



# *Autism, family, & relationships: A talk for autistic adults*

WEBINAR · DISCUSSION · Q&A

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Advonet  
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Providing Independent Advocacy



**Leeds  
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## What We Will Discuss:

- Focusing on 'personal' relationships (family and friends)
  - What do we know about relationships between autistic and non-autistic people?
  - What do we know about communication between neurotypes?
  - How can a diagnosis of autism impact our personal relationships?
  - How can we help each other and ourselves?
  - How can we protect our wellbeing while navigating personal relationships?



## A Brief Recap

- Social aspects of identity.
- Minority stress – Coined by Schwarz and Meyer (2010) to explain discrepancies in physical and mental health across race, sex, and disability – associated with victimisation, discrimination, ‘masking’ etc (developed in relation to autism by Botha and frost, 2020).
- What others say about us – Social reinforcement:



You don't seem autistic to me

Aren't we all a bit autistic, though?

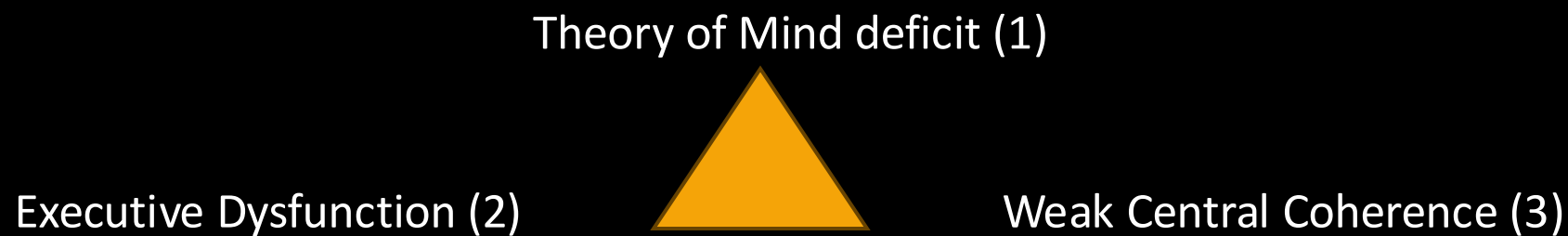
You seem more autistic since your diagnosis

## The 'Double Empathy Problem'

**Milton, D.E.M. (2012) 'On the ontological status of autism: the 'Double Empathy Problem' *Disability and Society* 27 (6) 883 - 887**



- Aims to answer the question of what autism 'is'.
- Traditional attempts at theorising what autism 'is' come mostly from the fields of cognitive neuroscience and psychology.
- They focus on behavioural indications of autism and concepts such as 'Theory of Mind' (the ability to understand that other people have mental states – beliefs, feelings, desires etc).
- The 'triad of dominant theories' of autism:



- These mean: (1) Lack of ability to understand the mental states of others; (2) Disruption in cognitive processes that regulate and control other cognitive processes; and (3) Difficulty 'seeing the bigger picture'.

## The 'Double Empathy Problem'

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- These theories fail to recognise the interaction and 'relationality' that go into making social reality (i.e., society is made in and through interactions and relationships).
- I.e., If social reality requires interaction and relationships across multiple 'sides' (between people of differing neurotypes), how can the 'fault' be only on one side?
- While traditional understanding of autism rests on the idea that social subtext exists in advance of, and external to people (and autistic people fail to understand and decode them), the DEP is based on the idea that people construct and agree social subtexts ('rules') in the process of interacting.
- 'Theory of Mind' (or 'empathy') is concerned with the ability of a non-autistic person to assume understanding of the mental states of other non-autistic people.
- However, when they try to understand the mental state of an autistic person, the conclusions reached are often very inaccurate (lack of shared cultural 'library' on which to draw).



## The 'Double Empathy Problem'

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“The ‘double empathy problem’: a **disjuncture** in reciprocity between two differently disposed social actors which becomes more marked the wider the disjuncture in dispositional perceptions of the lifeworld – perceived as a **breach in the ‘natural attitude’** of what constitutes ‘social reality’ for ‘non-autistic spectrum’ people and yet an **everyday and often traumatic experience for ‘autistic people’.**”

(Author’s concept and definition)

## Communication and Rapport Between Autistic + Non-Autistic People

**Crompton, C. et al., (2020) "Autistic peer-to-peer information transfer is highly effective" *Autism* 24 (7) 1704 - 1712**



- ▶ Transferring information requires social communication skills.
- ▶ Autism is defined by 'social communication deficits' so it would be expected that information transfer between autistic people would be especially deficient.
- ▶ **BUT** DE theory suggests the difficulties arise from a mismatch of neurotype. So Autistic - Autistic transfer may be more successful than Autistic – Non-Autistic.
  
- ▶ The study involved games of 'Telephone' in the following groups:
  - Autistic – Autistic
  - Autistic – Non-Autistic
  - Non-Autistic – Non-Autistic
- ▶ Relaying a story (30 details) along an 8-person 'Diffusion Chain'.

## Communication and Rapport Between Autistic + Non-Autistic People

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### Findings:

- Significantly steeper decline in detail retention among ‘mixed’ chains.
- Participant ‘rapport’ ratings showed significantly lower scores for mixed chains.
- Meaning that communication among autistic-autistic or NT-NT groups is more effective (and generates better rapport) than in mixed groups.

This supports the theory of the Double Empathy Problem – i.e., it challenges the diagnostic criterion that autistic people lack social communication skills.

Suggests that autistic people are “different without being deficient” (Crompton et al., 2020: 1710)



## Reflection Points:

- ▶ Understanding of the 2-sided nature of the social communication challenges experienced between autistic and non-autistic people is very important in shifting society's understanding of what it means to be autistic, and 'redressing the balance' as to where the 'fault' in communication lies.
- ▶ Findings about 'rapport' and preferences for same-neurotype interaction are helpful for understanding and working towards autistic wellbeing; and developing policy for social support of autistic children/young people in the future.
- ▶ HOWEVER – we live in a society of many different neurotypes and the contributions of each are important to the success of the species (neurodiversity). So, we need to work out how best to live, communicate, and interact with each other in ways that meet the social needs of all members of society and keep safe members of non-neurotypical social minorities (such as autistic people).

## Autism and Relationships – Impact of Diagnosis

**Heasman, B. and Gillespie, A. (2019) “Participants over-estimate how helpful they are in a two-player game scenario towards an artificial confederate that discloses a diagnosis of autism” *Frontiers in Psychology* 10 Article 1349**



- Growing recognition of role of non-autistics in shaping social opportunities for autistic people.
- Existing research shows that typical people experience difficulties in interpreting autistic perspectives.
- It also shows that disclosure of an autism diagnosis can improve how an autistic person is perceived.
- But autistic people also report that disclosure can trigger stigma.
- And research has found evidence of both positive and negative discrimination following disclosure.
- Also, media frequently represents autism as an illness.

## Autism and Relationships – Impact of Diagnosis

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- Study involved (non-autistic) participants playing a computer game with a player they believed to be human, who disclosed they have a diagnosis of autism or dyslexia (but was actually AI).
- Compared how participants believed they responded to the disclosure with their actual behaviour.
- Four categories of response: “Tolerance”; “Explained misunderstanding”; “Redundant”; “Ambiguous response”.
- Suggests disclosure increased the extent to which participants perceived they acted helpfully for the autism diagnosis (but not for dyslexia).
- Disclosure can be interpreted positively (increased tolerance or explaining misunderstandings) or negatively (sees disclosure as redundant or useless) – ‘**Cost/benefit analysis**’ explains anxiety around disclosure.
- Bias in how helpful participants perceived themselves to be compared with their actual behaviour. **Suggests non-autistic people think they are being more helpful/understanding than they actually are towards autistic people.**

## Autism and Relationships – Impact of Diagnosis

- **Sometimes little negative impact (or a positive impact)** – e.g., Newly diagnosed person is in a relationship with/friends with/a child of other autistic people, or when they have been through the process of diagnosis with their own children.
- **Sometimes misunderstandings or miscommunications arise** – e.g., Friend or family member assumes the newly diagnosed person wants to ‘play down’ their diagnosis or not be ‘defined by it’. May think comments like “Your diagnosis makes no difference” or “I just see you as ‘you’” are comforting – but if the newly diagnosed person feels their diagnosis *does* make a difference (e.g., by explaining past traumas or challenges) such ‘playing down’ can feel invalidating.
- **Sometimes close family or friends notice changes following a diagnosis** – this may lead to comments like “You seem more autistic since your diagnosis” or even accusations of exaggerating or ‘faking’ autistic traits. Often such changes are a result of acknowledging the benefits of e.g., ‘stimming’, or the stress involved in ‘masking’ and taking a chance to ‘unmask’.



## Autism and Relationships – Impact of Diagnosis

It's important to bear in mind that although communication (and the DEP) are two-sided, autistic people are at an added disadvantage as the social minority – society is not designed around our needs, and we miss out on positive social reinforcement.



### How can we help ourselves and each other?

- **As the newly diagnosed person:**
  - Get to know your 'autistic self'
  - Practise a 'script' of a couple of sentences to explain what being autistic means to you.
  - Take time to work out your communication needs and be prepared to experiment.
  - Consider whether a peer support group might help you to put your experiences in context.

The response of those close to us to our autism diagnosis and our newly developing autistic identity can sometimes feel difficult.

A 'new' identity can be fragile – Just like a young plant without strong roots, it can easily be damaged by lack of knowledge or understanding from others. And we can be left feeling vulnerable and rejected.

It can help to remember that this does not need to last forever. As we learn more about our autism and spend more time among the autistic community, our identity becomes stronger, and we become more confident in advocating for ourselves.

## Autism and Relationships – Impact of Diagnosis



### As a friend/family member:

Newly diagnosed autistic people unfortunately often find that one of the hardest parts of getting used to their diagnosis is dealing with the reactions of those closest to them.

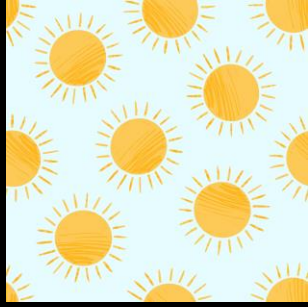
They report that loved ones comment that they “seem more autistic” since their diagnosis and can imply or even say that the person is exaggerating their needs. Some may be told that they’re “using” their diagnosis, as an “excuse”, or to “get away with things”.

This can feel invalidating and hurtful at a time when they’re making sense of an overwhelming disability and often ‘grieving’ for lost opportunities or past traumas.

- Be prepared to be flexible – an autism diagnosis brings with it a lot of ‘figuring out’.
- Be ready to try out new strategies to make social communication easier for your autistic person.
- Be patient – ‘the most important gift you can give an autistic person is time’.
- Be respectful of communication requests (e.g., avoiding telephones, writing rather than talking).
- Recognise that autism-related adaptations are usually about *needs* rather than *preferences*.
- Be prepared to ‘say what you mean’ – don’t expect an autistic person to ‘read between the lines’.
- Draw on your own circle of support to work through any ‘guilt’ about past experiences or actions.

## Looking After Ourselves & Keeping Safe in Relationships

### Some things we can do to protect ourselves:



- Research indicates that **autistic community** is key to wellbeing.
- Experiences like ‘Rejection Sensitivity’ can be debilitating – particularly among autistic people who also have a diagnosis of ADHD. Maybe have a **record of strengths and achievements** and a circle of support to draw on when feeling pain from rejection.
- We can be ‘People Pleasers’ – Important to **identify and enforce our boundaries** and listen to our ‘gut’ about the impact others have on us. Some people find **neurodivergence-affirming therapy** can help.
- Work out what your **ways of relaxing** are (these might not look like other people’s strategies)
- Consider having **a list of prompts** to remind you what helps in times of stress. You might put this on your phone to access it easily.
- Work on accepting that you may need more **‘recovery time’ and relaxation** than those close to you to get over the overwhelm of living in an inaccessible world. Guilt is not helpful!
- If possible, set up a WhatsApp (or similar) channel with a trusted friend or family member where you can **externalise your feelings and speak out with ‘filters down’**.
- Consider relationship **‘ground rules’** (e.g., checking-in after a conversation).

## Reflection Points:

- ▶ Diagnosis of autism can impact our personal relationships in a variety of ways – some positive and some more challenging. It can cause anxiety trying to work out whether to ‘disclose’.
- ▶ It seems that much of the time non-autistic people want to be helpful and understanding towards autistic people who ‘disclose’ their diagnosis to them but that they often over-estimate how helpful they are being.
- ▶ Both autistic and non-autistic people can take steps to improve their interaction and rapport – Autistic people can benefit from learning about their autistic needs and practising self-advocacy (‘scripts’) and non-autistic people can back up their intention to be ‘helpful’ with learning about what that help looks like from an autistic perspective.
- ▶ Inter-personal relationships can be challenging for those who belong to a minority-neurotype. It is important to be kind to yourself and practise self-care (whatever that looks like to you).