

**Moving from Acceptance to Inclusion**

# **Social Working with Autistic People**

A Guide to Respectful and Relational  
Working with Autistic People

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## Introduction

Written from the perspective of an Autistic social worker, this booklet aims to encourage and request you review how you relate and work with Autistic people in your work system. It offers advice around both the practical and attitudinal aspects of social work practice. It is not offering anything new, but an opportunity to review the lens through which you view, assess and relate to Autistic People.

This booklet is not an instruction manual. Nor is it a prescriptive collection of activities. This is for good reason and primarily because all Autistic people are different. We have different interests or passions. We are different ages, ethnicities, genders, class, that influence and informed our identities and lived experience. We may have additional aspects to our needs from other disabilities or health needs. We may be involved with you for varying reasons as a service user. However, we may also be your colleague, your manager, your student.

Whatever your position on the inclusion highway, whether that be developing your awareness of Autism generally, or progressing your inclusive practice, this guide aims to contribute to your continuous professional development as a social work practitioner.

Please take time to reflect on how you can make positive changes to your practice and I encourage you to enhance your knowledge and social work tool kit by accessing some of the resources listed at the end. These resources are only some examples of the wealth of informed, up to date information out there from Autistic people and their allies. Please learn from those of us who are living this experience.

## An Autism Analogy

Consider the neurotypical brain as the map of the London underground; there are a variety of confusing looking connections, some points with more than one connection, however when used regularly, you become aware of where it takes you and how to get there. You develop familiar routes based on your needs, experiences and environment that you rely on or become more confident with to be able to manage whatever it is you need to do. If anything changes, you have a map, that makes sense to you, to get to where you want to go and filter out unnecessary information.

Now consider the Autistic brain as the London underground, but that a second, even third underground system has been added, that overlaps but also adds extra connections and routes to different points. When there is a change of circumstance, the routes change, sometimes one underground is used, sometimes a mixture.

Suddenly, you know where you want to end up, but you cannot see a clear path and your route is taking you to all kinds of places. You cant distinguish between the different routes and you can see them all, at the same time. Your thoughts are the trains, the commuters, the stations. The noise is deafening.



And it takes time to get there. By the time you get to where you want to go, you are exhausted; its taken a lot of physical and emotional energy to keep on task. Imagine how frustrated you are at not being able to reach your goal, perhaps upset as you know the expectations were on you to get there earlier and may have impacted on other people. You may have missed out on doing something else so you feel angry. The anxiety you feel about missing your stop because you never know what's coming next still feels strong - and what if it happens again?

Now imagine asking a child with Autism "how are you feeling" or "what do you want to do today" in a busy classroom. Or asking an Autistic parent to attend a Child in Need meeting, then change the dates, times and possibly meeting chair the day before.

- What are the possible impacts on a child?
- What are the possible impacts on an adult?

## A note on Language use

The autistic community (Autistic people) generally favours identity first language (I am Autistic) however, this differs between individuals so please do not assume. I have used identity first language predominantly through this document, however, in respect of individual preferences, I have also used some person-first language (e.g. child with Autism).

If you are working with an Autistic person, please ask them what they prefer. Please ask the child as they may have a different view from their parent

## Autism Myths and Realities

### Communication and Understanding

- Not all of us have apparent difficulties with eye contact.
- Lack of eye contact does not mean people are not listening or attending.
- Not all of us have learning disabilities.
- Not all of us have "special talents" (savants).
- Not all of us are good at Maths or IT .
- We don't look or sound like 'the Good Dr.'
- We can be creative.
- We have imagination.
- We have empathy (just cant always express it).
- We can be incredibly insightful
- We understand others have feelings (we may just not be sure what these are). Sometimes we feel these very strongly which can also be problematic

### Relationships

- Some of us can make friends.
- Some of us want to be sociable (but may need support to do so).
- Some of us are in long term intimate relationships.
- Some of us are parents (and competent at it too!).

### Behaviour

- Some of our focused interests may not be obvious so appear like we don't have any.
- Not all Autistic children require therapy.
- A meltdown is not a tantrum - adults get meltdowns too. Its when we reach overload and we can't control the onset.
- A shutdown is not being intentionally avoidant or defiant.
- Children with Autism can be as "badly behaved" as neurotypical children (but what does that mean?).
- Stimming is not a negative behaviour (as long as it doesn't impact harmfully on others or self).
- We can achieve our potential if we are supported - educationally, socially, emotionally, societally.

### Parenting

- You don't have to "look" Autistic to "be" Autistic – have you considered a parent of an Autistic child may be neurodivergent too?
- When we appear to cope we are not resilient, we are using strategies which could be incredibly exhausting and have a significant impact on us physically and emotionally.
- We may connect with our children in different ways.
- We may communicate with our children in different ways- and that may be different to how we communicate with you.
- We may play with our children in different ways.
- Not all Autistic people have attachment difficulties.

## Hints and Tips: Respectful and Relational Social Work Practice when working with Autistic People

### Planning

- Assume I have capacity unless you have confirmed information to state otherwise (e.g. cognitive assessment).
- Ask or find out the best way to communicate with me. Ask me, ask my family, school, partner etc what works. Then commit to sticking to that, no matter how different that may be. Don't assume verbal communication because someone can talk in that instance. Don't assume non-speaking Autistic people can't communicate.
- Don't assume you know my experiences or what issues are for me. Ask me.
- Ask me if I need or want someone with me as support. Do not assume I can share my views at will. I may need someone to help me feel more regulated, or to help share my views in the way I want to.
- Advocates and supporters should be of my choosing and voice my views, not what they think I mean or want. Parent advocates are not necessarily the appropriate solution.
- Consider the environment. Choose somewhere familiar and safe-feeling identified by me, or someone who knows me well. Bright lights, noisy contexts, open plan offices, crowded spaces may affect my ability to concentrate, process and respond. It may make me feel unsafe and anxious.
- Consider time. Time of day to discuss important issues is necessary to plan carefully. Will I be tired from processing a day at school or parenting, or work? Have I had to navigate difficult contexts for me beforehand and need time to readjust? Do I need to travel and how will that affect my ability to attend to your questions or discussions?
- Communicate and negotiate arrangements clearly and concisely. A picture of the building you want me to attend may help. Tell me who will be there and why (role and purpose). Let me prepare for the meeting, visit, discussion etc, even if this is a planned phone call or virtual meeting. Consider and ask what you can do to help me successfully attend and participate. Write down arrangements and text or email if not in person.
- As much as possible, avoid last minute changes. These are highly problematic and difficult to regulate for some of us. Difficult in a busy overworked social work office I know, however, communicating (e.g. texting) any changes beforehand to give me time to adjust will mean our interaction will be more beneficial for both of us. It may mean I cancel. Please respect that. Do not record as "failed to engage" as you instigated that change and the resulting outcome for me.
- It may be helpful to both Autistic children and Autistic parents for you to book your next statutory visit, at your last one. Consider whether a visual calendar/timetable may be helpful to book this in – ask me before presuming this may be helpful. For Autistic children, this may be similar to the 'now and next' visual timetables that are sometimes given at school and may help me prepare for the next visit to my home. If visits need to include unannounced, be very clear about how this works and why.

## Communication

- Less is more! Use simple, clear language beginning with key messages
- I need time to process (you will need to work with silence)
- I need time to ask questions – don't leave that until the end and enable me to ask as we go. Let me know you are happy for questions to be asked.
- Explain key terms (e.g. child protection terms and processes).
- Avoid acronyms! They are extremely confusing and may mean more than one thing (e.g. CHIN)
- Avoid metaphors – they can be confusing and vague. Inferences are equally unhelpful. Say what you mean.
- Visual materials are helpful but make sure they are age appropriate and respectful.
- Examples are sometimes helpful but make sure they are relevant to my context, ethnicity, culture and experience.
- Don't ask too many questions and keep them short. Reflexive and circular questions are fine as long as they are not too vague or long-winded.
- Begin with the assumption that I can mentalise. Enable me to explain and express my understanding using the techniques above. Remember, this does not have to be verbally.
- If you have identified strengths, tell me! We are so used to being described in a deficit-heavy way. If you haven't identified any strengths, are you proactively looking for them?
- Consider demands, as these can be overwhelming, and how you can reframe these. "You need to" or "Can you" can be changed to "I was wondering if we could" for example. I am less likely to shut down and more likely to respond this way.
- Do not insist on eye contact – it is painful and uncomfortable and can actually detract from attending to what you are saying. It is also highly disrespectful.
- Make sure your speaking and non-verbal communication matches. We attend to both and are less trustful of you and more confused if you are saying one thing and showing me something else. I will most likely refer to your non-verbal behaviour more readily if that is the case.
- Do not assume my non-verbal communication. I may be focusing on something else (playing with a toy, looking elsewhere etc) but it is likely I am attending to what you are saying. Multi-tasking in that way can help me focus and process information.
- If I stop speaking or responding, there is a reason. You may have induced a trauma response, or a sense of anxiety around something that has been said or done. Notice and acknowledge, don't just carry on. Reflect on what has happened before this moment and do not ignore. It may not be appropriate to explore immediately but it will need to be understood– I may be trying to tell you something really important to me, or I may have lost interest.
- Check for understanding. Repeat back what I have said, ask me what I have heard in terms of plans or actions and repeat using the same terms if that is not clear.
- Back up any agreed actions, plans etc in writing or symbols using similar principles of clear accessible language.

## Context

In addition to the previous points, consider what the purpose of your involvement is with me, and how to make that as inclusive as possible:

- Ask how I would prefer to communicate at meetings. It may be that I prefer to write bullet points of what I would like to address ahead of the meeting. Bring this along, as opposed to verbally discuss them on the spot - especially if the meeting has many attendees. Be receptive and supportive of this. It may also be helpful to advise me of the format of the meetings (e.g. who will chair the meeting, first will be introductions to everybody, next will be the social care update, then health visitor etc.) and make sure this format is consistent.
- Meltdowns come in many forms and for both adults and children. I may withdraw. I may end the meeting and leave unexpectedly. I may freeze. I may become agitated, anxious or physically disruptive. Give me a safe space and time to self-regulate. Be patient and supportive. Don't ask me what I want, offer several choices or make demands – I won't be able to respond to that.
- Direct work with Autistic children. Consider that I may compartmentalise school and home. Trying to complete worksheets/direct work on a home visit may be confusing and potentially even distressing if this is out of my expected home routine (especially if you are the newly allocated worker to my family and you are a new visitor to my home too). Consider the potential benefit of my 1:1 worker/teaching assistant being present for familiarity in direct work at school if appropriate, but remember that all children will have different preferences.
- Masking – although not explicitly explored in this booklet, masking is a huge issue for Autistic people. Masking is trying to behave like Neurotypical people to fit in and avoid discrimination. It is hugely harmful to us with intense emotional and energy demand, and can impact on our mental health significantly if not addressed. Masking is a response to oppressive practice, stigma and harm in our environment. When considering Autistic people please be mindful how we present may not be how we are feeling and experiencing in that context. Further information sources are included in the Resources section.

If you are in any doubt about what to say, do or consider.....ASK!



## Being an Ally to your Autistic Colleagues

Consider all the previous points – they are relevant regardless of a person’s role and involvement with you

- Be aware of office environments and how these could be impacting on your colleague
- Be aware of the ever-changing nature of social work demands and how these could be impacting on your colleague on a day to day basis
- If they are openly Autistic, let them know of your awareness and ask if you can help in any way – or if there is anything YOU need to change
- If you are unsure about terminology, language or information, ask, don’t assume or ignore.
- Openly support Autistic identity in the workplace and challenge any misconceptions, bias or discrimination. Stigma remains high especially in health and social care fields and this may help someone feel safe and included enough to disclose their Autistic identity.
- Follow through with agreed actions or plans and if you need to change these for any reason, discuss in good time so that your colleague can process changes and implement their own strategies (or ask for support) without detrimental impact or embarrassment/shame.
- Consider the “small stuff” that could have a big impact – has anything changed in the working environment. For example, have different pens or stationary been ordered), have desks been rearranged due to managerial or departmental decisions, without considering impact. Is there a road closure or bus cancellations that may impact on travel time or arrangements?
- Don’t set us up to fail.
- If you manage Autistic people, are you holding Autism in mind when allocating work? This includes Autistic strengths and skills that could enhance outcomes for allocated families. Have you considered microaggressions, bullying and harassment as potential issues your worker may be experiencing?
- Don’t assume one Autistic colleague is the same as another Autistic colleague. Don’t homogenise us.
- Don’t assume we don’t want to be sociable – invite us to events or out of work arrangements unless we have asked you not to. Don’t view us as “not a team player” if we don’t want to join in.

If you think these are big asks and a lot to consider, imagine what it must feel like for us Autistic folk! Empathy is a two way street. Enabling a supportive, strengths-based feedback loop of encouragement, curiosity and reliability will foster trust; with shared communication and understanding.



## Resource library

If I could only recommend 3 books they would be:

- Brown, L.X.Z., Ashkenazy, E, and Onaiwu, M.G (2017) *All the Weight of Our Dreams; on living racialized autism*, Dragonbee Press, Nebraska
- Milton D. (2017) *A Mismatch of Saliency: Explorations of the Nature of Autism from Theory to Practice*. Hove, United Kingdom: Pavilion Press
- Gaynor, Z., Alevizos, K and Butler J (2020) *IS THAT CLEAR?: Effective Communication in a Neurodiverse World*, Acrobat-Global

Sadly there are a lot of ableist resources that claim to speak about Autism but are not valued by the Autistic Community due to their repeated disregard for Autistic voices. These include the following:

- Cure-focused charities, companies or organisations, please avoid!
- Anything associated with "Light it up Blue", ABA (Applied Behavioural Analysis), Spectrum 10K.
- Organisations where Autistic people are not active contributors including as directors, employees, researchers or spokespeople.

However, the following are equally valuable resources to strengthen and develop your understanding of Autism and other neurodivergent identities. Here are a few:

### Online resources (there are so much more – go explore!)

- Double Empathy problem series <https://youtu.be/TY1FBvJpzW8>
- Masking blog <https://www.spectrumnews.org/news/autistic-burnout-explained/>
- Social Work specific blog [www.autisticsocialworker.co.uk](http://www.autisticsocialworker.co.uk)

### Autistic advocates examples

- <https://www.youtube.com/channel/UCLsMY1ZY9-8IReQfGX-CvBQ>
- <https://theautisticadvocate.com/>

## Books

- Fletcher-Watson, S and Happe, F (2019) *Autism: A new introduction to Psychological Theory and Current Debate*, London, Routledge
- Silberman, S (2015) *Neurotribes: the legacy of autism and the future of neurodiversity*. Allen and Unwin, London
- The Autistic Self Advocacy Network (2012) *Loud Hands; Autistic People, Speaking*, The Autistic Press, Washington DC

## Reports

- BASW (2019) *Capabilities Statement for Social Work with Autistic Adults* <https://www.basw.co.uk/the-capabilities-statement-social-work-autistic-adults> accessed January 2021
- Crawford, L and Aiello, AH (2021) *Institutionalising parent carer blame The experiences of families with disabled children in their interactions with English local authority children's services departments*, Cerebra/LeAP/Leeds University <https://cerebra.org.uk/download/institutionalising-parent-carer-blame/> accessed July 2021
- Dept Health and Social Care (2021) *A Spectrum of Opportunity: an exploratory study of social work practice with autistic young adults and their families* <https://www.gov.uk/government/publications/social-work-and-autistic-young-people-an-exploratory-study/a-spectrum-of-opportunity-an-exploratory-study-of-social-work-practice-with-autistic-young-adults-and-their-families> accessed February 2021
- Equality and Human Rights Commission (2017) *Being Disabled in Britain; a journey less equal*, EAHRC [www.equalityhumanrights.com](http://www.equalityhumanrights.com) accessed January 2021
- HM Government (2021) *The National Strategy for Children, Young People and Adults; 2021-2026* <https://www.gov.uk/government/publications/national-strategy-for-autistic-children-young-people-and-adults-2021-to-2026> accessed July 2021

## Research

- Adams, D., Stainsby, M. and Paynter, J., (2021). Autistic Mothers of Autistic Children: A Preliminary Study in an Under-Researched Area. *Autism in Adulthood*. <https://doi.org/10.1089/aut.2020.0078>
- Bottema-Beutel K, Kapp SK, Lester JN, Sasson NJ, Hand BN. (2020) Avoiding ableist language: Suggestions for autism researchers. *Autism in Adulthood*, 3 (1), 18-29
- Crane, L., Lui, L.M., Davies, J. and Pellicano, E., (2021). Autistic parents' views and experiences of talking about autism with their autistic children. *Autism*, 25(4), pp.1161-1167.
- Fletcher-Watson, S., Adams, J., Brook, K., Charman, T., Crane, L., Cusack, J., Leekam, S., Milton, D., Parr, J.R. and Pellicano, E., (2019). Making the future together: Shaping autism research through meaningful participation. *Autism*, 23(4), pp.943-953.
- Milton, D. E. (2012). On the ontological status of autism: The 'double empathy problem'. *Disability & Society*, 27(6), 883-887
- Pearson, A and Rose, K (2021) A Conceptual Analysis of Autistic Masking: Understanding the Narrative of Stigma and the Illusion of Choice *Autism in Adulthood* 3, (1) 52-60
- Raymaker, D, Teo, A., Steckler, N, Lentz, B., Scharer, M., Delos Santos, A., Kapp, S. Hunter, M. Joyce, A and Nicolaidis, A (2020) . "Having All of Your Internal Resources Exhausted Beyond Measure and Being Left with No Clean-Up Crew": Defining Autistic Burnout *Autism in Adulthood*. 2 (2).132-143.
- Romualdez, A.M, Heasman, B., Walker, Z. Davies, J. and Remington, A (2021) "People Might Understand Me Better": Diagnostic Disclosure Experiences of Autistic Individuals in the Workplace *Autism in Adulthood*.3 (2) 157-167
- Talcer, M.C., Duffy, O. and Pedlow, K., (2021). A Qualitative Exploration into the Sensory Experiences of Autistic Mothers. *Journal of Autism and Developmental Disorders*, pp.1-16. <https://doi.org/10.1007/s10803-021-05188-1>
- Tromans, S., Chester, V., Gemegah, E., Roberts, K., Morgan, Z., Yao, G.L. and Brugha, T. (2021), "Autism identification across ethnic groups: a narrative review", *Advances in Autism*, 7 (3), 241-255.
- Wood, R & Happé, F (2021) What are the views and experiences of autistic teachers? Findings from an online survey in the UK, *Disability & Society*, DOI: [10.1080/09687599.2021.1916888](https://doi.org/10.1080/09687599.2021.1916888)

## Glossary

There may be a few terms in this booklet that you may be uncertain about. The definitions below are my interpretation of these terms and other Autistic people may offer a different take on how these relate to them. However, I hope my attempts offer some overall understanding of the concepts.

### Neurodiversity

Generally, there is difference in how people's brains work. However, some people's brains work more differently than others. It equates neurotype as a valid diversity identity alongside others such as ethnicity, and gender. The neurodiversity movement would argue that neuro "normal" is a social construct and there is no "right" neurodevelopment, rather what society determines it to be.

### Neurotypical

People whose brains work and think in accordance with the "normative" standards of the general population.

### Neurodivergence

People whose brains work differently from the general population. This can include how we process information, and how we respond to the world. Within the neurodivergent family there are several identities including Autism, ADHD, Tourette's etc

### Meltdown

Emotional, cognitive or sensory overwhelm. A process we cannot control. It can present in many different ways including emotionally, physically, verbally. Or it may be a more hidden process that is less obvious but equally distressing for us. It is an intense experience we often need to recover from in our own ways

### Shutdown

Autistic implosion. Similar to a freeze trauma response. It could present as inability to speak if usually I can talk. Or it may be inability to move, or have energy. It can come on suddenly or build over time. It is exhausting to experience and highly traumatic (in my experience).

These are a couple of excellent resources to explore various terms and concepts relating to Neurodivergence and Autism from other Autistic advocate voices.

<https://neuroclastic.com/autism-101-resources-from-the-autistic-community/>

[https://m.facebook.com/story.php?story\\_fbid=10158107189076821&id=635481820&sfnsn=scwspmo](https://m.facebook.com/story.php?story_fbid=10158107189076821&id=635481820&sfnsn=scwspmo)

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