

CRAE



UCL

Building a participatory framework for autism research: the what, the why and the how

Liz Pellicano

Centre for Research in Autism and Education (CRAE)
UCL Institute of Education



1 in 100 Children



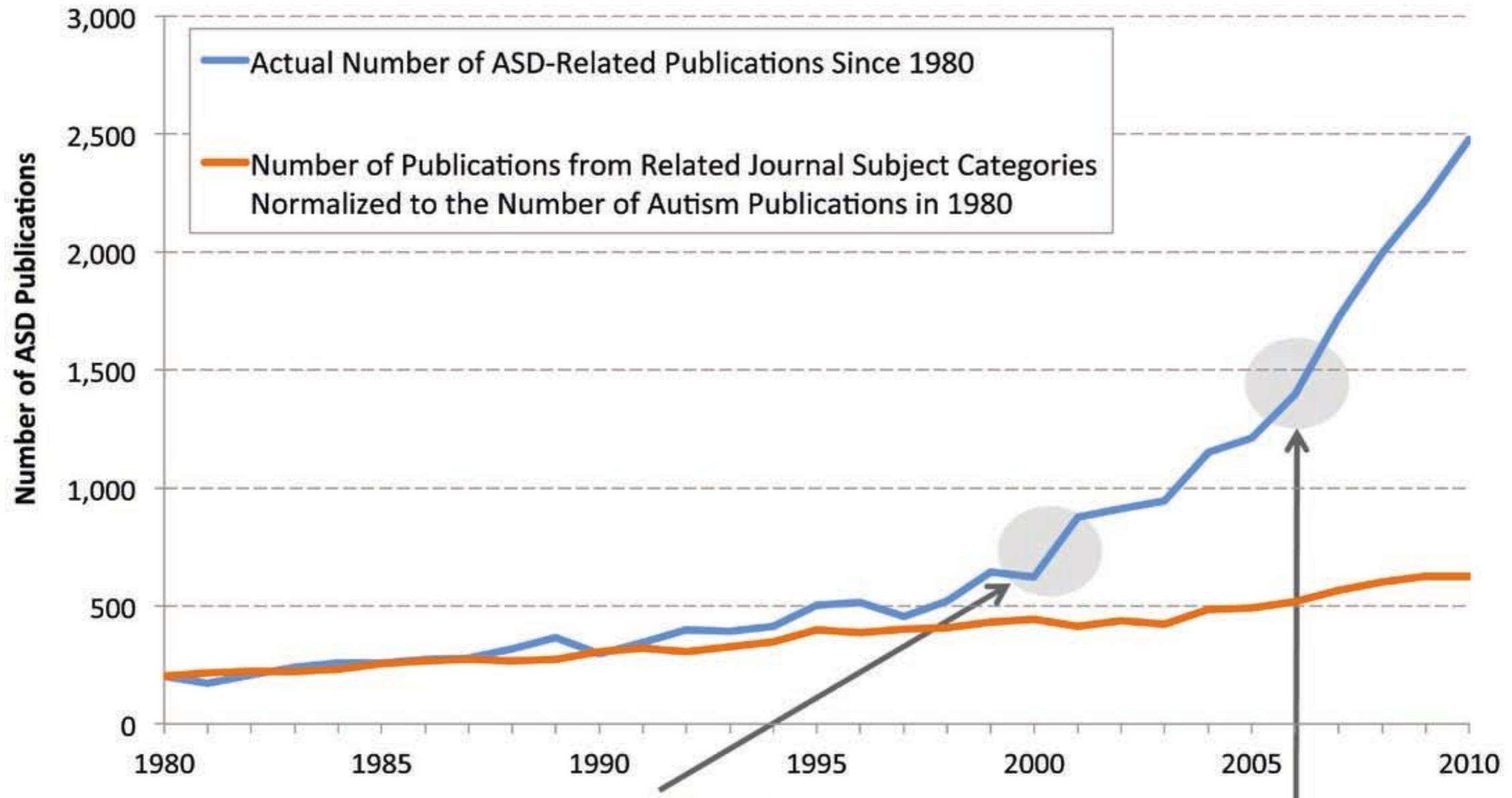
diagnosed with
Autism

autism in the UK

- in response, there have been recent policy and public service initiatives (e.g., Autism Act 2009) to enhance the life-chances of autistic people
- there has also been an explosion in autism research



dramatic increase in autism publications



... but there is still a huge “translational gap”

study aims

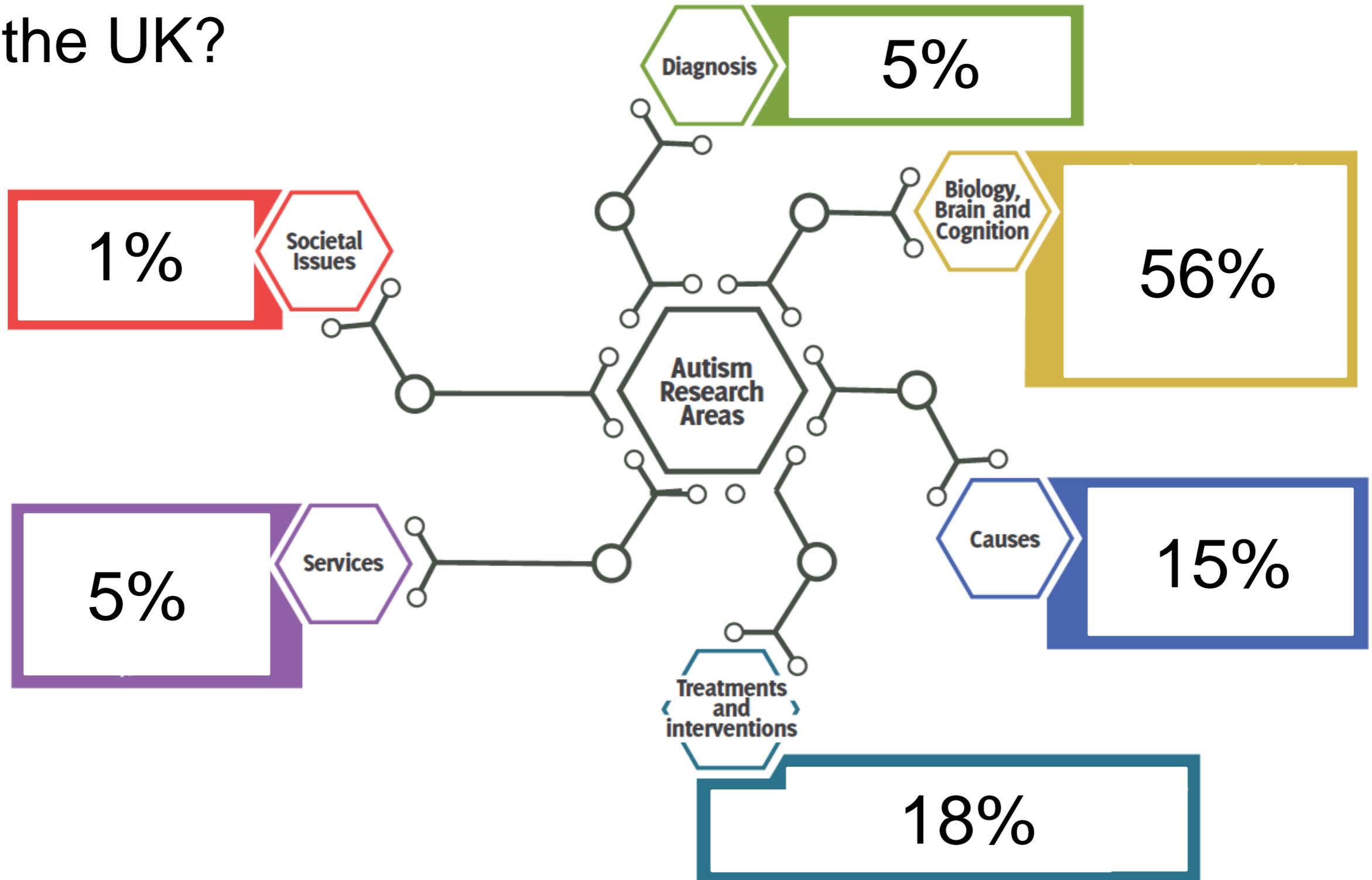
1. to describe the current landscape of autism research in the UK
 2. to compare the nature of the research being conducted with the views and perspectives of community members
 3. to understand the extent and nature of community involvement in UK autism research
- 

UK research funding

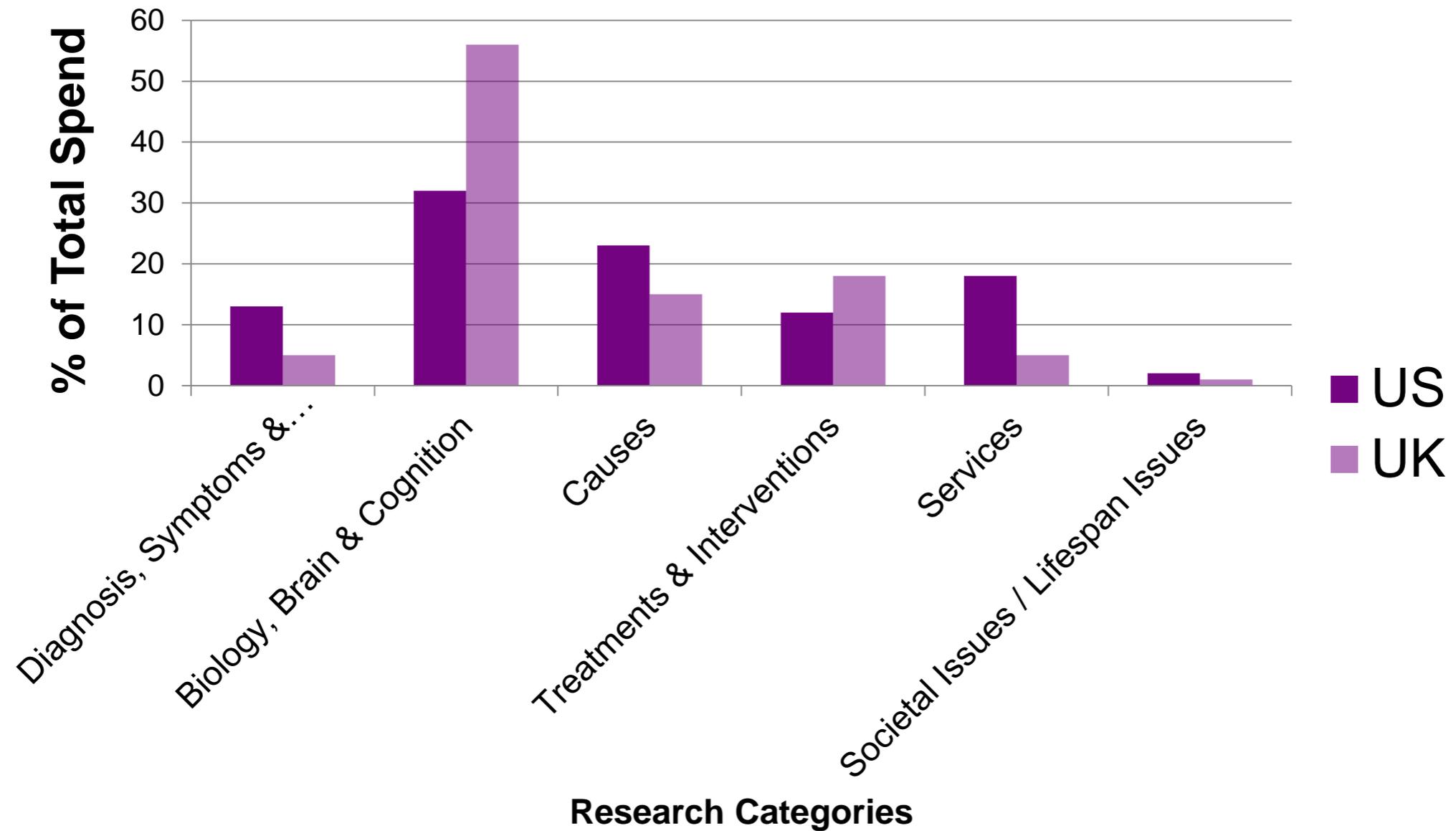
- between 2007 and 2011, the UK invested £20.8 million spread across 106 different projects
- in 2010 alone, the US spent £75.79 for every autistic person compared to £4.26 for every autistic person in the UK – 18 times the amount per head



what are the areas of autism research in the UK?



UK vs. US grant funding



identifying people's priorities

- >1,600 people responded to an online survey
- they rated the relative importance of 13 research questions on a 5-point scale

Questions	Mean rating
1. How can we better recognise the signs and symptoms of autism?	4.2
2. Are there different types of autism?	3.7
3. How common is autism?	3.4
4. How do autistic people think and learn?	4.5
5. How are autistic people's brains different from the brains of non-autistic people?	4.0
6. To what extent is autism caused by environmental factors?	3.5
7. To what extent is autism caused by genetic factors?	3.6
8. What are the best ways to treat the core symptoms of autism?	4.2
9. How can public services best meet the needs of autistic people?	4.6
10. What is the place of autistic people in society today?	4.0
11. What are the best ways to improve the life skills of autistic people?	4.6
12. What does the future hold for autistic adults?	4.4
13. Why do autistic people appear to be more at risk from some medical conditions than non-autistic people?	4.0

what people want from research

"We need to know how to work with the services to make sure everyone has a chance of having a better life."

28-year-old autistic woman

"I want to understand more about how my child sees the world so I can better understand his response to it."

Mother of young person with autism

"Research needs to be carried out and put into ways to teach life skills and social rules to create more independence for adulthood."

Sister of an autistic person

"We need to understand the most effective ways to educate autistic children and provide life skills whilst respecting them as individuals."

Mother of child with autism

→ huge mismatch between what is researched and what people want to be researched

why the mismatch?

some autistic adults noted that the research being done represented *“neurotypical priorities regarding us – not autistic people’s priorities”*

others emphasized that the research failed to speak to the reality of their lives in the here-and-now: *“you know that’s all researchers are interested in, what causes it, what causes it? Doesn’t say much for the kids that have already got it, does it?”* [parent]

Pellicano et al., 2014, *Autism*



who gets to decide what gets researched?

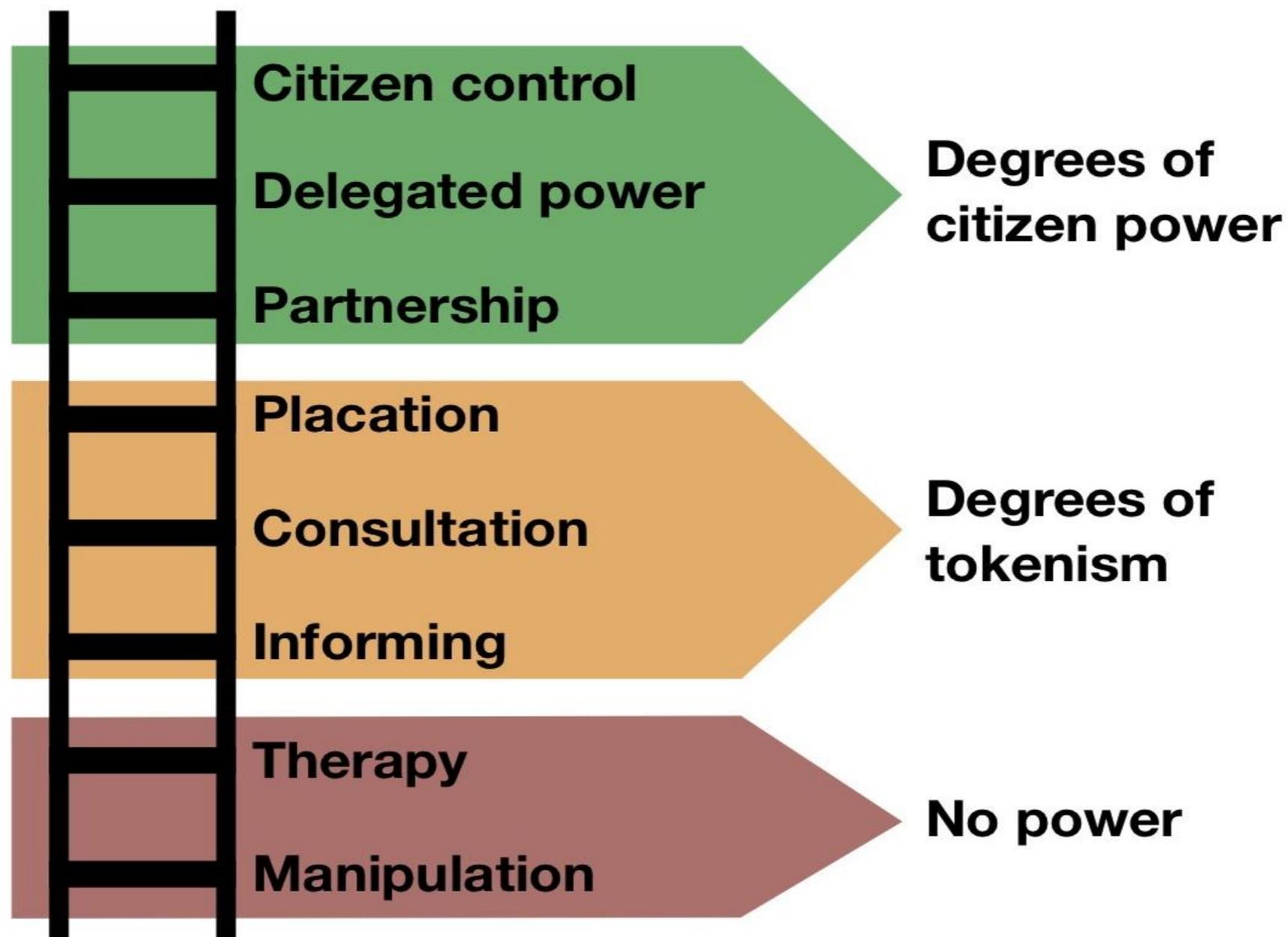
community participation in research

in biomedical research, such gaps have been closed by designing research processes that are:

- more thoroughly **relevant** to “patients” and communities,
- sufficiently **tailored** to the realities of their everyday lives, and
- **consistent with their values**



moving citizen involvement “further up the ladder” of participation ...



degree of engagement

- **public dissemination:** which could include newsletters summarising research findings, online blogs or public events
 - **dialogue:** which might comprise direct communication or consultation between researchers and research participants
 - **partnership:** which includes joint working between researchers and non-researchers, where research is carried out 'with' or 'by' community members rather than 'to', 'about' or 'for' them
- 

involvement in autism research

- while the majority of researchers said that they ‘frequently’ or ‘very frequently’ engaged in public dissemination and dialogue, only a minority of autistic people, family members and practitioners shared this view
- all groups of respondents agreed, however, that active research partnership was a rare occurrence

Pellicano et al., 2014, *PLOS One*

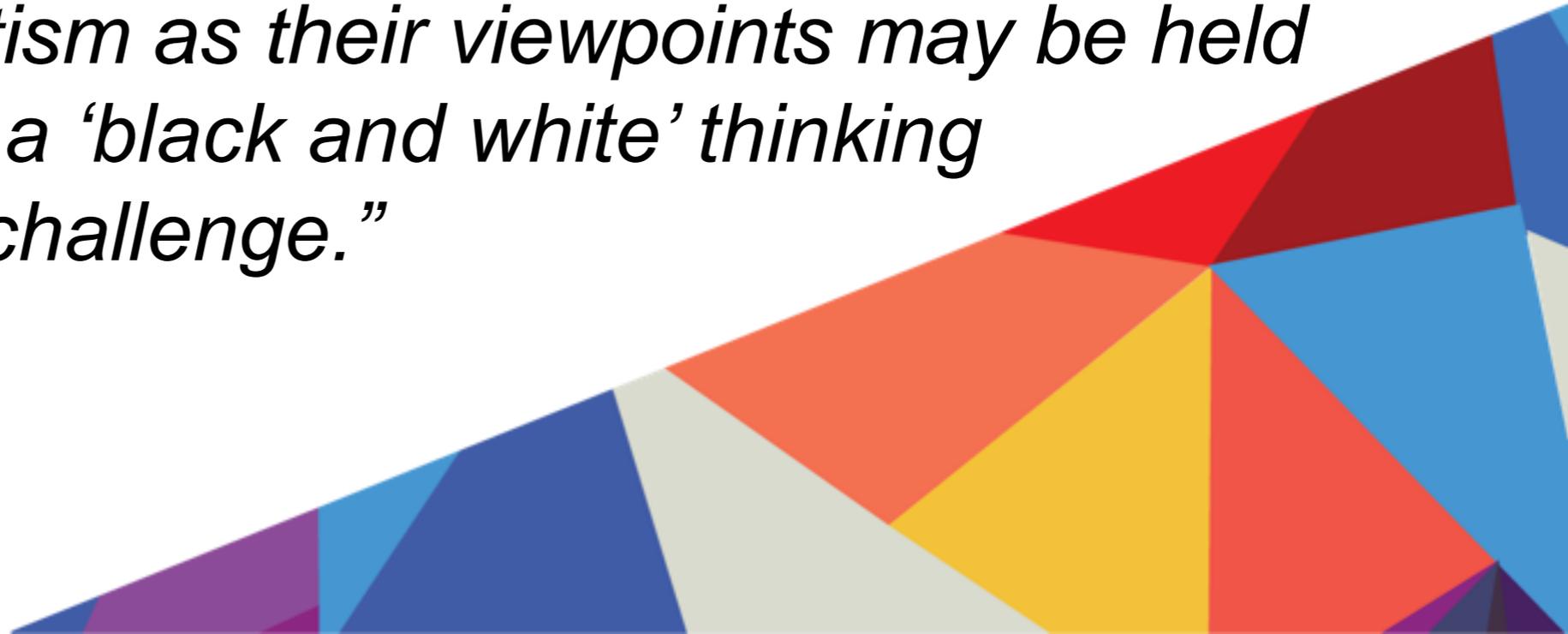


researcher perspectives

attitudes: *“the people making judgments about research and research funding have to be other scientists”*

definitions of partnership: members *“contributing feedback”* and *“being on steering groups”*

barriers: *“it can often be difficult to work with people with autism as their viewpoints may be held very firmly and a ‘black and white’ thinking style can be a challenge.”*

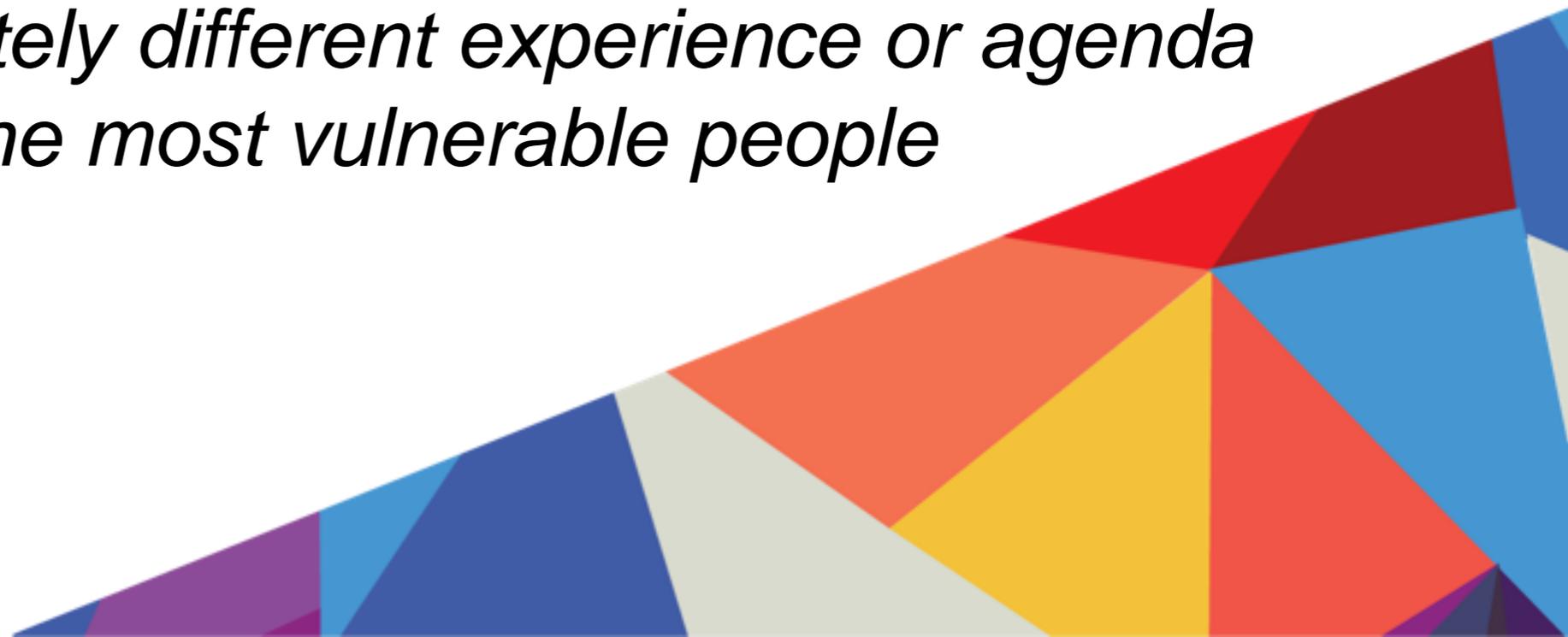


researcher perspectives

attitudes: *“the people making judgments about research and research funding have to be other scientists”*

definitions of partnership: members *“contributing feedback”* and *“being on steering groups”*

barriers: *“sometimes the most vocal individuals have a completely different experience or agenda than some of the most vulnerable people we engage”*



community perspectives

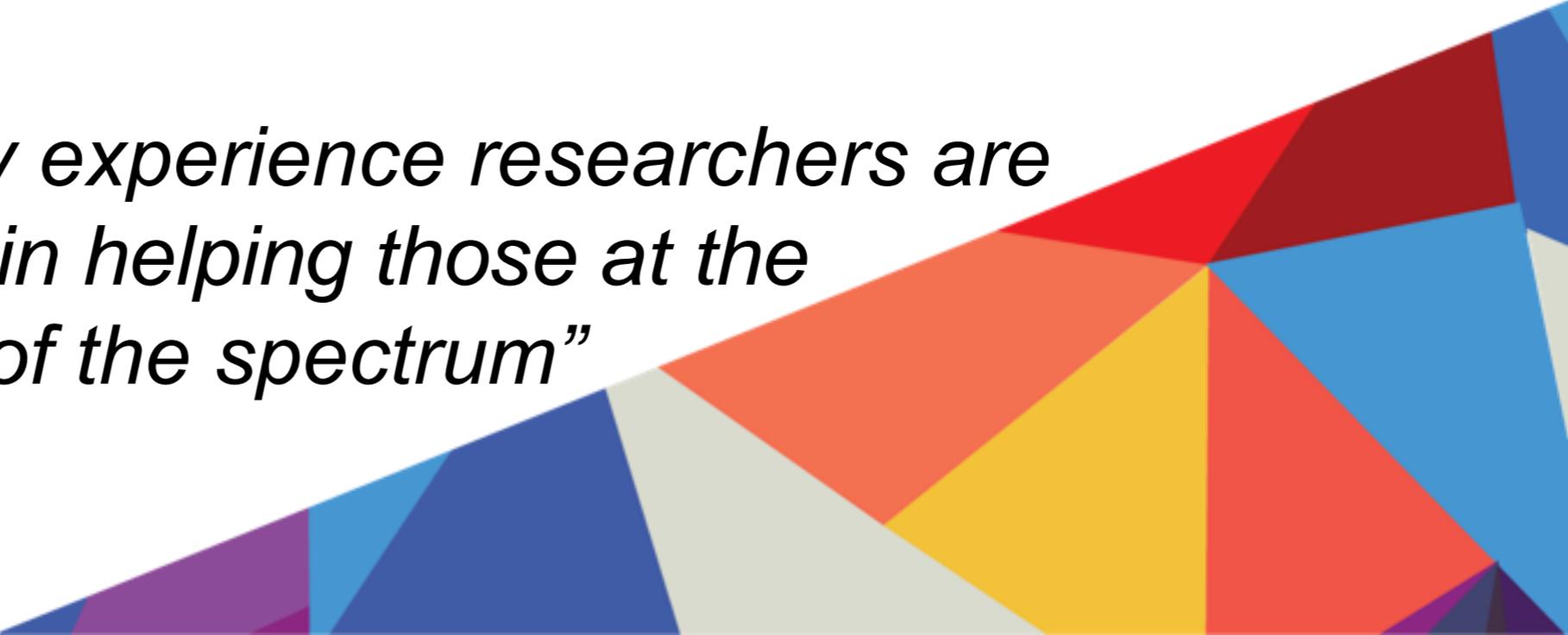
lack of awareness: *“I have very little knowledge of any research that may be going on or what its purpose is”* Parent

asymmetric interactions: *“researchers are more keen on collecting data, not providing results”* Parent

“sometimes we are a bit like monkeys in a zoo”
Autistic adult

barriers: *“in my experience researchers are only interested in helping those at the more able end of the spectrum”*

Parent



community perspectives cont.

different priorities: *“most UK researchers operate from ivory towers with very little contact with real autism”* Parent

“researchers are far too interested in causes and cures with intellectual understanding only and no practical application” Practitioner

skepticism towards research: *“I don’t think many researchers feel they can talk to autistic people as if they matter, they’re too busy studying them like specimens or looking for a ‘cure’”* Practitioner

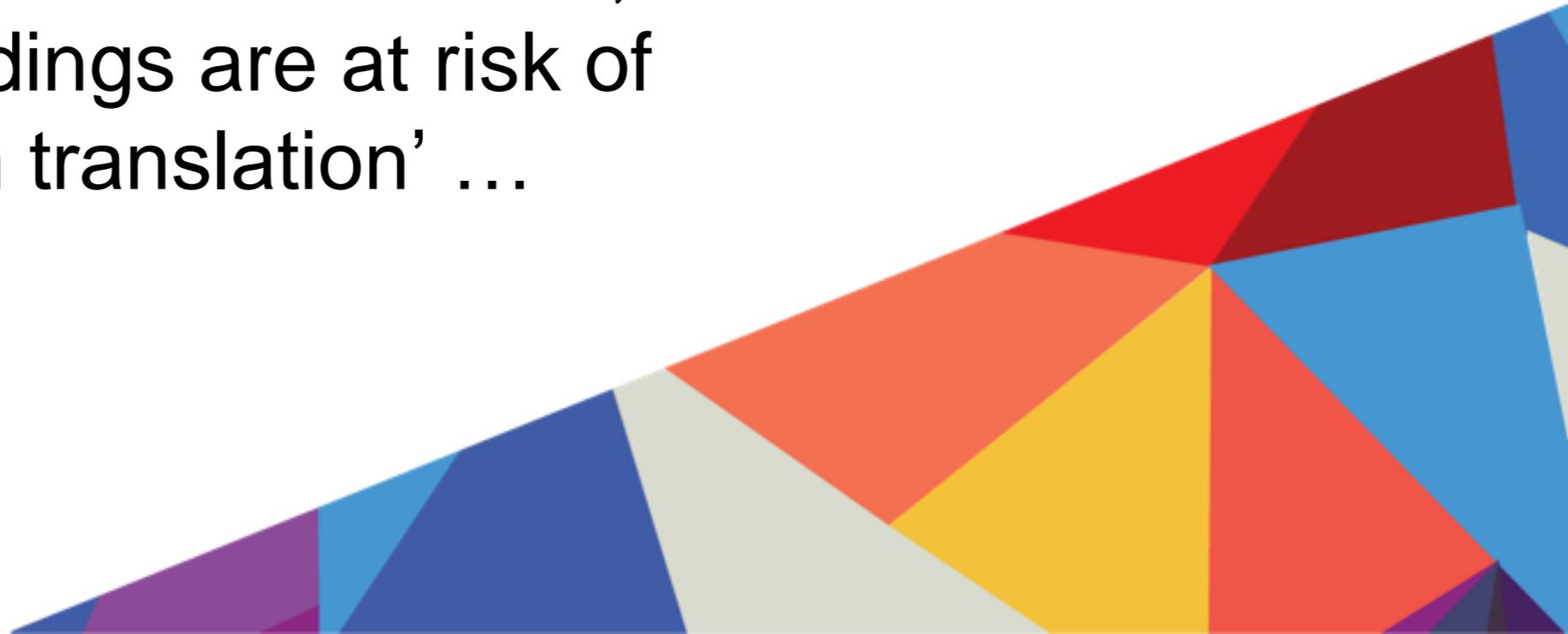


DISEMPOWERED



summary

- overall, autistic adults, family members and practitioners wanted greater involvement in research
- for some researchers, however, the very involvement of those with a vested interest (e.g., “patients”) potentially introduces bias
- but without such involvement, the research findings are at risk of being ‘lost in translation’ ...



conclusions I

- there is a clear disparity between the UK's pattern of funding for autism research and the priorities articulated by community members
- the lack of commitment to involving the community in research is one reason for this disparity, which might serve to undermine the process of translational research



conclusions II

- building and maintaining mutually supportive partnerships is key to ensuring that the advances in research impact upon those who need them most
- we need to give autistic people and their families the opportunity to voice their views and perspectives – and we need to listen ...
- *“In the world we live in, disabled people are always just around the corner -- but never in the room.”*

Ari Ne'eman



beyond tokenism

- should we involve the autistic community in ALL research? is that feasible/appropriate?
- HOW to we ensure that the many (and diverse) voices are heard in the process?
- what would (and should) involvement look like?
- how do we fund such involvement?





RESEARCH AUTISM

IMPROVING THE QUALITY OF LIFE

IDENTIFICATION INTERVENTION INCLUSION



Leading education
and social research
Institute of Education
University of London

A FUTURE MADE TOGETHER

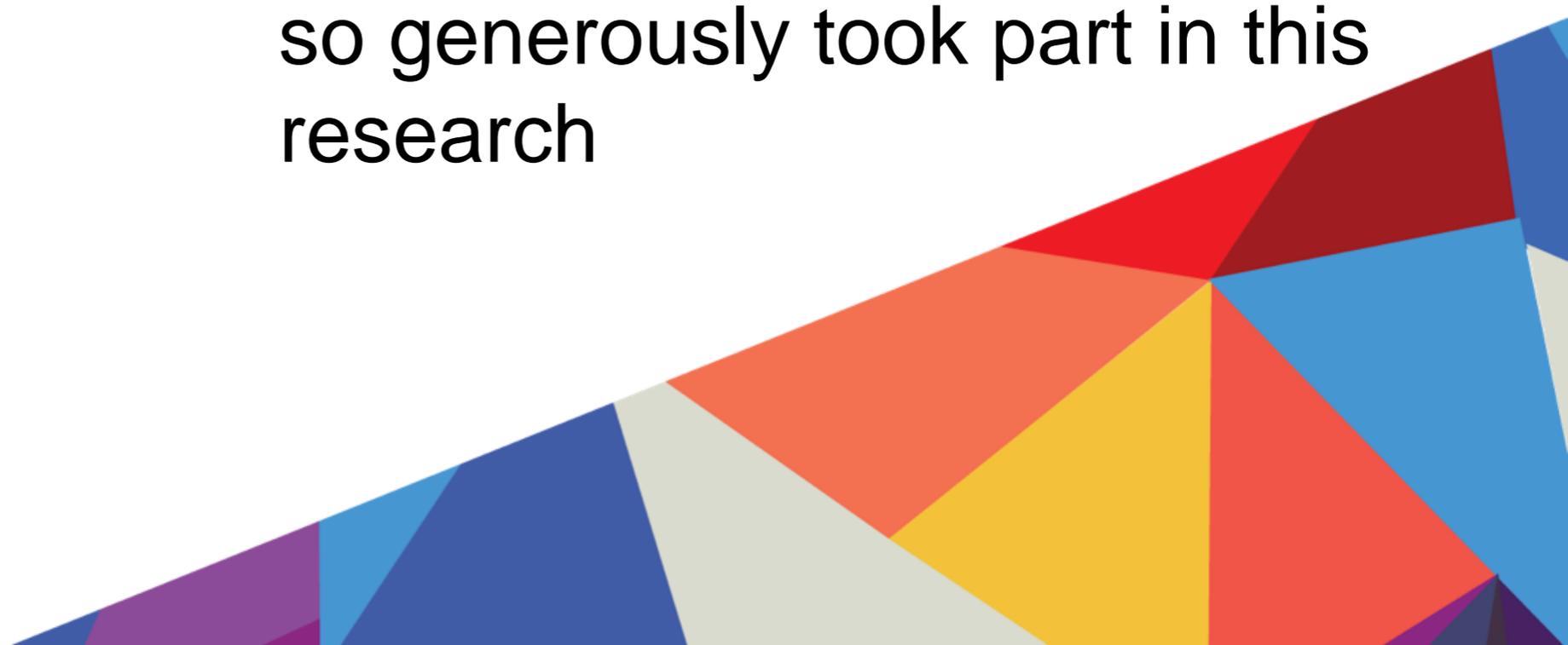
SHAPING AUTISM
RESEARCH IN THE UK

Centre for Research in Autism
and Education (CRAE)
Institute of Education
University of London
20 Bedford Way
London WC1H 0AL

+44(0)20 7331 5140
crae@ioe.ac.uk

ioe.ac.uk/crae

Thanks to Tony Charman,
Adam Dinsmore, our funders
and to all the autistic adults,
their families, teachers,
practitioners, clinicians,
academics and funders who
so generously took part in this
research



A young child with dark hair, wearing a light-colored sweater with a space-themed graphic, is sitting at a table. The child is smiling and looking towards a book being held by an adult's hand. The table is covered with a blue cloth and has several colorful stuffed toys on it. The background is a plain white wall.

Centre for Research in
Autism and Education (CRAE)