

Including people with learning disabilities and autism in research – Wed 9 June 2021 – Online Resilience Forum

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Topic Including people with learning disabilities and autism in research – a call to action for a systems-based approach – Anne Rathbone

Date This session ran on Wednesday 9th June 2021

The presentation slides and short film showcased at this forum are available below

Session Summary

Those of us who are people with learning disabilities and autism are often left out of research because researchers may feel that finding and involving us can present additional challenges in terms of time, adapting materials and finding creative ways of working.

When we are included, this is largely as research participants or ‘subjects’ rather than co-researchers – fully involved in all aspects of the research.

We know from existing research that most of us with learning disabilities and autism face major disadvantages and social exclusion and Covid 19 has exacerbated this. Research on health and other inequalities largely leaves us out. This in itself continues the cycle of exclusion from research. There is a growing movement in academia of undertaking more co-productive research and University of Brighton's Centre of Resilience for Social Justice is taking an active role in promoting this.

We believe that those of us with learning disabilities and autism should be included in research more, both as participants and co-researchers and that creative ways need to be found to do this. Such inclusion is fundamentally important and this is not just about our quality of life 'luxuries' but fundamental to mental health and to good research.

To achieve this, we need change across the whole system – a change in mindset of researchers but also Research Council and other funders' systems change in funding allocations and assessment of equality impact of their funding decisions.

In this forum, we will hear from people with learning disabilities and autism themselves, community practitioners and academics about what can and should be done to achieve positive impact on the inclusion of people with learning disabilities in research.

[Download presentation PowerPoint slides](#)



Watch Video At: <https://youtu.be/mDeKU1z7Bg>

Presenters

We are a group of learning disabled people, people with autism and our allies and

supporters. Anne Rathbone has led on this project following her PhD research with members of Arts Connect. Harry Fairchild , Sophie Halas, Laura McGowan, Dominic Steel and Mikey Reynolds did this research and Julia Roberts, the Arts Connect Programme Director supported it as well. Adam Williams is a Resilience Revolution Co-researcher and peer sessional worker in Blackpool. We have all been involved in research and all have things to say about why it's important to include people with learning disabilities in research. Here we present our own views and those of others in academia and the community about how research funders can adapt their systems to make research properly inclusive of people with learning disabilities.

Who might be most interested

The Forum is aimed at anyone who wants to explore with us how research can be made more inclusive for people with learning disabilities, through systems change. This includes academic researchers and strategic leads, PhD students, Research Council and other funders people with learning disabilities, community organisations, and their parents, carers and supporters. Let's work together to make some change.

Jargon-busting

You can find our jargon busting sheet [here](#)

Upcoming Forums

The Resilience Forum is for ANYBODY (with a pulse!) involved with or interested in resilience research. If you like what you see and you want more, More, MORE, why not [subscribe to our mailing list](#)? You'll receive our email newsletter with details of our upcoming Resilience Forums, training and other events, news and resources (most of which are free!), and any other products and services that might be of interest. This is a web-based service and it is very easy to subscribe, unsubscribe or update your email address at any time.

See below for links to our upcoming forums:



Previous Resilience Forums

You can find information about our previous Resilience Forums in Brighton, Blackpool, Hastings and online here. Many of our previous Resilience Forums and Centre meetings have slides you can download, blogs you can read, or short films you can watch.

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