

# Innovation in Autism Practice: The Future is Calling

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# Methodologies and methods in participatory research

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**The  
Participatory  
Autism  
Research  
Collective**

*Our aim is to build a community network where those who wish to see more significant involvement of autistic people in autism research can share knowledge and expertise.*

*For latest information on PARC related news and events visit our website or contact us at:*

**[www.PARCautism.co.uk](http://www.PARCautism.co.uk)  
damianmilton.sociology@yahoo.com**



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# what is research?

“Pure science”?

“Objective”?

“Fact”?

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# what is research?

What question is being asked?  
By who?  
To what purpose?

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# what is research?

Methodology - structural scaffolding/paradigmatic perspective  
Method/s - systematic, pragmatic, authentic, valid, robust

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# what is research?

Methodology

Quantitative: what, how many?

generalisation

Qualitative: who, why?

theory generation

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# what is research?

Safe bet research:

“As our circle of knowledge expands, so does the circumference of darkness surrounding it.”

**Albert Einstein** (although, on the bright side, so does our area of illumination)

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# what does autism look like?



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# what does autism look like?



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# what does autism look like?



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# what does autism look like?



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# what does autism look like?



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# what does autism look like?



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# what does autism look like?

Being Different and Belonging: Growing Up as an Autistic Girl with S



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# what does autism look like?



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# what is participation?

**Autism bias:** lack of research inclusion/missed and mis-diagnosis

**Gender bias:** expectations, pressures, vulnerabilities + internalised narratives of 'normalcy', deficit and marginalisation

In view but invisible

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# what is participation?

Autism and Mental Health:

lack of research

lack of research that asks autistic people

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# what is participation?

**Can the subaltern speak?** Gayatri Chakravorty Spivak

“...hones in on the historical and ideological factors that **obstruct the possibility of being heard for those who inhabit the periphery.**”

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# what is participation?

Can the subaltern speak?

What is autism?

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# what is participation?

What is autism?

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# what is participation?

## What is autism?

psychiatric

medical

genetic (+/- environment)

part of human neurodevelopment diversity

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# what is participation?

Who?

When - at what stage of the research process?  
In what capacity?

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# what is participation?

Retrieving lived experience as a valid source of data

**Facilitating voices:** methodological flexibility, methodical inventiveness  
eg In My Shoes interview software; online diaries/blogs, mixed media

**intersection:** females within the autism population having specific needs

**Disabilities/citizen/human rights:**

**reframing lived experiences of autistic (people)** as individuals with specific strengths, challenges, rights and entitlements

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## Positive processes within participatory survey research

**Belief** - Viewing the autistic person as an expert on their own experience

**Mutuality** - Establishing communication of a common goal

**Ethics** - Supporting consent and ensuring ethical protection and oversight

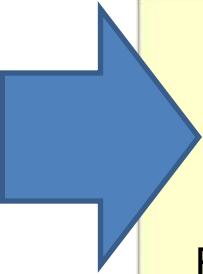
**Well being** - Reducing the potential for stress during research participation

**Cognitive support** - A mechanism to facilitate individual meaningful engagement

**Translation** - Sharing results and establishing ownership as part of knowledge creation

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Establishing question or statement using concrete references

**Supporting question comprehension and engagement**



Discussion Space

**Supporting receptive language and communication**

Emotional Labelling

**Supporting cognitive / emotional response**



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“Have you had a time when something went wrong in your service?”

10

?

Staff group photos




11

?

Who would you speak to if something was wrong?

Lee Ark (name)



Would you tell staff if something is wrong?

yes

No

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## **Inclusive Participatory Research – essential elements**

**A principle of participation *for all supported persons***

**Support to ensure informed consent and ethical protection**

**Any research exclusions based on well being considerations rather than ability**

**Detailed process of consultation and design of individualised engagement**

**Structured use of workspaces to frame questions and provide cognitive support within structured, facilitated discussion**

**Use of autistic interests to support relationship building, reduce anxiety and support emotional or labelling**

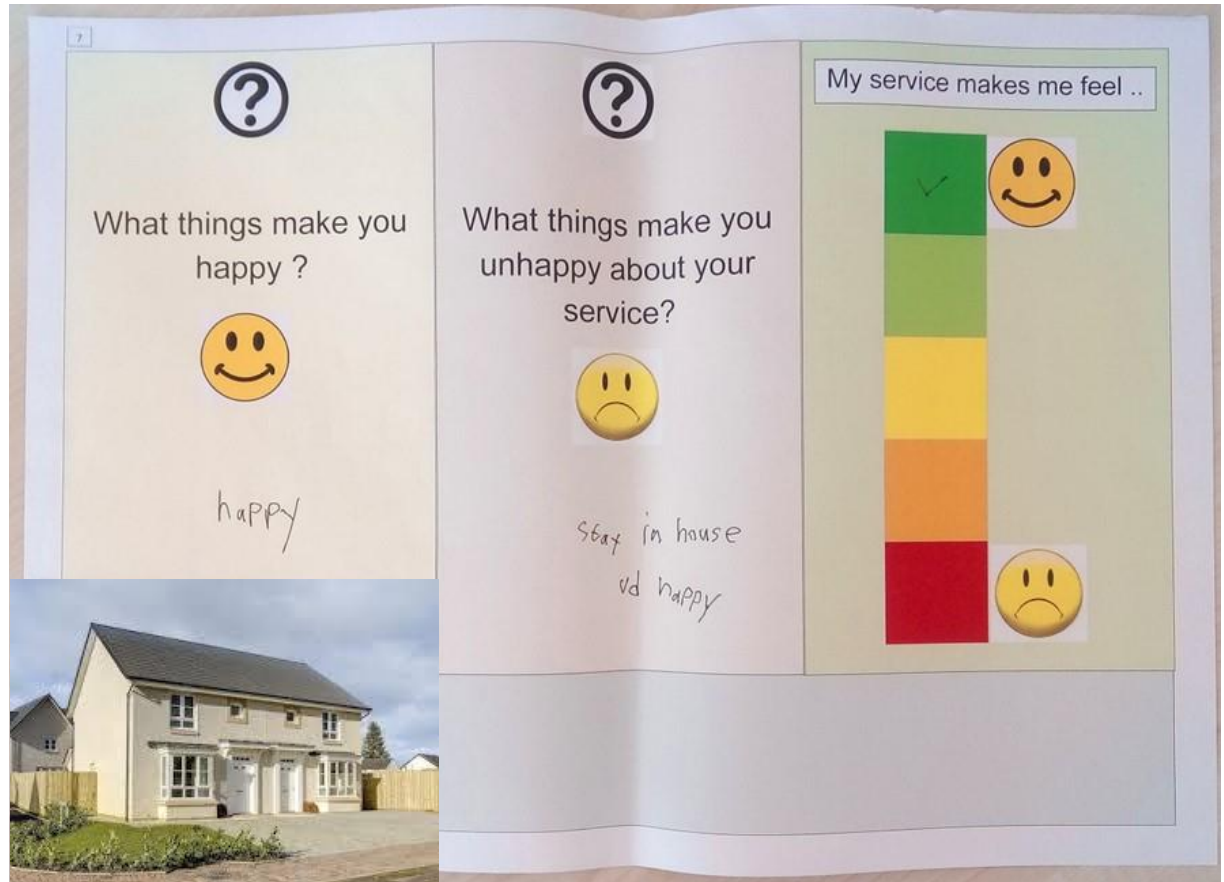
**Meaningful feedback and research output**

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## Positive outcomes from research engagement

- Feedback from questions not previously considered or asked
- Sense of inclusion and being listened to
- Expectation of sharing experiences with others
- Experience suggests supported individuals exceed expectations



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## Research principles and ethics

Do no harm; avoid unnecessary intrusion; **protect subjects' interests**

Informed consent and ongoing consent

Protection of confidentiality

Strategies for responding to disclosure

**Who benefits? In whose interests is the research being undertaken?**

**Is your research or consultation worth doing?**

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