

Through the looking glass: Investigating autistic health inequalities as an autistic researcher

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Trigger warning (or not?)

- Justifications for research into health inequalities usually includes statistics and stark facts about autistic people's health outcomes and life expectancy
- I find these statistics upsetting, so I have chosen to omit them in this café
- If you would like more notes or papers with quantitative detail, please email me!
- Topics that could bring up difficult emotions in this talk include thinking about co-occurring health conditions, stress and difficulties accessing health care, thinking about autism-hostile environments and institutions


About me

- Academic background in history, heritage and creative health research
- Hobby/special interest - comedy!
- Neurodivergent family, various combos (two children on autism pathways, one with ADHD diagnosis)
- Self-diagnosis
- Role of lived-experience in my research
- Keen to learn from everyone's different experiences of autism
- Excited to be working with A@M



About the project



- Autism@Manchester is an interdisciplinary research network that works closely with medical experts and local government to co-produce research with the local autistic community
 - ‘Marginalisation multiplied: Improving autistic health inequalities with collaborative interdisciplinary research and knowledge transfer through Autism@Manchester’
 - This project uses expertise within Autism@Manchester to co-design resources, and project plans to reduce health inequalities
 - Funded by University of Manchester’s Interdisciplinary Research Pump-Priming 2023-24, supporting Research Associate/Co-producer
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Background to health inequalities



Social and
emotional



Co-occurring
conditions




Institutional
barriers



Unique barriers



Social and emotional factors

- Past negative experiences
 - Social expectations 'keep calm and carry on'
 - Accepted levels of pain?
 - Fear of not being believed
 - Fear of NHS 'burden' due to awareness of waiting lists etc.
 - Trauma - beyond bad experiences
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Personal Experience

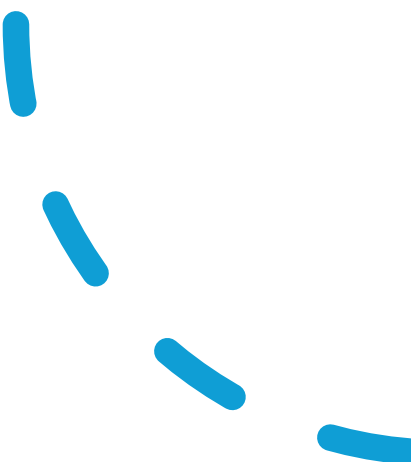
- Pain not taken seriously
- Previous gaslighting and mis-diagnosis
- Suspected endometriosis, fibromyalgia

'The highest-rated barriers by autistic adults were deciding if symptoms warrant a GP visit'

Doherty M, Neilson S, O'Sullivan J, *et al*, 'Barriers to healthcare and self-reported adverse outcomes for autistic adults: a cross-sectional study', *BMJ Open* 2022;**12**:e056904. doi: 10.1136/bmjopen-2021-056904

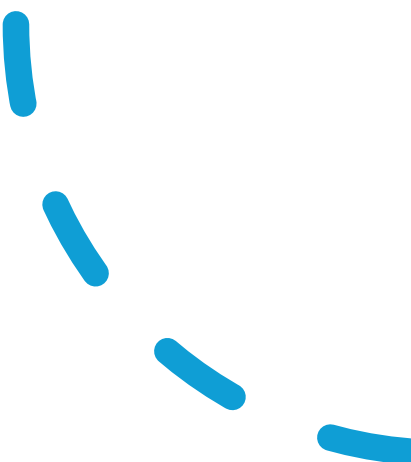



Impact of related health conditions

- Hypermobility
 - Rheumatology (eg Fibromyalgia)
 - Sensory motor pathway
 - Optometry
 - Dentistry
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Institutional barriers




- Environmental
 - Autism hostile systems
 - Perceptions of autism
 - Poor healthcare communication
 - Multi-agency involvement - who to ask?
- 



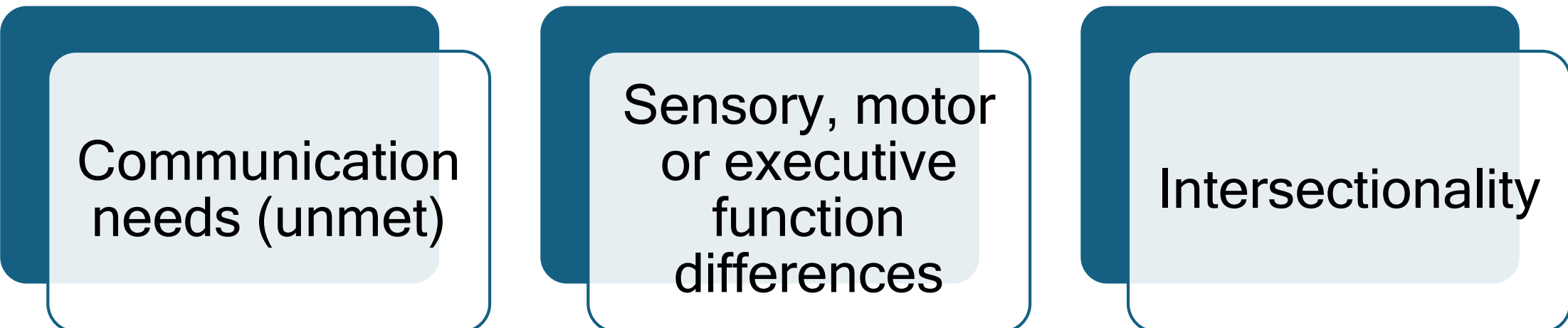
‘Communication is a two way process, and whilst social communication is a core difficulty for autistic people, professionals may not appreciate the need to adapt their communication style to communicate effectively with autistic people—or be unable/unwilling to do so.’



Mason, D., Ingham, B., Urbanowicz, A. et al. A Systematic Review of What Barriers and Facilitators Prevent and Enable Physical Healthcare Services Access for Autistic Adults. J Autism Dev Disord 49, 3387-3400 (2019). <https://doi.org/10.1007/s10803-019-04049-2>



Unique barriers for individuals with autism



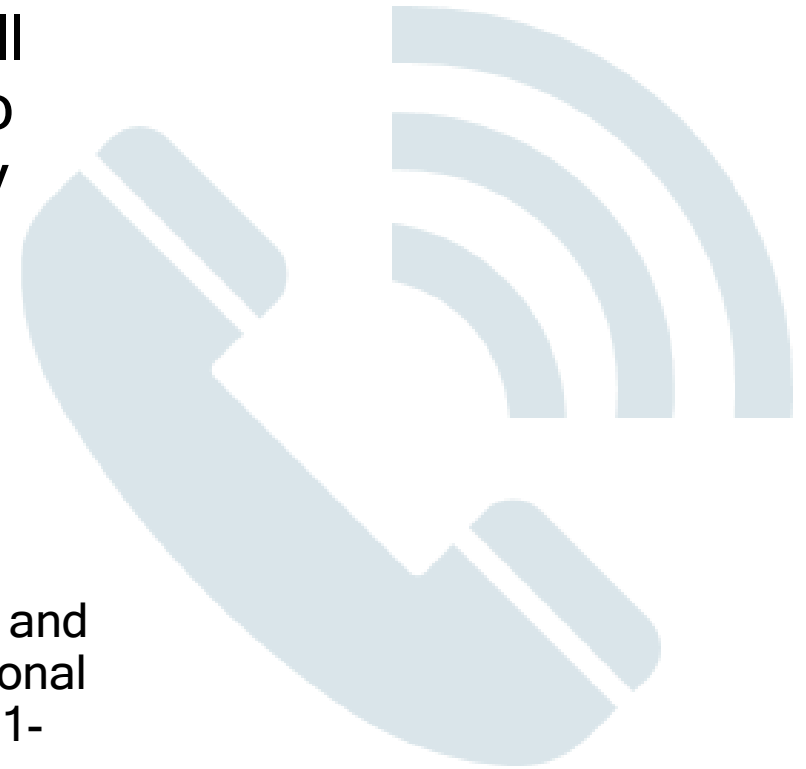
Communication
needs (unmet)

Sensory, motor
or executive
function
differences

Intersectionality

‘Difficulty using the telephone to book an appointment was significantly associated with all adverse outcomes apart from having to undergo more extensive treatment or surgery than if they had attended sooner.’

Doherty M, Neilson S, O'Sullivan J, *et al*, ‘Barriers to healthcare and self-reported adverse outcomes for autistic adults: a cross-sectional study’, *BMJ Open* 2022;12:e056904. doi: 10.1136/bmjopen-2021-056904



What's next?

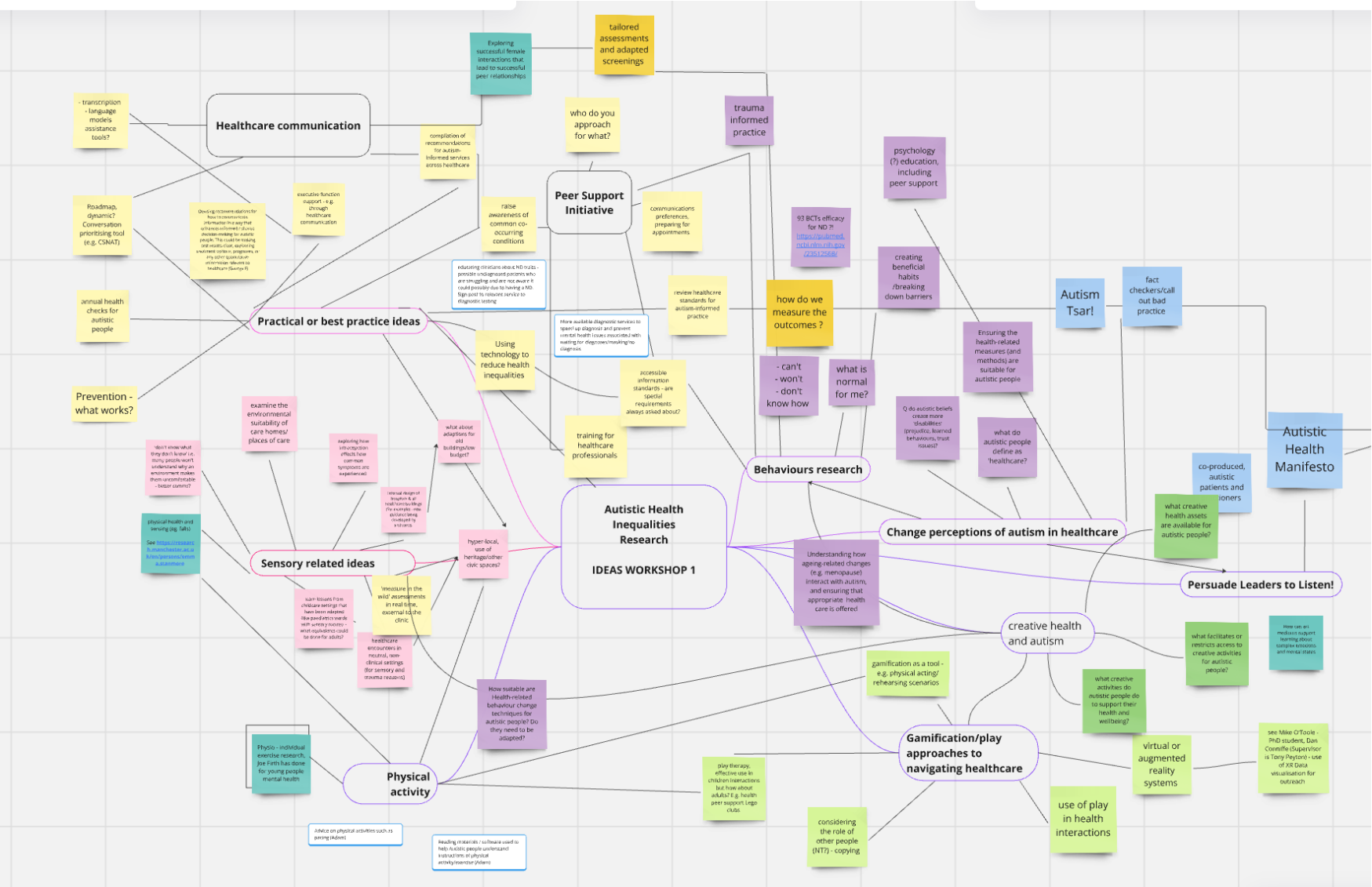
Narrowing the focus of research

Draw upon A@M strengths

Advice from partners

Advice from Experts by Experience Group

Write grant!



Thanks for listening!

Autism@manchester: aim to create research that has real meaning for autistic people, and have several initiatives - events, presentations, expert by experience group etc . Please visit:

<http://www.autism.manchester.ac.uk/>

I recently wrote an introduction to the project for the A@M blog:

<https://sites.manchester.ac.uk/autism-at-manchester/2024/10/07/behind-the-scenes-with-erin-insights-from-a-co-production-officer-on-her-latest-project/>

For more information on the project or to join our mailing list contact:

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