

# Diagnostics for adults with possible autism: Good Practice

Jeremy Parr  
Newcastle University

@jeremyrparr

Jeremy.Parr@ncl.ac.uk



Employed by Newcastle University; I work in the publicly funded UK National Health Service (NHS); 20 years clinical research experience; no lived experience

Various sources of clinical research funding – including from Autistica; NIHR, and NHS England; my employment is not directly reliant on funding

I will present results from a number of research papers describing research we've undertaken in Newcastle

I will mention some measures we have designed and evaluated, available from us 'not for profit'

**Clinical and research priorities: Improved diagnosis; improved identification and treatment of co-occurring conditions**

**Some solutions to barriers to accessing health care, and overcoming these**

**High quality diagnostic services: What does a high quality service provide? What about post diagnostic services?**

**Opportunities for change: The Autism Clinical Interview for Adults as part of an autism assessment**

Priorities for autistic people: Improved diagnostic assessments, and post diagnostic support; better mental health and other interventions; access to healthcare; improved wellbeing and quality of life (Newcastle meeting 2014; James Lind Alliance, 2016)

Autistic people are more likely to:

- Experience co-occurring conditions, in addition to autism. For example, anxiety, depression (and other mental health conditions), sleep difficulties and other conditions (e.g. UK data from >2000 autistic adults (Newcastle) – 50% anxiety across the lifecourse; 80% 1 or more mental health conditions; 25% sleep difficulties across adulthood) (Petrou, Brice 2022)
- Co-occurring conditions affect quality of life – and many can be treated

## A Systematic Review of What Barriers and Facilitators Prevent and Enable Physical Healthcare Services Access for Autistic Adults

### Mason: Three key areas identified across studies:

1. Challenging interpersonal communication with providers
  - Literal thinking
  - Lack of empowerment of autistic people
2. Limited knowledge of autism
  - Negativity in relation to autistic people
  - Lack of training opportunities
3. Sensory sensitivities
  - Waiting room to clinical area

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## How to improve healthcare for autistic people: A qualitative study of the views of autistic people and clinicians

Autism  
 2021, Vol. 25(3) 774–785

Autistic adults	Health professionals	Shared by both groups
Cognitive factors	External service availability	Healthcare access and adjustments to healthcare provision
Patient characteristics	Within service healthcare resources / constraints	
Healthcare professionals		Autism diagnosis affects provision

## Reasonable adjustments needed to access services

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The importance and availability of adjustments to improve access for autistic adults who need mental and physical healthcare: findings from UK surveys

*BMJ Open* 2021;**11**:e043336. doi:10.1136/bmjopen-2020-043336

### **Brice - Three main areas of adjustments needed:**

- Sensory environment
- Clinical and service context
- Clinician knowledge and communication (access to a clinician willing to adapt their approach particularly important in mental health services)

**Adjustments to healthcare important *but rarely available* – yet we live in an era of personalised health care...**

**‘Autistic people confirm the importance and limited availability of adjustments in current UK healthcare provision. To address this unmet need, healthcare managers and providers must offer adjustments as part of a personalised approach in order to tackle the health inequalities faced by autistic people’**

‘These adjustments do not require expensive technology or equipment but rather ongoing staff training, attention to aspects of the clinical settings and flexibility in ways of delivering clinical care’

**‘If adjustment interventions are effective, implementation across health care settings will likely ensure improved access to usual healthcare for autistic people, and improvements in health, quality of life, and life expectancy may follow’**



**NICE** National Institute for  
Health and Care Excellence



## Autism spectrum disorder in adults: diagnosis and management

Clinical guideline  
Published: 27 June 2012  
Last updated: 14 June 2021

[www.nice.org.uk/guidance/cg142](http://www.nice.org.uk/guidance/cg142)

## A National Guideline for the Assessment and Diagnosis of Autism Spectrum Disorders in Australia

### Summary and Recommendations

Prof Andrew Whitehouse, Dr Kiah Evans, Prof Valsamma Eapen  
and A/Prof John Wray

The aim is to focus on:

- An autism spectrum condition or not? If not, another diagnosis?
- If autism, are there additional diagnoses as well? Learning disability, Developmental Coordination Disorder, mental health condition? Other co-occurring condition?
- Based on the conclusions what recommendations are needed re future support, treatments/interventions?

## What does a good autism spectrum assessment service include?

Starts with clear referral pathway into the service; self-referral. Enough capacity and timely assessment – providing reasonable adjustments needed

The right expertise – ideally multidisciplinary team assessment, focusing on the person strengths, difficulties/differences in the context of an assessment of possible autism.

## What does a good autism spectrum assessment service include?

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Story over time: autism spectrum characteristics; neurodevelopmental condition, so needs a discussion about adulthood, with reference to childhood/lifecourse; the person's opinion, and ideally view of another/others who know the person well

Direct observation: Some use ADOS, not needed for everyone; do need to meet the person face to face

Other assessment as needed: Speech/Language/Cognitive/Occupational Therapist/mental health

Conclusions: Expert opinion of the team – not about scores on an algorithm

A timely meeting to feedback; face to face if possible

A timely written report, including recommendations

Post diagnostic discussion – how to meet someone's needs

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55 year old female. Wonders whether she has autism – another family member recently diagnosed. Always struggled in the workplace and to ‘fit in’ – requests assessment, pre-assessment provides information about adjustments


Assessment: Interviewed about adulthood and when younger; older sister able to report about difficulties in the teenage years, and in younger childhood. Meets team face to face – seen by clinical psychologist, occupational therapist, other team members. Gives consent for discussion with employer

Autism spectrum diagnosis made – and also

- Attention Deficit Hyperactivity Disorder identified – considers treatment, alongside strategies
- Anxiety disorder diagnosed – receives modified Cognitive Behaviour Therapy
- Sleep always been a problem – onward referral, Obstructive Sleep Apnoea identified, CPAP

Reasonable adjustments requested of employer; better understanding her needs in the workplace. Better able to do job (more focus, able to manage anxiety better, sleep better, more energy). Happier, and employer happy too

## **A survey of autistic adults, relatives and clinical teams in the United Kingdom: And Delphi process consensus statements on optimal autism diagnostic assessment for adults**

Sarah Wigham<sup>1</sup> , Barry Ingham<sup>1,2</sup>, Ann Le Couteur<sup>1</sup>,  
Colin Wilson<sup>1</sup>, Ian Ensum<sup>3</sup> and Jeremy R Parr<sup>1,2</sup>

Autism

1–14

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**Table 2.** Final II statements describing characteristics of optimal autism assessment services for adults.

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#### Referral process/pre-assessment

- Services across primary, secondary and specialist care should have access to a clear pathway of how people can access a local autism diagnostic assessment service
- Autism diagnostic services should give an update to people on their waiting list, for example, when it is around 12, 6 and around 3 months until their assessment if resources are available
- Information on autistic characteristics and co-existing conditions should be sought from informants and clinicians, before the assessment takes place to allow individualised planning of the assessment process and to give clinical context
- Autism diagnostic services should provide information to people before their assessment such as directions, a clear description of what will happen during the assessment, the environment and people they will meet (this may include photographs)


#### Diagnostic assessment

- There should be a separately resourced specialist multidisciplinary service within the 'secure estate' (e.g. prison, medium and low secure units) for diagnosis of autism and co-occurring mental and physical health problems
- As part of diagnostic assessment, with consent, services should always try to gather developmental and/or current information about social communication ability, rigidity/repetitive behaviours and co-occurring conditions. This could be from a family member or another person who knew/knows the person well (e.g. friend, tutor or employer)
- All autism diagnostic services should include someone trained in the use of a standardised observational tool, so it can be used if needed
- Training on use of standardised diagnostic tools should be available for autism diagnostic service members
- The core autism diagnostic multidisciplinary service should include a clinician with expertise identifying mental health conditions

#### Training/consultancy

- Delivering training to others should be part of an autism diagnostic service's commissioned service specification (as opposed to being ad hoc)
- A national network of multidisciplinary health professionals who work in autism diagnostic services should be created. There should be opportunities for meetings focusing on topics such as exchange of ideas, peer support and information sharing

## Consensus statements on optimal adult post-autism diagnosis support and services: Delphi process following a UK survey of autistic adults, relatives and clinicians

Sarah Wigham<sup>1</sup> , Barry Ingham<sup>1,2</sup>, Ann Le Couteur<sup>1</sup>, Colin Wilson<sup>1</sup>, Ian Ensum<sup>3</sup> and Jeremy R Parr<sup>1,2</sup>

Autism

1–12

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**Table 2.** Statements describing optimal post-diagnosis service characteristics in rounds 1 and 2 of the modified-Delphi process.

	Round 1 (n=27)	% agreement	Round 2 (n=29)	% agreement
1	All adults who receive an autism diagnosis should be offered an additional follow-up meeting 2–4 months after the feedback meeting to discuss implications of diagnosis, coping strategies and future planning.	71	–	–
2	Services across primary, secondary and specialist care should have access to a clear pathway of how people can access a local autism post-diagnostic support service	85	–	–
3	Dedicated post-diagnostic autism services should be commissioned/ resourced separately to (but closely coordinated with) the autism diagnostic assessment service	34	Diagnostic teams should be commissioned and resourced to provide (in partnership with other agencies) post-diagnostic support	86
4	Core members of post-diagnostic autism services should include people with expertise in autism, from multiple agencies/specialists	85	–	–
5	Post-diagnostic autism support should be available in both 1-1 and/or group settings depending on the needs of the autistic adult	89	–	–
6	A diagnosis of autism should not limit access to community and/or inpatient mental health services.	96	–	–
7	Autistic adults should be able to access (community and specialist) mental health and physical health services that can provide the reasonable adjustments to meet their needs	96	–	–
8	Dedicated autism post-diagnostic services should include occupational therapy	85	–	–
9	Dedicated autism post-diagnostic services should include speech and language therapy	85	–	–
10	Autism post-diagnostic services should provide opportunity to access step on/off support to protect mental health and maintain well-being moving forward from diagnosis	85	–	–
11	All areas should have an autism champion to facilitate implementation of statutory guidance as part of the local strategic partnership network	74	–	–

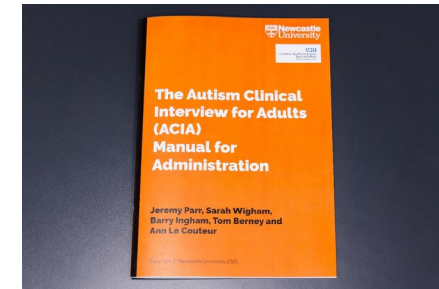
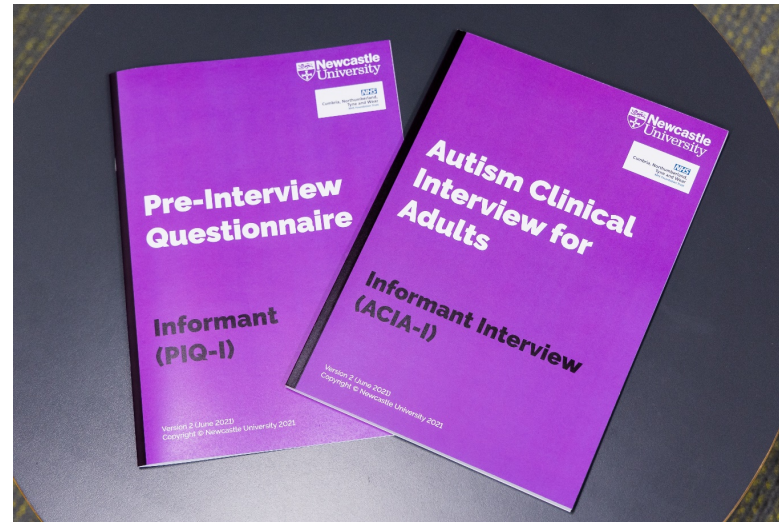
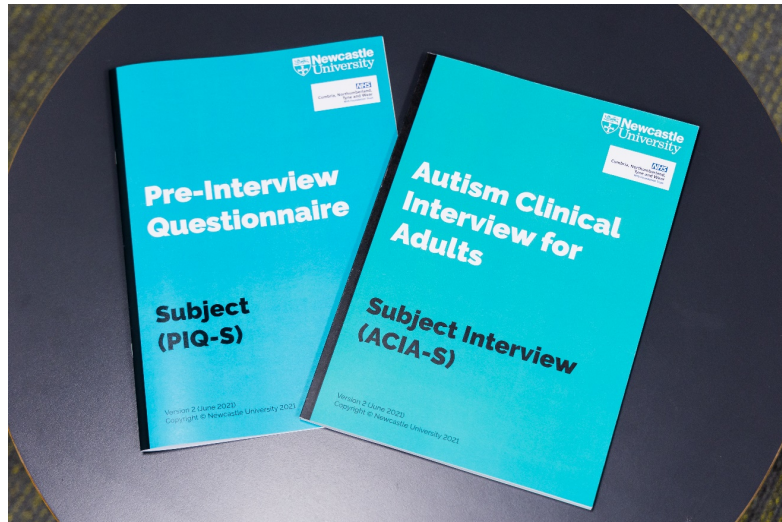


# Development and Initial Utility of the Autism Clinical Interview for Adults: A New Adult Autism Diagnostic Measure

Sarah Wigham, PhD,<sup>1</sup> Barry Ingham, DCLinPsy,<sup>1,2</sup> Ann Le Couteur, FRCPsych,<sup>1</sup>  
Tom Berney, FRCPsych,<sup>1</sup> Ian Ensum, DCLinPsy,<sup>3</sup> and Jeremy R. Parr, MD<sup>1,2</sup>

AUTISM IN ADULTHOOD  
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# The Autism Clinical Interview for Adults



1. **Pre-interview questionnaire (PIQ):**  
The aim of the PIQ is to gather some background information. It is designed as a self-report questionnaire to be completed by the subject prior to the ACIA-S interview.
2. **Autism Clinical Interview for Adults (ACIA):** This includes sections on:  
Personal details and background  
ASD characteristics [questions on core symptoms of ASD]
3. **Co-occurring Conditions Interview (CCI):** Designed to identify conditions that commonly co-occur with ASD and which may need further assessment.



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<https://research.ncl.ac.uk/neurodisability/ourstudies/autismclinicalinterviewadultstrainingacia/>

**Adjustments:** Understand the adjustments people might need, use them, reduce barriers to accessing services

**Diagnostic services:** Develop timely, reliable and valid diagnostic services; address inequalities in provision

**Post diagnostic support:** Provide high quality post diagnostic support for autistic adults

**Innovate in practice:** Make use of available evidence based methods of diagnostic assessment (e.g. the ACIA), and interventions (for example, anxiety – see workshop tomorrow)

## Thank you, and to...

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**Many autistic people, and relatives, supporters, carers**

**Professionals from child and adult healthcare services**

**Clinical research colleagues in Newcastle, across the UK and internationally**

**Research team:**

Colin Wilson  
Sarah Wigham  
Alex Petrou  
David Mason  
Samuel Brice

**Funders:**

Autistica

**Contact us:**

[ACIAtesting@newcastle.ac.uk](mailto:ACIAtesting@newcastle.ac.uk)

[Jeremy.Parr@ncl.ac.uk](mailto:Jeremy.Parr@ncl.ac.uk) @jeremyrparr