



# **A FUTURE MADE TOGETHER**

**SHAPING AUTISM  
RESEARCH IN THE UK**

# Executive summary



Autism directly or indirectly affects millions of people's lives in the United Kingdom. There have been several legislative, policy and service initiatives in recent years aiming to improve the life-chances of autistic people. Autism research has also taken great strides toward understanding autism, its causes and its consequences. This research if put into practice has the potential to transform the everyday lives of those with autism and their families.

Yet there remains a huge gap between knowledge and practice, which means that, for the most part, the advances in research fail to impact upon those who need them most: autistic people, their parents and carers and those who help support them. Many autistic people also feel they are unaware of what is being researched, what the key findings are and who gets to set the future research agenda.

This Report, commissioned by the UK charity Research Autism, aims to describe the current landscape of autism research in the UK, embedded within an international context, and to compare the nature of the research being conducted with the views and perspectives of key stakeholders, including autistic people, family members, practitioners and researchers.

## Methods

We set out to achieve these aims through detailed research and through direct consultation. We surveyed the

funding portfolios of 20 UK grant-giving organisations for the period of 2007 – 2011 and analysed over 6,000 journal articles published in 2001 or 2011.

More than 1,600 people responded to an online survey designed specifically for the project and more than 70 people spoke to us in-depth, either face-to-face or on the telephone. They told us about what they thought of current autism research in the UK and where the funds towards autism research should be prioritised.

## Key findings

The Report confirms that UK autism research output in terms of journal publications has grown dramatically over the past 10 years, with the number of articles doubling between 2001 and 2011. Funding for autism research has also risen. UK research organisations awarded almost £21 million spread over 106 research projects between 2007 and 2011.

The Report also shows, however, that the UK lags behind some other countries, with the average research spend per autistic individual being 18 times higher in the US than in the UK. Growth in autism research activity is also slower in the UK than it is in the US and other parts of the world and is heavily concentrated on a few key research 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 diagnosis, treatments and interventions, services, and societal issues.

The Report further shows that the UK autism community is critical of this research concentration. Two-thirds of all stakeholders were either dissatisfied or very dissatisfied with the pattern of current funding for UK autism research. There was broad consensus among autistic people, family members, practitioners and researchers that future research should be prioritised 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. They called for a more balanced profile of research, weighting research with a direct impact on the daily lives of autistic people more equally with core areas of basic science than is presently the case.

## Conclusions

We need greater investment in UK autism research, particularly in those areas that matter to autistic people, their families and those who work with them. We need to work together to know what matters, to ensure we set the right priorities, and to make UK autism research really count.

**The future of UK autism research must be made together.**

## Key recommendations

Given the discrepancy between the nature of the research currently funded and conducted in the UK and the priorities of the broader autism community, the Report stresses the need for researchers and research funders to work more collaboratively in future with the autism community in order to advance progress in UK autism research and make a real impact on the lives of autistic people and their families.

As such, the Report outlines three specific recommendations.

**1** We need significant investment in areas of autism research currently under-resourced in the UK, without undermining the centres of excellence that already exist. Research must be targeted towards enhancing the life chances of autistic people, including research into how autistic people think and learn, what the best ways are of promoting life skills and helping to identify effective public services.

**2** We call for greater strategic coordination, improved dialogue and joint agreement of funding priorities between research funders, researchers and the broader autism community. This can be achieved through the formation of a body with strategic oversight and by encouraging partnerships between researchers in well-established areas and those in other areas currently less well supported in the UK.

**3** While formal partnerships may take some time to be established, greater efforts can be made immediately by individual autism researchers and research funders to involve autistic people and the broader autism community in the design of research, in its conduct and in the translation of its findings to issues of everyday, practical concern.



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