



# What's in a Label? The Functions and Consequences of a Medical Diagnosis and Lay Diagnosis of Autism

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# What is autism?

- A set of heterogeneous neurodevelopmental conditions
- 1% of adult population medically diagnosed (UK)
- Aetiology contested
- No known cure



James Reed

# Medical Diagnosis & Lay Diagnosis

**Medical Diagnosis  
(Doctor)**

**Lay Diagnosis  
(Individual)**

- Disease categories
- Standardised 'master texts' (e.g. ICD)
- Formal training

- Subjective experience
- Personal inquiry (e.g. Internet search)
- Well-informed ideas

**Naming a 'problem'**

Different conclusion?

# The Sociology of Diagnosis



Steve Sepal

- Diagnosis-as-category
- Diagnosis-as-process
- Consequence of diagnosis

# Lay Diagnosis of Autism



- Online resources: Tests, checklists, chatrooms
- Disclaimer: Pro-medical diagnosis




# Autism

I prefer to do things with others rather than on my own.


- ☐ Definitely agree
- ☐ Slightly agree
- ☐ Slightly disagree
- ☐ Definitely disagree

## Autism: Your results


Where I would rather prefer to be \*  
*choose the most likely option*




Library



Party





Dinner

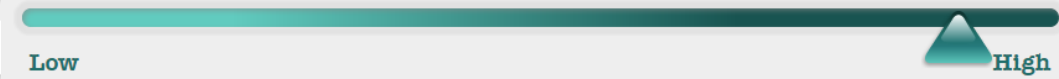


Home

Share

I've just tested myself for Autism using My MindChecker - channel4.com/mymindchecker for 8 mental health tests #mymindchecker





A higher than average score that is above the clinical threshold

Further information

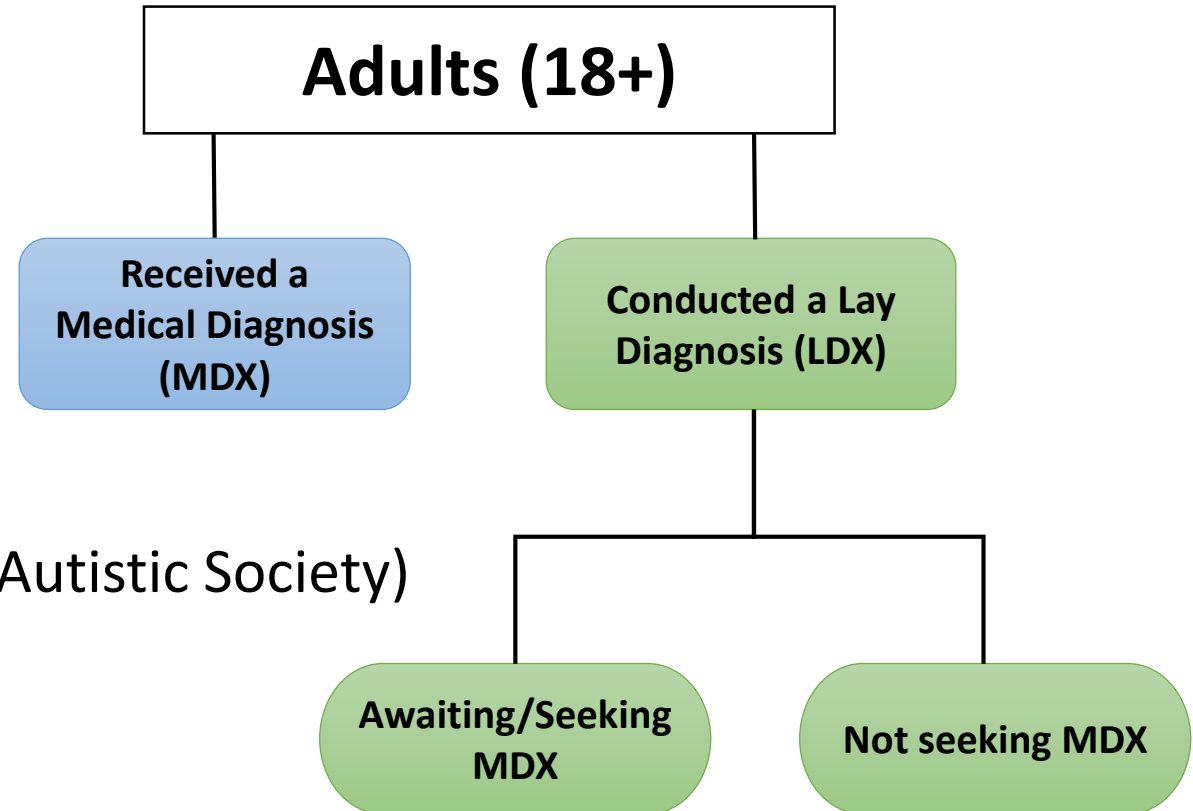


|   | True now & when I was young | True only now                    | True only when I was young | Never true                       |
|---|-----------------------------|----------------------------------|----------------------------|----------------------------------|
| It is difficult for me to understand how other people are feeling when we are talking         | <input type="radio"/>       | <input checked="" type="radio"/> | <input type="radio"/>      | <input checked="" type="radio"/> |
| Some ordinary textures that do not bother others feel very offensive when they touch my skin. | <input type="radio"/>       | <input checked="" type="radio"/> | <input type="radio"/>      | <input checked="" type="radio"/> |
| It is very difficult for me to work and function in groups.                                   | <input type="radio"/>       | <input checked="" type="radio"/> | <input type="radio"/>      | <input checked="" type="radio"/> |

# Research Questions

- 1) Why do people seek a diagnosis of autism in adulthood?
- 2) What determines whether they diagnose themselves (lay diagnosis) or seek a medical diagnosis?

# Method: Sampling



## Recruitment:

- Charity organisations (e.g. National Autistic Society)
- Online networks (e.g. Autistic Pride)



# Method: Data Collection

## Data collection

- Semi-structured interviews (30-40)
- Online interviews/chatroom discussions



Grace Goad

# Contribution & Output



Michael Tolleson

- Transformative power of diagnosis
- Sociological perspective on autism diagnosis
- Message for clinicians
- Transferability to other conditions

# Thank you!



Anjana Krishna

*Artwork was created by members of the autism & neurodiversity community and commissioned by the Exploring Diagnosis Team, University Exeter.*

*For more information please visit:*

*<https://blogs.exeter.ac.uk/exploringdiagnosis/artistsbiographies/>*