AUTISTICA
With knowledge comes understanding

One in a Hundred

Putting families at the heart of autism research

Simon Wallace, Jeremy Parr & Alison Hardy

Contents

This report contains photographs of children and adults with autism, children who are the siblings of those with autism, and donated or stock images. We would like to thank all of the families who have contributed photographs to this report.

www.autistica.org.uk

Welcome

Welcome to Autistica's One in a Hundred report, reflecting the views of one in every 100 families across the UK who experience the highs and lows of living with autism each day. We have learned a great deal from almost 1000 parents and individuals with autism who took part in our survey, and drawn inspiration from the stories shared by the 40 families who took part in our focus groups and interviews.

This report reflects our commitment to act as the bridge between families and researchers, and to ensure that the research Autistica funds is relevant, urgent, and full of impact. From this broad consultation, we have gained insight, ideas, direction, and above all, motivation.

We believe that it is unacceptable that 94 percent of parents worry about the future of their child with autism, and that 75 percent of adults with autism report that there is insufficient help for their difficulties. A third of respondents had tried interventions they knew had no evidence base, demonstrating both the level of desperation and the lack of options currently available. And, across the board, parents and adults with autism wish that diagnosis had come sooner.

But we are encouraged that so many families and individuals with autism feel positive about medical research. Ninety percent agree that there is a need for a greater scientific understanding of autism, and a similar number feel that more medical research would make a positive difference to their lives. We were heartened that 90 percent of our respondents would like to take part in research, and we are committed to making this as easy as possible.

It is clear that there is much to do, but with the support and partnership of families across the UK we remain ambitious that we can fund pioneering research that will bring real change.

This year, we launch our new science agenda in response to these findings. We plan to continue to invest in early diagnosis and early intervention, to ensure that every child with autism has the very best chance in life. We plan to explore autism across the lifespan, to gain understanding of how autism and its challenges change throughout adulthood and ageing. And we plan to invest in research to address the problems which too often go alongside autism: anxiety, depression, epilepsy, and sleeplessness; these problems may be among the most treatable, but when unmanaged can make life so much more difficult for families.

Above all, we plan to ensure that families remain at the heart of everything we do. We hope that you will join us on this journey.

Christine Swabey
Chief Executive

Edward Chandler
Chair of the Trustees

Forewords

**Richard Atterbury, Chair,
New Philanthropy Capital**

In 2007, New Philanthropy Capital reviewed the autism charity sector as a whole, and identified a real need for increased medical research. It is impressive that Autistica continues with its commitment both to support research and to raise awareness of how critical a need there is for more funding to be provided in this area.

The experiences shared here illustrate that there remains much to be done. There is no doubt that more funding can and should be channelled into autism research, to improve diagnosis, provide evidence for interventions, and promote widespread understanding of this complex condition.

**Dame Stephanie Shirley,
Founder and President, Autistica**

Since I founded the charity in 2004, Autistica has gone from strength to strength. It is now established as a pioneer in its field and the UK's leading charitable funder of autism research. This report shares the experiences and opinions of families living with autism across the UK, voices we too often do not hear. In placing families at the heart of its science strategy, Autistica continues its focus on research targeted to make a real difference, research aimed to produce tangible results in the sea of need. This consultation marks the beginning of an exciting new chapter for Autistica, and I urge all those who care about autism to lend their support however they can.

**Professor Martin Knapp,
London School of Economics**

Autism remains one of the UK's most expensive medical conditions, costing over £28 billion each year, largely in adult care and lost earnings. Yet we currently spend little on medical or social research to help us understand this highly prevalent condition and explore new interventions. There is no question that this spending imbalance impacts on the often terribly difficult lives of those with autism, and ultimately on the public purse. The views expressed in this document show that families and individuals with autism continue to struggle, and are desperate for more scientific progress. We must do more to explore early interventions to improve life chances, and to fund research to help remove barriers to work in adults such as anxiety and depression. In a time of austerity, the question is most certainly not 'Can we afford to invest in autism research?', but rather, 'Can we afford not to?'

> *"In a time of austerity, the question is not 'Can we afford to invest in autism research?' but 'Can we afford not to?'"*
>
> **Professor Martin Knapp**

Executive summary

Throughout 2012 Autistica, in partnership with Headstrong Thinking and Newcastle University, conducted a consultation with parents and individuals with autism* to collect information in four key areas:

1. Living with autism

Families wanted to highlight both the positives as well as the challenges of living with autism. Three quarters of parents felt they had learnt about autism and other disability issues, and adults with autism spoke of the importance of being part of an autism movement. Other adults with autism spoke of having special cognitive abilities such as good concentration. However, 94 percent of parents said that they worried about the future of their child, and adults reported feeling socially isolated. Perhaps the greatest difficulty that families reported on was being marginalised from society, with 72 percent of parents feeling judged or misunderstood by others.

2. Experiences of the UK health system

Families highlighted the challenges they faced getting a diagnosis and receiving adequate information and services. Three quarters of adults reported that no specific interventions had helped them in the months after diagnosis and 55 percent of parents reported not receiving enough information on autism when their child was diagnosed. Almost two thirds of respondents expressed some concern about the idea of using medication to treat aspects of their child's or their own autism, and there were mixed experiences in terms of interactions with GPs, with half of parents and adults describing the experience negatively.

3. Attitudes to scientific research

Ninety percent of families recognised the importance of science to improve our understanding of autism. Two thirds of adults and 84 percent of parents agreed that the government should consider autism as a medical research priority. Families clearly understood the important role science has to play when selecting interventions but 34 percent of parents and 28 percent of adults with autism reported using interventions which were not scientifically proven. Broadly speaking, families wanted to help shape the direction of research in partnership with scientists and funders, and almost 90 percent of respondents were interested in taking part in research.

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*We are using autism in this report to include the range of autism spectrum disorders – autism, Asperger syndrome, pervasive developmental disorders not otherwise specified and atypical autism.

4. Research priorities

Adults with autism prioritised research which would focus on improving diagnostic practice and getting diagnoses quicker, with 42 percent of respondents classifying the statement "I wish my autism had been diagnosed earlier" as their number one research priority. Interventions were also key for adults, in particular those that focus on improving anxiety and social skills. Parents' medical research priorities were for more interventions at the time of diagnosis and interventions that would focus on difficulties such as mental health problems and sleeping. Earlier diagnosis and understanding causes were also priorities for parents.

As a result of the challenges faced by people with autism and the lost opportunities there is a £28 billion[1] annual cost to the UK economy, yet spending on autism research in the UK is low. Government and charitable funders should prioritise medical research spent on autism to alleviate the difficulties that families across the UK face. By putting families at the centre of decision-making we can help target research funding to the areas which will bring the greatest change.

> *"I think science can help people understand and then that helps, that gains acceptance as well... one of the other areas is the stigmatism and the embarrassment and the social pressure that you find yourself under when you've got a child with autism. So the more people are aware and the more accepting they are, the easier your life is made."*
>
> **Father, Nottingham**

Introduction

Autism – Evidence shows that around one percent of the population,[2,3] or 600,000 people in the UK, have autism, although many people remain undiagnosed. As the prevalence and awareness of autism has increased, there has been an increase in the amount of research conducted.[4] However, despite advances being made by scientists, there remains relatively little funding for autism research. Only a small amount of research has led to practical improvements in the lives of people with autism and their families.[4]

Autism is typically diagnosed by identifying a range of behaviours that fall into certain categories. People on the autism spectrum have difficulties in developing a full range of social and communication skills. They may also be repetitively focussed on certain topics or they may like set routines. A large number of people with autism find the sensory world, for example the sight or feel of things, difficult to manage, which in turn can cause anxiety and stress.

As well as the core difficulties in social, communication and repetitive behaviours, people with autism have high rates of co-occurring difficulties, such as epilepsy, sleep disturbance, gastrointestinal issues, intellectual impairment and mental health problems.[5,6] Without effective support these difficulties have a significant effect on people's life chances and opportunities: only 15 percent of adults with autism are in full-time work and a substantial proportion require life-long care, which results in autism being one of the most expensive costed medical conditions at £28 billion per year in the UK.[1]

Despite the challenges faced by people with autism, they bring much joy to their families and communities, whether that is through their unique ways of seeing the world or their achievements in a particular field. For very many families, the greatest challenge they face can be to overcome the stigma attached to autism and the feeling of being isolated from society.[8]

Autistica – Autistica is the UK's leading autism research charity. Since being founded by Dame Stephanie Shirley in 2004, Autistica has raised and invested over £4 million in medical research to understand the causes of autism, improve diagnosis and deliver the best interventions and treatments. The charity is a member of the Association of Medical Research Charities (AMRC) and has a strong reputation of funding excellence in basic science (www.autistica.org.uk/research).

As part of an ongoing strategy to ensure that the research funded makes the greatest impact for families, Autistica partnered with autism researchers at Newcastle University and with Headstrong Thinking to consult with families about the daily challenges they are facing, their impressions of current research, and the questions they would like answered by research.

The consultation

The consultation combined qualitative interviews to provide in-depth insight and understanding, and large online surveys to provide robust quantification of opinions. Information was collected in these two ways from parents of children with autism, and from adults with autism themselves (henceforth simply referred to as parents and adults).

A total of 979 responses (793 parental responses; 186 adult responses) were included in the final survey data analysis, and 44 further individuals were interviewed. It is worth noting that only adults who were able to complete an online survey could be included, so our adult sample is not representative of all people with autism. More detail on the design of the consultation and limitations of the sample can be found at the end of the report.

This was a broad consultation and we received widely different opinions from the autism community. We feel that it is important that all opinions are considered valid and have therefore included in this report some strong statements made by people with autism, or parents, which, while by no means felt by all, reflect real experiences or feelings and deserve to be heard.

1. Living with autism

Many parents wanted to highlight the positive aspects that living with a child with autism brought to their lives. They spoke about their child being innocent, having a good sense of humour and having a unique way of looking at life. Parents also spoke about how much they learnt from their child and how much they benefited from the support that came from other parents.

Three quarters of parents felt that having a child with autism meant that they had learnt a lot about autism and other disability issues; two thirds felt that experience of autism had given them a perspective on what really matters in life.

> *"I've got a son with a diagnosis of autism, and he's got other associated difficulties. He's gorgeous, he's really funny and handsome, really lovely and I love his sense of humour."*
>
> **Mother, Newcastle**

> *"I always say, we're a package, this is our family, take us or leave us!"*
>
> **Mother, Birmingham**

Family members learnt a lot from each other, particularly when families had autism across generations and could support each other with personal insights.

> *"I really understand my son, and put in strategies to help him with his difficulties, as he has a diagnosis of Asperger syndrome also."*
>
> **Adult, North-West England**

Approximately 10 percent of parents who responded to the survey reported having an autism diagnosis and an additional 11 percent "strongly suspected" that they have autism. Approximately 18 percent of adults with autism reported having a child with autism. These findings need investigating further to be certain of how representative they are, but it does indicate that a significant proportion of families in the UK are living with autism across generations. If replicated, this pattern highlights the importance of considering the needs of all family members when planning interventions and services.

Adults with autism reported that a positive aspect of having autism was that they were part of a unique group. Many also celebrated autism culture and the self-advocacy movements. They also focussed on aspects of cognition that gave them advantages over people who do not have autism, in particular the ability to focus on specific tasks. For some people, special skills and areas of advanced intelligence were highlighted as positive aspects of having autism.

> *"I work in a job that requires high levels of concentration, focus, and the ability to process information quickly. These seem to come naturally to me."*
>
> **Adult, Survey**

There are diverse opinions from families when describing what autism has brought to their lives. Even among those who reported positive experiences, parents spoke about how having a child with autism puts increased pressure on day-to-day life. Twelve percent of parents reported that autism had not brought anything positive to their lives. In contrast, only one percent of parents said that there was nothing negative about living with autism. Parents cited a lack of sleep, the need to meticulously plan everything, having to juggle many things at once, or not having enough time for the children in the family who do not have autism.

> *"It controls every breath of your day, from the second you wake up to the second you go to sleep; you have to think about the preparation, the consequences, the rest of the family, in every decision you make concerning the person with autism."*
>
> **Parent, Survey**

> *"Everyone plans their life around their child but they don't have to plan for their child lying down in the middle of the road, with loads of shopping bags, and having to put the shopping bags down, physically wrestle the child up out of the road, and then ask a stranger to bring the bags from the middle of the road."*
>
> **Mother, Parsons Green**

Ninety-four percent of parents told us that they worry about the future of their child with autism. These worries were beyond those of parents of typically developing children. They worried about who was going to look after their child with autism when they are gone; how would social services support their child in adulthood and old age; what pressure and responsibility would be put on other family members to look after their child with autism?

> *"They are going to end up in some sort of residential home, and my children are non-verbal. So they can't tell you what's happening. It's scary that they'll be on their own. Who is going to listen to them? I don't want them to be shoved in a corner and forgotten about."*
>
> **Mother, Peckham**

Many families of people with autism report the life-altering impact of having a child who rarely sleeps, who may suffer from profound anxiety and who has regular outbursts. These reports from parents are in line with recently published data from Newcastle University researchers who surveyed parents about the rates of behavioural and medical difficulties most often faced within the family.[5] See blue box.

> *"It feels like you don't really belong in this world and you know that you never will."*
>
> **Adult, Survey**

Newcastle University Study: Emotional and behavioural problems in children with autism.[5]

Information was gathered from 863 families who reported on the emotional and behavioural problems of their children with autism. Parents reported a high rate of behaviour problems, with 53 percent of children having four or more types of problems, three or more times a week.

The following problems were more common in children with lower language level and attending special school: sleep, toileting, eating, hyperactivity, self injury and sensory difficulties. However, anxiety, tantrums and aggression towards others were frequent in children no matter what their age, ability or type of school.

Adults with autism reported some of the challenges they face in terms of understanding the social world around them, such as in making friendships or reading people's facial expressions. Other reports from adults focussed on the debilitating levels of anxiety they felt and how that interrupted their daily lives.

> *"There are many negative things about autism but I find the lack of being able to make social relationships hits the hardest. This is because many people tend to find you strange and therefore avoid you."*
>
> **Adult, Survey**

Overall though, both adults and parents highlighted that one of the major negative experiences of living with autism was being marginalised by society, not given the right opportunities and being stigmatised because of their own or their child's autism. Seventy-two percent of parents reported being judged or misunderstood by other people and 62 percent of parents felt that they were isolated from those around them.

> *"People do not see invisible disability."*
>
> **Adult, East Anglia**

2. Experiences of the UK health system

A significant challenge for people with autism and their parents is searching for and receiving a diagnosis of autism. For some families, there are long periods between when parents first express concern about their child's development, and when they finally receive a diagnosis.[7]

Recent findings from the National Autistic Society showed that a third of families wait more than three years for a diagnosis.[8] There is evidence that adults have an even greater struggle to identify clinical centres that are willing and equipped to provide them with the right clinical expertise.[9]

> *"We can look back at every single report and think, why didn't someone diagnose him then, or then, or then?"*
>
> **Mother, Birmingham**

Parents reported a range of emotions when they finally received the diagnosis, including: relief, despair, anger, and guilt. Some parents thought that they would have liked to receive the information from clinicians in a more comprehensive way (e.g. some had not received any information on the diagnosis in writing) and with a clearer explanation of what autism was, how severely their child was affected, and what the future held for their child.

> *"Every mother or every father has a child, and as soon as you have that child, you're thinking ahead, you're planning their whole lives, aren't you? And suddenly somebody says your child's autistic, and that whole life or the life you think your child's gonna have just absolutely crumbles to dust."*
>
> **Father, Newcastle**

> *"The paediatrician said he would grow out of it, there was nothing wrong with him… The priority should be diagnosis, better diagnosis, so we can influence better outcomes for the generations to come."*
>
> **Father, Nottingham**

Once a diagnosis was received, many parents and adults felt that there was very little help available to them. Three quarters of adults reported that there was "no specific help (e.g. information, strategies or interventions)" that they benefited from in the months after diagnosis, and 55 percent of parents reported not receiving enough information on autism once a diagnosis for their child had been given. When asked, 74 percent of adults reported that they wanted interventions to help reduce their worries and stress, and 61 percent reported wanting support to help with their social skills. Eighty percent of parents reported they would have liked to receive an intervention within the first month after diagnosis. It is noteworthy, however, that this figure leaves a fifth of parents who need time before they are ready to start with a programme of intervention.

> *"You get the diagnosis and you think it's going to be the magic key and then you open the cupboard and there's nothing in it."*
>
> **Mother, Birmingham**

Parents and adults were asked for their opinions on the use of medication to help with the difficulties that go along with autism, such as sleep, poor mental health or attention problems. Sixty-two percent of parents and 60 percent of adults responded yes to the statement: *"Do you have concerns about using medication to help with your or your child's autism now or in the future?"* Typical concerns were adverse side effects, lack of positive effect and potential dangers.

> *"I felt the diagnostician gave a very stereotyped description of my condition in the report, leading to recommendations which did not really apply to me."*
>
> **Adult, Survey**

The written responses in the survey relating to families' interactions with their GPs showed stark contrasts, with some describing the incredible support their GP provided and others highlighting their GP's lack of knowledge about autism. From the survey, two thirds of adults with autism reported seeing their GP about their autism; 59 percent regarded that experience as 'negative'. Similarly, half of the parents reported seeing their GP as part of their child's autism care; 50 percent of these parents regarded the experience as being negative. An example of good practice was reported by two adults with autism where their GP had employed them to act as autism specialists within the surgery.

> *"My GP was incredibly supportive on a personal level, but had no previous experience of autism in adults, and had very little idea where to find help. When she did discover where to refer me, the NHS repeatedly refused to fund the assessment, despite my GP's recommendation that this was appropriate."*
>
> **Adult, Survey**

3. Attitudes to scientific research

Most people surveyed recognised the importance of science to help us further understand autism. Ninety percent of parents and 89 percent of adults responded that there is a need for a greater scientific understanding of autism.

Eighty-two percent of parents and 57 percent of adults agreed that more medical research into autism would positively affect their lives. Two thirds of adults and 84 percent of parents felt that the government should consider autism a medical research priority. People with autism and parents reported being keen to participate in autism research projects, with 86 percent of adults and 90 percent of parents responding that they would be interested in taking part in autism research, though it should be noted that the sample had self-selected to take part in the survey, so were already arguably "pro-research".

Many parents saw that science has an important role to play in disproving some of the non-evidence-based practices that may be promoted.

> *"...it's so hard when there are unscrupulous people out there, touting…or providing parents with misinformation."*
>
> **Mother, West Kensington**

> *"How could anybody be against it? Scientific research, it can only be for good."*
>
> **Father, Newcastle**

Twenty-eight percent of adults and 34 percent of parents in the survey reported that at some point they had tried interventions which were not scientifically proven. In interview, parents recognised the importance of demonstrating the effectiveness of interventions and treatments by using scientific approaches.

> *"I am a strong believer in evidence-based approaches; I have no time for stuff that hasn't been properly researched in an academic setting and peer reviewed."*
>
> **Father, Kew**

Some families in the survey expressed concern about the purposes of research, and two main themes emerged. Half of adults and a fifth of parents agreed with the statement *"I worry about how the findings from autism research may be used".* In the interviews, parents were able to explain that while they wanted to understand their child's autism, they did not necessarily want a cure. Some were anxious about research, particularly genetic research, which might have prevention or cure as a goal. However, other parents were interested in more research on causes to learn about future chances for them or their children to have a child with autism.

"My daughter is now in her twenties, she's beginning to think about having children, she's an intelligent girl, she's started looking at the genetics and she was asking me recently, what's the statistical likelihood of me having an autistic child?"

Mother, Birmingham

The second theme to emerge from the qualitative data was that respondents wanted to see more evidence that findings from medical research were being used to improve the lives of families.

"I think we should be making science work harder for us to make life more bearable."

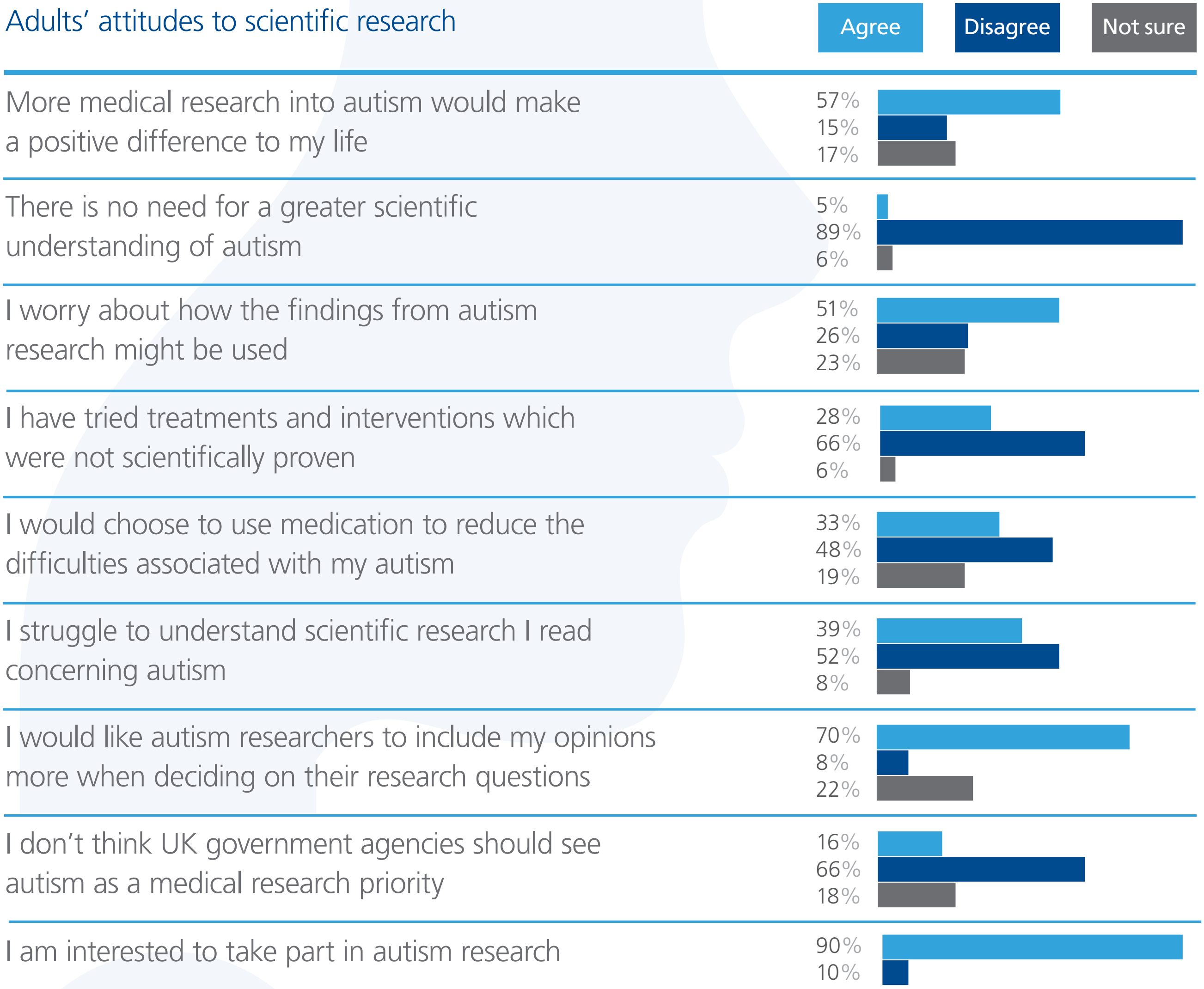
Father, Nottingham

Many families felt their opinions should help shape the direction of research. Two thirds of parents and adults agreed with the statement *"I would like autism researchers to include my opinions more when deciding on their research questions"*. There was a sense from some respondents that science had a role to play in terms of reducing the stigma and misinformation surrounding autism.

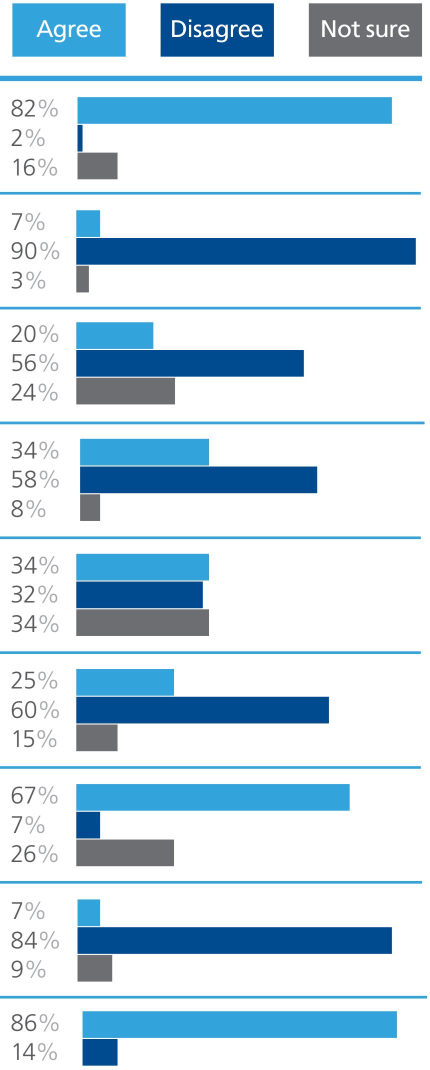
"People on the spectrum should be engaged more about influencing the direction of research."

Adult, Survey

Adults' attitudes to scientific research



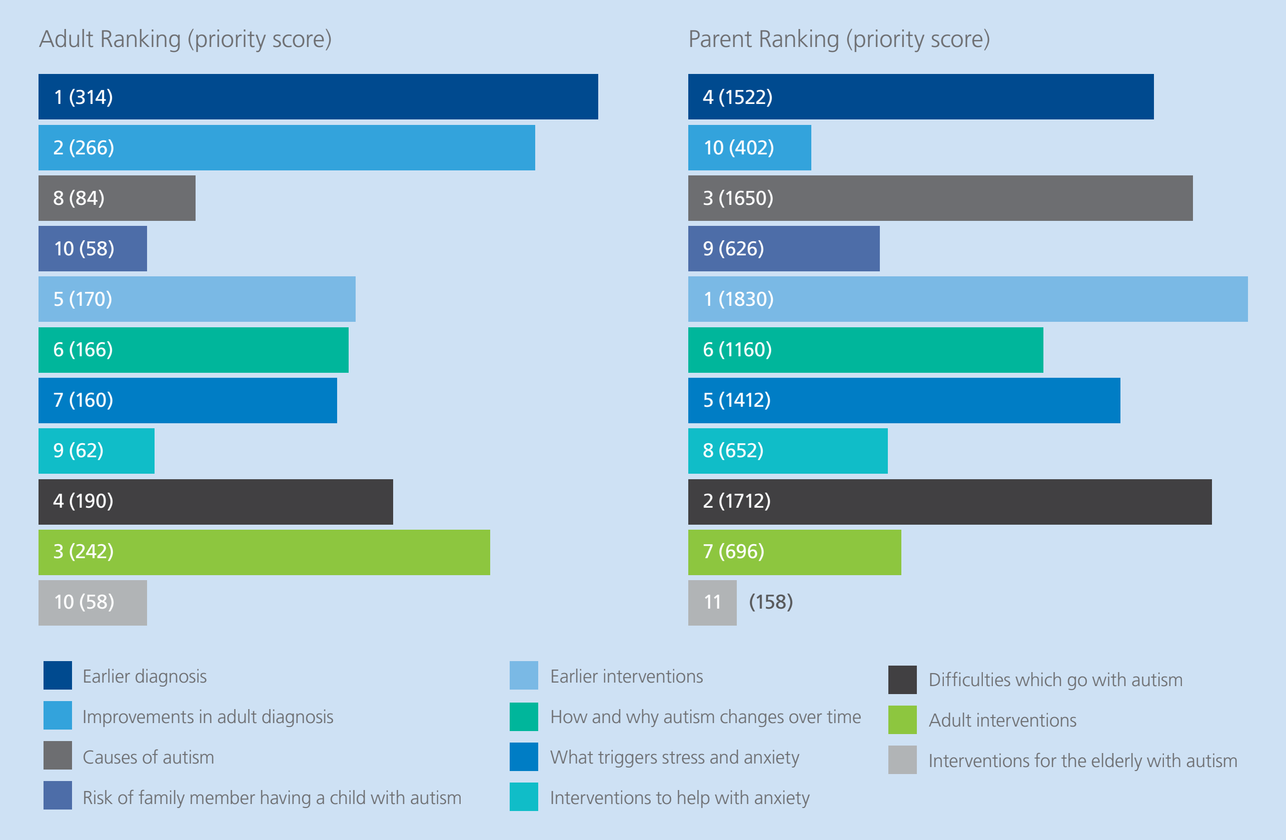
Parents’ attitudes to scientific research



	Agree	Disagree	Not sure
More medical research into autism would make a positive difference to our lives	82%	2%	16%
There is no need for a greater scientific understanding of autism	7%	90%	3%
I worry about how the findings from autism research might be used	20%	56%	24%
I have tried treatments and interventions which were not scientifically proven	34%	58%	8%
I would choose to use medication to reduce the difficulties associated with my child’s autism	34%	32%	34%
I struggle to understand scientific research I read concerning autism	25%	60%	15%
I would like autism researchers to include my opinions more when deciding on their research questions	67%	7%	26%
I don’t think UK government agencies should see autism as a medical research priority	7%	84%	9%
My family and I are interested to take part in autism research	86%	14%	

4. Research priorities

Parents and adults were asked to choose their five top priorities from a set of 11 possible medical research questions, and number these 1– 5, with 1 as their top priority. From this, we calculated an overall priority score and were able to rank research questions by priority for adults and parents (see full list of questions on page 30).



Priority score was calculated based on the number of times a research question was ranked first, second, third, fourth, or fifth by a respondent, with every first priority given 10 points, second given 8 points, and so on. As we had more parent respondents, the parent scores are higher.

Adults with autism felt most strongly about the diagnostic process. The overall number one priority statement for adults was *"I wish my autism had been diagnosed earlier"*, with 42 percent of adults ranking this most highly. The second priority statement was *"I would like to see improvements in the way adults are diagnosed"* with 19 percent of adults putting this at number one. They were also interested in better interventions, with "interventions for adults" as a third priority, "interventions for medical conditions which go with autism" fourth, and "interventions in the months after diagnosis" fifth.

> *"[I felt] deep grief for the 50 wasted years of pushing myself so hard against impossible odds and feeling so bad about myself."*
>
> **Adult, Survey**

> *"I would like more interventions for anxiety and other common mental health problems as related to autism needs and strengths."*
>
> **Adult, Survey**

Turning to parents, there was also a focus on interventions, and as early as possible. The overall highest priority was the statement *"I would like research to be funded into interventions that could be provided in the months after diagnosis"*. Parents wanted interventions for conditions associated with autism, as well as the core difficulties, as shown by their second priority being: *"I would like research and interventions into the difficulties that often go along with autism (e.g. sleep, picky diet, epilepsy)"*. The third priority statement for parents was a better understanding of the causes of autism, with 21 percent of parents putting this as their number one priority. Parents also wanted their child's autism to have been diagnosed earlier, in fact for 23 percent, this was the top priority: *"I wish my child's autism had been diagnosed earlier"*, although overall this came out with the fourth highest priority score. In summary, interventions, causes and early diagnosis were identified as parents' top research priority areas.

> *"She stopped smiling, she became very quiet and I sort of noticed a withdrawal from myself and it made me think that this child didn't really want me or love me. I didn't know it was autism. But when she was diagnosed, it was a flood of relief, to finally know that it wasn't me going mad, that there was something wrong but we could start working with it."*
>
> **Mother, Peckham**

In summary, adults in the survey prioritised areas of research that would focus on improving diagnostic practice for adults and greater research into interventions for adults. Parents focussed more on interventions, causes and earlier diagnosis.

As the interviews allowed for a wider expression about research priorities, there was greater variation in the responses collected. Parents spoke about the relief at diagnosis of understanding what was wrong, and wishing that it had come sooner or been easier. A strong interest in knowing more about what causes autism emerged, and the lack of awareness about the causes of autism had clearly left some parents feeling guilt or blame.

> *"I think people stay angry for a long time because the cause isn't defined, and it would give these people some definitive…this is what caused it, it wasn't your fault."*
>
> **Mother, Parsons Green**

> *"I am not one of those mothers who says: 'I wouldn't want a cure, I love my child exactly how he is.' I do love my child exactly as he is, but anything that could help him achieve a more independent life, a less worrisome financial future and to achieve normal relationships, and gain support and love from those around him, I would tick the box tomorrow."*
>
> **Mother, West Kensington**

Understanding more about associated issues that go along with autism (allergies; changes around puberty; anxiety) was raised by a number of parents as an area of research interest. There was a strong theme for researchers to do more to understand how autism changes with time and, in particular, how autism changes through adult life.

> *"I think, early intervention, great, but what about development across the life span?... You have to have hope that your child is going to make progress in their own way."*
>
> **Mother, Newcastle**

> *"The thing that would make the biggest difference would be mental health. We are beginning to know what ordinary people need to be well and we need to know if that's different for people with autism."*
>
> **Mother, Manchester**

Conclusions

Our survey reveals that parents and individuals with autism are enthusiastic about scientific research. They want to be involved in the process of research and they want to see outcomes from research that are relevant to the challenges that they face.

A number of key points emerge from our survey:

1. Awareness

Despite increased autism awareness, families still experience the daily stigma of autism. Seventy-two percent of parents feel isolated and misjudged by other people, and 94 percent worry about their child's future.

2. Driving Forward Research

Eighty percent of parents thought that more research would make a positive difference to their lives, and almost 90 percent of our survey wanted to take part in research themselves. Approximately one third of adults and parents had tried interventions that had no scientific evidence of effectiveness.

3. Early Diagnosis

Parents and adults want diagnosis to be earlier and easier. More parents and adults chose this as their number one priority than any other research area.

4. Effective Interventions

Even when a diagnosis is received, many families do not receive adequate early intervention or information. Three quarters of adults and half of parents reported a lack of useful information or interventions immediately after diagnosis. There is a strong desire for research into interventions which will address the problems which go alongside autism throughout life, such as mental health difficulties, epilepsy and sleep issues.

This Autistica consultation with parents and adults is a first step in an ongoing process by the charity to look at greater engagement with families and to improve communication between families, researchers, funders and medical practitioners in order to set research priorities.

Autism research continues to be poorly funded in the UK, despite the significant social and economic costs associated with the condition.[1] Families have communicated clearly what their research priorities are, and these will shape Autistica's future research strategy. We also urge other funders, both government and charitable, to hear the voice of families and invest in research that will ultimately lead to improvements in the quality of life for the one in a hundred people in the UK who live with autism day by day.

Design of the consultation

The consultation combined both qualitative methods, including face-to-face focus groups and telephone interviews to provide in-depth insight and understanding; and large online surveys to provide robust quantification of opinions. Information was collected in these ways from parents of children with autism, and adults with autism themselves.

Qualitative methods

The aim of the qualitative consultation was to provide insight and understanding into the lives of families affected by autism. We used a mix of focus group discussions, each involving between three and eight people, supplemented by paired and individual in-depth interviews. Each research session lasted between an hour and an hour and a half. Interviews were semi-structured with a discussion guide but respondents were also encouraged to talk about whatever was important to them.

Respondents were recruited via local networks, usually charities and schools. In total, 43 parents (33 mothers and 10 fathers) took part, as well as an adult male with Asperger syndrome. Care was taken to ensure a good geographic spread by visiting eight locations in five cities, and ensuring a good mix of income and education levels. Particular care was taken to ensure a good representation (n=7) of respondents from ethnic minorities. Telephone interviewing was used as an option when face-to-face was not culturally appropriate. Fieldwork took place between November 2011 and November 2012.

Participants included in the qualitative sample

Research location	Local authority	Mothers	Fathers
London: Peckham	Lambeth	4	0
London: Twickenham	Richmond upon Thames	2	1
London: Kew	Richmond upon Thames	1	1
London: West Kensington	Hammersmith & Fulham	5	0
Birmingham	Birmingham, Dudley, Calderdale	3	0
Nottingham	Nottingham City, Nottinghamshire Council	3	7
Manchester	Manchester, Trafford, Bolton, Stockport	5	0
Newcastle	Gateshead, North Tyneside, Durham, Newcastle	7	1
Telephone	Westminster	3	0
TOTAL		33	10

Large surveys

A total of 979 responses (793 parental responses; 186 adult responses) were included in the final survey data analysis from two sets of questionnaires. The first questionnaire asked families about living with autism and their experience of the UK health system. The second questionnaire was written and distributed in partnership with Newcastle University and consulted on families' impressions of science and what they see as autism research priorities.

The demographics of respondents to the Autistica and the Newcastle surveys were broadly similar and have been combined into single parent and adult sample descriptions. Survey data were collected via Survey Monkey and the questionnaire was open from early September to the middle of October 2012.

Eighty-five percent of the adults who responded to our survey had a diagnosis of Asperger syndrome or high functioning autism; eight percent had an autism spectrum disorder (ASD) diagnosis; seven percent had an autism diagnosis. The adult sample's mean age was 41 yrs old (range 16-77yrs) and 51 percent were male. Mean age of diagnosis was 34 yrs (range 2-65yrs). Ninety-seven percent of respondents classified their ethnicity as white. Eighteen percent of adults with autism reported also having a child on the autism spectrum.

Thirty-three percent of parents surveyed had a child with an ASD diagnosis; 32 percent with an autism diagnosis; 32 percent with a high functioning autism or Asperger syndrome diagnosis (the remainder had a pervasive developmental disorder – not otherwise specified, or an atypical autism diagnosis). The majority of parents had young children with autism (mean age was 12 yrs old, with a range of 2-60yrs) and 83 percent of the children were male. Forty-five percent of the parents had children with autism attending a mainstream school; 27 percent were in a special school; 14 percent were no longer in education; the remainder were in pre-school or further/higher education. The majority of the parents surveyed had children speaking in full sentences (56 percent); 22 percent had children speaking in simple phrases and the remainder used single words or used no speech. The majority of parents who responded were female (84 percent), defined their ethnicity as white (91 percent) and their mean age was 45 yrs old (range 17-80yrs). Ten percent of parents reported having an autism diagnosis themselves and 11 percent responded that they did not have a diagnosis but they strongly suspected that they have autism. Thirteen percent of parents had more than one child with autism. Parents came from England, Scotland, Wales and Northern Ireland. For more information on the geographic breakdown of our survey samples please visit our website: www.autistica.org.uk.

Both surveys allowed for the collection of descriptive data (e.g. percentages and frequencies) as well as qualitative responses (eg. open comments). The surveys were designed after extensive consultation amongst the research partners, with parents, adults with autism and with practitioners.

This process was extremely useful in guiding both the content and language included in the surveys. The survey questions were also selected to complement the qualitative consultation that was led by Headstrong Thinking and to fit with Autistica's previous and possible future priorities. The final questions selected did not cover the whole range of autism research (e.g. including social research) but rather focused on Autistica's medical research priorities.*

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*There is an ongoing consultation run by the Institute of Education looking at priorities across the research field and from a range of stakeholders – adults, parents, researchers and practitioners.

Each question was scored on the weight of the priority given by respondents, with every "number one priority" gaining 10 points, "number two priority" eight points, and so on, so that a priority score could be given. Percentages were also calculated for how often adults and parents marked a research statement as their first priority. We summarised these research questions in the graphs and text, but the full questions are below:

- I would have liked my/my child's autism to have been diagnosed earlier
- I would like to see improvements in the way adults are diagnosed
- I would like to know what causes autism
- I would like to know what the chances are for relatives to have a child on the autism spectrum
- I would like research to be funded into interventions that could be provided in the months after diagnosis
- I would like to know more about how and why autism changes over time
- I would like to know what triggers my/my child's stress and anxiety
- I would like to see interventions for my/my child's anxiety
- I would like research and interventions into the difficulties that often go along with autism (e.g. sleep, picky diet, epilepsy)
- I would like more research on interventions for adults on the autism spectrum
- I would like to see research into interventions that would help elderly people on the autism spectrum

Autistica disseminated the surveys through its own email list, and through those of the National Autistic Society, Ambitious About Autism, the Autism Alliance, as well as other regional partners. More targeted approaches were made by Autistica and Newcastle University to encourage participation of adults with autism. Newcastle University used the Autism Spectrum Database UK (ASD-UK, a national registry of families interested in research: www.asd-uk.com) and Daslne (the Database of Children with Autism Living in North East England) to share the survey link by email and website (http://daslne.org/). If families had more than one child with autism they were given the option of completing the survey more than once. Families were told that all information would be de-identified and permission was asked to use anonymised quotes.

Data were analysed by conducting a thematic analysis of the responses from the qualitative consultation and some of the survey questions, and by generating descriptive statistics from the remaining survey questions.

Notes and references

A note on the sample

Given that families self-selected to complete a survey related to research priorities, as well as the fact that a significant proportion of respondents were contacted through ASD-UK and Daslne (both family research databases), the sample is more likely to include individuals who are research active, as well as being interested in and opinionated about research.

In total there were 1,287 responses to the survey. After filtering out individuals where responses could not be included (largely because they were either a non-UK resident or that they decided not to continue with the survey after the first question) there were 979 usable responses. The demographics of the parent and adult groups responding to each of the surveys was broadly similar, although it is worth noting that the parents who responded to the Newcastle survey had slightly younger children, who were in more mainstream school settings, were more likely to have a diagnosis of autism spectrum disorder and had more language when compared with the children of the parents from the Autistica survey. The similarity of the sets of parents and adults with autism means that their demographic data are presented collectively.

It is important to note that due to the nature of our methods we were only able to survey the opinions of adults with autism who were able to complete an online survey, which excluded many people with severe intellectual impairment or poor verbal skills. We therefore recognise that our adult sample is not representative of all people with autism. It is also worth noting that approximately 50 percent of adult respondents were female, which is unusual given that the gender ratio in autism is 4 males to 1 female.

It is unclear as to why there was a higher than expected rate of females in the sample but for most of the questions there are no reasons to predict a significant effect of gender influencing responses.

Because of the restricted timescale and resources attached to this project, the surveys were only open to respondents online and so those without access to the internet were unable to complete the survey.

As with many other surveys, there was a predominance of respondents who classified their ethnicity as "white" and despite the fact that the qualitative research actively sought the opinions of parents from a black and minority ethnic backgrounds, future consultation should focus on ways of gathering more diverse ethnic opinion.

The survey questionnaires are available on request and will eventually be posted on the Autistica website with this report.

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About the authors

Alison Hardy

Alison Hardy is a director of Headstrong Thinking Limited, a consultancy that advises organisations on how to use marketing skills to achieve behaviour change for the social good. Her specialism is health-related behaviours and her recent work has involved insight and understanding into obesity, early presentation to NHS services (for cancer and dementia) and use of infertility services. Her son, Alfie, has autism.

Dr Simon Wallace

Simon studied psychology at the University of London before completing his PhD at the Institute of Psychiatry, London. He has been involved in autism research since 1994 and for much of his career worked as a psychologist on the International Molecular Genetics Study of Autism Consortium (IMGSAC), a project that aimed to identify the genes for autism spectrum disorder (ASD). In late 2008 Simon took up a post as Autism Speaks' European Director of Scientific Development and he joined Autistica in January 2012 as their Research Director.

Dr Jeremy Parr

Jeremy is a consultant in paediatric neurodisability, and senior lecturer at the Institute of Neuroscience, Newcastle University. Jeremy works in the North East's regional paediatric neurodisability service at the Great North Children's Hospital, and in the regional ASD diagnosis and management service. He sees children with autism each week. Together with colleagues, Jeremy is part of a strong ASD child development and disability research group at Newcastle University.

Thank you

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balloon dog

BRUNSWICK
Newcastle University
Autism Spectrum Database-UK
Daslne
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AUTISTICA

With knowledge comes understanding

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100a Chalk Farm Road, London NW1 8EH, United Kingdom.
T: +44 (0)5601 183 601 E: info@autistica.org.uk