



Case Study: Episode 38: Nothing about us without us



the british
psychological society
the psychologist

This article has been sourced from the BPS, podcast by Emma Palmer-Cooperon 14 June 2024 and can be accessed directly via the link below:

<https://www.bps.org.uk/research-digest/episode-38-nothing-about-us-without-us>

Article

This is a summary of an episode from the British Psychological Society's Research Digest, "PsychCrunch," that explores the critical importance of including neurodiverse voices, particularly those of autistic individuals, in psychological research. Hosted by Emma Palmer-Cooper, the episode features interviews with Dr. James Cusak, Chief Executive of Autistica, and Dr. Amy Pearson, a late-diagnosed autistic autism researcher.

Dr. Cusak highlights a significant shift in autism research from a traditionally medical approach focused on "curing" autism to one that acknowledges and addresses the significant inequalities faced by autistic people in quality of life, mental and physical health, and life expectancy. He emphasises the necessity of recognising both the contributions of autistic people and the unacceptable inequalities they experience. Engaging with and understanding the priorities of autistic people and their families is crucial for targeting research efforts effectively. This includes addressing issues like inadequate support post-diagnosis, mental health challenges (especially anxiety), and difficulties with employment.

Meaningful inclusion of autistic people throughout the entire research lifecycle is identified as a key change in the field. While priority-setting is important, genuine involvement at all stages is essential because being autistic constitutes a fundamentally different lived experience. Assumptions made by non-autistic researchers can be inaccurate, even if a researcher is autistic themselves due to the diversity of autistic experiences. Dr. Cusak notes that various tools for inclusion exist, and while participatory methods are valuable, consultation also plays an important role in accessing a broader range of perspectives. A primary goal of autism research should be to improve people's lives, requiring collaboration with a wide range of stakeholders to translate research ideas into tangible benefits, such as better diagnosis, support, and employment opportunities.

Dr. Pearson, drawing on her experiences as a late-diagnosed autistic researcher, echoes the shift towards a more humanising and neurodiversity-affirming approach in autism research. She describes her journey into participatory and co-research, often starting with informal relationships and evolving into collaborative projects. Her experience highlights that there isn't one "right" way to conduct participatory research, as long as it avoids being tokenistic or performative. The inclusion of lived experience provides insider knowledge, leads to more meaningful research questions, and results in more robust findings.

Both Dr. Cusak and Dr. Pearson acknowledge that while research is becoming more inclusive, there is still progress to be made. Dr. Pearson points out that the increasing number of adult and later diagnoses is leading to more diverse participation in some respects, such as the inclusion of more women, but cautions that research samples still tend to be homogenous, often primarily including white individuals. She stresses the importance of actively uplifting the voices of people in marginalised communities rather than simply replicating previous research with slightly different groups.

For researchers looking to improve their inclusion of lived experience, Dr. Cusak advises against trying to solve problems that are not relevant to autistic people and to avoid making assumptions without engaging with the community. Dr. Pearson emphasises the importance of embedding inclusive practices from the very beginning of a project by asking the community what research questions are important to them. She encourages researchers to challenge their own biases, unlearn previous practices, and build genuine relationships with people of all neurotypes. Funders are increasingly requiring lived experience involvement in research plans and including individuals with lived experience on review panels, which is a positive driver for change. Ultimately, involving lived experience leads to more impactful and relevant research that can truly improve the lives of autistic people and their families. The core purpose of research in this area should be to understand what neurodivergent individuals want to know and how best to support them.

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<https://www.bps.org.uk/collections/research-digest>

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Some key takeaways from the source includes:

- The move away from a purely medical "cure" model of autism towards addressing the significant inequalities faced by autistic people in areas like quality of life, health, and life expectancy.
- The importance of meaningful inclusion of autistic people throughout the entire research lifecycle, not just in setting priorities, due to their fundamentally different lived experiences.
- The recognition that lived experience provides invaluable insider knowledge, leading to more relevant research questions and robust findings.
- The caution against tokenistic or performative inclusion and the need for genuine relationships and proactive engagement with the community.
- The importance of researchers challenging their own biases, unlearning previous practices, and being open to doing things differently.
- The increasing recognition from funding bodies that lived experience involvement is essential for impactful research.
- The need to be mindful of homogenous research samples and actively work to uplift the voices of people in marginalised communities within the neurodiverse population.
- The ultimate aim of research in this area should be to improve the lives of autistic people by understanding their priorities and translating research into tangible benefits.

Links to Specification

7.1.7 Autism

- Therapies for helping children with autism.

7.2.5 Data analysis

- Analysis of qualitative data using thematic analysis and grounded theory.

9.3 Issues and debates

- Practical issues in the design and implementation of research
- Issues of social control
- The use of psychological knowledge within society
- Issues related to socially sensitive research
- An understanding of how psychological understanding has developed over time

Recommended revision and research activities:

1. Research autism charities in the UK and find an example of autistic led research. Summaries its findings.
2. Research the inequalities faced by people. Using this information explain why it is important to consider these inequalities when formulating research questions for possible research into autism.

3. Challenge task: Create a timeline or infographic showing the evolution of autism research—highlighting the shift from the medical "cure" model to a more social or neurodiversity-affirming model. You could organise using the following headings: 1940's-1970's Autism Disorder, 1980s-1990s Focus on Cure, 2000 Neurodiversity Emerges, and 2010-present Inclusion and Equality.

Exam style questions*

1. Describe how researching autism has improved? (2)
2. Explain one weakness of research methods into autism. (2)
3. Explain one problem of using a medical approach when investigating autism? (2)

[\(Click here to view Model Response sections\)](#)

Additional questions for which the content of the article can be used as part of a response

1. Evaluate the use of qualitative methods in child psychology. (8)
2. Assess the use of therapy for helping children with autism in terms of social control. (8)

*Exam style questions are not necessarily the exact format of those that will appear in the qualification examination papers but are written to elicit student responses that meet the assessment criteria, which are exemplified by the answers provided. The length of response in the answers is not indicative of expected student responses, and are provided to support centre teaching, student practice and self-assessment.





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Model Response - [Click here to return to question page](#)

Exam style questions:

1. Describe how researching autism has improved? (2)

Meaningful inclusion of autistic people throughout the entire research lifecycle is identified as a key change in the field, this is because assumptions made by non-autistic people can be inaccurate. For example, the inclusion of lived experience provides insider knowledge, leads to more meaningful research questions, and results in more robust findings. Research has moved from trying to cure autism to acknowledging and addressing the significant inequalities faced by autistic people in quality of life, mental and physical health, and life expectancy.

2. Explain one weakness of research methods into autism. (2)

One weakness of research methods into autism is that the samples can lack representativeness. For example, samples still tend to be homogenous, often primarily including white individuals. Therefore, samples can be ethnocentric and therefore not representative diversity within the autistic community. Consequently, the results from the findings are not generalisable because they don't include all voices of people in marginalised communities with autism.

3. Explain one weakness of using a medical approach to when investigating Autism. (2)

One problem of using a medical approach when investigating autism is that research focusses on curing autism. For example, Pearson (2024) argues that traditionally medical approach focused on "curing" autism instead of acknowledging and addressing the significant inequalities faced by autistic people in quality of life, mental and physical health, and life expectancy. This is a weakness because by focussing on a cure, researchers ignore the lived of experience of having autism and therefore do not understand how certain therapies may have a negative impact on an individuals' life. Making the medical approach a less effective way of researching autism.

Marks awarded and commentary

1. This response would achieve full marks because two improvements have been described: inclusive research (1), addressing inequalities (1).
2. This response would achieve full marks: identifying the weakness of representativeness (1) and justifying ethnocentrism affecting the generalisability (1).
3. This response would achieve full marks: identifying focus on curing autism(1) and justifying with less impactful research into therapies that will improve the lives of people with living with Autism(1).





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Model Responses - [\(Click here to return to question page\)](#)

Additional questions for which the content of the article can be used as part of a response

1. Evaluate the use of qualitative methods in child psychology. (8)

The following paragraphs could form part of the answer to this question:

AO1: Unstructured interviews can be used to find out about the lived experiences of someone with Autism. Unstructured interviews are generally conducted face to face and there are no pre-determined questions created prior to the interview with the individual with autism. During the unstructured interview, the researcher would ask a series of open-ended questions, that produce qualitative data to the individual with autism regarding their lived experience of having autism. The interview has a conversational tone between the researcher and the individual with autism.

AO3: This is a strength because unstructured interviews used to research autism produce more in-depth data. Pearson, before submitting a PhD proposal conducted some patient and public involvement activities, talking to people with experience of autism, so that they could understand the best approach to researching autism and mental health. The unstructured interviews improved the validity of their researcher as they were able to find out in depth detail because the researchers were able to find out why individuals with autism felt the way they did regarding autism and mental health due to the questions not being standardised. Making qualitative methods in child psychology a valid method to research autism.

2. Assess the use of therapy for helping children with autism in terms of social control. (8)

The following paragraphs could form part of the answer to this question:

AO1: Applied Behaviour Analysis (ABA) therapy, based on the principles of Operant Conditioning, includes many different techniques. All of these techniques focus on antecedents (what happens before a behaviour occurs), the behaviour and on consequences (what happens after the behaviour). The consequences will either reinforce or punish behaviour. ABA tends to use "positive reinforcement", when a desired behaviour for example, making eye contact or using speech, is followed by something that is valued (a reward such as a high five or a puzzle piece), that behaviour is more likely to be repeated. The therapist must identify the antecedents which prompt the desired behaviours (e.g. 'point to number 19') and provide reinforcements to the individual child which motivate them to repeat the behaviours e.g. having time to play on a computer. Detailed records of the success and failures and frequency of behaviours for the tasks are analysed to adapt the therapy to the child's progress.

AO3: ABA therapy can be used as a social control because rewards are used to encourage certain behaviour such as making eye contact or speech. This can be positive social control because it enables an individual with autism to manage in social contexts. This is supported by Gale et al. (2010) who implemented ABA with three children with autism focusing on improving disruptive behaviours at mealtimes such as refusing to eat, crying and pushing the spoon away. As part of the ABA therapy, they first identified what the target behaviours would be through observations and interviews, and identified what positive reinforcers would suit each child. They then presented the food on a spoon for 30 seconds and when food was accepted the child experienced their positive reinforcer. The meal ended after 20 presentations. They found that acceptance of the food increased and disruptive behaviours during mealtimes decreased, this was a sustained change five months later with parents reporting eating was no longer a problem. Suggesting that ABA as a therapy can be used as a positive social control as the children in Gale's study disruptive behaviour decreased and eating food increased, indicating that the children were managing in social settings such as eating much better. Therapy can be seen as positive social control for helping children with autism.

AO3: However, Pearson (2024) cautions that research into Autism seems to be not representative as the samples used in research into autism lack diversity as they tend to include mainly white individuals. Such was the case in Gale's research as the sample consisted of 3 children, therefore lacking in representativeness due to lack of diversity as all three children were boys. Therefore, ABA therapy could be used as negative social control because the findings that ABA helped children to change their behaviour through the principles of operant conditioning, is based on research that lacks generalisability. ABA may control their behaviour, but negatively because it could make it more distressing for the child rather than improve their behaviour in social situations. Therapy can be seen as negative social control for helping children with Autism.

Level awarded and commentary

1. Evaluate the use of qualitative methods in child psychology. (8)

The first paragraph (AO1) demonstrates thorough knowledge and understanding of a type of qualitative method, unstructured interviews, and it is applied to child psychology by linking it to Autism. Paragraph two (AO3) identifies the strength of qualitative methods producing more in-depth data. The justification links to the AO1 in the first paragraphs by linking with questions not being predetermined and then explains that it makes it valid. The strength is also linked to Child psychology. Judgement made at the end by stating that qualitative methods are a valid method in Child Psychology. Further, similarly structured paragraphs with different qualitative methods from the Child specification, this would be a level 4 response overall.

2. Evaluate the use of therapy for helping children with autism in terms of social control. (8)

The first paragraph (AO1) demonstrates thorough knowledge and understanding ABA, which is a therapy used to help children with autism. Paragraphs two and three (AO3) consider two competing arguments evaluating social control; how it can be used positively to help children with autism in social settings and negatively if applied since research into ABA lacks representativeness. The justification links to the AO1 in the first paragraphs by linking with the sample, followed by the implications of the strengths and weakness. Judgements are made after each competing argument. Further, similarly structured, this would be a level 4 response overall.

