Title: Bridge-building between communities: Imagining the future of biomedical autism research

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Summary

A paradigm shift of research culture is required to ease perceived tensions between autistic people and the biomedical research community. As a group of autistic and non-autistic scientists and stakeholders, we contend that through participatory research we can reject a deficit-based conceptualisation of autism whilst building a shared vision for a neurodiversity-affirmative biomedical research paradigm.

Keywords: biomedical autism research, participatory autism research, autism research, bridge-building

Main text

Introduction

Neurodiversity is a paradigm through which autism can be conceptualised as part of the natural spectrum of human biodiversity, like variations in ethnicity or sexual orientation. As the neurodiversity movement has gained momentum and autistic viewpoints have been amplified[1], contemporary biomedical autism research has become controversial. A salient example is the Spectrum 10k study, which was paused shortly after launch following concerns raised by the autism community with regards to ethical implications, privacy, transparency, and inadequate consultation. Shortly after, the term "profound autism" proposed in the Lancet Commission[2] was criticised as being misrepresentative of autism, and unhelpful for both research and clinical practice. This led to ongoing debate as to the value or risks posed by different terminologies and conceptualisations of autism[3,4]. The perceived gap between the perspectives of stakeholder communities and the focus and conduct of biomedical autism research raises the risk of research not being useful to the community it aims to help. This is both an ethical and utilitarian concern. It also represents a missed opportunity to stimulate scientific progress. Despite millions of dollars in funding every year, there remain very few rigorously evidenced support strategies for autistic people[5] and no validated biomarkers to help with diagnosis or prognostic planning, beyond highly-penetrant genetic changes relevant for a relatively small but notable proportion of autistic people. Biomedical autism research thus finds itself at a critical juncture. We contend that both scientific and societal goals can be better met through an urgent paradigm shift towards the construction of a neurodiversity-affirmative biomedical science.

In this commentary, we discuss core elements of a neurodiversity affirmative biomedical science in autism research, including reconceptualising autism and aligning research aims, practices, and culture. We emphasise the importance of authentic participatory research to bridge the disparate perspectives seen between our stakeholder communities. By this, we mean research which involves members of the autism community as non-tokenistic research collaborators. Our suggestions are not exhaustive but provide a starting point to drive the generation of a new paradigm that incorporates lived autistic perspectives into biomedical autism research.

Developing a neurodiversity-affirmative biomedical research agenda requires co-creation with community partners. Our authors are a group of people collaborating on AIMS-2-TRIALS, one of the world's largest autism research consortia. We are researchers, industry partners, clinicians, and those with lived experience of being autistic or caring for an autistic person; these roles are not mutually exclusive. We do not claim to speak universally for any of the groups of which we are members; rather, we write from our shared experience as collaborators in this field. To ensure that the diverse views of our authorship group were well reflected in this commentary, each co-author was asked to contribute individual reflections on 3 key topics: "What is autism?", "Priorities for biomedical autism research" and "Culture and practices within biomedical autism research." These contributions were synthesised into a core document and the narrative was iteratively developed through a collaborative approach, making this, in itself, a worked example of developing a participatory culture within biomedical science.

Breaking the cycle

From a historical perspective, biomedical research has its roots in the medical model, which conceptualises autism as a medical condition defined by a set of deficits[6]. Attempts by researchers and clinicians to understand and define the nature of autism from this external, behavioural perspective, without the input of autistic people, have contributed to stigmatising narratives which have ultimately harmed some members of the autistic community[7]. In the context of this legacy, some autistic people are sceptical of the intentions and actions of researchers working within a medical-model or deficit-oriented context, and are reluctant to engage with, guide or support them. This disengagement can lead to further mistrust, then exacerbated by perceived missteps on the part of the biomedical research community. An example of this is the launch of Spectrum 10k without, in hindsight, sufficient efforts made towards community consultation. Researchers must become aware of the existing cycle of disengagement and mistrust and do their part to break it, with the goal of developing a mutually respectful, end-to-end participatory research culture; this necessitates moving away from deficit-oriented perspectives that can alienate and stigmatise autistic people[8]. However, we believe that

moving away from a deficit-based model does not necessitate rejecting the potential of the tools and techniques of biomedical science to improve the lives of autistic people.

To break the cycle, we propose that biomedical researchers embrace a neurodiversity-affirmative approach to their work. This approach would utilise the methods, tools and techniques of biomedical science to develop supports for autistic people in ways which do not stigmatise neurodivergence or autism. Although multiple models of disability are compatible with the neurodiversity paradigm, the social relational model[9] may be most complementary to a neurodiversity-affirmative approach to biomedical research. This model recognises that illness and impairments cause real restrictions of activity and barriers to thriving, but also that disability can be a form of oppressive social reaction imposed upon those with impairments.

We recommend that biomedical researchers seeking to work in a neurodiversity-affirmative way should collaborate with those with lived experience of autism, to identify and alleviate impairments which decrease quality of life for autistic people. This should include collaborating directly with autistic people wherever possible, as well as with parents and carers, where appropriate. In the course of this work, researchers should seek to counter or minimise aspects of impairment and disability perpetuated or caused by external factors, such as ignorance, stigma and discrimination and poor environment-need match. Developing a more in-depth understanding of the biological underpinnings of autistic experiences could pave the way for the development of evidence-based supports, for those who would choose them, on a biomedical level (e.g., pharmacology) and for supports which counter oppressive factors contributing to poor outcomes (e.g., environmental changes). Precision medicine, in which prevention and interventions are tailored to the individual characteristics of each person, may be a particularly helpful tool.

All autistic people have the right to be a part of the development of, and to access, evidence-based support for aspects of their lived experience that are detrimental to their wellbeing. Under a neurodiversity-affirmative biomedical research framework, we believe it is possible to acknowledge the suffering of autistic people who need support without conflating this suffering with autism itself. This stance is compatible with the development of biomedical treatments

which have the potential to support autistic people and enhance their quality of life. Such an approach may be particularly beneficial for autistic people who have co-occurring medical needs which could be well-served by biomedical research progress, such as those with mental health difficulties, epilepsy, or gastrointestinal problems. Some autistic people, including those with co-occurring rare genetic conditions and intellectual disability, experience more complex medical difficulties (e.g., cardiac and respiratory problems) and behavioural challenges. For example, Prader-Willi syndrome is a rare neurodevelopmental genetic condition associated with a characteristic behavioural phenotype that includes hyperphagia (i.e., extreme, insatiable hunger), which can lead to excessive food intake and obesity. These will require biomedical research progress to improve quality of life and increase lifespan.

Autism through different lenses

In order to identify and work to alleviate impairments experienced by autistic people without perpetuating harm, researchers must re-examine the lenses through which they seek to understand autism. The behavioural definitions of autism included in diagnostic manuals (e.g. Diagnostic and Statistical Manual of Mental Disorders, DSM or International Classification of Diseases, ICD) has led to research design and recruitment practices which are external-observation oriented, with differences in behaviours from neurotypical 'norms' viewed as deficits to be addressed. Behavioural assessment tools have formed the basis for study inclusion criteria and fostered reliability across studies, as well as providing a basis for behavioural animal model work. However, whilst observational criteria can be helpful indicators for identifying some autistic people, they can be less accurate in women and other minoritized groups because of traits such as masking, or cultural differences in social behaviour.[10] Further, research and interventions designed solely around reducing the presence of externally observed behavioural signs of autism represent a fundamental misunderstanding of the nature of the challenges experienced by autistic people and are ultimately neither value neutral (a barrier to ethical research in some contexts), nor inclusive of all autistic people (a barrier to useful research in some contexts).

Autistic perspectives are essential to translating the full potential of existing autism research from the molecular to the experiential. We believe that flexible reconceptualization of autism which incorporates insights from lived experience and internal perspectives is needed, with enough translational applicability to generate useful and feasible working constructs for biomedical researchers to explore. For example, sensory processing has excellent translational potential, since it can be informed by the lived experience of sensory hyper or hyposensitivity, and can be modelled by those working with infants and animals. However, it is important to note that it may not be necessary to agree upon a universal definition of autism to conduct effective research into specific challenges faced by autistic people, as long as the lens through which autism is viewed for a particular project is made clear.

We also recommend the development of new standardised measures of aspects of autistic experience, in order to build a sufficiently robust conceptual infrastructure for translation to biomedical research and to facilitate research recruitment. An example of a new measure which could be used where suitable, is the Self-Assessment of Autistic Traits questionnaire[11] which aims to measure autistic traits as described by some autistic people. Care must be taken to ensure that all autistic people's interests, including people of all genders, culturally and ethnically diverse groups, those with intellectual disability, and those with high support needs, are represented in the development of future measures.

The heterogeneity of clinical presentations and biomedical characteristics associated with the diagnostic category of autism has arguably contributed to false negative (type-2 error) related replication issues in autism research. We recommend moving away from case-control comparisons that focus on comparing autistic participants with controls and towards biomedical research that models differences at the level of the individual participant. For example, using normative modelling, biomedical researchers could identify autistic participants whose neuroanatomical development diverges from an expected pattern, based on normative data. A particular strength of this approach is that it charts individual trajectories and does not require differences from the norm to be consistent across all participants. In keeping with a neurodiversity-affirmative approach, we recommend that researchers develop an ongoing dialogue with the autistic community in parallel in order to map lived experiences to this type of

research. Such conversations could both help to connect research findings to medically and personally meaningful prognostic pathways for autistic people, and to disentangle heterogeneity. It could also contribute to a much-needed evidence base for the development of the supports and precision medicine needed for truly person-centred outcomes. Emergent interest in precision medicine may help to foster explorations of transdiagnostic, dimensional and personalised supports for autistic people, especially if these can be developed in a neurodiversity-affirmative way. For example, autistic people's biology may represent a moderating factor or a stratifier to consider when exploring other medical conditions. To apply this further, anxiety in autistic people may have distinct biological or psychological underpinnings, and this may inform the choice of cognitive behavioural or pharmacological treatment offered. Future design of clinical trials for anxiety disorders should include measures of autism and other forms of neurodivergence, and consider whether treatment response may be impacted by this.

Recommendations for a neurodiversity-affirmative biomedical research culture

To produce ethical, responsible, and impactful biomedical research which will benefit all relevant stakeholders, we outline below some tangible neurodiversity-affirmative recommendations that biomedical researchers can implement across all stages of the research project.

1. ***Establishing participatory research practices***

To foster a true participatory research culture within a biomedical context, and bring about benefits to all stakeholder communities, researchers need to ensure that lived experience experts are involved to the greatest degree possible at all stages of the research pipeline. This means engagement not only at the stage of designing human clinical studies or trials, but from the beginning of the translational research pipeline (including wet lab research) where the fundamental discoveries that pave the way for later trials are made. We recommend using gold-standard participatory research principles such as those developed by the Academic-Autistic Spectrum Partnership in Research and Education (AASPIRE)[12], or for research concepts which may be relevant for autistic people with intellectual disability, looking to projects such as Assent,

COMRAD, and IDS-TILDA for inspiration. Where full co-creation or co-production of research is not possible, researchers should strive for comprehensive, non-tokenistic community consultation throughout the research process. We encourage researchers to make every effort to identify all relevant stakeholders and consult their perspectives appropriately and representatively. Whilst we acknowledge that this is not always achievable, care should be taken to avoid consultation that is too narrow, such as with people who already share your views, who are not empowered to challenge your ideas, or who represent a narrow sub-set of the autistic community. Researchers should consult autistic people directly, but where this is not possible, they should consider the value of consulting a wide range of stakeholders such as parents, caregivers, teachers, social workers, and family doctors. Techniques such as multilevel regression with poststratification may be useful in working towards representative consultation on a larger scale.

2. Deciding on the subject and purpose of the research

Deciding on the subject for research, and the purpose for researching it, is a step of the design process which could undoubtedly be improved with community input. Here, we give an example of applicability in the basic science setting, an area of autism research where participatory perspectives are under-utilised. Some animal model based autism research at present is overly focused on face validity, where a model system can be said to "look like" autism[13]. We propose a shift to prioritising construct validity, the degree to which a model system is capable of measuring a concept or trait. Here, consultation with autistic people, those who care for them, and, where appropriate, clinicians who work with autistic people, could help to determine traits of interest and suitability for translational research, and the reasons why these traits would be helpful to explore.

To apply this further, rodent model work is often used to explore the underlying mechanisms of what the DSM-5 terms "restricted and repetitive behaviours" (RRBs). To our knowledge, there has been no community engagement work by biomedical researchers investigating autistic people's perspectives when it comes to research on RRBs. Much research on RRBs tends to adopt a somewhat negative bias, as though these are all unequivocally undesirable. While some

autistic people experience considerable repeated injuries due to physically harmful RRBs such as eye gouging and head banging, other autistic people enjoy the benefit of RRBs such as self-regulatory "stimming"[14].

We recommend moving away from designing biomedical research primarily around broad categories with high face value, (in the above example, this would be RRBs as a blanket category), and toward designs that reflect clear, precise co-defined characteristics observed in, and where appropriate, corroborated by, autistic people. This will also help to clearly define the purpose of the research. Working with autistic people to understand the emotions and experiences underpinning *specific* RRBs, could help to develop a field where animal models pose better translational potential, as well as beneficence, for the community. From a translational perspective, it is important to note that clinical trials focused on reducing RRBs could lead to adverse effects, if the behaviours 'targeted' for reduction are personally adaptive to autistic people. As such, prioritising person-centred outcomes should be the goal throughout the research process.

3. Developing research design and protocols

Co-operative efforts to construct an appropriate research design and protocol, in lay terms if necessary, will ensure a common understanding of the process between those with lived experience and researchers. Researchers should involve autistic people in the development of the protocol and throughout all stages of gaining ethical approval for the study. This can enable the development of participant-facing documents, e.g. consent forms and information sheets, that are fit for purpose. Data management plans should also be co-developed with careful consideration given to the needs and wishes of the community. Autistic people must be included as equitable partners in decision-making regarding the selection of biological markers and phenotypic measures chosen for research. Good translational design and measure selection here should prioritise the establishment of construct validity as well as face validity. Co-developing data analysis plans with the community and publicly sharing these plans prior to data analysis (e.g. via preregistration) can also help to cultivate transparency and trust-building. The participatory research process should be bidirectional, with design decisions made based on sound scientific rationale.

4. Interpreting, and disseminating findings

Our author group can agree that there are biological underpinnings of a variety of autistic lived experiences, and that this biological dimension warrants further investigation and understanding. However, we also agree that the full nature of what it means to be autistic is not adequately represented by a biomedical essentialist model of autism, and, we argue, does not need to be, outside of strictly medical contexts. Thus, at the point of interpretation of results, any mechanism discovered, or treatment developed, should not be used as a basis for making generalist statements about the nature of autism. Using our RRB example, findings showing a reduction in RRBs could be misinterpreted or misrepresented as a reduction in the "severity of autism" as opposed to simply a change in emotional state, or functioning. This interpretation lacks construct validity, as it conflates behaviours performed by autistic people with autism itself. Engaging with the community on interpretation and establishing good science communication practices when it comes to dissemination of findings is one way to mitigate such potentially harmful misunderstandings.

Barriers in research practice & culture to community engagement

In the short exercise of collaborating on this paper, we have already identified some significant barriers preventing biomedical researchers from doing this necessary authentic, high-quality engagement work with the community. We must work together as a research community to eliminate these systemic barriers to engagement.

Decoupling funding narratives from "autism as disorder"

The most pressing of barriers to engagement is funding. Most funding for biomedical autism research is based on the narrative of autism as a biomedical disorder. In a landscape where biomedical autism research competes for funding against projects investigating cancer, stroke and cardiovascular disease, many researchers feel compelled to embed their proposals in a strong

medical-model philosophy of autism. However, this is disenfranchising to autistic people who might benefit from a medical model approach to support specific impairments (e.g., those who might benefit from the development of precision medicine with the goal of reducing debilitating sensory hypersensitivity), but who would be negatively impacted by pathologisation of the overall experience of being autistic. The medical-model can also be a useful lens for researching common co-occurring conditions (e.g., rare genetic conditions, ADHD, epilepsy, anxiety, or hypermobility spectrum disorder). Funders must consider a more nuanced approach wherein biomedical researchers may describe the challenges or impairments they seek to understand or support, centring autistic perspectives, without needing to tie this back to a broader "autism as disorder" narrative. A neurodiversity affirmative approach provides a new lens within which to formulate proposals, including the transdiagnostic and dimensional approaches mentioned previously.

Reconsidering funding infrastructure

Current biomedical funding infrastructure is not set up to support high quality participatory research. As described above, community engagement should be one of the first steps when scope-setting for new projects and creating proposals. This is particularly needed at the earliest stages of the research pipeline to ensure that years of research and investment can be translated into meaningful outcomes for autistic people. Funds are needed up-front to support this work. However, funding is typically only released after a successful proposal is accepted. Funders must support smaller preliminary scope-setting community engagement initiatives, in terms of meaningful time and funding allowances, and as a precursor to larger grants in the future. Investment in the development of participatory methods for biomedical research is also needed, especially training for biomedical researchers (e.g., as currently done in the R2D2 Mental Health consortium). This training should be available and incentivised across all research areas and career levels, especially for those who might not typically work directly with autistic participants (e.g. wet lab researchers, secondary data users). Dedicated funding towards facilitatory systems and discussion fora for biomedical researchers to engage with community partners would also help to scaffold better relationships between stakeholder communities.

Accountability and group harm

Researchers must take responsibility for broader risk-benefit assessment within biomedical autism research, including consideration of group harm, for example the perpetuation of stigma. This will require novel ethical solutions, such as oversight of research proposals by committees with autistic community representation, as well as the development of, and training in, clear metrics within which group harm can be understood. Care must be taken to ensure that perspectives of marginalised autistic people, such as those with rare genetic conditions and/or intellectual disability are meaningfully represented in these solutions, including the allocation of funding and time to achieve this in a non-tokenistic way. A system of checks and balances, including lived experience perspectives, would be useful to monitor the extent to which funded research reflects the priorities identified by its future users and beneficiaries, both alleged and actual.

Ways of working that support autistic community needs

Pre-existing issues in academic research culture around evaluating and incentivising research and researchers intersect unfavourably with longer-term, more ethical ways of working towards the support of autistic community needs. Funders, journals, and universities must incentivise and reward replication and building upon the work of others rather than solely the publication metric-driven focus on "ground-breaking" research (e.g., as per the San Francisco Declaration on Research Assessment).

Supporting neurodivergence in the workplace is another much-needed cultural change within the biomedical autism research landscape. Journals and hiring departments therefore have a key role to play in this endeavour, and must broaden their horizons when considering what autistic people have to offer. Progress in this area could be measured by increased numbers of those declaring themselves neurodivergent, either openly, or through anonymised equality and diversity monitoring processes in the workplace. To this end, there has been a recent survey within AIMS-2-TRIALS to assess diversity, including neurodiversity, with data analysis ongoing.

Shifting the culture

A successful, radical cultural shift towards truly participatory biomedical research will require a stepwise approach with change occurring both at individual and systemic levels. This is best outlined in the Center for Open Science's strategy for culture change which recommends the following steps for cultural change: Make the change *possible*, *easy, normative, rewarding* and then *required.*

Conclusion

Perceived tensions between the biomedical research and autistic communities pose a risk to realising the great potential biomedical science holds in improving outcomes for autistic people. Researchers can improve engagement and trust by working closely with people with lived experience of autism across a range of support needs. We believe that building a neurodiversity-affirmative approach to biomedical research provides a way forward, and requires discernment between impairments which may be suitable candidates for biomedical exploration or support, and aspects of disability caused by social factors such as stigma and discrimination. Precision medicine could provide the tools for identifying pathways to outcomes that are meaningful to autistic people. Insights from autistic people can improve both the beneficence and quality of such research through new mechanistic insights, better and more rigorous conceptualisations of autism, better translational targets, and parsing the appropriateness of biomedical and environmental support; fulfilling this vision requires support in training, infrastructure, funding and resources. As a community, we must rapidly work towards co-creating a neurodiversity-affirmative framework for biomedical autism research, which will enrich the quality of research output and establish the long-standing working relationships required to allow the resources of biomedical science to be harnessed to support quality of life in autistic people.

Declaration of Interests

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Inclusion and diversity statement

One or more of the authors of this paper self-identifies as an underrepresented ethnic minority in their field of research or within their geographical location. One or more of the authors of this paper self-identifies as a gender minority in their field of research. One or more of the authors of this paper self-identifies as a member of the LGBTQIA+ community. One or more of the authors of this paper self-identifies as living with a disability. One or more of the authors of this paper received support from a program designed to increase minority representation in their field of research.