

Reducing health inequalities for autistic people

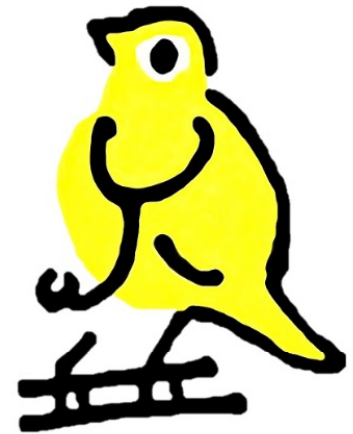
Dr Mary Doherty

Autistic Consultant Anesthetist

Founder of Autistic Doctors International

Honorary Clinical Research Fellow, Brighton & Sussex
Medical School

National Autistic Society, Mar 2, 2023



Perspectives

- Autistic woman, dx'd 2013
 - Parent of 2 ND kids
 - Consultant Anaesthetist
 - Autism researcher
 - Author
 - Advocate
 - Peer mentor
- Clinical
 - Consultant anaesthetist in Navan, Ireland
 - Academic
 - Honorary Clinical Research Fellow at Brighton & Sussex Medical School
 - PhD student at London South Bank University (Autistic psychiatrists)





- *“The way in which autism is framed will have a profound effect on outcome”*
- *Neurodiversity-affirmative approach for optimum outcome*

Outline

- Autistic Doctors International
- Healthcare outcomes for autistic people
- Barriers to Healthcare
- Physical & Mental Healthcare
- Our current healthcare projects
- Neurodiversity-affirmative resources
- Autistic SPACE

*Content
warning*



Key points (1)

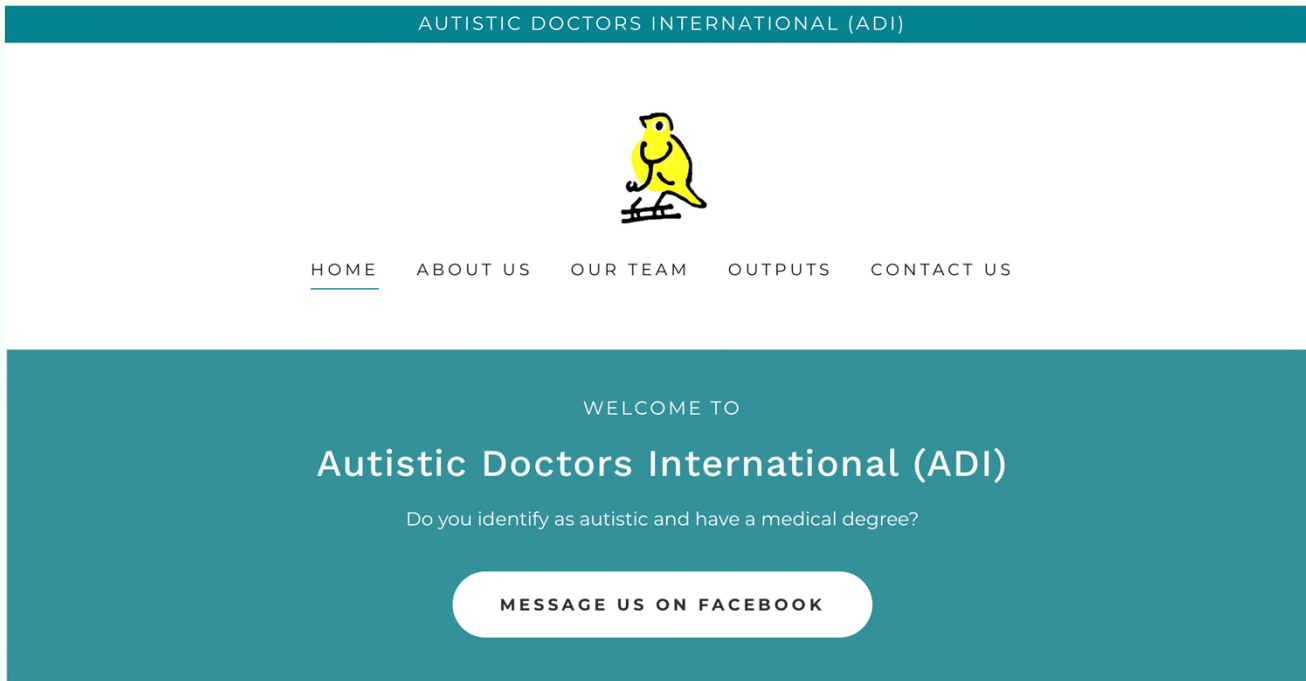
- Mortality gap
- Poor healthcare outcomes
- Well-described barriers to healthcare access
- Association between access barriers & poor healthcare outcomes
- Reasons for difficulty look different when viewed through an autism lens
- Solutions urgently needed
- A novel framework: Autistic SPACE



Key points (2)

- Negative framing of autism perpetuates stigma & impacts mental health
- Supports for autistic or neurodivergent patients or colleagues cost little
- Understanding is the primary need
- Re-framing our view of autism will improve health & save lives
- **Neurodiversity-affirmative approach recommended**





autisticdoctorsinternational.com
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About Us



- Autistic medical doctors with a shared vision
- Approx 700 autistic doctors worldwide
- We bring many strengths to healthcare, including benefits for autistic patients
- We adopt a neurodiversity-affirmative approach to our work, which centres around four core areas:
 - Peer support
 - Advocacy
 - Research
 - Education
 - Our ADI / AMS members
 - Our autistic community





Autistic Doctors International

Outputs from our members



Dr Mary Doherty and Dr Sebastian Shaw - Healthcare barriers for autistic adults



Barriers to healthcare and self-reported adverse outcomes for autistic adults: a cross-sectional study | British Medical Journal Open



A full CIRCLE: inclusion of autistic doctors in the Royal College Of Psychiatrists' values and Equality Action Plan | The British Journal of Psychiatry



Considering autistic patients in the era of telemedicine: the need for an adaptable, equitable, and compassionate approach | British Journal of General Practice Open



Recognising autism in healthcare | British Journal of Hospital Medicine



Autism: making reasonable adjustments in healthcare | British Journal of Hospital Medicine



Supporting autistic doctors in primary care: challenging the myths and misconceptions | British Journal of General Practice



Autistic doctors: overlooked assets to medicine | Lancet Psychiatry



The neurodiversity concept viewed through an autistic lens | Lancet Psychiatry



Autistic role modelling in medical education | Education for Primary Care



Vive la difference! Celebrating and supporting autistic psychiatrists with autistic doctors international | British Journal of Psychiatry Open



Autism in general practice | Australian Journal of General Practice



On Diagnosis | Secretly Autistic GP



How to prepare Autistically for COVID-19: Essential tips from an Autistic Doctor | Reframing Autism



What it is really like to be an autistic doctor



Secretly Autistic GP



Stories from the Spectrum: Harri Wilson



The Autistic Doctor: How finding my neurokin helped me to embrace my identity



Recognising human variation



This Doctor Can: The autistic doctor



Neurodiversity in practice: autistic anaesthetists can be an asset

<https://linktr.ee/autisticdoctors>

Current projects

- ADI survey
 - Qualitative
 - Specialty specific
 - Prevalence & outcomes
 - Survey in development
 - Secondary analysis of existing data
 - Autistic psychiatrists
 - Disclosure
 - Masking & Professionalism
 - Mental health services
 - Education
 - Experiences of autistic medical students
 - Reasonable adjustments for autistic clinicians
 - Autistic SPACE
 - BJA Education
- 

ADI Membership survey (NB preliminary data)

- Center for Autism & Neurodiversity, Jefferson, Philadelphia
 - Data analysis ongoing
 - 225 responses from autistic doctors
 - 60% in UK
 - 2/3 formally diagnosed
 - Age at dx: 3 – 61 yrs
 - Consultant : Trainee : Other
1. GP
 2. Psychiatry
 3. Anaesthesia



ADI membership survey

- Currently working 82%
- Three quarters:
 - usually enjoyed their work as doctors
 - felt that being autistic helped them in their work as doctors
 - felt that being autistic hindered their work as doctors
 - reported executive functioning challenges at work
 - reported sensory issues being challenging at work
 - experienced challenges in communication with peers, supervisors, and management
- 21% reported challenges in communication with patients



ADI membership survey

- Suicidal ideation 77%
- Suicide attempt 24%
- Self-harm 49%
- Autism as difference 83%
- Autism as disability 52%
- Autism as disorder 13%
- Preferred term: Autistic doctors 64%
- Considering autism to be a disorder was associated with preference for “doctors with autism” ($p < 0.001$)
- **Considering autism to be a disorder associated with having attempted suicide ($p = 0.019$)**



AJGP

Australian
Journal of
General
Practice

Formerly *Australian Family Physician (AFP)*

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Volume 50, Issue 3
March 2021

Neurodiversity: Adult and paediatric

Neurodiversity, which refers to variations between human minds occurring naturally within a population, is the focus of this month's issue.



[AJGP](#) > [2021](#) > [March](#) > [Neurodiversity Adult and paediatric](#)

“As GPs are commonly the first professionals consulted regarding child developmental concerns or adult diagnosis, there is a unique opportunity to influence family dynamics or individual self-perception, with consequent effects on mental health”

[AJGP](#) > [2021](#) > [June](#) > [Medical cannabis](#)

[AJGP](#) > [2021](#) > [June](#) > [June 2021 correspondence](#)



“All too frequently, an autism diagnosis is framed negatively, with language and demeanour more typical of ‘breaking bad news’. We would urge practitioners to resist this tragedy narrative as we accelerate the move towards a strengths-based approach to autism.”

[AJGP](#) > [2021](#) > [June](#) > [Medical cannabis](#)

[AJGP](#) > [2021](#) > [June](#) > [June 2021 correspondence](#)



*“That is not to deny the serious disability that may be associated with autism or the heterogeneity in presentation, but **the way in which autism is framed will have a profound effect on outcome.**”*

Mary Doherty FCARCSI,

Founder, Autistic Doctors International; Consultant Anaesthetist, Our Lady's Hospital, Navan, IE

Carole Buckley FRCGP,

Autism Representative, Royal College of General Practitioners, London, UK

Mona Johnson MRCGP,

GP Lead, Autistic Doctors International; Salaried General Practitioner, Derbyshire, UK

Tom Berney FRCPsych,

Chair of the RCPsych SIG in Neurodevelopmental Psychiatry, London, UK

Ian Davidson FRCPsych,

Autism Champion, Royal College of Psychiatrists, London, UK



Premature mortality in autism

- 27,000 people in Sweden diagnosed with autism
- Examine all-cause and cause-specific mortality
- Moderating role of gender & intellectual ability
- Mortality odds ratio for the autistic group was 2.56

Hirvikoski, T., Mittendorfer-Rutz, E., Boman, M., Larsson, H., Lichtenstein, P., & Bölte, S. (2016). Premature mortality in autism spectrum disorder. *British Journal of Psychiatry*, 208(3), 232-238




Premature mortality in autism

- Average life expectancy for general population was about **70 years**
- In the autistic group it was **54 years**
- With co-occurring cognitive disabilities it was just under **40 years**
- Leading causes of death were heart disease, suicide, and epilepsy
- Cause-specific analyses showed elevated mortality in autistic group for all diagnostic categories (except infections)

Hirvikoski, T., Mittendorfer-Rutz, E., Boman, M., Larsson, H., Lichtenstein, P., & Bölte, S. (2016). Premature mortality in autism spectrum disorder. *British Journal of Psychiatry*, 208(3), 232-238



Premature mortality in autism

- Overall x 2.5
 - Suicide x 9
 - Suicide x 6 male
 - Suicide x 13 female
 - Circulatory x 1.5
 - Cancer x 2
 - Nervous system x 7.5
 - Respiratory x 2.5
 - Digestive system x 3.3
 - Endocrine disease x 3.5
- 

Physical Health

- Diabetes
- Obesity
- Hypertension
- High cholesterol
- Stroke
- Epilepsy
- Parkinson's
- Sleep disorders
- Digestive disorders
- EDS / Hypermobility
- Known healthcare disparities
- Known access barriers
- Patient/provider communication
- Sensory sensitivities
- Executive function/planning issues
- **Prior negative experience**



Emergency Department Use by Autistic Adults

- One-third of ED visits by autistic adults led to an inpatient admission (34%) as compared to one-tenth of ED visits for non-autistic adults
- Almost 1% of autistic adults died in hospital after an ED visit as compared to 0.3% non-autistic adults
- Three times as likely to have a serious condition, over twice as likely to die
- Because autistic people delay seeing their own doctor, or have no doctor?

Vohra, R. et al, J Autism Dev Disord (2016) 46: 1441.



Mental Health

- Anxiety
- Depression
- Bipolar Disorder
- OCD
- Eating Disorder
- Substance misuse
- Personality Disorder *BPD / EUPD*
- ADHD/Dyslexia/Dyspraxia
- Suicide – an autistic crisis • 66% ideation
- 35% attempted
- 15% of hospitalized
- 10% of completed suicides
 - Cassidy et al



Experiences in mental health services

Autistic Adults and Psychiatry; Experiences and Barriers to Access

Mary Doherty¹, Jessica K Doyle², Monique Botha³, Stuart Neilson⁴, Sue McCowan⁵, Danni Burke⁶, Jane O'Sullivan⁷, Louise Gallagher²

¹Our Lady's Hospital, Navan; ²Trinity College Dublin ³University of Stirling; ⁴Independent; ⁵Dorset Healthcare University NHS Foundation Trust; ⁶Community Healthcare West HSE; ⁷Mater Private Hospital

Introduction

Autistic people are more likely to experience mental illness than non-autistic people, including anxiety, depression, and post-traumatic stress disorder.¹

Rates of anxiety and depression for are four to six times higher in the autistic community than the non-autistic community.^{1,3}

Furthermore, autistic people are at considerably higher risk of self-harm, and both suicidal ideation and suicide attempts.⁴

Despite this, little is known about how or when, autistic people access psychiatry, and what acts as facilitators or barriers to their engagement.

It is important to understand these experiences in order to shape psychiatric services to promote autistic engagement and wellbeing.

Objective

The aim of this study was to understand the experiences that autistic adults had of mental health and accessing psychiatric care.

Method

101 autistic adults engaged in an anonymous survey at Autscope, an autistic-led social event. See figure 1. Median age at diagnosis was 32 (range 6 - 66). A questionnaire with quantitative and qualitative responses was developed. The aim of the study was to investigate:

- The prevalence of self-reported co-occurring mental health conditions in autistic adults and associated inpatient psychiatric admissions
- Experiences of self-harm, suicidal ideation and attempts
- Preferred or avoided sources of help in crisis
- Experience of inpatient psychiatric care
- Barriers experienced in accessing mental health services

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Ethical approval was gained from the Trinity College Dublin Faculty of Health Sciences Research Ethics Committee prior to data collection.

This poster shows the descriptive analysis of the quantitative data with some representative quotes (in speech bubbles) to provide further insight.

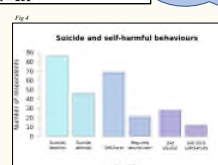
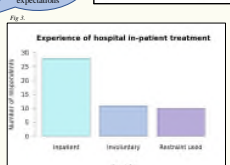
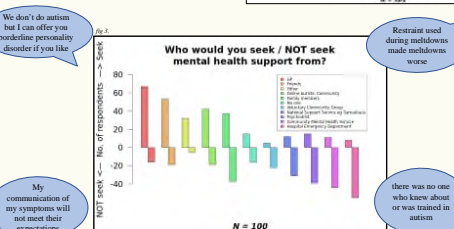
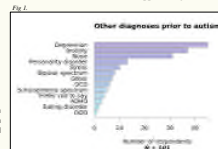
Results

Many participants reported psychiatric diagnoses prior to autism (fig. 1), in-patient psychiatric care (fig. 3), self-harm and suicidal ideation (fig. 4) and would seek help from different formal and informal supports (fig. 2).

Table 1.

	Mean	SD
Female	45.5	14.8
Male	48.0	11.9
Non-Binary	35.8	11.2
Other	45.0	20.8
Prefer not to say	47.2	27.2

78% were from the UK, 20% from Europe & 2% from Australia. 99% of respondents identified as autistic, with 92% reporting a formal diagnosis, specifically Asperger Syndrome (48%), Autism Spectrum Disorder (29%), High Functioning Autism (100%) and Autism Spectrum Condition (5%).



Contact:
Mary Doherty: drmdoherty@gmail.com

Table 2.

Use of Healthcare	
Respondents registered with a GP	94%
Currently attending psychiatrist	12%
Previously attended psychiatrist	64%
Good relationship with psychiatrist	21%
Expressed difficulty attending psychiatrist	44%

Discussion

High rates of co-occurring mental ill health reflect findings from previous studies¹.

Suicidality and self harm were higher than previously reported in an autistic cohort⁴.

There was a high rate of involuntary admission to psychiatric settings (10%), with multiple reports of seclusion and restraint.

Autistic people face barriers to accessing psychiatric care including prior negative experience with mental health services.

Ongoing thematic analysis will further explore experiences, barriers and facilitators to psychiatric care.

The sample was a non-probability sample limited to a specific autistic lead event. Further research on a wider and larger sample is needed.

Conclusion

This community led study shows the range of experiences that autistic people have with psychiatric care. Further research needs to explore reducing barriers to accessing high quality psychiatric care with staff trained in autism.

My psychiatrist is autistic and one of the best mental health experts I know

Autistic people can thrive

References

1. Gill, M. C., Hutton, C., Brown, R., Brown, R., Gill, M. C., Hutton, C., et al. (2019). Prevalence of co-occurring mental health conditions in autistic people: A systematic review and meta-analysis. *Journal of Autism and Developmental Disorders*, 49(10), 3500-3510.
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Autistic Adults and Psychiatry; EXPERIENCES AND BARRIERS TO ACCESS Participant Information and Survey

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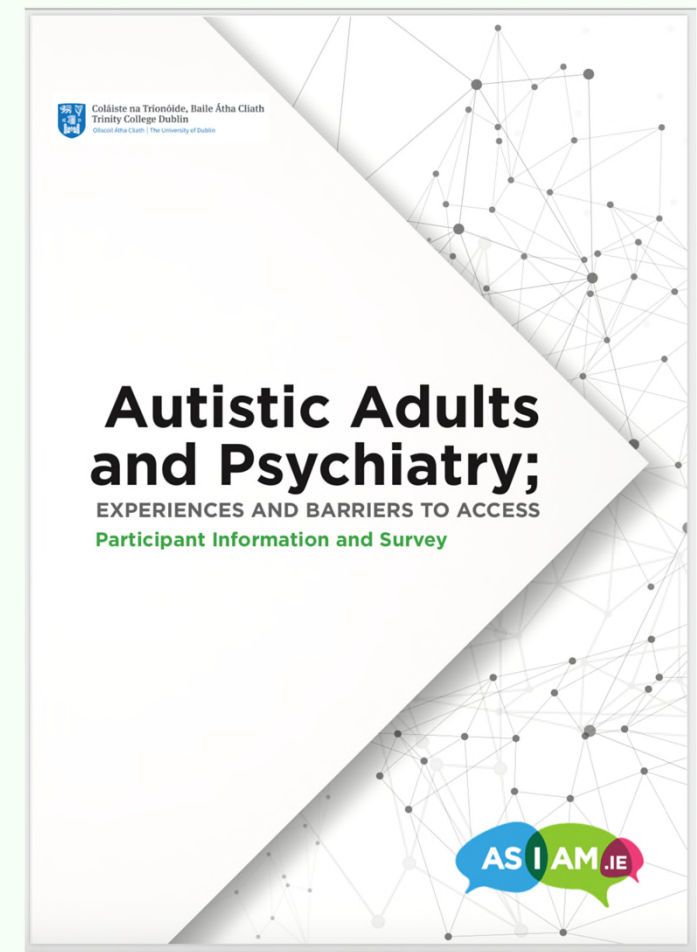
Autscope 2019: Making Connections

Experiences in mental health services

- N = 101
- Currently attending psychiatrist 18%
- Attended in past 61%
- Difficulty attending 43%
- Male 30
- Female 39
- Non-binary 23



Autscape 2019: Making Connections



Experiences in mental health services

- Suicide

- 86% ideation
- 47% attempted
- 65% self harm
- 21% medical care

Inpatient 27%

Sectioned 11%

Restraint 10%

Alcohol 28%

Illicit drugs 11%



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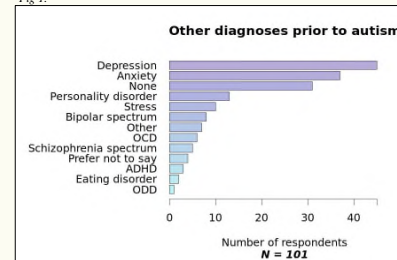


Fig 3.



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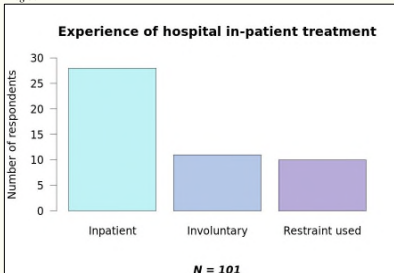


Fig 4

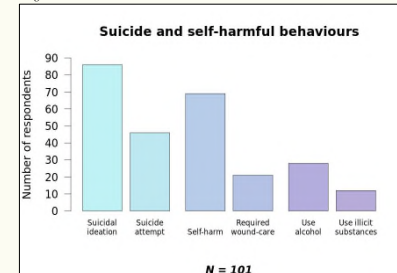


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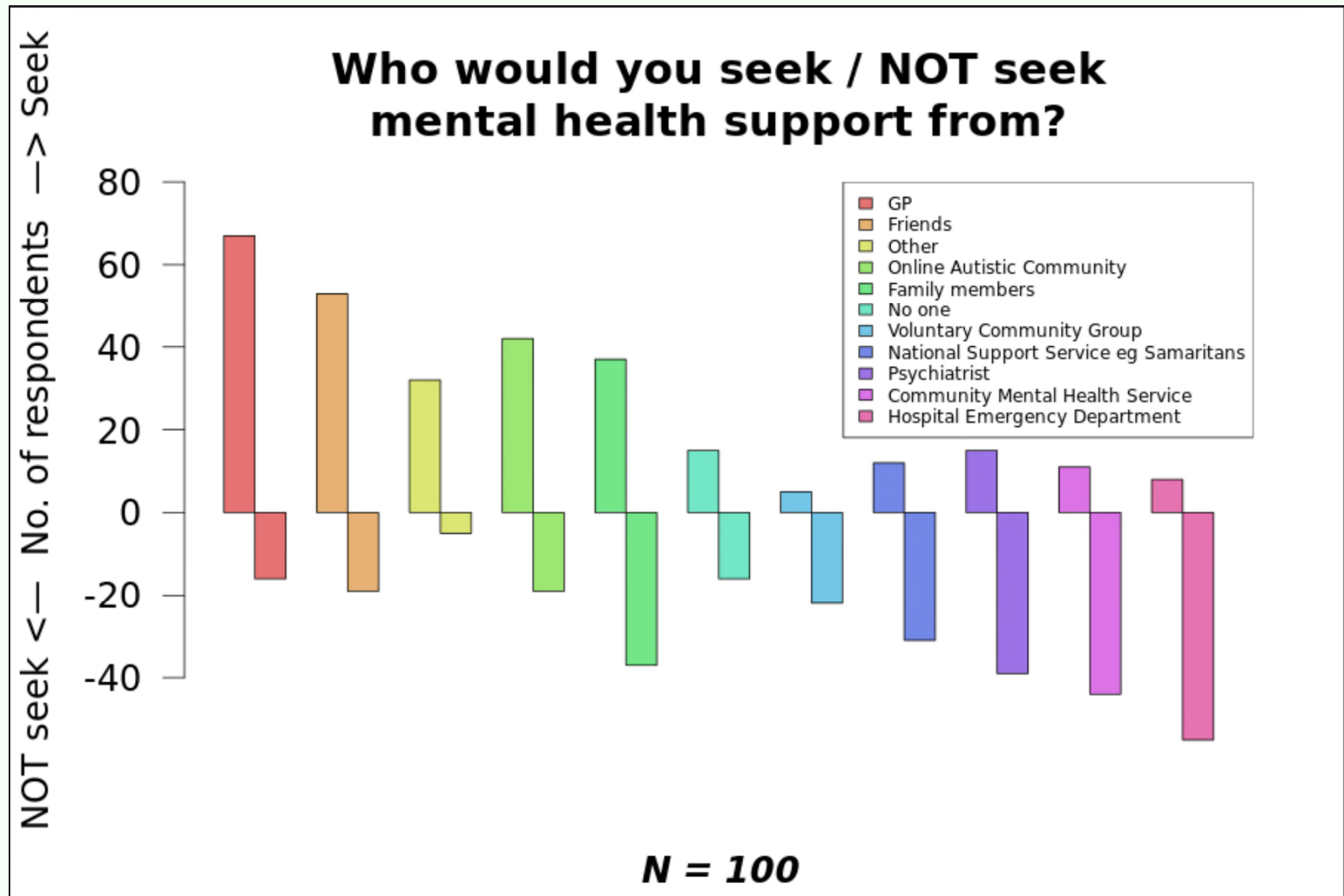
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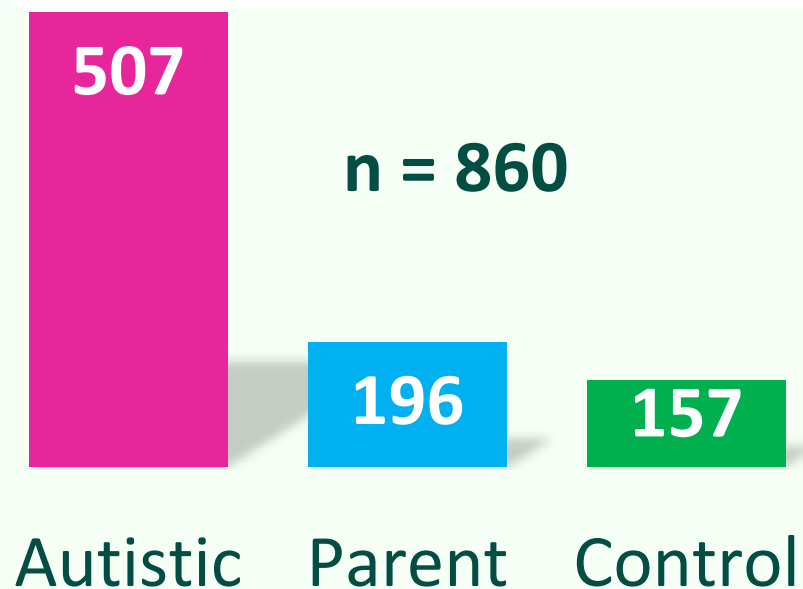
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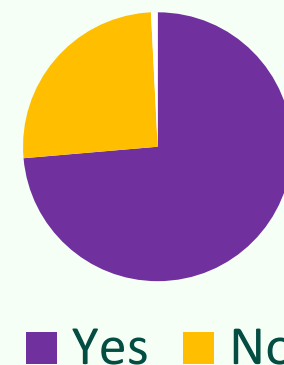


BMJ Open Barriers to healthcare and self-reported adverse outcomes for autistic adults: a cross-sectional study

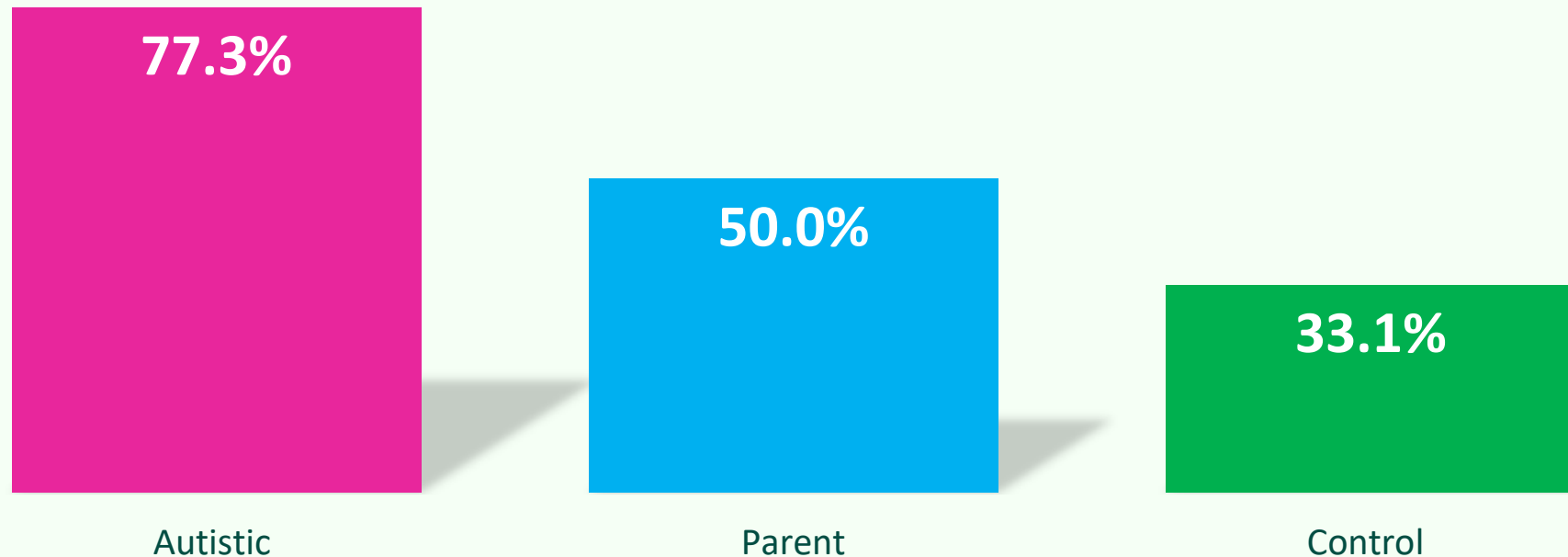
Mary Doherty ¹, Stuart Neilson,² Jane O'Sullivan,³ Laura Carravallah,⁴ Mona Johnson,⁵ Walter Cullen,⁶ Sebastian C K Shaw ⁷





Formal diagnosis



Do you have difficulty visiting your doctor when you need to?

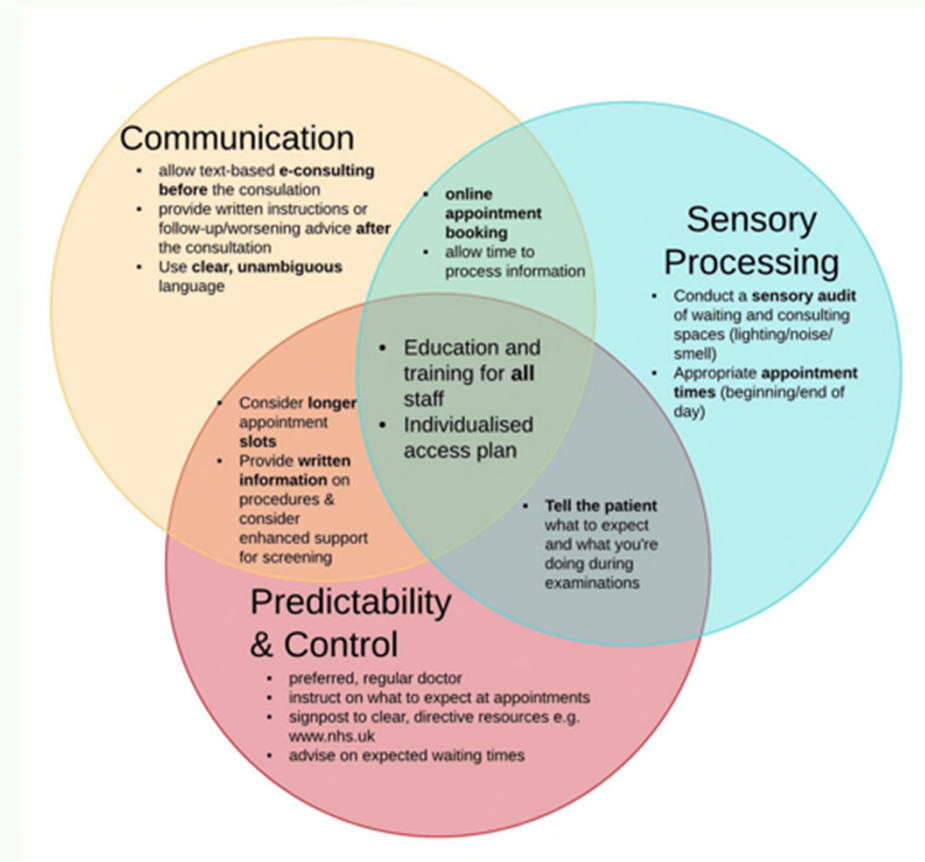


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Communication reduced by:

- Anxiety 72%
- Sensory 31%



Key Findings

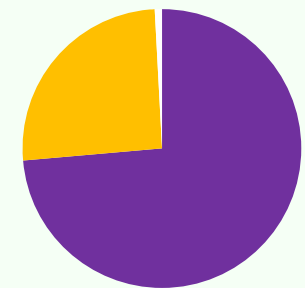
- 78% of autistic respondents avoid using telephone
- Most common barrier to healthcare access (60%)



- 55% of autistic respondents avoid or delay a GP visit because of not feeling understood

Formal diagnosis

- Sensory difficulties in waiting room
- Executive functioning / planning difficulties
- Concerns around disclosure of diagnosis



■ Yes ■ No

Consequences

	Autistic	Control
Mental health condition remain untreated	65%	17%
Physical health condition remain untreated	65%	26%
Did not attend referral to a specialist	51%	20%
Told you should have seen a doctor sooner	63%	38%
More extensive treatment or surgery	38%	14%
Potentially serious or life threatening condition untreated	32%	6%
Do not attend on schedule for screening programmes	42%	19%

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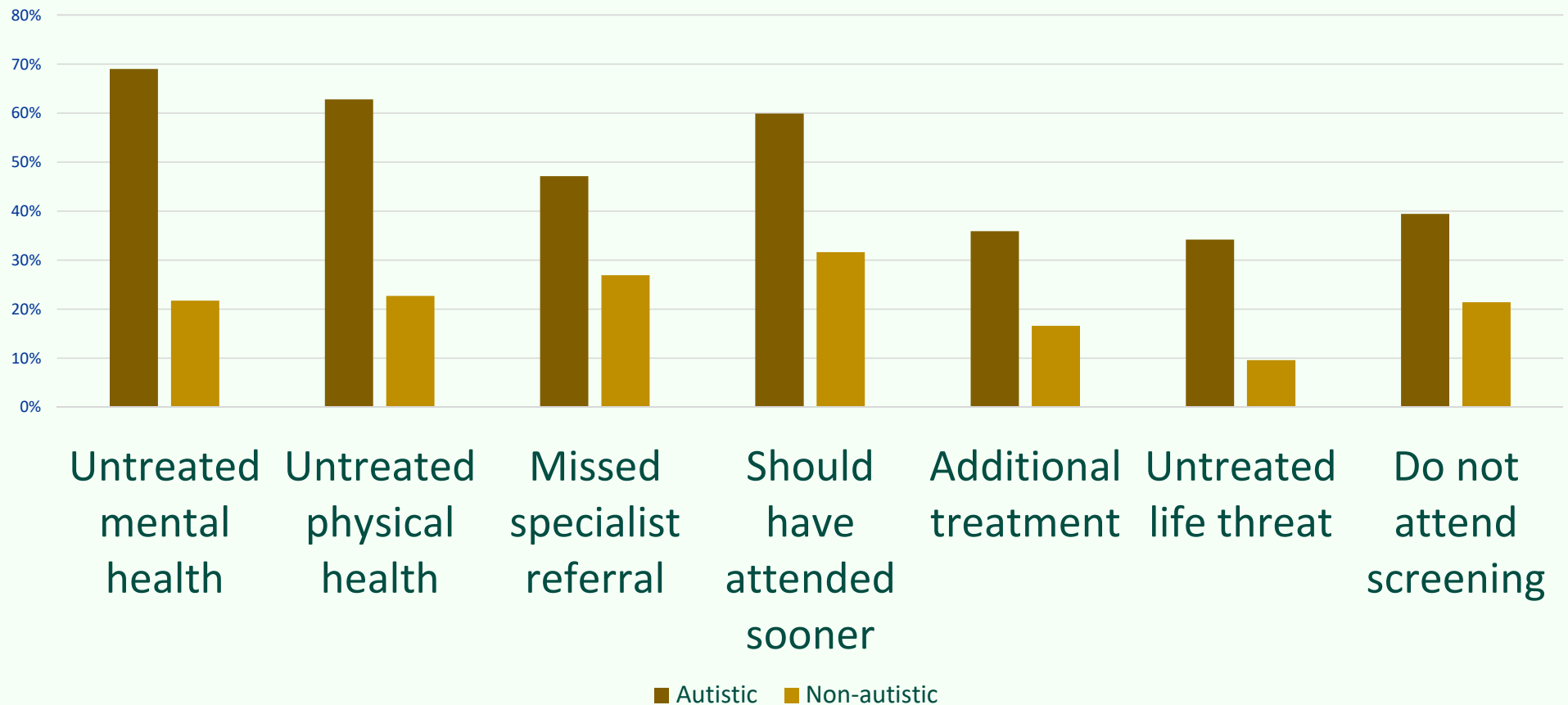
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Lack of support

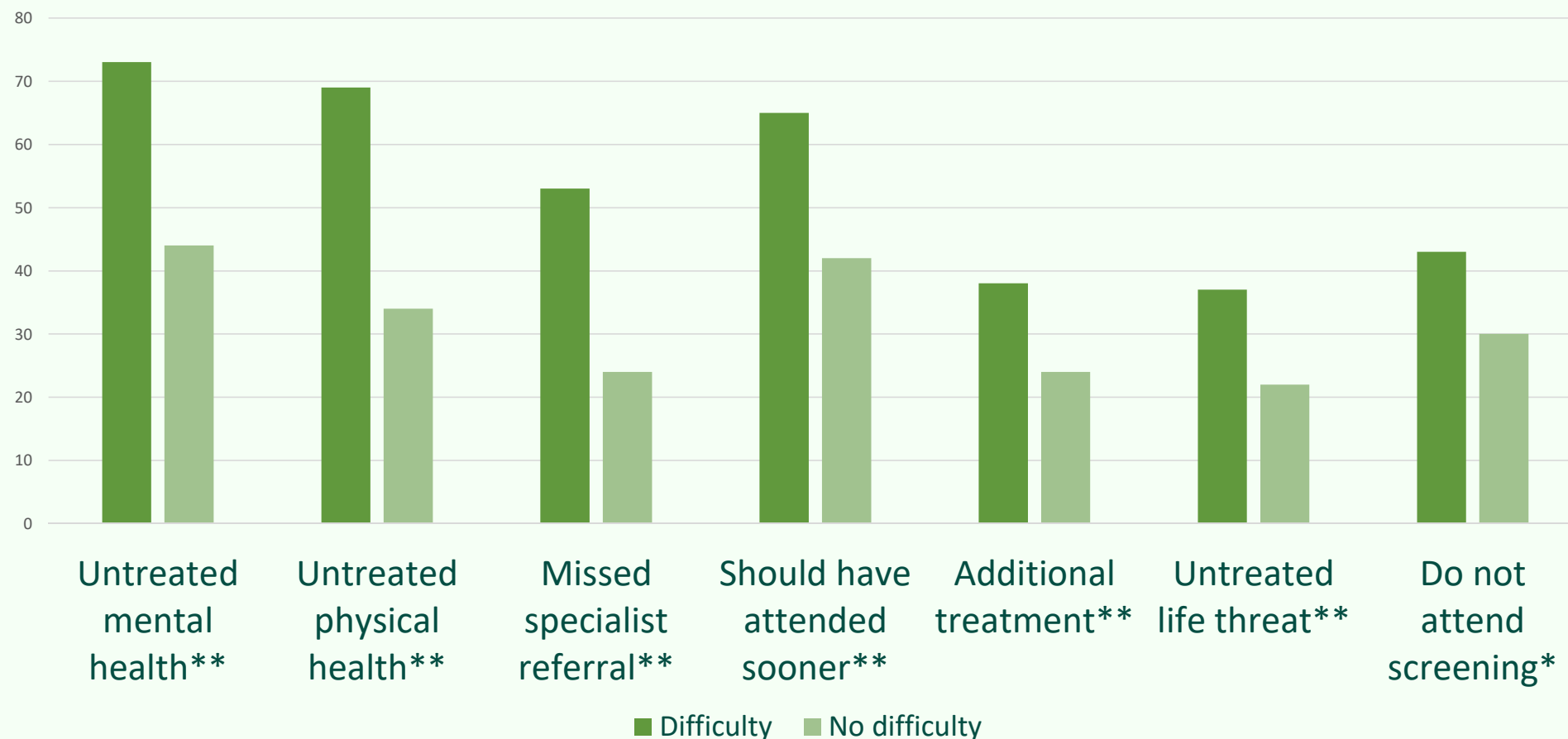
It should not be assumed that people have friends/partners/families who are willing and able to provide unpaid assistance

Who would be available to...	Autistic Nobody available	Control Nobody available
Bring your personal belongings to you in hospital	14%	6%
Collect you after a day case surgical procedure	17%	6%
Assist you at home after an operation	24%	8%
Care for your child if you were unable due to illness	5%	3%

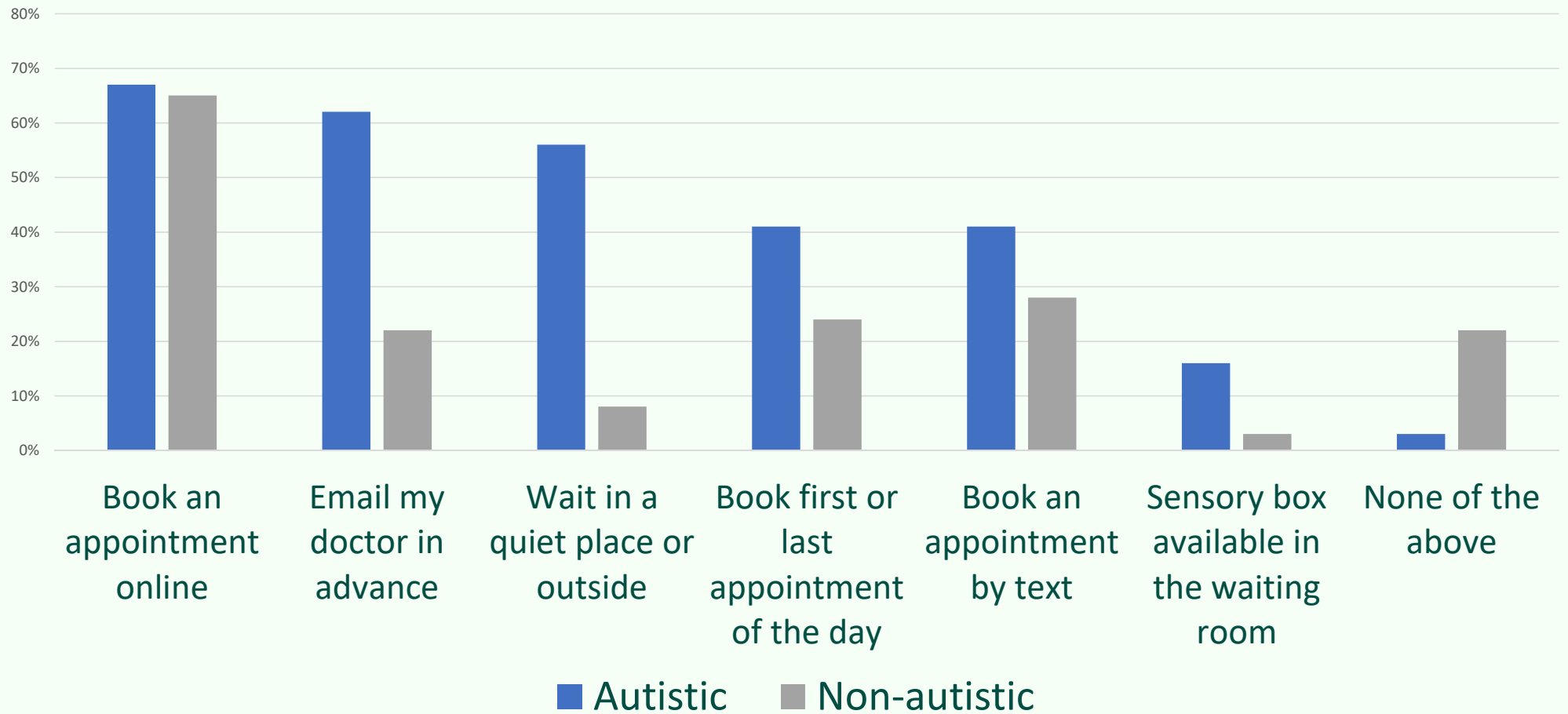
Adverse outcomes in delayed and additional healthcare treatment



Adverse outcomes for autistic adults according to expressed difficulty attending a GP



Facilitators



Key Findings - Consequences

- The consequences of access barriers to healthcare include
 - Untreated physical conditions
 - Untreated mental health conditions
 - Late presentations
 - Emergency admissions
 - More extensive treatment or surgery
- Many autistic adults have no access to primary healthcare
- **No difference between those self identified or formally diagnosed**

“The one question this survey does not address: I simply do NOT go to doctors for all the reasons listed”

“I don't "have" a GP or a doctor”

“I don't go to doctors”

“I avoid seeing any doctor as far as possible”

“I don't really go to a doctor at all”

“I don't know how to find a doctor”

What helps?

- Understand the difficulty attending
- Recognise distress behaviour
- Avoid the waiting room
- Triage
- Staff allocation
- Unambiguous communication
- Avoid small talk
- Minimize sensory issues
- Unambiguous safety netting



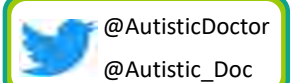


Barriers to healthcare, adverse outcomes and a triple empathy problem

Mary Doherty¹, Stuart Neilson², Jane O'Sullivan³, Laura Carravallah⁴, Mona Johnson⁵, Walter Cullen⁶, Nick Chown⁷, Sebastian C. K. Shaw¹

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Introduction

- Autistic adults have poor physical and mental health compared with the general population.
- Life expectancy for autistic adults is potentially reduced by 16–30 years, with increased mortality across almost all diagnostic categories.
- Mismatched communication and agendas within consultations, alongside poor doctor-patient relationships, form barriers to clinical care – leading to reduced standards of care and worse clinical outcomes. This may stem from the fact that medicine has its own culture, language, and practices.
- Prior negative experience is an independent barrier to future healthcare for autistic people.

Aim

We aimed to explore autistic people's experiences of barriers to healthcare access and self-reported adverse outcomes.

Methods

- Comparative, cross-sectional study. 52-item, self-report, online survey.
- Participants were a convenience sample of autistic adults and non-autistic adults.
- Data were analysed using descriptive statistics, a test of proportions, a Wilcoxon-Mann-Whitney U test, and thematic analysis.
- We are an autistic-led research team including autistic medical doctors.

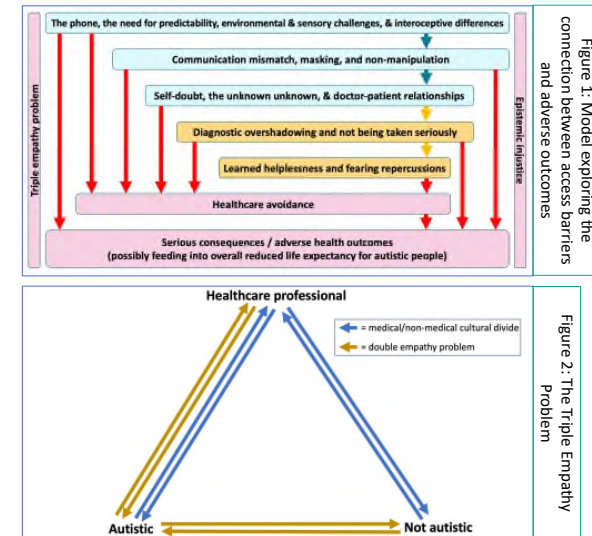
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- Mason D, Ingham B, Urbanowicz A, Michael C, Birtles H, Woodbury-Smith M, et al. A systematic review of what barriers and facilitators prevent and enable physical healthcare services access for autistic adults. *Journal of Autism and Developmental Disorders*. 2019;49(8):3387-400.

Results

- 507 autistic and 157 non-autistic adults participated.
- 80% of autistic adults and 37% of non-autistic respondents reported difficulty visiting a general practitioner (GP).
- Self-reported adverse outcomes were significantly associated with access barriers for autistic respondents.
- A third of autistic people reported being unable to access treatment for potentially serious or life-threatening conditions (34%).
- Autistic adults experienced difficulty deciding if symptoms warrant a GP visit (72%), difficulty making appointments by telephone (62%), not feeling understood (56%), difficulty communicating with their doctor (53%) and the waiting room environment (51%).
- No significant differences in difficulty attending GP, barriers experienced or adverse outcomes between formally diagnosed and self-identified autistic respondents.

Themes	Example quotes
Early barriers	"Often I'm so distressed after waiting so long in the waiting room... This confusion and unknowns means I am often very close to meltdown by the time I get in for the consultation"
Communication mismatch	"They don't believe my pain because I express it in words and my face and body language obviously 'don't match' to them"
Doubt – in oneself and from doctors	"GPs treat me like a stupid child & assume I don't understand what is being said to me because they know I have autism (I have a PhD!)"
Helplessness and fear	"The hardest thing about going to the doctor is making the big step of making yourself vulnerable in order to ask for help but often finding help does not come"
Healthcare avoidance and adverse health outcomes	"I'm gonna die one day because I didn't go to the doctor because it was so bloody frightening" "I have aortic stenosis and have recently had chest pains. I am afraid... afraid to schedule the appt... I haven't seen a cardiologist in years"



Discussion

- Autistic people face highly significantly increased difficulties accessing the healthcare system and interacting with healthcare providers – these may contribute to known healthcare disparities, including increased morbidity and mortality.
- Many autistic people have preferences around GP consultations that would be quite feasible to implement.
- Communication differences between autistics and non-autistics may be compounded by intersectional differences between medical & lay people (Triple Empathy Problem).



Preliminary data upcoming – please do not share

"I feel so disrespected by healthcare professionals that I'd rather suffer at home than set myself up for ridicule": a qualitative study of barriers to healthcare access for autistic adults"

Sebastian C. K. Shaw, Laura Carravallah,
Mona Johnson, Jane O'Sullivan, Nicholas
Chown, Stuart Neilson, Mary Doherty



Themes	Subthemes
Early barriers	Predictability; Environmental challenges; Sensory challenges; Interoceptive differences.
Communication mismatch	Communication differences; Masking; Non-manipulation
Doubt – in oneself and from doctors	Self-doubt; The unknown unknown; Doctor-patient relationships.
Helplessness and fear	Learned helplessness; Fearing repercussions.
Healthcare avoidance and adverse health outcomes	Healthcare avoidance; Adverse outcomes; Barriers have consequences.

Meta themes:

1. Epistemic injustice
2. Triple Empathy Problem



Healthcare avoidance

“I can no longer access healthcare so have been dealing with medical and dental issues without access to medical help for about 15 years now”

“It's unlikely I will ever return to A&E unless i'm unconscious and someone else takes me against my will”

“I also didn't seek help for my injuries or suicide attempts (such as ODs) from either the GP or A&E due to anxiety sensory difficulties and communication problems”



Healthcare avoidance

“Did not seek advice for chest pain because of anxiety about the process of seeking help”

“I feel so disrespected by healthcare professionals that I'd rather suffer at home than set myself up for ridicule”

“I'm gonna die one day because I didn't go to the doctor because it was so bloody frightening”



Medically serious consequences

“It was life threatening and nearly killed me because I was too ill and too disabled to access doctors”

“I believe I also have Parkinsons as I now realize I have many of the symptoms but have long since given up seeking to pursue a formal diagnosis following the recent poor treatment I've endured”

“Due to my difficulty describing my pain and symptoms it led to an undiagnosed... tumour nearly crushing my internal organs from its sheer size and needed emergency surgery which removed a melon sized tumor and an ovary”




Medically serious consequences

“Undiagnosed acute pancreatitis. Eventually rushed in to hospital. I lost my job”

“Heart attack... preferred to sit out the chest pain even though it was agonisingly very painful and might have meant death - despite having a known heart condition and previous heart attack... the visit to my doctor would be too much more anxiety than could cope with”

“I had ovarian torsion and a ruptured ovarian cyst and was in agony and was not believed by ambulance service who forced me to make my own way to gp who sent me to hospital where I was not believed and left for hours in pain ”



Medically serious consequences

“I have rheumatoid disease. I saw a Dr. at my college clinic shortly after onset of symptoms but was treated like she didn't believe me... I waited THREE YEARS to seek treatment again because I was so upset by my treatment. Letting it go so long without treatment has left me with irreversible joint damage ”

“I got hit by a car and didn’t go to the doctor”

“I had an ectopic pregnancy and the fallopian tube burst. I was afraid of going to the doctor for symptoms. When I finally went I got transferred to the ER for emergency surgery and they called my next of kin to say I might not come out of the surgery”



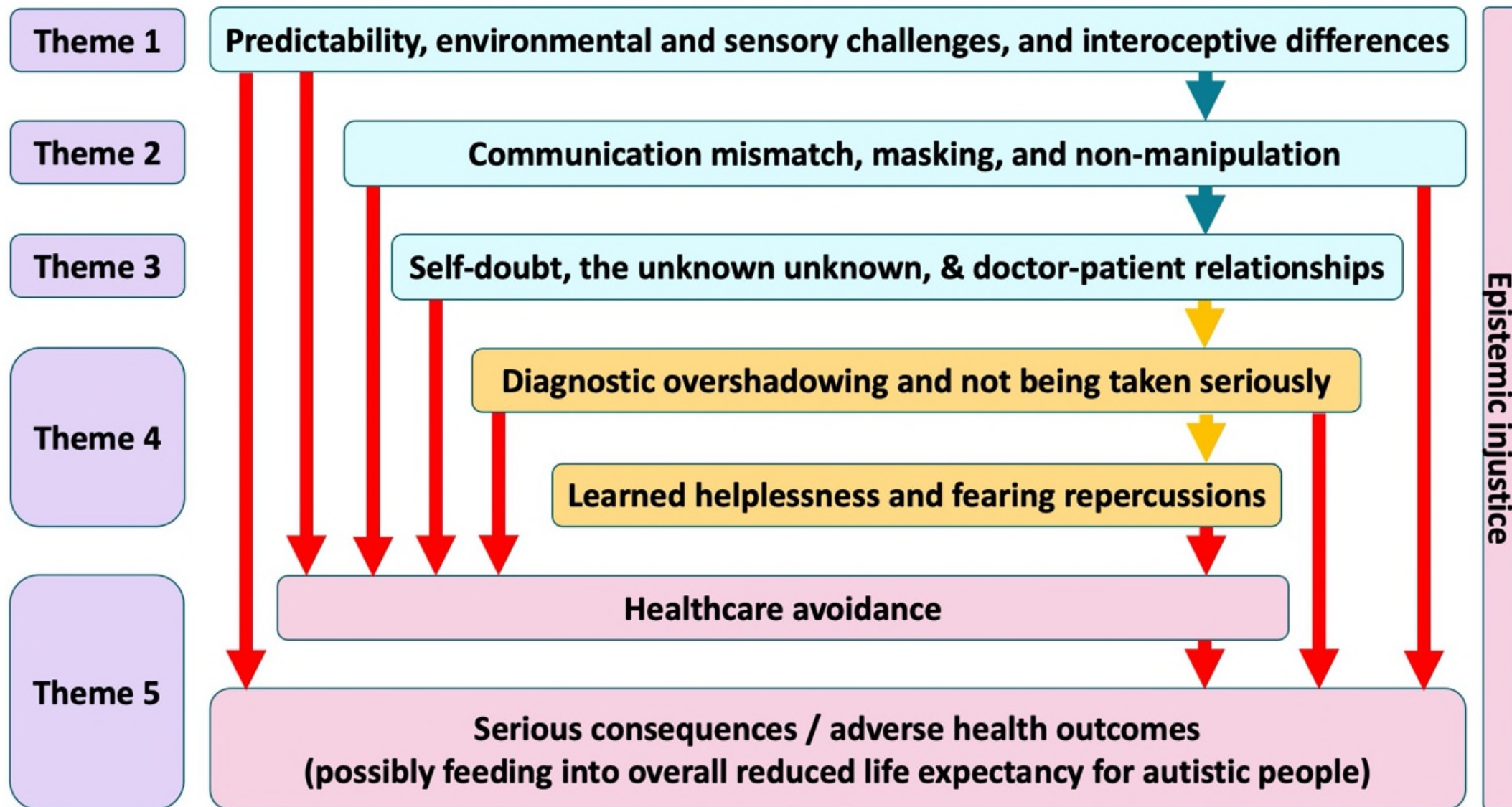
Medically serious consequences

“I sincerely believed I would die or be left with results I did not want to live with if I went through the public system on their terms. Delayed until my condition was life-threatening then had private surgery that I could not really afford ending up in debt for over a year afterwards”

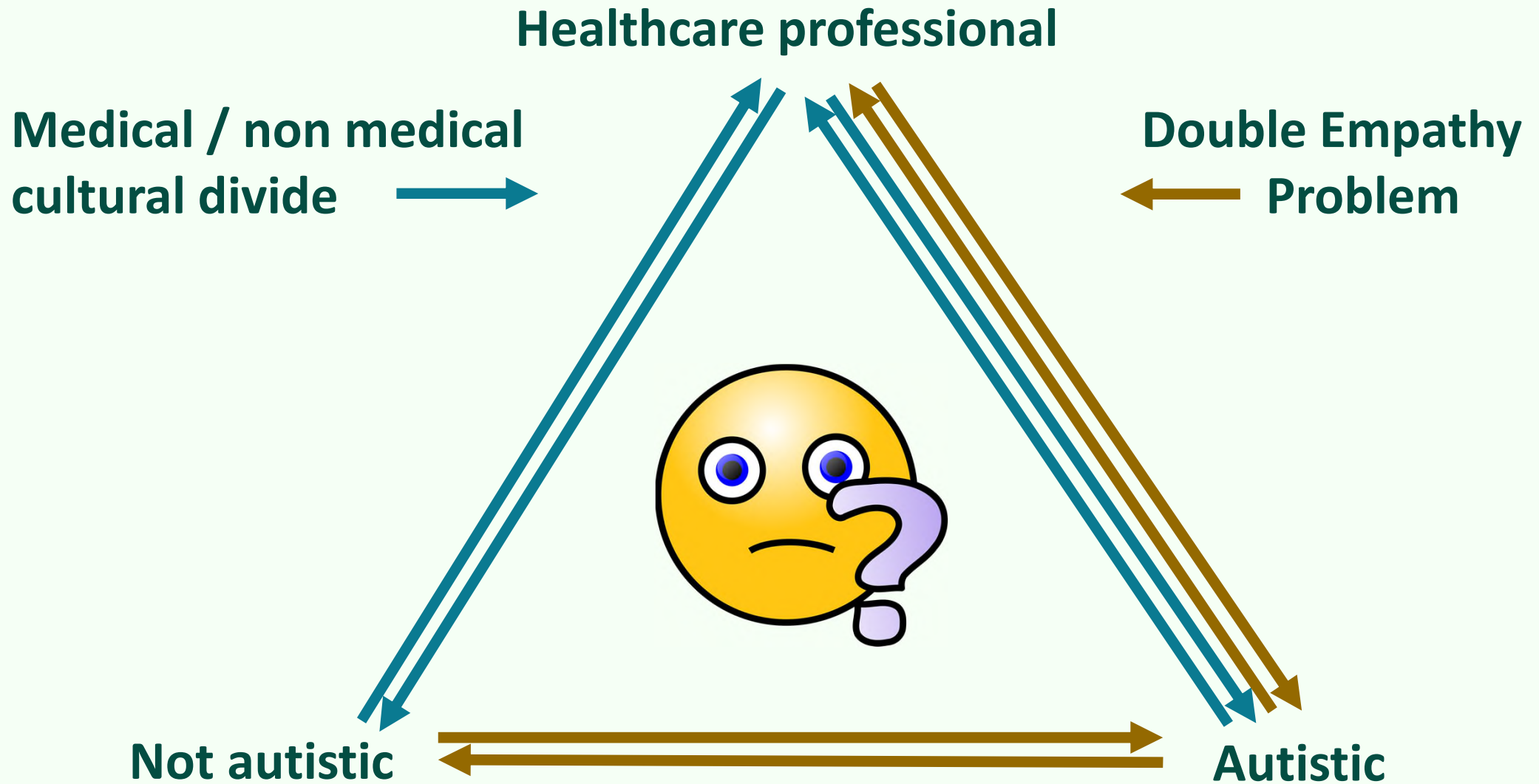
“Ended up in icu on dialysis and nearly died because I delayed seeking treatment after drinking anti freeze”

“I have been suicidal and not been able to seek help”





Triple empathy problem



Triple empathy problem

Healthcare professional

Training common
for doctors



Training NOT
common for
doctors



Not autistic

Autistic



Barriers: conclusion

- Address access barriers
- Resist the tragedy narrative
- Neurodiversity-affirmative approach
- Education and training for healthcare providers
- Autism Friendly Healthcare
 - for autistic staff as well as patients



Overcoming barriers to autistic health care: towards autism-friendly practices

Mona Johnson, Mary Doherty and Sebastian CK Shaw

British Journal of General Practice 2022; 72 (719): 255-256. DOI: <https://doi.org/10.3399/bjgp22X719513>

Article

Figures & Data

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This article has a correction. Please see:

- [Corrections - July 01, 2022](#)

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Overcoming barriers to autistic health care: towards autism-friendly practices.





- Consider patient may be autistic
- Sensory adaptations
- Interoception
- Predictability & focus
- Situational mutism
- Support use of AAC
- Double Empathy Problem
- Pay attention to words
- Trauma informed care
- Support access to services



<https://www.boingboing.org.uk/wp-content/uploads/2022/09/More-than-words-supporting-effective-communication-with-autistic-people-in-health-care-settings.pdf>

Pain

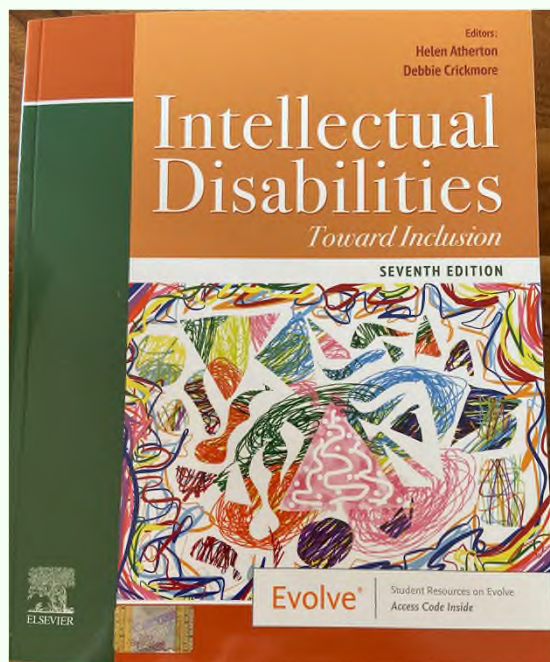
- Altered pain perception
- Unaccounted for bruising
- Unnoticed dental abscess
- Late presentation of injuries
- Incongruous presentation
- Variable attempts to “perform pain”



1800 Seconds on Autism

'I don't know how much pain I'm in'





BRITISH JOURNAL OF
**HOSPITAL
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British Journal of Hospital Medicine, Vol. 82, No. 12 • Review

Recognising autism in healthcare

Mary Doherty, Clair Haydon, Ian A Davidson ✉

Published Online: 8 Dec 2021 | <https://doi.org/10.12968/hmed.2021.0313>



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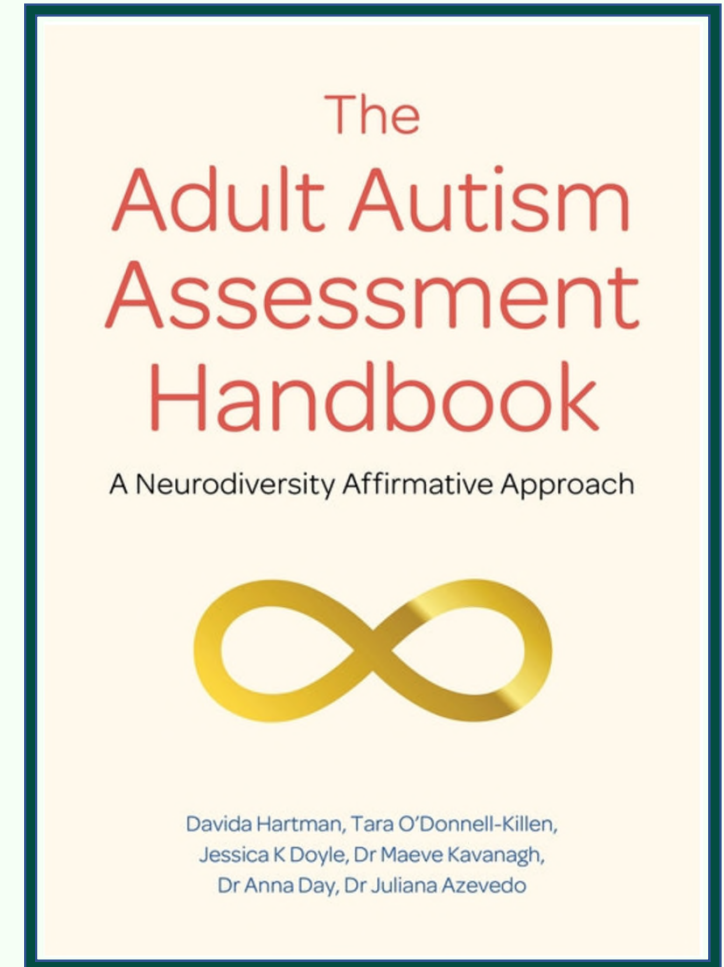
Autism: making reasonable adjustments in healthcare

Clair Haydon, Mary Doherty, Ian A Davidson ✉

Published Online: 8 Dec 2021 | <https://doi.org/10.12968/hmed.2021.0314>

Neurodiversity-affirmative resources

- Neurodiversity-affirmative autism assessment
- Davida Hartman et al
- **adultautism.ie**



Primary prevention of mental ill health

- What does it mean?
- Is it possible?
- Where would we start?
- Implications for autistic people experiencing mental illness
- Access to appropriate treatment



Towards a Neurodiversity-Affirmative Approach for an Over-Represented and Under-Recognised Population: Autistic Adults in Outpatient Psychiatry

Sebastian C. K. Shaw¹  · Mary Doherty² · Sue McCowan³ · Jessica A. Eccles²

Journal of Autism and Developmental Disorders

<https://doi.org/10.1007/s10803-022-05670-4>

LETTER TO THE EDITOR

“Changing the narrative around autism will reduce stigma and may prevent mental ill health for some autistic people.”

June 2022



“We also hope the discussion may prompt general psychiatrists to adopt a neurodiversity-affirmative approach, routinely considering autism as part of their global, holistic assessment of individuals referred to their services.



*“Furthermore, we argue that it is time to turn our attention towards the **primary prevention of mental ill health** in the autistic population through the adoption of neurodiversity-affirmative practices.”*



Recommendations

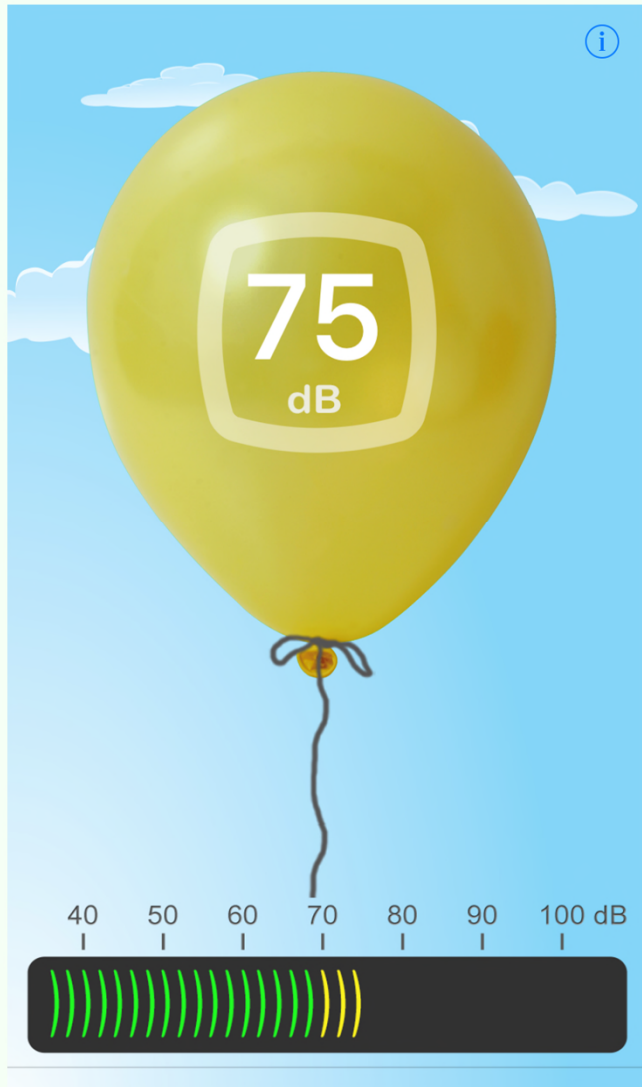
1. All psychiatrists should continue to improve their expertise in autism through training and experience, and particularly, by familiarity with the autistic world.

- Recommendation 1, RCPsych CR 228, 2020

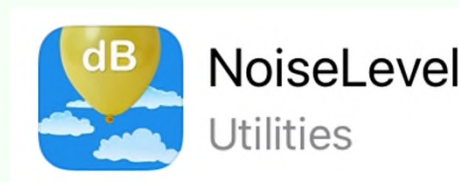
“Familiarity with the autistic world”



Photo credit @AnnMemmott



- Chatting to an interested colleague about autism
- Me: *for example, I'm struggling to focus on our chat because of the noise from the air handling unit above our heads.*
- *I have to actively focus, whereas you might just filter it out*
- Him: ***what noise?***



Autistic psychiatrists on autism: perspectives from behind the mask

Mary Doherty^{1,2}, Nick Chown¹, Nicola Martin¹, Sebastian C. K. Shaw^{1,2}

¹London South Bank University, London, United Kingdom; ²Brighton and Sussex Medical School, Brighton, United Kingdom.



“...a sensory kind of issue and the parent says “Oh I'm so sorry... he's going on about it and it makes no sense”

and I say “it makes perfect sense” and I... explain and the child is like “yes yes” and the parents are like what [on earth] has just happened.”

(Lisa, autistic psychiatrist)

Preliminary data upcoming – please do not share

Autistic SPACE: A novel framework for meeting the
needs of autistic patients in healthcare settings

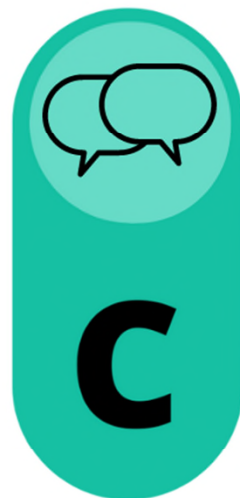
Mary Doherty

Sue McCowan

Sebastian CK Shaw



AUTISTIC



Physical

Processing

Emotional

Sensory

Predictability

Acceptance

Communication

Empathy

- Thank you for listening
- Questions?

Contact: mary@autisticdoctorsinternational.org
<https://autisticdoctorsinternational.com>

