



# **Barriers & Facilitators to Physical Health Care Access**

**NAS Autism Adulthood Conference**

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## Background (*Autistica report*)

- People with autism experience some co-occurring health conditions more frequently than those in the general population (Cashin et al, 2018)
- People also engage with 'usual healthcare' less frequently for various reasons (some due to difficulties with access, lack of adjustments) (Nicoladis et al., 2015)
- In combination, this leads to high levels of morbidity and early mortality (Hirvikoski et al, 2016)



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# Health conditions experienced (Croen et al, 2015)

- Diabetes 7.6% vs 4.3% (Autistic people vs non-autistic people)
- Cardiovascular 37% vs 23%
- Obesity 34% vs 27%
- Thyroid diseases 7% vs 3%
- Cancer 1.7% vs 2.2%
  
- Epilepsy 12% vs 0.7%
- Gastrointestinal 35% vs 27.5%
  
- Sleep 17.6% vs 9.6%

# Potential Interventions

- Screening & Management
- Cardiometabolic monitoring
- Health checks
- Lifestyle advice (diet; physical activity)
- NICE guidelines (with adjustment/adaptation)

# Improving the Health of Autistic Older People

## Research Questions

1. What healthcare do older people need?
2. What are the challenges faced by professionals providing this healthcare?
3. Are there specific changes/adaptions within current service provision that can address these challenges, or older people's priorities?
4. What impacts do specific service changes/adaptations that include facilitating access to physical health care for older people with autism have on their uptake of healthcare, their physical health conditions and quality of life?

*Stage 1: A systematic literature review, followed by interviews/focus groups and surveys to identify key challenges*

- Proportionate literature review on ways in which access to physical health care is facilitated
- Engage with older autistic adults and local health professionals
  - Interviews/focus groups/survey that aims to identify:
    - Health needs;
    - Gaps in provision;
    - Barriers/boosters;
    - Potential risks
- Use information from above to inform intervention design in Stage 2

# Review of Barriers/Facilitators to accessing health for autistic people

(Mason, Ingham, Urbanowicz, Michael, Birtles, Woodbury-Smith, Brown, James, Scarlett, Nicolaidis & Parr, 2019) [link](#)

- Journal of Autism and Developmental Disorders – Open Access
- Six Papers
- Findings
  - Challenging interpersonal communication with providers
    - Literal thinking
    - Lack of empowerment of autistic people
  - Limited knowledge of autism
    - Stigma toward autistic people
    - Lack of training opportunities
  - Sensory sensitivities
    - Waiting room to clinical area

What matters for autistic people, their supporters and clinicians in improving healthcare?

- Ideas?
- Focus groups & interviews undertaken
- Themes and what these mean for next steps

## *Stage 2: Intervention design and provision Implement intervention and evaluate impact*

- Participants
  - Identified through specialist community teams, autism diagnosis services, adult cohort
- Measures @ baseline
  - Diary keeping
  - Semi-structured interviews
  - Health record review
- Intervention
  - Health facilitation to be designed following Stage 1 and undertaken by clinical researcher
- Follow up – repeat measures

# Autism specific health checks consortium

Professor Jeremy Parr (Co-lead). UK, US, Australia expertise including:

- Autistic people and relatives of autistic people
- GPs
- Academic clinicians
- Health economists
- Human Computer Interaction researchers
- Commissioners
- NHS England
- Third sector (NAS)



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## Design & evaluation of an autism specific health check: Aims

1. Identify the facilitators and barriers to primary care access for autistic adults (Jan 19 – July 19)
2. Design an autism-specific health check (including a health checklist and digital pre-appointment tool); for people with/without learning disabilities (Aug 19 – Aug 2020)
3. Pilot trial: assess feasibility, acceptability of a primary care autism-specific health check (including initial economic analysis, some data on effect/utility); Sept 2020 – Nov 2021
4. Disseminate findings (NHS, autism community, academic)



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# Summary & potential outputs

The research will:

- Develop resources that improve access to healthcare
- Identify reasonable adjustments that are needed by autistic people
- Ascertain initial information on commissioning, pricing and resource requirements
- Make new knowledge available to clinicians across the UK NHS and to professionals in other public sector and private sector organisations

With the aim to:

- Reduce health care costs through reduced long term provision for people with multiple long-term conditions
- Reduce premature morbidity and mortality
- Improve the health, wellbeing, and quality of life of autistic adults
- And in turn improve the lives of relatives, carers and supporters



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Questions?

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