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"In my title, I ask “academic, activist, or advocate?”—and my answer is that I am all three. You cannot belong to a community that suffers from violence, marginalization, and suicide and not be." (Botha 2021, p9).

[#WorldMentalHealthDay](#)

You want to know why I am so passionate about autistic-rights, so passionate about good quality inclusive scientific method-based research & practice (which are typical standards) in autism; the above quote.

We know from various statistics that autistic persons are generally treated atrociously by broader non-autistic society & it seems to be the cause much of our mental health issues & high rates of suicide attempts & suicide.

<https://www.tandfonline.com/doi/full/10.1080/09687599.2017.1328157>

It is because so many autistic persons are suffering from violence, marginalization, and suicide. Things need to change, not today, not tomorrow, but YESTERDAY. This is something I have been passionate about over the last several years.

I have consistently argued for inclusion of autistic persons, & our rights. Such as here:

<https://www.tandfonline.com/doi/full/10.1080/09687599.2018.1454380?src=recsys>

Here:

<http://www.larry-arnold.net/Autonomy/index.php/autonomy/article/view/CO2/html>

Here, and also problems that we face by broader society.

https://link.springer.com/referenceworkentry/10.1007/978-1-4614-6435-8_102297-2

While many autistic researchers, & stakeholders will claim to pretend they are being scientific. I think in most of those they are likely kidding themselves. I will give examples.

As part of scientific-method, you test your hypothesis, you attempt to falsify it. We know with things like many ABA studies & portrayal it is argued to be "scientifically-proven". This is not how scientific research works.

[@milton_damian](#) this point here:

<https://www.youtube.com/embed/xkjhN4O0zMs>

Another example, has to go Mottron for calling a return to subtypes. If many studies are showing no-differences between autistic persons & non-autistic persons, then that should tell WE ARE FULLY HUMAN & stop trying to pathologise us.

Same point can be made about much social cognitive theories around autism, as has been made by [@KristenBott](#)

"This could mean that researchers will need to develop new theories about social functioning in ASD."

I would also argue that much of the PDA literature seems to a self-validation exercise, like ABA; as it seems to be done with the assumption "PDA is a Profile of ASD"; to get that outlook widely accepted.

"it is likely that many of the original cohort of children assessed by Newson and her team would today meet the diagnostic criteria for Autism Spectrum Disorder using DSM 5." (Eaton & Weaver 2020, p34).

I.e. there are non-autistic persons in Newson's cohort.

Yet that research only diagnosed PDA in autistic persons. Best explanation I have is apparent agenda to "PDA Profile of ASD" accepted.

Yes, I am ranting here, this is important. It is not that science method is being used to harm autistic persons. It is that scientific method-based principles are NOT being applied in much/ most autism research.

It is likely due to the poor quality ethics, standards in practice & research associated with autism. Has allowed communities of practice to form, that allows for typical research standards to NOT be practiced with autism.

"I then make a call to action urging all those who write or speak about autism to engage reflexively with how their values shape their understanding and construction of autistic people." (Botha 2021, p1).

I would suggest as part of critical reflections on how their values shape understandings of autism & its construction; that those engaging with autism, ask themselves are they actually being scientific?

Are they actually open to being mistaken? Are they actually open to being wrong? Are they actually open to developing new ways of thinking on a topic?

Heck, I am basically asking those engaging with autism to intrinsically adopt Critical Autism Studies principles, because the present values associated with autism as they are good as getting us dead.

<https://www.tandfonline.com/doi/full/10.1080/09687599.2018.1454380>

"These critical explorations of power dynamics and autism perceptions allow new lines of inquiry while maintaining epistemological integrity." (Woods et al 2018, 978).

I am not making unreasonable requests or demands, to ask for at least typical research & practice standards to be associated with autism; these are things which SHOULD ALREADY BE DONE FOR US!

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Do non-autistic persons really value us, & our lives, so poorly, that they are happy to accept the accepted status quo, in relation to autism research & practice standards?

I am going to stop ranting, I think I have made my point. I will post a link to the Mottron paper, & mine and other's rebuttal. Also links to any other points that have been made where relevant.

I need to say, that for autistic persons, we basically have no choice, but to call & strive vigorously for better standards in research & practice, because things ARE that bad for us.

Link to Mottron's article calling for a return to autism subtypes.

<https://onlinelibrary.wiley.com/doi/full/10.1002/aur.2494>

[@DrAmyPearson](#) [@HayleyMorganAut](#) [@DrMBotha](#) response to Mottron & Frith.

https://www.researchgate.net/publication/354438100_Creating_truly_radical_change_in_autism_research_A_response_to_Frith_and_Mottron_Running_Title_Response_to_Frith_and_Mottron

Link to [@KristenBott](#) systematic review & meta analysis on autism social cognitive theories.

<https://onlinelibrary.wiley.com/doi/abs/10.1002/aur.2055>

Link to paper by [@DrMBotha](#)

<https://www.frontiersin.org/articles/10.3389/fpsyg.2021.727542/full>

Link to PDA paper that is mentioned.

<https://www.ingentaconnect.com/contentone/bild/gap/2020/00000021/00000002/art00005>

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Thank you in advance.

https://twitter.com/Richard_Autism/status/1447251534820040714

This is vital, it is vital to explain WHY so many studies are conducted into questionable research areas, why so much research efforts & resources are expended to poor quality theories.

Screenshot of where Botha 2021, p8 explains the issues with poor theory, poor quality evidence.

"it seems we cling to them because we cannot get past an idea of autistic people as blank pages, empty shells, bare slates, who cannot think about themselves,...

... nor other people, who are less capable with empathy, socialization, who are wrapped up in restrictive, repetitive behaviors" (Botha 2021, p8).

I think my hypothesis for this clinging to poor quality theory compliments Monique's proposed explanation.

I would add many autism researchers have conflicts of interests in maintaining status quo in poor quality theory, research, & practice. Some researcher's career's & livelihoods, entire autism industries are dependent on not being open to being mistaken.

There are huge vested interests in maintaining the status quo, to not truly follow scientific principles by implementing typical research & practice standards with autism.

I do not think it is as simple as "we cannot get past an idea" (Botha 2021, p8). I think it is partly because some parties, & stakeholders literally cannot afford to get past the idea, &/ or implement typical research & practice standards with autism.

I wish to give another example of this. Many persons, like myself now think that there will never be any definitive biomarker evidence for autism. Already so much research time, effort, & money has expended to produce nothing of tangible use.

I, [@KeatesResearch](#) & [@HayleyMorganAut](#) discuss the issue here (among other things).

https://www.researchgate.net/publication/337171306_Empathy_and_a_Personalised_Approach_in_Autism

By the way the situation with failing to find biomarkers with autism, is the same with other Disorders within the DSM-5.

As part of scientific principles, is being open to being wrong. How many failures to produce tangible results do many persons need before accepting that we cannot successfully divide autism, especially with biomarkers?

There are reasons why I say this, because one can level the point they are being unscientific to Spectrum10K researchers, do they honestly believe they are going to do something, ALL these other researchers have failed to do?

I genuinely believe that Spectrum10K is likely to produce nothing useful, in relation to biomarker evidence for autism. To me it is a vanity project, a huge waste of resources & an highly effective means at annoying the UK autistic population.

We know, at least traditionally Biology, Brain & Cognition dominated UK autism research funding (Pellicano et al 2014, p758).

Can those involved with Spectrum10K afford to admit the rationale for biomarker research in the study is a bit naff? Can S-B-C afford to admit his well-known autism theories, are naff?

Another example. Can prominent "PDA Profile of ASD" supporting researchers/ advocates admit that PDA should also be diagnosed in non-autistic persons?

I should have said, that I think the levels of conflicts of interests in much autism research & practice, probably impacts the abilities of parties to be open being mistaken/ being wrong, to actually implement scientific principles.

I am going to end these extra musings, with links to pertinent articles relevant to this thread, around ethics and standards of autism research & practice.

Link to Pellicano et al (2014) for historic UK autism research funding.

<https://journals.sagepub.com/doi/full/10.1177/1362361314529627>

Link to [@mitziwartz](#) article on relationship between ethics & research quality, using studies from autism literature as examples.

<https://www.tandfonline.com/doi/abs/10.1080/17437270701614840>

Research by [@MichealSandbank](#) & [@KristenBott](#) on lack of adverse event reporting in autism intervention research with young autistic children.

<https://journals.sagepub.com/doi/10.1177/1362361320965331>

Link to [@KristenBott](#) & [@MichealSandbank](#) research into lack of conflict of interest disclosure in autism intervention research.

<https://acamh.onlinelibrary.wiley.com/doi/epdf/10.1111/jcpp.13249>

Link to [@KristenBott](#) research into pervasive lack of disclosure of conflict of interests in ABA research.

<https://www.frontiersin.org/articles/10.3389/fpsyg.2021.676303/full>

Commentary by [@SueReviews](#) & [@autismcrisis](#) & how all autism researchers have a duty to raise standards of autism away systemic poor quality associated with it.

<https://acamh.onlinelibrary.wiley.com/doi/full/10.1111/jcpp.13315>

Another commentary by [@SueReviews](#) & [@autismcrisis](#), this time describing what poor quality ethics does to autism research standards.

<https://journals.sagepub.com/doi/10.1177/13623613211031403>

Final link this time to [@journalautism](#), in how it is trying to raise standards of the autism research it publishes.

<https://journals.sagepub.com/doi/10.1177/13623613211019830>

Until we are absolutely, beyond reasonable doubt, are sure scientific principles are systemically practiced by those engaging with autism, which includes being open to being mistaken & being wrong on a topic...

... autistic persons are likely to suffer from violence, marginalization, and suicide, because typical standards of research & practice are NOT being implemented for autistic persons.

I need to point out, that better theory, research & practice is mainly going to come about by working with autistic persons, as are often the ones creating innovative theory, research methodologies & practice.

Which is a central argument in this essay of mine.

https://link.springer.com/referenceworkentry/10.1007/978-1-4614-6435-8_102297-2

Takes me back to the beginning point about autistic persons suffering from societal treatment. It is directly linked to poor quality research & practice associated with autism; my passion for inclusive scientific method-based research & practice is logical.

Hopefully, I have gone full circle in explaining the importance behind my passion for my central values as a social model neurodiversity supporter. It is relevant to do so on [#WorldMentalHealthDay](#).

I will add, *yes*, I do practice what I preach. I am open being mistaken on PDA. As part of my PhD I have been designing a study which should test if my views on PDA are valid or not, to try & falsify my hypotheses on the nature of PDA.

I am open being wrong on PDA. The study I am designing should allow me to test my own views on PDA & others like Help4Psychology. I should be able to replicate their results on nature of PDA.

The study should be able to produce a result where my hypotheses on PDA are falsified, while replicating the results of Eaton & Weaver around the nature of PDA, & not assuming PDA is an ASD. I am willing to metaphorically "have egg on their face" on the PDA.

<https://www.youtube.com/embed/xFiUWN3y9ho>

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Thank you in advance.