

Why The Lancet Commission on Autism Got It Wrong

Easy Read Version

By Dr Chloe Farahar

About this document



This is an Easy Read version of a blog post.



It is about a big research paper called **The Lancet Commission on Autism**.

This paper was published in 2022.

It was written by researchers and doctors.



It made suggestions about how to help Autistic people.

We think the paper **got some important things wrong**.

This document explains why.

1. Autistic people were not involved



When people make plans about Autistic people, Autistic people should help make those plans.

This is called co-production.



Co-production means working together as equals.

It means Autistic people and their families help decide what happens.

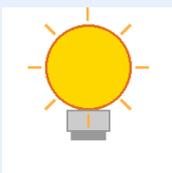


This paper was mostly written by non-Autistic researchers.

It tells stories about Autistic people.

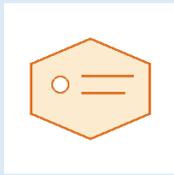
But those stories were written **about** Autistic people, not **by** them.

Families were not involved in making the plans either.



If you make plans about people without them, you will probably get it wrong.

2. The new label “profound autism”



The paper suggests a new label called “**profound autism.**”

This label would be for Autistic people who need a lot of support every day.

For example, people who need someone with them all the time.



We think this label is not helpful.



The label is not really about autism. It is about having a learning disability or not using spoken words.

These are different things from autism.

Putting them all together in one label makes things more confusing, not less.

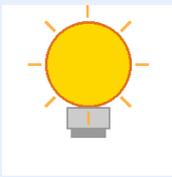


The Autistic community has said for a long time that labels like “high functioning” and “low functioning” are harmful.

These labels put people in boxes.

They do not show how people's needs change from day to day.

“Profound autism” is **another version of the same kind of label.**



**We need to understand each person's needs
— not put them in a box.**

3. The paper contradicts itself



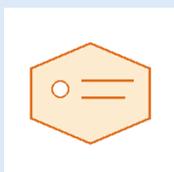
Contradict means to say two things that cannot both be true.



In one part, the paper says that autism changes over time.

It says people's needs are different at different ages.

It says some children who looked like they needed a lot of support went on to need less support when they were older.

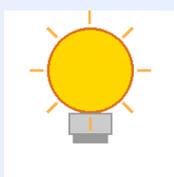


But then the paper says we should give people a **fixed label** — “profound autism” — based on how they are at one point in their life.



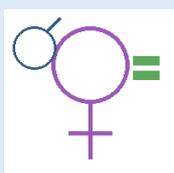
You cannot say that people change and then give them a label that does not change.

That does not make sense.



If needs change over time, labels should not be fixed.

4. Women do not have “different autism”



The paper suggests that autism looks different in women and girls.

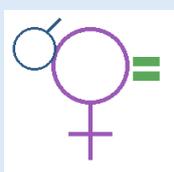


We disagree with how they say this.



Autism is autism.

It is the same whether you are a man, a woman, or non-binary.



What is different is how other people treat you.

Women and girls are often expected to behave in certain ways.

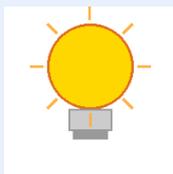
This can mean they hide their autism. This is called masking.

Doctors may not notice their autism because they do not expect women to be Autistic.

They might get the wrong diagnosis instead.



The problem is not that women have different autism. The problem is that **the systems for finding autism were designed around men and boys.**



We need to fix the systems, not create a new type of autism.

5. The treatments they suggest



The paper says we should use treatments that have good evidence.

Evidence means proof that something works.



But then the paper suggests a treatment called EIBI.

EIBI stands for Early Intensive Behavioural Intervention.

This means doing 20 to 40 hours a week of training to change an Autistic child's behaviour.

That is as much time as a full-time job.



A big review by **Cochrane** looked at whether EIBI works.

Cochrane is a respected group that checks if health treatments actually work.



They found the evidence for EIBI is **weak**.

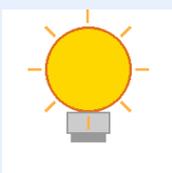
The studies were small and not very well done.

EIBI did not reduce autism or change what the paper calls "problem behaviour."



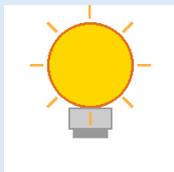
Some Autistic people have also said that these kinds of treatments caused them harm.

The paper does not talk about this.



You cannot say you care about evidence and then ignore what the evidence says.

6. What we think should happen instead



We think the paper should have asked a different question.



Instead of asking “**How do we change Autistic people?**”



It should have asked “**How do we change the world to be better for Autistic people?**”



All Autistic people are whole human beings.

This includes people with learning disabilities.

This includes people who do not use spoken words.

This includes people who need support every day.



What helps Autistic people most is:



✓ **Community** — being with other Autistic people



✓ **Belonging** — feeling accepted for who you are



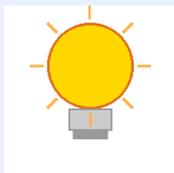
✓ **Good environments** — places that work for Autistic people



✓ **Understanding** — people who listen and learn



✓ **Being involved** — having a say in your own life



The word “profound” should describe the change we make — not the label we give people.

About the author



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