

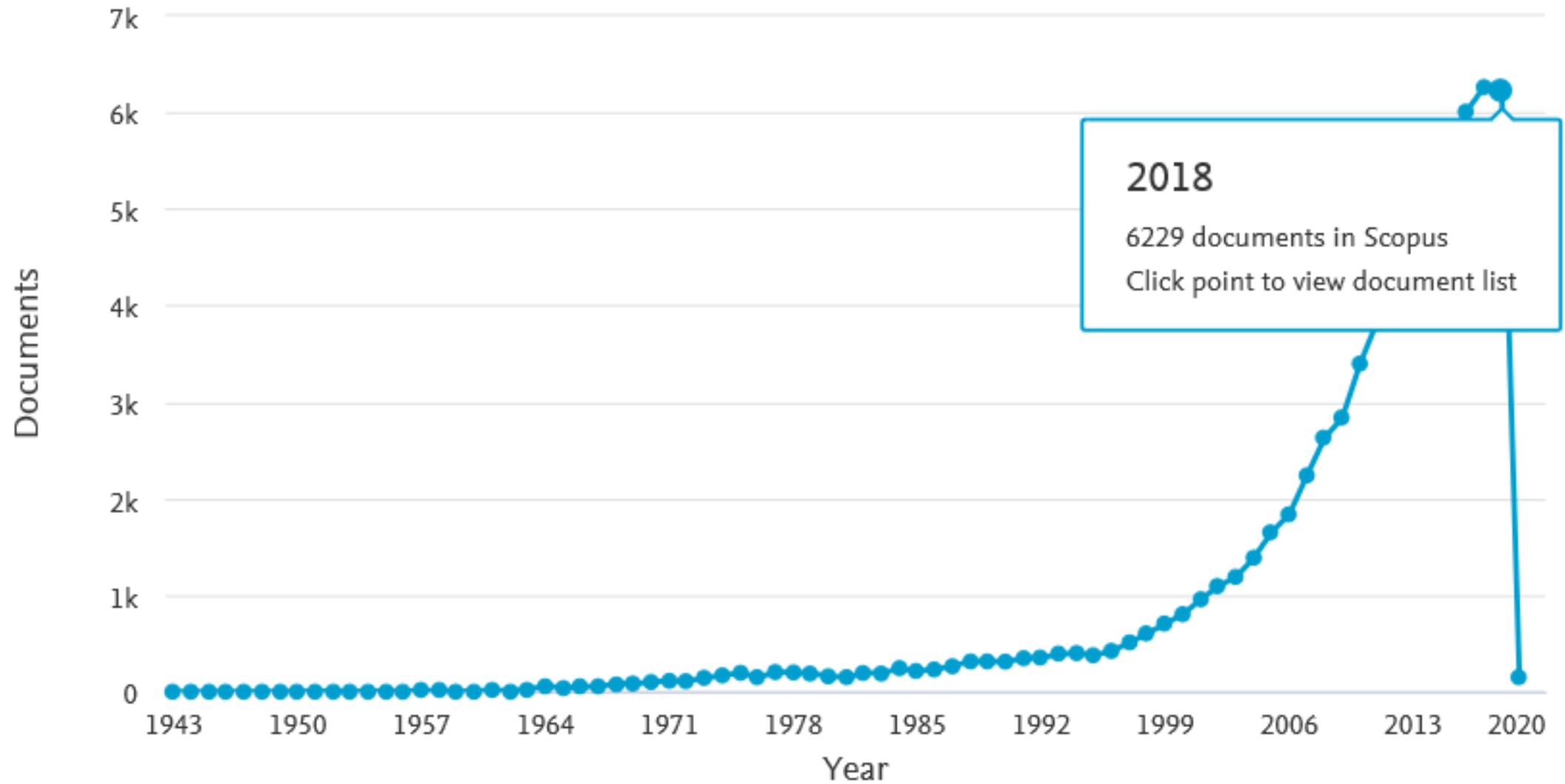
Research update: driving practice forward

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AUTISTICA
Building brighter futures through autism research

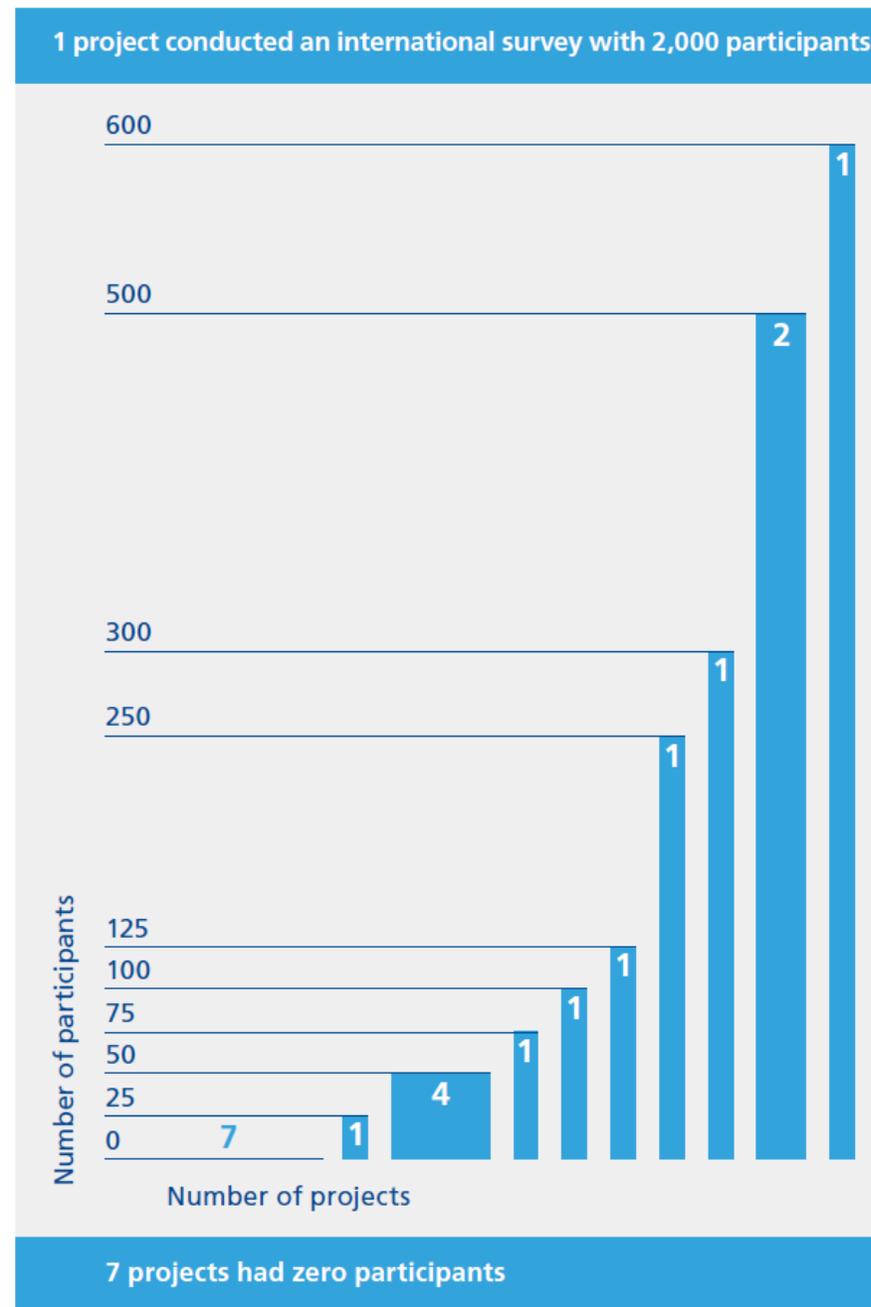
Our vision is a world where all autistic people and their families live a long, healthy, happy life.

Documents by year



Who has been taking part in autism research in the UK?

- Small samples
- Children



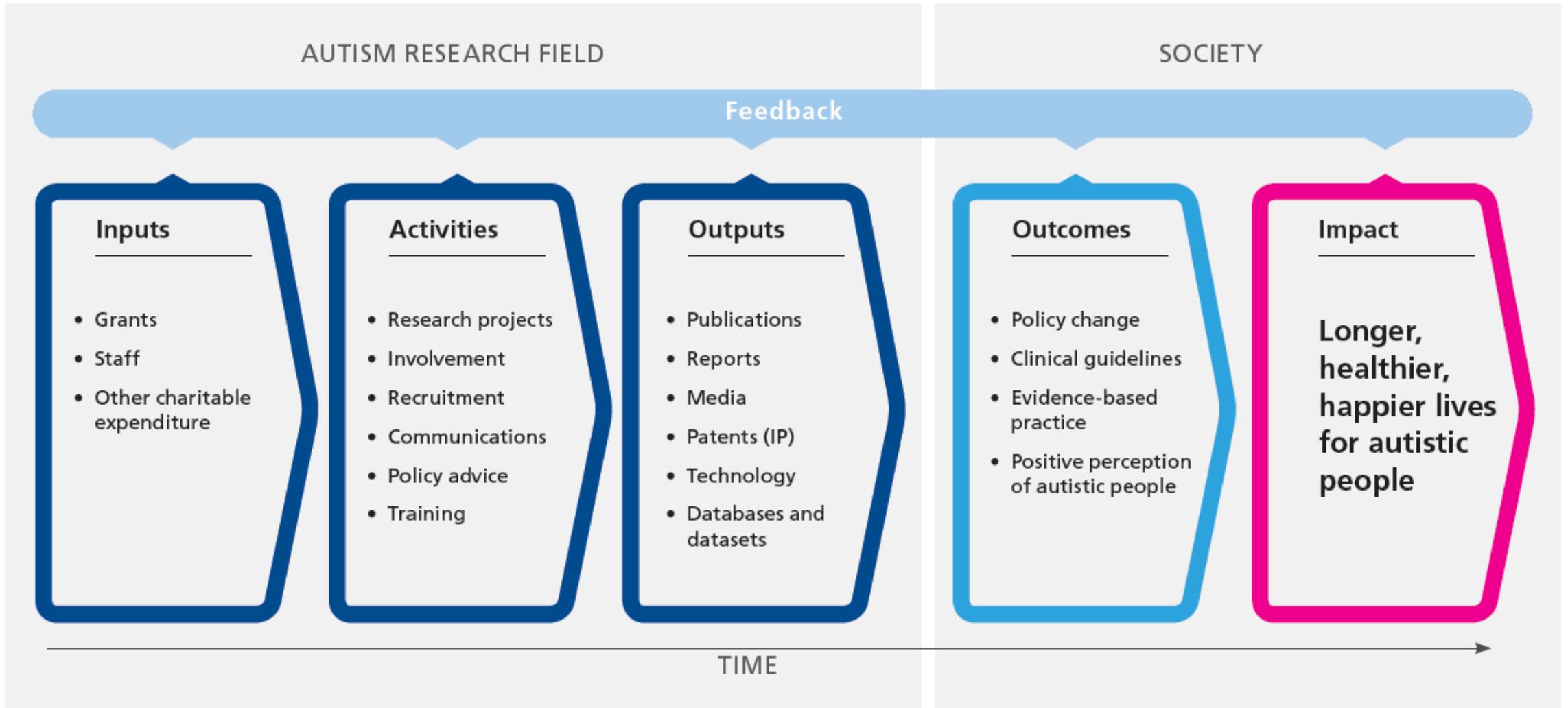
- Older adults (50+ years)
- Adolescents (14-17 years)
- Adults (18+ years)
- Children (0-13 years)

44% of UK autism research funding was spent on animal studies

3 studies recruited people with a learning disability

2 included minimally verbal people

How can research make a difference?



How research can change the weather

-  Autism is strongly genetic but varies greatly
-  There is an environmental link
-  Diagnosed based on behaviour
-  Language and cognitive ability at age 5 are the best predictors of later life outcomes
-  Autistic people die younger
-  More likely to be under employed

The community's top 10 questions for research



Priority Setting Partnerships

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With knowledge comes understanding



- 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?
- 2 Which interventions are effective in the development and 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 and 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?

What research has told us about our priorities: mental health

- A substantial number of people experience mental health problems and suicide is a big problem
- There are likely to be biological and environmental reasons for this.
- That typical approaches may not work for some people
- We know in children that some types of cognitive behaviour therapy seem to help alleviate anxiety, but not always.
- Problems with mental health are related to a range of other issues such as employment.
- Many autistic people with a learning disability have untreated or mistreated mental health problems.

How research can be translated: uncertainty and anxiety



How emerging research can make a difference: anorexia and autism

1. We know that in 1 in 5 of people with anorexia might be autistic
2. Current approaches are unlikely to work

Thus...

1. Ensure we identify autism more pro-actively
2. Ensure autism-enabling adjustments are in place
3. Invest in finding new approaches to help autistic people

Examples of things we don't know (yet!)

1. Could we identify anxiety and depression in autistic people who speak few or no words?
2. Could we understand why autistic women are more likely to have anorexia nervosa?
3. Could an app help autistic people to manage their own anxiety?
4. Could we prevent future suicides by learning from suicides of the past?
5. Could we learn how to manage seizures in autistic people?
6. What are the sensory experiences of autistic people in day to day life?

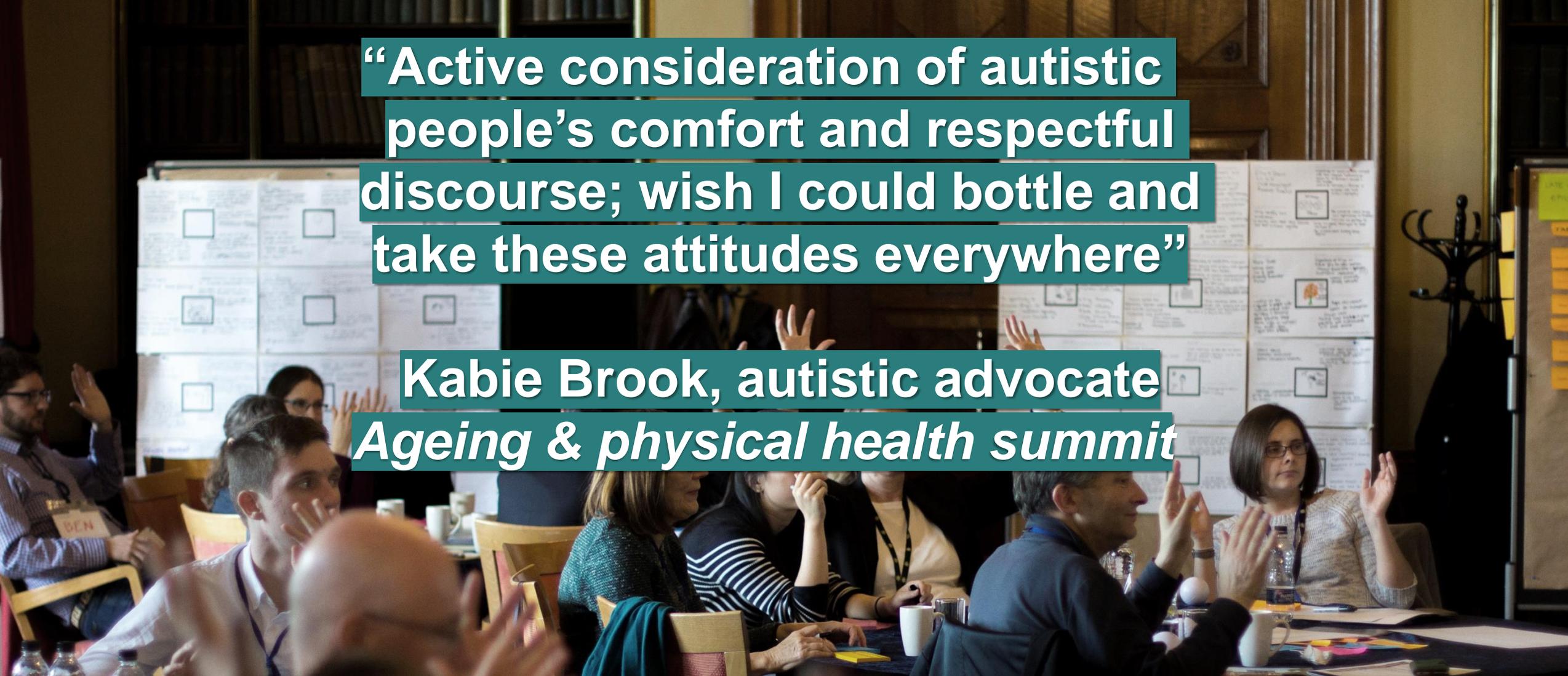
But barriers to research do exist...

- We fund virtually no research in key areas like social care and in priority areas like autism and epilepsy
- Groups are neglected
- Issues around authenticity of findings
- Specificity of findings: how useful is it to look across heterogeneous groups?
- What do people actually want from research?
- We fall miles behind other conditions in terms of evidence quality
- Lack of strategic action to address gaps in knowledge

1. Boost autism research in the UK



2. Maximise involvement at all levels

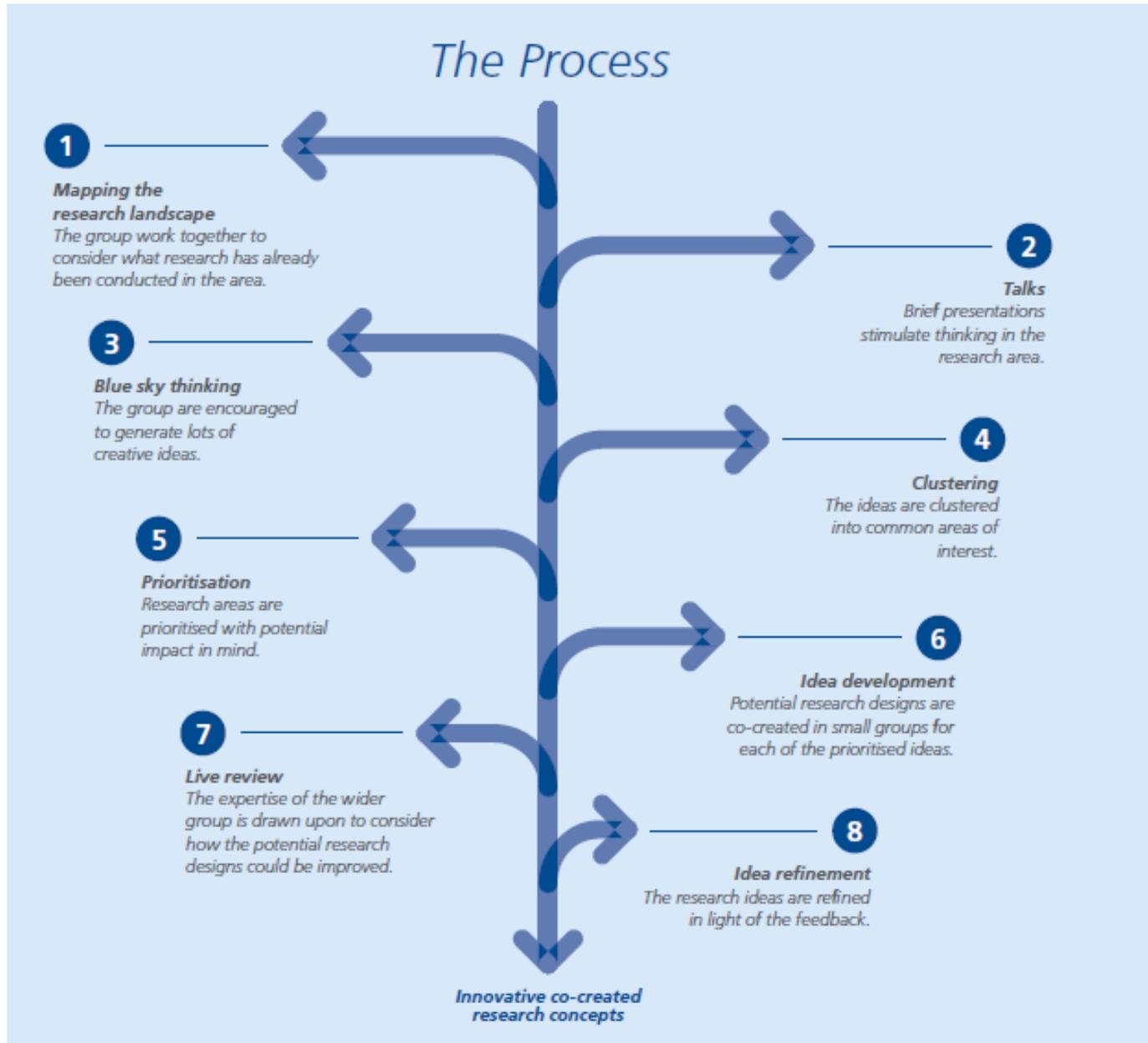


“Active consideration of autistic people’s comfort and respectful discourse; wish I could bottle and take these attitudes everywhere”

Kabie Brook, autistic advocate
Ageing & physical health summit

International summits

International summits





Insight Group



Study Groups



Charles Sharland scheme - Grants for autistic researchers



Conclusions

Research has told us a lot already, but we have only really just got started.

Groups and areas are neglected but we can tackle that through strategic action.

Need to work more collaboratively to bring research and evidence closer to real life by involving autistic people, families and professionals.

We need to become better at personalisation and understanding individual needs. There is no “one size fits all” approach and research needs to adapt to this.

Research and evidence are key for many people if we are to ensure that all autistic people can live a long, healthy, happy life

“ Research is the only way to get the services we and future generations need. If we don't research, nothing will change.

Malcolm, autistic adult and parent

DISCOVER



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