A Critical Response to The Lancet Commission on the Future of Care and Clinical Research in Autism

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Contents

Setting the Scene

February 2026 and *The Guardian* publishes another "autism" article, the hot topic for many news outlets in recent years. This time, informing the public that:

> **A new diagnosis of 'profound autism' is under consideration. Here's what parents need to know.**
> Category describes people who have little or no language, an IQ of less than 50 and require 24-hour supervision...

Autism

Explainer

A new diagnosis of 'profound autism' is under consideration. Here's what parents need to know

Category describes people who have little or no language, an IQ of less than 50 and require 24-hour supervision

Kelsie Boulton, Marie Antoinette Hodge and Rebecca Sutherland for the Conversation

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This comes from an article published in January 2022 by *The Lancet* - a sweeping Commission on the future of care and clinical research in autism (Lord et al., 2022). Led by Catherine Lord and Tony Charman, with contributions from researchers, clinicians, and some Autistic advocates, the Commission set out to answer what it called an urgent question: what can be done in the next five years to address the needs of Autistic people and their families worldwide? The result is a 64-page document that proposes, among other things, a “stepped care” model of intervention, a renewed focus on early intervention research, and – most controversially – the introduction of a new administrative term: “profound autism.”

I want to be clear from the outset: I recognise the scale and ambition of this Commission. I acknowledge that many of its contributors care deeply about improving Autistic lives. And I welcome any serious attempt to address the catastrophic health inequalities that Autistic people face globally. But caring about outcomes and getting the framing right are not the same thing. Simply put, this Commission – for all its good intentions – reproduces many of the power dynamics and paradigmatic assumptions that have caused harm to Autistic people for decades.

I begin by examining the Commission's proposed concept of “profound autism.” I then turn to the broader framing of the document, its relationship with the neurodiversity paradigm, and what I see as significant missed opportunities for genuinely transformative change.

The Problem with “Profound Autism”

The Commission proposes the designation “profound autism” as an administrative term to describe Autistic people who require 24-hour access to a carer, are unable to be left alone, and cannot manage basic daily needs independently. The Commission is clear that this is defined not by Autistic characteristics themselves, but by learning disability and/or language ability – specifically, an IQ below 50 or being non-speaking or minimally speaking.

There is something deeply uncomfortable about this. The Commission claims to be creating a term that will help prioritise resources for an underserved group. But what it has actually done is create a sub-category of autism defined entirely by deficit – by what a person *cannot* do – and then attached the word “profound” to it. This is not a neutral choice. It carries weight, and it carries consequence.

Several critical problems emerge.

First, the term conflates autism with co-occurring conditions. The Commission itself acknowledges that “profound autism” is defined not by Autistic features but by learning disability and language differences. This means the term does not describe a *type* of autism at all. It describes the intersection of autism with other experiences

– experiences that have their own research bases, their own communities, and their own advocacy needs. By collapsing these into a single label attached to autism, the Commission risks obscuring rather than illuminating the actual support needs involved.

Second, it reinstates functioning labels by another name. The Autistic community has spent years articulating why terms like “high functioning” and “low functioning” are harmful. These labels reduce complex, fluctuating human experiences to a binary that serves administrative convenience rather than individual understanding. The Commission acknowledges this critique and yet proceeds to create what is, in effect, a new functioning label – one that carries even more pathological weight than its predecessors. Quite simply, renaming the binary does not dismantle it.

Third, it centres non-Autistic perspectives on Autistic lives. The case studies presented in Panel 1 of the Commission – Adir, Franco, Sofia, Samir – are written about Autistic people, not by them. The stories are told through the lens of parents, carers, and clinicians. This is not a minor stylistic choice: it reflects the Commission's broader orientation. The voices that are most marginalised by the proposed term – non-speaking Autistic people with learning disabilities – are precisely those who are given the least agency in its creation. The principle of “nothing about us, without us” is referenced but not enacted.

Fourth, the evidence base is thin and culturally narrow. The Commission analyses three cohort samples (from Norway, the UK, and the US) to estimate the prevalence of “profound autism.” These are all high-income, predominantly white, Western populations. The Commission acknowledges that the term may not translate well across languages and cultures (noting, for example, that the Spanish *profundo* carries different connotations), yet proposes it as a globally applicable category. This is a significant epistemological overreach.

The Neurodiversity Paragraph

Perhaps the most revealing section of the Commission is its treatment of the neurodiversity paradigm. In a document of over 60 pages, the neurodiversity movement receives approximately one page of discussion – and even that page is hedged with caveats.

The Commission acknowledges that neurodiversity “refers to the natural variability within human brains and minds” and that it has the potential to “create stronger and wiser communities.” It then immediately pivots to a series of qualifications: that not all Autistic people identify with the movement; that controversy exists about whether those with the “highest support needs” are adequately represented; and that concerns about access to services exist if autism is regarded as “natural variation”.

I want to be direct about what is happening here. The Commission is positioning the neurodiversity paradigm as one perspective among many – a philosophical preference rather than a rights-based framework. This is a misrepresentation. The neurodiversity paradigm is not merely an identity movement or a feel-good narrative. It is a framework for understanding neurological difference that has real and important implications for how we design services, conduct research, and treat Autistic people in clinical settings. To reduce it to a sidebar in a Commission that will shape global policy is, as I see it, a significant failing.

Moreover, the Commission sets up a false tension between the neurodiversity movement and the needs of Autistic people with high support needs – as though advocating for neurological difference as natural variation is somehow incompatible with providing intensive, personalised support. This is a tired and harmful argument. The neurodiversity paradigm does not deny that some Autistic people need substantial, lifelong support. What it challenges is the assumption that the *need for support* means there is something fundamentally wrong with the person. These are overwhelmingly different positions.

What the Commission Gets Right – and Why That Makes the Failures More Troubling

It would be dishonest not to acknowledge the Commission's strengths. Its call for personalised, stepped models of care is welcome. Its emphasis on the need for research that asks “what works, for whom, when, and at what intensity” is exactly the kind of question that has been missing from autism research for decades. Its recognition that Autistic people face significant health inequalities, including premature mortality, aligns with the evidence base that is driving work across the NHS (including, directly, the work we are doing in Kent and Medway).

The Commission's acknowledgement that services in low- and middle-income countries are desperately under-resourced is important. And its call for governments to invest in cross-sector coordination between health, education, and social care is a message that urgently needs amplifying.

But this is precisely why the failures of framing matter so much. When a document of this stature and reach gets the paradigm wrong, it does not simply reflect existing power structures – it reinforces them. Clinicians will read this Commission. Policy-makers will cite it. Researchers will design studies around its terminology. And so, the language of “profound autism,” with all its deficit framing and its sidelining of Autistic agency, becomes embedded in the very systems that Autistic people must navigate.

What Was Missing

Several critical absences weaken this Commission considerably.

Environmental and systemic factors are under-examined. The Commission focuses heavily on individual-level interventions – early intervention, behavioural programmes, pharmacological treatments – whilst giving comparatively little attention to the environmental and systemic factors that disable Autistic people. Luke Beardon's equation – *Environment + Autism = Outcome* – is nowhere to be found. The role of sensory environments, hostile institutions, inaccessible communication norms, and societal attitudes in producing poor outcomes for Autistic people is acknowledged only in passing. This is a Commission that looks at the Autistic person and asks, "how do we change them?" far more than it asks, "how do we change the world they live in?"

Co-production is gestured at, not practised. The Commission includes self-advocates among its listed contributors. But authorship and co-production are not the same thing. Genuine co-production means that Autistic people – including non-speaking Autistic people, Autistic people with learning disabilities, and Autistic people from the Global Majority – are not merely consulted but are decision-makers. The House of Lords' recent *Time to Deliver* report (2025) makes this distinction with far greater clarity, noting that co-production "will be doomed to fail if we try to develop policy in the ivory tower."

The distinction between harmful stimming and self-harm is invisible. The Commission references self-injury and aggression as features associated with "profound autism," but makes no attempt to distinguish between psychologically-driven self-harm and sensory-regulatory stimming that may cause injury. This is a critical clinical gap – one with direct implications for intervention. Treating all self-injurious behaviour as pathological, without understanding its function, leads to harmful interventions including inappropriate restraint and medication.

Trauma is barely mentioned. For a Commission that discusses inpatient care, restrictive practices, and lifelong support, the near-total absence of trauma-informed perspectives is striking. Many of the poor outcomes described in this document are not simply consequences of autism – they are consequences of what has been *done to* Autistic people within systems that were not designed for them. The thematic review of Care (Education) and Treatment Reviews by the Department of Health and Social Care (2021) makes this abundantly clear. The Commission's silence on iatrogenic harm is a significant omission.

Ultimately

This Commission represents a missed opportunity. It had the resources, the platform, and the contributors to produce a document that could have genuinely shifted the paradigm for global autism research and care. Instead, it has produced a document that, for all its data and its ambition, remains fundamentally rooted in a medical model that positions autism as a "disorder" to be managed, measured, and – where possible – mitigated.

The Autistic community deserves better. Autistic people with learning disabilities and high support needs deserve better. They deserve a framework that recognises their full humanity, centres their voices (or the voices of those they trust to speak alongside them), and invests in changing the environments that disable them – not simply in categorising the depth of their perceived deficits.

The word “profound” should describe the change we commit to making, not the label we attach to the people who need it most.

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