

# **Adults ASD Diagnostic Assessment and Post-diagnosis Service Provision Workshop**

**November 27th 2018, 1100–1700**  
**Exhibition Space**  
**Great North Museum: Hancock, Newcastle NE2 4PT**



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**Exhibition Space, Great North Museum: Hancock, Barras Bridge, Newcastle NE2 4PT**

**Directions:** The museum is opposite Haymarket Metro; or a 20 minute walk from Newcastle Central Station; or 20 minute taxi ride from Newcastle International Airport.

**Registration:** Please enter the Museum through the front doors. Staff at reception will direct you through the Museum where a staircase will take you up to register outside the Exhibition Space. Registration is between 1100–1130.

### **Workshop aims:**

- to disseminate the research findings to clinicians, and inform everyday clinical practice, and diagnostic and post diagnostic service design
- to disseminate information about a new adult diagnostic measure that can be used in clinical services
- to inform a report that we will make publicly available, including to clinical teams, autistic people, policymakers and commissioners

For the purposes of the meeting we will use the term autism to mean all autism spectrum conditions including Asperger syndrome.

The research has been led by clinical academics from Newcastle University and Northumberland Tyne and Wear NHS Foundation Trust, in collaboration with colleagues from across the UK. The research and workshop were funded by the UK autism charity Autistica.

We are expecting around 80 delegates. This includes some staff members from Autistica, and the research team. At a separate event, we will discuss the research findings with autistic people and hear their further views on service design. In early March 2019, we will meet with policymakers to feedback our findings and recommendations.

Thank you once again for attending. We hope you enjoy hearing about our findings, and future clinical research opportunities. We look forward to the discussions about current and future services.

### **The research team includes:**

Professor Jeremy Parr, Newcastle University; Northumberland Tyne and Wear NHS Foundation Trust (Consultant Paediatrician and Chief Investigator)

Dr Tom Berney, Newcastle University (Developmental Psychiatrist)

Professor Ann Le Couteur, Newcastle University; Northumberland Tyne and Wear Foundation Trust (Child and Adolescent Psychiatrist)

Dr Barry Ingham, Newcastle University; Northumberland Tyne and Wear NHS Foundation Trust (Consultant Clinical Psychologist)

Dr Sarah Wigham, Newcastle University (Clinical Research Associate)

Mr Colin Wilson, Autistic advocate

## **Programme**

1100 – 1130 Registration in the Exhibition Space, and refreshments

1130 – 1135 Welcome, housekeeping and aims for the workshop Professor Jeremy Parr

### **Session 1: 1135 – 1415 Pre-assessment and diagnosis services (Chair: Dr Ian Ensum)**

1135 – 1200 Findings from the autistic people and relative's surveys about diagnostic experiences Professor Jeremy Parr and Mr Colin Wilson

1200 – 1220 Findings from clinical diagnostic teams about current and future services Dr Barry Ingham and Dr Sarah Wigham

1220 – 1300 Round table discussions. In the light of the findings, what might optimal diagnostic services provide?

1300 – 1345 Lunch (including time for informal discussions and networking). Arrange taxi transport for 1700

1345 – 1415 2 minute feedback from each table, followed by discussion

### **Session 2: 1415 – 1600 Post diagnostic services (Chair: Professor Ann Le Couteur)**

1415 – 1435 Findings from surveys of autistic people, relatives and clinicians regarding post diagnostic service provision Dr Sarah Wigham, Dr Barry Ingham, Mr Colin Wilson

1435 – 1500 Round table discussion: How should clinicians contribute to post diagnostic services for autistic people?

1500 – 1515 Break to collect refreshments

1515 – 1600 2 minute feedback from each table, followed by discussion

### **Session 3: 1600 – 1700 Diagnostic measures (Chair: Dr James Cusack)**

1600 – 1615 Development and availability of the Autism Clinical Interview for Adults (ACIA): New informant and subject diagnostic interviews for use in UK clinical services Professors Jeremy Parr and Ann Le Couteur

1615 – 1645 Discussion: Further ACIA development, requirements for use in services, and provision of free training

1645 – 1700 Final summing up and close at 1700

## **Adults ASD Diagnostic Assessment and Post-Diagnosis Service: Study Summary**

The aims of this study were to: survey adults on the autism spectrum and relatives about their experience of diagnostic services. We also surveyed UK professionals who diagnose adults with autism, about current NHS diagnostic care pathways. Using information from the surveys, and discussion groups, the study aims were to investigate what people consider is the best way to assess and diagnose autism across NHS services.

In addition, the team carried out a review of the evidence underpinning measures currently used to diagnose autism in adults. Through links with local and national clinical services, the best combinations of measures were identified that are most effective for diagnosing autism in adults across the age and ability range.

Finally, during the study a new diagnostic interview was developed and piloted for use to identify autism in adults in situations when there is little or no early developmental history available.

The study was carried out by the Neurodevelopment and Disability Team at Newcastle University and was funded by the UK charity Autistica and Northumberland Tyne and Wear NHS Foundation Trust.

### **Autistica**

Autistica is the UK's autism research charity. They work with autistic people and their families to identify and address their priorities for research.

In 2016, Autistica revealed the autism mortality crisis to the world and now focus on developing evidence-led solutions to the health inequalities facing autistic people.

In 2017, they set up Discover, the UK's national network for autism research to bring the scientific and autistic communities closer together.

This year the Communiqué, Civil Society and Charity Times Awards each recognised Autistica as a 2018 Charity of the Year.

### **The Neurodevelopment and Disability Team**

The Neurodevelopment and Disability Team at Newcastle University includes clinicians and researchers who provide evidence about ways to improve the everyday lives of people with neurodevelopmental conditions, and their families.

Our research focuses on a wide range of conditions, and people's experiences across the life course. We strongly value children, adults and relatives who work with us in designing our research, and those who participate.

Newcastle University, Level 3, Sir James Spence Institute, Royal Victoria Infirmary, Queen Victoria Road, Newcastle Upon Tyne, NE1 4LP.

**We are grateful to the following organisations:** the UK autism research charity Autistica for funding the workshop and this research, which is part of the Autism Spectrum Lifecourse and Ageing Research Programme; and Northumberland Tyne and Wear NHS Foundation Trust, for Research Capability Funding.