Psychological Therapy for Autistic Adults

A Curious Approach to Making Adaptations

"Our aim is for a therapist to think from the autistic person's perspective"

Authentistic Research Collective

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Introduction

There is a strong rationale for psychological therapies to be adapted for autistic adults in order to reach the best possible outcomes, as research has shown outcomes are less favourable for autistic adults when compared to non-autistic adults (with this research focusing upon autistic adults without co-occurring learning disabilities). However, very little is known or widely available about how talking psychological therapies could best be adapted for autistic adults.

The 'Authentistic' group aimed to produce an accessible document for therapists, researchers, autistic adults and other interested parties, highlighting suggestions for adaptations that can be made to CBT, and highlighting existing gaps in knowledge. We acknowledge that there are other forms of therapy (e.g. art or drama therapy) where adaption for autistic adults may be more intrinsic, or some forms of therapy that do not easily allow for adaptations contained within this document.

Our collaboration was co-produced from beginning to end by a team of autistic and non-autistic researchers and clinicians. As a group, we felt it was crucial to have the safety and freedom to be our 'authentic' selves, reflected in our group name 'Authentistic', and defined by one group member as:

> "Authentic is when our actions and words are congruent with our beliefs and values. It is being ourselves, not an imitation of what we think we should be or have been told to be." GM 3

Our group name 'Authentistic' comes from a blending of authentic and autistic. A main aim of our group was to provide a space where all group members could be free to be their authentic selves, without the need to mask, and feel able to work in the manner in which they felt most comfortable. We wanted to create a safe space where people could be validated and accepted as themselves.

We have chosen to use "autistic person" throughout the document, firstly, for simplicity and consistency, secondly, due to our group's preference for identity-first language, and, lastly, in recognition of research that shows this is the preferred term for many autistic people. We do recognise that individuals have different preferences and that autism is referred to in many differing ways (e.g. ASD, ASC, Asperger's Syndrome, "Aspie"), and also respect that some people may prefer person-first language (e.g. person with autism). We have utilised "neurotypical" and "non-autistic" interchangeably throughout this document to identify people not on the autism spectrum.

We hope that this document, that draws on our own lived experience, will inform and inspire future practice-based research to improve CBT adaptations for autistic people.

Who are we?

We are a group of 7 autistic adults – from various backgrounds, including psychology, neuroscience, media and mental health – all 'late-diagnosed' with autism in adulthood (see Appendix 2 for our "Personal Profiles"), and one non-autistic psychologist and researcher. We are based across England and Wales, and we came together with a shared aim to co-produce a document that hoped to make Cognitive Behavioural Therapy (CBT) more accessible and applicable for autistic adults.

We recognised as a group, that it is important in any project for researchers to think very carefully how their own views and values have impacted on the research process and their goals.

Our team was made up of autistic and non-autistic members. The former shared some positive and negative experiences of therapy and were motivated by a hope to contribute with their experiences to ways that therapy could be improved in the future for other autistic adults.

We all shared the belief that, though autistic people can have very debilitating difficulties and co-occurring conditions, autistic people are valuable members of society and adaptations should be made to help autistic people live long and happy lives. We shared values of curiosity, respect, open-mindedness and, above all, authenticity. This had an effect on how we worked together in general and, specifically, how we thought about adaptations to CBT.

We have also reflected that autistic people form a large spectrum, therefore we felt it was vitally important to recognise we are not representative of the full diversity of autistic people, for the following reasons:

- All members of our group were diagnosed with autism in adulthood, so our life experience will differ from other autistic adults diagnosed in childhood;
- Our group does not reflect a diverse ethnic population;
- We are a group of young/middle-aged adults, so are not representative of all autistic people of differing ages;
- Our group was formed via online means, so may not be reflective of all social economic groups;
- None of our group members have co-occurring learning disabilities;
- All members of our group are able to communicate through spoken language, which is not reflective of the percentage of autistic people who are non-speaking or non-verbal;
- All of our group members have a strong interest in academic research, which may not be representative of the educational background/ academic interests/academic attainment diversity amongst autistic adults;

We reflect it is therefore important to include a great diversity of autistic people in future co-production projects, and to carry out many different projects with many different groups of autistic people. For example, autistic people with learning disabilities or those who are completely non-speaking might require different adaptations to CBT therapy than the ones we discuss within this document.

Therefore, although we all have a shared commonality of being autistic, we wish to strongly emphasise that we cannot be representative of all autistic perspectives.

What is autism?

“A relatively common neurodevelopmental condition, usually associated with normal range IQ, that represents a form of natural variation, bringing both challenges and strengths” (Mandy, 2019)

In its definition, autism has had a long journey from its first appearance in medical literature in the 1940s: a rare and narrowly defined ‘disorder’ in the past, it is now diagnosed as a dimensional spectrum, identifying autistic people in all their diversity.

Autism is a lifelong neurodevelopmental condition that brings both strengths and challenges to the autistic individual. Autism impacts upon the manner in which we, as autistic people, interact with and experience the world around us. The clinical diagnostic criteria summarise autism as difficulties in social interaction and communication, and the presence of restrictive or repetitive behaviours and interests. **While our autism is often characterised by our differences in social communication and interaction, we experience the additional challenge of non-autistic people having difficulty knowing or understanding what we, as autistic people, think or feel.**

The way that autistic people, like ourselves, process the surrounding environment creates areas of strength or difficulty, which are very individualised. We can possess a huge passion for our special interests, strong attention to detail and advanced technical skills or tremendous creativity, alongside strongly held values such as honesty and loyalty; yet, conversely, experience challenges such as differences in sensory-reactivity (over-sensitivity and under-sensitivity), and difficulty knowing and understanding what (usually non-autistic) people think or feel.

Autism is often referred to as a spectrum. However, it might be best not to think of it as a linear spectrum, as autistic people are not ‘more’ or ‘less’ autistic. Each autistic individual differs in the features of autism that they may exhibit, and this may also vary over our lifespan. How we present in our familiar environments may not be representative of how we present in other environments, particularly when we are in an unfamiliar setting.

> "I never make overarching statements like "As an autistic person …", as I feel there is such variability amongst autistic people (e.g. I am very quiet and reserved and tend to overthink all my responses, whereas I am aware that a differing autistic person may be more forthright when stating their opinion/thoughts). We are all so different … and also differ within ourselves in differing contexts and emotional states." GM 2

We therefore feel, as a group of autistic people who are all very individual and unique, that it is vitally important that clinicians understand autism varies widely. The way an autistic person relates to their diagnosis may also vary widely between individuals and over time in one person.

For instance, there are many ways that autism is still thought about: as a disorder that requires treatment and a cure, as a disability that needs environmental adaptations or as a difference – a component of neurodiversity. Some people may draw on all three or only one of these models, at one or different points in time.

Furthermore, some autistic people may not see autism as a "big deal", or an aspect of identity that requires special focus in therapy. Although we, as a group, feel positively about the idea of neurodiversity in relation to autism, we strongly acknowledge other autistic people might have very different understandings and we do not wish to minimise these.

We think it is essential for therapists to always hold a positive and hopeful stance when working with autistic people but also stress the importance of respecting autistic people's views regarding their diagnosis and, where appropriate, discussing such views in a curious, compassionate, sensitive and non-judgemental way.

The prevalence of autism

The prevalence of autism is thought to be 91.92 per 10,000 populations in a worldwide study (92 autistic people in every 10,000 people) which is equivalent to 700,000 autistic people in the UK. Autism is presently thought to be three times more common in men than women, but recognised to be underdiagnosed in women, adults, gender-fluid and non-binary people, those from ethnic minorities and those originating from lower social-economic groups.

In past years, autism was thought to be a rarity, but the increasing prevalence of autism is reflective of the greater recognition of the diversity of autism presentations. Firstly, the recognition that autism has historically been under-diagnosed in certain societal groups, as commented above; and secondly, the recognition that the current diagnostic methods do not adequately recognise differing presentations of autism, for example in women/girls/non-binary people, or adults without co-occurring learning disabilities.

Finally, our group felt, drawing upon our lived experience of receiving an autism assessment in adulthood, that access to diagnostic assessment will obviously impact upon the recorded prevalence of autism.

The difficulties of access to diagnostic assessment as an adult are multiple, and in our group's lived experience include:

- Persuading GPs or other health professionals to request an autism assessment for ourselves, often due to the GP's lack of knowledge of the presentation of autism in adults;
- The skill and knowledge of diagnostic clinicians: to recognise that camouflaging is highly likely to be happening within an autism assessment, which could skew assessment findings; and knowledge of the diversity of the presentation of autism in adults;
- In some areas of the UK, it is only very recently that adult autism diagnostic services have been available;
- Some adults may be able to afford a private autism diagnostic assessment if refused an autism assessment under the NHS, but due to social-economic reasons this will not be an option for everyone, again creating a bias in the current recorded prevalence of autism in adults;
- Waiting times on the NHS are often up to two years long;
- Other adults, who are likely to be autistic but undiagnosed, may prefer not to pursue an autism diagnosis, perhaps because they feel it would not enact any change in later stages of life, or possibly due to concerns about public stereotypes of autism, or concerns about experiencing stigma and/or discrimination in their employment, should an autism diagnosis be disclosed.

Diagnosis

Autism is currently clinically diagnosed through a combination of clinical behavioural observations and developmental history, coupled with comparison to the autism diagnostic criteria of ICD-10 and DSM-5.

It has been recognised that the concept of camouflaging and compensation (the masking of autistic behaviours or traits, consciously or unconsciously, so that an autistic individual may appear non-autistic), can delay a diagnosis of autism. Research has shown autistic people, particularly autistic women, report camouflaging has an extremely damaging effect on their mental health. Although the NICE guideline recommend an autism diagnostic assessment is conducted within 3 months of referral, UK surveys indicate an average waiting time from the point of wondering about the possibility of autism with a health professional, such as a GP, and actually undergoing assessment and receiving an autism diagnosis, is often in excess of two years for adults.

It is therefore important for therapists to recognise that they may already have encountered, or will do so in the future, undiagnosed autistic adults, due to autism in adults (particularly adults without co-occurring learning disabilities) being significantly under-diagnosed.

Receiving an autism diagnosis can be a positive experience, as it can provide a degree of explanation for autistic people. This may be especially pronounced when receiving an autism diagnosis in adult life, as our group members did. The ICD-10 and DSM-5 criteria can also explain our wide-ranging ongoing challenges in many different areas of functioning and life experience.

> "My immediate feeling when being diagnosed with autism (as an adult female in my forties), was a rush of tremendous relief. It explained so much, the difficulties around sensory sensitivities, social interaction and acute anxiety that I had experienced since young childhood. For the first time I felt compassionate towards myself, after decades of extremely punishing internal self-criticism, for not being 'likeable', for getting things wrong, for my paralysing anxiety... I always felt so 'flawed' ... and now I knew my difficulties were never my 'fault' ... I am autistic." GM 2

> "We function differently to the majority of the world and we definitely need support and understanding, but actually it is just a neurological difference. We are in the minority, so the world is set up for the neurotypical. But it is not a bad thing to be autistic. It just is. It's just how we are.
>
> It means we are more sensitive than most people and we need time to recover from things that neurotypicals may not even register as being problematic. For example, I need a few days to recover from being out in the world - travelling on public transport with all its noise and people exposure can be done, but there will always be an impact. That's where autism becomes a disability." GM 6

Having a formal diagnosis of autism also brings protection under disability law, which can lead to additional support and/or adaptions from health services, educational settings, employment and social services. **However, it is also important to remember every individual will have a different experience, and some autistic people's experiences may also be negative. As such, we again stress for clinicians to approach each person's story without strongly held assumptions and with sensitivity and compassion.**

In terms of the diagnostic criteria, many autistic people like ourselves feel that the current criteria are highly-deficit focused, utilising terminology such as 'deficits', 'impairments', 'abnormalities' and 'failure'. While many autistic people do have significant struggles, there often is no recognition of the special interests and passions that autistic people possess.

Whilst we wish our difficulties to be acknowledged, and appropriately and sensitively supported, we also wish for our passions and special interests to be recognised. We understand that DSM-V criteria involve clinically significant difficulties – however, we argue that it becomes more complicated when an atypical mode of functioning can be both a strength and a difficulty depending on the context e.g. detailed-focused perception. Furthermore, as the criteria for an autism diagnosis encompass areas arguably very important and significant for human function and identity, recognising only difficulties can, in some instances, reduce most of the person to a 'deficit'.

> "I see differences in myself that I can relate to as having a functional purpose, rather than being a deficit as the 'DSM-5' criteria would describe them. The challenges and difficulties that arise out of those differences such as being misunderstood, cause frustration and misunderstanding that I think would be better treated by respectfully seeing autism as a difference." GM 1

Although each autistic person is unique, just like everyone else, autistic people may especially possess some of the following strengths directly linked to autistic traits:

- Excellent attention to detail, often coupled with a very structured and methodical approach
- Deep focus with excellent concentration
- Strong ability to utilise keen observational skills, with good visual memory and recall
- Ability to develop high expertise, combined with in-depth knowledge
- Logical problem-solving abilities
- Creative and innovative thought processes
- Determination, tenacity and resilience
- Instinctive acceptance of difference, non-judgmental attitude, prepared to challenge opinions/norms
- A tremendous capacity for empathy (though may be atypically expressed)
- Strongly held values of integrity, honesty, loyalty and commitment
- Willingness to observe and evaluate self

Just as anyone else, we can be very passionate, take pleasure in things and want to live a fulfilled life. We believe it is important to not see us as a 'deficit', but, instead, valuable and complete individuals who have differences and highly individual strengths and challenges. We need to be appropriately supported through adaptions and other resources, to enable us to reach our full potential and achieve fulfilment within our lives.

“With the knowledge of my diagnosis has come self-acceptance. All of us can only ever be the best us (if that makes sense), and that is what therapy needs to focus on – enabling an autistic person to be accepting of themselves and become the best version of their authentic self.” GM 6

“Autism can be seen positively, not as something to be cured and changed – acknowledged as something real which we need to respect but not something that, in itself, needs to be taken away in order for a person to function. We need to accept ourselves and listen to our minds and bodies – and then we can lead a full life. A different type of life, maybe, but a life all the same.” GM 6

The Mental Health of Autistic Adults

Key idea

Recent research has emphasised the urgent need to discover or adapt effective psychological interventions for reducing distress in autistic adults.

> “Because autistic people experience the world differently, mental health difficulties that are common in the general population may also affect us in a different way. Furthermore, we may experience less common difficulties more frequently.” GM 4

Autistic people and their carers and families recently highlighted mental health as their top priority for research and innovation, and anxiety specifically as their fourth highest priority.

Research is increasingly illustrating autistic people have a greater prevalence of mental health conditions than non-autistic people. Autistic people are at greater risk of developing mental health conditions such as depression, social anxiety, eating disorders and obsessive-compulsive disorder (OCD).

	Autism population	General population
Anxiety Disorders	20%	7.2%
Depressive Disorders	11%	4.7%
Sleep-wake disorders	13%	3.7%
Obsessive-compulsive and related disorders	9%	0.7%
Bipolar and related disorders	5%	0.71%
Schizophrenia and psychotic disorders	4%	0.46%

> "Having diagnoses of both autism and an obsessive-compulsive disorder is challenging and complex, as I feel that my autistic traits of a strong desire for set routines, intolerance of uncertainty and significant anxiety of the thought of change, make it much more difficult to treat my obsessive-compulsive disorder. My therapist has had to learn and develop both an understanding of autism, and also an understanding of the manner in which my autism interplays with my obsessive-compulsive disorder, in order to tailor my treatment most effectively." GM 2

The reasons why autistic people have a greater prevalence of mental health conditions than non-autistic people are complex and multi-dimensional.

Our group draw upon our lived experience, plus recent research, to suggest the following could be contributing factors to explain the greater prevalence and mental health difficulties amongst autistic people:

- difficult interactions with non-autistic people
- the **'double empathy' problem** between autistic and non-autistic people
- exhausting impact of **'camouflaging'**
- negative social interactions and consequent **lack of social support,** which impacts upon our self-esteem and self-identity,
- **difficulties with recognising and regulating our own emotional experiences** (e.g. alexithymia, meltdown/shutdowns)
- **sensory sensitivities** (e.g. hyper-sensitivity and hyposensitivity) triggering emotional distress
- **'executive functioning' difficulties** with planning, organising and daily living skills which causes additional stress and distress
- **neurodivergence,** having a differing cognitive style, which presents challenges, but also strengths that may not be recognised or valued by non-autistic people

The highest rate of prevalence of mental health difficulties amongst autistic people occurs with anxiety disorders and depression. Higher rates of anxiety and depression in autistic people have been associated with lower life satisfaction, greater social difficulties, loneliness, externalising problems (including self-injury), and insomnia.

Additionally, there is some emerging evidence suggesting depression and anxiety may function differently in autism. For example, research has highlighted that difficulty with recognising feelings and emotions (alexithymia), difficulty with changing repetitive thoughts ('cognitive rigidity') and differences in sensory experience appear to play an important role in anxiety and mood for autistic people. However, to our knowledge, there is currently no research into treatments that take specific account of these differences.

As a direct consequence, we believe that models of mental health that are widely used to inform CBT may be largely based on the mental health of non-autistic people and may need adaptations or even radical change to better serve those on the spectrum.

> "I am diagnosed with anxiety, but I'm not sure that the anxiety I experience as an autistic person is the same as that experienced by people without autism – and if it's different then I don't know if evidence-based treatments are relevant to me – since I'm not like the people the treatment was trialled on." GM 6

Adapting Therapy

In 2018, the Department of Health and Social Care published the 'Think Autism strategy: governance refresh (2018)' which set a priority that autistic people have support adapted to their needs if they have a mental health difficulty, and in addition, the 'NHS Long Term Plan (2019)' aims to improve mental health support for autistic people in the community. Yet, there is currently little published evidence on how CBT could best be adapted for autistic adults, and few guidelines for therapists.

We believe it is important this need is addressed, as adaptations to both the style and the content of talking psychological therapies have been historically under-researched. We believe this is an ethical, social and research priority. We aimed to highlight the areas about which we need to know more. We also aimed to draw on previous ideas for how therapy can be adapted, current evidence and lived experience.

As a group, we decided we did not wish to tell therapists how to work with autistic people. Instead, we wished to **highlight areas that require further research and clarification,** and also to **highlight areas that therapists**

may find helpful to explore with the autistic person accessing therapy. For example, we do not recommend in what way a therapy room should be laid out in a prescriptive fashion, but rather we make suggestions as to which aspects of the room the therapist may wish to discuss with their autistic client.

We assume that when therapists utilise psychological therapy to help support an autistic person's mental health, the goal is not to address or reduce their autistic characteristics. Rather we strongly feel, as a group of autistic adults, **the aim should be to help an autistic person thrive and to improve their quality of and engagement with life by building on their unique strengths, special interests, and addressing any specific difficulties.**

We also hoped that this document might be of interest to some autistic adults, either to compare against their own experiences or to provoke thoughts about areas they may wish to discuss with their therapist.

Most of all, we wanted to allow an autistic adults' perspectives on the process of receiving therapy to be heard. We hope this document may be helpful to researchers, clinicians, and autistic people accessing psychological therapy.

Coproduction with Autistic Adults:
Reflections from the Authentistic Research Collective

An article about the process of our working together has been published by Autism in Adulthood:

Stark, E., Ali, D., Ayre, A., Schneider, N., Parveen, S., Marais, K., Holmes, N., Pender, R. (2020). ***Coproduction with Autistic Adults: Reflections from the Authentistic Research Collective.*** Autism in Adulthood.

Abstract

This article explores coproduction in relation to autistic people. We reflect on the coproduction process with autistic adults from the Authentistic Research Collective at University College London. We aimed to support the autistic population's mental health needs by coproducing a document on adapting psychological therapy, and by developing a set of reflective guidelines to guide and encourage future coproduction initiatives between autistic and nonautistic team members. We reflect upon six elements that are of potential importance for future coproduction projects with autistic adults: (1) the meaning of coproduction; (2) ground rules and a traffic light system; (3) environmental adaptations; (4) digital communication tools; (5) encouraging authenticity; and (6) supporting autistic strengths. We conclude by discussing future research avenues into optimizing coproduction with autistic people, and how such research may influence both practice and policy.

1 The Therapeutic Environment

Key ideas

Adapting the environment of waiting rooms and therapy rooms may improve the therapy experience for autistic people accessing therapy.

Collaboratively examine ways to adapt the client's outside environments (including home, work and shared spaces).

Exploration of the use of sensory tools may also be beneficial.

The 'sensory world' of autistic people

As autistic people, we experience differences in how we experience sensory information, which can manifest as hyper- (high) or hypo- (low) responsivity to sensory input. For example, we often find it overwhelming when we are exposed to bright artificial lighting, loud noises and close proximity to other people. Some of us also have a need to seek out strong sensory input, such as powerful tastes, smells and touch.

> "I personally have huge hypersensitivity to most sensory experiences, but also crave some sensory experiences at other times (mainly tactile stimulation via stress balls and textures such as velvet or fleecy material)." GM 3

However, not all of us experience sensory input the same way!

> "When really stressed from sensory overwhelm, it has been helpful when asked whether touch or pressure would help. A firm squeeze has been what I needed to calm, whereas light touch triggers the instant effect of alarm/fright." GM 1

> "For me, I find it's not as simple as the brain being hyper or hypo sensitive in one modality, it is the cumulative effect of the nervous system being bombarded, overwhelmed from processing too much information. I can get sensory overload from a country walk – the wind, the soft sound of leaves crunching under my feet is still a sound I'm processing – and I will be different on different days depending on how much I have been processing." GM 6

For this reason, we felt it is very important for healthcare workers to:

- think carefully and flexibly about the **impact of the sensory environment** on autistic people using services
- to seek **continual input and feedback** from the autistic people to ensure spaces are **accessible, calming and safe.**

We provide some more specific suggestions of adaptations that might be made to environments, in order to provoke reflection and discussion.

The impact of the surrounding environment

Adaptation of waiting rooms

Try to appreciate how the experience of a busy waiting room may feel for autistic people accessing a service. Waiting rooms are often busy, noisy, crowded, and unpredictable.

This might raise our anxiety about attending appointments, create a heightened state of anxiety and stress upon entering appointments, or even sometimes make us less likely to be able to attend appointments.

- Try to avoid using, or shield, overhead lighting if possible, as harsh/ fluorescent lighting can trigger discomfort.
- Constant music, radio or sudden loudspeaker announcements can trigger auditory overwhelm.
- Is it clear how a person should proceed when entering the waiting room?
- Are there easily visible instructions to reception desk/electronic sign-in?
- Are therapy rooms clearly signposted from the waiting room?
- Ensure reception staff are aware of existing schemes like ‘Sunflower lanyards’ (to identify a person with a ‘hidden disability’).
- Have sensory aids available to borrow behind the reception desk if possible, e.g. ear noise defenders /dark glasses /fidget items such as ‘Rubik’s Cube’.
- Improve natural lighting if possible (e.g. raising blinds at windows)
- Consider having flexible seating arrangements – rows of chairs can be intimidating.
- Is it possible for chair positions to be moved to allow for increased need for personal space?

- Try to ensure noticeboards contain essential information only and that magazines/ pamphlets are stored tidily to reduce visual 'clutter'.
- Is it possible for the floor surface to be altered to soften the acoustics e.g. a rug?
- Identify a small quiet space for autistic visitors who would struggle to wait in a busy waiting room … or alternatively, could they be allowed to wait in the therapy room as soon as they arrive?

"Waiting in a loud, (to me) threatening space prior to a session, meant that when I walked into therapy, my baseline of anxiety and stress was already extremely high. It then often took, sometimes most of the session, to calm down – or to spend all my energy on masking/compensating to bury down the stress. This meant though, that I could not concentrate on the actual session." GM 4

"When I need to go into a waiting room, I get really panicky. I get so confused and lost trying to work out who I need to report to and where I need to wait. The more anxious I get the more sensitive I become to all the sounds around me. By the time I get seen I've usually forgotten what I wanted to say." GM 6

Individualised approach to adaptation of therapy rooms

Try to put yourself in our shoes and experience the therapy room environment through our eyes. Listening to our needs within the therapy room environment can be an important first step in establishing a good, understanding relationship.

All of these ideas are only suggestions, not prescriptions, as we wish to empathise that every autistic person will have a different experience.

- Be curious, flexible and think creatively about how to make the environment better for the autistic person. Would they feel more comfortable sitting on the floor or perhaps they would feel more grounded if they took their shoes off?
- Many autistic people are sensitive to light, especially strip or harsh lighting. Lamps are a great alternative if available, or the autistic person may like to wear sunglasses.
- Make the room welcoming: cushions, blankets and rugs, if available, may help soften the acoustics.
- Chairs that directly face one another can make eye contact difficult. Consider placing the chairs at a different angle so you can talk without constant eye contact, or ask where the autistic person may like the chairs to be placed.
- Provide a third chair so an autistic person can bring a partner/friend/family member with them if desired.
- Fidget toys, such as stress balls or tangle toys, may help the autistic person self-regulate their sensory environment, or they may like to doodle or draw. Introduce these ideas carefully and offer choice.
- Check room temperature and air quality.
- Noise from outside of the corridor can be distressing. Strive to use a quieter therapy room. Give advance warning of expected noise, such as fire alarm testing.
- Provision of a table, if available, practically assists alternative communication via writing/creative activities/art.
- Create emotional and physical safety. Consider placing a sign on the door to prevent interruptions.
- Consistency can be very helpful, so consider keeping the same room and layout for every session.

- Be mindful that the colour of the walls, patterns on the wall or floors, and clutter, such as posters, may all be distracting.
- Provide access to drinking water when possible and allow food to be consumed (if desired).
- Ensure clear, unhindered access to the door as the autistic person may wish to leave if feeling overwhelmed.

> "I would like to feel comfortable enough to bring headphones to wear when noise outside the therapy room is distracting, and a blanket to cover myself as this makes me feel safer, but feel like I need therapist's 'permission' to meet my sensory needs in the therapy session. And as my therapist is unaware of my sensory needs, those needs go unmet, increasing my (highly camouflaged) anxiety and distress." GM 2

> "In therapy, I have found it useful to minimise the impact of the sensory environment so that I have more "processing space" for the words of the therapist and the ongoing discussion. For example, I take my shoes off, sit on the floor, turn the lights off and close the blinds, and take the batteries out of the noisy clock! We used the same room every time and made sure the chairs were all in the same place. It was really helpful to have these minor adjustments that made a big difference to the experience." GM 3

> "Having fidget toys, such as stress balls, fidget spinners, and small weights really helps me to stay 'in the moment' during sessions as I can better regulate my sensory environment so as not to feel overwhelmed. It also helps me to pay attention as I find that I often need extra stimulation during conversation in order to focus more deeply on the content and how it relates to me and my personal experiences. Having my therapist encourage and allow me to use fidget toys, and even sometimes pick them up and play with them herself, has therefore been of great help." GM 3

Modifying wider environments (home, work etc)

> “If an individual is working in an inflexible system, change cannot occur.” GM 4

There are increasing calls for more attention to environmental modifications and for reducing the emphasis on expecting us, as autistic people, to change ourselves. As a result, **it can be very helpful to think about how environments can be altered, rather than expecting us, as autistic people, to continually adapt ourselves to cope within our surrounding environments.** This can feel like an especially non-blaming and supportive approach.

An example of positive adaption is the “Autism Hour” initiative by the National Autistic Society. The initiative has businesses reduce background noise, educate the staff and public about autism, dim their lights, provide quiet spaces and reduce harsh smells. Some shops, cinemas, football stadiums, museums and public attractions have already signed up to provide “Autism Hour” on a regular basis.

We believe it might be helpful for therapists to take time to think about how autistic people might access such schemes, if felt useful to do so.

> “My region’s ‘Autism Diagnostic Service’ gives all newly diagnosed autistic individuals an ‘Autism Card’ (which are distributed to autistic people across my country of the UK). The card has a consistent logo illustrating autism on one side of the card, and space on the other side of the card to add a brief description of your needs as an autistic person when in the community. The transport services, plus healthcare services (e.g. hospitals/GP practices) were initially trained to recognise these cards, which an autistic person can show to indicate they have autism and may need additional assistance.”
> GM 2

It could also be helpful to think about how our homes and workspaces could be adapted to better meet our sensory needs:

- What are the spaces in our homes like?
- Which aspects most help or hinder a calm, productive and enjoyable experience within the home and wider community environment?
- What is the lighting like? What are the sound levels like?
- How crowded are our workspaces?
- Are there quiet spaces in our homes or at our workplaces, and how and when might we be able to access these?
- As autistic people, we are entitled to reasonable adjustments at work, in line with the Equality Act (2010). What support might we need to conduct this conversation with our employer if we wish to do so?
- Could we benefit from any advocacy or further support in seeking reasonable environmental adjustments?

"Working in an open plan office environment was very uncomfortable, as I was unable to concentrate or relax when constantly interrupted by conversations, movement, smells and small background noises which I found very difficult to ignore." GM 1

"Because I have grown up trying to suppress my distress/discomfort coming from sensory differences – and was taught I had to be the one to make changes to myself in order to fit into my environment, it still feels like a revolutionary idea to make small accommodations for myself. Small accommodations can, however, make such a big difference. Because it's such a new way of thinking for me, I need guidance in thinking about these strategies. For example, even something as simple as using earplugs/headphones to help with noise was not obvious to me. So, it would be great to have someone help me think about adaptations to my environment." GM 4

Sensory Tools

We reflected as a group that we have found **sensory tools can be a useful way to manage difficult environments, at home, in public or at work.** We suggest it may be useful for therapists to discuss with autistic people any difficulties currently experienced within their surrounding environments and explore whether sensory tools would be of benefit.

In CBT, there can be a focus on understanding **safety behaviours** (behaviours that people utilise in order to reduce anxiety and stress). Often in CBT, an important part of helping with anxiety is assisting people to **drop some or all of their safety behaviours,** as evidence shows safety behaviours can often get in the way of overcoming anxiety.

However, we believe it is important that therapists **try to distinguish safety behaviours that keep people stuck, from helpful sensory coping tools that might help an autistic person manage their sensory overload and actually promote coping.**

Each person and each situation is different, and careful thought and experimentation is important on a **case-by-case** basis; however, we felt the following aids may be helpful:

Environmental Stressor	Coping Aid
Bright artificial lighting	• Wear dark/polarised/colour-tinted glasses. • Sit facing away from lights or in darker areas of the room.
Loud noises	• Ear defenders/noise cancelling headphones. • Request reasonable adjustments to noisy air conditioning. • Use headphones to provide background/white noise. • Limiting time exposure in noisy environments and leaving in a planned fashion.

“Generalised background noise, such as humming fans, buzzing or beeping sounds, alarms and phones, feels very intrusive. I am unable to ‘fade out’ these small sounds, which frequently cause distress and impact upon concentration. Wearing noise-cancelling headphones has helped greatly by reducing my awareness of the amount of generalised background noise.” GM 1

“I use a white noise machine at home to “take the edge off” intrusive environmental noise such as lorries, motorbikes and car doors slamming.” GM 7

“I tried noise-cancelling headphones, but wearing the headphones unfortunately increased my sensory difficulties, as I hated the feeling of the tight headband. I was sad about this, as this is commonly suggested for autistic people who experienced noise-sensitivity, but I found a solution by wearing custom made silicone earplugs.” GM 7

Environmental Stressor	Coping Aid
Harsh smells	• Inhaling through mouth only. • Covering nose and mouth with scarf/clothing. • Chewing scented gum or holding alternative scent to nose to mask offensive smells. • Limiting time exposure in strong smelling environments and leaving in a planned fashion.

Environmental Stressor	Coping Aid
Crowding	• Choosing to sit in a quiet area of a room. • Physically moving seat to create greater personal space. • Visiting public spaces during quieter times. • Walking, as an alternative to using public transport, if travelling within a reasonable walking distance. • Travelling at off-peak times. • Choosing quiet carriages or sections of public transport. • Consider utilising schemes such as the 'Sunflower Lanyard' (indicating a 'hidden disability') to possibly reduce need for queuing in public spaces.

> "I walk wherever I can to avoid public transport in the city where I live. On public transport, there are far too many people, no rules, endless phone calls, loud screaming children (and adults) – it's complete chaos!" GM 7

Environmental Stressor	Coping Aid
Touch	• State personal preference of touch to other people (e.g. request they do not insist upon shaking hands). • Stepping physically back from other people to create greater personal space/state preference for personal space. • Wear soft, loose, layered clothing. Cut out labels from clothing if triggering irritation. • Wear seamless socks/turn socks inside out if seams trigger irritation. • Utilising weighted blankets/lap pads/weighted eye-masks. • Utilising fidget toys, stress balls or artists' clay.
Temperature	• Requesting reasonable adjustments to heating and air flow. • Wear extra warm clothing/wear layers of clothing that can be removed as necessary. • Utilising blankets, hand warmers, fans and ice packs.

Part 1 - Summary

What do we know?

- Autistic people often experience feelings of overwhelm when exposed to high levels of sensory input.
- Waiting rooms and therapy rooms can also be sources of distressing sensory input for autistic people using health services.
- Home, work and public spaces can equally be overwhelming, crowded or distressing.
- There is an increasing recognition many spaces are designed with non-autistic people's needs in mind. It can feel especially non-blaming and helpful to look at ways to change environments, rather than expect an autistic person to always need to change themselves to fit the environment.

What do we need to know?
Further recommendations for research:

- What good models of practice informing the creation of autism-friendly healthcare settings are already available? How can these autism-friendly models be more widely adopted in healthcare settings?
- How can the impact of adaptation to the sensory environment upon therapeutic engagement be best accessed? Which adaptions can be evidenced to have the greatest impact on engagement?
- Does evidence from therapeutic practice reflect how adaptation of the sensory environment impacts upon attendance and completion of therapy?
- Does evidence from therapeutic practice suggest adaptation of the sensory environment affects therapeutic outcomes? How can this be objectively measured in practice?
- How helpful is it to dedicate some therapy time to thinking about adapting environments at home or at work?

2 Adapting the Style of Therapy

The Therapeutic Relationship

The term ‘therapeutic relationship’ can be defined as:

- the bond between the client and the therapist,
- the shared goals that are defined,
- the agreed tasks client and therapist will do towards those goals.

We believe a strong therapeutic relationship, in which we feel safe to be our authentic self, is one of the most important elements of successful therapy. The bond between a therapist and the autistic client refers to the quality of **trust, rapport and positive feeling** that they have towards one another.

We believe that amongst many other factors that are already well-understood by clinicians, **three key ideas might be helpful** when considering the therapeutic bond between a non-autistic therapist and an autistic person:

- The ‘double empathy’ problem;
- Camouflaging;
- Neurodiversity and intersectionality.

The ‘double empathy’ problem

Key idea

Autistic people’s social behaviour has historically been described in very negative terms as a ‘deficit’, yet evidence shows autistic and non-autistic people may have difficulty understanding each other’s communication styles. We find that we can often understand other autistic people more easily, and non-autistic people can be prone to judgemental responses to autistic people like ourselves.

The ‘double-empathy’ problem, whilst acknowledging autistic people may struggle with processing and interpreting other people’s emotions and intentions and, therefore, face challenges in socialising with other people, places this problem in the interaction rather than a ‘deficit’ within ourselves.

It suggests **neurotypical and autistic people find it relatively difficult to empathise with and understand each other’s behaviour,** due to different styles of thinking and experiencing. Some evidence shows we find communicating with other autistic people easier than communicating with neurotypical people, due to similar communication styles and greater flexibility around our social interactions.

Conversely, when we attempt to communicate with neurotypical people, we may struggle with recognising unspoken rules of neurotypical communication and feel forced to adopt exhausting and effortful camouflaging to meet neurotypical expectations of social behaviour.

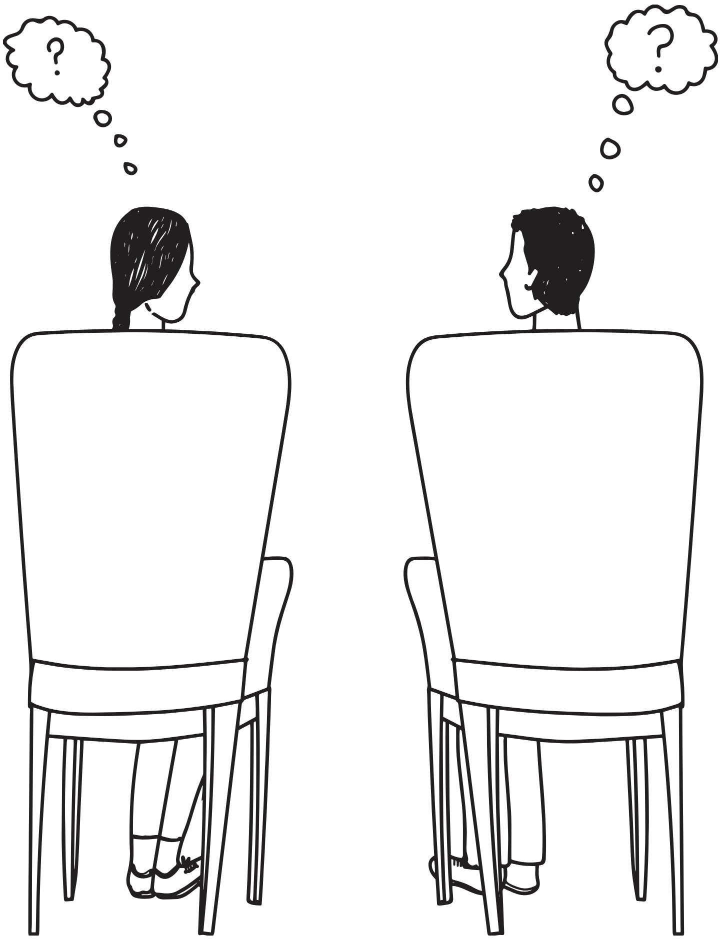
“I find it easier to relate to other autistic people – but when they are masking and ‘acting’ more neurotypical, I find it harder. I also find any neurotypical person who has invested time in understanding autism easy to be around.” GM 6

A therapist who appreciates the impact of the ‘double empathy’ problem upon communication within a therapeutic relationship with us, as autistic people, is able to authentically communicate that **difference can be explored from an equal footing.**

We believe a therapist should fully acknowledge the distress, challenges or difficulties that we face whilst socialising in a world that is governed by non-autistic norms and rules, but without 'blaming' us for these challenges.

> "Especially at times of high anxiety and stress, I notice my loved ones and I miscommunicate/misunderstand each other a lot more. Maybe it's because I lose my 'masking'/compensatory strategies – I am not sure.
>
> This also applies to interactions with my therapist. At first, it was difficult to get through times like that, however when we explored what was happening more overtly, we became conscious of the need to be aware of our communication/thinking styles and how they might both lead to miscommunication. Therapy then started to feel a lot safer." GM 4

Our group drew on our lived experiences to share the view the 'double empathy' problem may play an important role in communication in psychological therapy:



From a non-autistic therapist's perspective...

- Non-autistic therapists might assume if we are not making eye-contact, have a neutral facial expression, or show a posture involving self-holding, that we are disengaged or defensive, when actually we might be self-soothing, comfort-seeking, regulating our anxiety or listening/thinking carefully.

- Non-autistic therapists might assume that if we are smiling and being socially engaged, we are feeling emotionally well, and, therefore, don't need to ask about our mood.

- Non-autistic therapists might assume that if we speak in a "monotone" or unvarying vocal pitch, we might be feeling bored, disengaged or even hostile – when it might just be our natural or preferred way of speaking.

- Non-autistic therapists might assume if we ask lots of personal questions about their lives we are trying to "cross a boundary" or be intrusive, when it might be our way of increasing the bond, showing liking, practicing social skills or reducing uncertainty. We might also have always been taught it's polite to ask lots of questions, and therefore be part of our masking/camouflaging repertoire.

- Non-autistic therapists might assume if we are late due to transport-related anxiety or difficulties with planning, that these are "therapy-interfering behaviours" or signs of resistance or unwillingness, rather than genuine reasons due to sensory difficulties or executive dysfunction.

- Non-autistic therapists might make some negative judgements about our communication styles and assume that they therefore ought to give us corrective feedback or incorporate this into our therapy goals.

From an autistic person's perspective...

- We may experience a non-autistic therapist's body language (e.g. leaning in, with intense eye-contact) as threatening, intrusive or intense.
- We may experience a non-autistic therapist's facial expressions (e.g. pained or concerned) as ambiguous, critical, bored, or rejecting.
- We may experience a non-autistic therapist's verbal communications (e.g. suggesting an alternative way of thinking about a situation) as critical correction, judgement, or dispute.
- We may experience feelings of shame, guilt and anxiety if/when misunderstandings or misinterpretations occur, due to previous adverse experiences of being 'blamed' or 'criticised' for our perceived social inadequacies.
- We may not be excited or "jollied-up" by a non-autistic therapist being 'over-friendly', enthusiastic or excitable.
- We may find that some forms of especially effortful social engagement from a therapist might activate our masking – a more neutral, lower-effort style might allow some of us to more easily be ourselves.

Therefore, we recommend that therapists and autistic people accessing therapy may wish to explicitly discuss the double empathy problem, and to continually acknowledge their differing communication styles.

> "I feel that as autistic adults we may have learnt very good skills at assessing others' emotions and supporting them, without getting understanding from others of our own." GM 1

A Note on Empathy

One of the pervasive stereotypes about autistic people is that we lack empathy. This is a very damaging stereotype on a societal level and may also be damaging in a therapeutic context. We therefore feel it is important for non-autistic therapists to think about what empathy means, and how it is displayed and recognised by both parties within a therapeutic relationship.

> "Before I got diagnosed, I did not understand why I felt different. It was lonely. Just as I didn't understand neurotypical people, they did not understand me. There was an assumption sometimes that people with autism lack empathy, but when a neurotypical person talks to an autistic person, it can actually be the neurotypical person who lacks empathy." GM 3

Although the concept of 'empathy' may seem straight-forward, the phenomenon has many layers, and can encompass any or all of the following:

- Noticing emotional behaviour in another person
- Interpreting the emotion/behaviour accurately
- Feel the emotions of another person ('affective empathy'), resonating with/mirroring them
- Responding behaviourally to the emotions of another person

Arguably, the common understanding of empathy is held within the third definition of 'affective empathy', and we, as autistic people, are not different from non-autistic people in this respect.

Evidence suggests we may struggle with noticing emotional cues and interpreting emotions, and that our genuine, affective empathic responses may be misunderstood, due to being expressed atypically in contrast to the actions of non-autistic people. However, most autistic people feel and resonate with things deeply, are sensitive, caring and loving.

Many autistic people describe an empathetic over-arousal and a deep sensitivity to other people's emotions, which may become overwhelming, creating difficulties in processing and responding to others' emotions. Therefore, far from lacking empathy, some of us may actually have 'too much'.

Within the context of a therapeutic relationship, it may therefore be worth keeping in mind the many aspects of having and showing empathy – not as something that we lack but a phenomenon that is complex, nuanced and may simply be different, not less, in autistic people.

> “I am extremely sensitive to others’ moods, feelings and often extremely subtle changes in these. However, I cannot interpret or understand them parallel to being aware of them – it is very confusing and bewildering. It affects my own mood/mental health, especially when someone is in pain, as I often cannot regulate my own emotions in response to their pain. Ironically, this can seem as though I lack empathy as I become so overwhelmed, that I freeze or become upset/irritable.” GM 4

> “I am always hyper-observant of other’s moods and feelings, in order to cognitively judge how I should best respond. This strategy does causes considerable anxiety however, as expressed high emotions such as irritation and anger, particularly when directed at myself, scare me profoundly, and I become totally unable to respond, retreating into silence.” GM 2

Camouflaging

Key idea

Many autistic people have learned to consciously and subconsciously hide or suppress some of their behaviours to “fit in” with non-autistic people’s expectations.

Extensive camouflaging is linked to lower mood and well-being.

Camouflaging indicates the gap between an autistic person’s innate abilities and skills, and the abilities and skills observed by people around us. **Camouflaging refers to the idea that some autistic people may “mask”, camouflage or compensate for their autistic characteristics.**

Camouflaging may lead to us suppressing our autistic behaviours. We might learn to keep interrupting ourselves to stop us from speaking for very long, or we might try to alter the kinds of things we talk about or how we make jokes to try to “fit in” with non-autistic styles of communication. We might suppress our need to “stim” (meaning self-soothe), when expressing our enthusiasm for certain topics.

“For me, my stimming is not a sign of distress … it can be energising.”
GM 6

Camouflaging may lead to forcibly learning and practising socially acceptable behaviours (e.g. learning to look around another person’s face to give the impression we are making eye contact).

“I learned from an early age that you are expected to make eye contact, then read that actually, people do not keep constant eye contact, which was something of an epiphany for me. So, I started to look away for two seconds for every four sentences of a conversation.”
GM 3

Increasingly, evidence has shown camouflaging plays an important role in autistic people's lives. Autistic people, especially autistic adults who have lived in a neurotypical world for many years, may camouflage, having built up 'masks' around themselves that are not reflective of the person's authentic self, and which may consequently impact upon their sense of self.

> "I learnt that being my authentic self wasn't ok and I had to change and adapt and pretend to be what I wasn't in order to fit in. Now I don't want to have to choose when I camouflage and mask my autism. Sometimes it will still be useful – but mostly I don't want to bother anymore. I just want to allow myself to be my actual self." GM 6

As a consequence, **autistic people have described camouflaging as "exhausting", and camouflaging has been linked to increased rates of depression, anxiety, and suicidal thoughts/behaviours in autistic people.** While camouflaging our autistic traits might help us at times (e.g. fitting in at work, avoiding difficult social feedback or maintaining our safety), **it seems likely extensive camouflaging is having a negative effect on mood and well-being for many autistic people.**

> "I am learning to be more authentically autistic and authentically myself, even if that means that I sometimes stand out. With people I do not know, I feel the need to fit in still … for example if I had a job interview, I would feel I had to camouflage. But with friends and family, and increasingly larger circles, I'm learning to be authentic and just be me. It's wonderful and very liberating." GM 3

Autistic people may camouflage in therapy for a number of reasons. It may be automatic – we may not even be aware it is happening, or we may be acting in a manner that we think is expected of us.

"At times, I believe that everyone consciously camouflages their true selves to 'fit' social situations. However, I feel that I personally camouflage unconsciously and continually, due to learning the necessity of camouflage at a very young age (possibly before clear memory), and negative associations (being told off for behaviours that can be seen, in hindsight, as directly related to my autism).

I also think that being late diagnosed with autism plays a significant part, as I (when undiagnosed) had to mould myself in order to gain employment etc, therefore 'cementing' my camouflage as part of my identity. The impact of the resulting psychological stress to achieve constant camouflaging is immense." GM 2

We therefore **recommend therapists discuss camouflaging and compensation with an autistic person accessing therapy,** and to work together to identify how autistic characteristics may be masked/compensated, both inside and outside of the therapy room. The therapist also needs to consider the impact extensive camouflaging has upon our well-being and self-esteem. **The CAT-Q questionnaire** (see Appendix 3) is a validated measure that can be used to usefully guide reflection and discussion.

"If an autistic individual is very aware of how they 'mask' … then acceptance/ accommodation to encourage autistic people to "drop their mask" is fantastic if it allows true self-expression. But if an autistic person doesn't know where their camouflaging begins and ends … camouflaging unconsciously … how is it possible to "drop the mask" when you don't even know what your mask looks like?" GM 2

Members of our group have drawn on our lived experience to **highlight our strong concern that extensive camouflaging and compensation can have an important effect on communication within the therapeutic relationship and therapy process itself.**

> "In my personal experience, I have to work very hard to understand what specific behaviours I am doing and sometimes, even if something feels exhausting for me, I cannot imagine not doing it (maybe because I picked up/mimicked the behaviour at a very early age and thus it became, albeit a very uncomfortable, second nature). If the latter is true, putting (some aspects at least) of the 'mask' down can be a very time-consuming, strenuous and conscious process."
> GM 4

Our group suggests that **camouflaging** may lead to:

- suppressing our sensory needs and hiding our discomfort and anxiety;
- focusing on our "acceptability" to a therapist and working especially hard to "please" them;
- trying very hard to figure out and do the "right" thing;
- suppressing feelings of distress because we have had negative feedback in the past about how we express our pain, which may mean we struggle to process what is being discussed;
- seemingly stop functioning/having an emotional crisis 'out of the blue', as the true emotional state was hidden under camouflage, until the point where it became unmanageable and out of control;
- working hard to appear engaged, happy, social and enthusiastic to the therapist, because we have learned this is what is required of us. Inwardly however, we might be experiencing emotional distress, heavily camouflaged. It will depend on the circumstances and the person, but it may help if the therapist is curious about our experience even if we seem to be doing "well".

> "I spent my therapy sessions trying to work out what the therapist wanted me to be like and then attempting to become this person. I was not genuinely self-reflecting and changing based on new knowledge I had learnt about myself; it was solely a guessing game of what I perceived the therapist to want from me. As in life, I had an amazing ability to totally subjugate a part of myself perceived to be unacceptable and then create a totally new part in its place." GM 6

> “Camouflaging can make it difficult to track mental health progress because increased energy/improved mood can automatically go into increased camouflaging, making it seem that I am doing better than I actually am.” GM 4

> “I initially constantly camouflaged whilst in therapy sessions so I was seen to be “engaging in therapeutic goals”, as I intensely feared being viewed as “not engaging”, and my access to therapy consequently being withdrawn if it was judged that I was not making expected progress. Conversely, as I camouflaged in order to seemingly meet the expectation of positive therapy outcomes, this risked my therapy being prematurely ended, when I was actually still in need of therapeutic support.” GM 2

> “At times when receiving therapy, I “appeared” to be doing better (when actually still struggling), and then found myself in situations where I could not apply the skills I had pretended to learn. I feel that this might be a common experience for autistic people, and maybe therapists need to be more aware of this when treating autistic people, and ask more direct questions about the actual efficacy of their models? How can we stop people ‘conforming’ and enact real change?” GM 3

We encourage therapists to make the therapy room a safe space for autistic people. We recommended that therapists discuss camouflaging in the therapy room and assist us to experiment with connecting with our more natural behaviours and expressions, to explore with curiosity what effect this has upon our sense of safety, self-expression and feelings of social connection. We wonder whether we may be able to experience a more authentic connection with our therapist if we have the permission to ‘drop the mask’.

“My therapist accepts me in my entirety. Having her accept me just as I am helps me in accepting myself and stops me from feeling I need to mask – I feel I can bring anything to the therapy room without needing to hold myself back.” GM 6

As a group, we felt the following suggestions could help:

- Encourage stimming: provide sensory toys, give verbal permission to allow us to utilise self-soothing behaviours within the therapy room

“When a therapist allows me to stim, this helps me build trust.” GM 6

- Try out no eye contact

“One suggestion would be for the therapist and autistic person to sit almost side-by-side to avoid having to stare at one another, which may be a preferable option for some autistic people receiving therapy?” GM 3

- Be cautious that general social pleasantries (e.g. How are you feeling today?”) may inadvertently trigger camouflaging through activating scripted responses
- Targeted questions may be a better approach (e.g. “How has your mood been?”)
- Show interest in our passionate hobbies and interests
- Try out unconventional seating arrangements if we would feel more comfortable with them, e.g. suggesting that we both sit on floor facing the window
- Try out adjusting the sensory environment of the therapy room
- Try out writing down or drawing our thoughts and feelings in session, rather than spoken communication, when we may feel more overwhelmed

> "Drawing has always been a very important form of communication for me, as well as something I can lose myself in and feel a deep sense of calm. I've started using drawing in and outside of therapy, to convey things I struggle to put into words. You don't have to be an amazing artist – that's not the point. It's about making connection (with another person and a sense of peace). My therapy is not 'art therapy', but my therapist has been very flexible in accommodating this form of expression." GM 4

- Validate and support our authentic modes of communicating distress

> "My therapist has begun to recognise some of my non-verbal mannerisms when I am masking distress. She will reflect back to me that I am rubbing my forehead, or not making any eye contact at all, or remaining very quiet and still, and ask me to rate my (internalised) anxiety/distress. She accepts the anxiety/distress rating I give (even if another person who didn't know me so well, may think that I appear calm), and will then work with me to bring down my levels of heightened anxiety/distress." GM 2

Neurodiversity and intersectionality

Key ideas

A neurodiversity perspective considers that neurodevelopmental differences such as autism are part of the natural variation in the ways the human mind develops.

A great deal of public and health-related information and research on autism has a deficit focus, describing autism as a series of "lacks" or deficiencies. While it is undoubtedly very helpful to be clear about the difficulties we, as autistic people, face, we believe it is also critically important to discuss these challenges alongside our **special interests** and talents, and, where possible, to talk about **'differences' rather than deficits.** Instead of expecting autistic people to conform to non-autistic norms, a neurodiversity perspective places the emphasis on helping us to value our special interests and differences, while addressing our difficulties, and to thrive in our own way.

A neurodiversity perspective considers that neuro-developmental differences such as autism and ADHD are part of the natural richness and variation in the ways the human mind develops.

Attention-Deficit Hyperactivity Disorder (ADHD)

Our group's neurodiversity is reflected in some members' lived experience of ADHD (which stands for **Attention-Deficit Hyperactivity Disorder**), alongside their diagnosis of autism. ADHD is a neurodevelopmental condition, like autism, with diagnostic criteria including symptoms of inattention and/or hyperactivity-impulsivity. Just like autism, ADHD is very underdiagnosed in some demographic groups e.g. women. Just like autism, we think there are some misunderstandings about the experience of ADHD that can lead to mis- or under-diagnosis:

> “Relevant is the stereotyped understanding that exists for ADHD as being hyperactive in the fidgety sense, or not having an ability to focus, as exists for autistics having no empathy. I have met amazing hyper-empathic autistic people and people with ADHD that hyper-focus alongside efficient problem-solving and entrepreneurship.” GM 1

There is a large overlap between autism and ADHD, with 28-44% of autistic people meeting ADHD diagnosis criteria. It is believed the two conditions share common genetic factors. **We think it is important for clinicians to recognise this link and take into account how ADHD might impact on therapy and the communication between the autistic person with ADHD and the therapist.**

One aspect we think clinicians should be aware of is how ADHD may impact on emotion regulation, attention and executive function, in ways that are perhaps less known about:

> “My thoughts often race and, in therapy, without my therapist asserting some sort of structure, I can cover 20 different topics within a space of ten minutes, and everything feels chaotic and out of control. I found some forms of psychotherapy and counselling very difficult because they let me talk, and my talking would be as confused and random as my thoughts. Or sometimes, I would be silent because I couldn’t get anything out, since I was thinking a million things at once and had no sense of hierarchy i.e. what to prioritise.
>
> Furthermore, I think to some clinicians, my difficulty with staying ‘focused’ was a sign of not properly engaging. It is very helpful to me my current therapist understands my thought processes, can now better gage how much control I have (or don’t have) over them at any given time and, if I lose focus or go on a random tangent, gently notes it is happening.” GM 4

> “I think the way attention is understood in ADHD is very incomplete. Yes, my mind wanders a lot, my thoughts race and sometimes I struggle to focus. I think, however, what really strikes me most about my ‘attention differences’ is the intense ‘hyper-focus’ I experience, which impacts on my well-being, both negatively and positively.
>
> Positively, because if I put my attention to something I am passionate about, I feel fulfilled and happy and am very ‘productive’ by the standards of the neurotypical population. Negatively, because I can often get very exhausted if I lose sight of my physical/mental health needs.
>
> I think it is important for therapists to be aware of the intense focus some autistic people may have – even those without ADHD. Neglecting one’s needs may be interpreted by some as a disregard for one’s worth/well-being (as in depression or in people with very low self-esteem for example), but, in the case of my experience with ADHD, the problem comes from the inability to regulate myself, despite a great desire to look after my own well-being.” GM 4

Furthermore, just as with some autistic traits and behaviours, some people with ADHD ‘camouflage’ or ‘compensate’ for specific aspects of their ADHD. For example, a person with ADHD may rely on careful, consistent and detailed planning and, therefore, mask their difficulties with executive function or mind-wandering. The difficulties may only become apparent when that person becomes very overwhelmed or stressed and is unable to carry out their compensatory strategies.

> “For my situation this is a similar concept to autistic masking. Looking back, I could see that the ADHD symptoms were met even if they were not noticed by others at the time.” GM 1

> "My entire day is strictly planned, from the moment I wake up, to the moment I go to sleep. I know for many people this may seem excessive and very restrictive but, actually, for me – it gives me the freedom to function and engage with life. I was very unhappy before I begun learning planning strategies and letting go off how I thought I should function. Of course, it does require a lot of discipline and energy and, sometimes, I have neither. Then – my entire ability to look after myself, from emotion regulation to carrying out simple tasks like brushing my teeth, comes crashing." GM 4

Pathological Demand Avoidance (PDA)

Another aspect of our group's neurodiversity is some members' lived experience of PDA (which stands for **Pathological Demand Avoidance**), an increasingly identified profile on the autism spectrum. It is very rarely diagnosed in adults, due to the lack of standardised diagnostic tools to identify the features of adult PDA.

An individual with PDA will struggle with many every-day demands to an extreme extent, simply because they are demands. A demand could be anything the individual thinks they have to do, including getting washed and dressed, eating meals or going to bed, as well as fun activities the individual may want to do/enjoy.

> "I have recently begun to recognise the features of PDA in myself (in addition to a previous diagnosis of autism spectrum disorder). Being asked questions makes my head instantly go blank, due to the anxiety of being expected to come up with an answer. It's not the task itself which is the problem – it's the expectation that I need to do something that makes it impossible for me." GM 6

Expectations or demands can cause the individual with PDA to feel a lack of control and heightened anxiety, which results in them experiencing great difficulty complying with the 'demand'. The individual may use social strategies as part of avoidance, for example distraction, procrastination, making excuses, or reducing meaningful conversation.

"It doesn't help to be nagged, to have people make observations, to have people call me lazy, to try to bully me into doing the thing they want me to do. The best thing is to leave me alone and I will do it in my own time, in my own way. It's the freedom of not having any expectations that enables me. I totally cannot be told what to do." GM 6

When PDA is present, we suggest adaptions to the therapeutic relationship and therapy process are necessary such as: a more flexible, indirect, therapeutic approach; greater consideration of spoken communication so the therapist's reflections are not interpreted as 'demands'; holding more open-ended, collaborative discussions to identify therapeutic goals, rather than targeted questioning; and holding more flexible timescales.

Autistic people may also have other 'neurodivergent' diagnoses, including dyslexia, dyspraxia and dyscalculia. These may share some features of both autism and ADHD, and it might be useful for clinicians to think about how these additional diagnoses impact on therapy and day-to-day life.

Exploring intersectionality

Intersectionality describes how aspects of a person's identity (e.g. race, ethnicity, sexuality, class), interact within a society, resulting in specific modes of advantage/disadvantage.

We believe that neurodiversity might most helpfully be explored alongside a range of aspects of identity. **Intersectionality** refers to the idea that aspects of our identities "intersect" with one another to produce meaningful differences to our life experience, and the power we have in society.

"I believed and felt that being gay was the source of my feelings of difference, but now I see that being autistic explains a lot more of that feeling of difference as played out in my stress levels and interactions (and am learning the strengths of those differences and feeling proud of them)." GM 1

A neurodiversity perspective considers that neuro-developmental differences such as some instances of autism and ADHD are part of the natural richness and variation in the ways the human mind develops. These differences can undoubtedly come with difficulties that, in an environment made for and by neurotypical people, can turn into a disability. However, neurodiversity perspective encourages the support of both strengths and difficulties, usually via environmental adaptations, rather than trying to change the intrinsic identity of a person.

Intersectionality is a theory, historically rooted in black female experience, that each person has different aspects that make up their identity as a whole, for example, their race, gender and sexual orientation, that 'intersect' to inform our life experiences and the power we have in society. We think it is important to include disability/neurodivergence, within this framework, and to explore how other aspects of identity impact on autism.

In light of the fact competencies lists have been developed for working with a range of client groups (e.g. transgender clients), we believe it would be **helpful for counselling, therapy or psychology boards to develop a competency framework for working with disability.**

> "With each aspect of identity we adopt, there are others who stereotype it and from a limited understanding of what it means. How can we explain that diversity exists within the spectrum to our therapists, and to assist the therapist in mapping out a unique profile in collaboration with the person accessing therapy?" GM 1

It is important that attention to neurodivergence does not overshadow attention to other facets of identity and experience. We reflected that the social 'GRACES' might provide a helpful framework to guide therapists' reflections on the multiple aspects of an autistic person's identity.

The social GGGRRAAACCEEESSS
Gender
Gender identity
Geography
Race
Religion
Relationship diversity
Age
Ability
Appearance
Class
Culture
Education
Ethnicity
Economics
Sexuality
Sexual orientation

Autistic people are a diverse group, and our identities cover all sexualities, genders, ethnicities and other facets of identity. We believe it is important for therapists to let go of their assumptions and to accept autistic people's experiences of their identities as meaningful and real. This is especially important when it comes to societally marginalized aspects of identity, such as being a minority ethnic group, having a marginalized sexual orientation/gender identity, or being in a non-monogamous relationship.

For example, there is some evidence of a significant proportion of autistic people identifying as LGBT+. Therefore, it is especially important for therapists to provide a safe space where autistic people can be their authentic selves. Being autistic may itself bring marginalization and, thus, this 'intersection' with other stigmatized aspects, may need an especially sensitive and compassionate understanding and approach.

> "I get really frustrated with the pathologising of sexuality. I also feel that people have different preferences and needs at different times in their life, and what is comfortable in one relationship might not be the case in another, at a different stage of life. Polyamory to monogamy, bisexuality, straight or gay, very sexual to asexual. There is change over time." GM 1

> "I think it's so important for therapists to be aware and well trained in different aspects of identity. For example, I see both biological sex and gender in a very non-binary fashion. I don't feel as either male or female - and never have. I think both gender and sex are so much more complex than the binary that is prevalent in mainstream culture. Since adolescence I have experienced both dysphoria and worsened eating difficulties – having a therapist that was aware of these things would have helped me to understand my experiences better. When I tried to talk about this in therapy, the approach was to make me accept that I was a female/girl/woman and that whatever that is, was an unequivocal fact. The feeling I got was that I was being silly and difficult and trying to go against what was 'natural'. Plus, I believe having significant, including communication, difficulties made clinicians discount my experience i.e. that I didn't, nor couldn't, know myself. I think the human brain and body are wonderfully complex. Now, a bit older, I am more confident in trusting my own perceptions and advocating for compassionate care." GM 4


A QUEER AUTISTIC PERSON
(artist, writer, student, scientist, survivor, friend, sibling, lover, OCD-anxiety-eating disorder-sufferer, researcher, binge-watcher, story-obsessive, frequent non-speaker, library-dweller, migrant and much, much more)
SEEKS A COMPASSIONATE THERAPIST
WHO WILL BELIEVE IN MY REALITY

It is also essential to understand the relationship between race and disability, including autism. Black, Indigenous, People of Colour (BIPoC) autistic children and adults are often under-diagnosed or mis-diagnosed with other conditions such as conduct or adjustment disorders. Furthermore, due to the structural and daily racism BIPoC, including autistic, people experience, trauma may be a life-long chronic experience, which may impact on mental health. This structural racism may be experienced in medical, as well as mental health contexts, and it is important for therapists to understand this. **It is also important to understand that different cultures/ethnicities/races may have differing relationships to and conceptualisations of disability, including autism. This may also extend to how autism 'presents' in different cultural, racial and ethnic groups.**

Lastly, some autistic behaviours may endanger BIPoC, especially black, autistic adults and children, especially in public or in contact with law enforcement, if they are misinterpreted as defiant or violent. Thus, BIPoC autistic children and adults disproportionately experience physical and emotional harm, on top of the harm experienced at the hands of society from the autistic experience alone. We believe it is **essential** for therapists to be aware of this, to further educate themselves, to take a social justice stance and for this knowledge to inform their approach when working with BIPoC autistic people accessing services.

Therapeutic transparency

Key idea

If a therapist frequently and explicitly shares their feelings and the contents of their thoughts, this may help reduce mutual misunderstandings and stress.

In light of evidence regarding the double-empathy problem, camouflaging and neurodiversity, our group drew on our lived experience to reflect that we felt **increased therapeutic transparency** would be one helpful suggestion to address some of these difficulties in interaction. By transparency, we mean **therapists sharing the contents of their minds and their own experience especially frequently.** We suggest that this might help reduce double-empathy misassumptions, reduce the cognitive burden on the client, facilitate emotional exploration and promote authentic relating.

Transparency of thoughts and feelings

One of the most important ingredients in the therapeutic relationship is **congruence,** where the therapist and autistic person feel able to honestly communicate their internal experiences. An important aspect of therapeutic congruence is transparency, where **the therapist honestly and openly shares the contents of their mind, and communicates their internal feelings in a warm, compassionate and constructive manner.**

It might be helpful for non-autistic therapists to be **especially transparent and explicit about their own internal thoughts and feelings when working with autistic people like ourselves.** Sometimes, the therapist's internal experiences may be clear or obvious to us, but at other times (especially if body communication is ambiguous or we are very stressed), it might be helpful for us to have additional information to make sense of the therapist's communications. It may also help reduce our cognitive burden of needing to work harder to 'read' the therapist's responses.

"The therapeutic relationship is nothing like any other interaction I have in the 'real world'. This means that all the rules, all the 'templates' I have, all the scripts, just don't apply. It may seem very obvious to some people how therapy (and the interaction with a therapist) works – but, on some level, it is not very obvious to me."

Therefore, having a therapist be very overt, literally explaining the broad rules and expectations of the situation, vocalising their thoughts and feelings in a constructive way – it is the only way that will enable me to exist in that space. Otherwise I am preoccupied with worry that I will act in a way that is not appropriate in that context." GM 4

"It helps to have the option of texting my therapist after sessions which I sometimes use to clarify my understanding of her communication. An example of this was my perception that my therapist was frowning in displeasure when I outlined my attempts to progress towards agreed therapy goals.

When I finally expressed the (camouflaged) distress I was experiencing due to thinking that my therapist was displeased with my efforts, my therapist explained that her facial expression was actually one of thoughtfulness, as she considered alternate approaches that could be helpful to enable me to experience greater success." GM 2

Curiosity

> “If the therapist remains curious and questioning, then the client is less likely to latch onto what the client perceives the therapist wants – since the therapist wants nothing other than to truly know and understand the client. There are not rights, no wrongs – just what the client’s reality is.” GM 6

We feel (almost!) all therapists are naturally very curious about the people they see in their practice. It is important for both therapist and the autistic person accessing therapy to hold a willingness to be curious - without preconceived ideas and stereotypes - with the therapist holding a desire to gain understanding of the person undertaking therapy, to enable them to better understand themselves. It might be very helpful for therapists to be informed about autism, **and** to remember that every autistic person is very different, despite the similarity of receiving the same diagnosis

We believe it is important the therapist is making an enthusiastic choice to work with an autistic person and is committed and hopeful towards a positive outcome. The therapist should be compassionate, validating and empathetic. However, we may also find it more difficult to intuitively “know” that the therapist holds hope and warmth for ourselves. It may therefore be helpful for the therapist to explicitly state their feelings towards us, including their hopefulness. It may also be helpful to explicitly explain the reasons for the therapist’s curiosity towards us, as autistic people– and that this stems from their care, warmth, positivity and hope for all their clients.

> “It has been vital for me to hear that my therapist held hope of recovery for myself, as when immersed in continual daily struggle due to my mental health difficulties, at times I have found it nearly impossible to have hope of a different future. It has also been helpful to hear expressions of concern and care, and genuine enjoyment of working with me within our therapeutic relationship from my therapist, to combat the constant negative self-criticism within my mind.” GM 2

We believe it is helpful for therapist and autistic person to work from a platform where autism is accepted and not seen as something that is in need of fixing – as this attitude could increase our likelihood of camouflaging to please the therapist. On the other hand, although we may share broad traits as autistic people collectively, every autistic person is different. Therefore, we suggest it is extremely important for therapists to hold autism flexibly and remain curious throughout the therapeutic process.

> “It is only through asking meaningful, relevant and respectful questions that the autistic person is able to uncover who they really are.” GM 6

As a group, we also reflected that, for quite a few of our group members, **autism is not a separate trait but integral to how we think, feel and behave.** Identity is a very complex concept, made up of multiple interacting dimensions. Intersectionality within therapy is important because we all have different lived experiences based on other aspects of our identities.

Explore misunderstandings and make frequent repair

In line with the double empathy problem, it might be natural there will be misunderstandings and miscommunications between ourselves, as autistic people accessing therapy, and a non-autistic therapist. We suggest it is helpful to keep reviewing these misunderstandings in a spirit of curiosity, and for the therapist to take responsibility for their part in these.

Emotional coaching

Therapists may sometimes act as an emotional “coach” to the people they see in therapy, meaning that the therapy relationship is viewed as a safe space in which emotions can be recognised, named, processed, accepted and soothed.

There is increasing evidence a high proportion of autistic people have difficulties in recognising and naming our own and others’ emotional state (alexithymia, see Part 4). For this reason, when therapists ask us “how are you feeling right now?” or even simply “how are you today?” it can present a great challenge to us to know how to answer this question.

> “Whenever I was asked in therapy ‘How are you feeling?’ and I again and again said ‘I am not sure’, it was not an act of disengagement/disinterest. I genuinely did not, and still do not know (unless I work it out slowly).” GM 4

Instead of asking such broad questions, we suggest it might be helpful to dedicate a little extra time to curious joined exploration in order to help become better equipped to recognise our own emotional states. Our group drew on lived experience to suggest it would be helpful for therapists to be **more exploratory about emotions,** noticing and understanding them in the early stages of therapy and **less focused on challenge and change.**

Safety

Across different kinds of therapy there is some agreement that the therapeutic relationship should be a “containing” relationship, which enables the person accessing therapy to feel safe and have trust that the therapist can cope with emotional expressiveness.

> “The crucial factor for autistic people within therapy is safety. Therefore, it is so important that the therapist has a compassionate understanding of autism to enable the autistic person to experience a feeling of safety within the therapeutic relationship, and hopefully then be more able to achieve successful therapeutic outcomes.” GM 2

Psychological therapy is an interpersonal relationship, and we anticipate autistic people, like ourselves, may require more time and support in order to experience a sense of therapeutic safety, when compared to non-autistic people. This need may stem from previous aversive interpersonal experiences, but can also be driven by the double empathy problem and non-autistic therapists' difficulties understanding, reading and relating to us, as autistic people.

> "Therapists should perhaps ascertain what kind of experiences an autistic person has had with services/other therapists. People may have gone through intentionally/unintentionally harmful experiences in clinical contexts and, at worst, feel traumatised. If the therapist is not aware of this and does not make it part of the intervention (e.g. being extra careful/conscious of setting clear boundaries), then this can maybe get in the way of successful therapeutic outcomes." GM 4

We suggest that a sense of therapeutic safety in the relationship can be enhanced by employing the strategies in this document, and that especially the following could be useful:

- Recognising we may enter the therapy sessions in a heightened state of anxiety, so introduce soothing strategies from the very beginning of the session
- Allowing us to experience maximum comfort in the therapy room by altering the sensory environment to meet our sensory needs
- Introducing multiple breaks, and allowing greater processing time
- Actively demonstrating an accepting, non-judgemental stance
- Actively demonstrating a positive attitude towards the autistic person
- Explicitly discussing the 'double empathy problem' and camouflaging
- Allowing additional time for a sense of safety and bond to build

> "It's very hard to think analytically or practically when feeling unsafe or overwhelmed." GM 1

"When I have arrived at a session in a considerable state of anxiety and/or distress, my therapist works to bring down my heightened emotions first, as she explains she feels I am cognitively unable to engage when in such a heightened emotional state.

A recent example involved looking out of the window to name the hills I could see (an interest of mine is hill-walking). My therapist asks me to rate my anxiety after a few minutes, and if I am still very anxious/distressed, we continue with self-soothing and distraction techniques." GM 2

"I have been seeing a therapist that specialises in autism for the past couple of years. I have had lots of therapy in the past, before I was diagnosed as being autistic - which was helpful but limited because it didn't take account of my autism. The therapy I am having now feels so healing and helpful because my therapist has adjusted it for my autism.

For example, I find it really hard to transition and leave quickly at the end of the session – so my therapist now leaves the room at the end of the session and lets me stay in the room and leave when I'm ready. I find this so helpful." GM 6

Explicit hopefulness

When accessing therapy, evidence has shown that a person's expectations of treatment outcome make a large contribution to the change that is experienced. We suggest that, in light of the double empathy problem, therapists should not assume that the hope they implicitly hold for the autistic person is obvious to the individual.

It could be very helpful to build positive expectations of therapy if the therapist and autistic person discuss the process of change and set realistic collaborative goals. It is particularly helpful if the therapist explicitly states they hold positive hopes for the person's future and goals, as hopelessness in both clinician and the person accessing therapy has been shown to increase the risk of suicide.

In addition, when people accessing therapy hold relatively little hope of therapeutic success, this may impact on motivation. In these cases, it can be helpful to employ motivational interviewing techniques as part of initial engagement, which involve getting a sense of the person's stage of change, enhancing agreement about goals and collaboration. In particular, it involves exploring expectations of treatment and the risks involved, and a person's feelings towards change.

We, as autistic people, may fear the process of change itself, and have a natural preference for maintaining consistency and sameness. In this case, motivational interviewing can be used to weigh the costs and benefits of specific changes, and to plan manageable steps. It can also be used to facilitate a discussion of coping skills, strengths and soothing strategies that can be employed to assist us to mitigate the costs of change.

> "I find security in known routines … in learnt strategies and in familiar behaviours to 'manage' my emotions, even when these are highly damaging behaviours … resulting in tremendous ambivalent about change. Motivational interviewing enabled me to consider how making small changes could help me move towards desired life goals and live more in occurrence with my values, as well as considering the benefits of change against the costs of remaining immersed in damaging coping behaviours. This process has been enhanced by teaching distress tolerance skills and soothing strategies to alleviate my significant anxiety triggered by the prospect of change." GM 2

Explicit warmth

In light of the double empathy problem, we suggest therapists should not assume that their non-verbal expressions of warmth (such as facial expressions, gestures, body posture), as well as their spoken communications (such as voice tone), will be experienced as warm by the autistic person. Rather, we suggest that the therapist should curiously inquire how these communications are received by the autistic person.

If the autistic person does not find the therapist's speech and cues abundantly clear, we suggest it could be helpful for therapists to explicitly vocalise the feelings of warmth they have towards them – e.g. "I'm noticing that I'm smiling gently, nodding a lot and leaning towards you at the moment! That's just because I care about your wellbeing, as my client, and I guess I'm showing that through my non-verbal expressions. What does that seem like to you?"

We would caution against too direct a statement of liking however, which could be received by the autistic person as intrusive, as a pressure or expectation to reciprocate, or as a confusing blurring between professional and friendly styles of relating.

> "I have found it helpful to have an explicit conversation with my therapist about her feelings for me. I explained how I was conscious of the imbalance of the relationship - that I have her as my sole therapist, whereas I am aware that I am one of many individuals with whom she will have a therapeutic relationship. My therapist reflected that she understood that imbalance, that she has learnt a lot about me for my disclosures; whereas in contrast, she reflected that I knew very little about her as a person.
>
> My therapist empathised that she would not be motivated to work as a therapist if she did not care about the individuals she sees as a therapist, and therefore she reassured me that she also cared about myself. That was helpful to hear and helped to challenge some of the highly negative beliefs I hold about myself as a person." GM 2

Part 2 - Summary

What do we know?

- Camouflaging plays an important role in autistic people's lives and some instances of camouflaging are linked to decreased mood and well-being.
- Social communication difficulties experienced by autistic people have historically been seen as deficits in the person. They are perhaps better seen as differences, which are often poorly understood and treated harshly by non-autistic people. There is a double-empathy problem, in which autistic and non-autistic people may frequently misunderstand or mis-read one another.
- A neurodiversity perspective means instead of seeing autism as an illness, syndrome or disorder, it can better be seen as a difference and part of the diversity of human experience.
- Intersectionality means that multiple aspects of a person's identity, including their gender, ethnicity, class background and sexuality interact with one another and shape their experience of life and their position in society. Neurodivergence intersects with other aspects of a person's identity to produce different experiences and difficulties. It might be helpful for therapists to explore multiple aspects of identity with an autistic person accessing therapy.

What do we need to know?
Further recommendations for research:

- Does any current evidence from therapeutic practice reflect how non-autistic therapists and autistic people read and/or mis-read each other's communications in therapy sessions? Is this an area that requires further research?

- Does any current evidence from therapeutic practice explore how autistic people camouflage their thoughts, feelings and behaviours in therapy sessions?

- Does evidence from therapeutic practice suggest exploring the effect camouflaging has on therapy outcomes and the therapeutic relationship? How can the effect of camouflaging be best assessed?

- Does any current evidence from therapeutic practice reflect upon which factors promote autistic people to feel safe and act in ways that they feel are authentic?

- What difference does a neurodiversity narrative versus a medical narrative have on therapeutic engagement, rapport and outcome? How are these narratives defined?

- In what ways have multiple aspects of autistic people's identities been acknowledged and explored in psychological therapies?

- Does any current evidence from therapeutic practice reflect whether race and/or ethnicity relates to differences in autistic people's experiences of accessing and receiving psychological therapy?

- Does any current evidence from therapeutic practice reflect whether therapeutic transparency affects the therapeutic relationship and outcomes between a therapist and an autistic person accessing therapy?

3 Agreeing a Preferred Style of Therapy

Key idea

The therapist actively exploring individual preferences in some key areas with an autistic person accessing therapy could help improve rapport, comfort and authenticity within the therapeutic relationship.

A number of very helpful adaptations to therapy have been suggested in high-quality guides for therapists (e.g. Valerie Gaus, Ailsa Russell), and we would recommend these guides when seeking full and rigorous instructions of adapting CBT.

We have drawn on these very helpful guides, together with our lived experience, to produce a list of adaptations we suggest therapists might like to discuss with their autistic clients. None of these are intended to be one-size-fits-all recommendations, but rather a toolkit for guiding the kinds of questions or topics that might prove helpful for further discussion.

Psychological Assessment

Key idea

It may be beneficial to explore some additional autism-specific areas when conducting an initial assessment with an autistic person.

A psychological assessment is the first stage of psychological therapy, when the therapist works to understand the experiences and mental health difficulties being experienced by an autistic person.

We are calling this a "psychological assessment" to distinguish it from a diagnostic assessment, which is when a clinician decides whether to give somebody a diagnosis of autism or other psychiatric condition.

Our team drew on evidence relating to mental health of autistic people, lived experience of autism, and clinical experience, to make a list of suggestions for topics it could be helpful for therapists to explore during a psychological assessment.

Before the initial psychological assessment session

- **Offer directions that are as detailed as possible** to help reduce uncertainty and worry before the appointment, such as:
- Maps and pictures of the appearance of the inside and outside of buildings (if possible)
- Clearly describe which entrance should be used
- Specify the location of the waiting room and toilets
- Outline any sign-in procedures
- Clarify whether the therapist will call on a tannoy system, or display person's name on screen, or whether the therapist will collect us from the waiting room at the appointment time
- Provide the full name (and photo if possible) of the therapist that will be completing our initial psychological assessment

- **Provide information about the psychological therapy style,** clarify expectations and describe as clearly as possible what sessions will be like in terms of both content and structure.
- **Provide dates, times and duration of several future appointments** if possible (these can be renegotiated as necessary).
- **Consider including an additional alexithymia questionnaire** in your questionnaire pack and ensure clear guidance for completion is included with any paperwork that is needed to be brought to the initial psychological assessment.

Setting up an initial psychological assessment session

The therapist needs to ensure that we feel safe enough to participate in the initial assessment (and subsequent early therapeutic sessions) and reassured that our presenting difficulties are appreciated and 'heard'. The following suggestions may help ensure a sense of safety:

Be sensitive to the reality that in order to procure an initial psychological assessment for CBT (particularly from NHS services), we are likely, as autistic individuals, to have experienced considerable challenges navigating the 'gateway' process, both due to factors connected to our autism, such as difficulties with communicating with non-autistic people, the recognised health inequality that we face as autistic people, and the strict and often complex criteria for obtaining an assessment with NHS mental health services.

- **Follow guidance for enquiring about the sensory environment and adjust the sensory environment** (where possible).
- **Establish the personal gender pronouns** that we would like to be utilised during therapy sessions.
- **Agree language about autism:** The majority of autistic people prefer identity-first ("autistic person") to person-first ("person with autism") language but this can be very individual. It is also helpful to ask which diagnostic terminology is preferred – for example, some autistic people prefer "autism", whereas others prefer "Asperger's" or "Autism Spectrum". It is helpful for therapists to ask us about our personal preferences, and respect and utilise these preferences during therapy sessions.
- **Set an agenda and provide as much clarity as possible** about the purpose of the meeting and how assessment sessions differ from later sessions. This is immensely helpful, to alleviate our anxiety, reduce uncertainty, outline boundaries and to enable us to cognitively 'script' the upcoming assessment session. Invite clarification questions.

There has been reflection from practitioners (such as Gaus) that more than one assessment session may be required when working with autistic people.

This may be due to factors including:

- the recognition we are highly likely to be experiencing heightened anxiety (even if highly camouflaged), and therefore will require time to allow some of our anxiety to disperse, in order to be able to meaningfully engage in a psychological assessment
- sensory challenges the unfamiliar physical environment will present to ourselves, as autistic people
- the unfamiliarity of the therapy scenario, therefore the importance of recognition of the requirement to pace the initial sessions, so as not to trigger overwhelm
- the challenge of social interaction when we, as autistic people, are striving to communicate effectively with an unknown therapist

> "I feel there is often significant oversight in services … firstly the expectation that an autistic person should be able to successfully engage with non-adapted CBT, often without any preparatory work on managing presenting anxiety to enable their focus on therapy … and secondly, due to the lack of understanding of autism, the fact accessing therapy in itself is a significant trigger of anxiety for an autistic person (due to the unfamiliar environment, unknown expectations, social interaction with unknown therapist) is often underappreciated. Consequently, accessing therapy as an autistic person can be a fine line between personal costs/benefits as a result." GM 2

- the therapist's need to learn our communication styles as unique autistic individuals, which may be idiosyncratic in nature, and require more follow-up questions to elicit the necessary information to undertake a thorough assessment

> "We, as autistic people, can differ hugely in our communication styles and so I suggest that individual response need to be explored in an accepting way in therapy. Criticism and self-criticism, responding to what's expected by other people, and communication within the family, socially, at school and work is my suggestion for how themes of difference could be explored to get a nuanced individualised picture." GM 1

- the therapist's need to be cautious about their own use of language, as we may interpret it in a very literal manner, and also may be hyper-sensitive to perceived criticism or judgement, due to probable previous negative experiences

> "It's important to know how the person responds to criticism. I am very all of nothing in relation to perceived criticism, as I will instantly reject my own thoughts and believe the new ideas presented. It is very confusing for me." GM 6

Explore the autistic person's relationship to their diagnosis

We strongly recommend exploring our relationship to our autism diagnosis, drawing upon our lived experience as a group of autistic adults, as we feel that holding a positive (or negative) autistic identity has a significant impact upon our mental health.

Useful questions to encourage exploration may include:

- when and how we were diagnosed?
- how did we feel when receiving our diagnosis?
- how was our view of our autism at that time?
- how has our view of autism changed or evolved over time?
- what positives and negatives do we currently relate to our diagnosis?
- how do we feel about our identity as an autistic person?

"My immediate feeling on receiving my late diagnosis of autism was a feeling of overwhelming relief. My life was brought into sharp focus, re-interpreted in the face of this new knowledge. The intense self-criticism that has accompanied all of my self-perceived "failings", when the challenge of my tremendous anxiety has resulted in feeling unable to achieve my ambitions and live the life of which I dreamed.

I had always felt so "innately flawed" when comparing myself to others who managed with ease all the things in life that I found so difficult. But now I knew, I am not "flawed"... I was, and have always been autistic, without myself or anyone else recognising that fact.

Secondary, was a feeling of grief, when I looked back over my life and with hindsight, reflected how so many of my distressing life experiences (which triggered lifelong severe mental health difficulties), could be attributed to the lack of recognition of my autism, and the consequent total absence of any adaption or accommodation. I mourned for what could have been ..." GM 2

"I went through a rollercoaster of emotions and attitudes. At first, I felt relief – I had been looking for an 'answer' for years and had felt like I was living underwater. Then I felt shame (as I believed I now had proof there was something intrinsically wrong with me). Then I felt frightened, as I worried people could use my diagnosis against me, to dismiss me or take away my rights. Then I felt 'overly-positive': autism was my superpower, a gift, a superior difference, and anyone who referred to autism as a disease, illness or even disability made me feel extremely unsafe and upset. It was as if I was over-compensating for the previous years of negativity and self-hatred. Now – I feel I have settled into a balance. Autism is neutral to me. I have difficulties and strengths, just as anyone else (albeit maybe different in nature and scale). I try to respect everyone's views and not to feel threatened by them. Would I 'get rid of' whatever I believe 'autism' is? No. But I want to evolve, learn and grow, as many other autistic and non-autistic people." GM 4

Explore current difficulties

It is vitally important that the therapist recognises presenting difficulties may be heavily influenced by simply living life as an autistic person. This is particularly likely if societal expectations, lack of understanding/ accommodations, or negative experiences of stigma may have led to an autistic person believing they need to strive to change innate aspects of their autistic selves, their autistic thoughts, and their autistic behaviours.

The following suggestions may help explore current difficulties:

Discuss the referral and establish a shared understanding of how and why the referral was made, and why now.

Agree together that not all aspects of the presenting issue needs to be perfectly understood in one session - and reduce pressure on immediate mutual understanding.

Consider whether we may like to invite friends/family members/ significant others to attend any sessions, either for support or to provide information. Discuss whether friends/family members/supportive others are understanding and validating of our interpretation of our autism diagnosis, the impact of autism upon ourselves and our lifestyles. Where our family members are included, it would be helpful to validate the challenges faced by our families, provide accurate information, offer realistic hope, and non-blaming explanations. Family inclusion can allow the therapist to orient families to treatment, bring all parts of the system together, and link together with services.

> “Bringing friends to therapy sessions has the additional benefit of encouraging communication struggles between people to be explored, and sometimes might help when the friend understands the autistic person more than the therapist does initially.” GM 1

Autistic people, like ourselves, may find it relatively difficult to identify emotions (due to ‘alexithymia’). **Refrain as much as possible from open-ended questions relating to emotions,** such as “how are you feeling today?” It may be helpful to assess our emotional repertoire, and to ask concrete and specific questions such as “what do you notice in your body right now?” and “could you describe what you have done today?”

Explore what we find most difficult in life, and in which situations. Establish how long these difficulties have been present, and the impact they have on the autistic individual's daily functioning.

Explore our social supports: including our living situations, social connections, perceptions of socialising and other people, intimate and family relationships, employment and study, activities, special interests and leisure time.

Enquire about our physical health: including sleep, eating and nutrition, concentration and attention, exercise, drug and alcohol use, co-occurring conditions and medication. Consider an onward referral if appropriate.

Enquire about current and past support from services. It will be helpful to understand where autistic people are currently receiving support, including factors that helped and hindered engagement and progress in past work; and where there may be a need for supportive referrals and advocacy on the autistic individual's behalf.

Discuss coping: how do we cope with our difficulties and how effective do we think our current coping strategies are presently? Consider suspending judgement about whether coping strategies are "safety behaviours" and making assumptions that they need to be removed. It may be the case that we, as autistic people, require more "safety behaviours" (e.g. time-limiting our social interactions and/or spending most of our time in our familiar and safe home environment), due to differences in our sensory and cognitive profile.

> "After my autism assessment - where I answered questions about my life history and the repeated difficulties I have experienced with anxiety, social interaction, self-confidence and self-esteem over my lifetime, which has had significant impact on my relationships, education, employment and independence - I reflected that there were so many occasions where I felt I had "failed."
>
> Conversely, the psychologist who had assessed me reflected that in her opinion, I had achieved a tremendous amount, considering I had undiagnosed autism and therefore no adaptions and accommodations were ever made for myself. This validation was very affirming for me to hear." GM 2

As a group of late-diagnosed autistic adults, we feel it is crucial for health professionals to be aware presenting difficulties may 'mask' underlying autism, as the individual's presenting issue may be a means of maladaptively coping with the anxiety and distress triggered by their undiagnosed autism, and the consequent lack of accommodation and adaption. As such, the present document might be useful for understanding all clients, since therapists will inevitable encounter undiagnosed autistic adults.

Explore sensory profiles

Explore the autistic individual's sensory profile, looking for hyper (high) or hypo (low) sensitivity to each of the five main senses:

- vision – including light, patterns, colour and movement;
- sound – including volume and pitch;
- touch – including weight, pressure, contact and texture;
- taste – including flavour, texture and eating habits,
- smell

Also **explore additional senses,** including interoception (including awareness of hunger, thirst, tiredness, bladder fullness, emotion recognition), balance and movement.

> "I have been able to access a formal assessment of my sensory profile (completed via means of a questionnaire, followed by a discussion with a specialist Occupational Therapist).
>
> I found it very useful to reflect upon the areas in life where I experience sensory difficulties and discuss possible solutions, as well as gaining greater understanding and compassion towards myself, when striving to accept that the challenges presented by my sensory sensitivities stemming from my autism are not my "fault." GM 2

Explore the autistic individual's sensory experiences, including how they both seek out and reduce sensory input. Note any particular recognised sensory experiences which trigger anxiety/distress.

Additionally, **explore how the autistic individual soothes themselves using their senses** (e.g. stims, such as hand movements, tapping and rhythmic movement; weighted blankets and pressure; listening to or making sounds; temperature, textures; seeking out dark spaces; self-holding or self-stroking).

Explore whether sensory experiences have changed over time, and whether a reduction in using self-soothing may be associated with camouflaging.

Consider exploring whether it may be helpful to try using sensory soothing strategies in-session or using strategies outside of sessions to regulate emotion.

> "I do think it's important to have a formulation that includes the themes of sensory processing difficulties (which for myself result in conflict in my own relationships, difficulties relaxing in noisy social places and affecting ability to focus at work or study, as well as seizure-like physical symptoms affecting motor control when on buses or in public spaces)." GM 1

Formulation

Key idea

It may be beneficial to explore some additional autism-specific areas when creating a formulation with an autistic person.

A formulation is the "psychological map" that the autistic person accessing therapy and therapist co-produce, which describes the difficulties currently experienced and what is causing and maintaining them.

This brings several benefits:

- it normalises the difficulty as being understandable,
- it enables a complex problem to be understood relatively simply and visually,
- and it focuses the attention of the shared work to be done.

When producing a formulation with autistic individuals, we suggest the following may be helpful:

- Therapists and autistic people accessing therapy, could work together to develop a formulation that **incorporates our autistic strengths and challenges.**
- **Formulations could make use of visual media:** a visual (diagram or picture) formulation can be especially helpful as a supportive supplement to a spoken or written formulation.

"When discussing and producing a 'formulation' of my difficulties, my therapist used a large whiteboard to write thoughts down, with interlinking arrows and little stick figures to illustrate ages and simple faces to illustrate emotions. The visual presentation assisted my understanding of the links that my therapist was proposing she saw within my formulation, and this creative means of jointly producing my formulation was very helpful." GM 2

- **Formulations do not need to become over-complicated.** It can be helpful to incorporate one or two key autistic challenges (e.g. double empathy problem-related social challenges; sensory challenges) and one or two key strengths that can be used to counter-balance these (e.g. honesty, loyalty and integrity help build trust in relationships; detail-focused processing helps with work-related tasks).

> "A structured focus is necessary for me, expanding on layers of a problem is vital to making changes, but checking that we've got the focus and priority right is essential." GM 1

Therapists may wish to focus their formulations **less on reducing all safety behaviours and more on working together to identify both helpful and unhelpful coping strategies.**

Some strategies that would traditionally be considered safety behaviours may be helpful or even essential coping supports (e.g. cutting social encounters short may provide much-needed sensory processing and recovery time).

The guiding principle for whether a coping strategy is helpful or unhelpful is whether it supports us to move closer to the life we want. Rather than working to eliminate all safety behaviours, therapists could try to identify the most workable balance between safety and challenge.

> "I feel, in terms of specific defined difficulties and goals, that it's better to be structured and stick to an agenda. I think, for me at least, it becomes more complex when trying to 'relearn' an entire way of relating to oneself within the context of long-term therapy. Generally, it is a balance between challenging the person, but also understanding when that person is working at their maximum capacity at that point in time – this is difficult but important." GM 4

A helpful formulation is one that is most meaningful. Therefore, working collaboratively and listening carefully is key. In light of the double empathy problem, therapists should be especially motivated to check out their own assumptions and suspend automatic judgements about what is right, what works or what is unhelpful.

> “I feel respected and like a partner in my therapy.” GM 6

In summary, we recommend that formulations are:

- best kept simple and visual without overwhelming goals,
- focusing on the here and now,
- focusing on one or two very specific difficulties,
- incorporating autistic strengths and challenges,
- focusing especially on coping strategies.

Further suggestions of adjustments of style of therapy

Small talk on the way to sessions and therapy room:

We might all feel differently about small talk on the way to the session. For some of us, it might help us feel relaxed and accepted; for others, it might activate our masking; and for yet others, it might activate negative thinking and make us feel anxious. It can be helpful to check out an autistic person’s preferences.

> “I prefer not to engage in small talk whilst walking to session, and personally do not mind if my therapist speaks to me about general topics (e.g. the weather), but it triggers masking if any personal comments are made (e.g. complimenting appearance), as I then fall into scripted conversation/masking when searching for an appropriate response.” GM 2

Clarity about therapy relationship:

What are the boundaries and agreed style of the therapeutic relationship? Some people accessing therapy may have had past experience of a therapy where no questions were allowed to be asked of the therapist, for example.

Context about the therapist:

To build trust, it can be helpful for the therapist to be somewhat open, and to encourage curiosity even when they are not able to answer a question. Autistic people accessing therapy may find it confusing, anxiety-provoking or unnerving if the therapist is an uncertain person, especially if therapist appears like a blank slate.

Where neutral and non-personal information can be revealed, it might be helpful to do so. In other cases, it might be helpful to explore the intention behind the question and to explore and acknowledge uncertainty.

"When accessing Dialectical Behavioural Therapy (DBT), I found it very helpful that the therapists also gave feedback on how they had practised DBT skills in the weekly "skills feedback" session. They gave information about their lives/experiences to a point which they personally felt comfortable, but it helped me to see the therapists as people who also struggle with their emotions and emotional reactions, which helped me to normalise my own difficulties." GM 2

Self-disclosure:

It can be especially helpful to use some appropriate self-disclosure to help validate a person who feels that aspects of their experience are unusual or unique only to them.

"As an individual who is gay, I'd personally like to know if my therapist was gay and would always choose one who disclosed that over one who didn't." GM 1

Eye contact

Is it helpful for the autistic person not to engage in eye-contact?

> "I have started consciously avoiding eye-contact (since having greater contact with other autistic people and observing them choosing not to make eye-contact), so I tried this out myself. I found I actually feel better not making eye-contact, but that other people really want to make eye-contact with me!" GM 7

> "I felt a need to have eye contact and it became an awkward social situation rather than an opportunity to reflect on how my thoughts and behaviours affected my emotions." GM 6

Method of communication

It may be helpful for some autistic people to use non-speaking means of communication. Some of us may feel much more comfortable communicating via alternative means, which may be particularly helpful when experiencing heightened emotion and distress.

> "Spoken communication has been very difficult for me all my life – I 'can' speak most of the time, but it comes at a great cost (e.g. exhaustion of mental energy). GM 4

Turn-taking (frequency of talking and listening)

Some of us may find it helpful to have a 50:50 talking arrangement, whereas others may prefer some supportive listening at first. Autistic people may experience open-ended questions as challenging and difficult to answer. Instead, it can help to offer a menu of options, like multiple choice.

Processing time

Would it be helpful to plan to take five-minute breaks to process what has been discussed so far? Or to agree to have some thinking time before answering questions?

Give warning of the approaching end of the session:

(e.g. "We have 10 minutes left … let's summarise our joint understanding of what we have talked about in today's session").

As autistic people, we may find it distressing to have to abruptly stop a session if we wish to convey more to the therapist, so pre-warning allows us time to gather our thoughts. We may also be less attuned to non-verbal signals from the therapist that the session is drawing to an end (e.g. checking watch, closing notes etc), when we are very focused upon the effort of the social-communicative interaction.

> "I find it really hard to transition and leave quickly at the end of the session – so my therapist now leaves the room at the end of the session and lets me stay in the room and leave when I'm ready. I find this so helpful." GM 6

Camouflaging

It can be very helpful to explore how a person may disguise their autistic traits in therapy session, and how they may mask their distress.

> "I spent my CBT sessions trying to work out what the therapist wanted me to be like and then attempting to become this person." GM 6

Therapy approach

It may be very helpful to include some psychoeducation, emotion recognition and regulation work, practical emotion-coping skills, daily living skills or problem-solving.

> "Recognising, processing and responding to emotions has been, and continues to be, one of my key challenges. Working on emotion recognition, tolerance and other related strategies has had a huge impact on my distress levels – as well as improved my responses to situations." GM 4

Length of therapy sessions

We may prefer to have a longer session (than standard 50 minutes or 1 hour sessions). It can be helpful to ask and work to the autistic person's preferences where possible.

> "My (occupational) therapist gives me 1.5 – 2 hour sessions, because I need half an hour initially to rant and then I am able to settle. I find that 1 hour sessions are not sufficient." GM 1

Regularity of therapy sessions

Some of us may find we like to have weekly sessions, whereas others may prefer fortnightly sessions to allow more processing time in-between. It can be helpful if the therapy sessions are able to be scheduled at the same time/day each week.

Virtual means of access (e.g. video-calling such as Skype/Zoom) could also be helpful. This option may remove the barriers of tolerating a non-adapted environment for autistic individuals who experience extreme sensory sensitivity, or who may not be able to manage to travel to/tolerate unknown locations.

Reviewing after each session

Doing a quick review at the end of each session, collaboratively summarising the discussion and agreeing the structure of the next session can be helpful to produce structure and reduce uncertainty.

Homework

Some of us may find the idea of homework between sessions quite daunting and off-putting, while others of us might like the structure and continuity.

Some of us might find it difficult to plan and execute the task, particularly if we have significant 'executive functioning' difficulties, or co-occurring conditions such as ADHD.

It can help to ask how the autistic person accessing therapy feels about completing written homework; whether they need help to plan and schedule the completion of the task, and whether they would prefer practical or skills-based tasks.

It may also help to consider the possibility of allowing homework-free weeks.

> "I find it difficult to tolerate demands and expectations and will find myself shutting down to avoid them. This impacts on the ability to do homework and work in between sessions. I learn best by working things out myself, not by being told – being pressurised to commit to doing something at a specific time increases anxiety in me and can result in total paralysis and inability to do the task set." GM 6

Leaving a session prematurely

It may be useful to agree what would happen if an autistic person becomes so overwhelmed/anxious/distressed that they leave the room before the end of the therapy session. A pre-discussed protocol may be helpful, such as the therapist would wait five minutes, then come and help the individual calm down to enable their return to the therapy room, or if an autistic individual has left the therapy setting, the therapist will make email contact before the next therapy session.

Missed sessions

The therapist should be open, clear and precise about the process around missed sessions:

- number of missed sessions before discharge
- process of assertive follow-up (e.g. therapist will call you if you miss a session)
- notice period required for cancellation

The therapist may wish to plan with the autistic person for what will happen if they do not feel like coming to a session, and how they will help get themselves to the appointment if they are particularly struggling.

E-mails/text contact between sessions

While it is not always possible in every therapy context, some of us might find it helpful to have an option to express ourselves via e-mail or text messaging between sessions.

> "It's invaluable – because I formulate my thoughts in writing more than in speech, it's so helpful to write down what I'm thinking in the moment and I gain so much insight in that moment. If I don't email my therapist a thought it gets forgotten, and I also find I cannot wait until the next session to express a thought, so this way I have it out of my head and can move on, rather than have it going round and round my head because it isn't expressed.. My therapist brings the e-mails which I send to her into our sessions, and we look through them together." GM 6

Review after discharge

If possible, it would be useful for therapists to keep a window of time for review, rather than discharging completely (i.e. an extended period left for review prior to discharge – up to 6 months?). This would be helpful to ensure that an individual's difficulties have not resurfaced after the end of the therapy.

Hopefully, the suggestions we have made above concerning possible adaptions to initial assessments and formulations, drawing on our lived experience, will prove useful and informative in providing therapists with points they might like to discuss with their (possibly) autistic clients.

Part 3 - Summary

What do we know?

- Exploring additional autism-specific areas and having a clear structure may be beneficial when conducting an initial assessment with an autistic person. This may include enquiring about the sensory environment, agreeing preferred language about autism, and being mindful of providing as much clarity as possible, utilising concrete and specific questioning. It may be useful to explore feelings around autism diagnosis.
- A greater number of sessions may be necessary when conducting an initial assessment with an autistic person.
- Including additional autism-specific areas may also be beneficial when creating a formulation with an autistic person. Formulations may usefully incorporate autistic strengths and challenges, and focus on identifying helpful and non-helpful coping strategies to achieve a workable balance between safety and challenge.

What do we need to know?
Further recommendations for research:

- Does any current evidence from therapeutic practice suggest adaptations to the therapy room, therapy session length, processing time and other session practicalities, increase engagement and/or improve therapy outcomes?
- Does any current evidence from therapeutic practice suggest adaptations to therapeutic discourse, including asking multiple-choice instead of open-ended questions and agreeing turn-taking rules, increase engagement and/or improve therapy outcomes?
- Does any current evidence from therapeutic practice suggest which aspects of the therapeutic relationship be measured between autistic clients and non-autistic therapists, and how can these identified measures be best assessed?

4 Coping Skills to Consider

Coping with difficult feelings

Key Idea

Many autistic people may experience ‘alexithymia’, which means that it is difficult for us to recognise or understand how we feel and put it into words. This may make responding to and coping with emotions very difficult.

‘Alexithymia’ …“I’m not sure how I feel…”

Many autistic people may experience ‘alexithymia’, which means it is difficult for us to recognize/understand how we feel and put this into words. This may make responding to and coping with our emotions very difficult. **Alexithymia includes difficulty identifying and recognising our feelings, difficulty distinguishing between our differing feelings and emotions, and difficulties in recognising other people’s feelings and emotions.**

Alexithymia is more common for autistic people like ourselves (about 50%), when compared to non-autistic people (about 10%). We, as autistic people, are known to have differences within our cognitive processing of emotions, when identifying and describing our feelings, and also with emotion perception, facial expression recognition, recognition of tones of speech and body movement. In a non-autistic society that expects us to quickly recognise and be responsive to emotional cues, this can cause great social difficulties.

"I find it very hard to identify emotions in myself and others. I struggle to recognise faces and read facial expressions. I can only identify very basic emotions." GM 6

"Recognising, processing and responding to emotions has been, and continues to be, one of my key challenges. I think sometimes people assume (for whatever reason), that this is an intrinsic ability." GM 4

Alexithymia as a concept provides an explanation why, as autistic people, **we may experience challenges with managing our emotions,** and this appears to play an important role in mood and anxiety difficulties. Also, psychological therapy often assumes that we can recognise, name, and link our emotions to our thoughts and behaviours. If we struggle to understand and name our internal experiences (which may also link to difficulty with interoception – awareness of our body sensations), this might affect how we engage in therapy.

"On an intellectual level, I can understand how our thoughts, feelings and behaviour would be linked but my reality is different. I mostly don't know what I'm feeling, and I tend to 'think' possible feelings, rather than genuinely feel them. I only really become aware of my feelings when they are very strong and out of control, and I am entering meltdown." GM 6

For this reason, we thought it might be helpful if therapists do not assume that autistic people are able to easily identify and recognise our feelings or distinguish between our differing emotions. Others might find that we need some coaching and support to help us work out how we feel – and this could be a really helpful therapy goal in itself.

As a group of autistic adults, we felt the following suggestions may be useful:

- It might be helpful to look through names of different emotions and understand **the role of emotions.**
- It might be helpful look at some **body maps of emotions,** and practice noticing how we feel in the moment.

> "When I struggle to identify emotions/body signals, I sometimes use my behaviour to help me with this, as well as physiological signs: - Am I sweating/tense? Am I pacing? – maybe I am anxious, - Am I going in/out the kitchen a lot? – maybe I am hungry … " GM 4

Some **mindfulness** practices might help to notice what is going on in our bodies. If interoception is especially difficult, it may help to shift attention to considering our body posture (e.g. tension, clenched or relaxed fists, areas of pain or discomfort).

> "Personally I find when asked to practice Mindfulness exercises that focus on raising my awareness of my bodily sensations, that this tends to increase rumination on my thoughts and bodily feelings, which in turn increases my anxiety …I find the 'body scan' exercise is the worst!" GM 2

Some **progressive relaxation technique** practice might help us notice the difference between when we are tense and when we are relaxed. Engaging/experimenting with 'stimming' may also be helpful to induce a feeling of relaxation in autistic people.

> "Within the DBT distress tolerance 'TIPP' skill, I find 'Paired Muscle Relaxation' helpful, as I am often not aware that I am holding my muscles so tautly, and the process of tightly tensioning and then relaxing my muscles in turn, makes me much more aware of the tension I often carry within my body, and how different my body feels when my muscles are relaxed." GM 2

It might be helpful to receive some **psychoeducation** about different emotions and how to recognise them (e.g. body sensations, physical posture/body movement, action urges associated with specific emotions).

Recognising, managing and accepting emotions

Key idea

There is increasing evidence a high proportion of us, as autistic people, experience difficulty in recognising and naming our own emotional state, which is known as 'alexithymia'.

Alexithymia is known to be closely related to difficulties with managing emotions, otherwise referred to as 'emotion regulation'.

Emotion regulation means either automatically or deliberately changing how we feel. Some evidence suggests difficulties with emotion regulation might be a core feature of the experience of autism, with research illustrating some strategies for managing emotions seem to be more helpful than others.

Some **emotion regulation strategies** have been shown to be particularly helpful (and are linked to better health and well-being) for autistic people. These include:

- acceptance (allowing ourselves to feel how we feel)
- problem-solving (taking practical steps to improve a situation)
- re-appraisal (trying to think differently about a situation).

> "I have appreciated the focus on 'acceptance' inherent within the Dialectical Behavioural Therapy (DBT) that I am currently receiving, as change can seem very threatening to an autistic person who may find security, even identity, in known routines and in learnt strategies to manage emotions (even if these learnt strategies are damaging). I have also found acceptance to be a crucial strategy to enable me to begin to process my late diagnosis of autism." GM 2

Some **emotion regulation strategies** have been shown to be less helpful for autistic people, like ourselves. These include:

- avoidance (opting out of activities)
- rumination (repetitively going over and over something in our minds)
- suppression (pushing feelings away).

> "I have a great tendency to ruminate over perceived 'mistakes' that I have made, particularly within social interactions, when reviewing tasks previously completed (due to my perfectionism), or in decision – making. I find my rumination negatively impacts upon mood and concentration, and it can take days before the constant rumination of negative thoughts lessens." GM 2

Research has shown that autistic people are more likely to use **avoidance as a strategy to manage our emotions** than non-autistic people, which in turn is linked to **greater prevalence of anxiety and depression.**

Acceptance

Key Idea

Some evidence is starting to show that acceptance of emotions might be an especially helpful strategy for autistic people.

As a group of autistic adults, we drew on our lived experience that acceptance of emotions has been an important part of our journeys.

We suggest it may be helpful for therapists to consider introducing **acceptance strategies** to the autistic person accessing therapy, enabling us to notice and name our feelings and emotions, have more understanding of our feelings and emotions, and finally, build up our willingness to experience our feelings and emotions.

Acceptance of feelings and emotions may initially be very difficult for autistic people, as experiencing emotions (particularly difficult feelings and emotions), may seem very unpredictable, frightening and unpleasant in terms of sensory experience. However, by building skills to enable us to feel more able to accept our feelings and emotions, rather than seek to avoid them, our feelings and emotions may become more understandable and predictable.

> "Borrowing some "radical acceptance" from DBT is useful for accepting anxiety – acknowledging that we can function and be successful despite being anxious." GM 3

It also might be especially helpful for us, as autistic people, to be able to call upon one consistent strategy to manage our feelings, which we can use whatever the situation, such as emotional acceptance-based strategies. It has been shown acceptance-based strategies strongly promote psychological well-being and significantly improve mood, particularly in autistic people.

> "Learning to accept things, and stay with them is so helpful, especially with sensory differences, as such strategies help you to pause, stay calmer and figure out if there is anything you can do to make things better (rather than just reacting or going into meltdown/shutdown)."
> GM 4

Examples of emotional acceptance strategies may include:

- **Self-compassion and self-forgiveness** (e.g. techniques from 'Compassion Focused Therapy' may be helpful here - such as 'Compassionate Letter Writing')

"One suggestion is compassionate letter writing to ourselves to assist us in accepting our emotions.

An example might be: "I would like you to know that"... (e.g. a letter might point out that as we become depressed, our depression can come with a powerful set of thoughts and feelings –so how you see things right now may be a depressed view of things).

Given this, we can try and 'step to the side of the depression' and write and focus on how best to cope, and what is helpful." GM 4

- "This too will pass" (e.g. DBT skill **'Radical Acceptance'**)
- **Sensory-calming or self-soothe techniques** (e.g. "inside out and inside in" techniques)

"Squeezy toys (like my little rubber 'brain' and a textured spiky ball that has a light inside that flashes) are useful attention focusing, calming tools for myself." GM 1

- **Grounding techniques** (e.g. 'soles of the feet' meditation, or naming 5 things you can see, hear, touch, smell in the immediate environment)

"I find Mindfulness useful to 'ground' myself when my anxiety is rapidly rising. My immediate impulse is to use harmful behaviours as a way of numbing or avoiding my anxiety. However, by trying to switch my attention to my immediate surroundings whilst 'sitting' with my anxious feelings, such as watching the clouds drift outside the window or studying the detail of a leaf or flower very closely, I find the intensity of my urge to 'avoid' my anxiety through harmful behaviours does lessen." GM 2

- **Distraction** (e.g. possibly utilising our special interests)

Valued activities

Key idea

Using emotional acceptance strategies, rather than avoiding our feelings and emotions (such as our anxiety), may be difficult for autistic people accessing therapy.

Therefore, it may be helpful and motivating for us to have a sense of what we would like to change, and how we would like our lives to be, in order for us to understand why we are trying to relate to our feelings and emotions (such as our anxiety) differently.

Many autistic people like ourselves, may wish to have full lives in multiple areas that matter to us. However, sometimes, our detail-focused thinking may mean that we focus especially intensely on certain areas of our lives and put less time or energy into others. For example, one of the reasons autistic people like ourselves can become highly skilled in our work, hobbies or studies is that we can be highly committed and dedicated, spending a lot of our time and energy on one or two main areas.

Sometimes, especially when we are experiencing low mood or low self-esteem, we might put less attention into work, study or hobbies, but invest heavily in a single means of coping (e.g. getting very absorbed in a single activity that we find soothing or comforting, even though we don’t feel very fulfilled by it).

It can sometimes be difficult for autistic people to switch our attention between different tasks and transition between activities, even activities we enjoy. This can also make it difficult for us to have a life that includes many different activities, hobbies or interests – for example, we may find it very difficult to transition between spending time immersed in activities relating to one hobby, and then switching our attention to differing activities relating to another hobby. This can result in autistic people like ourselves, living a ‘narrow’ lifestyle, even when we may wish we were felt able to manage and enjoy a more varied one.

"I have difficulties with transitions, particularly when I am immersed in an activity. Having to transition to a differing activity (even out of necessity, such as needing to go to bed) can be difficult, as I fear I will not be able to refocus my attention on my return to that activity.

It is especially hard if it is a sudden and unexpected request to stop an activity, as that halts my thought processes abruptly and I know I will experience difficulty 'regathering' my thoughts, and as a consequence, I can be irritable when unexpectedly interrupted.

I also struggle with transitioning between two simultaneous activities, which was a particular difficulty in employment, as it feels like I am trying to hold on to so many thoughts in my head. My preference is to complete one activity before I start the next activity, as leaving activities 'incomplete' makes me feel very unsettled and anxious, until I have the opportunity to return to enable 'completion'." GM 2

Our lifelong experiences of camouflaging may also contribute to difficulties with valued activities. We may have focused so heavily on masking and hiding our autistic traits that we have missed out on chances to explore what genuinely matters to us. We may have stopped certain activities to mask our enthusiasm for them. We may have lost touch with what we want, because our priority has been to figure out what others want and expect from us, taking continual effort and often leading to significant exhaustion, which prevents us from leading the more fulfilling life we may desire.

"Figuring out how I wanted to relate to others, and what I liked to do with my time, and what is important to me required going off script and learning from experience, and trial and error." GM 1

Some therapies like **Acceptance and Commitment Therapy (ACT),** explore what it is that **we value in multiple areas of our lives,** and how we can become more proactive and less avoidant, to come closer to the life we desire.

This might include looking back at our life history, drawing upon our autobiographical memory, to help identify what has been important to ourselves at differing stages of our lives, or completing a 'Values Questionnaire' (see Appendix 4), which gives multiple choice options to help a person rate and rank which values are most important to them.

> "My interpretation is that there is no 'normal' in ACT - the goal is being able to act according to one's own values; rather than there being right vs wrong way of thinking/behaving, there are only unhelpful/helpful ways specific to you and your values." GM 4

The table below contains some possible areas to explore in relation to values, but there are also many others that people may identify.

Valued area	Questions to consider
Family	What kind of relationships would you like to have with your family? How would you like to be with members of your family?
Couple / intimacy	Are couple relationships important to you? What kind of relationship would you like to have? How would you like to be in a relationship?
Parenting	Is being a parent important to you? What kind of parent would you like to be?
Friendships / social life	What sort of friendships would you like to have? What makes someone a friend? What kind of social life matters to you? What kind of friend would you like to be? How would you like friends to view you?
Career / job	Does a career or having a job matter to you? What kind of work matters to you? What kind of employee would you like to be?
Education and learning	What would you like to learn? What skills would you like to develop?
Fun	How would you like to enjoy yourself? What helps you feel playful and have fun?
Community	What causes or issues matter to you? Would you like to feel like you can contribute to something? What local concerns in your area matter to you?
Health	How important is your physical health? What kinds of health-enhancing activities matter to you?

Coping with difficult thoughts

Key idea

Worrying and upsetting thoughts are a common human experience, but they also play an important role in a range of mental health difficulties.

Cognitive Behavioural Therapy (CBT) sometimes uses “thought challenging” (often technically called “cognitive restructuring”).

Thought challenging means identifying our thoughts that are associated with negative emotions and unhelpful behaviours, and then using techniques to find more accurate or helpful ways of thinking about a situation, including:

- working out probabilities
- replacing thoughts
- identifying and challenging thinking errors

Thought challenging may be especially difficult for autistic people, as it has been noted that **we often struggle to challenge or change our thoughts about a topic at will** (sometimes described as “all or nothing” thinking). This may be due to the pre-assumption by therapists of ‘cognitive flexibility’, (the ability to easily to change one’s mind about something), rather than recognising that we, as autistic people, may need **more support to develop our ability to challenge our own thoughts.**

> “Many of the ‘faulty thinking’ CBT seeks to modify, is a function of how the autistic brain is wired. For example, I will always have ‘all or nothing’ thinking. I pretended to modify my thinking for the benefit of my therapist, but I am not able to genuinely think in a way that isn’t ‘all or nothing’.” GM 6

Our group drew on lived experience of psychological therapy, to suggest that in some cases **thought challenging may also be experienced as invalidating** if the person has had life-long experiences of worrying about being different, wrong or strange, and that the autistic person may find it upsetting to think that we have been "thinking wrongly".

> "There have been occasions when my therapist has challenged my thinking, which triggered me to feel upset and criticised, and I responded by becoming very quiet, closed and withdrawn. I now am able to recognise that my response has a basis within in a lifetime of feeling my thoughts are somehow "wrong" and "strange". Historically other people have criticised (and occasionally sadly ridiculed) my thoughts at times when I was brave enough to express them, as my thoughts were very different from their own." GM 2

> "I find it so hard to cope with trying to respectfully listen and take on board a different opinion as being valid and true, and trying to process how there can be a differing opinion when my brain is so black and white in its thinking." GM 6

Interviews with autistic people, and our own experiences, led us to wonder if it might be helpful for therapists to also consider a more **acceptance-based approach** for their clients, **changing our relationship with our thoughts,** rather than changing the thoughts themselves.

> "We suggest that therapists consider helping their autistic clients change their relationship with their thoughts and emotions. This might be more realistic and empowering than trying to get rid of certain emotions and thoughts altogether." GM 4

Changing our relationship to thoughts

Key idea

There are forms of CBT called ‘mindfulness and acceptance-based’ approaches (sometimes also called “third wave” CBT), which do not ask us to try to change the contents of our thoughts, but instead our relationship to our thoughts.

> “If we change how we think, than we change how we feel - if we change how we think, then we change what we do, if we change what we do, then in turn we change how we think and feel” GM 5

In **Mindfulness-based Therapy,** we might try to **“observe”** our thoughts, not changing or interfering with them, but simply noticing the way the mind is. Mindfulness has been found to be helpful in reducing anxiety and depression in autistic people, as well as helping us to identify our feelings and emotions.

> “As an autistic person, I have found it extremely difficult to engage in Mindfulness-based group therapy… when multiple aspects of the therapy (e.g. social interaction with unknown therapists and other therapy group members, unknown expectations, in unfamiliar environments with sensory challenges) … trigger me to feel very unsafe.” GM 2

In **Acceptance and Commitment Therapy (ACT),** we might try to **“defuse”** from our thoughts (gain distance from our thoughts) by using techniques to take them less literally – for example, singing them out loud, or repeating them until they sound like meaningless noise.

Acceptance and Commitment Therapy has been found helpful in reducing depression symptoms, and increased psychological flexibility, social function and quality of life in autistic people.

Autistic people might be likely to **take language more literally,** and this might also apply to our thoughts, and therefore mindfulness and acceptance-based approaches may help us to observe our **thoughts as just thoughts** (products of our tricky minds), **rather than as the literal truth.**

> “Flexibility of attention, and defusion from our thoughts, could be helpful for autistic people if they feel this might support them with frustration or feeling stuck or overwhelmed; however I would want to talk about our focus and ‘black and white’ thinking as positives too.” GM 1

> “I’ve done all sorts of therapy in different settings: CBT, DBT, psychoanalytic, compassion-focused and now, ACT. I think ACT, combined with a compassion-focus, aligns the best with my understanding of the world/people. It feels like there is no ‘normal’ in ACT – you come to understand your personal values. Then you learn acceptance strategies to allow you to engage in behaviours and activities that align with your own personal values. I’ve always held very strong (and consistent) values – but even if you have no idea what you deeply value, ACT can help you figure it out.” GM 4

These approaches suggest that it is possible to develop a different relationship with our thoughts.

Coping with anxiety

Key Ideas

Autism, when co-occurring with alexithymia and poor interoception, may make recognising and identifying emotions (such as anxiety) more problematic.

Autism also involves a different relationship to sensory experiences, which may involve hyper (high) or hypo (low) response to the sensory world.

Evidence has shown that having more sensitivity to sensory experience is linked to more likelihood of anxiety and more difficulty coping with uncertainty.

Anxiety seems to be a difficulty that many autistic people experience, with around 40% of autistic adults having at least one symptom, as compared to 18% in the general population.

One explanation could be that, for many autistic people, just existing in the world can be anxiety provoking, due to our sensory differences, such as hypo/hypersensitivity. Anxiety may also be a response to difficulties we may regularly face that non-autistic people may find less challenging, such as socialising.

> “Anxiety is not a short-term episode for me, it is chronic and severe, and this is not understood well by clinicians I have seen, and has resulted in disconnection from friends, family members, colleagues or employers.” GM 1

Autistic people may experience difficulty recognising their feelings and bodily sensations as anxiety, due to possible difficulties with alexithymia and/or interoception. Some psychoeducation about anxiety may be helpful, such as explaining the purpose of anxiety as an acute stress response, due to fear of physical or psychological threats.

It may also be helpful to **discuss commonly experienced physical symptoms of anxiety,** to assist autistic people like ourselves who may experience alexithymia, to be more able to recognise our own feelings and bodily sensations.

One suggestion is to explain the physiological reasons behind these bodily responses to anxiety (e.g. a 'butterflies in the stomach' sensation is due to slowed digestion, as our body diverts blood flow towards large muscle groups to prepare for action).

It might also be helpful to **distinguish differing levels of our anxiety,** perhaps through identifying methods of rating our anxiety.

> "I think anxiety presents in autistic people differently. I am so in the moment. I will be totally beside myself with anxiety … and then thirty minutes later, I couldn't even tell you what I was so upset over."

It may be that standardised anxiety measurement scales are not as applicable to autistic people, since they are not adapted to encompass difficulties with alexithymia and/or interoception. Personalised rating scales to assist us to better recognise our differing levels of anxiety could therefore be created and adopted, such as analogies related to our special interests, or our own idiosyncratic (chosen) terms that we utilise when describing our anxiety.

> "We use a "swan measure" to rate my anxiety when in therapy sessions, in recognition that I often strongly camouflage my anxiety (like the vigorous unseen paddling of an apparently serene swan). I often outwardly appear very calm, when inwardly I am experiencing significant anxiety. I give a number between 1-10, relating to how strongly I am "paddling" under the surface, to indicate the level of my anxiety." GM 2

Sensory overload

Higher levels of sensory sensitivity have been linked to more severe anxiety. Autistic people may react especially strongly to sensory stimuli because we may struggle to disengage our attention from it. It may be that our sensory experiences can seem uncertain and unpredictable, and consequently feel threatening, and therefore we may find it more difficult to accept and tolerate strong sensory input.

"The more tired/stressed/upset I am, the more the bright lights and noise on the tube bother me. It's as if they get even louder and brighter!" GM 7

"My anxiety is mostly caused by sensory input – my nervous system just gets so overloaded and I feel so jumpy and I label this as anxiety. After I've been overwhelmed with sensory information, I get so exhausted and I need to lie down in a dark room until my nervous system has re-set. Before I understood I was autistic, I labelled this as depression. I didn't know that the cause was actually sensory overwhelm." GM 6

"My experience is that I get so overwhelmed (e.g. by sound/vibration when travelling). I have learnt to focus upon strategies to enable me to reduce the impact of these factors upon myself. I however would not label this as anxiety, more as sensory overwhelm." GM 1

Self-soothing techniques

The experience of sensory experiences feeling uncertain and threatening led our group to feel curious whether some **self-soothing techniques and calming strategies** might be a useful part of therapy, to help us cope when we are feeling particularly overwhelmed and anxious.

> "I feel that an autistic person cannot 'think' themselves out of anxiety if the cause is sensory overload, i.e. thoughts might be less useful here. However, do we know much about how effective behavioural interventions can be, or would psychoeducation (e.g. teaching people to regulate their sensory experience through stimming, shutdown, headphones, ice cubes etc) be a good starting point to try to lower baseline anxiety?" GM 3

This could involve "outside-in" techniques
(changing the environment to reduce sensory overload):

- using sensory tools like noise-cancelling headphones
- adapting the environment so it is less overwhelming for us

Some of the self-soothing techniques recommended in **Compassion-Focused Therapy** may be helpful to manage triggered anxiety and/or feeling threatened by our sensory experiences. It may also be helpful to use mindfulness or attention retraining techniques to help gain greater control of attention, in order to help disengage from distressing strong sensory stimuli.

This could involve "inside-out" techniques
(skills we can learn and use):

- progressive muscle relaxation techniques
- calming breathing exercises
- grounding techniques, such as focusing on the 'soles of the feet'

> "Sound really helps me, music or voice or relaxing tones (sometimes heavy, fast or intense music too – it's not always calm I seek) and using this as a focus is soothing." GM 1

"As part of DBT distress tolerance 'TIPP' skills, I have learnt to use an app on my phone to assist me to focus on calming my breathing when feeling particularly anxious.

The app uses a symbol which indicates when I should breathe 'in' (when the symbol is increasing in size), and when I should breathe 'out' (when the symbol is decreasing in size). I can set the timings on the app to trigger me to slow my breathing and spend more time focuses on my 'out' breaths, therefore pacing my breathing. As an autistic person, I find the visual nature of the app helpful as a prompt to focus on consciously calming my breathing. GM 2

Coping with uncertainty

Higher levels of sensory sensitivity have been linked to greater difficulties managing uncertainty. Autistic people can often find uncertainty and unpredictability challenging. When things are uncertain or ambiguous, they feel very threatening, and it has been known for a long time autistic people often find it difficult to cope with unpredictability and change.

"As a new mother, I was totally perfectionist at the same time as being utterly clueless as to what I was meant to do. I didn't know how to change a nappy, how to feed a baby. It was utterly terrifying, but at the same time, a hugely emotional and amazing time. I now have support as an autistic parent of autistic children. I think it is important for autistic parents to be offered tailored support, considering the fact that autistic mothers typically will have mire sensory challenges and feel more anxious about change." GM 6

Although difficulties with uncertainty are well-known to be linked to anxiety for everybody, autistic people find this difficult to a greater extent (sometimes referred to as having an "intolerance of uncertainty"), with some autistic people consequently striving to avoid uncertainty at all costs. Recent interviews with autistic adults have shown we commonly find unpredictable events and unexpected things in the future confusing, frustrating and worrying, and consequently, uncertainty can feel particularly distressing, which in turn leads to greater levels of anxiety.

> "Intolerance of uncertainty results in changes in sleep and mood before travel or planned social events in a major way for me." GM 1

One strategy some autistic people use to help them feel safe from uncertainty is 'scripting'. This might mean we make quite detailed and specific plans for how things are likely to be, to help us cope with uncertainty. For example, if we are attending a first therapy appointment, it will really help us feel calmer if we know what is going to happen, what the environment will look like and how the session will be structured.

Helping us 'script' as much as possible can help us manage our anxiety as autistic individuals. However, there will naturally be times when we cannot script, and we might be likely to get overwhelmed or want to avoid such risks. In those circumstances, we felt there are several potentially helpful strategies to manage anxiety and uncertainty.

We suggest the following as a possible strategy for **anxiety and uncertainty** management work:

- Helping us recognise how we are feeling through psychoeducation
- Helping us build tolerance for our bodily sensations of anxiety and uncertainty through self-soothing techniques
- Helping us cope with managing anxiety and uncertainty through utilising acceptance-based strategies
- Helping us reduce avoidance of anxiety and uncertainty by utilising our desire for involvement in personally valued life activities as motivation

Coping with low mood, depression, trauma, self-injurious behaviour and suicidality

Key ideas

Autistic people are more likely to experience low mood and depression. Some autistic people may struggle with suicidality and be at greater risk of suicide than non-autistic people, though this may be atypically presented. Autistic people are also more likely to have been exposed to or experience traumatic life events.

Risk assessments and crisis plans therefore need to be adapted to include autism-specific factors and presentations.

Low mood and depression

Autistic people are more likely to struggle with low mood, and to be diagnosed with depression.

> "I experience "depression attacks",
> a very intense, sudden drop in mood." GM 1

It appears that **alexithymia, anxiety and avoidance** all contribute to low mood for autistic people, alongside **lower social support and negative/traumatic life events.**

Depression appears to increase with age for autistic people. This may be because, **as we get older, the social world becomes more complex and we encounter higher likelihood of experiencing painful rejection and judgement of our attempts at social interaction**, plus, with age, we also develop a greater awareness of our 'difference'. **It is possible autistic people may have less friendships/relationships, and, consequently, lower social support.**

Helping us recognise our emotions, manage our anxiety, and engage in valued activities might all help with improving our tendency to experience low mood and depression.

Trauma

We suggest it may also be helpful for therapists to hold in mind **autistic individuals may have experienced significant adversity and trauma during our lives,** as evidence shows autistic people are more likely to have been exposed to or to have experienced traumatic events.

As a group of late-diagnosed autistic adults, we feel late-diagnosed adults may have experienced trauma in their past life experiences, rooted in misunderstandings and societal treatment of 'difference'. Our group reflected that this may be felt particularly acutely when an autistic person is late diagnosed, as understanding from other people, and/or self-understanding and self-compassion were often absent.

> "The questions that needed to be asked were never asked directly so remained unanswered ... the vulnerability of a young autistic girl, particularly an undiagnosed autistic girl who was immensely shy, quiet, compliant, polite, rule-abiding and dangerously naïve, due to her inability to 'read' other's unscrupulous intentions ..." GM 2

Our lived experience of significant experience of childhood bullying has been echoed in research findings that autistic children are bullied more often than peers with other disabilities or their own non-disabled siblings. As autistic adults, we are also more likely to have experienced significant stigma, as well as sexual abuse and assault.

We also feel it is also important that therapists acknowledge autistic people, like ourselves, may show intense threat responses to apparently "harmless" situations, including social situations, sensory stimuli, or changes in our routine. These atypical stressors may trigger similar symptoms of exposure to traumatic events (e.g. PTSD), just as often as "objectively" traumatic events. We therefore think it is essential therapists validate our autistic experience of trauma.

A thorough assessment of adverse childhood experiences and other traumatic events may be beneficially integrated into clinical assessments of autistic adults, and a trauma-informed approach to therapy may subsequently be advisable.

Self-injurious behaviours, suicidality and suicide risk

More autistic adults struggle with self-injurious behaviour (often described as "self-harm"), when compared to non-autistic adults, though the self-injurious behaviours appear to serve broadly similar features and functions to self-injury in non-autistic adults. However, **we suggest, for autistic people, self-injurious behaviours could be linked to extreme stress reactions triggered by autistic meltdowns, shutdowns or burnout.**

Some autistic people may also struggle with suicidality and present a greater risk of suicide than non-autistic people, even when universally common risk factors for suicide, such as employment difficulties, depression and dissatisfaction with current living arrangements are taken into account. Autistic adults are evidenced to have elevated rates of suicide, suicidal thoughts and behaviours, with autistic women being at particularly heightened risk, a trend unlike the general population, where men are more at risk than women.

> "I have always been very honest about my experiences but when it comes to something as sensitive as expressing my thoughts of suicide, many therapists still don't know how to approach it. There has been a lot of panic (and making things worse – which, ultimately, has made me a lot more cautious with my honesty). On the other hand, I have also experienced therapists minimizing what I was telling them. That is dangerous. Self-awareness and disclosure do not mean that there is no real risk." GM 4

We would therefore suggest, when working with autistic adults, to conduct a thorough risk assessment, including an assessment of current and past suicidal thoughts and behaviours, and current and past non-suicidal self-injury. We also suggest, in light of recent evidence, that **support (social, family and services)** and **camouflaging and compensation** should be carefully assessed and considered in light of an autistic individual's risk profile.

Crisis Plan

If it is felt necessary to create a collaborative crisis plan, it may be helpful to include family and supportive others to attend a crisis planning session (with the autistic individual's consent).

We would also suggest a crisis plan should be adapted to include additional autism-specific factors, such as:

- The autistic individual's diagnosis and their preferred style of communication
- The autistic individual's sensory profile
- How the autistic individual communicates distress, including shutdowns, meltdowns and burnout (see later in this section for further information)
- Whether the autistic individual experiences large and highly distressing shifts in mood linked to meltdowns
- How the autistic individual can find ways to communicate an escalation in risk (including non-speaking and non-verbal strategies)
- How others can best communicate with the autistic individual when they are distressed
- What the autistic individual finds comforting and reassuring when distressed or at risk

We feel, drawing from our group's lived experience of mental health difficulties, it is vital that therapists recognise that **risk factors for suicide in autistic people can be very different to those in non-autistic people.** The risk factors may include non-suicidal self-injury, lack of support due to social interaction difficulties, and camouflaging disguising extreme distress and consequent suicide risk. We may appear calm and 'rational' while highly distressed. **Therefore, standardised suicide prevention plans used for non-autistic people might not be appropriate, and a more individualised approach may be necessary.**

“I think, especially when working with autistic people – but, to be honest, more generally – the conversation about suicide (prevention) needs to change. I think listening to individuals, not making a sweeping assumption of suicidality, and making the space safe enough for individuals to share are good initial steps. In addition, we live in a society where talking about death (even if it’s not suicide) is often considered taboo and morbid, despite being a natural part of life. Therefore, I think all therapists should be equipped and willing to talk about death as exactly that - a normal and inevitable part of life. That in itself can be healing.” GM 4

“I think autistic people present differently with suicidal behaviour. I may be suicidal in the moment, but once the overwhelming feelings have passed, I am not – whereas a neurotypical person would remain suicidal. Autistic people (could be) just overwhelmed in the moment, and not truly suicidal.” GM 6

Strategies to cope with low mood, depression, trauma, self-injurious behaviours and suicidality

We reflected that we tend to blame ourselves for our difficulties, particularly as we were all late diagnosed with autism. We can therefore struggle with feelings of shame and low self-esteem, which can trigger a very negative self-identity. For this reason, supporting autistic people to feel more positively about themselves might be a helpful goal of therapy, through increasing **self-acceptance** and fostering a **positive identity.**

We suggest the following as possible strategies for coping with low mood, depression, trauma, self-injurious behaviours and suicidality:

- Helping us **recognise how we are feeling through working on alexithymia and identifying emotional states**
- Helping us **develop practical skills for reducing hyper-arousal** (e.g. the DBT ‘**TIPP**’ skill - involving **T**emperature regulation, **I**ntense exercise, **P**aced breathing techniques and **P**aired muscle relaxation)
- Helping us **increase our skills in emotion regulation and build acceptance of difficult feelings**
- Helping us develop **self-acceptance and a positive relationship to our autistic identity**
- Helping us **develop self-acceptance and a more positive relationship with ourselves**

Positive autistic identities

Key idea

Helping autistic people develop a more positive relationship with our autism diagnosis could, for some, be an important therapy goal in itself.

> "Accepting myself and seeing my strengths would probably be just as life-changing, as learning skills and coping mechanisms." GM 4

Research has shown that holding a positive or negative autistic identity is strongly related to our likelihood of experiencing difficulties with self-esteem, depression and anxiety. For some, getting an autism diagnosis can lead to a sense of shame and worries about being "not normal".

> "I can only speak for myself, but I think there is a lot of internal shame attached to being autistic (and prior to being diagnosed, feeling 'different' and even 'wrong')." GM 4

Evidence has shown that having more acceptance of our autism diagnosis predicts less likelihood of experiencing depression and reframing our autism as a 'difference' rather than a 'deficit', provides validation and promotes greater self-acceptance for some people. Interviews with some autistic adults and young people have shown a recurring theme of a strong desire to be authentic to ourselves and taking pride in our neurodivergence.

> “I learnt that being my authentic self wasn’t ok and I had to change and adapt and pretend to be what I wasn’t in order to fit in. Now I don’t want to have to choose when I camouflage and mask my autism. Sometimes it will still be useful – but mostly I don’t want to bother anymore. I just want to allow myself to be my actual self.”
> GM 6

As a group of late-diagnosed autistic adults, we reflected receiving a late diagnosis may have possibly increased the likelihood of experiencing painful/traumatic life experiences, as adaptions/accommodations for our autism were historically absent. Conversely, however, receiving an autism diagnosis in early life may also create limitations, due to caregivers feeling a need to ‘protect’ an autistic child/teenager, or stereotypes about the achievements/life expectations of autistic people, serving to place limitations on the expectations and aspirations of autistic children/teenagers.

Based on this, we thought it would be important for therapists to explore with autistic people accessing therapy how they feel about their autism. It might be helpful to:

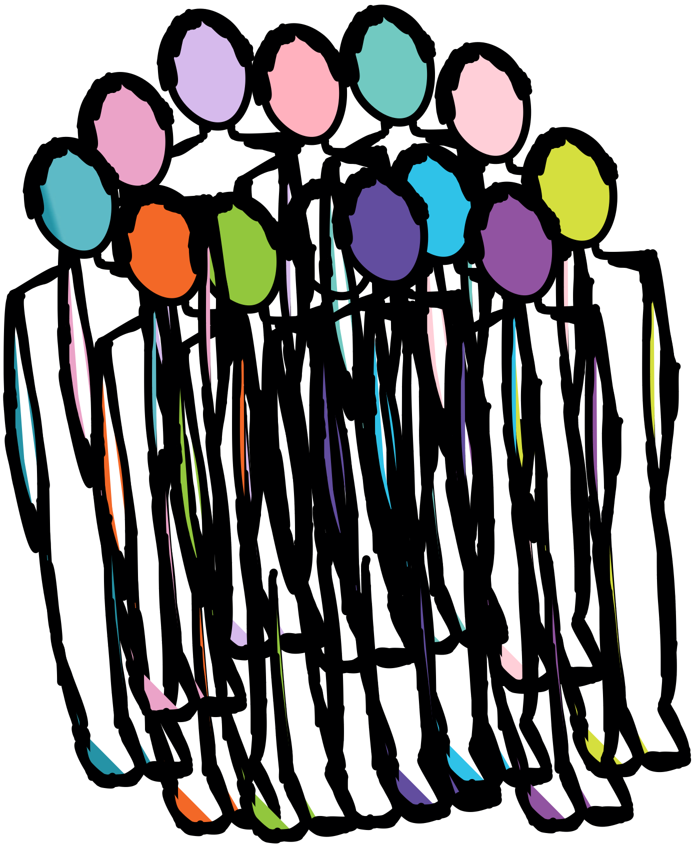
- Acknowledge real challenges, but also take pride in the **many strengths associated with autism.**
- Consider if it could be helpful for a person to consider autism as a **difference, rather than just as a “disorder”** – and **emphasise that we can be different from, and also be of equal value to, non-autistic people to reduce any feelings of guilt/shame for our differences and disabilities.**
- Help the autistic person to **relate to their difficulties with more compassion** – to develop a more self-compassionate way of relating to one-self.

> “When I got my (autism) diagnosis, it just clicked into place and I found there were other people like me, and I was not the only one. Diagnosis as a child would have made a difference – I would have understood myself better and been able to have a more positive autistic identity, rather than feeling like a part of me was missing.”
> GM 3

We suggest when an autistic person's family or significant others hold a strongly deficit-focused view of autism, it may be helpful to consider including them within therapy to enable exploration of autistic strengths and challenges together.

This allows us to recognise and validate families' challenges, feelings and concerns, and to take a sensitive, exploratory approach. The aim is not to challenge or change people's opinions, but to hear and explore multiple perspectives collaboratively.

> "A therapist with a deeper understanding of autism could act as an 'interpreter', when considering how psychoeducation can help the family of an autistic person. For me, it's been wonderful to connect with other autistic people and online groups have been really helpful, but my family members who I suspect also have autistic traits don't have that positive exposure, and I don't know how to talk to them about autism." GM 1



Autistic strengths

Key Idea

Helping some autistic people develop a more positive relationship with their autism diagnosis could be an important goal in itself, and help to alleviate anxiety and/or depression

Psychological therapies, including CBT, often involve recognising and celebrating a person's strengths and talents, especially when individuals struggle to identify these themselves.

We expect therapists will, as a matter of course, look for an autistic individual's unique strengths and talents, and these will inevitably vary, since autistic people are all different with individual talents and challenges. As well as these personalised and very individual strengths, additionally **we suggest therapists seek to look at strengths that are specifically connected to being autistic.** We think this might be helpful because how we feel about our autistic identity affects how we feel about other aspects of our identity and our lives.

As the graphic above shows, **there are a huge range and diversity of strengths that autistic people can possess.** As autistic people, we each have our unique strengths, and additionally some of these may relate specifically to our autistic traits.

> "Autism comes with challenges and difficulties; there are many areas in which I need support. However, there are also so many abilities, skills, and strengths that my autism gives me – if I didn't have an autistic brain, I would lose these aspects too.
>
> For example, initially both my children were refused assessments to make provision for their special needs. My autism meant I obsessively learnt absolutely everything there was to know about special educational law; I spent every waking hour researching what I needed to do and became an expert. Now I have one child in an independent special school and my other child has therapies and extra support provided as part of his mainstream education. It was exhausting and all consuming, but I now have two happy (autistic) children." GM 6

Furthermore, some core autistic characteristics that have sometimes been seen as **"deficits"** or **"limitations"**, can also be seen as strengths. For example, it is sometimes said autistic people have difficulty with understanding the **"big picture"** or **"seeing the wood for the trees"** ('central coherence difficulties'), but this can equally be seen as a strength for detail-focused thinking.

> "I often fixate on small details, which can be frustrating both for myself, as it triggers significant perfectionism whenever I try to produce anything, even within my special interests, and also triggers frustration in those close to me, as I often do not intuitively appreciate wider considerations that are apparent to others. Conversely, this tendency of mine for attending comprehensively to the fine details of any task, resulted in frequent praise in my employment for the high standard of my work." GM 2

As autistic people, we often have a thinking style that is relatively less flexible than non-autistic people, which may trigger difficulties with changing routines or changing our minds, but can also lead to a greater sense of loyalty, integrity, commitment and staying-power (even to change our minds!). **Asking us about our strongest interests can help us notice and explore our strengths – including our passion, enthusiasm and knowledge, problem-solving skills, dedication and expertise.**

Possible strategies for exploring autism-related strengths:

- Brainstorming autism-related strengths together
- Identifying which strengths we might find relevant to ourselves
- Looking at both unique, individual strengths and autism-related strengths
- Therapist flagging and highlighting noted strengths in biographical accounts given during therapy or in the course of therapy discussions
- Keeping a strengths diary and finding examples of our own strengths within our daily lives
- Looking to our interests and activities to help us identify our own strengths, and encouraging us to expand on these interests and activities
- Use our own strengths towards solving our problems and achieving our goals

Coping with meltdowns, shutdowns and burnout

Key ideas

Many autistic people may experience ‘meltdowns’ and ‘shutdowns’, when we are entirely overwhelmed by our emotions or sensory experiences.

Some autistic people also experience periods of burnout, an experience partly caused by chronic stress, where a person becomes exhausted, loses skills and becomes more sensitive to sensory stimuli.

High levels of anxiety may lead to **‘meltdowns’** and **‘shutdowns’**, where we are entirely overwhelmed by our emotions or sensory experiences. These tend to happen when experiences become particularly intense.

A **meltdown** is **a strong response** to being very overwhelmed e.g. physically shaking, screaming, shouting or crying. This can sometimes look like “losing control”.

A **shutdown** is **a muted response** to being overwhelmed e.g. becoming very quiet and withdrawn, “zoning out”, and being unable to speak or otherwise communicate.

> “I was diagnosed with anxiety and depression based on the scores I achieved on formal measurements of depression and anxiety. However, the cause of the symptoms is not really considered and, now that I am diagnosed as autistic, I wonder if I was ever truly depressed/anxious, or if this would be better explained as meltdowns/shutdowns. Learning why I have meltdowns and learning to regulate them would therefore be more appropriate for me than attempting to modify my thoughts and behaviours.” GM 6

> “I get extremes of emotion, which I now think are meltdowns caused by being overwhelmed, and what I need is a dark room with no stimulation and to be left alone.” GM 6

Both meltdowns and shutdowns may be the body’s response to reduce our feelings of extreme overwhelm.

Meltdowns

Meltdowns are an **emotional and behavioural reaction to extreme and overwhelming stress**, driven by the 'fight or flight' response. Meltdowns can be very unpredictable. Though there are some common features, **every autistic person experiences a meltdown uniquely.**

Some of the frequent **characteristics** of a meltdown are:

- Sensory/cognitive overload
- Loss of ability to articulate ourselves
- Loss of ability to process and answer questions
- Hypo/hyper-sensitivity to sensory stimuli e.g. noise, light.
- Shouting
- Crying
- Increase in repetitive stimming behaviours
- Repetitive behaviours (e.g. pacing)
- Self-injurious behaviour (with decreased awareness of pain)

What are some general **triggers** of meltdowns?

- Sensory/cognitive overload
- Expectations from other people that can feel overwhelming
- Reaction to severe stress (cause of which is not always obvious to the autistic person or people around them)
- New situation or sudden change
- Too many choices
- Not given clear answers to questions
- Vaguely defined tasks
- Being taken by surprise

Following a meltdown, a person may feel ashamed or humiliated and worry that relationships have been harmed irreparably. Meltdowns are a relatively short, though often unpredictable, response (as opposed to, for example, burnout).

Shutdowns

Though the characteristics and triggers of autistic shutdown can be very similar to autistic meltdown (e.g. high stress or sensory overload), unlike a meltdown, during shutdown an autistic person may partly or completely withdraw from the world around them. Though there are some common features, **every autistic person experiences a shutdown uniquely.**

Some common signs of a shutdown are:

- Outward physical signs of rising anxiety (e.g. shaking legs, trembling hands)
- Inability to respond to other people
- Unable to talk/communicate
- Increase in repetitive stimming behaviours
- Covering head/face with hands
- Repetitive behaviours (e.g. rocking)
- Unable to physically move body (e.g. may remain in curled body position)
- Lack of awareness/unable to respond appropriately to pain or cold

"I believe it might be useful to think of the shutdown state as a 'non-responsive state' as is observed, but I think that it's possible to conceptualise this also as a highly charged, intensely stressful experience. Social interactions may be intensely thought, felt and analysed during this 'trauma-like' state, but not responded to in an observable way." GM 1

"I experience what I would describe as 'shutdowns', occasions when demands, sometimes external demands from other people, sometimes demands I place upon myself (e.g. from my tendency for perfectionism), overwhelm me. I feel like I cannot stop my racing thoughts, and repeatedly ruminate on the negative thoughts flooding my mind. I lose the ability to effectively process my thoughts or problem-solve to think of solutions and feel completely overwhelmed.

I react by retreating so I am alone, curling myself into a ball, hiding my face against my knees, rocking backwards and forwards, often pressing myself into small spaces between furniture.I can stay in this state for hours, as I totally lose comprehension of time, and have significantly decreased awareness of my bodily sensations, such as cold or pain. I can hear what is going on around me, but responding feels beyond my capabilities.

Eventually, the extreme discomfort of my bodily position enters my awareness and forces me to move, but then my emotions erupt into my awareness, and I cry. After shutdowns occur I am exhausted, and often need to retreat into solitude and silence, wrapping myself in soft blankets, making small repetitive movements such as rubbing my feet together to self-soothe, and find oblivion in sleep." GM 2

‘Autistic burnout’

Key idea

While meltdowns and shutdowns are responses to very brief, intense feelings, **autistic burnout is a response to chronic stress and expectations outweighing abilities.**

‘Autistic burnout’ appears to be an experience very specific to autistic people - one that is both very common and very disabling. Although there is very little research on this experience, a recent study asked autistic adults about burnout, concluding that autistic burnout is different to both depression and occupational burnout experienced but non-autistic people.

Autistic burnout may occur after being in a stressful environment for a prolonged period of time, without sufficient support, resulting in expectations outweighing abilities.

Three core features of autistic burnout have been suggested:

- Chronic exhaustion
- Loss of skills
- Decreased tolerance to stimuli

Other **symptoms** may also be present:

- Intense anxiety and/or increased symptoms of depression
- Increase in repetitive behaviours
- Frequent meltdowns/shutdowns
- Suicidal behaviour
- Memory loss
- Inability to camouflage/compensate

Some **triggers** to burnout have been suggested:

- External/internal expectations chronically outweighing intrinsic ability
- Chronic and/or extreme camouflaging and compensation
- Sensory overstimulation (especially prolonged)
- Stress (especially prolonged)
- Important life events/change
- Inability to recover from meltdowns/shutdowns and previous burnouts

As a group of autistic adults drawing on our lived experience of burnout, we feel burnout is distinct from other difficulties, such as depression (although they may overlap and/or co-occur, and are very difficult to distinguish in practice).

> "I have been experiencing burnout myself for years, on and off, which has at certain points led to very harmful misdiagnoses and treatment." GM 3

> "I've experienced 'burnout' multiple times – in fact, when I map out the timeline of my life in my head, burnout seems to be the key event into which different parts of my life are divided. It's terrifying, overwhelming and there seems to be no understanding.
>
> For me, it's not the same as experiencing depression. It's being trapped in an exhausted body, having lost access to many valuable skill, As I don't lose interest in things and I still 'feel' and want to do things (motivation, at least on some level, remains intact) – but simply cannot.
>
> At times of burnout, I've often been (mis?)diagnosed with depression, given medication and encouraged to try to take part in life (e.g. go outside, meet people). This is difficult because one of the strategies to recover from burnout is complete rest, with complete reduction of sensory stimuli. So, often, advice at these times actually exasperated the exhaustion." GM 4

We suggest that it would be helpful for therapists to be aware of **meltdowns, shutdowns and burnout**, and to ask autistic people about these experiences. Our lived experiences of burnout describe its debilitating nature and the uncertainties of how best to handle/address the experience.

> "Long term if I neglect myself, I end up burnt out. I spent a year recovering in a mental health day centre, but I wasn't mentally ill: I was autistic, and I was burnt out." GM 6

> "It's so important to empathise burnout as a significant event. Identifying autism and getting a diagnosis is only the first step for late diagnosed adults. It made me feel really sad at how alone I've felt in the struggle post-burnout, and despair at the lost opportunities pre-burnout, to have been heard or supported." GM 1

> "When in autistic burnout, my body and mind are in complete shutdown and this is worse than depression because I feel far more trapped. Initially, I don't experience low mood, anhedonia nor loss of motivation. It's just complete exhaustion, involving memory loss, as well as ability to do basic things. If other autistic people who experience burnout feel this way, this could well be linked to the high suicide/suicidal ideation rates." GM 4

Strategies to cope with meltdowns, shutdowns and burnout

We suggest it might be helpful to plan together around ways to prevent or reduce experiences of meltdowns, shutdowns and burnout, such as looking at possible triggers, lifestyle factors and coping/calming strategies**.**

- From a CBT perspective, it might be useful to work with a therapist to create a **"burnout plan"**. This may be similar to a "crisis plan", incorporating past experiences which have triggered burnout; reviewing coping strategies, warning signs and triggers; and planning how to respond if the early signs of burnout are evident (e.g. a list of supports and helpful coping strategies).

However, we suggest that if a **"burnout plan"** is created, therapists are mindful of the following concerns:

- Being clear to distinguish 'burnout' as a distinct experience, differing from other mental health difficulties e.g. low mood.
- The impact **alexithymia** may have on recognising impending burnout, as even if an autistic individual intellectually knows their own early signs, they may not recognise their own emotional/bodily signals and link them to these.

> "My own big difficulty is not being able to recognise and interpret my own emotions/bodily sensations and this is what often leads to, sometimes massive, trouble. I tell myself and believe I am doing fine – until it hits." GM 4

- The impact of **camouflaging**/compensation in disguising burnout.

> "I often push myself further (when in burnout), due to messages from others, such as that once I am used to a new environment it will "get better". The problem is, that's not how it works. If the default is that the environment is extremely over-stimulating (even when the novelty aspect is finally removed), then it will naturally just get worse because I am exposing myself to a situation that is not diminishing in its impact on me." GM 4

- The impact upon the therapeutic relationship of the loss of language skills, compensatory mechanisms, worsened short-term memory and/or difficulties in social cues interpretation, which autistic people describe being associated with a burnout state.

> "I have lost therapists in the past because a burnout caused a complete disconnection that, neither of us at the time, could interpret nor make sense of. This makes therapy hard." GM 4

Drawing on our lived experience as autistic adults, we recommend the following **strategies to manage and prevent meltdowns and shutdowns:**

- Remove self from triggering situations as soon as possible when experiencing meltdowns/shutdowns
- Use self-soothing techniques to calm
- Try to learn frequently experienced triggers of meltdowns/shutdowns
- Allow sufficient recovery time after experiencing a meltdown/shutdown

Drawing on our lived experience as autistic adults, we recommend the following **strategies to manage and prevent burnout:**

- Identify daily stresses that contribute to chronic stress and try to see if they can be practically reduced
- Identify over time which situations are most likely to trigger burnout
- Identify signs of approaching burnout (e.g. some autistic people describe feeling disconnected from their bodies or experiencing tunnel vision)
- Create a burnout plan (see above)
- Make a list of things that helped to recover from a previous burnout and try to use these strategies
- If able, slow down lifestyle/take time out
- If able, share strategies/symptoms/signs with a loved one, who may help to identify approaching outward signs of a burnout

Coping with co-occurring physical health conditions

Key Ideas

Physical health is known to have a direct impact upon mental health. Some physical health conditions are known to be more prevalent in the autistic population, which may place a greater burden on our mental health. It is also known that autistic people experience greater health inequality, and face greater difficulties in accessing healthcare, due to differences inherent within our autism but also due to stigma and discrimination.

There is strong evidence **autistic people commonly experience health inequality, alongside experiencing increased physical health challenges,** when compared with non-autistic people. Evidence also shows improving support and treatment for health conditions can improve quality of life for autistic people. The NHS Long Term Plan (2019) states services should commit to lowering health inequalities, including the development of annual health checks for all autistic people to increase detection of health conditions.

Exploring physical health may be especially important with autistic adults accessing therapy. As a group of autistic adults, we recommend **therapists enquire about physical health as part of an initial psychological assessment** (and considering an onward referral if appropriate). Therapists might enquire about sleep; eating and nutrition; exercise; drug and alcohol use; difficulties around menstruation; diagnosed conditions and medication.

'Third Wave' CBT-based therapies, such as Dialectical Behavioural Therapy (DBT) have highlighted the impact of physical health and wellbeing upon mental health and especially upon an individual's ability to effectively regulate their emotional state. DBT techniques, such as the 'PLEASE' skill, aim to reduce vulnerability to emotional dysregulation, through prompting an individual to focus upon "taking care of your mind by taking care of your body".

Co-occurring physical health conditions

Drawing on our group's lived experience, we mention below some physical health issues that are often more pertinent to autistic people.

It is known that some physical health conditions occur more commonly in autistic people, which we have experienced in our lived experience as autistic adults. These include:

	Autism population	General population
Epilepsy	11.94%	0.73%
Neurological Conditions	39.28%	22.05%
Gastrointestinal disorders	34.70%	27.47%
Sleep disorders	17.58%	9.60%
Cardiovascular Diseases	36.96%	23.03%
Nutrition Conditions	37.25%	18.72%
Genetic Disorders	3.45%	0.21%

Anorexia Nervosa

In very recent years, research has shown there is a significant connection between eating disorders and autism, particularly Anorexia Nervosa (AN). Recent studies found 20–35% of women with AN meet the diagnostic criteria for autism, opposed to less than 1% of the general population of women. **The prevalence and presentation of AN (and eating disorders in general) is currently significantly under-researched in non-binary/male autistic individuals.**

However, despite a higher proportion of autistic individuals within Eating Disorder services, there is currently no standardised adaption for their needs, resulting in low recovery rates when compared to non-autistic individuals with AN. This could be because development and maintenance of an eating disorder in autistic people may be attributed to different factors or the factors having a stronger influence, when compared to non-autistic people, e.g. sensory and interoceptive difficulties, a higher need for control due to increased sensitivity to uncertainty, and difficulty with cognitive flexibility. Therefore, for autistic individuals who also have a diagnosis of AN, their lowered chances of recovery may lead to significant negative impact upon ongoing physical and mental health.

ARFID

Avoidant Restrictive Food Intake Disorder (ARFID) commonly co-occurs with autism. ARFID is characterised by avoidant and restrictive eating patterns; failing to meet nutritional and/or energy requirements, leading to significant weight loss/failure to gain expected weight; nutritional deficiencies; and/or significant difficulties with psychosocial functioning.

As ARFID is more commonly considered in children, it is often overlooked in autistic adults, or misdiagnosed as AN in adults with low weight. Individuals with ARFID tend to restrict their food intake due to sensory sensitivities concerning food, a lack of interest in food, or because of feared negative consequences of eating food, but there is currently very little known about effective treatments. As ARFID is more common in autistic individuals, the restrictive food intake associated with ARFID is highly likely to have a negative impact upon wellbeing.

Disordered eating

A high number of autistic people experience disordered eating, without meeting the criteria for formal diagnoses, such as Anorexia Nervosa or ARFID. A high number of autistic children (up to 90%), experience such disordered eating. Interviews with some autistic adults show that disordered eating, due to autism-related difficulties, such as ‘rigidity’, sensory sensitivity and executive dysfunction, persists into adulthood. Disordered eating may include pica (consuming non-edible substances), sensory sensitivities (avoiding food because of certain textures), behavioural rigidity (an autistic person might like to eat a very specific kind of food) and rapid eating behaviours.

When these eating difficulties affect an autistic person in an extreme way e.g. significant change in weight, an autistic person may be diagnosed with an eating disorder, such as Anorexia Nervosa or ARFID (described above). However, because being diagnosed with autism often prevents a secondary diagnosis of an eating disorder (unless its symptoms are judged to be very severe), it is very difficult to know how many autistic people have disordered eating that have a day-to-day (but not necessarily immediately life-threatening) impact on mental and physical wellbeing. Furthermore, even when autistic people’s eating difficulties progress into an eating disorder, current diagnostic criteria may not capture our experience (we will not fit into any existing diagnosis) and, therefore, we may not receive appropriate nor timely treatment.

Medication

There is concerning evidence medications that affect psychological functioning are over- prescribed to autistic people. Public Health England has reported autistic people are more likely to be inappropriately prescribed these medications than the general population, and at higher dosages, with the NHS responding by launching a campaign to reduce over-prescribing of these type of medications to autistic people.

> "I wish instead of being prescribed strong medications for distress triggered by sensory sensitivity, professionals would instead have suggested options like custom made silicone earplugs, white noise machine or a weighted blanket. Not to mention the cost of my medications and the administrative costs of needing to be overseen by secondary mental health services, or the impact on my quality of life." GM 7

Menstruation

Although periods are a normal part of life, it is also normal for people to struggle with them. People who have developmental and intellectual disabilities have described being particularly negatively affected by menstruation. In terms of autistic people, many have said they experience a lot of pain before or during their periods, increased sensory sensitivity, mood changes and that they struggle a lot more to regulate their emotions. This means it is especially important for therapists to be aware of the way periods can impact on the mental health of autistic people.

It is very important for therapists to stress that, while periods are a normal experience that it is okay to talk about, it is also very normal to struggle with them and find them distressing – and that it is also okay to talk about the distress/discomfort. We suggest, when the therapist feels it is appropriate, a therapist could broach a conversation about menstruation to explore how the autistic person accessing therapy relates to or experiences it.

Sleep

Many autistic people report sleep difficulties, including difficulties with getting to sleep and having restful, restorative sleep, as well as adhering to a good sleep hygiene, which is echoed in the lived experience of our group. Within DBT, the importance of sleep is particularly empathised within the ‘PLEASE’ skill, with useful suggestions also included within DBT’s ‘Sleep Hygiene Protocol’.

> “I use a weighted eye mask every night and it really helps me – so much so that I purchased the entire set of weighted eye masks.”
> GM 7

> “Sleep and routine have been a very important factor in getting me well again, and I measure this with my Fitbit and record it in my bullet journal. I use wordsearch puzzles and scrabble games to calm my thinking and it helps me get ready to sleep away from my phone.
>
> Medication prescription has been really important, monitoring over several months to get right, as has identifying and trying to reduce the physical effects of the levels of stress I experience.” GM 1

Accessing Services

Many autistic adults are likely to have experienced significant difficulty in accessing services, and in being adequately heard and understood. We reflected as a group, drawing upon our lived experience, that difficulties such as camouflaging/compensation and the double empathy problem impact upon our ability to effectively communicate with health professionals; and our sensory sensitivities can negatively impact upon our ability to easily access healthcare environments.

> "Unfortunately, as a late-diagnosed autistic adult with no post diagnostic support, I had no idea there was anything I could do (or learn about) that may help with my sensory sensitivities. I wish I had access to specialist Occupational Therapy input, as mental health OT's and physical health OT's seem not to have any training or knowledge around sensory sensitivity. This lack of specialist input meant that unfortunately I purchased a weighted blanket that is too heavy for myself, which was a very expensive mistake." GM 7

Research has shown GPs and psychiatrists self-report a lack of confidence in providing care for their autistic patients. The Royal College of General Practitioners' Autistic Spectrum Disorders Toolkit provides guidance to support autistic people, and schemes such as Sunflower lanyards can inform professionals a person is autistic. The National Autistic Society's 'hospital passport' is useful to provide autism-specific information in medical settings.

In 2019, the Department of Health and Social Care funded training on learning disability and autism for health and social care staff, covering topics such as making reasonable adjustments and adapting communication styles, but in our group's lived experience, often the communication and access needs of autistic adults without co-occurring learning disabilities, are not considered.

> "One of the things I have liked about CBT is a structured intention to monitor and reflect on any changes made. This systematic approach has also been useful for medication changes I've made. It has been good to reflect on what works and what doesn't, as well as to monitor using apps or charts or notebook." GM 1

We therefore recommend a therapist enquires about **current and past support from services**. It will be helpful to understand where autistic people are currently receiving support and any difficulties currently encountered, and where there may be a need for supportive referrals and advocacy on our behalf.

Advocacy

Advocacy can be helpful to support autistic people effectively access services and request adaptions/accommodations for our specific needs in the following ways:

- being a source of information about an individual's legal rights (including our right to access our historical records),
- helping to write letters, make phone calls or arranging appointments with supportive organisations,
- providing information and preparing for important meetings,
- advocating within meetings to promote our 'voice', ensure we are listened to, and that any assessments made are within our best interests, inclusive of our wider, possibly complex, needs,
- suggesting relevant reasonable adjustments and advocating for implementation,
- providing encouragement and reassurance.

An advocate may therefore assist in alleviating challenges presented by lack of autism understanding when navigating services, such as: difficulties within social interactions with professionals; 'executive functioning' difficulties which may impact on our ability to write letters, organise appointments or prepare for meetings; and advocate for reasonable adjustments so that environments are better adapted for our needs.

Alleviating some of these challenges would ensure easier access to services, more effective communication with treating professionals, and possibly improved outcomes for autistic clients.

Coping with organisation and socialising

Key Idea

Some autistic people struggle with “executive functioning” (our brain’s ability to plan and switch between competing demands), which can impact upon daily living skills, involving organisation and planning. Possible interventions to help build daily living skills and promote planning and organisation may be useful.

‘Executive functions (EF)’ are a number of processes that help a person have control over their behaviour, especially to select and work towards a goal. These functions may include: working memory; being able to switch between different things; having control over one’s attention; the ability to tune out things that are not important for achieving a set goal; and stopping oneself from acting on impulses that do not align with what one has set to do.

People can struggle to carry out even small day-to-day tasks if they have a difficulty with any of these functions. For example, in order to have breakfast, a person has to:

1. Remember to have breakfast and what it involves to make it
2. Able to juggle other things that might be capturing one’s attention as they try to focus on the goal of making breakfast
3. Be able to set continuous attention on the goal of making breakfast
4. Be able to block out things that can wait after the goal of having breakfast has been achieved
5. Stopping oneself from carrying out other tasks that would get in the way of making breakfast

It is known that many autistic people often experience difficulties with executive functioning. It may be helpful for therapists to explore the following: how we function with self-care (such as washing, housework, cooking, washing clothes, tidying); our ability to manage our time effectively; ability to organise and plan our days; and our ability to manage simultaneous demands within our daily lives. **It may help to work specifically on our ability to be kind to ourselves, in view of the far-reaching impact of executive functioning difficulties on many areas of our lives.**

"As an autistic person, I struggle with executive functioning. I find it hard to do two things at once, to plan several things in a day, to remember what I need to do. I desire a tidy home and function better in a tidy home but lack the skills to achieve this, as even when my tendency to avoid tasks is taken away, I still struggle to actually have the ability to tidy. I yearn for a clutter-free environment." GM 6

"Adjusting my routines and planning for things gets noticed by my partner and some of the routines I have set in place have been taken up by him through habit – such as talking about ideas for the weekend on a Thursday evening (I get a reminder on my phone to think about this weekly). We can use some of our preference for routine and schedules as a way of setting good patterns in place that others embrace too." GM 1

It can help to work with autistic people on **practical skills, including diary management, making and keeping lists, structuring time, problem-solving and prioritising.** It can also be helpful to work on **practicing how to take breaks, reduce procrastination, switch attention and cope with distraction.** These difficulties can cause challenges with employment and independence, which are not necessarily related to our levels of articulation or intelligence.

"I find I learn about myself through parenting my children. I find it hard to organise my time. I find I am pushed to my limit and beyond. The love I have for my children and the desire to be a good parent pushes me through and I manage somehow to do all that is demanded of me. But it is also very hard, and I have a lot of support in place so that I can manage each day. I can't believe I could have learnt how to raise them, but they are not only living, but also happy and thriving." GM 6

"I think some therapists find it very difficult to believe a person can be highly capable in some areas and struggle extremely in others – especially when such capabilities are in highly abstract things, while the difficulties are in very basic things. It may not occur to them that there is an actual fundamental difficulty there (even if they know that you are autistic)." GM 4

Executive Functioning

Some suggested strategies to address executive functioning difficulties:

- Creating and adopting daily routines, even for seemingly simple tasks such as getting up/getting dressed, can help to decrease the conscious thought and decision making.
- Organising areas of the home/workplace, so that everything needed to complete tasks in that area is easily accessible, can help to reduce stress.
- Having routines when leaving/entering the house, so essential items needed to be taken out of the home are readily to hand, can help with both organisation and transition. This may involve storing items in particular places, such as near the external door, or having visual prompts when leaving the house as reminders to collect essential items e.g. phone/keys.
- Focusing on one task at a time can prevent overwhelm, and tackling an easier task first to achieve a feeling of success can be helpful if procrastination tends to trigger avoidance.
- Breaking larger tasks into small manageable steps can also help to prevent overwhelm and avoidance and create a sense of successful completion. Techniques such as the ‘Pomodoro Technique’, which alternates periods of timed focused activity with short breaks, may be helpful.
- Establishing realistic and achievable daily/weekly routines can be useful to ensure daily living tasks are regularly completed (e.g. cooking/shopping/washing clothes/cleaning), possibly with support from other people initially. It may be helpful if daily/weekly routines are displayed visually in a frequently visited area of the home.
- Utilising technology, such as online daily schedules, weekly calendars, reminders and alarms on a mobile phone can alleviate executive functioning difficulties.
- Family members/friends may help to assist in organisation and completion of daily living tasks.

> “I will feel totally unable to clean my messy house. I find I have to trick my brain, and once I’ve got started on a task, I’m normally ok. So, to clean my house I set a timer for 20 minutes, and I tell myself I only have to clean for 20 minutes. Once I’ve actually started, I can usually carry on until the job is done, and then I often wonder to myself why it was so difficult to do this very easy task in the first place!” GM 6

> “Adjusting my routines and planning for things gets noticed by my partner and some of the routines I have set in place have been taken up by him through habit – such as talking about ideas for the weekend on a Thursday evening (I get a reminder on my phone to think about this weekly). We can use some of our preference for routine and schedules as a way of setting good patterns in place that others embrace too.” GM 1

We therefore suggest possible interventions to help build daily living skills and promote planning and organisation may be useful. A number of helpful interventions have been suggested in high-quality guides (e.g. Valerie Gaus) which we would recommend, as well as onwards referral for assessment (e.g. by an occupational therapist), if felt necessary.

Executive functioning difficulties may also impact upon therapy, as autistic people may find some aspects more difficult, such as processing information in the session, keeping and remembering appointments, attending on the right day and being on time, as well as focusing for a prolonged period.

We reflected executive functioning difficulties may be negatively and mistakenly interpreted as “therapy interfering behaviours” within a therapeutic relationship, rather than as a part of autism or other neurodivergent condition, and are therefore not indicative of an autistic individual’s therapeutic engagement. Simple strategies, such as sending a text reminder of an appointment, may help to alleviate the impact of executive functioning difficulties upon successful therapy.

Coping with socialising

Key idea

Many autistic people wish to have social connections to others but face challenges, as evidence shows autistic and non-autistic people may have difficulty understanding each other's communication styles.

We may also find socialising very effortful and therefore need to find an individual balance between social and non-social time.

Social support has been recognised as a particularly important contributor to **improving quality of life and well-being** and reducing suicide risk in autistic people. In order to assess our social supports, we suggest a therapist asks questions about our living situations, social connections, perceptions of socialising and other people, intimate and family relationships, employment and study, activities, special interests and leisure time.

"Having children has helped me with many of my challenges as an autistic person, as I have to put my children first and am able to do things, because it is for them. For example, I find it hard having to socialise with other parents, but I can go to crowded school concerts, drop children off at the houses of strangers, hold birthday parties. I would far rather hide inside my house and not speak to anyone, but because I have to look after my children, I find myself very much a part of society." GM 6

There has historically been a long-standing and arguably **flawed assumption** that autistic people lack social motivation. Conversely, evidence has shown autistic people experience loneliness, and that feeling **a sense of belonging matters to us** and impacts upon our quality of life.

"I find social interaction exhausting, but I have a need to connect to someone else and feel a part of the world." GM 6

> "I have always struggled with loneliness throughout my life. I watch as others make connections with one another in a manner that I struggle to comprehend, let alone replicate. 'Small talk' takes such conscious effort, and despite my best efforts, others within my daily life tend to view me as a polite acquaintance, rather than a friend. Yet, I long for connection, for the ability to share my thoughts and my experiences, to abate the distressing feeling of loneliness which is recurring theme though my life." GM 2

"Difference not deficit"

Often, psychologists have focused on helping autistic people with socialising by trying to help us improve our "social skills". Sometimes this may be helpful – for example, if we find it hard to understand the expectations of a certain situation, or if we want to learn how to navigate a particular part of the social environment.

> "I do not instinctively understand the social world – I have had to work very hard to learn my social skills and using them exhausts me. I appear very articulate, but there is a huge discrepancy between my ability to think and my ability to communicate my thoughts. I find it hard to communicate verbally and in real time with another person." GM 6

Increasingly however, evidence shows, **instead of focusing upon the improvement of "social skills", it may be more beneficial to support us in feeling more accepting and positive about ourselves and our autistic identity, to enable us to feel a greater sense of social connection and belonging.**

> "I spent much of my teens and 20's trying to fit in and compensate for my autistic quicks, but as I hit my 30th year, it dawned on me that it doesn't really matter whether I do "fit in" and actually, as long as I am flourishing in my own individual way, I can drop the compensation, camouflaging and my mask – and that is ok." GM 3

Greater contact with like-minded others has been shown to reduce loneliness. Therefore, encouraging us to develop social connections within other autistic people may foster a sense of belonging.

It may be helpful for therapists to signpost towards formal autistic peer support when available. Some autistic people find peer support offered by other autistic people useful, providing sources of information, practical and emotional support; as well as offering acceptance which might enable us to feel more accepting of ourselves and more positive about our autistic identity.

> “What has been helpful for me has been suggestion from therapists to find other autistic adults and connect with them. Meeting other autistic people was an invitation to look inward and accept what I found.” GM 1

> “We can create our own groups and belong there.” GM 6

Social and non-social time

It might be helpful to explore **finding a balance between social and non-social time,** which will naturally be a very individual balance. One way of exploring this is to think visually about how much energy we have to spare and acknowledging that, as autistic people, **it is common for our energy levels to be drained in social situations,** particularly with neurotypical people.

> “Socialising is a bit like being amongst a crowd of people and all of a sudden you forget how to walk. Everyone around you is walking around nonchalantly, and you have to think through every aspect of how to put the motor sequence together to stay upright and transition from one foot to the other. That’s what it is often like to be autistic, but trying to fit in. It takes energy, thought, and even though you might appear to walk just like everyone else, it takes a lot more effort to appear normal.” GM 3

It can be helpful to think about planning how much social time is manageable for us, and in which contexts. It might be useful to consider developing strategies to assist us manage the balance between social and non-social time, such as setting a time-limit when engaging in a social situation. This may help to ensure our necessary or desired social interactions are manageable (and hopefully enjoyable), without triggering significant fatigue, which may impact upon our health and well-being.

> "As autistic people, it's so important that we give ourselves the time we need to recover from social interactions instead of pushing on, because most people don't understand what we are feeling – because for them, it just isn't something within their own experience. I need to have proper recovery time, as the impact can last several days." GM 6

Developing social connections

It may be helpful to discuss our important social relationships, to consider whether we are content with our relationships with others, or whether we would like to improve our social relationships.

If we would like to improve our social relationships, it would be useful to clarify whether this means working on improving one specific relationship (e.g. relationship with partner/family member), or developing a greater number of social connections (e.g. forming one additional friendship might be a manageable step initially).

As autistic people, we are often painfully aware of the difficulties that we have in forming and maintaining social relationships.

> "Especially since diagnosis, but even before that, I felt/feel immense pressure to not mess up social interactions, so as not to play into stereotypes of autism. It gets exhausting. It leaves no room for mistakes – and, of course, making mistakes is human. Non-autistic people mess up all the time, but I feel I can't afford it. I know I don't actually represent every single autistic person in the world, but it can start feeling that way when you play into a stereotype – and re-affirm harmful ideas. Then I feel awful for letting people down."
> GM 4

It therefore may be useful to look at strategies that support the development of social relationships, as included in some 'third wave' CBT therapies, such as Dialectical Behavioural Therapy (DBT). The DBT 'Interpersonal Effectiveness' module includes skills to manage and enhance interpersonal social relationships.

For example, the DBT 'GIVE' skill (be **G**entle, act **I**nterested, **V**alidate, use an **E**asy manner) strives to enable an individual to "act in such a way that you maintain positive relationships and that others feel good about themselves and about you", even when misunderstandings or differences of opinion occur.

Flexible communication

It can also be helpful to **consider the impact of the type of communication.** Many autistic people find socialising in a group more tiring than a one-to-one interaction, due to the greater demand on our processing abilities from the fast-moving dynamics of a group.

> "For me, when it's just one person, I can usually muddle my way through the interaction, If I'm in a group, it usually becomes impossible. Sometimes I try to focus on one person in a group, but then it looks weird (or maybe even rude), that I'm ignoring everyone else." GM 4

The type of communication utilised can also impact upon our energy levels and our abilities to communicate more effectively. **Some autistic people may find non-speaking means of communication easiest within their social interactions, and some autistic people do not use spoken speech at all, yet have full comprehension of other's spoken communication.**

Some autistic people prefer to conduct the majority of their social interactions within online environments, as this reduces the demands of the immediacy of spoken communication and the need for eye-contact, remaining within their familiar and safe physical environment.

> "Even when I feel very comfortable around a person, this does not translate into speaking being easier for me. I'm becoming more confident that I could rely on non-spoken communication on many more occasions – I am not sure how this will be accepted in my day-to-day life but could be very beneficial for me." GM 4

Non-spoken e.g. written/sign, means of communication can be particularly helpful when we are experiencing heightened emotion, such as conflict or distress.

> "Using other forms of communication, other than spoken, is a helpful option for others to suggest when trying to help me. I have switched to texting my partner to have an argument that doesn't escalate as much as if I was experiencing the sound of our voices raising and resolves a lot easier. Offering "Would you like to communicate with paper, or on a tablet or phone?" would be so lovely to hear and see happening when somebody (like me) is in distress." GM 1

Therefore, reflecting on our lived experience, **socialising with other people, both autistic and non-autistic, can hugely enhance our lives, but needs to be managed in compassionate ways to avoid a negative impact of our well-being.**

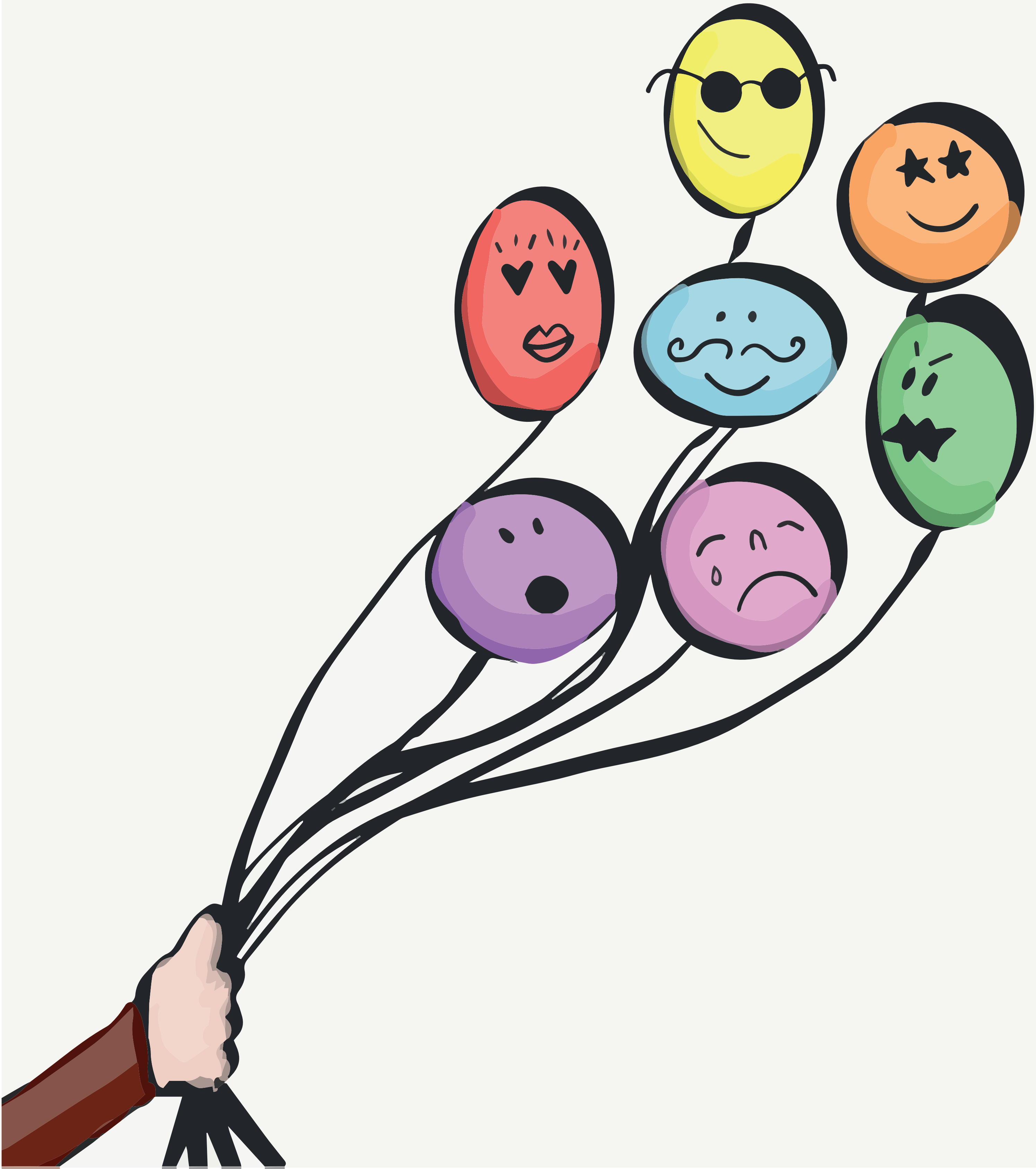
Part 4 – Summary

What do we know?

- Many autistic people experience alexithymia, which makes identifying, accepting and regulating emotions more difficult.
- Acceptance-based approaches, such as Mindfulness-based therapies and ACT, which create distance from thoughts through “observing” or “defusing”, may help with emotional acceptance in autistic people. Motivation for change may be aided by exploring an autistic individual’s goals and values, thus putting emotions, thoughts and behaviours in context.
- Autistic people are known to experience heightened levels of anxiety, depression, and elevated rates of suicide, suicidal thoughts and suicidal behaviours, but may have atypical presentation of these experiences. Holding a positive or negative autistic identity is strongly related to the likelihood of experiencing difficulties with depression and anxiety. Identifying autistic strengths can help promote a positive autistic identity.
- Many autistic people experience meltdowns and shutdowns when overwhelmed by emotions or sensory experiences. Some autistic people also experience periods of burnout in response to chronic stress and expectations outweighing abilities. It is helpful to explore strategies to reduce and manage meltdowns, shutdowns and burnout.
- Autistic people are known to experience a greater prevalence of co-occurring physical health conditions. Addressing inequalities and ensuring access to healthcare can alleviate the impact of co-occurring physical health conditions.
- Autistic people commonly experience loneliness and desire social connections, but face challenges due to differences in communication styles. Encouraging connection with other autistic people can provide a sense of greater social connection and belonging.

What do we need to know?
Further recommendations for research:

- How does alexithymia relate to autistic functioning and the higher prevalence of mental health conditions?
- How effective are third-wave therapeutic approaches (such as ACT, Mindfulness-based Therapies and Compassion-Focused Therapies) for autistic people? Are we measuring autistic people's outcomes and wellbeing against neurotypical standards? We therefore believe it is important to understand an individual's goals and values as an important barometer for change.
- How do we best support autistic individuals during life stages/ changes involving uncertainty and transition (e.g. starting education, changing schools, beginning menstruation, attending university, living independently, commencing employment, changing jobs, pregnancy and birth, adapting to parenthood, navigating menopause, entering retirement, moving into care settings in older age)?
- How could anxiety and distress be most effectively recognised and measured in autistic people, especially in the context of camouflaging?
- What causes high rates of suicidal behaviours and suicide in autistic individuals? Who is most at risk and how can we bring these rates down? How can we prevent the high rates of trauma in autistic individuals?
- What determines an autistic individual's sense of identity? What is the role of stigma? What can we do to promote a positive autistic identity in people with existing or new autism diagnoses?
- How can we explain the high rates of comorbidities (both physical health conditions and mental health conditions or co-occurring neurodevelopmental conditions such as ADHD and Tourette's) and how could treatment be modified in these circumstances to lead to the best outcomes for the individual?



Appendices

Appendix 1: Suggested Further Reading

CBT, ACT, CFT, DBT and Mindfulness

Gaus, V. L. (2018). ***Cognitive-Behavioral Therapy for Adults with Autism Spectrum Disorder.*** Guilford Press.

Gilbert, P. & Choden (2013) ***Mindful Compassion – Using the Power of Mindfulness and Compassion to Transform Our Lives***. Robinson.

Hayes, S. (2019) ***A Liberated Mind – The Essential Guide to ACT.*** Vermilion.

Linehan, M.L. (2014) ***DBT Skills Training Manual. 2nd Ed.*** Guildford Press.

Russell, A., Jassi, A., Johnston, K., & Russell, D. (2019). ***OCD and Autism: A Clinician's Guide to Adapting CBT.*** Jessica Kingsley Publishers.

Other suggestions

Attwood, T. (2008). ***The Complete Guide to Asperger's Syndrome.*** Jessica Kingsley Publishers.

Bargiela, S., & Standing, S. (2019). ***Camouflage: The Hidden Lives of Autistic Women.*** Jessica Kingsley Publishers.

Barkley, R. A. ***Taking Charge of Adult ADHD.*** Guilford

Beardon, L., & Worton, D. (2011). ***Aspies on Mental Health: Speaking for Ourselves.*** Jessica Kingsley Publishers.

Bogdashina, O., & Casanova, M. F. (2016). ***Sensory Perceptual Issues in Autism and Asperger Syndrome, Different Sensory Experiences - Different Perceptual Worlds.*** Jessica Kingsley Publishers.

Booth, J. (2018) ***Autism Equality in the Workplace: Removing Barriers and Challenging Discrimination.*** Jessica Kingsley Publishers.

Brown, L. (2017) ***All the Weight of our Dreams: On living Racialized Autism.*** DragonBee Press.

Cat, S. (2018) ***PDA By PDAers: From Anxiety to Avoidance and Masking to Meltdowns.*** Jessica Kingsley Publishers.

Fletcher-Watson, S., & Happé, F. (2019). ***Autism: A New Introduction to Psychological Theory and Current Debate.*** Routledge.

Hallowell N., & Ratey, J. (1995) ***Driven to Distraction: Recognising and Coping with Attention Deficit Disorder from Childhood Through Adulthood.*** Touchstone.

Hendrickx, S. (2015) ***Women and Girls with Autism Spectrum Disorder: Understanding Life Experiences from Early Childhood to Old Age.*** Jessica Kingsley Publishers.

Mendes, E. A., & Maroney, M. R. (2019). ***Gender Identity, Sexuality and Autism: Voices from Across the Spectrum.*** Jessica Kingsley Publishers.

Lipsky, D. (2011) ***From Anxiety to Meltdown: How Individuals on the Autism Spectrum Deal with Anxiety, Experience Meltdowns, Manifest Tantrums, and How You Can Intervene Effectively.*** Jessica Kingsley Publishers.

Steward, R. (2019) ***The Autism-Friendly Guide to Periods.*** Jessica Kingsley Publishers.

Stark, E., Ali, D., Ayre, A., Schneider, N., Parveen, S., Marais, K., Holmes, N., Pender, R. (2020). ***Coproduction with Autistic Adults: Reflections from the Authentistic Research Collective*** Autism in Adulthood.

Appendix 2: Personal Profiles

With further acknowledgement of other group members who have made hugely valuable contributions to this document.

Annalise Ayre

A late-diagnosed autistic person, wishing to positively utilise my lifelong experience of severe mental health challenges, as a 'lens' to inform suggestion of individualized adaptions and positive change for autistic people accessing therapy.

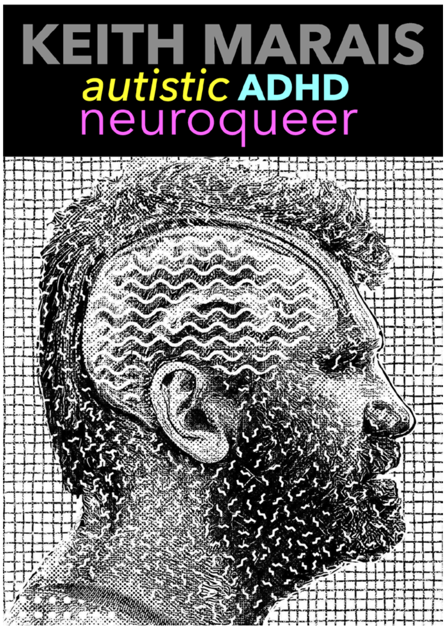
Naomi

Special interests:
running, creative writing
reading fiction, art,
autism research

ELOISE STARK

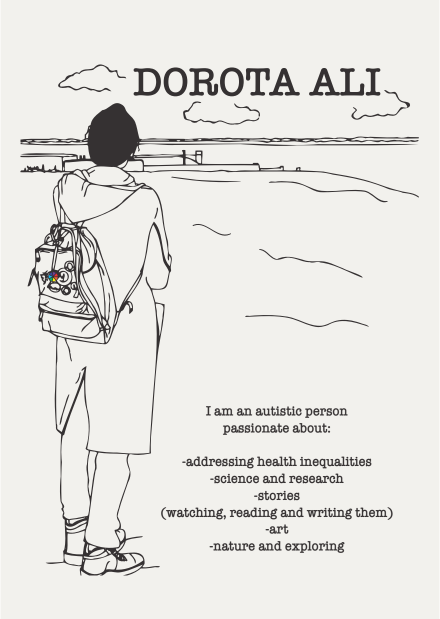
Postdoctoral Researcher
at the University of Oxford &
Assistant Psychologist in the NHS

Passionate about:
complexity, trauma-informed practice,
curiosity, cognition, compassion,
flourishing and eudaimonia.



KEITH MARAIS

autistic ADHD
neuroqueer



DOROTA ALI

I am an autistic person
passionate about:

-addressing health inequalities
-science and research
-stories
(watching, reading and writing them)
-art
-nature and exploring

Appendix 3: Questionnaires

Self-Report Questionnaire of Camouflaging Autistic Traits (Q-Cat)

Hull, L., Mandy, W., Lai, MC. et al. Development and Validation of the Camouflaging Autistic Traits Questionnaire (CAT-Q). Journal of Autism and Developmental Disorders 49, 819–833 (2019).

Valued Living Questionnaire (VLQ)

Wilson, Kelly & Sandoz, Emily & Kitchens, Jennifer & Roberts, Miguel. (2010). The Valued Living Questionnaire: Defining and Measuring Valued Action within a Behavioral Framework. The Psychological Record. 60. 249-272.

Appendix 4: Acknowledgements

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Co-ProductionCollective
www.coproductioncollective.co.uk

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“Our aim is for a therapist to think from the autistic person’s perspective”

Authentistic Research Collective