

Improving lives through research



AUTISTICA

Building brighter futures through autism research

**IMPACT
PLAN**

autistica.org.uk/impact

CONTENTS

- 01 Our vision, mission and values
- 02 The need for our research
- 03 What we do
- 04 A history of impact
- 05 How we make a difference
- 06 GENERATING IMPACT**
- 07 High quality science
- 08 Involving our community
- 10 Making the UK a world leader in autism research
- 11 Working in partnership
- 12 DEMONSTRATING IMPACT**
- 13 Practical, ethical and appropriate research
- 15 TACKLING OUR BARRIERS TO IMPACT**
- 16 Five barriers to impact
- 17 Addressing our barriers to impact
- 21 CONCLUSION**
- 21 Committed to improving lives

Front cover image: Ashleigh at a play session run by community organisation A2ndVoice

Image on this page: Martin, playing cards at a day centre run by the Kent Autistic Trust



Our vision

Our vision is a world where every autistic person has a long, happy, healthy life.

Our mission

- To improve outcomes for autistic people of all ages through world-class research.
- To grow autism research in the UK through innovative collaborations with other funders, campaigning for increased state investment and developing capacity and infrastructure within the research community.
- To be the bridge between researchers, policymakers and autistic people, ensuring that services are evidence-based and research responds to the autism community's needs and desires.

Our values

1

COMMUNITY

Our community is involved at all levels

Our research priorities are largely derived from the top ten questions for research as identified by autistic people and their allies. We are already leaders in involvement but our new involvement strategy takes this to new heights. It ensures autistic people are involved during the full research cycle through dialogue between researchers, autistic people and families. This means research will have greater, faster impact for the people we serve.

2

CONFIDENCE

We are confident in our vision and in autism research's capacity to change lives

We don't accept the life chances that autistic people currently face. When that meant facing up to the early deaths of autistic people, we campaigned worldwide to make this a research priority. Now we will fund vital studies to address this appalling inequality. We have clear ideas based on cutting-edge evidence and we fund innovative ideas and kick-start research in new areas. We make the right decisions, not the easy ones.

3

COLLABORATION

We collaborate with others

Progress is best made together. We work in partnership and want everyone to win. Autistica is working with international funders to develop autism research, including initiatives to understand global trends in funding for autism research. We proudly work with national and international research funders, and charities for autism, neurodevelopmental disability and mental health.

The need for our research

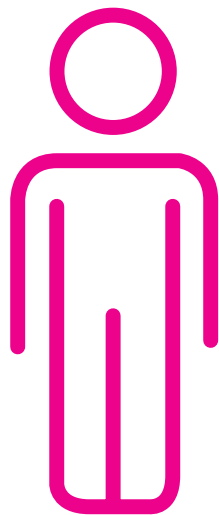
Autistica aims to offer autistic people and their families the chance of a long, happy, healthy life.

Despite scientific advances, too many autistic individuals and their families still tell us that they face a life-long struggle to access appropriate support and services.



70% of autistic people have a mental health condition

Many autistic people face shorter life expectancy due to poor health



On average just £9 is spent on autism research per person per year

Research has the capacity at national and global levels to transform this experience, raise awareness, and ensure that services are based on the latest evidence. However, autism research is greatly underfunded compared to other medical conditions and a coordinated and focused effort is required to deliver changes for the one in a hundred autistic people in the UK and around the world.



Image: Samuel on the beach

What we do

We harness the potential of cutting edge science to improve the lives of all autistic people and their allies by:

- Funding and promoting ground-breaking medical research on autism and related conditions.
- Improving understanding of autism.
- Advancing new therapies and interventions.

As a small charity with a desire for major impact, we fund and develop research where gaps exist, and ensure the outputs result in increased funding and practical outcomes.

Our priorities

We work with autistic people to understand their priorities for research so that we can make a difference at every stage of their lives. As a result our current areas of focus (2017-2021) are:

- Addressing mental health and suicide
- Physical health
- Language and communication
- Epilepsy and autism
- Sensory processing and environments

A history of impact

Autistica has achieved a great deal but there is so much more to do. This plan presents examples of our notable activities to date and sets out how we will improve our impact, and record and report on our achievements.



OUR LEGACY

2004	2007	2008	2010	2013	2014	2015	2016
Founded by Dame Stephanie Shirley	Funded the British Autism Study of Infant Siblings (BASIS)	Co-funded the first chair of autism research in Wales Funded the establishment of the Brain Bank for autism at the University of Oxford	Joined the Association of Medical Research Charities	One in a Hundred Report published - a community consultation on research attitudes	Set up the Autistica Research Centre for Ageing with Autism	Launched mental health research programme	Published 'Personal tragedies, public crisis' report Led James Lind Alliance priority setting partnership

OUR LEGACY

2017	2018	2019
Held first international research summit Launched Discover national autism research network	Recruited the first 10,000 people into the Discover network Gave £1.3m in grants, the largest investment made in a year to date Autism announced as a clinical priority in the NHS long-term plan	Require grantees to submit a Researchfish® report and participate in an impact interview Launch first citizen science project in partnership with the Alan Turing Institute

OUR FUTURE AMBITIONS

2020	2021	2022	2023
Begin reporting on the impact Autistica are having on an ongoing basis using Researchfish® and impact interview insights	Update our Annual Report to include annual highlights from our ongoing impact reporting	Launch a fund to cover open-access fees for Autistica-funded publications	Publish an updated impact plan



How we make a difference

We fund research projects across the UK and work with international partners to showcase and build on our world-class research to achieve global impact. The impact we strive to have is clear: to ensure all autistic people and their families live long, healthy, happy lives.

We've made great strides towards achieving our vision but, the early mortality rates, physical health disparities and common mental health difficulties among autistic people remain unacceptable. We need to generate knowledge relevant to the daily lives of autistic people, while maintaining the world-leading quality of autism research in the UK. We need research to go beyond standard scientific publications. We need to practically improve interventions and supports, inform decision-makers, and change outdated and stigmatising attitudes about autism.

1

GENERATING IMPACT

At Autistica, we are led by our research strategy, which places the autistic community at the heart of research and decision-making.

2

DEMONSTRATING IMPACT

To reach our vision faster, we view our scientific grants as just the beginning of a journey towards real-world change. Measuring key indicators along the way will allow us to better understand what can increase or hinder our impact.

3

MAXIMISING IMPACT

We view ourselves as much more than just a funder. We take responsibility for influencing national and local policy, changing attitudes and awareness through the media and catalysing new collaborations between academics and the community we serve.

Generating impact

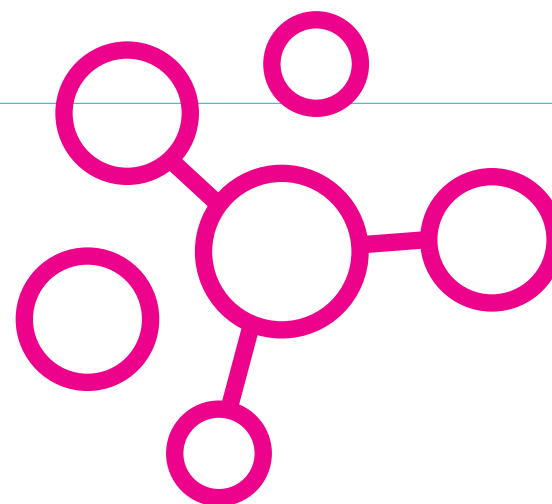


Image: Maddy and Mia, at a play session run by
community organisation A2ndVoice

High-quality science

At Autistica, our focus is on improving outcomes for autistic people by acting as a catalyst. We fund the most promising early-stage scientific ideas to demonstrate their potential to other, larger funders, ultimately building projects with lasting impact and global reach. We recognise the importance of supporting the entire scientific 'pipeline' from basic laboratory science to applied research.

We fund the best science thanks to robust governance with high quality community and scientific review in line with the gold-standard Association of Medical Research Charities (AMRC) guidelines.



Identifying the earliest signs of autism and an intervention to fit

Autistic children and their families can wait a long time for diagnosis and support which meets their needs. One reason for that is we don't properly understand how autistic babies are different from non-autistic babies. This means that diagnosis is not possible until 2 to 3 years old with the average age of diagnosis being 5 years old.



Image: Infant in the Babylab at Birkbeck College

BASIS (British Autism Study of Infant Siblings) is an innovative study based at Birkbeck College, University of London, which followed the very early development of children who are more likely to be autistic because they have an older sibling who is autistic. The study used experimental psychology methods and brain imaging techniques to understand the differences between babies who were and were not likely to be autistic. Thanks to our £1.2 million of funding, BASIS achieved the following:

- The first study to identify signs of autism in the first 12 months of life – in one study from four months old.
- Evidence that infants likely to be autistic respond less to eye gaze but are superior in visual search tasks.
- Over £10 million of research funding leveraged.
- 54 peer-reviewed studies.
- A novel intervention to support parents at the earliest possible stage.
- A European network of infant siblings research, now used across Europe.
- A range of studies looking at other neurodevelopmental conditions.
- A new generation of award-winning early career researchers.

Involving our community

Autistica plays a crucial role in bringing people together to make change happen. In 2017, we launched Discover, the UK's national autism research network.

The results of autism research must be better communicated with those for whom it matters most: autistic people, their families and friends, and the professionals who support them. That's why, through Discover, we communicate updates about research and we host events like the annual Discover Conference and regular Discover Talks to take research out to the community.

DISCOVER
autism research network

Autism research has tended to focus on the interests of autism researchers which have historically been poorly aligned with the interests of autistic people and their families.

Insight Group

To date, Autistica has helped 26 research projects recruit for participants enabling over 1,000 people to take part in research. Discover makes it even easier for researchers to recruit participants. As we increase the efficiency with which autism research can be conducted, we enable more of the investments we and other funders make to be spent making a difference.

As part of Discover, we've established an Insight Group made up of over 250 autistic people and parents of people on the autism spectrum who work with researchers to ensure research is appropriately designed and relevant to their lives. In the last four months of 2018, 113 people consulted on 14 different projects.



Providing tools for research shaped by the community

Dr Sarah Cassidy, Assistant Professor, University of Nottingham

"I am funded by Autistica for a project looking at what drives feelings of suicide in autistic people.

I'm extremely impressed with Autistica's approach to involvement which has really helped me to improve the quality of my research. They provided me with access to their Insight Group – a group of autistic people and parents who fed back on the design of an online survey which formed a key part of my research. The group helped make the language and formatting clear and ensured we were asking the right questions.

We made several changes as a result and I am sure this contributed to the excellent response and positivity towards the survey when we launched.

Given that poor study design and a lack of participants are the main reasons autism research projects fail, Autistica's infrastructure makes it easy for any researcher to succeed in not only their research project, but also in engaging the community we aim to serve. I look forward to using both the Discover Network and Insight Group to shape and share future projects."



Image: Autistic people, parents and professionals discussing research priorities

Study Groups

To foster a more collaborative research environment, we're facilitating Autism Study Groups made up of senior and junior researchers, professionals and members of the wider autism community. We've established groups to work on complex needs, ageing and physical health, mental health, and language and communication.

Expert summits

Through Discover, we host global summits focused on areas that the autistic community believes urgently need further research. These areas have often gone under-investigated because they are difficult for individual researchers to resolve alone. These facilitated workshops bring together leading experts: both research leaders from different fields and those with a direct connection to autism, often known as 'experts by experience'. They aim to develop co-created research plans that can be transformed into high quality research projects.

We've hosted three summits to kick-start research into epilepsy, autism-enabling environments, and physical health and wellbeing. Our first summit has already leveraged over £530,000 of further funding.

WORKSHOPS

Physical health & wellbeing

SEPTEMBER 2017

Many serious medical conditions are more common in autistic adults than the general population. Yet, physical health and wellbeing remains under-researched.

Autism and epilepsy

NOVEMBER 2017

Epilepsy is a leading cause of death for autistic people. The combination of disabilities significantly impacts on quality of life as well as physical and mental health, but remains under-researched.

Autism-enabling environments

JUNE 2018

Understanding the appropriateness of environments for autistic people and how they can be designed or adjusted to enable positive outcomes is a top research priority for the autism community.

OUTPUTS

Residential care in older age

UNIVERSITY OF EDINBURGH

Developing the necessary infrastructure to facilitate meaningful future research in residential care for elderly autistic adults.

Autism-specific health checks

NEWCASTLE UNIVERSITY

Design and evaluate an autism-specific health check for use with autistic adults in NHS primary care.

Impact of anti-epileptic drugs

CORNWALL NHS TRUST

Utilising an existing NHS database to consider the response to Levetiracetam (a common anti-epileptic drug) in autistic and neurotypical people.

Using citizen science to understand autistic people's sensory experiences

THE ALAN TURING INSTITUTE

Asking autistic people to share examples of their sensory experiences



Making the UK a world leader in autism research

We have come to understand that positive change can only happen if we involve the right people, if we develop the research workforce needed and if we bring people together.

Investing in autistic talent

Autistic researchers have a unique vantage point from which to combine research expertise with lived experience to generate important insights about being autistic. Our innovative Charles Sharland Grant Scheme for Autistic Researchers pairs autistic people with research mentors, providing them with the funding needed to make their research ideas a reality. In 2019 we chose our first four recipients for what will be an annual scheme.

Developing future leaders

We need the most innovative future leaders if we are to deliver impactful research. Scientific investment is typically concentrated around relatively inexpensive PhD students, and established senior leaders. This creates an employment gap for early career researchers who are potential future leaders. Many leave autism research altogether. Our Future Leaders Award invests in the future of autism research by fostering the development of early autism researchers' careers.

Supporting autistic people as researchers of the future

Joseph Scanlon, Charles Sharland Autistic Researcher grant recipient

"I first came in touch with Autistica through my work with another autism charity. I joined their Discover network and heard about a workshop they were hosting on epilepsy. As an autistic person who has suffered for years with epilepsy and poor medication, I jumped at the chance to be involved. The workshop was fantastic! It was great to be in a room full of individuals all dedicated to making a real difference in people's lives. From clinical specialists, geneticists, neurologists, psychologists, neuroscientists, parents, autistic people with epilepsy and more, there were so many perspectives to draw on, which I think greatly contributed to the success of the research project ideas that came out of the workshop.

The day inspired me to take up a career in

research. I began researching postgraduate psychology courses across the country. I heard about Autistica's Charles Sharland Autistic Grant Scheme which offered funding and a mentor to support autistic people like me into a career in autism research. To my astonishment I was successful. I'm now embarking on my very own research project supported by a senior researcher that I chose to work with.

Autistica are taking a unique approach to building the next generation of autism researchers. They are supporting autistic people into autism research and as a result harnessing a personally motivated team of scientists who I expect will dedicate their career to this fascinating area of research."



Image: Joseph was inspired by Autistica to start a research career

Working in partnership

We know we cannot achieve our vision alone. We're committed to working collaboratively with others who can help us make that vision a reality.

Media

Accurate representations of autism research in the media play a huge role in tackling misconceptions, accelerating adoption of new discoveries and helping the autism community feel understood. We influence how the media portray autism science through our media guidelines. As well as publicising our own funded discoveries, we provide the media with case studies and comments on others' research. This provides an independent and accessible voice on autism research, and crucially reduces the reporting of low-quality science.

Policy

Influencing national, regional and local policy is a vital strand of our impact work. Too often, research funders see their job ending when research is published but true change only happens when evidence is turned into service recommendations, clinical guidelines, plans and strategies. Our team work with policymakers at all levels to highlight the latest evidence and push for policy change and improvements to services.

We work with researchers to involve the community, communicate effectively and increase the policy impact of their work. Many of these skills are not easy to acquire in academia and we are investing in resources, training and guidance to help autism researchers become more powerful advocates for change.

Organisations

We work with many other large and small charities within autism and beyond to increase their understanding of research and its importance, reduce duplication and achieve common goals. In a fragmented sector facing many challenges, we aim to create an environment where collaboration is the norm, not the exception.

Influencing national and international policy to improve life expectancy

Our 2016 policy report, *Personal tragedies, public crisis*, had a huge impact on national policy-making: tackling the mortality gap faced by autistic people is now a national priority in the UK and the US as a direct result of our campaign.

We also played a major role in the adoption of autism as a clinical priority for the NHS for the first time in history. Our lobbying of MPs and civil servants has highlighted the unacceptable outcomes autistic people and families experience and called for urgent national action to support people across the lifespan.

Locally, we have been able to influence suicide prevention guidance to include autistic people as a high-risk group and encourage the spread of evidence-based interventions.



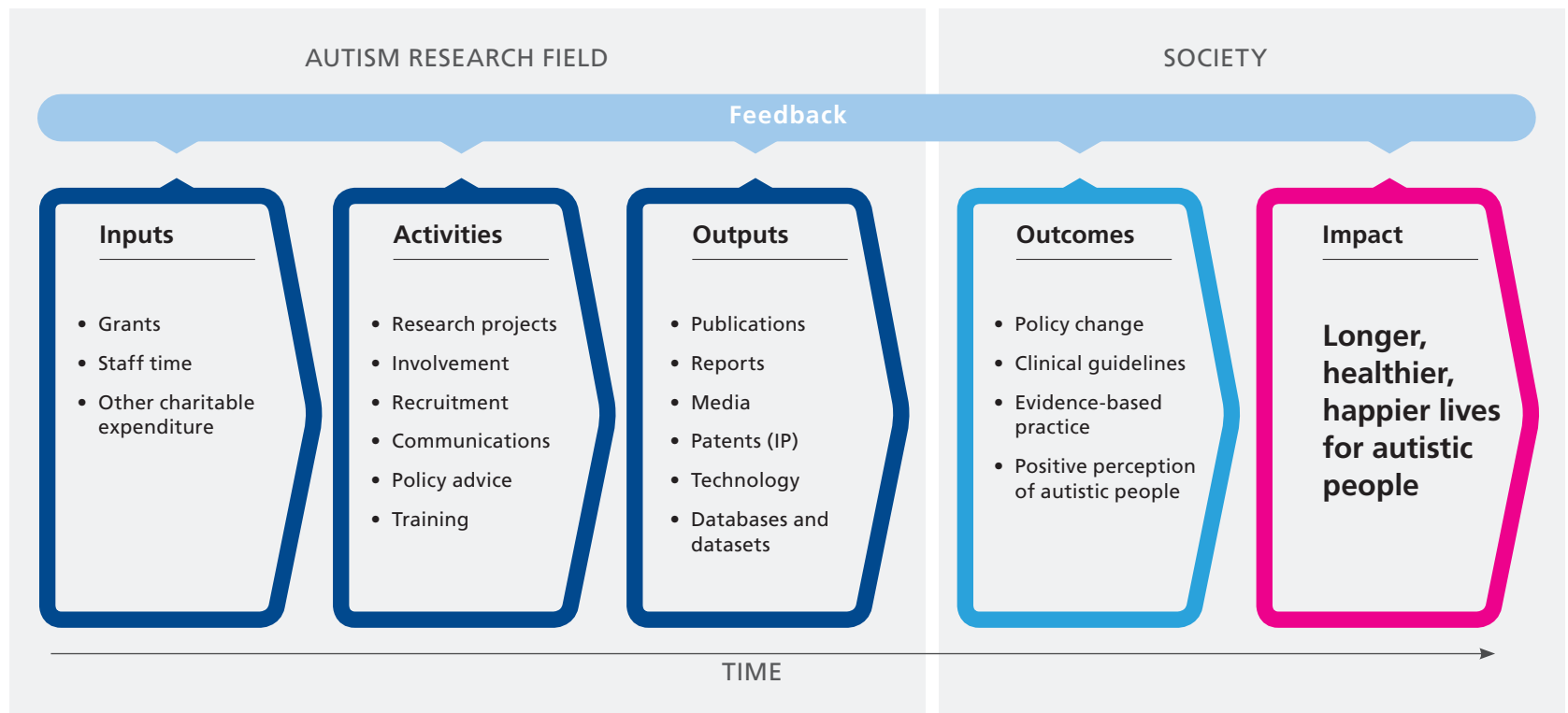


Demonstrating impact

Image: Luke, with dad Tom, watching videos and practising language skills at home

Practical, ethical and appropriate research

Demonstrating the impact research has on society is critical to ensure that projects are practical, ethical and appropriate in their aim to benefit the community. The donors we rely on to fund our work must see that their valuable investments in research have a real-world impact that goes beyond laboratories and academic publications. We owe it to our community to ensure research delivers practical outcomes.



Our impact model

Adopted from the impact model of the Commonwealth Scientific and Industrial Research Organisation

Our approach to demonstrating and managing impact is based on a programme logic model, adapted from the Commonwealth Scientific and Industrial Research Organisation and Cancer Research UK. This model plots the pathway to creating impact from inputting investment, through conducting research-related activities and producing outputs, to ultimately generate real-world impact.

Measuring how long, healthy and happy autistic people's lives are and directly attributing any

changes in these outcomes to investments we make is not straightforward. Instead, our model allows us to capture indicators of impact at each stage of the pathway giving us a good picture of the path between research investment and our ultimate charitable vision. This means we can identify enablers and barriers to impact and maximise impact through strategic decision-making.

In future, we will require researchers we fund to report the wide variety of activities, outputs

and impact their work achieves via the online platform Researchfish®. We will supplement this with an interview after a researcher submits their Researchfish® report.

Molehill Mountain app

An app designed to help autistic people live better with anxiety

Over 5,000 people have downloaded our app to build autistic people's understanding and skills to live better with anxiety. Based on research we funded at King's College London, the app demonstrates our commitment to seeing research through until it achieves a tangible result.



Image: Jack, testing an early version of the Molehill Mountain app





Tackling our barriers to impact

Image: Faith at a play session run by community organisation A2ndVoice

We work hard to support research that makes a positive difference to autistic people's lives. Our new impact model (see page 13) will guide us in continuously improving our approach to measuring and reporting the impact our research has on society. We also want to address common barriers to impact that prevent research findings from being translated into real, tangible improvements in autistic people's lives.

Five barriers to impact

1

Research decisions that are not based on questions relevant to users of research

2

Inappropriate research design, method, and analysis

3

Inefficient research regulation and management

4

Inaccessible research information

5

Biased and unusable research reports

A 2009 report estimated that 85% of investment in biomedical research never translates into improvements in healthcareⁱ. Further to this, recent research has demonstrated that between two-thirds and one-half of psychological research findings could not be replicated^{ii,iii}. Such findings have sharpened the scientific community's focus on the barriers to impact that exist in the research process.

A special issue published in 2014 in the *Lancet* addressed five common but avoidable barriers to impact in biomedical research and made specific recommendations about how to increase value and reduce waste.

We take these barriers seriously. It's no longer enough to fund research in the hope that it will lead to change. While we've made huge strides in generating and maximising impact, there is more progress to be made so we continue to achieve all that we can through the science we support.

ⁱ Chalmers, I., & Glasziou, P. (2009). Avoidable waste in the production and reporting of research evidence. *The Lancet*, 374(9683), 86-89.

ⁱⁱ Open Science Collaboration. (2015). Estimating the reproducibility of psychological science. *Science*, 349(6251), aac4716.

ⁱⁱⁱ Klein, R. A., Vianello, M., Hasselman, F., Adams, B. G., Adams, R. B., Jr., Alper, S., ... Nosek, B. A. (2018, November 19). Many Labs 2: Investigating Variation in Replicability Across Sample and Setting. <https://doi.org/10.31234/osf.io/9654g>

Addressing our barriers to impact

1 Asking the right questions^{iv}

Involving autistic people in priority setting

The story so far

We include the community in setting the research agenda. We have developed an Involvement Promise, setting out how we will continue to involve the autism community in shaping autism research in the UK.

What next?

- Consult with the autism community on interventions and desired outcomes.
- Reach out to those from hard to reach groups and to those with disparate views – those with and without learning disabilities and those with additional health conditions.

Newly funded research should be justified in the context of what is already known

The story so far

We require that each researcher who submits a funding proposal states the need for the research within the context of current literature. However, given historic chronic underinvestment in autism research, we do not currently demand that all proposals are justified by a systematic review of what is already known.

We have established collaborative Study Groups who will focus on key topic areas in autism research. As part of these collaborations, some groups have decided to conduct systematic or scoping reviews to establish what is already known and where gaps in the evidence base exist.

What next?

- Our funding recommendations will move toward prioritising new research where our study groups tell us clear gaps exist.

Create the infrastructure needed to reduce duplicated effort

The story so far

As the leading autism research funder in the UK, we keep abreast of new developments in the field of autism research here and overseas. Through Discover, we prioritise and incentivise collaboration and actively create an environment where experts (through lived experience and research) can share knowledge and build research plans together.

What next?

- Develop and maintain sources of information about completed and ongoing research on a national and international level.
- Make this information available to the public and researchers and aid them in developing new and innovative projects.
- Move towards insisting on the publication of protocols at study inception for projects that we fund.
- This will inform researchers across the UK about planned and ongoing activity to minimise duplication and to share knowledge.

^{iv} Chalmers, I., Bracken, M. B., Djulbegovic, B., Garattini, S., Grant, J., Gülmezoglu, A. M., ... & Oliver, S. (2014). How to increase value and reduce waste when research priorities are set. *The Lancet*, 383(9912), 156-165.

Identifying the top ten priorities for autism research

Autistica has committed to placing the experiences, interests and concerns of autistic people at the heart of our research. In 2016, we partnered with the National Autistic Society, the Autism Alliance UK, the Autism Research Trust and others to lead a James Lind Alliance Priority Setting Partnership. In this formal process 1,213 autistic people, professionals and family members put forward 3,331 research questions. Following a rigorous process of sorting and prioritisation, the top ten and top 25 research priorities for the autism community were established. Our research strategy is now shaped by these priorities and we work closely with other funders to ensure their investments are aligned with these results. Far more autism research today is aligned with the needs of the community and not the areas that researchers previously focused on.



Image: Participants in the final priority setting workshop

Supporting national research databases

In 2010 we funded Newcastle University to set up a national database of parents and autistic children: ASD-UK. The database allows families to take part in research, helps researchers recruit families to studies, and collects data about autistic children and their families. The database is still recruiting families today and has over 4,785 registered - it is the largest outside the USA. We are now in the process of linking ASD-UK with Discover to boost recruitment.

In 2014, as part of our Research Centre for Ageing with Autism, Autistica funded Newcastle University to set up a national research cohort of autistic adults and their relatives. The aim was to understand more about the experience of autism across the life-course – including mental health, quality of life, physical health and how lives change with time. The cohort is made up of 1,800 autistic adults and 750 relatives of adults and is among the largest of its type in the world. In a 2018 study, quality of life was found to be lower for autistic adults than the general population in every measure (physical, psychological, social and environmental), highlighting the urgent need to improve outcomes for adults.

We continue to support these valuable national resources to allow researchers to do meaningful research and create practical solutions to help people live well from childhood through to old age.



Image: Parents like Erika pictured are keen to get involved in research, but many don't know how. The Newcastle database lets families know about relevant opportunities.

2 Ensuring the appropriate research design, methods and analysis are used^v

Fund and encourage research that is high quality and relevant

The story so far

Autistica have a gold-standard peer review process to select the best research, as demonstrated by our proud membership of the AMRC. Each application for funding is peer-reviewed by scientific experts and reviewed by members of the autism community. This ensures that funded projects are of a consistently high quality, both in scientific approach and relevance to those we serve.

What next?

- Introduce clearer criteria surrounding the justification of research design and analysis decisions in grant proposals. E.g. formal sample size justifications, collaborating with methodologists on complex research designs or pre-registering a sequence of analytic decisions.
- Adopt increasingly stringent criteria for researchers who wish to recruit participants via our Discover network to ensure the best designed research is prioritised and researchers are incentivised to improve the impact and integrity of their research.

Make publicly available the full protocols, analysis plans or sequence of analytical choices, and raw data for all designed and undertaken research

The story so far

Transparency in research is an increasingly debated topic, in relation to both replication of results and ethical participation. The importance of pre-registration in research is only recently established. By writing up and publishing a research plan prior to beginning research, the quality of the study design is immediately apparent, and the manipulation of design or findings for desired results is less likely.

Many domains of science have been slow to adopt this approach, which means that autism research in the UK can become a leader in this area. However, as with the introduction of any innovative practice, there is a risk of outpacing the skills of the research community.

What next?

- Invest more in training the autism research community in transparent and reproducible practices.
- Introduce the requirement that all Autistica-funded research to be publicly pre-registered by 2020 and we will consult on a new requirement for all data and materials to be open access and open source by 2025.
- Consider where we can work in partnership with other funders to share resources which enable transparency.

Create a well-trained methodological research workforce and provide continuing professional development opportunities to maximise the quality of research conducted

The story so far

Our Discover network is the first national autism research network in the UK. Discover brings together autistic people, researchers and other professionals. We provide training to autism researchers, which addresses gaps in skills needed to generate impact. Our new Future Leaders Awards help to build a community of early career researchers, redressing the loss of skilled autism researchers forced to move into other disciplines or leave academia due to the lack of post-PhD career development opportunities.

What next?

- Develop further training opportunities for researchers that target the main barriers to impact.

3 Efficient research regulation and management^{vi}

Reward reproducibility practices and reproducible research, and enable an efficient culture for replication of research

The story so far

We are striving to build a transparent research environment where sharing of study designs and methodologies will allow for easier replication of research.

What next?

- As we move toward required pre-registration for all research studies, researchers' experience with preregistration will be looked on favourably.
- In new funding calls and strategic initiatives, we will incorporate recognition for reproducibility practices.

^v Ioannidis, J. P., Greenland, S., Hlatky, M. A., Khoury, M. J., Macleod, M. R., Moher, D., ... & Tibshirani, R. (2014). Increasing value and reducing waste in research design, conduct, and analysis. *The Lancet*, 383(9912), 166-175.

Regulators should use their influence to reduce other barriers to impact and inefficiency, and to streamline and harmonise the laws, regulations, guidelines, and processes that govern whether and how research can be done

The story so far

We have worked with and advised other funding organisations, including UK Research Councils, to support them in developing appropriate governance for autism research.

What next?

- Continue working with other funders around the world to promote collaborative practices and harmonise the policies and procedures that govern how autism research is done.
- Continue to build structures that will embed innovative involvement within all our activities.

Increase the efficiency of recruitment, retention, data monitoring, and data sharing in research

The story so far

At Autistica, it is our priority to place the experiences and expertise of autistic people at the centre of our research. Through our Discover network and the Autism Research Database, we have built a large network of autistic people and other interested community members keen to engage with research and share their lived experience. This unique infrastructure makes it quicker and easier for researchers to include the right people in their research, as co-researchers and as research participants.

What next?

- Build a broader, more diverse panel of participants to truly reflect the autism community and those who support them.
- Increase our work with researchers to encourage them to analyse pre-existing datasets, instead of always collecting new data, where appropriate.
- Provide researchers with the skills needed to make the data they collect during projects we fund transparent and open.

Promote integration of research in everyday clinical and educational practice

The story so far

We have been increasingly working with education and healthcare commissioners (public officials who decide which services are available in a given area) to increase the appetite for including evaluation within the commissioning of services. Through this type of work, we hope to increase the investment in action research and to foster a culture where researchers embedded within professional services will increase the applicability of their findings.

What next?

- We will continue to test new approaches to improving how research and services interact.
- We will invest in services research to develop the evidence base for service change and increase expertise and capacity for conducting research among professionals.
- We will work with bodies like NHS England to drive a culture shift leading to a more research-active health and care workforce.

^{vi} Salman, R. A. S., Beller, E., Kagan, J., Hemminki, E., Phillips, R. S., Savulescu, J., ... & Chalmers, I. (2014). Increasing value and reducing waste in biomedical research regulation and management. *The Lancet*, 383(9912), 176-185.

4 Making research outputs fully accessible^{vii}

Institutions and funders should adopt performance metrics that recognise full dissemination of research and reuse of original datasets by external researchers

The story so far

There is a mismatch between the amount of research that is conducted and the amount of research that is published. Further, researchers often collect much more data than is reported upon in published research. This is for a variety of reasons: there has been limited uptake of standardised reporting guidelines, journal articles have strict word limits and complete reporting is challenging.

What next?

- We will disseminate research outputs via Discover.

Funders, sponsors, regulators, research ethics committees, journals, and legislators should endorse and enforce study registration policies, wide availability of full study information, and sharing of participant-level data for all health research

The story so far

This practice is not widespread in autism research and has not been a priority for Autistica in our work so far.

What next?

- Work with journals to increase the number of autism journals who endorse and enforce study registration policies.
- We will upskill researchers in making full study information and participant-level data available.

^{vii} Chan, A. W., Song, F., Vickers, A., Jefferson, T., Dickersin, K., Gøtzsche, P. C., ... & Van Der Worp, H. B. (2014). Increasing value and reducing waste: addressing inaccessible research. *The Lancet*, 383(9913), 257-266.

5 Creating unbiased and usable research findings^{viii}

Research funders should shift research regulations and rewards and create reporting infrastructure that supports complete reporting and good archiving

The story so far

We are a member of the Association of Medical Research Charities (AMRC), who have launched an open-access publication platform, called AMRC Open Research.

What next?

- Increasingly work with researchers to report all aspects of their research even when publication in classic peer-reviewed journals is not feasible.
- In 2019, along with hundreds of other funders and researchers, we will sign the San Francisco Declaration on Research Assessment (DORA). This pledges that Autistica will not evaluate research outputs based solely on publications in peer-reviewed journals but recognise that outputs from research are many and varied.
- Develop and implement a policy that sets out pragmatic standards for the content of pre-study protocols, full study reporting and data sharing practices required by Autistica grant recipients.
- Autistica will require grantees to report activities and outputs via the Researchfish® online platform. We will also interview grantees at the end of a grant period to capture impact not covered by Researchfish®.
- We will work to influence autism-relevant academic journals to adopt standardised reporting guidelines.

Funders, institutions, and publishers should improve the capability and capacity of authors and reviewers in high-quality and complete reporting

The story so far

We have always worked with researchers to maximise the usability of their research. We help them to communicate with non-scientific audiences, to understand how research can influence policy, to ask relevant research questions.

What next?

- Through training and feedback from the research community, we will identify and implement further initiatives to increase skills and build capacity.

^{viii} Glasziou, P., Altman, D. G., Bossuyt, P., Boutron, I., Clarke, M., Julious, S., ... & Wager, E. (2014). Reducing waste from incomplete or unusable reports of biomedical research. *The Lancet*, 383(9913), 267-276.

Committed to improving lives

At Autistica, we're committed to shaping a world where autistic people can live long, healthy and happy lives. Since our founding in 2004, we've made some incredible progress in focusing on the autistic community's priorities and establishing some of the most important resources for autism research in the UK.

We've set ourselves the challenge of transforming how we track and measure our impact. Directly measuring the impact of our work on people's lives can be difficult, and we need to look beyond simple output metrics to examine the support and inclusion that we create to propel world-class research projects focusing on an under-served population.

We're building an approach to world class research that focuses on community building, knowledge sharing and inclusive practices at every stage. This challenge involves a constant cycle of listening, learning and innovating.

What got us where we are today won't get us where we need to be. Thanks to our donors, our researchers and the vast community we serve, we can continue to strive for maximum impact. We welcome your help, your views and your ideas to make the future brighter for autistic people and their families.

Thank you to Pears Foundation for their generous support of this Impact Plan.

“

We are delighted to support Autistica's first Impact Report, and the powerful commitment this signals to research which is responsive, relevant and has real-world impact. At Pears Foundation we aim to invest in organisations and initiatives that make a genuine difference to the lives of autistic people and their families.

”

Pears
Foundation

Supporting our work

Our research and campaigning would not be possible without funding from individuals, trusts and companies who share our vision.

We receive no Government funding.

Donations

Sustainability is key and multi-year gifts or monthly donations help us to build on our long-term mission to improve lives. You can set up a regular or one-off gift at autistica.org.uk/donate

Legacies

To find out more about how to leave the most personal gift of all please visit:

autistica.org.uk/leave-a-legacy

Keep in touch

If you are unable to give a gift at this time, but want to receive updates on our activities and the impact we are making, visit autistica.org.uk to register for our mailing list.

Corporate Partnerships

If your company can help us to make greater impact through fundraising and expertise, or if we can help you to improve the neurodiversity of your workforce, get in touch with our corporate team.

autistica.org.uk/partner

Trusts and Foundations

If your Trust or Foundation is interested to learn more about us, visit autistica.org.uk/trusts and get in touch.

AUTISTICA

Building brighter futures through autism research

Registered with the Charity Commission in England No. 1107350 | Company No. 5184164



**IMPACT
PLAN**
autistica.org.uk/impact