

**DOCUMENT SUMMARY** This 2023 scoping review is a foundational text that validates the process of adult self-identification of autism, concluding that self-identified adults often have a reasonably accurate understanding of their own autistic traits. The paper systematically documents the numerous barriers in the formal diagnostic system that necessitate self-identification, including clinician skepticism, outdated stereotypes, and a history of misdiagnosis. It serves as a powerful argument for a more client-centered, neurodiversity-affirming assessment process that values lived experience and self-knowledge.

**FILENAME** [Overton\\_2023\\_RESEARCH\\_scoping\\_review\\_Self-Identification\\_Autism\\_Adults.md](#)

**METADATA** **Primary Category:** RESEARCH **Document Type:** research\_article **Relevance:** Core **Update Frequency:** Static **Tags:** #self-identification, #self-diagnosis, #late-diagnosis, #adult\_autism, #assessment\_barriers, #lived\_experience, #neurodiversity, #medical\_model, #misdiagnosis, #gender\_bias, #validity **Related Docs:** [Lerner\\_2018\\_RESEARCH\\_handbook\\_chapter\\_ASD\\_Assessment\\_Critique\\_History.md](#), [Hall\\_2008\\_RESEARCH\\_conference\\_abstract\\_ADI-R\\_Critique\\_PDDBI\\_ADOS.md](#)

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## Understanding the Self-identification of Autism in Adults: a Scoping Review

### Why This Matters to Enliten

This scoping review is a cornerstone document that scientifically validates our entire reason for existing. It systematically outlines the profound failures of the traditional diagnostic pathway for adults and provides powerful, evidence-based support for the accuracy and importance of self-identification. The paper's findings on the barriers to diagnosis—particularly the skepticism and lack of knowledge among healthcare professionals—are the very problems Enliten was created to solve. We can use this research to affirm our clients' journeys, educate other professionals on the legitimacy of self-discovery, and justify our interview-based, client-centered model as the necessary solution to a deeply broken system. This paper provides the academic backing for our revolutionary stance.

### Systemic Barriers That Force Self-Identification

The review identifies numerous barriers within the healthcare system that prevent adults from receiving a formal autism diagnosis, often leading them to self-identify as a necessary alternative.

- **Clinician Skepticism and Lack of Knowledge:**
  - General Practitioners (GPs) and other healthcare professionals often fail to recognize the presentation of autism in adults.
  - During initial appointments, many adults report not being taken seriously by professionals.
  - Clinicians often hold strong, stereotypical views of autism based on non-verbal children and have little awareness of how it presents across the lifespan.

- This lack of understanding from professionals was a commonly reported barrier.
- **Fear and Invalidation:**
  - Many adults experience a fear of being disbelieved by their doctors, which acts as a significant barrier to even seeking a referral.
  - Difficulties in verbalizing their experiences and providing specific examples during the assessment process can prevent a referral or diagnosis.
- **History of Misdiagnosis:**
  - Adults frequently report a lifetime of being labeled with a broad range of mental health conditions (e.g., anxiety, personality disorders) that they felt did not fully explain their experiences.
- **Practical and Financial Barriers:**
  - Country-specific barriers are significant, including long waiting times in the UK and Canada and the expensive cost of assessments in the USA.

## **The Validity of Self-Identification**

The review provides strong evidence that adults' self-identification is a legitimate and often accurate process.

- The authors conclude that adults who self-identify "seem to have a reasonably accurate recognition of autism/autistic traits in themselves".
- Multiple studies included in the review found that the results from self-identified autistic adults were "very similar" to the results from adults with a formal diagnosis.
- Despite this accuracy, this self-understanding is "often distrusted or ignored by healthcare professionals".
- The process of self-identification itself is deemed "an essential stage in the process towards the positive acknowledgment of an autistic identity".

## **The Journey of Self-Discovery**

The review outlines the common process adults go through when self-identifying.

- The process often begins with a realization, sometimes starting in childhood or adolescence, of perceiving the world differently from peers and relatives.
- This consideration is often prompted by family members, friends, or media portrayals of autism.
- To validate this possibility, adults engage in extensive research, including online searches, reading books and articles, and watching documentaries.
- For many, self-identification is highly beneficial, providing an explanation and self-understanding that had been missing their entire lives.
- Online autism forums and groups often provide a crucial "space of safety and personal reassurance".

## **A Call for a Neurodiversity-Affirming Approach**

The review concludes by advocating for significant changes to the referral and diagnostic process, aligning directly with the Enliten model.

- It highlights the need to develop "neurodivergent-friendly" clinical tools for use in assessment.

- It emphasizes the importance of a client-centered approach that gives adults the "opportunity to express in their own words the main strengths and difficulties they experience in real life".
- The authors suggest that tools like the Autism Spectrum Identity Scale (ASIS) could be used as facilitators in the diagnostic process to help clinicians understand clients' views from a client-centered, not just a medical, perspective.
- The review critiques the medical model's view of autism ("a mental health disorder that must be treated") and contrasts it with the neurodivergent approach ("a condition that is characterized by a broad range of strengths and weaknesses").

## Quotes We Might Use

- **On clinician failure:** "...healthcare professionals seemed to have strong stereotypical views of the presentation of autism (more common in non-verbal children that are autistic), and little awareness and understanding of the different forms of autism through the lifespan".
- **On the validity of self-identification:** "In several of the studies that were reviewed in this scoping review... it was found that the results from adults who self-identified as autistic were very similar to the results of adults with a formal diagnosis of autism".
- **On the importance of lived experience:** "...it is important to give adults that self-identify as autistic in clinical settings... the opportunity to express in their own words the main strengths and difficulties they experience in real life".
- **On the benefit of self-discovery:** "The majority of adults... considered self-identifying as autistic to be beneficial, from a personal perspective, because it had a positive influence on understanding who they really were".
- **On the need for new tools:** "...there are currently no neurodivergent-friendly (complementary) clinical tools in the referral and diagnostic process of an adult autism assessment, that have been developed and validated in the UK (or elsewhere) and consider the views of adults that self-identify as autistic".

## Sources



Video

Deep Research

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