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A FUTURE MADE TOGETHER

**SHAPING AUTISM
RESEARCH IN THE UK**



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RESEARCH IN THE UK

Liz Pellicano,
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and Tony Charman

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Foreword



As someone who has campaigned over many years to achieve better outcomes for people with autism, I am delighted to be writing this foreword. This report presents a robust and detailed analysis of autism research in the UK and internationally, alongside the views of autistic people and their families about what the research agenda means to them. The research team has analysed several thousand sources of data and collated the views of many hundreds of people. In building the most comprehensive picture yet of the autism research landscape, the report provides a real opportunity for progress and change.

We are facing challenging times: there are increasing financial constraints and funding cuts; many organisations are being asked to do

more for less; and there is fierce competition for limited resources. It is also a time for the autism community as a whole – autistic people, families, researchers, policy makers and others – to grasp the opportunities presented by the heightened interest in, and awareness of, autism.

It is therefore vital that we have available the best possible information in order to make informed decisions about future investment in autism so as to make a tangible, positive difference to people's lives. And I firmly believe that A Future Made Together provides just that.

I commend Research Autism for commissioning this seminal report, and the research team of Professor Tony Charman, Dr Liz Pellicano and Adam Dinsmore for producing a high quality report which makes such a rich contribution to the autism research agenda.

Baroness Browning
Patron, Research Autism
Vice President, National
Autistic Society

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.

Preface



The charity Research Autism was established following a project conducted a decade ago to provide an initial mapping of UK autism research activity.¹ As a 10-year follow up, Research Autism commissioned Professor Tony Charman (King's College London, Institute of Psychiatry), Dr Liz Pellicano and Adam Dinsmore (Centre for Research in Autism and Education, Institute of Education, University of London) to lead the research upon which this Report is based. The authors are solely responsible for its content, including any errors or factual inaccuracies.

We are very grateful to our funders, the Inge Wakehurst Trust, the Charles Wolfson Foundation and The Waterloo Foundation, to Sir Christopher Ball

for spearheading the fundraising for this project, to our partners, Deepa Korea, Richard Mills and Helen Finch at Research Autism, and to members of the Advisory Group: Chris Atkins, Virginia Bovell, Baroness Angela Browning, Barry Carpenter, James Cusack, David Ellis, The Goth, Sarah Shenow, Helen Pearce and Simon Wallace.

We are also indebted to the autistic adults, parents of autistic children, headteachers, teachers, SENCOs, practitioners, clinicians, academics and funders who so graciously gave up their time to take part in the survey, focus groups or interviews. In particular, we would like to thank ADHD and Autism Support Harrow, London Borough of Barnet Autism Advisory

Team, Merton Mencap, the National Autistic Society's West London Branch, Phoenix School, Queensmill School, and the Pan London Autism Schools Network (PLASN).

Thanks also to all those who made this research and the Report come together: to Janina Brede and Rebecca McMillin for assistance coding thousands of articles, to Erica Salomone and Mark Taylor for help during the focus groups, to Dan Sinclair for design and production, to Simon Baron-Cohen, Virginia Bovell, Patricia Howlin, Jane Lewis, Damian Milton and Marc Stears for helpful comments on a previous draft of this report, and to all the individuals, families and schools who contributed photographs to this report.

Abbreviations

APPGA

All Party Parliamentary Group on Autism

ARM UK

Autism Rights Movement UK

ASD

Autism Spectrum Disorder

CSO

Chief Scientist Office

DfE

Department for Education

DH

Department of Health

DSM-IV/DSM-5

Diagnostic Statistical Manual of Mental Disorders 4th/5th Edition

EPSRC

Engineering and Physical Sciences Research Council

ESRC

Economic and Social Research Council

IACC

Interagency Autism Coordinating Committee

ICD-10

International Statistical Classification of Diseases and Related Health Problems 10th Edition

IMFAR

International Meeting for Autism Research

MRC

Medical Research Council

NAS

National Autistic Society

NICE

National Institute for Health and Care Excellence

NIHR

National Institute for Health Research

OARC

Office of Autism Research Coordination

Introduction

Setting the Scene

Autism affects the way a person interacts and communicates with others and experiences the world around them. 1 in every 100 people in the UK is on the autism spectrum. This means if you are not autistic yourself, you will know someone who has autism, whether they are your son or daughter, your mother or father, your cousin or neighbour or your colleague or pupil.

Despite the high prevalence of autism the opportunities and life-chances for autistic people remain often severely limited in comparison with the non-autistic population. Autistic people are less likely to have a well-paying job than non-autistic people, many have problems in their social lives, with a limited number of friends outside their immediate family, and many also struggle with their health and their material well-being.^{2,3} In a time of shrinking public services, many autistic people and their families also worry that the services that have made their lives more manageable are in danger of being reduced.⁴

Two recent developments have promised to improve this picture.

First, policy-makers have begun to be more alert to the specific concerns and requirements of the autism community. In the UK, this has been reflected in several public policy and service developments, including the Autism

Act 2009 and similar policy initiatives in the devolved authorities in Scotland, Wales and Northern Ireland, the 2010 Department of Health Adult Autism Strategy, and the suite of three guidelines from the National Institute for Health and Care Excellence (NICE) on the identification, diagnosis and management of autism in children, young people and adults.

Second, academic researchers have begun to learn more about autism itself and have secured greater amounts of funding to be able to accelerate their work. It is increasingly suggested that research is on the edge of some major 'break-through' moments, capable both of enhancing our understanding of the nature of autism and of enriching the lives of autistic people and those who care for them.

It is the second of these developments that provides the subject for this Report. For although it is widely suggested that research into autism is capable of making a real difference to the well-being of autistic people, very little is yet known about how that might happen or whether autistic people themselves, their families, friends and carers share in that optimism. In fact, remarkably little is known at all about what research is being conducted in the UK, how it relates to the real-world concerns of autistic people and how it might be shaped more effectively in the future.

It is to that end, therefore, that our first aim is to present the first detailed overview both of what research is currently being conducted and funded in the UK and to compare that with the research conducted and funded elsewhere, especially in the United States.

Our second aim is to establish how directly that research maps on to the concerns and interests of autistic people themselves and the broader autism community.

It is our belief that this is a vital first step in ensuring that the research that is conducted and funded here in the UK is able to contribute not only to expanding our knowledge about autism but also to enhancing the opportunities and enriching the lives of those who

are autistic or who in other ways live with autism.

About this Study

A very large proportion of autistic people and their families will have



participated in academic research at some point in their lives, either as children in educational studies or psychological investigations or later as adults participating in projects examining medical phenomena or, occasionally, public service delivery. Often, however, the results of these projects and their consequences for both scholarship and the future of autism services remain unknown by participants. Some individual research projects in autism hit the headlines and gain widespread public attention. But many others go largely unreported by the media, although they can have significant impact in the scientific world.

In 2004, partly to respond to this lack of awareness, a report was published titled *Mapping Autism Research: Identifying UK Priorities for the Future*,¹

which captured both recent and current research activity in the autism field and identified priority areas for future funding and research activity. This report found that while the UK was seen to have many strengths in autism research, funding and research activity into interventions and education and into family and service issues were severely lacking.

This current Report is the follow-up to that earlier study. It sought to be more comprehensive and far-reaching in its approach.

The main objectives were:

1. To provide a systematic summary of the current state of UK autism research both in terms of research funded (grants awarded) and research output (published articles) and to make comparisons with

research activity internationally, especially in the US.

2. To conduct a large-scale consultation with a broad range of stakeholders, including autistic people, their families, practitioners and researchers about their research priorities, via online surveys and more in-depth interviews and focus groups.

About the Methods

There are several channels through which UK researchers can obtain funding for autism research:

- Competitive grants through government research organisations (e.g., Economic and Social Research Council; Medical Research Council) and the National Health Service (National Institute for Health Research).

- Competitive grants through non-government, charitable organisations, which may be specific to autism (e.g., Autistica; Research Autism) or include autism as part of a broader portfolio (e.g., Wellcome Trust; Leverhulme Foundation; The Waterloo Foundation).
- Competitive funding via specific government tenders for autism-related research projects (e.g., projects funded by the Department of Health as part of the Adult Autism Strategy; Department for Education).

We searched and catalogued all funding awards made by these different channels between 2007 and 2011 in the UK and compared these to what has been funded in the US.

What is autism?

According to current diagnostic criteria, people with autism show a set of core behaviours or characteristics, including difficulties in social communication and rigid and repetitive ways of thinking and behaving.^{9,10} Unusual reactions to some sensations (such as the feel of clothes or the smell of perfume) are common,¹¹ as are co-occurring mental health problems, especially anxiety and attentional difficulties.¹²

There is, however, much variation in the way that children, young people and adults with autism manifest these different behaviours. Some individuals may also have a severe intellectual disability, while others will have average or advanced intellectual abilities. For some individuals,

spoken language is limited or absent altogether while for others, speech can be fluent, but their use of language to communicate with others can seem awkward and often one-sided to non-autistic people. Some individuals want to be around others and to have friends, while others prefer to be alone. The autism spectrum therefore includes children, young people and adults who vary considerably. In addition, the capabilities and difficulties of any individual will also change with age, waxing and waning as the person develops.

Autism can usually be diagnosed well before the age of 5 years. But some individuals, especially those with good language skills and of average or above-average intellectual ability, might not be identified as autistic until much later, making it even less likely

for their needs to be satisfactorily met. Autism is more common in boys and men (than in girls and women) but this sex difference is not well understood and one area of current interest is whether the presentation may be different in girls and women.

The core features of autism are thought to be underpinned by differences in various aspects of cognition, that is, the way that autistic people think and learn. Psychologists have pinpointed many strengths in autistic cognition, including the way that autistic people perceive, attend to, and remember certain types of information. Other research has highlighted difficulties in understanding and thinking about other people and other situations and in the ability to flexibly regulate thoughts and actions.

Research has not yet identified genetic or biological signature(s) for autism. We know that autism is a strongly genetic condition, which can consist of both heritable and sporadic (non-inherited) forms. In some cases, autism might be caused by non-genetic factors, but such instances probably account for only a small minority of cases.¹³

Although there are many treatments and interventions available for children, young people and (to a lesser extent) adults with autism, the reality is that many of these approaches have not been rigorously tried-and-tested and even in those that have, we do not know which approach works best for any individual.^{14,15}



We also surveyed UK autism research activity via research publications. We searched and analysed journal articles containing any of a selection of autism-related search terms in 12 online academic databases published in 2001 or 2011. This allowed us both to summarise the current state of UK autism research output and to compare it to what it was like 10 years earlier.

For these purposes, we defined primary research as activities that involve the collection and analysis of new data, or new analysis of existing data. The methods used can vary across research projects and disciplines and can include quantitative research (collection and analysis of numerical data), qualitative research (systematic enquiry into meaning, such as ethnography and case-study methods) or a combination of the two. Literature reviews, editorials and commentaries are considered to be secondary research and are therefore not included in our survey.

To gain an understanding of stakeholders' priorities for the future of UK autism research, we conducted in-depth interviews and focus groups with autistic people, parents of children with autism, autism practitioners and autism researchers and funders. The views and perspectives of a large number of stakeholders were also captured via an online survey. This exercise continues a much-needed dialogue between these communities and researchers. Their responses have the potential to shape the future of UK autism research.

At present, research priorities are largely set within individual organisations. They are influenced by researchers' intellectual interests, peer reviewers' views and interests, the amount of research capacity in a particular area and, to varying degree, the interests of key stakeholders.

Each organisation currently has its own processes to help with setting

priorities. Unlike in some other countries, for UK autism research, there is currently no high-level systematic process for identifying and coordinating autism research across organisations to ensure that funds are directed to areas where they are most needed and can make the most impact.

Research efforts have been more strategic in the United States^{5,6}. The Interagency Autism Coordinating Committee (IACC) was established through The Children's Health Act of 2000. The IACC is responsible for establishing priorities, communicating trends, monitoring autism-related activities, and developing a strategic plan for autism research through extensive consultation with federal agencies, scientists, advocacy and research organisations, autistic people and their families and the general public. On the basis of these activities, the IACC makes regular recommendations for autism research funding to the US federal government.

In 2010, the IACC published its *Strategic Plan for Autism Spectrum Disorder Research*, organised around critical areas related to biomedical and services-related research, which were identified as being important to autistic people and their families. It has since published two key documents, one comprehensive analysis of the funding portfolio of major US federal agencies and private organisations in 2010⁷ and a second thorough evaluation of autism-related English-language research articles published globally between 1980 and 2010⁸. Throughout this report, we refer to the findings of both IACC reports and make direct comparisons between autism research activity in the UK and that of its major comparator, the US.

About the Report

This report is structured into 3 chapters and a conclusion.

The first chapter describes the results from the survey of UK funding for autism research. The second presents the findings from the analysis of autism research publications. The third provides an overview of the findings from the extensive consultation with stakeholders. The conclusion further summarises the findings and offers recommendations, highlighting key strategic messages.

This Report is aimed at the research community, the autism community and people who work with them on a daily basis, and the public. Research has the potential to transform the lives of autistic people and their families. Only by working together can we find the common ground between what is good for autism research and what is in the best interests of the autism community.

Terminology

Autism: This term refers to the condition of all children, young people and adults who fall on the autism spectrum, including those meeting diagnostic criteria for childhood autism, Asperger syndrome, atypical autism and pervasive developmental disorder (in DSM-IV) and autism spectrum disorder (in DSM-5).

Autistic person and person with autism: The term "autistic person" is the preferred language of many people on the spectrum. In this report, we use this term as well as person-first language to respect the wishes of all individuals on the spectrum.

Stakeholder: anyone with an interest in autism research.

UK autism community: This term refers to those UK residents who are autistic themselves, who care for those with autism, or who work with autistic children, young people and/or adults.

A History of Autism: Key Dates

“A unique syndrome”

1943: Leo Kanner, working in Johns Hopkins Hospital in Baltimore, USA, describes a unique syndrome, 'infantile autism' in 11 children with autism.

Asperger Syndrome

1944: Hans Asperger, working in Vienna, describes 'autistic psychopathy' in a series of intellectually able children, which later becomes known as Asperger syndrome.



Theory of mind

1985: Simon Baron-Cohen, Alan Leslie and Uta Frith (London, UK) propose that autism is caused by fundamental problems in theory of mind.

DSM-III

1980: DSM-III recognises infantile autism under the umbrella of pervasive developmental disorders.



Early research

1965: Michael Rutter publishes his first peer-reviewed paper on 'childhood psychosis'.

1962: The UK parent-advocacy group, now known as the National Autistic Society, is founded.



NAS formed

1970: London-based researchers, Neil O'Connor and Beate Hermelin, provide the first in-depth study of the psychological features of children with autism.

Autistic perception

1977: The first twin study by Michael Rutter and Susan Folstein shows that autism is highly heritable.

“Highly Heritable”

DSM-IV Revision

1994: The diagnostic criteria for autism are broadened once more in the fourth revision to the DSM (DSM-IV).



Autism journal founded

1997: *Autism: The International Journal of Research and Practice* is founded, in association with the UK's National Autistic Society.



False MMR Link

1998: The immediately controversial and now retracted Wakefield study is published, which suggests a possible causal link between the MMR vaccination and autism.

“The Autism Spectrum”

1996: Lorna Wing coins the term “autism spectrum” to describe the wide variability in symptom presentation.

“Don’t Mourn For Us”

1993: Autistic self-advocate Jim Sinclair challenges the notion of ‘autism as tragedy’ in his widely acclaimed paper titled “Don’t Mourn For Us”, presented at the Autism Network International.

1991: Uta Frith provides the first-ever English translation of Asperger's 1944 paper.



Frith translation

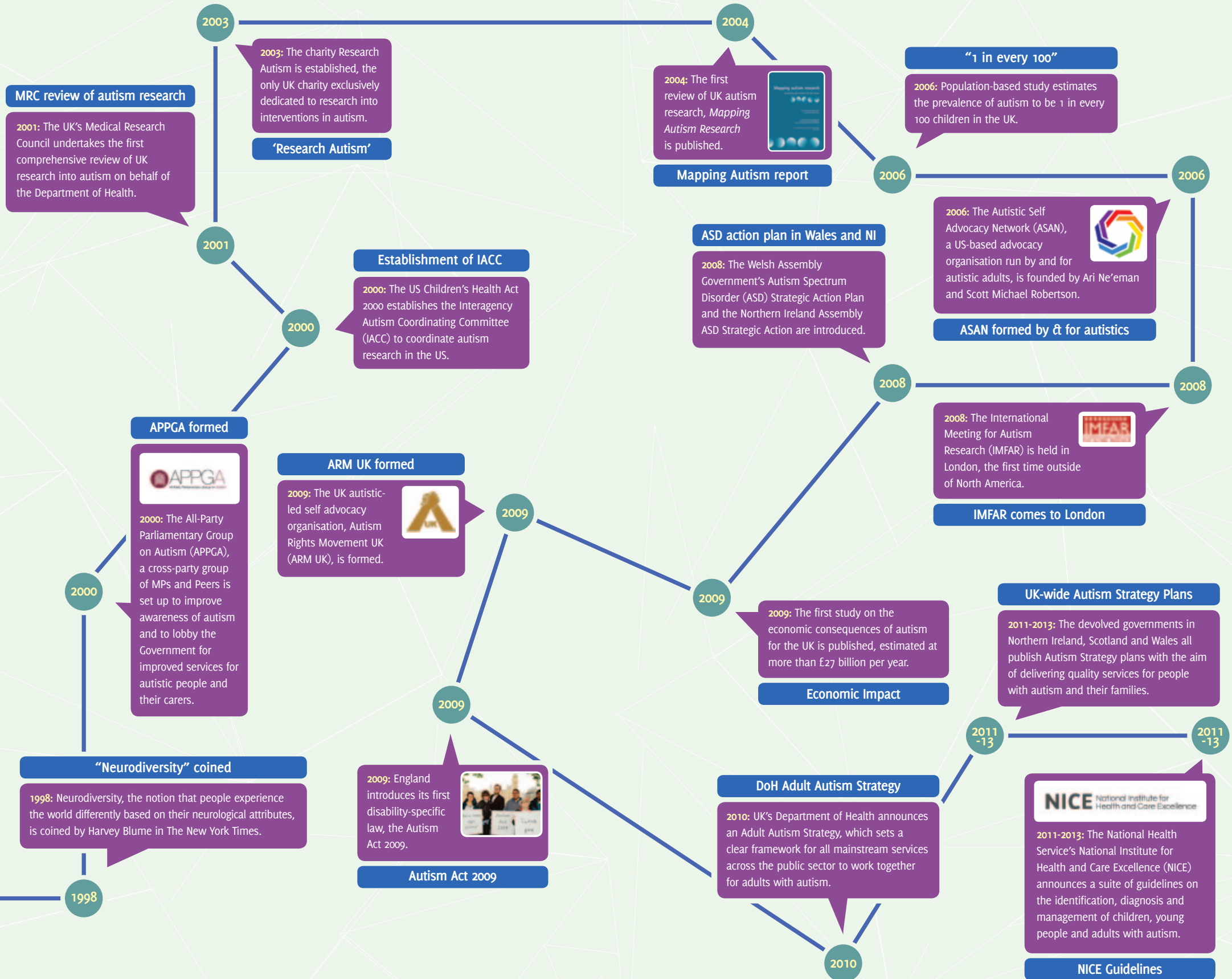
1987: The revised DSM-III broadens the definition of autism, which becomes known as 'autistic disorder'.

Autistic Disorder

1989: World Autism Awareness Day is celebrated for the first time, before being designated by the United Nations' General Assembly in 2007.



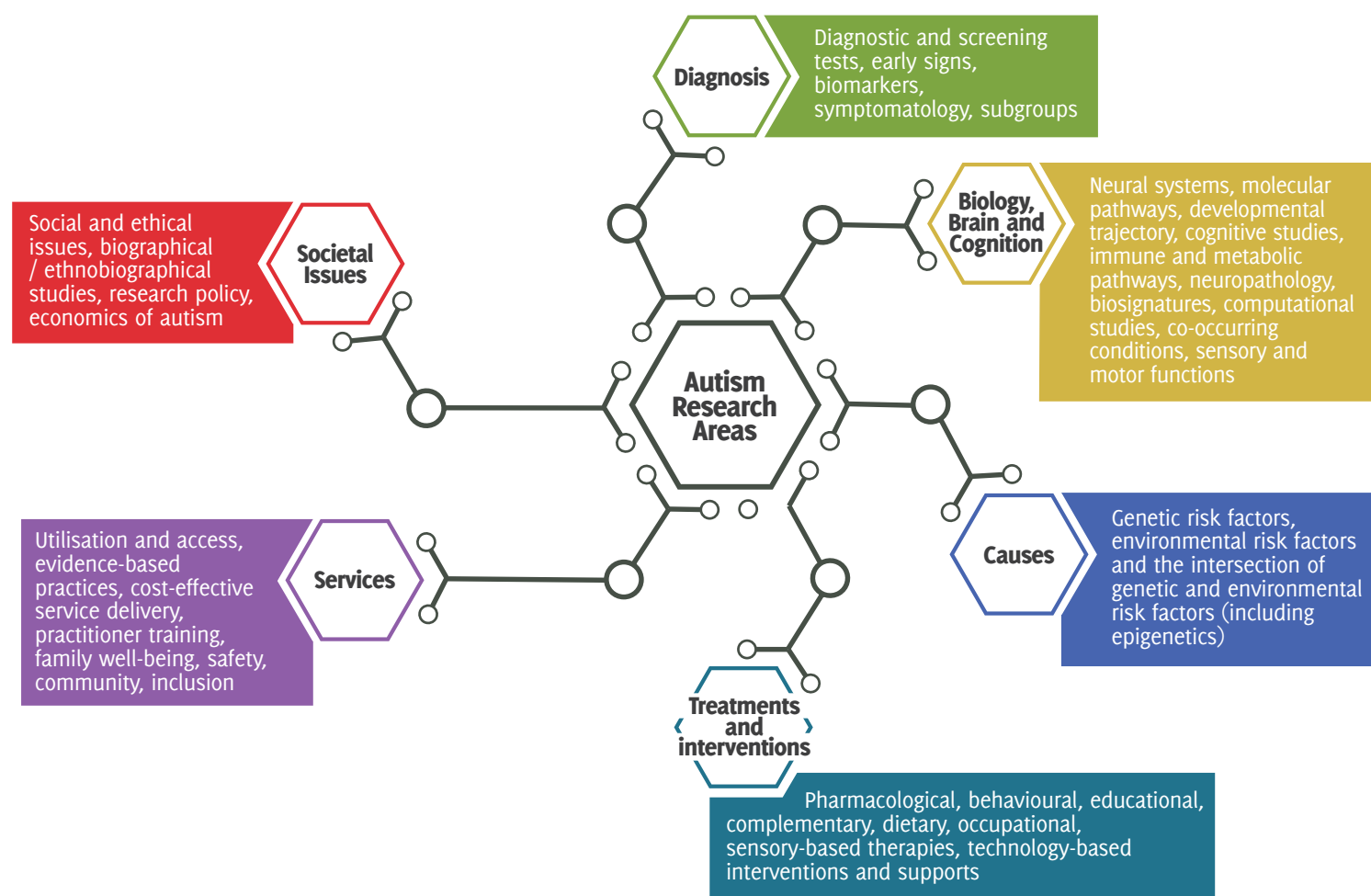
World Autism Awareness Day



Key areas of autism research

One of the primary aims of this report was to provide knowledge of the current landscape of autism research across the UK – that is, what type of research is being funded and published. We therefore developed a taxonomy of research areas, which drew heavily on the research questions from the US's 2011 IACC *Strategic Plan for Autism Spectrum Disorder Research*^{5,7,8} (see Appendix C for details of changes). These research questions were developed with extensive input from key stakeholders in the US, and their use allowed us to make comparisons between the UK and the US in terms of both research funding and research output.

There were 6 different research areas, shown opposite, which capture a range of different research topics. These research areas were broken down further to enable more fine-grained analysis. The full list of topics covered in each area is provided in Appendix C.



Autism research activity in the UK: funding



We conducted a comprehensive review of government and non-government funding for UK autism research. This review sought to answer three main questions:

1. How much UK autism research was funded between 2007 and 2011 and who funded it?
2. What areas of research are being addressed?
3. How does the pattern of UK funding compare to that of the world-leader in autism research, the US?

To begin, we systematically searched all publicly available (online) information for successful funding awards for autism-related research from 20 UK funding organisations. For each funded

project, we extracted the project title and abstract, the total amount of the award and, where possible, the age of the participants involved in the research. When this information was not available, we made direct contact with these agencies requesting access to such information (see Appendix A for details).

How much UK autism research was funded and who funded it?

Our search identified a total of 106 competitive funding awards made between 2007 and 2011. Over this period £20,829,118 was spent on autism research by UK funders, approximately £4 million per year. The total number of projects represents a significant increase on an earlier period (1996 – 2000) during which 46 projects were funded.¹ This increase is largely due to an expansion in investment in research generally^{16,17} and in autism research in particular by existing and new UK funders.

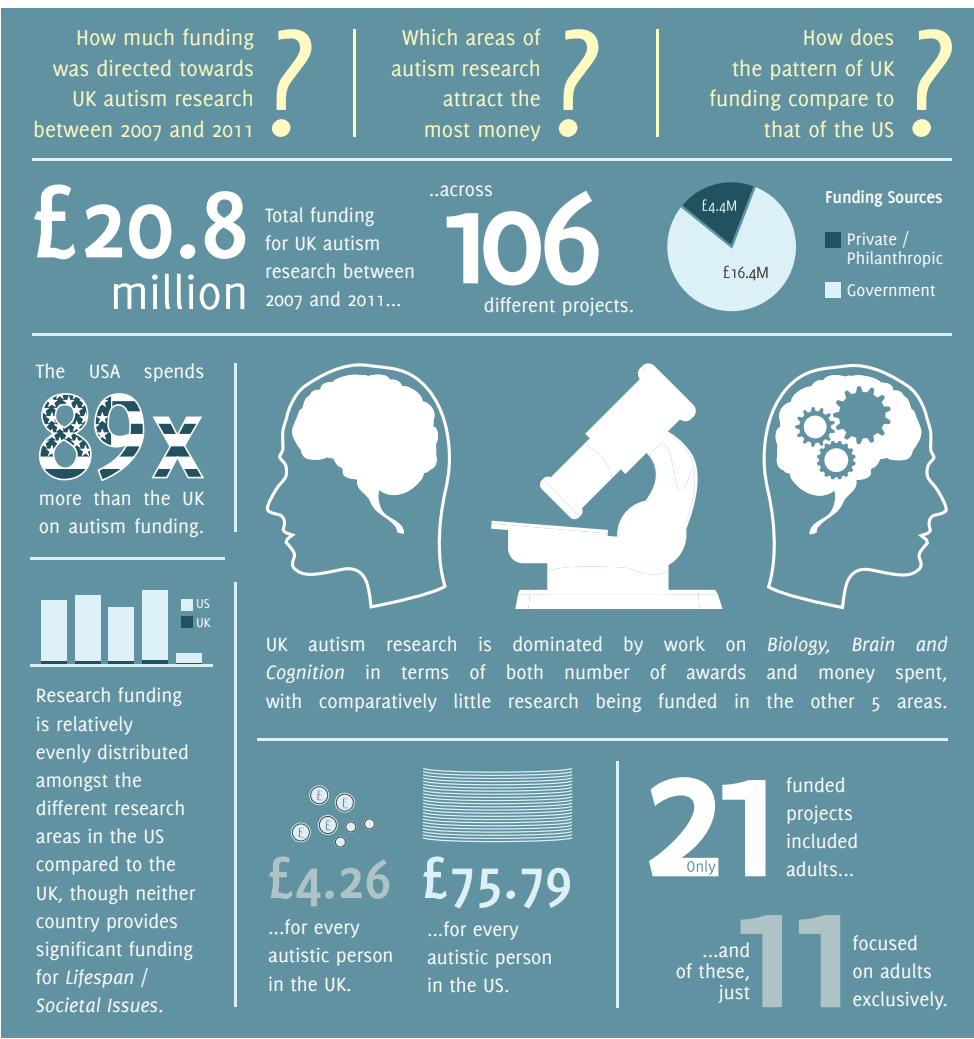
Table 1 shows how the funds are distributed across the various sources. The Economic and Social Research Council (ESRC) made more funding awards than any other organisation (total of 24) while the Medical Research Council (MRC) awarded more money for autism research than any other organisation (£8.7 million across the 5 years) and more money per grant than any other organisation (average of £791,000 per grant).

Government organisations provided £16.4 million (79%) between 2007

Table 1

Source of Funding	Projects funded	% of Funding	Total Funding
MRC [§]	11	42%	£8.7m
ESRC [§]	24	19%	£4.0m
DH/NIHR [§]	7	9%	£1.9m
Wellcome Trust [†]	9	8%	£1.6m
Autistica [†]	10	7%	£1.5m
British Academy [§]	16	3%	£0.6m
EPSRC [§]	1	2%	£0.5m
CSO [§]	6	2%	£0.5m
Waterloo Foundation [†]	10	2%	£0.4m
Research Autism [†]	5	2%	£0.4m
Nuffield Foundation [†]	3	2%	£0.4m
DfE [§]	1	1%	£0.2m
Inge-Wakehurst Trust [†]	3	1%	£0.1m

§ = Government Funding; † = Philanthropic Funding



and 2011 and private/philanthropic organisations funded £4.4 million (21%), a ratio that parallels the distribution of public/private funding for autism research in the US.⁷

The overall increase in number of projects funded suggests continued support for, and investment in, autism

research in the UK. But this investment is not on par with recent figures from the US. These figures show that, in 2010, the combined total spend on autism research (from public and private sources) was \$357 million (currently £234 million).¹⁸ In 2010, the UK spent just £2.6 million. When adjusted for population size, the amount spent on autism research



in the UK during 2010 was £0.04 per capita¹⁹ compared to £0.76 in the US.²⁰ When we adjust this figure again to examine amount of research spend per individual with autism, the UK spent £4.26 for every person with autism. The US spent £75.79 per autistic individual – 18 times the amount spent in the UK.

This pattern is in line with spending on research more broadly, where the UK's gross expenditure on Research & Development is below that of several key comparator countries, including the US, both proportionally and in absolute terms.²¹ Yet the differential gap in spending between the UK and the US in autism research is significantly higher.

What areas of research are being addressed?

To determine which areas of autism research were funded during 2007 – 2011, we conducted a content analysis of all 106 competitive grants. Grants were classified in terms of the area of research (see 6 categories on p.18-19) and the age of the participants involved in the research (e.g., children, adolescents, or adults). Figure 1 illustrates the breakdown of UK research grant funding for each area.

Funding awards in the area of *Biology, Brain and Cognition* far outstripped all other areas of autism research – both in terms of number of awards made and money spent. More than half (56%) of the UK grant expenditure for 2007 – 2011 went towards grants on *Biology, Brain and Cognition*, totalling £11.6 million spread across 60 research grants. These included grants on cortical development, social cognition and animal models of autism.

The next largest category of funding was *Treatments and Interventions*, making up 18% of all funding in the UK. A total of £3.8 million was spent on 14 projects in this area during the 5-year period, including grants on cognitive behavioural therapy, socially assistive technology and parent-mediated interventions. Fifteen percent of funding addressed the *Causes* of autism (£3.1 million), 5% of funding was devoted to research on *Services* for autistic people and their families (£1 million) and 5% was directed towards research on *Diagnosis, Symptoms and Behaviour*. Research into *Societal Issues* received the least total funding (£0.3 million), only 5 awards in total.

“As far as research is concerned, it is as if people on the spectrum don’t exist much after the age of 7.”

Autism researcher

How does the pattern of UK funding compare to that of the US?

If we compare the pattern of UK research funding between 2007 and 2011 to the pattern in the US in 2010,⁷ there are distinct similarities and differences.

As in the UK, the US research area receiving the most autism research funding in 2010 was devoted to understanding the underlying *Biology, Brain and Cognition* of autism (32%). Yet 2010 autism research funding in the US was more evenly distributed across the 6 research topics than in the UK (across 2007-2011), with the exception of funding for *Societal Issues / Lifespan Issues* for which funding was scarce in both countries. This difference in emphasis is likely attributable to the strategic oversight provided by the IACC in the US and the comparative lack of oversight in the UK.

Who was the research targeted towards?

We categorised each research grant according to the age of the participants taking part in the research. Of the 74 grants from which a target age could be clearly identified, the majority of these (71.6%) focused on children and adolescents. Only 21 projects (28.4%)

included adults and, of these, 11 (14.9%) focused on adults exclusively. Given that the majority of autistic people in the UK are adults, the proportion of research funding directed towards adulthood is low compared to that directed towards children and young people.

Key findings

- Total funding for UK autism research between 2007 and 2011 amounted to £20.8 million spread across 106 different projects, mostly focused on children with autism.
- The amount spent in the US on autism research in 2010 alone is 89 times that spent in the UK. This difference in investment is striking even when population rates are taken into account.
- Research funding is relatively evenly distributed amongst the different research areas in the US compared to the UK, though neither country provides significant funding for *Lifespan / Societal Issues*. UK autism research is dominated by work on *Biology, Brain and Cognition* in terms of both number of awards and money spent, with comparatively little research being funded in the other 5 areas.

Fig 1. Autism Research Funding by Research Category in the UK (2007-11)

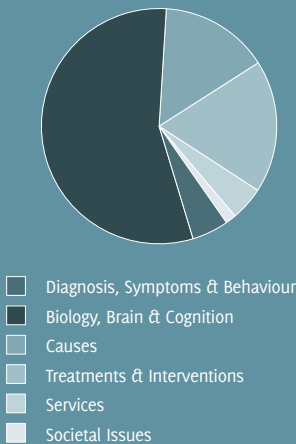
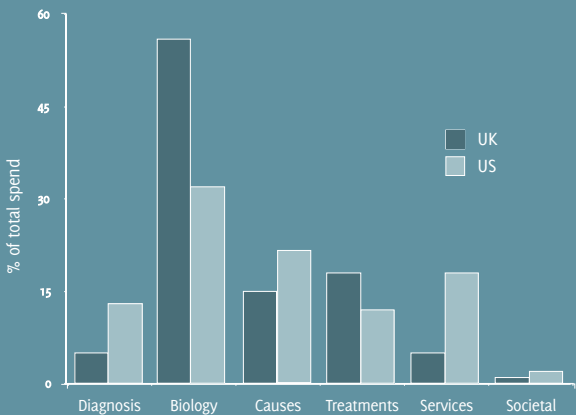


Fig 2. Autism Research Funding by Research Category: UK vs. US



Autism research activity in the UK: publications

Publications represent a major indicator of research activity. We used the available online publication databases to collate information on UK peer-reviewed research published in 2001 and 2011. Articles were classified according to research area (see p.18-19). This analysis allowed us to address the following four questions:

1. How much has UK autism research grown?
2. What areas of research are being addressed?
3. Are there any patterns of change in UK autism research activity?
4. How does the pattern of UK research activity compare to such activity in other parts of the world, particularly the US?

6,190 English-language articles were located from 12 electronic databases using a selection of autism-related search terms. Of the autism articles included in the analysis (see Appendix

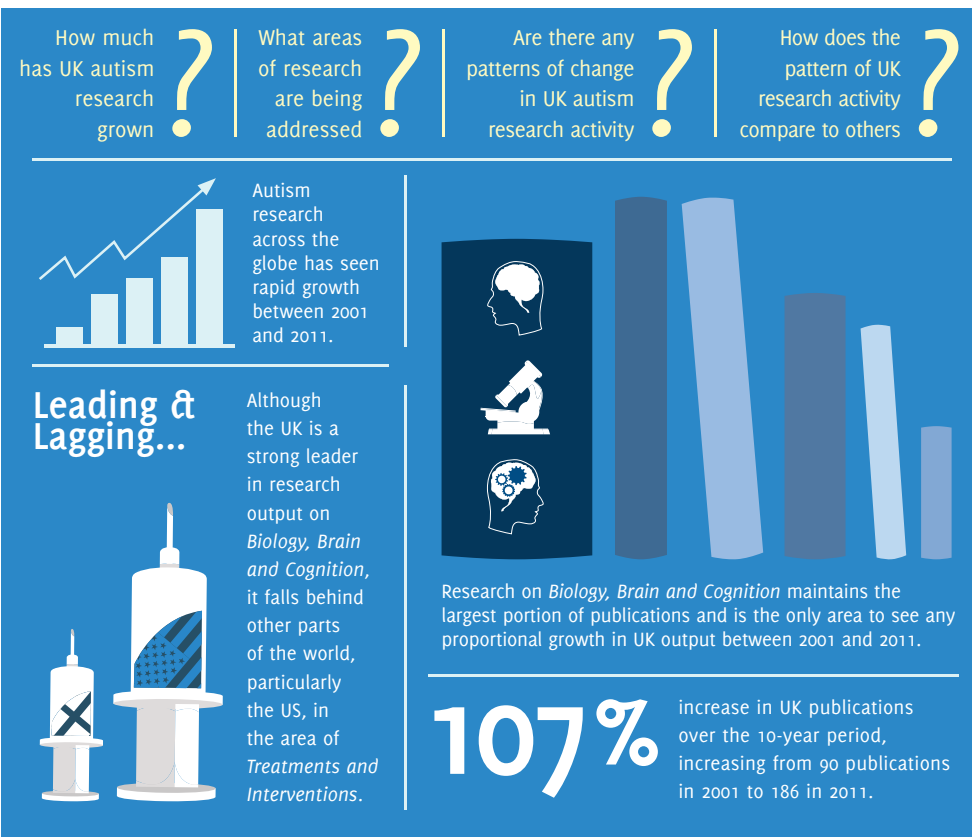
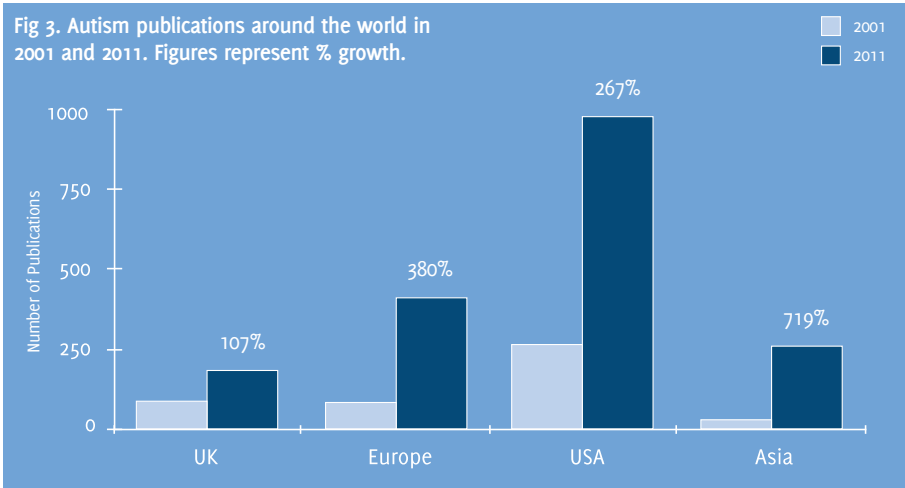
B for inclusion criteria), 548 were published in 2001 and 2,101 were published in 2011, suggesting a remarkable (283%) increase in research activity across the globe.

This increase mirrors the findings of the IACC's *Research Publications Analysis Report*⁸, which also showed that the growth in autism publication rates far outpaces the research literature in comparable areas, such as child psychiatry and developmental psychology. This huge surge in the field is most likely due to the dramatic increase in measured prevalence and the increased public awareness and appreciation of individuals with autism and the challenges they face.²²

How much has UK autism research grown?

UK autism research saw a 107% rise in publications over the 10-year period, increasing from 90 publications in 2001

Fig 3. Autism publications around the world in 2001 and 2011. Figures represent % growth.



to 186 in 2011. Figure 3 shows how this growth in autism publications compares to other parts of the world. There has been strong growth in autism publication output in the US, Europe and especially in Asia. But as the figure clearly shows, the rate of growth in autism publications in the UK has not kept pace with other parts of the world.

When rates for the UK and the US are adjusted for population size, the pattern remains the same. The UK published 1.5 articles on autism

research per million residents in 2001 and 2.9 articles in 2011, reflecting a 92% increase.¹⁹ The US published fewer articles than the UK in 2001 (0.9 articles per million residents). But this rate rose considerably to 3.1 articles per million residents in 2011, reflecting a 232% increase.²⁰ While the 2011 rates for the UK and the US are similar, the growth in volume of autism publications for the UK is lagging behind the US.

Despite the very strong history and achievements of UK autism research,



the publications analysis shows that the growth in autism research output over the past decade is substantially higher in Europe, Asia and the US. This remains the case even when productivity is adjusted for population size, with the UK being overtaken by the US. This finding echoes that of a recent report on the UK's research base, which suggested that other countries, especially the US, are outpacing the UK in terms of overall research output.²¹

What areas of research are being addressed?

Figure 4 shows the trends in areas of UK autism research in 2001 and 2011. At both time points, work on

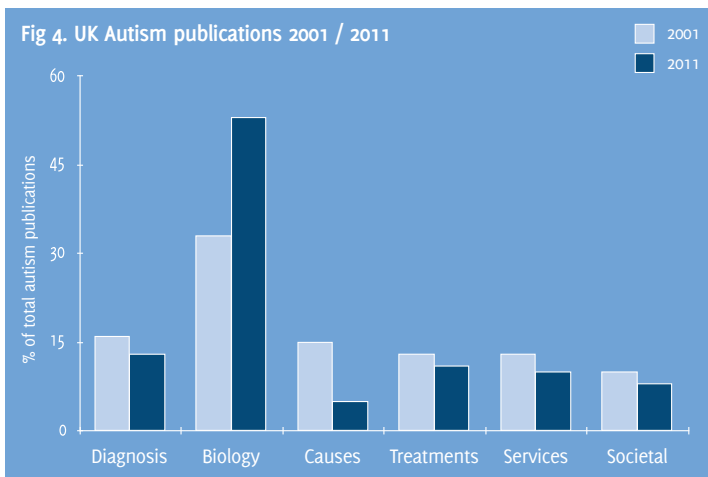
Biology, Brain and Cognition is a strong component of such research, encompassing 33% of all autism research in 2001 and more than half of all such research (53%) in 2011. When broken down into its subcategories, Cognition research had the greatest number and proportion of publications, reflecting the UK's strength and leadership in this area (see Key Dates, p. 14-17), while the fields of Computational and Immunological/ Metabolic research had the smallest number and proportion of publications.

Are there any patterns of change in UK autism research activity?

Research on *Biology, Brain and Cognition* also benefits from a healthy

amount of growth over the 10-year period. In fact, it is the only research area to have witnessed a proportional increase in publication output during this period.

Fig 4. UK Autism publications 2001 / 2011



This pattern is despite widespread calls for more translational research – research into treatments and interventions, services and societal issues – in the report

on the state of UK autism research field published 10 years ago.¹

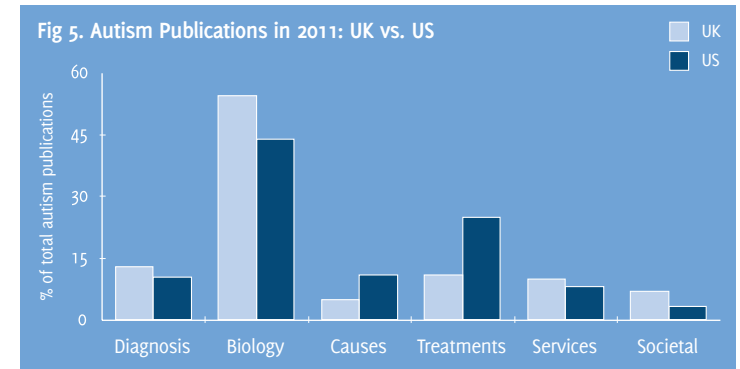
How does the pattern of UK research activity compare to such activity in the US?

Figure 5 shows the similarities and differences in the pattern of autism research output between the UK and the US in 2011. Research focused on *Biology, Brain and Cognition* accounts for the largest portion of publications in both the UK and the US.

There are, however, two notable differences. While research into *Biology, Brain and Cognition* is a strong area of research for both countries, it is the UK that leads the way in this research area: 53% of the UK's output is in this area compared to 44% in the US. This pattern remains the same if we compare the UK and other parts of the world. This pattern is no doubt due to the UK's strong tradition in studying the biological, neural and cognitive underpinnings that help explain autistic features (see Key Dates, p.14-17).

The UK published proportionately fewer research articles on *Treatments and Interventions* than other parts of the world, with this research area making up 11% of all UK autism research output in 2011 compared to a marked 23% of all research published in the

Fig 5. Autism Publications in 2011: UK vs. US



US. A breakdown of this category revealed that, while the UK is ahead of the curve in terms of technology-based interventions and supports (representing 40% of all Treatment and Interventions publications in 2011 compared to 13% in the US), the UK produced no publications in other key areas, including Complementary, Dietary and Alternative, Medical/ Pharmacological, and Occupational, Physical and Sensory-based treatments.

Key findings

- Autism research across the globe has seen rapid growth between 2001 and 2011.
- UK autism research has increased two-fold during this 10-year period but the rate of growth of autism research in the US outpaces that of the UK.
- Research on *Biology, Brain and Cognition* maintains the largest portion of publications and is the only area to see any proportional growth in UK output between 2001 and 2011.
- Although the UK is a world leader in research output on *Biology, Brain and Cognition*, it falls behind the US and other parts of the world in the area of *Treatments and Interventions*.

Views from the UK autism community

We consulted four broad stakeholder groups who have a major interest in UK autism research, including (1) autistic people, (2) parents of autistic children, (3) people who work with autistic children and adults (educators, clinicians) and (4) researchers (academics, funders). This consultation sought to answer the following questions:

1. What are peoples’ priorities for future research?
2. What are peoples’ views and perspectives on current UK autism research?
3. What are peoples’ experiences of engaging with researchers?

To address fully these questions, our consultation took two forms. The first was a large-scale online survey completed by 1,633 people. The second was a series of focus groups and one-to-one interviews involving 74 people. Full details of the methods are available in Appendix D.

The survey, focus groups and interviews all followed the same structure. They were devised in such a way as to allow participants the opportunity (1) to voice their views and perspectives on future priorities for autism research, (2) to reflect on the current state of funding for UK autism research, and (3) to consider their experiences of engaging with the autism/research community.

What are peoples’ priorities for future research?

In the survey, respondents were asked to rate the relative importance of 13

questions, which were derived from the 6 key research areas on p.18-19, and their priorities for future research.

Respondents were asked to rate the relative importance of the 13 questions on a 5-point scale from ‘not-so-important’ (score of 1) to ‘very important’ (score of 5). Overall, there was broad agreement across all four stakeholder groups that all 13 research questions were of value, each obtaining a rating of at least ‘moderately important’ (see below).

When asked to indicate which three of the 13 questions were the most important for research, there was remarkable convergence of views between the groups of respondents.

Questions	Mean rating
1. How can we better recognise the signs and symptoms of autism?	4.2
2. Are there different types of autism?	3.7
3. How common is autism?	3.4
4. How do autistic people think and learn?	4.5
5. How are autistic people's brains different from the brains of non-autistic people?	4.0
6. To what extent is autism caused by environmental factors?	3.5
7. To what extent is autism caused by genetic factors?	3.6
8. What are the best ways to treat the core symptoms of autism?	4.2
9. How can public services best meet the needs of autistic people?	4.6
10. What is the place of autistic people in society today?	4.0
11. What are the best ways to improve the life skills of autistic people?	4.6
12. What does the future hold for autistic adults?	4.4
13. Why do autistic people appear to be more at risk from some medical conditions than non-autistic people?	4.0

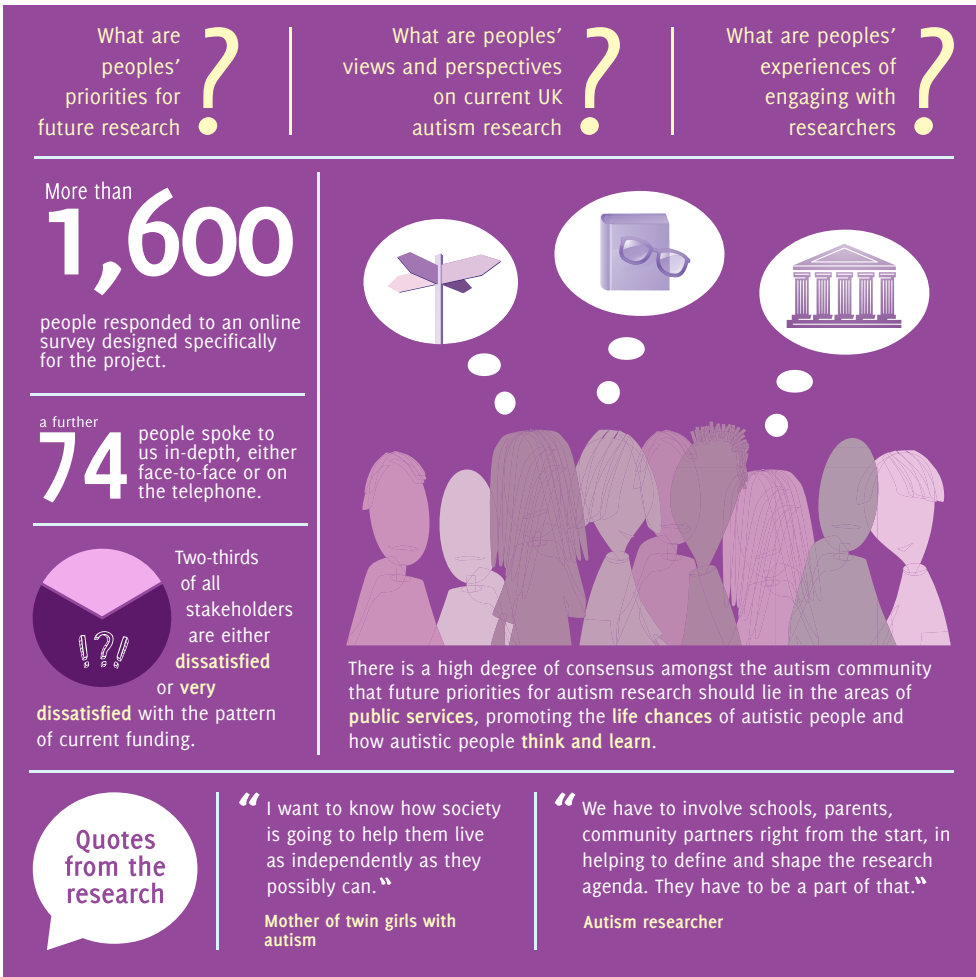


Figure 6 overleaf shows the three questions rated as most important by each stakeholder group, including the percentage of each group who placed this question within their top 3 (total percentage for each group can therefore exceed 100%).

Autistic people, family members, practitioners and researchers all prioritised research into (i) improving

the life skills of autistic people; (ii) identifying how public services can best meet the needs of autistic people; (iii) understanding how autistic people think and learn; and (iv) future outcomes for autistic adults.

In focus groups and interviews, people talked about the urgent need for research on effective services for autistic people throughout their lives.

Figure 6. Views of survey respondents

Autistic Adults (n=125)	Family Members (n=827)	Practitioners (n=427)	Researchers (n=120)
1. How can public services best meet the needs of autistic people? (61%)	1. What are the best ways to improve the life skills of autistic people? (61%)	1. What are the best ways to improve the life skills of autistic people? (48%)	1. What are the best ways to improve the life skills of autistic people? (66%)
2. What are the best ways to improve the life skills of autistic people? (43%)	2. How can public services best meet the needs of autistic people? (43%)	2. How do autistic people think and learn? (48%)	2. How do autistic people think and learn? (52%)
3. What does the future hold for autistic adults? (39%)	3. How do autistic people think and learn? (35%)	3. How can public services best meet the needs of autistic people? (37%)	3. How can public services best meet the needs of autistic people? (51%)

“We need to know how to work with the services to make sure everyone has a chance of having a better life.”
28-year-old autistic woman

They also discussed the importance of developing effective ways to teach life skills to individuals with autism, promoting independence in adulthood.

“Research needs to be carried out and put into ways to teach life skills and social rules to create more independence for adulthood.”
Sister of an autistic person

“We need to understand the most effective ways to educate autistic children and provide life skills whilst respecting them as individuals.”
Mother of child with autism

All four groups of stakeholders also emphasised the need to understand how autistic people think, learn and interpret the world around them.

“We must try to understand how the autistic person thinks/ processes the world around

them so we are able to better understand and support them.”
Mother of a preschooler with autism

“I want to understand more about how my child sees the world so I can better understand his response to it.”
Mother of young person with autism

There were, however, some clear differences between the stakeholder groups when ranking their priorities. Of note, autistic people gave greater priority to recognition of the signs and symptoms of autism than the other three groups. Also, while family members, practitioners and researchers all considered research into interventions for the core symptoms of autism a priority, this was reported to be a low priority for autistic people.

Autistic people also ranked research into the place of autistic individuals in society as a crucial area for research.

If I could have just one thing...

Survey respondents were also asked to provide details on (1) the one topic of research that they would like to be researched in the coming decade (total of 1,238 responses) and (2) any questions that were not covered by the 13 research questions but that they thought should be investigated by researchers (total of 618 responses). The pattern of responses for these questions was very similar.

Many autistic people, family members, academics and practitioners called for more research into co-occurring conditions, especially sensory sensitivities or overload, anxiety and depression. Family members also highlighted the need to understand the causes of gastrointestinal problems in autism.

“If I had to choose, it would be how to help autistic people deal with the co- occurring symptoms of other conditions, particularly anxiety / panic and depression.”
Early career autism researcher

There were general calls for research on services particularly from autistic adults but also from practitioners and academics, with many respondents expressing a general dissatisfaction with the services currently available to them.

Parents and autistic people specified a need for greater support for individuals and families following diagnosis, a finding that echoes with another recent consultation with stakeholders.²³

“It would be helpful to know how services and support could be improved for adults, i.e., actually have some!”
Autistic woman

“We need to understand the impact on families supporting a child with autism and how they can be further supported. An educated and empowered parent actually reduces the need (and then cost) on public services as they are less likely to need regular ongoing outside help.”
Mother of adolescent with autism

“One of the biggest issues is that you get the diagnosis and as a parent, you are just left to deal with it.”
Parent of young person with autism

Family members, practitioners and academics also prioritised treatments and interventions for autistic children, young people and adults, although particular treatments were rarely specified.

“Innovative treatments to help adults/ young people with Asperger syndrome – this area is really lacking.”
Early career autism researcher

“We need application of psychological research to treatment and education.”
Senior autism researcher

All stakeholder groups called for research into ways that ‘neurotypical society’ might change to better accommodate autistic people rather than research targeted towards identifying ‘cures’ or ‘prevention’ of autism. There was also considerable frustration expressed by autistic people and by parents about the way that autism was sometimes portrayed in the media and the need for greater and more accurate awareness of autism amongst the general population, especially in public services.

“I would like to see work on how society can adapt to incorporate autistic people, rather than autistics having to change to live in a neurotypically-driven world”
Young adult with autism

“The need for social attitudes to change with regards to autism so that people diagnosed live stable, happy and productive lives.”
Young adult with autism

Key topics raised by stakeholders

- co-occurring conditions
- services and treatments
- post-diagnostic support
- neurotypical/societal attitudes
- dissatisfaction with education provision
- sex differences
- lifespan issues

What are peoples' views and perspectives on current UK autism research?

In the second part of the consultation, participants were presented with the summary of UK research funding (see Figure 1, p.23). In the context of participants' priorities, it is not surprising that, when asked how satisfied they were with the current funding pattern for UK autism research, the four stakeholder groups reported being dissatisfied. Researchers were the most satisfied of the four and autistic adults the least. Autistic adults, family members and practitioners also felt that this pattern did "not really" map on to their own priorities, while academics felt that it "somewhat" did.

In focus groups and interviews, many people suggested not that we should invest less in certain research areas but that research funding should be more evenly distributed amongst the primary research areas – that is, that autism research needed to be much more "balanced" than it is currently.

"Philanthropic groups in the US have been able to change the conversation around autism; to help validate the advice parents can access, to understand how best to work with their kids, to help their children fulfill their potential. My sense is that we've not done as well as that."
Charitable funder

What are peoples' experiences of engaging with researchers?

An increasing priority for research funding agencies across science – both public and philanthropic – is that research should be a partnership

between researchers and the communities they study.

In the UK, this need for partnership in the research process is recognised to varying degrees by government funding agencies including the Research Councils and the National Institute of Health Research (NIHR). Research Councils UK (RCUK) is committed to funding research that makes a significant impact on society. RCUK states that "working in partnership generates new ideas, policies, and insights into stakeholders' needs, but also leads to an improved understanding of the research and skills needed for particular sectors."²⁴ Deliberate expansion of public participation has also been seen across the National Health Service (www.invo.org.uk).

To date, in the autism field there is little information as to how successful researchers are at such forms of engagement and, furthermore, how satisfied non-researchers (autistic people, family members and practitioners) are with the attempts that researchers make at such engagement activities. This consultation offered a unique opportunity to address this question.

We asked both researchers and non-researchers about how frequently they experienced such engagement activities (see definitions opposite) and how satisfied they were with these experiences.

While the majority of researchers said that they 'frequently' or 'very frequently' engaged in public dissemination and dialogue only a minority of autistic people, family members and practitioners shared

We defined 3 different levels of community engagement:



1. Public dissemination: which could include newsletters summarising research findings, online blogs or public events.



2. Dialogue: which might comprise direct communication or consultation between researchers and research participants often as part of research being conducted.



3. Partnership: which includes joint working between researchers and participants, family members and practitioners, where research is carried out 'with' or 'by' community members rather than 'to', 'about' or 'for' them.²⁵

this view. All groups of respondents agreed, however, that active research partnership was a rare occurrence.

In terms of satisfaction with the engagement they had experienced, the responses varied greatly across all four stakeholder groups, with researchers most commonly reporting 'dissatisfaction' with the level of engagement, and non-researchers most commonly endorsing 'neither satisfied nor dissatisfied'.

When open-ended responses were analysed from the survey, focus groups and interviews, three main themes emerged, which were common to all non-researchers (autistic people, family members and practitioners). The first of these was *attitudes*. All three stakeholder groups stressed the importance of researcher attitudes to their level of satisfaction with engagement and related largely positive experiences of interacting with researchers.

"Those [researchers] I have come into contact with have had a genuine interest and concern for people with autism." **Mother of young person with autism**

"Some of the researchers have been informative and collaborative. Others have no interest in what practitioners need or have to share."
Experienced autism practitioner

The second theme was *lack of reciprocity*. Non-researchers commonly spoke of the frustration caused by researchers who make little or no contact following their participation.

"I don't think many researchers feel they can talk to autistic people as if they matter; they're too busy studying them like specimens or looking for a 'cure'."
Early career autism practitioner

"Researchers are more keen on collecting data, but not providing results." **Autistic woman**

"I would like more details of the results of research, particularly when I have given time and effort to helping with it." **Mother of child with autism**

"It feels like researchers are working in their own world, with little direct engagement with us,

isolated from the practical issues people face.”

Mother of preschooler with autism

Many respondents also spoke of *barriers to engagement*, the third theme, which included difficulties (i) accessing research findings, particularly in accessible formats for lay audiences, (ii) finding the time for engagement in research in their otherwise already very busy lives, especially the demands of caring for an autistic child, and (iii) identifying research relevant to their lives.

“As an autism professional, I have to seek out any information regarding research myself. Very rarely is it in a format that is easy to comprehend for a non-academic/researcher.”

Experienced autism practitioner

“There is just so little research that I’m aware of. Once [your child is] diagnosed, you’re left to get on with it unless you have the time and inclination to get involved in support groups.”

Mother of young adult with autism

“Most of the research centres on the high functioning, Asperger’s type of autism. It’s not relevant to my son’s life.”

Mother of adolescent with autism

“It is important for research to have practical outcomes. Researchers need to be closer to those affected by [autism].”

Older autistic man

Academics spoke of similar issues, although from the ‘other side of the fence’.

Many academics mentioned that the autism community had been receptive and supportive in their attempt to engage them in research.

They also, however, identified several *barriers to engagement*, particularly the lack of consensus within the autism community on various issues and the communication challenges faced by autistic people.

“The experiences of individuals with autism and their families are many and varied. Sometimes

the most vocal individuals have a completely different experience/agenda than most of the vulnerable people we engage.”

Senior autism researcher

“Some of the challenges people with autism may face makes the interactions quite difficult – trouble taking on board another person’s point of view, commenting in a sensitive way that does not cause offense, etc. I would favour more partnership, but very different goals and methods of interaction make this a formidable challenge.”

Senior autism researcher

Some researchers also expressed concerns regarding the attitudes and practices regarding engagement within academia. For example:

“I feel that [engagement] can be tokenistic, i.e., asking the same panel of people with autism to contribute to policy, practice and decision-making, almost to ‘tick the box’ to say that people with autism had been involved.”

Early career autism researcher

The survey findings highlight a disparity in how well academics feel that they are engaging the autism community and the experiences of the community itself.

The majority of autistic people, family members and practitioners had not experienced dissemination or dialogue frequently. More active research partnership was rated as infrequent by researchers and non-researchers alike.

Encouragingly, though, when researchers spoke of ways that engagement with the autism community could be improved, they often said that they would like to see autistic people and their families given more input

into setting the goals of research and should be involved directly during the development of new research projects.

There is a need for researchers to be made aware of their relative lack of success in engagement with the broader autism community. There is a role for funding agencies to work jointly with autistic people and their families to help determine the best mechanisms of engagement – be it dissemination, dialogue or partnership – especially for those individuals with autism who might not be able to communicate their views and perspectives so easily. The field could profitably learn from participatory methods, which are well developed in other fields,²⁶⁻²⁸ but rarely applied to the study of autism. We need to work towards moving away from traditional ‘us’ vs. ‘them’ models of research to collaborative ways of working together.

Key findings

- There is a high degree of consensus amongst different parts of the autism community (autistic people, family members, practitioners and researchers) that future priorities for autism research should lie in the areas of public services, promoting the life chances of autistic people and how autistic people think and learn.
- Two-thirds of all stakeholders are either dissatisfied or very dissatisfied with the pattern of current funding – it does not match up to their stated priorities.
- Academics perceive themselves to be engaged with the broader autism community but this is not shared by other stakeholders, most notably autistic people and their families.
- Autistic people see the challenges as societal and attitudinal ones and not about ‘curing autism’.



Conclusion



There has been a substantial increase in autism research publications and funding during the past decade, both in the UK and abroad. But while there have been some significant advances, we still have not come close to a full understanding of autism. Research into effective ways of responding to the needs of autistic people and their families is less advanced still. This means that the promise of research, although rightly championed by many, is far from fulfilled.

The purpose of this Report has been to document the nature of autism research currently funded and conducted in the UK and to map that on to the priorities of autistic people and the broader autism community.



It is our belief that this knowledge should be of immediate practical help to all those seeking to ensure that future autism research provides the most benefit for the most people.

In addition to this general ambition, we conclude by highlighting three main recommendations, which emanate from our findings.

First Recommendation: Investment in new areas of autism research

Many of the recent UK policy and practice initiatives on autism are a direct response to the recognition that autism is both common and has a substantial impact on individuals and society.²⁹ The amount of autism research activity – both in terms of funding and publications – has also grown significantly.

Our analysis suggests, however, that UK funding and productivity is not keeping pace with developments in some other parts of the world, particularly the US. We recommend that the UK thus continues to accelerate the level of investment into autism research. We recognise, of course, that at a time of economic difficulty for the whole country this will not be easy. It is,

therefore, important to be selective in this and other areas in which new funds are directed and for which efforts are made to raise additional support.

As we have documented here, the UK has a strong history and tradition as a world leader in autism research, particularly in the area of cognition. There are very good reasons not to undermine these areas of comparative advantage. It is important to value established expertise, to recognise the importance of one generation passing its knowledge to another and to acknowledge that it is impossible for one country to possess centres of excellence in all areas. High start-up costs in new areas and lack of guarantees of return can be prohibitive, especially in small countries like the UK. We thus believe that these areas of research should continue to receive substantial support.

There is an urgent need to invest in currently under-served areas, especially in work that translates basic scientific knowledge into practice for those with autism. The UK autism community demands greater emphasis on research targeting how autistic people think and learn, how we can promote the life skills and independence of people with autism and how we can develop and identify effective public services for autistic people and their families.

“Just because it is being done in the US, doesn’t mean it’s necessarily going to work in the same way here in the UK.”

Senior UK academic

For the UK to maintain its position as one of the world’s leaders in autism research, it needs **greater investment in under-researched areas and in under-served populations, new strategic oversight and coordination and the involvement of autistic people and the broader autism community in decisions about research.**

This is partly because such work is significantly under-funded at present. It is also because as new interventions are developed elsewhere, we will need evidence about whether such policies or services will work here in the UK in similar ways to the places in which they have been developed. Too often it is presumed that services can be delivered in the same way in different cultural, institutional, social and



political settings and thus UK-specific research is not required. We believe this is a mistake.

Even in straitened times, therefore, we recommend that funds should be allocated to ‘build capacity’ in under-researched areas within the UK and also to fund research in areas of significant importance and interest to the broader autism community, especially autistic people. Care should be taken to ensure that these areas are not squeezed out in an ever-more competitive research funding environment.

Second Recommendation: The need for strategic partnerships

To ensure that the investment in autism research is directed towards areas that are the most needed, we

need a body to identify and coordinate UK autism research, helping to connect experts in established areas of excellence with researchers in new and less-well supported areas of concern. Such a body should have responsibility for strategic coordination and planning of UK autism research funding and must include the views and perspectives of autistic people and the wider autism community. Its recommendations should inform both governmental and non-governmental funding agencies and encourage researchers and non-researchers to reach out to each other across established disciplinary divides.

A more immediate way of developing under-researched areas would be to draw on best practice and expertise from already well-established areas

through the development of new cross-disciplinary partnerships. We suggest that researchers should take on directly the responsibility of ‘translation’, such as by applying their own expertise or the expertise of their teams directly to other areas of concern. Examples could include efforts to develop cross-disciplinary research moving expertise from psychological science into education, from epidemiology into service delivery and design, from biomedical research into socio-cultural, legal and ethical investigations.

“Our autism research portfolio would probably increase if there were more researchers working on autism in the UK. Our portfolio reflects the considerable strengths of existing groups.”

Government funder

Third Recommendation: Listening, engaging and involving

Most important of all, though, is an ethic of engagement. There is, unfortunately, a disconnect at present between the UK’s investment in autism research and the life-chances for autistic people and their families. We need to reduce this gap.

One clear way of doing so is developing more widespread mechanisms of engagement between researchers and the autism community.

As this Report shows, 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. There needs to be greater involvement of the autism community both in priority-setting exercises in specific areas and in research more broadly to ensure that resources are targeting the critical needs of autistic people and their families. Strong

community relationships are also necessary for translation of research into practice.

Developing these research-community partnerships takes time, effort and often funding. Grant-giving bodies and government agencies should actively encourage partnerships that are genuinely participatory and not just tokenistic, where autistic people and other key stakeholders are ‘co-producers’ of the research. Building such institutional mechanisms of engagement requires sustained effort. But researchers can act now to develop their research and their aspirations differently. Researchers should listen to the views and perspectives of the autism community to appreciate what it is like to be autistic, to care for someone who is autistic, or to work with someone who is autistic. And the autism community should work towards gaining a better understanding of research and the challenges involved.

We – researchers and funders, the autism community and the public – need to work together towards advancing autism research in the UK. We need to invest more in those areas that are under-resourced and in populations that are under-served, we need to join together in innovative new partnerships, and we must seek to ensure that everyone with a stake in the research process is given an opportunity to make their voice heard.

The best priorities are made through involvement of all these stakeholders.

The best priorities are made together.

Appendix A: Identifying autism-related funding awards

The online research funding database Europe PubMed Central and the organisational websites/annual reports of 20 UK research funding bodies were searched for funding awards containing any of a selection of autism-related search terms. The search was limited to awards made between 2007 and 2011. The search terms entered and funding bodies surveyed are listed below.

This systematic search was followed up with e-mail requests to the identified funding bodies for any further information on autism-related funding awards not available in the public domain.

Funding awards made in support of primary research involving the collection and analysis of new data, or new analysis of existing data, were included in the review. Each award was then categorised according to primary topic (see Appendix C), target age and target demographic.

Search Terms

• ASC

• ASD

• Asperger

• Asperger's

• Autis*

• Autism

• Autistic

• PDD-NOS

• PDD NOS

• PDDNOS

Funding Bodies

• Arts & Humanities Research Council

• Autistica

• Baily-Thomas Charitable Fund

• Biotech & Biological Sciences Research Council

• British Academy

• Chief Scientist Office

• Department for Education

• Department of Health/NIHR

• Economic & Social Research Council

• Engineering & Physical Sciences Research Council

• Inge-Wakehurst Trust

• Leverhulme Trust

• Medical Research Council

• Natural Environment Research Council

• Nuffield Foundation

• Research Autism

• Royal Society

• Science & Technology Facilities Council

• Waterloo Foundation

• Wellcome Trust

Appendix B: Identifying autism-related research publications

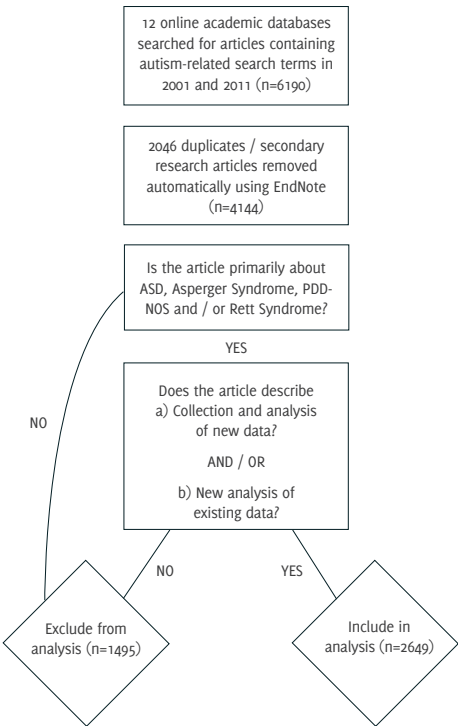
12 online academic databases were searched for articles containing any of the search terms listed in Appendix A in their title, abstract or key words. The search was limited to articles published in 2001 and 2011. The databases searched are listed to the right.

Articles with identical titles and primary authors were excluded. Articles were also excluded if their 'type of article' was listed as anything other than Article, Case Report, Case Study, Clinical Trial, Comparative Study, Controlled Clinical Trial, Meta-Analysis, Randomised Controlled Trial, Research Support, or Review.

These steps ensured that only those articles containing primary research were included in the review.

Remaining articles were included in the review, and were systematically categorised according to the following characteristics: Primary author name, Year published, Article title, Primary topic (see Appendix C), Target age, Target demographic, and Country of primary author.

Of the autism articles included in the analysis (n=2,649), 548 were published in 2001 and 2,101 were published in 2011.



Online Journal Databases

• ISI Web of Science (WoS)

• Medline

• Applied Social Sciences Index and Abstracts

• British Humanities Index

• Education Resource Information Center (ERIC)

• International Bibliography of the Social Sciences

• PsycInfo

• Science Direct

• Social Services Abstracts

• Sociological Abstracts

• The Cochrane Collaboration

• The Campbell Collaboration

Appendix C: Categorising the primary topic of autism-related funding awards and research publications.

The primary topic of all funding awards and articles identified were systematically assigned to one of 6 research areas using a protocol adapted from the 2010 IACC ASD Research Portfolio Analysis Report.^{7,8} The 6 research categories were comprised of 35 research topics. The protocol is listed below in full.

i. **Diagnosis, Symptoms and Behaviour** - Projects that aim to recognise the symptoms and signs of autism, define the typical characteristics that combine to form an autism spectrum diagnosis and explore variation in the symptoms and severity associated with autism.

1) Diagnostic and screening tools: This subcategory includes projects that are developing new autism diagnostic and screening tests for clinical use, as well as those establishing the usefulness of new or revised assessments for autism symptoms. It also encompasses projects aimed at adapting clinical assessments into other languages for use in multi-lingual community settings.

2) Early signs and biomarkers: Projects which use a variety of methods to search for signs of autism in very young children (generally under age 3) that could be used for diagnosis, such as eye-tracking, physiological measures, and autism- specific behavioural patterns are included in this subcategory. More examples

include projects investigating metabolic measures, such as the levels of specific chemicals, hormones, or proteins in the blood that could be used as biomarkers of the condition.

3) Intermediate phenotypes/Subgroups: Included in this subcategory are projects aimed at identifying distinct subgroups of people with autism, or those that share common morphological, physiological, or behavioural features (i.e., the broader/ extended autism phenotype). Projects in this subcategory use a variety of methods to identify and distinguish these groups for diagnostic purposes.

4) Symptomatology: Projects in this subcategory focus on the defining symptoms of autism, as defined by standard diagnostic criteria (e.g., DSM, ICD). These projects seek to define the broad range and severity of autism symptoms, including both biological and behavioural characteristics. Among these studies are some that examine how children and adults with autism vary in their development of social communication and language. Other projects seek to understand how neurocognitive impairments can contribute to symptom development and phenotypic variability in those with an autism diagnosis. N.B. Some ambiguity is to be expected between this subcategory and 6) Cognitive studies; in such cases articles which descriptively investigate the phenotypic/ phenomenological manifestation of the core symptoms of autism should be coded here.

5) Prevalence/Epidemiology of autism: Projects that investigate the prevalence of autism in a given population.

ii. **Biology, Brain and Cognition** - Projects that aim to understand the biological and cognitive underpinnings that help explain autism symptoms and identify biological signatures that differentiate between subgroups of people with autism.

6) Cognitive studies: These are studies of psychological and mental processes, including memory, producing and understanding language, solving problems, and making decisions. Projects in this subcategory consist of those that investigate theory of mind, social cognition and empathy, understanding facial expressions of emotion (and how and why this is impaired in autism), IQ, and recall and memory. Projects investigating academic achievement are not included in this category. N.B. Some ambiguity is to be expected between this subcategory and 4) Symptomatology; in such cases articles which investigate the explanatory mechanisms (i.e.,

‘why’ and ‘how’) which underlie cognitive processes should be coded here.

7) Computational science: Computational methods and modelling allow for the synthesis and study of large and complex sets of data. Some projects in this subcategory collect extensive experimental biological and behavioural data and use powerful computing techniques to reveal new insights. Other aspects of computer science are also included, such as developing statistical modelling techniques to better understand the biology of autism.

8) Co-occurring conditions: Research on conditions that often co-occur with autism is included here, such as seizures/epilepsy, sleep disorders, gastrointestinal dysfunction, wandering/elopement behaviour, attention deficit hyperactivity disorder (ADHD), familial autoimmune disorders, oppositional defiant disorder, conduct disorder, schizophrenia, aberrant eating behaviour, aberrant motor behaviours, self-injurious behaviour, challenging behaviour, emotional and behavioural difficulties, CNS/cranial anomalies, diabetes mellitus type 1, muscular dystrophy, depression, anxiety and other mental health problems.

9) Developmental trajectory: Projects in this subcategory often include longitudinal studies following various aspects of biological and behavioural development in the same individuals over time. Examples include brain growth, face processing, change in neural connectivity over time, and development of communication skills and language processing. These studies often compare children with autism to typically developing children or to their unaffected siblings. Data collection MUST include longitudinal study involving follow-up of the same participants over time. Neither cross-sectional studies that claim to investigate developmental processes nor studies that investigate developmental processes retrospectively are included in this subcategory.

10) Immune/Metabolic pathways: These projects focus on understanding the biological mechanisms of metabolism and the immune system that may be altered in autism, typically in cells and animal models. This largely includes studies on inflammation and inflammatory molecules (i.e., cytokines), as well as on the role of mitochondria, energy metabolism, and oxidative stress. Also included in this group are projects seeking to identify specific immune and metabolic triggers in early prenatal and post-natal life, such as maternal infection, maternal auto-antibodies, and toxic exposures.

11) Molecular pathways: This subcategory includes studies on specific molecules and proteins (other than the immune and metabolic systems) that may be involved in the development of autism and related genetic disorders (e.g., Fragile X syndrome and Rett syndrome). Many of these projects use cellular models to explore the biological effects of specific candidate genes and to identify common molecular pathways, including alterations in synaptic functioning and intracellular signalling cascades. N.B. Some ambiguity is to be expected between this subcategory and 20) Genetic Risk Factors; in such cases articles which explicitly investigate the synaptic/neural effects of specific candidate genes should be coded here.

12) Neural systems: Studies in this subcategory explore the structure and activity of the brain and underlying neural systems involved in autism, including functional connections between brain regions. Many projects seek to identify the precise neural networks underlying communication and language processing, social interactions, and behavioural issues. These studies frequently employ imaging techniques, such as functional magnetic resonance imaging (fMRI) and diffusion tensor imaging (DTI), and other physiological measures of brain activity, such as electroencephalography (EEG).

13) Neuropathology: These projects typically include post-mortem examination of brain tissue from autism individuals. Many of the studies in this subcategory explore how the architecture of the brain may be altered in individuals with autism or how gene expression varies in different areas of the brain.

14) Sensory and motor function: Projects in this subcategory explore the neural underpinnings of motor skills and abilities in children with autism and assess visual, auditory, perceptual, and other sensory processes in the brain. These include behavioural/experimental studies on sensation, perception and motor skills as well as brain imaging studies.

15) Subgroups/Biosignatures: Because there is so much heterogeneity among individuals with autism, research to understand how certain subgroups of individuals that share certain behavioural or biological characteristics could help understand some of the underlying biology in autism. This can be done by searching for certain biological factors (“signatures”), such as hormone levels or structural abnormalities in the brain, that define a particular subgroup. Many of

these projects try to make the connection between certain genes with a known or suspected link to autism and the observable characteristic, or phenotype, that they purportedly cause.

16) Model systems: Animal models mimicking behaviours of autism and those that are being used to develop or test new drug treatments, as well as cell lines used to discover new drug targets or to screen potential drug candidates, are included in this subcategory.

iii. **Causes** - Projects that aim to identify genetic and environmental risk factors that may confer greater susceptibility to the development of autism.

17) Environment: This subcategory includes a number of projects investigating potential environmental risk factors for autism. Example projects include studies of the effects of the microbiome, environmental contaminants and toxins, maternal dietary factors, medications taken during pregnancy or to induce labour, assistive reproductive treatments, child and maternal response to immune challenge, and registries where many of these factors can be tracked simultaneously.

18) Epigenetics: Epigenetics is the study of heritable changes in gene function that occur without a change in the DNA sequence (such as methylation of DNA). Environmental factors can cause these changes in gene expression, and projects in this subcategory seek to identify some of the environmental influences that may lead to these epigenetic changes.

19) Gene-Environment: These studies search for combinations of environmental risk factors and genetic susceptibility that increase the risk for autism.

20) Genetic risk factors: Projects in this subcategory seek to identify new genes that are implicated in increased risk for ASD or to better understand genetic risk factors that were previously identified.

iv. **Treatments and Interventions** - Projects that aim to develop treatments and interventions for autism and evaluate their efficacy and safety.

21) Behavioural and Developmental: Projects in this subcategory involve a wide array of behavioural research and training methods, including applied behaviour analysis (ABA), cognitive-behavioural therapy, discrete trial training, Early Start Denver Model, imitation training, joint attention training, Lovaas method, pivotal response training, parent

and/or sibling-mediated interventions, and social skills training.

22) Complementary, dietary, and alternative: This subcategory includes research on acupuncture, antioxidants, cholesterol supplementation, glutathione metabolism, nutritional supplements, vitamins, and minerals, probiotics, and special diets (e.g., gluten-free, casein-free).

23) Educational: Nearly all research in classroom settings falls under this subcategory, including studies of academic achievement by autistic people, curricula, educational best practices, inclusive education programs, math and reading training, positive behavioural supports, special education programs, TEACCH (Treatment and Education of Autistic and Related Communication- Handicapped Children), and the “Social Stories” approach. Studies aiming to investigate and/or improve teacher efficacy should not be included in this subcategory [see 30) Practitioner Training].

24) Medical/Pharmacologic: This subcategory includes research on drugs (e.g., antidepressants, anticonvulsants, antipsychotics, anxiolytics, melatonin, and stimulants) to treat autism and its co-occurring conditions, as well as medical therapies such as transcranial magnetic stimulation (TMS).

25) Occupational, physical, and sensory-based: Therapies in this subcategory encompass art therapy, motor training (including fine motor skills such as handwriting as well as gross motor training involving balance and posture), music therapy, occupational therapy, pet (animal) therapy, physical activity plans and exercise therapy (bike riding, swimming), physical therapy, sensory integration, therapeutic horseback riding, training in self-care and daily living skills, and vocational rehabilitation.

26) Technology-based interventions and supports: Augmentative and alternative communication (AAC), computer applications and software, picture exchange communication system (PECS), social robots, teleconferencing, video modelling and virtual reality (including virtual and 3D environments to mimic social situations), and wearable sensors are all examples of the types of technology in the projects in this subcategory.

v. **Services** - Projects that aim to identify, develop and evaluate services and supports for people with autism and their families and explore issues surrounding accessibility, cost-

effectiveness and ease of transition between services aimed at different age groups.

27) Community inclusion programmes: These programmes provide instruction in social, communication, and leisure skills to enable individuals with autism to participate in sports, recreation, and social-integration activities in fully integrated settings and to build successful relationships with others.

28) Efficacious and cost-effective service delivery: This subcategory includes programs involving web-based curricula and interventions as well as telehealth methodology, all of which could benefit those in underserved areas. Studies to improve dental care are also in this subcategory for effective service delivery.

29) Family well-being and safety: Studies in this subcategory evaluate issues of caregiver stress and measures of quality of life for individuals with autism and their families, as well as assess programs to help parents navigate the service system after their child receives an autism diagnosis. It also surveys safety issues for those with autism, including wandering and bullying.

30) Practitioner training: Projects in this subcategory seek to increase skill levels in service providers, including medical providers, direct support workers, education staff, and public service workers.

31) Services utilisation and access: These projects include surveys of service systems available in different states/nations, evaluations of patterns of medical service use among children with autism, online resources for autism services, and specific efforts to coordinate services for people with autism. They also evaluate disparities in diagnosis and service utilisation as well as barriers to access for racial and ethnic minorities. vi. Societal Issues - Projects that examine the place of autistic people in society and explore the social, ethical, economic and political issues relevant to autism and neurodiversity.

32) Economics of Autism: Projects that primarily investigate or discuss the economic impact of autism on a given economy/group of economies. N.B. This code should not be used for projects discussing the provision of specific services [see codes 27-31].

33) Research Policy: Projects that primarily investigate or discuss political, philosophical, methodological, ethical and/or legal issues specifically surrounding autism research.

34) Social and Ethical Issues: Projects that primarily investigate or discuss moral, ethical

and/or political issues surrounding ASD including autism advocacy, disability rights, and neurodiversity. N.B. This code should not be used for projects discussing the ethical implications and responsibilities specific to service provision [see codes 27-31].

35) Biographical/Ethnographical: Projects that explore the lived experience of autistic people and their families/carers using journalistic, biographical and/or ethnographical methods.

Modifications to IACC protocol

1. The ‘Infrastructure and Surveillance’ research area, intended to capture funding awards made in support of research infrastructure, data tools, biobanks, workforce development etc was excluded from this review.
2. The ‘Lifespan Issues’ research area, intended to capture projects specifically targeted at adult diagnosis, symptomology, interventions, service needs etc was also excluded from this review. Each award/article was instead coded according to its ‘Target Age’ in addition to its primary topic (see Appendices A, B), to ensure our review remained sensitive to these issues.
3. The ‘Diagnosis’ research area was renamed ‘Diagnosis, Symptoms & Behaviour’ to better reflect the scope of the research topics it contains.
4. The ‘Biology’ research area was renamed ‘Biology, Brain & Cognition’ to better reflect the scope of the research topics it contains.
5. The ‘Prevalence/Epidemiology of autism (5)’ topic was added to the ‘Diagnosis, Symptoms & Behaviour’ research area.
6. The list of conditions covered by the ‘Co-occurring conditions (8)’ topic was expanded to better reflect the current literature on autism co- morbidity.
7. The ‘Model Systems (16)’ topic was re-assigned from the ‘Treatments & Interventions’ area to ‘Biology, Brain & Cognition’ to better reflect the nature of the projects captured. N.B. All US funding data presented in the report reflects this change.
8. The ‘Societal Issues’ research category was added to capture projects that examine the place of autistic people in society and explore the social, ethical, economic and political issues relevant to autism and neurodiversity.
9. Some US-specific wording was altered to reflect the UK focus of this study.

Appendix D: Interviews and focus groups with the broader autism community

The programme of interviews and focus groups was intended to provide insight into the views of the UK’s broader autism community, and to inform the design of an online survey to be disseminated among large numbers of stakeholders (see Appendix E).

Potential participants were contacted via the Centre for Research in Autism and Education’s (CRAE) contacts and the NAS Autism Services Directory. Twenty one consultations were conducted involving 74 participants, yielding 26 hours of discussion. The majority of interviews were carried out either at the Institute of Education, London, or a mutually convenient location in Greater London. Where face-to-face meetings were not possible, interviews were conducted by telephone/ Skype. Details of the consultations are listed in the adjacent table.

Each consultation proceeded according to a semi-structured discussion guide, though participants were encouraged to speak about whatever they deemed appropriate. During each session participants were presented with provisional findings from the review of UK autism research funding detailed in the report. With some minor audience-appropriate alterations, each discussion proceeded largely as described below.

1. What do you know about autism research currently going on in the UK?
2. How do you access this information?
3. What do you think are the current priorities?
4. Do you feel these are the right areas to focus on? Why/why not?
5. Presentation and discussion of provisional findings of UK autism research funding review.
6. What are your experiences of engagement between autism researchers and the broader autism community?

Ethical approval for this study was granted by the Faculty of Policy and Society’s Research Ethics Committee at the Institute of Education, University of London. All participants gave informed consent prior to participation.

Stakeholder Group	Number of Participants	Type of consultation
Autistic Adults	14	Face-to-face interview; Skype; focus group
Family Members	27	Focus group; face-to-face interview
Practitioners	20	Focus group; face-to-face
Researchers and funders	13	Focus group; face-to-face interview; telephone interview

Appendix E: Online survey

The online survey aimed to elicit both quantitative and qualitative responses from large numbers of the UK’s broader autism community regarding their views on autism research. The survey was hosted by SurveyMonkey between December 2012 and February 2013 and attracted 1,633 respondents. The survey’s design and content was the result of discussion between the researchers and was informed by the themes arising in the focus groups and interviews conducted to that point (see Appendix D). A link to the online survey was disseminated among CRAE contacts and partner organisations across the UK.

Though the items presented by the survey differed slightly between stakeholder groups (e.g., family members were also asked to indicate the age and gender of their autistic relative), each participant was required to respond to items about the relative importance of different research questions, their satisfaction with the current profile of UK autism research, their priorities for future research, and their experiences of engaging with researchers/the autism community. Survey items are available from the authors on request.

Glossary of terms

Advocacy: Efforts made in support of the desires, needs, and rights of a particular person or group of people.

Animal models: The use of genetic techniques to re-capitulate the symptoms of a condition in an animal population for use in research. Animal models are often used to trial drug treatments before they are tested on humans.

Basic research: Research that aims to increase understanding of fundamental principles without necessarily providing any immediate implications for clinical practice.

Broader autism community: Those UK residents who are autistic themselves, who care for those with autism, or who work with autistic children, young people and/or adults.

Cognition: Any psychological or mental process including understanding, awareness, perception, reasoning, judgement, etc.

Cognitive behavioural therapy: A type of talking therapy designed to help a person manage their problems by altering the way they think and behave through pragmatic, goal-oriented strategies.

Cortical development: The growth and maturation of the cerebral cortex – the outermost sheet of neural tissue of the brain.

Focus group: An interview involving more than one interviewee i.e., an interview which takes place in a group setting rather than one-on-one.

Government funding: Funding which is provided and administered by government, and is therefore primarily comprised of public funds raised through tax revenues.

Intellectual disability: A condition characterised by concomitant impairments in general mental abilities and adaptive behaviour that first manifest early during development.

Neurotypical: A label used to describe people with no apparent neurological disorder or atypicality.

Online academic journal database: An online database which provides access to summaries of journal articles and other research outputs published by academic journals (see Appendix A for a list of online academic journal databases used in this study).

Participatory research: The active participation of the people being studied in the design, conduct and interpretation of research and research findings.

Peer review: The process by which anonymous experts in a given field evaluate the quality of new research, often to determine its suitability for publication.

Philanthropic funding: Research funding provided by the private or charity sectors, typically comprised of charitable donations or endowments.

Primary research: Activities that involve the collection and analysis of new data, or the new analysis of existing data.

Secondary research: The summary or review of previous primary research. Common examples of secondary research are literature reviews, commentaries, editorials, etc.

Skype: Software that allows two or more people to see and hear each other via the Internet.

Socially-assistive technology: Any technology which assists people in communicating or learning social skills e.g. various computer applications and software, Picture Exchange Communication System (PECS), socially-assistive robots, etc.

Stakeholder: Anyone with an interest in autism research, be it personal or professional.

Translational research: Research conducted with the explicit purpose of translating scientific knowledge into clinical practice.

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