

Autistic People's Experiences with Physical Healthcare Services: An Umbrella Review

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Umbrella review aim

To synthesise the experiences and interactions of autistic people, their families and healthcare providers, within the physical healthcare system.

Background

Autistic people require access to more physical healthcare services than non-autistic people, yet experience higher unmet healthcare needs. This umbrella review was conducted to understand the factors that contribute to, or reduce, this disparity with the intention to inform future physical healthcare service guidelines and programs.

Method

A systematic umbrella review was performed in December 2022 across nine databases. The review followed PRISMA guidelines and JBI methodology for umbrella reviews. It was preregistered on PROSPERO (CRD42023395763). Eligibility criteria included: systematic review, published in a peer-review journal, reports on autistic people (self-report or by proxy), and discusses autistic experiences with physical healthcare services. This could include healthcare provider attitudes and interactions, service access, and delivery methods.

Community participation

Autistic and autism community members were involved throughout this umbrella review. Autistic and neurodivergent people, and members of the autism community, were on the authorship and review team. They provided input into the search terms, results synthesis and interpretation. In the 34 included reviews, community involvement was only described in detail in one review. Two other reviews reported on community involvement in included studies.

Results

From an original 2,644 studies, 34 reviews met inclusion criteria. These reported on 520 primary studies and 870,844 autistic participants.

All reviews were rated as high quality using the JBI Critical Appraisal Tool for Systematic Reviews.



Key findings across reviews

Autistic people and their families report:

- significant problems** with accessing physical healthcare services.
- healthcare providers have **limited knowledge, understanding, and experience of autism**.
- less satisfaction** with their encounters with physical healthcare services than non-autistic people and their families.
- accommodations are not routinely made** to support autistic people to be able to access healthcare.
- requiring **more physical healthcare services** than non-autistic people.
- experiencing **greater unmet healthcare needs and financial burden** associated with healthcare than non-autistic people.
- standard practices and communication methods **provide challenges** for autistic people which may impact access to routine, preventative or emergency healthcare.
- telemedicine** can provide a beneficial, alternative mode of service delivery.

Autistic people and their families report that physical healthcare professionals lack knowledge of autism and ways to tailor approaches to support autistic people under their care.

Research gaps and future priorities

- 1 Identifying services accessed, unmet service needs and barriers to healthcare for Australian autistic individuals;
- 2 Co-designing autistic-specific resources to support access to healthcare services and evaluating the impact of these; and
- 3 Improving health professionals' knowledge and understanding of autism through training that is co-developed and co-delivered with autistic people.

Conclusion

The findings of this umbrella review highlight inequity and challenges for autistic people across physical healthcare systems. Enhancing the level of autism knowledge of health professionals and greater collaboration with autistic people are important factors in improving the experiences of those requiring physical healthcare. Further research and attention to this area is required to identify effective supports for autistic people accessing physical healthcare.

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