

Hilary Gilfoy, Chief Executive, Autistica Speech at the House of Commons, 3 March 2010



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This is an historic day for those affected by autism. As the Minister has just described, the Government has fulfilled its commitment under the historic Autism Act to publish a strategy for meeting the needs of adults with autism in England. And the level of commitment shown in the strategy is something we should certainly celebrate, although it will be up to those in this room today to ensure that real and measurable change takes place.

However the very first commitment in the Autism Act and core element of the strategy – providing straightforward access to diagnosis – is indicative of the scale of the challenge to come as professionals with the skills and experience to do this are – as those here know – currently few and far between. And whilst building awareness of autism is rightly defined as key to the strategy, it is difficult to see how we can actually deliver this without knowing far more than we do now about autism in adults, or indeed about autism full stop.

It is of course possible to provide services for people with autism without this knowledge – it has been done in some form for more than forty years – but an improved evidence base would make the task more rewarding and effective for both service providers and recipients. I was struck by the observation in recent press coverage of the dementia strategy – with which the Minister is also very much involved – that the research spend on conditions such as dementia remained low because the burden of cost fell not on the NHS but on families and social services. Exactly the same is true of autism – indeed the ratio of state research spend to economic impact at 0.01% could not be more dramatic – or low.

But our task in Autistica is not to sit on the sidelines and complain. Our task is to raise – and stimulate – the funds necessary to fill the gaps in our knowledge. We believe that just as people with autism have the same right as all other citizens to appropriate public services, so they also have a right to a clear understanding of what autism is. Many people with autism and their families seek this understanding, as we know from their active participation in autism research.

And so today is historic for another reason, as we announce with great pride the results of our first call for proposals for pilot projects. This is the first ever such open call for research proposals by a charity in the UK, and to say that we were addressing an area of pent-up demand would be putting it mildly. We received 48 outline proposals from researchers in 24 different universities right across the UK and invited 20 researchers to submit full proposals. Of these four have been selected for funding at a total value of some £300,000 and we are delighted to announce these today.

The purpose of pilot projects is to explore promising ideas that either address new research questions or accelerate the research process on a small, test scale, before larger resources are committed. For us a key selection criterion is how well these drive towards answers that will directly benefit people with autism, and we have chosen projects that we believe have the potential to do this.

Each is different:

Dr Jeremy Parr at the University of Newcastle is piloting an Autism Research Register to underpin UK-wide autism research. The families of children with a recent autism spectrum diagnosis will be invited by child health teams in nine pilot areas to join the register, which will be both a valuable resource for researchers and enable large numbers of children with autism and their families to contribute to research. Early work in Newcastle has shown that around 50% of families are keen to do so.

Dr Janine Lamb at the University of Manchester is exploring whether variations in microRNAs – small molecules that regulate gene function including in brain development – might have a role to play in increasing risk for autism. This kind of research may help us to understand the biological basis of autism and potentially indicate new therapeutic targets and treatments.

Dr Joseph McCleery at the University of Birmingham will explore whether toddlers at risk for autism (those with a diagnosed older sibling) respond differently from other children to speech and non-speech sounds. This project, which builds upon the work of the British Autism Study of Infant Siblings will contribute to the development of methods for early detection and diagnosis of autism and language-learning delays.

And finally, Professor Peter Kind at the University of Edinburgh will extend his work on the single gene disorder Fragile X syndrome, which produces autism-like symptoms, to explore the point in brain development when loss of this key gene has greatest impact. This type of work provides valuable insight into the point when therapeutic interventions designed to address damaging alterations in brain function may be most beneficial.

We hope that when these pilot studies are completed in two years time they will each in their own way contribute to the better understanding of autism that we believe must go hand in hand with improved services if the vision for improved outcomes for people with autism enshrined in the Autism Act and Adult Strategy is to be achieved.

Thank you