

Adult Autism Spectrum diagnosis and post-diagnosis support

Monday 21st January 2019, 6.00-7.30pm

**Research Beehive (Old Library Building),
Newcastle University, NE1 7RU**



The Research Beehive

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The aim of the meeting is to present the findings from the research project about autism spectrum diagnosis in adults including our major national survey of more than 370 autistic adults and relatives.

During the meeting we will:

- Present the research findings about diagnostic services and post-diagnostic support
- Show what UK clinicians think are features of optimal autism diagnostic services for adults
- Seek your views on those optimal features of services, and the most important changes that could be made for autism diagnostic services for adults

After we have presented the research findings there will time for questions, and some time for discussion in small groups.

Your views in the discussions will help inform what we suggest to policy makers and other stakeholders on the ways autism diagnostic pathways for adults could be developed and improved.

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 was funded by the UK autism charity Autistica.

We are expecting around 40 delegates. This includes the research team.

Thank you once again for attending. We hope you enjoy hearing about our findings and the discussions.

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 LeCouteur, Newcastle University; Northumberland Tyne and Wear NHS 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

Meeting Itinerary

1730 – 1800	Arrival and refreshments
1800 – 1810	Welcome, housekeeping and aims for the meeting (Professor Jeremy Parr)
1810 – 1830	Findings from surveys of autistic people and relatives regarding diagnostic and post-diagnostic support (Colin Wilson and Jeremy Parr)
1830 – 1850	The views of UK clinicians on the features of optimal autism diagnostic services for adults (Dr Sarah Wigham & Dr Barry Ingham)
1850 – 1855	Short break*
1855 – 1915	Discussions in small groups
1915 – 1925	Time for any questions comments and views from the discussions to the wider group
1925 – 1930	Final summing up and close at 1930 (Professor Jeremy Parr)

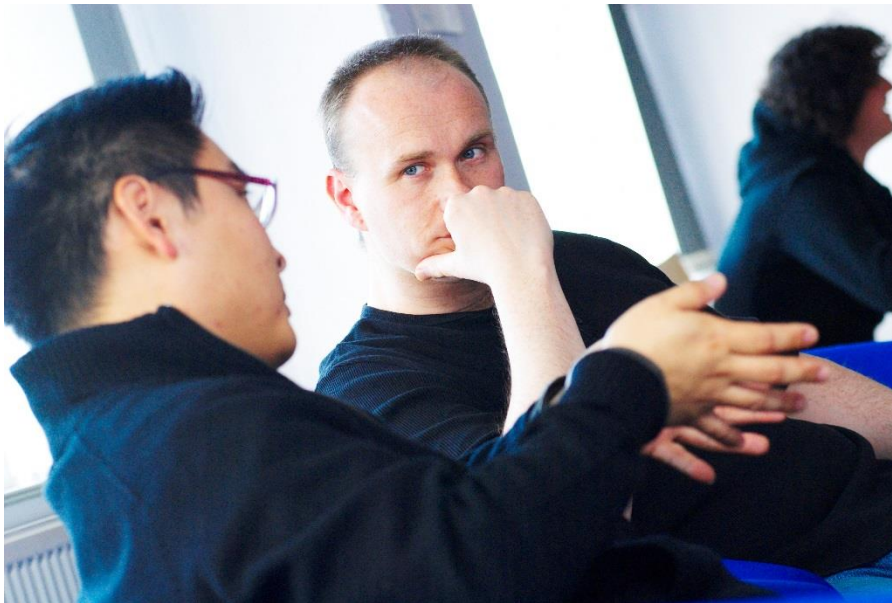


Photo Images: John Donoghue & Jim McAdam

*We understand that some people may like to come to the meeting and hear the results of the study but would rather not take part in the discussions. If you would rather leave before the discussions begin there will be a short break at 18.50.

There will be access to a quiet room during the meeting. There will be signs showing you how to get to the quiet room.

Directions

Research Beehive (Old Library Building) Newcastle University, NE1 7RU

The Research Beehive is on campus opposite Haymarket Metro; or a 20 minute walk from Newcastle Central Station.

Staff at reception will direct you to a staircase that will take you up to Level 2 to the meeting area where refreshments will be served between 1730 and 1800. There is a quiet room on Level 2 that you are welcome to use.

Entrance to the Research Beehive

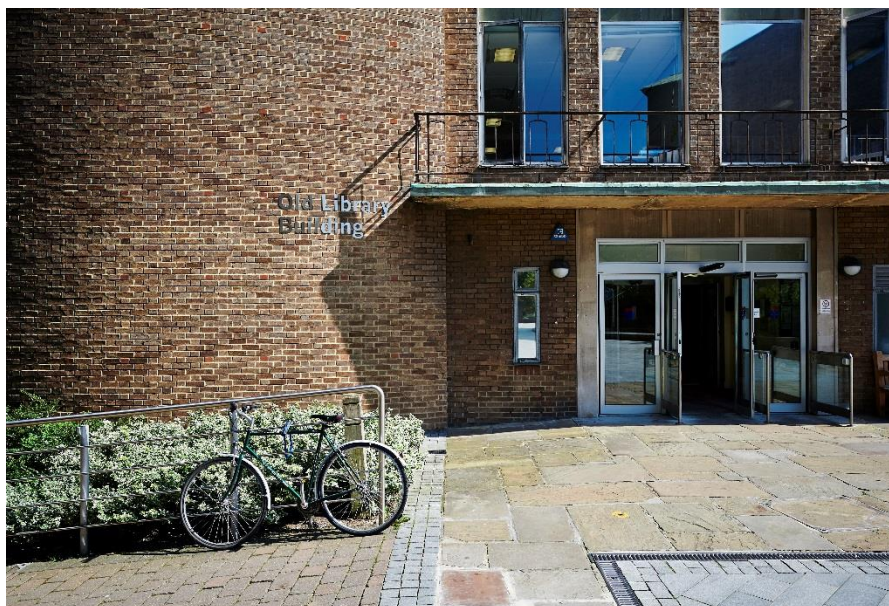
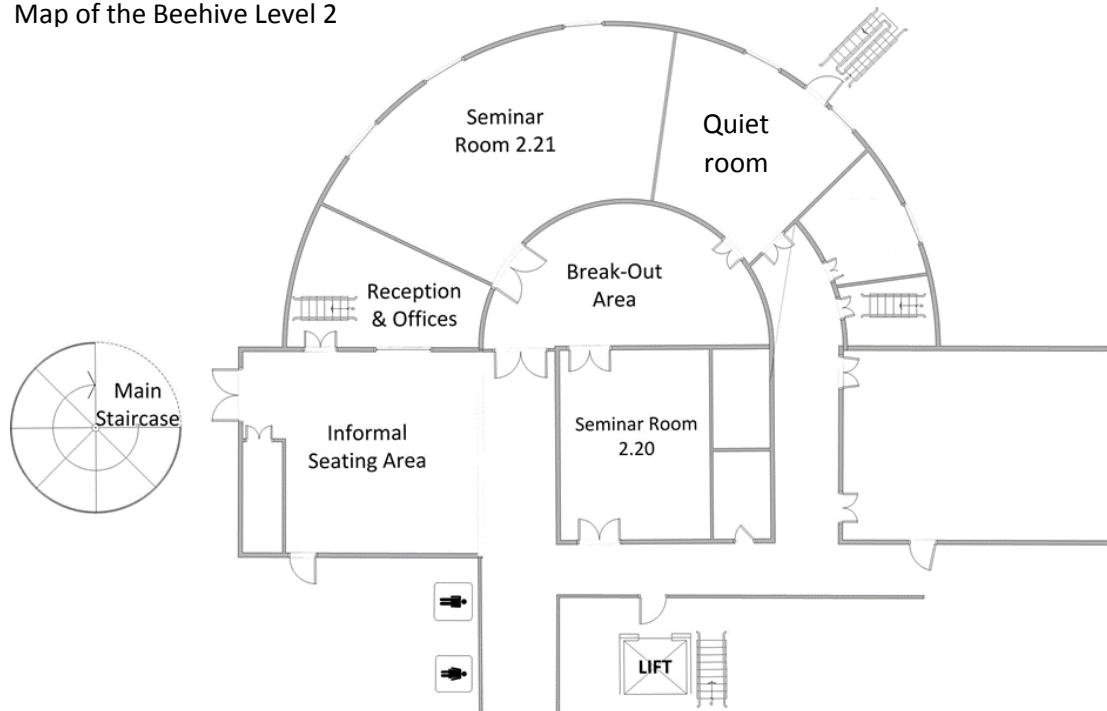


Photo Images: John Donoghue & Jim McAdam

Map of the Beehive Level 2



The closest bus and Metro station is Haymarket. Newcastle University is just a 20 minute walk or two stops on the Metro from Newcastle railway station. The red dotted line shows directions to the Research Beehive (Old Library Building) from Haymarket Metro and Bus station. Nearest Car Parking– Claremont Road (circled in blue) £1.30/hour. Please note, there is no car parking available on campus.



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.

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 this research, which is part of the Autism Spectrum Lifecourse and Ageing Research Programme.



Space for notes