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We wish to address the Lancet Commission as a committee of autistic people, the *Global Autistic Task Force on Autism Research,* comprising autistic professionals and representatives of organisations run by and for autistic people, focusing on advocacy, service provision, education and participatory research.

We are autistic clinicians, therapists, educators and researchers, parents and family members of autistic people of all ages and with all types of support needs, as well as individuals with high support needs. Among us are also autistic people of colour, autistic people from the Global South and Asia, autistic women, and autistic people belonging to gender minorities. Despite aiming to bring together different stakeholders, representation within the Lancet Commission was limited in these respects. We hope to bring more voices to the discourse.

We find it encouraging that the Lancet Commission mentions the importance of collaborative participation when discussing the future of autism research, and we look forward to being increasingly included as collaborators.

While the urgent needs of autistic adults have been briefly discussed by the Lancet Commission, it seems that as autistic adults and producers of knowledge on autism we have remained largely invisible to the authors. For example, key studies and reports mapping autistic people's priorities regarding autism research have not been cited (1,2,3, ). These provide some broader context: most autistic people’s primary wishes for the next five years would not concern clinical interventions but matters of law, ethics, policy and how these translate into support practices and realisation of human rights.

Over three decades of individual and collective advocacy by autistic people were covered by the Commission under the heading of parent and family advocacy, in three words: 'increasingly, self-advocacy'. Autistic people who offer their expertise and experience-based knowledge appear to be generalised as 'more able' despite our widely varying support needs, and despite some of our organisations focusing partly or primarily on the needs of those who are less able to advocate for themselves (4,5,6). Similarly, we appear to be grouped under the title of the neurodiversity movement, despite our different approaches and varying levels of emphasis on the concept, and despite the history of the autistic rights movement preceding it (7,8).

Regarding the neurodiversity paradigm, we wish to point out that considering something as natural variation does not equal claiming that it ‘does not need intervention’. It means preferring interventions that target systems and environments, supporting individuals to thrive as they are, instead of trying to bring them closer to the norm (9-13). We agree with the Commission’s observation that ‘*not all autistic people and stakeholders identify with the neurodiversity movement*’. We would welcome research on the distribution of people identifying with the neurodiversity movement or paradigm versus identifying with clinical and other portrayals of autism.

On a fundamental level, we need to be seen from the dual perspectives of minority and disability. We find it positive that the Lancet Commission suggests using the International Classification of Functioning, Disability and Health in research. However, the authors consistently refer to autistic traits as ‘disorder’, rather than ‘disability’, while equally consistently using the expressions ‘intellectual disability’ and ‘learning disability’’. This terminology appears to signal that autistic traits in themselves belong in the category of illness or disease, rather than neurodivergence or disability, both of which would allow for the inclusion of positive characteristics as part of the core definition of autism ( ).

*The term ‘profound autism’*

We do not agree with the proposal to adopt ‘profound autism’ as an administrative term. For more than thirty years, autistic people have resisted functioning labels as misleading and offensive (14). ‘Profound autism’ would be a step back, even as ‘low-functioning’ is falling out of use.

The term would not be sufficient to steer service provision, just as functioning levels never were. It provides no useful information to others who may need to interact with the autistic person. High support needs are associated with co-occurring characteristics and health issues in many combinations, and the level of support needs often fluctuates. It is clearer to use brief descriptions like ‘autistic person with intellectual disability’, ‘autistic person with minimal language’, or ‘autistic person with extreme anxiety and co-occurring physical condition’. Expressions like ‘autistic person with high support needs’ or ‘autistic person requiring 24-hour care’ are also useful.

The term would also give the false impression of intellectual disability and impaired language development being core characteristics of autism, an autistic person with these characteristics being somehow ‘more autistic’, or closer to the deep end of an imaginary linear spectrum, than an autistic person without them. ‘Profoundly autistic’ would misleadingly refer to people who actually have *profound impairments* that are not autism specific, while not necessarily having any particularly extreme autistic characteristics.

*Participatory research*

Participatory research has been mentioned by the Commission, but not defined. Yet the participatory approach is a crucial element in all future autism research. A body of literature exists on its principles, practices and significance (16-19). Anything that will truly help needs to be co-designed, developed and evaluated with the involvement of autistic people; we need approaches that value and centre autistic voices, experiences and expertise. This requires more than the roles the Lancet Commission has suggested: consulting on the details of clinical trials and outcome measures.

As participants, autistic people can correct misperceptions regarding concepts developed by autistic communities, researchers and scholars, including neurodiversity (20-22), the double empathy problem (23), autistic inertia (24), monotropism (25), hyperfocus (26) and autistic space (27). We can introduce emerging ideas such as the co-creation of extended autistic families and community-based mentoring (28). These concepts have implications to clinical research, including topics such as early intervention (29, 9, 13), and can lead to new, more effective directions.

*Research topics and approaches*

We do not believe that the Commission’s recommendation of focusing research on randomised controlled trials for short-term interventions, including medication and behavioural trials, can lead to improvements in the lives of autistic people, or the lives of our autistic children, within the next five years.

Instead, we urge focusing more resources on causes of mortality, improving our access to health care (30-33) and mental health support (34-36), and large-scale monitoring of the effects of better access. This should include the effects on detection and treatment of co-occurring conditions. We find it particularly surprising that the mortality studies published over the past few years (37-41) received very little attention.

We need clinical research to tackle the problem of harmful pseudoscientific treatments; mapping their use and effects on mental and physical health, as well as improving awareness among clinicians and carers. Autistic children, adolescents and adults with limited ability to advocate for themselves need to be actively protected from malpractice (42).

We need more research on assisted and augmented communication (AAC) and supported decision-making in the context of clinical work and care. To autistic people with limited communication, they are crucial to accessing health care and to the appropriate delivery of both medical and care services. Advocacy organisations often appear to be needed to ensure the right to use them, when this should be part of the work of clinical and care staff (43,44).

We need more research on how stressful environments, being misperceived by others (45), lack of appropriate social and disability services, lack of reasonable accommodations, stigma, discrimination, and bullying (46) affect the health of autistic people, contributing to anxiety and depression, and how such effects can be mitigated (47,48). Counselling methodology for autistic and other neurodivergent people needs to be developed and tested.

We also urgently need research on large-scale, affordable and accessible screening and diagnosis for all age groups, in all parts of the world, but especially in low-income and middle-income countries (LMICs) (49,50). Diagnostic services must be seen as a basic right for all autistic people, not something that clinicians grant at their discretion or only when the diagnosis can lead to the provision interventions. Diagnosis helps both children and adults to develop identity, self-knowledge and personal strategies, and to start engaging in peer support, self-advocacy and collective advocacy. These can be crucial to well-being, quality of life and realisation of basic rights, especially when very little else is available (51).

The Commission has recognised the importance of research on adolescents and adults. However, we find that the recommendations for clinical research fall short, offering no concrete suggestions for topics or types of research. Repeating that something is urgently needed does not provide sufficient guidance.

The social (52) and human rights (53) models of disability should be understood and applied in the context of clinical work, leading to research and practice models that target systems, not just us as individuals. The existence of interventions with the goal of ‘optimising person-environment fit’ has been recognised by the Commission, which is a promising first step, but again this is not linked to concrete recommendations. Studies focusing on the Double Empathy Problem (10), and unconscious negative perceptions of autistic people (15, 45), provide both theoretical frameworks and examples of practical interventions (10,11,13). Some aspects of the TEACCH programme, covered by the Commission in two sentences, might also offer starting points as a decades-old approach focused on adjusting environments (55). Educational and employment interventions need to be developed that promote positive uses of autistic people’s intense interests and capacity for passionate focus, seeing the potential at the system level, instead of dismissing them as signs of ‘restricted’ thinking.

Studying system change may not be amenable to controlled trials or commodification of intervention services. This does not diminish its significance. We need clinical research to work in collaboration with other fields of autism research, becoming part of a fundamental cultural shift in approaching autism, instead of falling outside it and operating in isolation.

*Addressing harmful research and treatments*

Early autism research often objectified autistic people, and in many cases caused immense harm. Unfortunately, this can still happen. Historically, autistic children and dependent adults who are unable to give informed consent have been enrolled in experiments that would probably not have been allowed on non-autistic people, based on weak, far-fetched hypotheses. This has fed the creation of new pseudo-treatments. Research that focuses on pseudo-cures decenters the voices of autistic people about our actual needs and priorities.

While we were glad to see the Lancet Commission discuss the problem of dangerous pseudo-treatments being promoted online, we wish to draw attention to the fact that many pseudo-treatments have been initially trialled at universities and other research institutions, or promoted by them, including ‘packing’ (56,57), holding therapy (58), secretin (59), hyperbaric oxygen (60), fecal transplants (61, 62), oxytocin (63) and injections of stem cells (64), to name only a few. Clinical trials can be driven by the promise of commercialising a new “solution”. It is necessary to recognize that some structures and practices of the academic world allow or even support the development of pseudo-treatments, which seek a thin veil of apparent academic credibility to attract followers and funding.

Autistic people’s organisations have attempted to draw attention to the fact that defining the behavioural characteristics listed in diagnostic criteria as ‘core’, and trying to develop biological treatments with behaviour as the primary target and means of measuring success, is both unwanted by many autistic people and ultimately destined to fail (65); similar behaviour does not equal similar biology. The inherent fallacy in this approach is likely to contribute to continuous generation of pseudo-treatments. We urge researchers to focus the development of medications on co-occurring health problems that autistic people identify as distressing, and to target clearly identifiable biological factors instead of behaviours, with the aim of improving autistic people’s quality of life. We predict that for many of us, better health would automatically lead to some positive changes in cognition and behaviour.

*Behavioural concepts and interventions*

We are particularly concerned about the dominant role of behavioural interventions, concepts and interpretations of autism that is evident throughout the Commission’s text. Autistic-led organisations have engaged in widespread criticism, activism and campaigning focusing on behavioural approaches, including recent appeals to the UN Committee on the Rights of People with Disabilities (66). We see this especially in countries where the methods have been used extensively.

Changing behaviour, as such, should not be the main goal of clinical research or treatment for autistic people of any age. Appearing autistic or acting in typically autistic ways should not be considered an illness. Clinicians need to be aware of the potential mental health risks of ‘camouflaging’ (67,68) and avoid encouraging or manipulating autistic people to engage in it, even through naturalistic or play-based methods. Keeping in mind health and wellbeing as the goals of clinical work, and the fundamental principle of beneficence, research should explore the long-term effects of behavioural interventions on autistic adults who have been subjected to them, as there have been reports of adverse effects.

The lack of evidence base for older forms of Applied Behavior Analysis (ABA) has been mentioned by the Lancet Commission. However, there are other concerns that need to be addressed. In the past, unethical ABA practices included physical abuse and using the method in gay conversion therapy. Those who applied such practices included key developers of the methodology such as Dr O. Ivaar Lovaas (69,70). This history needs to be openly admitted and the practices clearly renounced. There are other, continuing ethical concerns (71), as well as issues with the evidence base of behavioural approaches more generally. For example, Cochrane Review and meta-analysis of early-intervention ABA (EIBI) (72) found the overall quality of evidence low or very low. Seventy percent of ABA research has been reported to involve conflicts of interest, with less than 6 percent of the researchers declaring the conflicts (73). A recent US Department of Defence report on their ACD program, which involves 47,000 certified ABA professionals and provides services to nearly 16,000 autistic people, mostly children and adolescents, expressed serious concern about the lack of results from their ABA provision (74).

Because of the emphasis on behavioural interventions, the Commission also appears to have ignored a number of more recently developed, promising possibilities. Researchers need to hear the many families that are seeking more neurodiversity-aligned approaches.

In the light of the above, elevating behavioural approaches above other therapeutic, habilitative and educational methodologies to the status of medical treatments, and promoting them as treatments in LMICs,is considered by numerous autistic people a mistake of massive proportions.

*Call for action*

To illustrate our ongoing work, we wish to name a few examples that clinical researchers might want to be aware of, and that could function as starting points for further discourse.

In 2017, a *Starter Pack for Participatory Autism Research* (75) was published by the participatory Research Collective in the UK, followed in 2019 by a German *Checklist for Autism Friendly Research* (76). Also in 2019, the National Autistic Taskforce published *An Independent Guide to Quality Care for Autistic People*, describing quality provision for those with high support needs (77), and a Dutch autistic-led project published a report on *Onderzoeksagenda Autisme*, the most detailed study available on the research priorities of autistic people and other stakeholders (78). In 2021, The European Council of Autistic People presented preliminary results of a survey mapping the research priorities of autistic people in twelve languages (79). This year (2022), the Autistic Self Advocacy Network released a report titled “*For Whose Benefit? Evidence, Ethics, and Effectiveness of Autism Interventions*”, creating a template for a core set of underlying ethical principles for autism-related services (80).

We invite researchers and clinicians to join the critical conversation about ethics in autism research and services, and to actively include the voices of diverse autistic individuals and communities in their work. We wish to draw attention to power imbalances and lack of accessibility in such discourse. We lack platforms and channels to reach the research and clinical communities effectively. Current common practice that exacerbates the power imbalance is inviting individual autistic people to take participatory roles in research projects, representing their own ‘lived experience’ only; in these roles, they are isolated, engaging with powerful organisations as individuals, often with very limited personal resources. We call for the creation of shared platforms for continuing discourse on autism research at the global level, engaging autistic individuals as well as the organisations we have formed to advocate for our rights collectively.

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