms that they are expected to adhere to (Spath & Jongsma, 2019).

Autistic people may also struggle with other social conventions, such as when (and when not) to interject in a conversation. There can be a cognitive processing delay which makes keeping up with conversation or following instructions difficult, and the presence of echolalia - the repetition back of a part of a heard sentence - may wrongly indicate an understanding of that comment or instruction (van Santen et al., 2013).

Autistic people may also not be able to decode when people are saying one thing but meaning another, find it difficult to tell lies and, in particular, may find it difficult to tell half-truths or 'kind lies', or to keep a consistency between an initial lie and further statements (Li et al., 2011). Giving 'a straight answer to a straight question' can cause difficulties in communication. This may mean that autistic people can also be more vulnerable to exploitation – especially if a close friendship may be in prospect (Fisher M et al., 2013).

Autistic people may not be able to decode body language, and can struggle with personal spatial distance. For some the usual standards of personal proximity are too close; and others find it difficult to recognise that personal space matters at all, and are perceived as constantly 'invading' others' space or of over-sexualised behaviour (Asada et al., 2016). Participating in groups or meetings can be extremely exhausting, as can sitting a metre across a table from an assessor or interview panel.

Autistic people are often thought to be without empathy for others and unable to feel and understand emotion, a myth challenged by Damien Milton in his work on double empathy (**https://network.autism.org.uk/knowledge/insight-opinion/double-empathy-problem**) (Milton, 2018). Here, if interaction is usually two-way, then communicative difficulties will also be two-way. Thus, although autistic people are commonly thought to be without empathy, society also makes little effort to empathise with autistic people who themselves claim they can feel things more intensely than others but struggle to express their feelings. It is others who fail to recognise this – in other words, empathy works both ways.

Co-occurring conditions

Like anyone, autistic people can live with a variety of physical and mental health conditions. However, there are some conditions that have a higher incidence in autistic people: Attention Deficit Disorder (ADD) / Attention Deficit Hyperactivity Disorder (ADHD), Pathological Demand Avoidance (PDA), and epilepsy, for example (Gillberg & Billstedt, 2001; Cusack et al., 2016). There are also higher incidences of learning disabilities in autistic people, although the relationship is complex (O'Brien & Pearson, 2004).

Attention Deficit (ADD) or Attention Deficit Hyperactivity (ADHD) 'disorders' are where someone's ability to pay attention and stay focused can affect learning and participation (Rosello et al., 2018). *Pathological Demand Avoidance* (PDA) is beginning to be accepted as a potential 'characteristic' of autism but it is a condition that non-autistic people can also have. It presents as the avoidance of expectations and tasks, at times instinctive and reactive, at others extremely well thought out and pre-planned – although research into PDA is in its infancy (Egan et al., 2019).

Some research has shown that autistic people may be at greater risk of traumatic and stressful life events (Fuld, 2018; Cusack et al., 2016) – and levels of anxiety and depression can be higher in autistic people, understandable when living with an array of differences in what can be a confusing world – which can then have an impact on key aspects of everyday life (**www.autistica.org.uk/what-is-autism/signs-and-symptoms/anxiety-and-autism**). See, also, **www.autism.org.uk/about/behaviour/anxiety.aspx.** Suicide rates are 16 per cent higher in autistic people than in the general population (Harper et al., 2019).

There may also be a lack of engagement with, or access to, health care – something specifically earmarked for action in the *NHS Long Term Plan*, which commits to piloting a specific health check for people with autism (NHS England, 2019).

Impact on everyday lives

Autistic people can have engaged and productive lives and there are many positive aspects of autism. Some autistic people are very adaptable and manage to adapt to challenging external circumstances, finding ways to achieve in their personal or public lives (although this can come with an impact on their physical and psychological energy levels) (Russell et al., 2019). However, many autistic people struggle, in varying degrees, to meet external expectations in what can feel like a confusing and often hostile world.

Mainstream education can be a difficult experience for some autistic people (Goodall, 2018). This may not always be obvious. Some autistic people who are adept at 'masking' may quietly comply with conventions and instructions, rarely display 'behavioural issues', yet may be struggling to keep up with rigid curriculum demands; others may feel isolated, unsupported and misunderstood (Goodall, 2018).

Autistic people are also thought to be over-represented in the criminal justice system (Pearce & Berney, 2016). This is partly because of an autistic person's susceptibility to inducements to commit criminal acts, including the desire to please somebody in order to develop a closer relationship; but it may also be through difficulties with expressing thoughts or emotions, or not being able to think beyond the impact of an action (Pearce & Berney, 2016).

Hate crime against autistic people is thought to be an issue, and autistic people can also be more vulnerable to 'mate' crime - where others will give the impression of making friends with a vulnerable person with the intent of exploiting that person for personal financial, psychological or sexual gain. Autism Together has produced autism-friendly information on how to spot and report hate and mate crimes: **www.autismtogether.co.uk/hate-crime-reporting**

Stigma can also extend to the families of autistic people, with misconceptions regarding the behaviour of parents, siblings and carers. Myths of bad parenting and poor attachment as causes for autism or autistic behaviours persist, and parents can feel blamed for their child's difference (Lodder et al., 2019). In fact, families have often not been provided with the knowledge and skills to support an autistic person (Crane et al., 2018).

Ask, don't assume, is always a good mantra when thinking about the impact somebody's autism has on their everyday life and family. Further resources on autism and safeguarding can be found on the National Autistic Society website: **www.autism.org.uk/professionals/health-workers/safeguarding.aspx**

Transitions

There are likely to be several transition points for autistic people. Good preparation for, and positive support during, these transitions is important because, for some autistic people, moving on from established routines, environments and processes to new ones can cause difficulties (Sevin et al., 2015). Coping strategies, such as stimming or masking, may increase during times of transition. 'Transition strategies' are a central part of support, as highlighted by the National Autistic Society: **www.autism.org.uk/about/behaviour/preparing-for-change.aspx**

The following table outlines some typical life 'pinch points':

Approximate Ages	Event
0-7	First entry into more social and, therefore, challenging and anxiety-inducing environments, such as nursery to junior school.
7-11	From junior education to the bigger 'pond' of secondary education.
13-19	Teenage years, when emotional and physical growth hormones and expectations form a perfect storm - together with a growing realisation of 'otherness'.
16-19	Going from structured lower school to more self-directed sixth form in upper school, even when it's the same school or college.
16-21	Leaving school to go to university or into employment at all levels – very possibly with intervals of unemployment or low-level jobs and potentially low income.
14-25	First relationships and then a point in the late twenties and early to mid-thirties where others are 'settling down' in long-term relationships.
16-40	Maternity and parenthood - with drastic changes to established routines, neurotypical expectations of parenting, and where demands and incoming stimuli increase.
25-35	Contemporaries/friends begin to 'settle down' into jobs and personal partnerships.
25-45	Difficulties in sustaining employment where individuals leave jobs because of difficulties and/or the lack of support around managing strategies and career progression.
25-45	Difficulties in initiating and sustaining relationships. This can occur at all ages, but particularly 25-45 when things go wrong, with little access to maintenance or repair skills.
35-55	Middle to later life - when the likelihood of a permanent relationship, entrenched behaviours and poor career prospects combine to re-emphasise the otherness and loneliness. Autistic women may also experience some aspects of menopause differently.
50+	When the reality of continued isolation and prospect of retirement or continued unemployment difficulties hits.
70+	Older age when being 'cared for' increases the potential for inflexible processes and procedures, and sensory-invasive environments and practices.

4 Autism inclusive practice

Person-centred reasonable adjustments

The social model of disability, outlined by Disability Wales (**www.disabilitywales.org/rights/social-model**), underpins the concept of reasonable adjustments. Its guiding principle is that it is the environment and practices that someone is subject to that are disabling, *not* the condition of the person. The *Equality Act 2010* (**www.legislation.gov.uk/ukpga/2010/15/contents**) underpins this. Autism comes within the Act's definition of disability, and therefore it carries the expectation that employers and service providers will make reasonable adjustments.

Determining reasonable adjustments for autistic people can be difficult, given the hidden nature of autism and the diverse and sometimes unpredictable nature of autistic characteristics. However, reasonable adjustments are more likely to be required in the sensory and spatial aspects of environments and to standard process and practices, since autistic people are more likely to be disadvantaged by these.

This can be seen in working environments. Being in open-plan offices with high levels of noise and distraction can be unbearable for some autistic people, as can the expectation to participate in meetings, or attend interview processes (National Autistic Society, 2016).

In health and social care, an autistic person may experience difficulty with processes and environments where assessment and care planning begins. It may be because of a physical environment, such as an organisational office or interview room. Autistic people may find triage, assessment or interviews over the telephone difficult and will struggle to process and answer complex three-part questions. Therefore, it's better to split them up and give the question in written form as well as verbally. Unclear instructions and lengthy forms may also be a challenge. Interviews and assessments, even with strengths-based and outcome-focused approaches, may also be stressful (SCIE, 2011).

Reflective question

> Where are the 'points of entry' to your organisation for autistic people and have those points been audited for autism inclusion?

Training sessions, especially those co-produced and co-delivered by autistic people, can be a good way for practitioners to gain insight into the experiences of autism, learn about positive behaviour support (**www.cqc.org.uk/sites/default/files/20180705_900824_briefguide-positive_behaviour_support_for_people_with_behaviours_that_challenge_v4.pdf**), and improve practice. Details can be found at the British Association of Social Workers (**www.basw.co.uk/the-capabilities-statement-social-work-autistic-adults**) and Health Education England Competencies (**www.skillsforhealth.org.uk/services/item/945**). The Department of Health and Social Care also issued a response to a consultation on mandatory autism training in December 2019: **https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/844356/autism-and-learning-disability-training-for-staff-consultation-response.pdf**

Good practice examples

While it's really important to learn from good practice elsewhere, fitting the person within pre-existing frameworks is less helpful than adopting wider person-centred practice principles. Keeping the individual at the centre is the best way to work with the many potential permutations and adjustments an autistic person may need. Using the guides and frameworks signposted in this briefing as a springboard for reflecting on individual need is a positive way to do this.

The Greater Manchester Autism Consortium Reasonable Adjustment Guide (**www.sheffieldautisticsociety.org.uk/wp-content/uploads/2019/02/GMAC-Reasonable-Adjustment-Guides-2018.pdf**) provides a detailed breakdown of the type of adjustments autistic people may require across a range of settings, including in health and social care.

The guide breaks reasonable adjustments down into four components:

1. **Premises** - where an interaction takes place.
2. **Processes** - which the autistic person is being asked to undergo.
3. **Communication** - the methods that will be used;
4. **Planning and preparation** - activities that should be undertaken before the interaction to ensure it is autism-inclusive.

Reflective question

> Consider the sensory profile of the person in section 3. What might be the reasonable adjustments to consider across the four categories above?

Other useful examples of templates and frameworks include a one-page profile template from Helen Sanderson Associates (**www.helensandersonassociates.co.uk/person-centred-practice/one-page-profiles/one-page-profile-templates**) and useful resources from the Social Care Institute for Excellence (**www.scie.org.uk/person-centred-care/one-page-profile/what-is**).

Good practice examples

After self-advocate feedback, a national organisation conducted interviews for positions on its Governance Board using a quiet, spacious room and plain walls with limited distractions and variable lights. It ensured no three-part questions were asked, provided printed copies of the verbal questions and a flip-chart for interviewees to draw on rather than simply describe answers.

In another example, a hotel was the setting for a workshop attended by autistic people. Before the workshop, the hotel took photos of the workshop rooms and emailed them to the delegates. They also provided clear directions to the hotel, with information on how to navigate spaces within the hotel, again supported by photographs.

Other good practice examples and supporting resources can be found on the Think Local Act Personal (**www.thinklocalactpersonal.org.uk**) and National Development Team for Inclusion (**www.ndti.org.uk**) websites.

Good practice example

Autism East Midlands has a clear structure for the involvement of autistic people they support called Voice, with a two-way interactive 'golden thread' running from individuals to the Board of Trustees. This is supported by a clear set of principles and training, which uses a variety of methods to gather and share information, and influence decision-making in recognition that different people need to contribute in different ways.

www.autismeastmidlands.org.uk

Practitioners can use strength and asset-based work with autism – because, as well as challenges, autism can bring a number of positives to people's lives (Russell et al., 2019). As an example of strengths, resiliencies and unique characteristics of autism, a poster produced by Leeds University (**www.leeds.ac.uk/forstaff/news/article/5897/working_with_students_on_the_autism_spectrum**) lists several positive qualities associated with autistic people:

1. Attention to detail
2. Deep focus
3. Observational skills
4. Absorb and retain facts
5. Visual skills
6. Expertise
7. Methodological approaches
8. Novel approaches
9. Creativity
10. Tenacity and resilience
11. Accepting of difference
12. Integrity

These are qualities any employer would value and Tony Attwood discusses such attributes in a positive light in his work on Discovery Criteria (**www.tonyattwood.com.au/index.php?option=com_content&view=article&id=79:the-discovery-of-aspie-criteria&catid=45:archived-resource-papers&Itemid=181**). He argues that setting out to identify an autistic person's strengths or talents can change the process and outcome of professional practice.

Co-production, defined under the *Care Act* as '...when you as an individual influence the support and services you receive, or when groups of people get together to influence the way that services are designed, commissioned and delivered', goes hand in hand with person-centred, assets-based approaches. More detail can be found at TLAP: **www.thinklocalactpersonal.org.uk/co-production-in-commissioning-tool/co-production/In-more-detail/what-is-co-production**

5 Conclusion

Autism inclusive practice can be achieved by remembering that each autistic person will have their own set of differences, needs, and strengths. Good person-centred assessment planning, flexibility around reasonable adjustments, careful use of language, co-production with autistic people, and awareness training co-delivered by autistic people will all support autism inclusive practice. This approach is in line with statutory requirements, health and social care competency frameworks, best practice, and what autistic people themselves advocate for.

Learning points for practice

	Practice challenge	Towards inclusive practice
1.	Autism is a lifelong spectrum condition that cannot be treated nor cured.	Whilst some of the day-to-day consequences of living with autism can be clinically treated, such interventions are mainly crisis related and so only temporary. Practitioners can focus, via strengths-based working, on an autistic person's strengths and resiliencies rather than only the challenges of autism.
2.	It can be hard to assess what is inclusive for one person given the potential matrix of difficulties that autistic people can experience and the variable nature of such experiences.	Get to know the individual and their preferences. When assessing strengths and difficulties, attention to individual sensory and communication needs will pay off.
3.	An autistic person might experience 'shutdowns' and 'meltdowns' when triggered by certain experiences. This can lead to labelling for the autistic person as having 'challenging behaviours' or experiencing mental health 'crisis'.	Seeking to understand the meaning behind an autistic person's behaviour can help avoid individual and family distress, reduce stigma, escalation and, in some circumstances, restrictive interventions and admission to mental health beds.
4.	Reasonable adjustments to processes and environments for individual autistic people can be hard to assess and, therefore, implement.	Core principles can be applied to each individual's situation to best determine what will work best for them.
5.	The positives of autism need to be assessed and considered.	An assessment of an autistic person's strengths, and how best to build upon them to improve resilience, should form an equal part of support plans.

Reflective questions

	Issue	Learning point
1.	Avoiding autism myths	> Does your practice avoid, challenge and explore myths of what autism is? > Does your practice routinely question what is supposed to be 'best' for autistic people and their families?
2.	Behaviours	> Do you look behind an autistic person's behaviour, searching for its meaning, when assessing and supporting autistic people and their families?
3.	Environment and process	> Do you reflect on the processes that autistic people are expected to undergo, and the environments within which they take place? > Do you consider how these experiences might affect each autistic person differently?
4.	Assessment and care planning	> Are your processes and practices autism capable and, therefore, inclusive of autistic people?
5.	Strategic planning	> Does your locality have an Autism Partnership Board, attended by autistic people and parents, with an autistic co-chair and a co-produced joint autism strategy with key partners?
6.	Commissioning	> Does your area have a co-produced autism commissioning strategy based upon local consultation, addressing gaps identified in previous Autism Self-Assessment Frameworks and in line with the *National Autism Strategy* and *Good Practice Commissioning Guidance*?
7.	Person-centred support	> Is practical support to autistic people, their parents and siblings assessed and delivered from a position of autism inclusive practice, which starts with the person and doesn't try to shoehorn them into what already exists?
8.	Training	> Does your organisation have a comprehensive, tiered and targeted programme of generic and specialist autism training that is planned and delivered co-productively and to the national competency framework?
9.	Safeguarding	> Are safeguarding teams and chairs autism trained and aware of hate and mate crime experienced by autistic people, fake cures for autism, and how behaviours related to spatial or sensory needs can be misinterpreted?
10.	Statutory autism leads	> Each local authority is required to have a statutory autism lead. Do you know who this is, and do your corporate and member leads liaise with that statutory lead?

Appendix One: Think Autism Statements. Department of Health, London 2015.

An equal part of my local community

1. I want to be accepted as who I am within my local community. I want people and organisations in my community to have opportunities to raise their awareness and acceptance of autism.
2. I want my views and aspirations to be taken into account when decisions are made in my local area. I want to know whether my local area is doing as well as others.
3. I want to know how to connect with other people. I want to be able to find local autism peer groups, family groups and low level support.
4. I want the everyday services that I come into contact with to know how to make reasonable adjustments to include me and accept me as I am. I want the staff who work in them to be aware and accepting of autism.
5. I want to be safe in my community and free from the risk of discrimination, hate crime and abuse.
6. I want to be seen as me and for my gender, sexual orientation and race to be taken into account.

The right support at the right time during my lifetime

1. I want a timely diagnosis from a trained professional. I want relevant information and support throughout the diagnostic process.
2. I want autism to be included in local strategic needs assessments so that person-centred local health, care and support services, based on good information about local needs, is available for people with autism.
3. I want staff in health and social care services to understand that I have autism and how this affects me.
4. I want to know that my family can get help and support when they need it.
5. I want services and commissioners to understand how my autism affects me differently through my life. I want to be supported through big life changes such as transition from school, getting older or when a person close to me dies.
6. I want people to recognise my autism and adapt the support they give me if I have additional needs such as a mental health problem, a learning disability or if I sometimes communicate through behaviours which others may find challenging.
7. If I break the law, I want the criminal justice system to think about autism and to know how to work well with other services.

Developing my skills and independence and working to the best of my ability

1. I want the same opportunities as everyone else to enhance my skills, to be empowered by services and to be as independent as possible.
2. I want support to get a job and support from my employer to help me keep it.

Appendix Two: Derbyshire County Council

Top tips to help you communicate with someone living with autism

1. Be clear and precise with your language - using plain English.
   - Do not rely on the person to pick up on the meaning of your questions and body language
   - Avoid using open questions, words with double meaning and humour that could be misunderstood.
2. Give the person enough time to process and understand the information you are sharing.
3. Ask them what help they need.
4. Explain at every stage what you are about to do, what will happen next and when.
5. Be consistent in your actions and do what you say you will do.
6. Don't be surprised if there is lack of eye contact, unusual body language or if inappropriate language is used.
7. Respect repetitive behaviours; they might be someone's coping mechanism.
8. Think about the environment and be aware that some things cause sensory overload (for example, light, movement, sounds, smell and touch).
9. Back things up in writing.
10. Always consider the person's behaviour in terms of his or her autism, even if it becomes challenging.
11. **www.derbyshire.gov.uk/site-elements/documents/pdf/social-health/adult-care-and-wellbeing/disability-support/autism/top-tips-for-communicating-with-someone-with-autism.pdf**

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Research in Practice
The Granary Dartington Hall
Totnes Devon TQ9 6EE

tel 01803 869753
email ask@researchinpractice.org.uk

Author: Trevor Wright
InSightautismawareness@gmail.com

Cover photo: This artwork is part of a larger mural designed and painted by the artist Joe Coghlan, who worked in collaboration with young people with a diagnosis of autism during an artist residency at a Midlands SEN school. For more **information contact: joecoghlan@yahoo.co.uk**

With grateful thanks to:
Kevin Halden, Eric Heath, Oriana Morrison-Clarke, Tim Nicholls and Zandrea Stewart

Research in Practice is a programme of
The Dartington Hall Trust which is a company
limited by guarantee and a registered charity.
Company No. 1485560 Charity No. 279756 VAT No. 402196875

Registered Office:
The Elmhirst Centre, Dartington Hall, Totnes TQ9 6EL

ISBN 978-1-911638-36-0

www.researchinpractice.org.uk