the autism show

The national event for autism (including Asperger syndrome)

THE AUTISM MATTERS THEATRE
The top ten autism research questions according to autistic adults, families and clinicians

Dr James Cusack, Research Director at Autistica
Your Top 10 Autism Research Priorities

Dr James Cusack – The Autism Show
Autistica and myself

• I have worked in autism for about 15 years.

• Autistica is the UK’s largest autism research charity

• We want to deliver autism research which will improve outcomes for people affected by autism
Why do things have to change?

It all comes down to outcomes…

• Poor health outcomes

• Research suggests that, on average, autistic people die 16 years earlier than the general population.

• Poor quality of life for too many

We can change these outcomes through research
Background

One in a hundred report by Autistica

Future made together report by Research Autism

Failure to fund/pursue research which reflects community priorities

We all want to see research which leads to longer, happier, healthier lives for autistic people
What can the James Lind Alliance achieve?

• Validated method use in others conditions
• A consensus across funders and groups
• The basis of a national strategy for autism research
• Track record of increasing research investment
• Ultimately improve lives
Stage 1 - Partners

1. Finding partners who would like to be part of the process.
2. Question submission
3. Ranking
4. Deciding the top 10 questions
Stage 1 - Partners

Funders

Some of our many partners ...
Stage 2 – Question submission

1. Finding partners who would like to be part of the process.

2. Question submission: We received 3331 questions from 1213 people. Summarised in to 89 questions.

3. Ranking.

4.Deciding the top 10 questions.
1. Finding partners who would like to be part of the process.

2. Question submission: We received 3331 questions from 1213 people. Summarised in to 89 questions.

3. Ranking: Selection and ranking of 10 questions from 40. Top 25 taken forward. 1375 responses received.

4. Deciding the top 10 questions.
Stage 4 – Deciding the top 10

1. Finding partners who would like to be part of the process.

2. Question submission: We received 3331 questions from 1213 people. Summarised in to 89 questions.

3. Ranking: Selection and ranking of 10 questions from 40. Top 25 taken forward. 1375 responses received.

4. Deciding the top 10 questions: The workshop decides the top 10 research questions.
The final workshop – stage 4
The final workshop – stage 4
The Top 10
How should service delivery for autistic people be improved and adapted in order to meet their needs?
How can sensory processing in autism be better understood?
How can we encourage employers to apply person-centred interventions and support to help autistic people maximise their potential and performance in the workplace?
How can autism diagnostic criteria be made more relevant for the adult population? And how do we ensure that autistic adults are appropriately diagnosed?
How can parents and family members be supported/educated to care for and better understand an autistic relative?
Which environments/supports are most appropriate in terms of achieving the best education/life/social skills outcomes in autistic people?
4 Which interventions reduce anxiety in autistic people?
3

What are the most effective ways to support/provide social care for autistic adults?
Which interventions are effective in the development of communication/language skills in autism?
1. Which interventions improve mental health or reduce mental health problems in autistic people? How should mental health interventions be adapted for the needs of autistic people?
Why this all matters

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?
Why this all matters

- This is happening to real people
- Research can change this
- Improve quality of life
- Improve opportunities and options in life
What we will do

• We will work hard to ensure these questions are answered.

• We will change our own research strategy, and fund research which answers these questions.

• We will work with in partnership with other funders/autism organisations.

• We will lobby the government to have these questions answered.
What can you do?

• You’re the most important part of this

• Get involved

• Join our newsletter. Social Media. Share with your networks.

• Lobby for more research!
An opportunity

• We must work together as a community

• If we do, the UK could lead the world in having a consensus and national strategy for undertaking autism research

• Improve outcomes and transform the lives of the 700,000 autistic people in the UK
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