

IAMHEALTH: Grounded or Isolated? The practice and experience of researchers, patients and carers in collaborative research

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FUNDED BY

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for Health Research

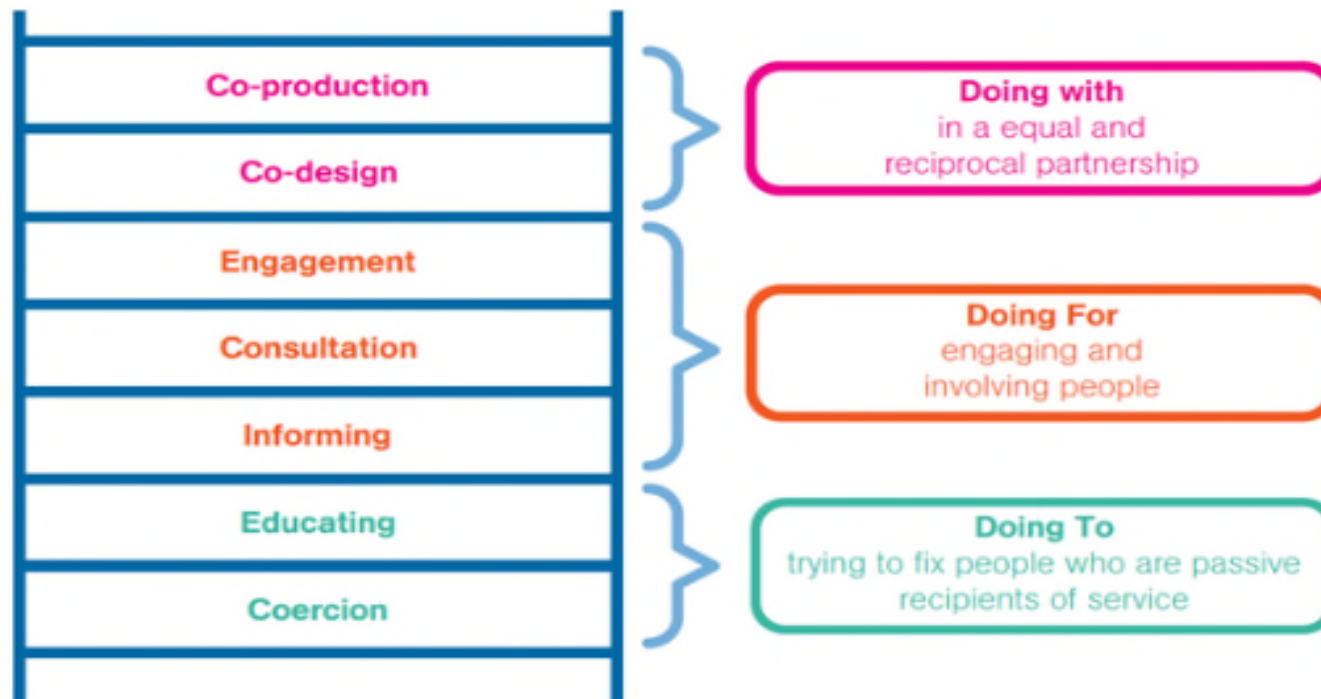
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Community priorities in Autism Research

- Autism research has not always represented the opinions of people with autism and their families/carers.
- There is a growing recognition of the value of designing and conducting research using a collaborative partnership.

What is Patient and Public Involvement?



A Ladder of Citizen Participation. – S R Arnstein. (1969) Journal of the American Institute of Planners, 35(4); 216-224. <http://lithgow-schmidt.dk/sherry-arnstein/ladder-of-citizen-participation.html>

IAMHealth



Improving Autism
Mental Health

PPI

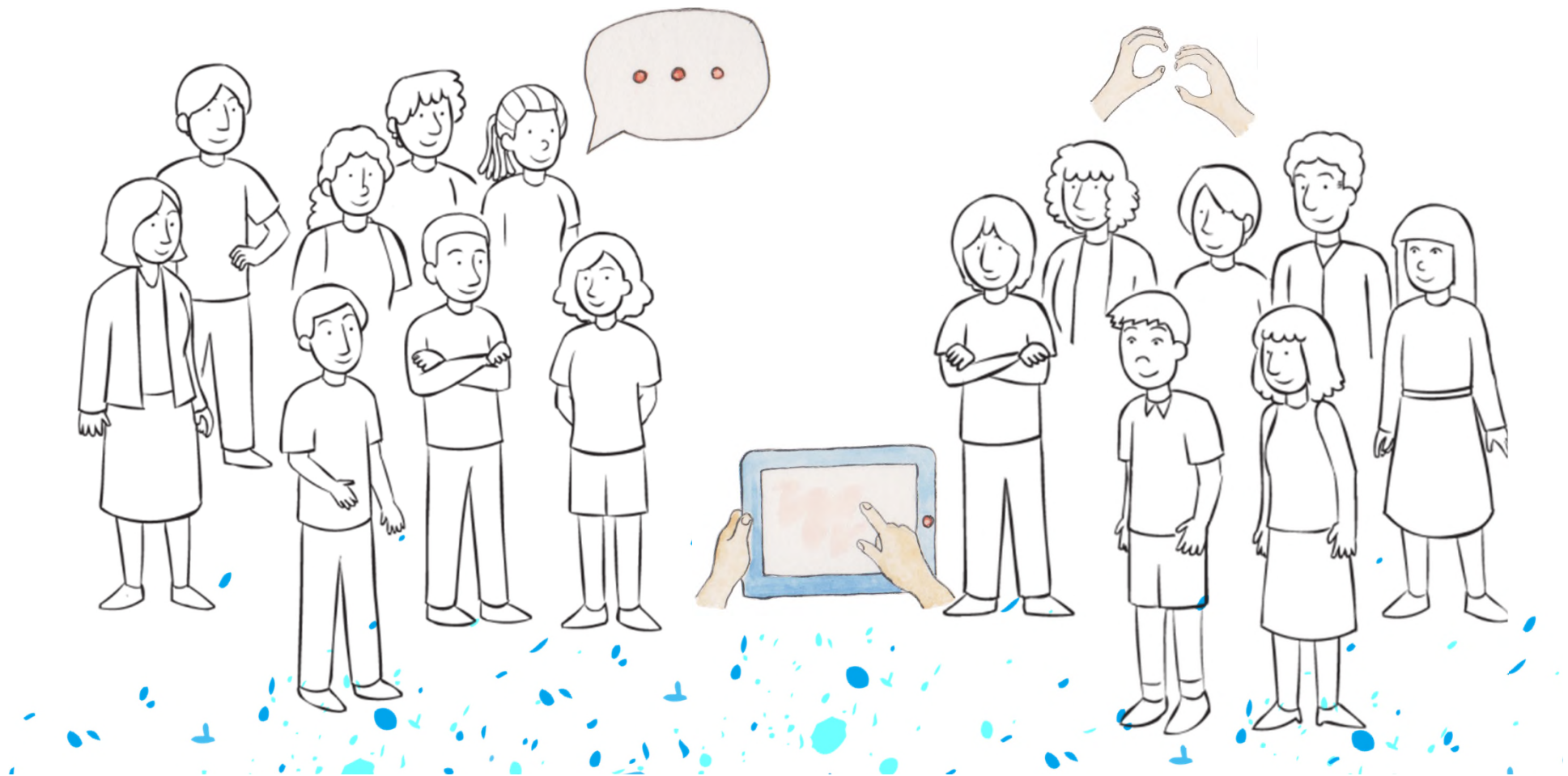
Development
of an
Assessment
of
Concerning
Behaviour
(ACB)

Biographies

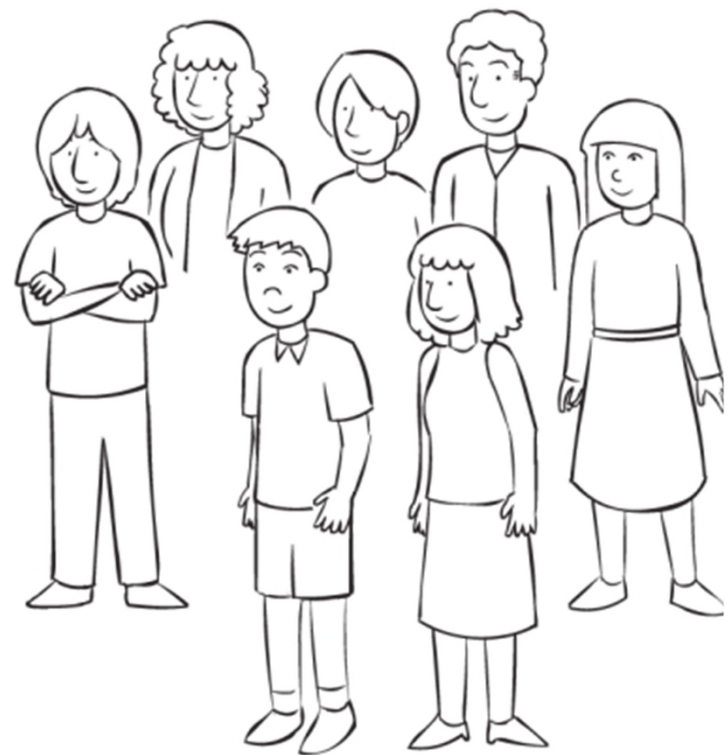
Predictors

Treatment

Recruiting the Patient and Public Involvement groups



Diversity in PPI groups



**Reimbursement for
time and travel**

**Assumptions about
which costs could be
met**

**Adapted
communication**

**Distance
involvement options
(email, skype,
conference call)**

Barriers and adaptations

**PPI autistic adults and
PPI parents group met
separately with a
shared lunch**

**Verbatim notes with
summaries for panel
members**



The Impact of PPI in IAMHealth

BMJ Open. 2016 Mar 22;6(3):e010693. doi: 10.1136/bmjopen-2015-010693.

Protocol for the development and validation of a questionnaire to assess concerning behaviours and mental health in individuals with autism spectrum disorders: the Assessment of Concerning Behaviour (ACB) scale.

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Advice ranged from use of language to thinking about a child, adult and parental perspective on the actual aims of the work. With respect to the intervention this helped form ways the team thought about the content of the group as well as what was important to capture in the research protocol.

"Practically, they helped with the design of the... study interview schedule and with the tools we used... They provided feedback around our data analysis which helped us with deciding on areas of importance..."

It was extremely satisfying knowing that the research grant was solely focused on what the ASD population wanted and felt was missing in their current clinical treatment...I found that when recruiting participants it was easier as this was a research project that felt relevant for families to take part in.



Examples of Involvement

Patient context

- PPI in research (INVOLVE)
- Expert by Experience
- Patient advisor board
- Patients as part of the **workforce**
- Peer support work

Education context

- Parent – teacher associations
- School governors
- Student councils
- Buddy systems
- Disabled students networks
- Pastoral care systems

Please get in to groups to consider how
you could introduce or improve your
strategies for including people with
autism in any role

i.e. autistic patients, students and/or
colleagues.

- a) People who currently include autistic people in their workplace (in health or education or other settings) and feel this needs improvement
- b) People who do not yet formally include autistic people in their work setting but would like to do so
- c) Autistic people and parents of autistic people who are contributing in a PPI or similar role or who would like to contribute in the future



Thank you!

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