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Date of publication: 3<sup>rd</sup> July 2013



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## **A Future Made Together: Shaping Autism Research in the UK**

Many of you will have either been involved in, know about or have used in some way research about autism – whether it has been coming up with a burning research question, helping to find participants, being involved as a participant or reading about the findings once the study is complete.

I am sure that all of you will agree that research on autism is critical to understanding autism, both its causes and its consequences, and that it has the potential to transform the everyday lives of those with autism and their families.

But how close does UK autism research come to living up to its promise?

My colleagues Tony Charman, Adam Dinsmore and I recently conducted the most comprehensive review of autism research in the UK ever undertaken. We set out to discover how much was spent on UK autism research and which areas were being addressed.

We also sought to know what *you* – the broader autism community – wanted from autism research. We consulted with over 1,700 autistic people, their families, practitioners and researchers to understand what they thought of current autism research in the UK and where the funds towards autism research should be prioritized.

Our Report highlights the many strengths of autism research in the UK but also notes considerable challenges in the years to come. One of these challenges was highlighted in a discussion with parents of children with autism. While they were impressed by the amount of work that goes into it, they were not convinced that research had made an impact on their lives.

One woman said:

*“I fill in all these questionnaires and do everything I can to help and there’s a very nice paper at the end with nice results and it’s like “great”.*

*“But when it comes down to it, it’s not real life. It’s always missing the next step. It’s great you’ve done this research, you’ve listened to my views, you’ve asked for them and I’ve given them to you ... but now do something with it.”*

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It turns out that too many people feel that there is a huge gap between knowledge and practice. It doesn't help their child catch the train by themselves or keep themselves safe. And it doesn't say how to get autistic adults into jobs and keep them there.

The people we spoke to said that they don't want to – or more often than not can't – read about research in academic papers. They want to see real changes and real things happening on the ground for them, for their child, or for the person they work with.

It turns out that, according to our analysis, British academics haven't been taking much notice of real-life issues.

We discovered that research in the UK is heavily concentrated on a few key areas. More than half of all autism research published and funded in the UK is devoted to understanding more about the underlying biology, brain and cognition of autistic people. Comparatively little research in the UK is conducted on identifying effective services for autistic people and their families, on diagnosis and interventions, or on societal issues.

Just like the parents in the discussion above, the majority of our respondents were generally dissatisfied with the pattern of current funding – it simply did not match up to their stated priorities. Instead, they want to see research prioritized on those areas that affect the day-to-day lives of autistic people and their families – research on public services, life skills, cognition and learning and the place of autistic individuals in society.

It is not that people do not value research on causes or on biological markers. They just want to see a more balanced profile of research, where research that has a direct impact on the daily lives of autistic people is weighted more equally with the core areas of basic science than is presently the case.

*How do we ensure that our research makes a difference to people's lives?*

Without doubt, we need significant investment in areas of autism research currently under-resourced in the UK. But in order to work out which areas need the greatest investment, we need to listen to what the community – what *you* – want from research.

Our Report showed that autistic people, their family members and practitioners are rarely actively engaged in the research process – in deciding how an issue is researched, how it becomes funded, who undertakes the research and so on. It turns out that us researchers need to connect more with the people that we “study”. And the autism community needs to become more involved at all stages of the research process, including in helping to set the research agenda.

Network Autism has a huge part to play in this “future made together”. It is a place where practitioners, clinicians and educators who work with autistic children, young people and adults on a daily basis come together to discuss good (or not-so-good) practice, to enhance knowledge about autism and simply to connect. It is also a place where researchers can go to find out what matters, to understand what the right priorities are, and to make sure that the research that we do in the UK really counts.

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