

Why autistic people must be at the heart of autism research

May 20 2024, by Gemma L. Williams, Aimee Grant and Willow Caroline Holloway



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When the term "social model of disability" was coined by British sociologist [Mike Oliver](#) in 1983, it helped form the basis of the disability rights movement.

To mark the birth of that movement, as well as the 30th anniversary of the autistic rights movement, [our new report](#) reflects on why it is vital that [autistic people](#) are always at the center of [autism research](#).

During the 1980s, the term "[social model of disability](#)" challenged how society largely regarded disability as a personal tragedy. Disablement was seen as something that belonged to individual disabled people, with heavily medicalized personal "impairments."

But Oliver argued that disablement came from how society treated disabled people and from the systemic lack of equitable access. The social model of disability ultimately informed disability awareness and equality training.

Not long after, in the early 1990s, as people began having access to the internet, autistic people began [finding one another](#) on chat boards and email lists.

Around the same time, autobiographical texts written by autistic people began to be published online. They helped introduce the voices of autistic people to neurotypical people for the first time. However, reflecting the perspective of that period, much of the tone of the writing [conveyed the message](#) that autism was a "tragedy" that needed to be mourned.

It was against this backdrop that the American autistic rights activist Jim Sinclair gave a seminal speech at the 1993 International Conference on

Autism in Toronto, Canada. Addressing parents of autistic children, his ["Don't Mourn For Us"](#) speech called for a move away from a parental perspective that "grieves" the disabled child. Instead, Sinclair advocated for an empowered, autistic perspective. The speech helped spur the autistic rights movement.

Autism research

Historically, autism research has been conducted by non-autistic researchers. The consequence of this has been a pathologizing and often [dehumanizing take](#) on autism.

For example, in one 2019 study, autistic people were [found to be more generous](#). But instead of seeing this as something that is advantageous to society, the researchers interpreted the findings as an example of how autistic people struggle to tell the difference between themselves and other people.

Likewise, despite the progress that has come from a shift towards a social model of disability, funding for research into autism still tends to be given to [non-autistic researchers](#). This is often for research that [doesn't address](#) the needs of autistic people or tackle our significant health and well-being inequities.

Even when the stated aims of research appear to be about cultivating autistic well-being, there are often glaring concerns. One example of this was the [Spectrum 10K project](#), which was launched in 2021 by researchers at the University of Cambridge, the Wellcome Sanger Institute and the University of California Los Angeles.

The project planned to generate a large autism DNA database, which was something that [alarmed](#) many autistic people. It provoked [protests](#) over the potential for it to lead to [eugenics](#), where gene pools are altered

according to which people are deemed to be superior or inferior. The study is currently [paused](#), with a long-awaited consultation report overdue.

In recent years, there has been an [increasing call](#) for research that meaningfully involves autistic people in all stages of research, from design, through delivery to dissemination.

Collaboration

Building on this, our new report describes how we are working together as a mutually supportive, fully autistic team on the [Autism: From Menstruation to Menopause project](#). This project was set up to address the knowledge gap about autistic reproductive experiences.

Our first task was to recruit an autistic community council. We wanted to ensure that it included people who were usually underrepresented in research. Once it had been established, the next step was for [academic researchers](#) and community council members to work together to develop accessible recruitment materials for our study's 100 autistic participants.

Although it is early days, we anticipate that our community council will have an important role in helping us interpret our findings and in preparing our reports.

We aren't suggesting that good autism research can't be done by non-autistic researchers. But autistic people should always be involved in research [in a meaningful way](#) and should be listened to at every stage of a project. By doing that, researchers can avoid inadvertently doing research that is either harmful to autistic people, or which misinterprets the findings.

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