

Optimising general practice support for autistic adults

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Newham Autism Residents Advisory Group (ARAG), 11th May 2006

Background and aim

Background:

Compared to non-autistic adults, autistic adults:

- Have higher rates of health conditions (e.g. cancer, heart disease, epilepsy)
- Experience greater unmet healthcare needs
- Face more barriers to accessing general practice
- Report lower satisfaction with healthcare

Aim:

To understand how, why, and when general practice best supports (or not) autistic adults, with and without learning disabilities, throughout the lifespan.

What we did: literature review

- Type of literature review
- Theory driven
- Involves stakeholders throughout
- Six stages worked through iteratively



What we did: initial theory


Developing an initial programme theory (IPT)

- Our initial idea about how general practice works (or doesn't) for autistic adults
- Developed through stakeholder discussions, scoping searches, team knowledge
- Mapped to the patient pathway

- Identifying a problem
- Deciding to seek help
- Obtaining an appointment
- Getting to the appointment
- General practice interaction
- Post-appointment & supporting long term outcomes

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Optimising general practice support for autistic adults: a realist review protocol

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Abstract

Background

Mental and physical health conditions are more common in autistic than non-autistic people, including anxiety, depression, suicidality, gastrointestinal problems, cancer, epilepsy, and heart disease. General practice is often the first point of contact for patients, yet research has found that autistic people face barriers to healthcare, report lower satisfaction with healthcare, and have more unmet health needs than non-autistic people. This can be due to misunderstandings about the needs of autistic people, different communication styles, the clinic environment, and challenges making and



<https://link.springer.com/article/10.1186/s13643-025-02936-7>

Check the supplemental file for our initial programme theory:

https://static-content.springer.com/esm/art%3A10.1186%2Fs13643-025-02936-7/MediaObjects/13643_2025_2936_MOESM2_ESM.pdf



What we did: gathering and selecting evidence

Inclusion criteria

- Population: autistic adults (no upper age)
- Setting: UK general practice
- Type of document: any
- Study design: any

Searches

- Electronic databases: Medline, Embase, CINAHL, Psychinfo, ASSIA, SCOPUS
- Grey literature

Selection

- 2 stage screening process

Appraisal

- Relevance & rigour

What we did: stakeholder involvement

Approaches
Public co-applicant (EC)
<ul style="list-style-type: none"> • Attending core team meetings • Critical friend • Data extraction & interpretation • Dissemination strategy
Advisory groups (5 autistic adults, 1 parent, 6 professionals)
<ul style="list-style-type: none"> • Developing IPT • Data interpretation • Identifying existing resources
Autistic assistant reviewers (4)
<ul style="list-style-type: none"> • Developing IPT • Screening titles/ abstracts and full texts • Extracting study characteristics • Giving reflections on documents • Dissemination – poster design, co-authorship

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A realist review of general practice support for autistic adults: Early results and insights from stakeholder involvement and work with autistic assistant reviewers

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Aim: to review the existing evidence to understand how, why and when general practice optimally supports (or not) autistic adults with and without learning disabilities throughout the lifespan.

Background

- Autistic adults are twice as likely to die prematurely compared to non-autistic adults, often due to preventable conditions and suicide.
- General practice involvement is critical to address health inequalities, yet autistic adults are underserved by primary care services and research.
- Research often overlooks the needs of autistic adults to focus on children.
- Autistic people are often excluded from research processes, perpetuating stigma, pathologisation and a deficit view of autism, which impacts research focus and quality.

Implications

- This realist review is enriched through the inclusion of stakeholders and autistic assistant reviewers.
- Centring autistic experience will help prevent epistemic injustice, and provide opportunities for autistic and non-autistic early career researchers.
- Sufficient time and funding should be allocated to ensure stakeholder and assistant reviewer involvement is meaningful, not tokenistic.

Methods

Findings so far

- 12,749 records identified from searches across seven databases.
- Assistant reviewers collectively screened 4,180 (33%) titles/abstracts.
- 10% of title/abstract records second screened, conflict rate of 7.4%.
- 11,518 records excluded, 1,231 records through to full-text screening.
- Core research team must work flexibly, adapt to people's needs, discuss differences of opinion within stakeholder groups, and between stakeholders, assistant reviewers and the core research team.
- Ways to understand and manage the impact of exposure to harmful or stigmatising research on assistant reviewers are being explored.

Poster designed by Sophie Longley and Cathy Stratton

As an autistic adult who has had mixed experiences navigating General Practice support, I was enthusiastic to be involved in research that could help shape the direction of health equalities for autistic people in the UK. – Sophie Longley

It's a privilege to have the flexibility and support I need to be able contribute to such an important project (as a late diagnosed autistic adult with ongoing health issues). – Cathy Stratton

References

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Results

Screening and inclusion:	No.:
Title and abstracts screened	12,749
Full texts screened	898
Included in review (so far)	24

- Identifying a problem
- Deciding to seek help
- Obtaining an appointment
- Getting to the appointment
- General practice interaction
- Post-appointment & supporting long term outcomes

Results: Deciding to seek help (1)

If autistic individuals have had previous poor experiences of healthcare, where their needs have not been understood or met, they may avoid or delay seeking help, because they feel they won't be taken seriously or believed.

Doherty 2022: *Not feeling understood was a reason to avoid or delay for 56% of autistic respondents compared with 13% of non-autistic respondents.*

Doherty 2022: *Autistic respondents reported being 'concerned I won't be taken seriously when I describe my symptoms' (67%); worried about 'wasting the doctor's time' (66%) and 'being considered a hypochondriac' (65%).*

O'Nions 2023: *Many autistic people experience anxiety, confusion, stress, and distress over society's lack of understanding; and, as a result, isolate themselves.¹¹ In terms of health care, this can result in delayed presentations and a lack of help seeking.*

Results: Deciding to seek help (2)

If the healthcare system is not designed to meet the needs of autistic individuals, they may try to self-manage their health, because they feel appropriate support is lacking.

Coleman-Fountain 2020: Support that is seen as lacking or inadequate can leave autistic people reliant on themselves to manage symptoms and difficulties.^{20,21}

Coleman-Fountain 2020: ‘... if people are trying to help ... it probably would be for the best but ... you’re used to doing things your way and I guess you’d think someone’s trying to interfere.’ (YA08S, M).

Mason 2021: Two participants described specific instances of selfmanaging their health conditions. One acute case involved a participant who sewed together a cut in his foot. His reasons for doing so were: First thing, it was a Sunday. I wasn’t driving at the time . . . Second thing was I could have fixed it quicker, and be back on my feet . . . I have a fairly high pain tolerance. [Participant 7]

Results: post-appointment & supporting long-term outcomes

If follow-on support is inappropriate or non-existent, health outcomes may worsen because autistic people may be ‘bounced’ around the system and feel frustrated, confused and anxious.

Mason 2021: *Clinicians discussed the services available to autistic people (or a lack of services) and the disconnect between services that meant autistic people were passed from service to service: So I think [my colleague] was very acutely aware that people with autism drop into our mental health services and they shouldn't be here because autism isn't a mental disorder but it's kind of where do you place these people and that just kind of compounds their confusion. [Clinician 4]*

Mason 2021: *Participants and clinicians recognised the importance of maintaining patient–provider relationships. One participant noted this was to avoid being ‘pushed around the system’. Clinicians who can provide this continuity of care are likely to improve the health outcomes of autistic people – something that has been documented in the general population (Cabana & Jee, 2004; Maarsingh et al., 2016).*

Unigwe 2017: *Once diagnosed, one GP commented on having a ‘sense of hopelessness about lack of appropriate help’, with ‘no offer of support, therapy, or follow-up’.*

What do you think?

- We would like to know if these findings make sense to you?
- Do they seem familiar or are they surprising?
- Did anything else come to mind when you saw/heard these results?
- Please let me know in the Q&A section, or after the meeting, or via email

Conclusions

Assistant reviewer concerns

- Lack of diverse participants; poor reporting of demographic characteristics in research; poor reporting of demographic characteristics in general practice
- Treating autistic people with or without learning disability as one homogenous group/ no consideration of different care needs.
- People's experiences being invalidated

Next steps

- Continuing to analyse the data and discuss with stakeholders
- Producing guidance for:
 - General practice on potentially helpful changes to services
 - Autistic people to help navigate general practice
- Share any existing guidance/ resources that we find

Thanks to

- Stakeholders: autistic individuals, professionals
- Salford Autism
- Autism@Manchester



For more information



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Any questions?