



AUTISTICA

Building brighter futures through autism research

Your questions: shaping future autism research

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Why your priorities for autism research are so valuable

It might seem obvious to ask those living and working with autism what research they want to see happening but traditionally medical research is decided by funders and researchers. We know that these groups have very different ideas of what is important, so in order to get the autism community setting the research agenda, in January 2016, we launched a process to set about defining a list of research priorities: a James Lind Alliance Priority Setting Partnership.

This independent initiative works in partnership with the National Institute for Health Research (NIHR) by bringing together individuals affected by a condition, carers and clinicians asking them to identify and prioritise the top ten uncertainties, or 'unanswered questions', that they agree are most important. The process has a track record of encouraging research funding in the areas identified by the process, and has been carried out previously for other conditions such as asthma, dementia and diabetes.

Autism is one of the most poorly funded areas of research (we spend less than £6 per person with autism per year), yet autistic people and their families face outcomes which would be totally unacceptable to other groups.

Autism research has a complex history and given the broad nature of the autism spectrum and the diverse views within the community, finding agreement across such a mixed group has always been challenging. With the successful consensus that this process has produced, UK organisations and funders can work together to form a national strategy that really responds to the needs of autistic people and their families, so that research has the greatest impact.

This report explains the process that was followed to reach the agreed list of priorities, who was involved to make sure that it was made as inclusive and as independent as possible, and what's behind each of the questions that you chose.



To find out more visit the project web page:
www.autistica.org.uk/top10



Top ten questions for autism research

- 1 Which interventions improve mental health or reduce mental health problems in people with autism? How should mental health interventions be adapted for the needs of people with autism?
- 2 Which interventions are effective in the development of communication/language skills in autism?
- 3 What are the most effective ways to support/provide social care for autistic adults?
- 4 Which interventions reduce anxiety in autistic people?
- 5 Which environments/supports are most appropriate in terms of achieving the best education/life/social skills outcomes in autistic people?
- 6 How can parents and family members be supported/educated to care for and better understand an autistic relative?
- 7 How can autism diagnostic criteria be made more relevant for the adult population? And how do we ensure that autistic adults are appropriately diagnosed?
- 8 How can we encourage employers to apply person-centred interventions and support to help autistic people maximise their potential and performance in the workplace?
- 9 How can sensory processing in autism be better understood?
- 10 How should service delivery for autistic people be improved and adapted in order to meet their needs?

Which interventions improve mental health or reduce mental health problems in people with autism? How should mental health interventions be adapted for the needs of people with autism?

The issue

Mental health problems have a devastating effect on an individual's quality of life. 70% of autistic children have a mental health problem¹ with 79% of autistic adults meeting criteria for a mental health problem (for example, bipolar disorder, depression, anxiety, obsessive compulsive disorder, schizophrenia)² at some point during adulthood. Data from Sweden indicates that autistic adults with no intellectual disability are over nine times more likely to kill themselves than the general population,³ with data from the UK suggesting that two thirds experience suicidal thoughts.⁴

What we know

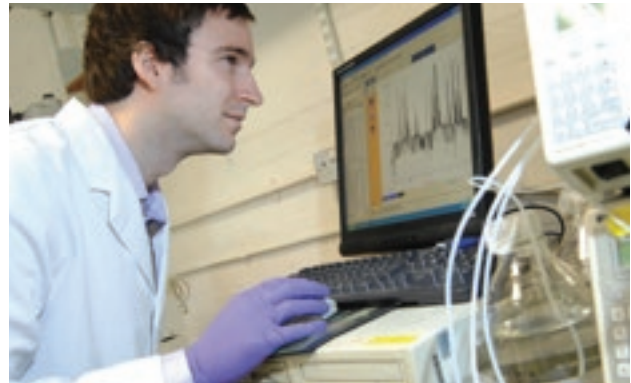
Research suggests a genetic link between autism and mental health problems, but mental health problems may also be triggered or influenced by environmental factors, such as social exclusion, bullying, and experiencing stigma. Emerging evidence suggests suicidal thoughts and behaviours may be different in autistic people.⁴

"I feel that the anxiety and depression I have suffered over the years is the result of my autistic mind having to cope with a neurotypical world."

Jon Adams, autistic adult who attended the final priority setting workshop

How research can help

We are starting to know what mental health treatments are effective for people without autism. Currently there are no autism-specific treatments, as research has done very little so far to address mental health and autism together. There are a number of approaches which may be beneficial, such as anti-depressants, cognitive behavioural therapy, mindfulness and dialectical behavioural therapy, but these all need further research.^{5,6}



The National Institute for Health and Care Excellence (NICE) aims to improve health and social care through evidence-based guidance. NICE recognises that some of these interventions could be beneficial for people with autism but stresses the need for further research to address the following questions:

NICE recommendations for research:

Adults

What is the clinical- and cost-effectiveness of selective serotonin reuptake inhibitors (SSRIs) for the treatment of moderate and severe depression in adults with autism?

What is the clinical- and cost-effectiveness of facilitated self-help for the treatment of mild anxiety and depressive disorders in adults with autism? (Currently being funded by the NIHR).

What is the clinical- and cost-effectiveness of Cognitive Behavioural Therapy (CBT) for the treatment of moderate and severe anxiety disorders in adults with autism?

Children

What is the comparative clinical- and cost-effectiveness of pharmacological and psychosocial interventions for anxiety disorders in children and young people with autism?

2

Which interventions are effective in the development of communication/language skills in autism?

The issue

Autism is primarily a disability that affects how a person communicates with and relates to other people and the environment around them. Difficulties with communication and language affect autistic people's ability to do everyday things. One in four people with autism can speak few or no words, whilst many other autistic people find it hard to apply and adapt their communication skills to different environments and situations.⁸ We also know that language ability at five years old is a good indicator of long-term outcomes, with higher ability also reducing the likelihood of challenging behaviours.

What we know

There are a wide range of approaches aiming to improve communication and language skills in autism. AAC (Alternative and Augmentative Communication) is one such approach – this includes PECS (Picture Exchanges Communication System) where cards with images are used to communicate. There is some evidence to support the use of PECS, and similar tech-based tools.⁹ The Royal College of Speech and

Language Therapists have highlighted the use of parent-led, teacher-led (often behavioural interventions which are shared between teachers and parents), and computer-based interventions as potentially promising avenues.¹⁰ Social skills groups seem to be helpful for many, but further research is needed to know how effective they are for different people and how effectively the skills learnt in the group can be expanded to real-world situations.¹¹

How research can help

Research is needed to understand the effectiveness of interventions which are currently in use, and to develop new and innovative interventions to give autistic people the communication skills they require to navigate the world and live as independently as possible.

NICE recommendations for research:

[What is the clinical- and cost-effectiveness of augmentative communication devices for adults with autism?](#)

3

What are the most effective ways to support/provide social care for autistic adults?

The issue

Social care services provide community-based support for autistic people and their families, and include advocacy, residential care or supported living, short breaks and social groups. Although there is limited data available (particularly in ageing populations and those without learning disability), a survey from the National Autistic Society suggests that a very high proportion of autistic adults live with their parents (38%) or in residential care or supported living (17%).¹²

The Winterbourne View report found that people with learning disability and/or autism are admitted to inpatient settings unnecessarily or for reasons which could have been avoided.¹³ The report also found that many are often placed in inappropriate settings, which are distant from their home town and family. In addition, inappropriately high levels of anti-psychotic use are also reported in such settings.¹⁴ This is shown in the Mazars report, which demonstrated the need to investigate unexpected deaths in those with a learning disability.¹⁵

What we know

There is a significant lack of investment in social care research. It seems clear that the recent moves this century from institutionalised care to supported living have had a substantial and positive effect on the quality of life of autistic people.¹⁶ There is also some research looking at structured behavioural programmes, generally with the aim of reducing challenging behaviour, but these studies are lacking in scale and quality, and don't reflect the outcomes valued by autistic people.^{17, 18} Respite care is also included in social care research. The limited research in this area finds positive impacts on parental wellbeing.^{19, 20}

How research can help

A culture of research is critical for ensuring that social care practices meet high standards and focus on clear outcomes. There is a clear need for research funders and those delivering social care to work together to build research into practice to accelerate our understanding of the best ways to deliver social care.

4

Which interventions reduce anxiety in autistic people?

The issue

Anxiety can be defined as “a feeling of unease, such as worry or fear that can be mild or severe”. Most people experience fleeting worry, but this can develop into anxiety when it becomes persistent, overwhelming and beyond the person’s control so that it limits the ability to complete daily activities and significantly lowers quality of life. 54% of autistic adults have had an anxiety disorder,² and 41.9% of children with autism have an anxiety disorder at any given time.¹ Like other mental health problems, anxiety in autism is likely to have both social and biological causes. Anxiety can be exceptionally debilitating and is likely to be different for each individual.

What we know

Anxiety may be treated with Cognitive Behavioural Therapy (CBT), which is a talking therapy that can help people manage their problems by changing the way they think and behave. Although this is effective for the general population,²¹ it is likely to require adaptation to work for autistic people.

How research can help

Research can help us better understand and define how anxiety works for each autistic individual, which can lead to better treatments. Early findings suggest that CBT could work well in children with autism, but further research can tell us how effective this is for different groups and how to tailor it based on needs (for example, communication style).²² ²³ One study has found that the TEACCH (Treatment and Education of Autistic and related Communication-Handicapped Children) programme lowers anxiety in pre-school children.²⁴ Other treatments for anxiety disorders, including other types of psychotherapy (such as mindfulness) and drug treatments, could help with the management of anxiety in autism but also require research to ensure they are autism-appropriate.



5

Which environments/supports are most appropriate in terms of achieving the best education/life/social skills outcomes in autistic people?

The issue

We know that the environment plays a role in affecting developmental outcomes, autistic or not.²⁴ Providing the appropriate educational environment is critical to this end. We also know that some people with autism can make vast improvements on certain autism-specific outcome measures, whilst others do not, but we do not know why this is the case.

What we know

Much of the limited research in this area has been on using cognitive or genetic factors to predict long-term outcomes in autism,^{25, 26} but research into which environments make a difference is limited.

Another extensive piece of work consulted with autistic adults, families and professionals to consider environmental changes which could lead to educational outcomes which were deemed as desirable by these stakeholder groups.²⁷ Recommendations included breaking down targets, ongoing consultations with pupils, flexible curricula which allow the development of self-awareness and autism-specific knowledge for pupils, better training, and ensuring that each school has a staff member with specialist knowledge of

autism. Preliminary research has shown that when steps are taken to ease transition between primary and secondary school, there is an improvement in wellbeing and daily functioning in autistic pupils.²⁸

How research can help

Whilst these proposals seem logical, like other environmental accommodations, we have little in the way of empirical evidence to examine their effectiveness. Analysis of older datasets and adaptation of datasets currently collecting data could allow us to understand this question in further detail. Another key to being able to answer this question will be closer working between research and services to understand which environmental accommodations make the largest differences. Standardised autism-appropriate quality of life measures would help compare different environmental adaptations.

6

How can parents and family members be supported/educated to care for and better understand an autistic relative?

The issue

Parent-training approaches, where parents are taught adaptive strategies and approaches to address the needs of their autistic child and reduce parental stress, have been subject to increasing levels of research over the last decade.

What we know

The National Autistic Society has developed a three-month programme of weekly sessions for parents with the aim of understanding autism and the needs of their young child following diagnosis,³¹ with parents reporting emotional benefits.³²

The National Institute for Health Research has recently funded a parent training intervention which aims to develop the communication skills of children with autism.³³ Autistica is also funding pilot trials of a stigma protection intervention, family therapy, and an intervention which aims to address challenging behaviour, all of which are delivered with parents or families.³⁴

How research can help

Further research is required to ensure that this work can be sustainably implemented in services, and whether technology could increase the reach of any intervention. Much of the research focuses on childhood, but there is also a need to consider family/parent-centred supports for autistic adults.

NICE recommendations for research

Is a group-based parent training intervention for parents or carers of children and young people with autism clinically and cost-effective in reducing early and emerging behaviour that challenges in the short- and medium-term compared with treatment as usual?

Are comprehensive early interventions that combine multiple elements and are delivered by parents and teachers (for example, the Learning Experiences – an Alternative Program for Preschoolers and their Parents [LEAP] model) effective in managing the core symptoms of autism and coexisting difficulties (such as adaptive behaviour and developmental skills) in pre-school children?

7

How can autism diagnostic criteria be made more relevant for the adult population? And how do we ensure that autistic adults are appropriately diagnosed?

The issue

Many autistic people do not receive an autism diagnosis until adulthood, whilst many more don't receive a diagnosis at all, leaving them unrecognised and unsupported. Autistic adults often report finding the process of seeking a diagnosis lengthy and difficult. Diagnostic instruments currently used have not been validated for use in an adult population, and there is little in the way of professional training for clinicians supporting adults.

What we know

A lack of validated instruments for diagnosis of autism in adulthood lowers the accuracy of diagnosis, and increases the time it takes. In some cases, the lack of appropriate measures prevents an adult from receiving a diagnosis which they desperately need to access services. The lack of adult-appropriate diagnostic criteria and tools also creates issues for clinicians who may have to use more subjective measures to confirm diagnosis, in a population whose autism is already

challenging to identify.³⁵ Recent research shows that paediatric clinicians use standardised methods for diagnosis ten times more frequently than clinicians working with adults.³⁶

How research can help

The role of research in respect of this issue is very clear: to develop adult-appropriate autism diagnostic criteria and tools for diagnosis which function across all sections of society regardless of gender, culture, and age, amongst other factors. Autistica is currently funding the pilot stages of this work at Newcastle University, but further funding is necessary to deliver maximum benefit to autistic adults.

“Diagnosis in adulthood unlocks the door to a better quality of life for the autistic adult and gives service professionals access to information that will help them support each individual appropriately.”
Cos, autistic adult

8

How can we encourage employers to apply person-centred interventions and support to help autistic people maximise their potential and performance in the workplace?

The issue

15–20% of autistic adults are in full-time employment, but according to the National Autistic Society, 79% of autistic adults who do not work or are on benefits want to work.³⁷ A survey from the National Autistic Society also found that a third of those with autism aged 16–24 are not in education or employment. US research shows that 50% of autistic youths do not take part in employment or education in the first two years after leaving school, and that those who do work are paid substantially less than the national average.^{38, 39, 40}

What we know

The failure to get autistic people into work is something which has a demonstrably negative effect on quality of life in a group of people who commonly have unique and valuable skillsets.⁴¹ The high unemployment and underemployment of autistic people has obvious, negative economic consequences, and represents a missed opportunity for society to utilise the talents of autistic people. Employment training and interview training interventions have been shown to be effective for autistic people in terms of likelihood of getting a job, salary,

employment length, and quality of life.⁴² Research evaluating the cost-benefit of employment training for autistic people suggests that the benefits outweigh costs in economic and social terms.^{43, 44, 45, 46, 47}

How research can help

Research Autism is in the process of creating resources and investigating ways to improve existing employment training programmes. Participants in the JLA process were keen to see employment training programmes that are individualised, and don't just get people into work, but into a job which they can maintain and which reflects their skillset and abilities.



9

How can sensory processing in autism be better understood?

The issue

Although experiences are different for every individual, sensory processing differences have been reported in autism across all of the five senses, including: visual (sight), olfactory (smell), auditory (hearing), gustatory (taste) and tactile (touch).⁴⁸ These differences commonly result in high sensitivities to lighting, sudden or loud sounds, and specific or strong smells. They can make daily life exceptionally challenging for autistic people (for example, lighting which provides an unpleasant sensory experience may negatively impact on a child's learning). Many autistic people report that their unique sensory system can aid them in both their daily lives and their work by giving them a unique perspective. Alternatively, others have identified sensory processing differences as reflecting the most negative thing about their autism, and the root of challenging behaviour.

What we know

Recent research has used our emerging understanding of sensory differences to identify potential subtypes within autism,^{49, 50} and to use those differences within autism to develop more tailored treatments and supports.⁵¹

How research can help

Understanding sensory processing differences in autism could help us to deliver treatments or supports which make any problems sensory difficulties cause more manageable, and make the world a more autism-friendly place, allowing autistic people to feel comfortable in their surroundings and reach their full potential.

10

How should service delivery for autistic people be improved and adapted in order to meet their needs?

The issue

Service delivery refers to how services are provided to people, and the systems and pathways that are in place. Service delivery can cover the diagnostic pathway right through to accessing health and social care, as well as education and other public services.

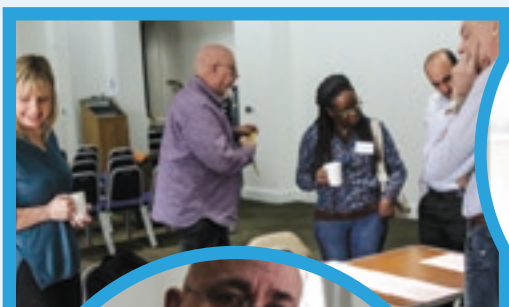
What we know

The accessibility and quality of services is likely to play a role in recent findings which shows that autistic people face poor health³ and life expectancy.⁵³ We know that average age of diagnosis has not reduced in the last ten years.⁵³ Recently work has been undertaken by the Royal College of General Practitioners (RCGP), The National Autistic Society, Research Autism, Autistica and other autism charities to try and make services such as GP surgeries more autism-friendly. Recent research has also considered how to make paediatric surgeries and dental services more autism appropriate.⁵⁵

How research can help

Research could consider innovative ways to efficiently deliver autism-specific services to autistic people and their families. Understanding which environment is best for delivering autism-specific services is key as is whether online or tech

approaches are useful options. Research could also consider making other general services (health care, social care, education) appropriate to the needs of autistic people and their families. Finally, an appropriate first step may be to strategically consider specific questions related to service delivery which could be answered through research. For example, research could consider the range of available methods for diagnosis of autistic children within the UK.





Your other priorities

- 11 Which interventions are effective in the treatment/management of challenging behaviour in autism?
- 12 How can training for health and social care professionals be improved so that they are more able to recognise symptoms of autism/treat autistic people appropriately?
- 13 Which early interventions are most effective in autism? And do they lead to better outcomes?
- 14 What is the impact of adolescence on autism? And what support is effective in helping autistic adolescents into adulthood?
- 15 How can we diagnose autism earlier? And does diagnosis/earlier diagnosis improve outcomes and wellbeing?
- 16 Which interventions improve social skills in autistic people?
- 17 What training do school and nursery teachers need to achieve the best possible experiences/outcomes/employment prospects for children with autism and/or identify the early signs of autism?
- 18 Which interventions improve sensory processing in autistic people?
- 19 What is the experience of living with autism? How can non-autistic people better understand what it's like to be autistic? How can autistic people better understand themselves?
- 20 What are the causes of autism?
- 21 How can the benefits of autism/special talents of autistic people be recognised and used more widely?
- 22 How can public understanding and tolerance of autism be improved? And what is the impact of any improvement in awareness on the wellbeing of autistic people?
- 23 What mental health problems are common in autism?
- 24 Does Applied Behaviour Analysis improve wellbeing/developmental progress in autistic people?
- 25 Which behavioural interventions are most effective for autistic people?

The full list of 89 top questions will be published on www.jla.nihr.ac.uk

How we got to the top ten

To make sure every voice was heard, we went through a carefully considered, inclusive process to reach your top ten autism research priorities.

Getting the right people involved

In January 2015 we formed a steering group made up of charity and health organisation representatives with experience of autism, as well as autistic individuals. Together we invited partner organisations to help us to get a broad range of community views heard. This group guided the entire process to keep it as independent and inclusive as possible.



**January
2015**

Question gathering

In May 2015 the steering group drew up a large-scale survey to collect questions from anyone who had an interest in autism, and partners circulated this to get a broad range of responses. We asked people for their top three questions for autism research to answer.

**May
2015**



**1,213 people took part.
This resulted in
3,331 'raw' questions.**

Those that took part:

23%

individuals on the autism spectrum or strongly suspect they are on the spectrum

52%

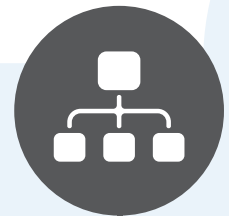
family members and caregivers

25%

clinicians and professionals

Sorting your responses

The 3,331 questions were sorted and grouped into topic areas and duplicates were removed. The questions were then checked against previous research to see if they had already been answered.



**3,331
questions were
sorted into
89
questions**

Prioritising

It was decided by the steering group that the 40 most frequently submitted questions of the 89 would go forward to the ranking stage. So, in March 2016, we sent out a further survey and asked the community to choose their top ten questions. The results from this ranking exercise identified top 25 questions, which went forward to the next stage.



1,266
people voted
for their
top ten

The future

The next stage in the process is to get answers to our top ten, and use these answers to shape policy and practice.

July
2016
onwards
➔

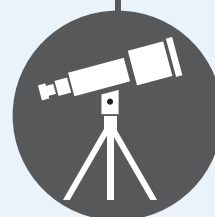


April
2016

Narrowing down to ten

In April 2016 a workshop was held to discuss the top 25 questions. The workshop had equal numbers of autistic adults and young people, parents and professionals. They shared their views, heard different perspectives and came to an agreement on the ten most important questions.

The workshop decided on the final top ten



10

What is the James Lind Alliance (JLA)?

The JLA is an independent, internationally recognised non-profit organisation with an established transparent process of bringing together people with health conditions, carers and healthcare professionals to identify and prioritise research, whilst taking into account existing evidence. They've worked with a wide range of health conditions, including diabetes, depression, schizophrenia, dementia and stroke. Previous JLA projects have been successful in encouraging research spend in the areas identified by the process.

What are Priority Setting Partnerships?

These are groups of people – those with a particular health condition and organisations representing them, together with carers and healthcare professionals – who work together to identify and prioritise unanswered research questions.

Who was involved in the autism partnership?

The partnership was overseen by a steering group made up of representatives from the JLA, Autistica, The National Autistic Society, Autism Alliance, Research Autism and others, with support and funding from partner organisations. You can see who was involved on page 16.

How do you know these are the true views of the autism community?

By involving partner organisations we were able to reach out to a wide range of individuals, families and professionals. When we launched both surveys, we monitored responses and targeted our communications to ensure that numbers of each respondent group were as balanced as possible. We also looked at age, gender, ethnicity, geography, language and intellectual ability to ensure a range of experiences were shared.

It is difficult to involve those who are young, isolated or unable to communicate their needs, but by working with support and service groups, providing easier to read paper surveys and involving parents who can advocate for these individuals, we ensured their views could be heard.

What's next?

Answering the Top Ten

We know that this process has a track record of increasing investment from research funders.

Autistica will:

- Work with partner organisations and funders over the coming months to get these questions addressed.
- Put out a call for research proposals, which will fund a study on the topic of one of the top questions.
- Review our own research strategy following this process.

- Use these results to ensure we campaign for a national strategic approach to autism research.
- Lobby to establish a body responsible for identifying and coordinating UK autism research including the views and perspectives of autistic people and the wider autism community.
- Lobby for increased investment in autism research.

How can you get involved?

Join us on the journey

Although the consultation has finished, we still have a lot of work to do in deciding how to go about answering these questions. We'd love to work with you, keep you updated or hear from you.

- Join our campaign for more autism research based upon community priorities.
- Share your experiences of the issues discussed in this report.
- Put us in touch with anyone you think might be interested in supporting our work.
- Join our mailing list via autistica.org.uk for updates.
- Follow us on social media for the latest research news and developments on this project.

Use the top ten

If you are a researcher, funder or organisation working with autistic individuals, please refer to this list as it will help guide your strategy, giving your work the greatest impact for those affected by autism.



Take part in research

Are you autistic or are you a family member? One of the major things holding back autism research is the lack of people taking part in research. Taking part in research can mean as little as sharing your experiences in a survey, or could be as transformational as involving your whole family in an early intervention study. What you agree to is completely up to you. You can register with one of the nationwide databases at autismspectrum-uk.com. You can take part as a family member or as an autistic adult. This will help us build a huge bank of experience and volunteers for trials to drive our knowledge and understanding forward.

Help us fund the research

Now we have the top ten, we need to fund work in these areas. Support Autistica and any partner charities that plan to address these questions, so that we can maximise the scale and quality of the work we can do together.

Collaborate

The key to future success will be working together in partnership. If we work together, the UK can lead the world in having a consensus-driven national strategy for autism research. We can then forge a path for transformative autism research which will lead to longer, happier healthier lives for the 700,000 autistic people in the UK.

For more information, to request updates or to let us know how you are using these questions, get in touch: info@autistica.org.uk

References:

1. Simonoff, E. et al. (2008) Psychiatric disorders in children with ASD: prevalence, comorbidity and associated factors in a population-derived sample. *Journal of the American Academy of Child and Adolescent Psychiatry*, 47, 8, 921.
2. Lever, A. G. & Geurts, H. M. (2016) Psychiatric Co-occurring Symptoms and Disorders in Young, Middle-Aged, and Older Adults with Autism Spectrum Disorder. *Journal of Autism and Developmental Disorders*, 46, 6, 1916–30.
3. Hirvikoski, T. et al. (2016) Premature mortality in autism spectrum disorder. *The British Journal of Psychiatry*, 207(5), 232–8.
4. Cassidy, S. et al. (2014) Suicidal ideation and suicide plans or attempts in adults with Asperger's syndrome attending a specialist diagnostic clinic: a clinical cohort study. *Lancet Psychiatry*, 1, 2, 142–7.
5. Spain, A. A. et al. (2015) Mindfulness-based therapy in adults with an autism spectrum disorder: A randomized controlled trial. *Research in Developmental Disabilities*, 34, 246–253.
6. Williams, K. et al. (2013) Selective serotonin reuptake inhibitors (SSRIs) for autism spectrum disorders (ASD). *Cochrane Database of Systematic Reviews*, Issue 8. Art. No.: CD004677.
7. Wallace, S. et al. (2013) One in a Hundred: putting families at the heart of autism research. *Autistica*.
8. Howlin P. et al. (2014) Cognitive and language skills in adults with autism: a 40-year follow-up. *Journal of Child Psychology and Psychiatry*, 55, 1, 49–58.
9. Howlin P. et al. (2007) The effectiveness of Picture Exchange Communication System (PECS) training for teachers of children with autism: a pragmatic, group randomised controlled trial. *Journal of Child Psychology and Psychiatry*, 48, 5, 473–481.
10. Enderby, P. et al. (2009) Resource Manual for Commissioning and Planning Services for SLCN. *Royal College of Speech and Language Therapists*.
11. Reichow, B. et al. (2012) Social skills groups for people aged 6 to 21 with autism spectrum disorders (ASD). *Cochrane Database of Systematic Reviews*.
12. Bancroft et al. (2012) The way we are: autism in 2012. *National Autistic Society*.
13. Department of Health (2012) Transforming care: A National response to Winterbourne View Hospital. Department of Health Review: Final Report.
14. Public Health England (2015) Prescribing of psychotropic drugs to people with learning disabilities and/or autism by general practitioners in England.
15. Green, B. (2015) Independent review of deaths of people with a Learning Disability or Mental Health problem in contact with Southern Health NHS Foundation Trust April 2011 to March 2015. *NHS England*.
16. Sines, D. et al. (2012) Evaluating quality of life in adults with profound learning difficulties resettled from hospital to supported living in the community. *Journal of Intellectual Disabilities*, 16(4), pp. 247–263.
17. Gerber, F. et al. (2011) Comparing residential programmes for adults with autism spectrum disorders and intellectual disability: outcomes of challenging behaviour and quality of life. *Journal of Intellectual Disability Research*, 55(9), pp. 918–932.
18. Van Bourgondien, M. E. V. et al. (2003) Effects of a model treatment approach on adults with autism. *Journal of Autism and Developmental Disorders*, 33(2), pp.131–140.
19. Dyches, T. T. et al. (2016) Respite care for single mothers of children with autism spectrum disorders. *Journal of Autism and Developmental Disorders*, 46(3), pp. 812–824.
20. Harper, A. et al. (2014) Respite care, marital quality, and stress in parents of children with autism spectrum disorders. *Journal of Autism and Developmental Disorders*, 43(11), pp. 2604–2616.
21. James, A. C. et al. (2015) Cognitive behavioural therapy for anxiety in children and young people. *Cochrane Database of Systematic Reviews* 2015, Issue 2. Art. No.: CD004690.
22. Sukhodolsky, D. G. et al. (2013) Cognitive-behavioral therapy for anxiety in children with high-functioning autism: a meta-analysis. *Pediatrics*, 132, 5, 1341–50.
23. Wood, J. J. et al. (2014) Cognitive behavioral therapy for anxiety in children with autism spectrum disorders: a randomized, controlled trial. *Journal of Child Psychology and Psychiatry*, 50, 3, 224–34.
24. De Elia, L. et al. (2013) A Longitudinal Study of the TEACCH Program in Different Settings: The Potential Benefits of Low Intensity Intervention in Pre-school Children with ASD. *Journal of Autism and Developmental Disorders*, 44, 3, 615–26.
25. Shattuck, P. T. et al. (2007) Change in autism symptoms and maladaptive behaviours in adolescents and adults with an autism spectrum disorder. *Journal of Autism and Developmental Disorders*, 37, 9, 1735–47.
26. Magiati, I. et al. (2014) Cognitive, language, social and behavioural outcomes in adults with autism spectrum disorders: a systematic review of longitudinal follow-up studies in adulthood. *Clinical Psychology Review*, 3, 4, 1, 73–86.
27. Wittemeyer, K. et al. (2011) Educational provision and outcomes for people on the autism spectrum. *Autism Education Trust*.
28. Mandy, W. et al. (2016) The transition from primary to secondary school in mainstream education for children with autism spectrum disorder. *Autism*, 20, 1, 5–13.
29. McConachie, H. et al. (2005) A controlled trial of a training course for parents of children with suspected autism spectrum disorder. *Journal of Pediatrics*, 147, 3, 335–40.
30. Green, J. et al. (2010) Parent-mediated communication-focused treatment in children with autism (PACT): a randomised controlled trial. *Lancet*, 375(9732), 2152–2160.
31. Shields, J. (2001) The NAS EarlyBird Programme: Partnership with parents in early intervention. *Autism*, 5, 1, 49–56.
32. Cutress, A. L. & Muncer, S. J. (2014) Parents' views of the National Autistic Society's EarlyBird Plus Programme. *Autism*, 18, 6, 651–657.
33. NIHR (2016) EME – 13/119/18: The Paediatric Autism Communication Trial – Generalised (PACT-G). Accessed June 2016 at: <http://www.nets.nihr.ac.uk/projects/eme/1311918>.
34. Cridland, E. K. et al. (2014) Family-focused autism spectrum disorder research: A review of the utility of family systems approaches. *Autism*, 18, 3, 213–222.
35. Van Nierkerk et al. (2011) Diagnosing autism spectrum disorders in elderly people. *International Psychogeriatrics*, 23, 5, 700–10.
36. Rutherford et al. (in press) A national study to investigate the clinical use of standardised instruments in autism spectrum disorder assessment of children and adults in Scotland. *Research in Autism Spectrum Disorders*.
37. Redman, S. et al. (2009) Don't write me off. *National Autistic Society*.
38. Shattuck, P. T. (2012) Postsecondary education and employment among youth with an autism spectrum disorder. *Pediatrics*, 129, 6, 1042–9.
39. Roux, A. M. et al. (2013) Postsecondary Employment Experiences Among Young Adults With an Autism Spectrum Disorder. *Journal of the American Academy of Child and Adolescent Psychiatry*, 52, 9, 931–9.
40. Roux, A. M. et al. (2016) National Autism Indicators Report: Vocational Rehabilitation. *Philadelphia, PA: Life Course Outcomes Research Program, A.J. Drexel Autism Institute, Drexel University*.
41. Scott, M. et al. (2015) Viewpoints on Factors for Successful Employment for Adults with Autism Spectrum Disorder. *PLoS ONE* 10(10): e0139281.
42. Mawhood, L. and Howlin, P. (1999) The outcome of a supported employment scheme for high functioning adults with autism or Asperger syndrome. *Autism* 3, 3, 229–254.
43. Howlin, P., Alcock, J. and Burkin, C. (2005) An 8-year follow-up of a specialist supported employment service for high-ability adults with autism or Asperger syndrome. *Autism* 9, 5, 533–549.
44. Taylor, J. L. et al. (2012) A Systematic Review of Vocational Interventions for Young Adults With Autism Spectrum Disorders. *Pediatrics*, 130, 3, 531–8.
45. Morgan, L. et al. (2014) Interview Skills for Adults with Autism Spectrum Disorder: A Pilot Randomized Controlled Trial. *Journal of Autism and Developmental Disorders*, 44, 2290-300.
46. Nicholas, D. B. et al. (2015) Vocational support approaches in autism spectrum disorder: A synthesis review of the literature. *Autism*, 19, 2, 235–245.
47. Jacob, A. et al. (2015) The Costs and Benefits of Employing an Adult with Autism Spectrum Disorder: A Systematic Review. *Plos One*, 10, 10, e0139896.
48. Robertson, A. & Simmons, D. (2015) The sensory experiences of adults with autism spectrum disorder: A qualitative analysis. *Perception*, 44, 569–586.
49. Ausderau, K. K. et al. (2014) Sensory subtypes in children with autism spectrum disorder: latent profile transition analysis using a national survey of sensory features. *Journal of Child Psychology and Psychiatry*, 55, 8, 935–44.
50. Lane, A. E. et al. (2014) Classification of children with autism spectrum disorder by sensory subtype: a case for sensory-based phenotypes. *Autism Research*, 7, 2, 322–33.
51. Faller, P. et al. (2016) Application of Data-Driven Decision Making Using Ayres Sensory Integration(®) With a Child With Autism. *American Journal of Occupational Therapy*, 70, 1, 1–9.
52. Croen, L. A. et al. (2015) The health status of adults on the autism spectrum. *Autism*, 19, 7, 814–823.
53. Brett, D. et al. (2016) Factors Affecting Age at ASD Diagnosis in UK: No Evidence that Diagnosis Age has Decreased Between 2004 and 2014. *Journal of Autism and Developmental Disorders*, 46(6), 1974–1984.
54. D. Koski et al. (2016) Interventions for paediatric surgery patients with comorbid autism spectrum disorder: a systematic literature review. *Archives of Disease in Childhood*, pii: archdischild-2016-310814.
55. Autism: Parent Experiences of Dentistry (APEX-D), viewed May 2016; link: <http://www.pencru.org/projectsmeetings/researchprojects/dentistry/apexd/>

Who was involved

Steering Group

Katherine Cowan – JLA Advisor – (Chair of the group)

Dr Carole Buckley – RCGP
(GP and parent of child with autism)

Dr James Cusack – Autistica

Dr Ian Ensum – Clinical Psychologist

Dr Richard Mills – Research Autism

John Phillipson – Autism Alliance
(UK network of specialist autism charities)

Carol Povey – The National Autistic Society

Margaret Skerritt – Parent of a child with autism

Dr Vicky Slonims – Speech and Language Therapist

Dr Andrew Stanfield – Clinical Research Fellow,
Honorary Consultant Psychiatrist (Edinburgh)

Robyn Steward – Individual on the spectrum,
autism consultant and trainer

Ayesha Walawalkar – Sibling of an adult with autism

Data support

Dr Eva Cyhlarova

Funding partners:

Autistica
The National Autistic Society
Autism Alliance
Autism Research Trust

Supporting partners:

Action for Aspergers
Asperger Syndrome Foundation
Autism NI
Autism Anglia
Autism Bedfordshire
Autism East Midlands
Autism Oxford
Autism West Midlands
Autism Hampshire
British Academy of Childhood Disability
Daisy Chain
Fragile X Society
Parents Talking Aspergers
Kent Autistic Trust
MENCAP
Positive Autism Support & Training (PAST)
Peninsula Cerebra Research Unit
Research Autism
Royal College of General Practitioners (RCGP)
Royal College of Speech and
Language Therapists
Treating Autism

About Autistica

Autistica is the UK's leading autism research charity. We work to transform the lives of children and adults with autism through funding, stimulating and leveraging investment in groundbreaking research. We receive no direct funding from government, but work in partnership with statutory and other funders to build autism research capacity in the UK and ensure that resources are deployed where they can bring greatest benefit. We work with scientists, health services and individuals and families across the UK, so together we can understand autism better, improve diagnosis and develop the best ways to support people, so that everyone with autism can fulfil their potential.

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Thank you

We would like to thank everyone who took part in the surveys and helped share the survey online. In addition to those listed above, who have been extremely supportive throughout the process, Autistica would like to extend special thanks to:

- All workshop participants
- Margaret and John Skerritt
- **bigdog**
- All partner organisations and individuals
- All who took part in the surveys
- Dr Simon Wallace
- Christine Swabey

Find out more and support us at www.autistica.org.uk

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