



# Kent Academic Repository

**Milton, Damian (2017) *So who exactly are those at risk?* . Participatory Autism Research Collective Blog post article.**

## Downloaded from

<https://kar.kent.ac.uk/62681/> The University of Kent's Academic Repository KAR

## The version of record is available from

<https://participatoryautismresearch.wordpress.com/2017/08/12/so-who-exactly-is-at-risk/>

## This document version

UNSPECIFIED

## DOI for this version

## Licence for this version

UNSPECIFIED

## Additional information

## Versions of research works

### Versions of Record

If this version is the version of record, it is the same as the published version available on the publisher's web site. Cite as the published version.

### Author Accepted Manuscripts

If this document is identified as the Author Accepted Manuscript it is the version after peer review but before type setting, copy editing or publisher branding. Cite as Surname, Initial. (Year) 'Title of article'. To be published in *Title of Journal* , Volume and issue numbers [peer-reviewed accepted version]. Available at: DOI or URL (Accessed: date).

## Enquiries

If you have questions about this document contact [ResearchSupport@kent.ac.uk](mailto:ResearchSupport@kent.ac.uk). Please include the URL of the record in KAR. If you believe that your, or a third party's rights have been compromised through this document please see our [Take Down policy](https://www.kent.ac.uk/guides/kar-the-kent-academic-repository#policies) (available from <https://www.kent.ac.uk/guides/kar-the-kent-academic-repository#policies>).

# So who exactly are those at risk?

---

By Dr. Damian E M Milton

*It has come to my attention that the NICE guidelines on Autism were not published until 2014. Thus the clinician in this case could not have disregarded them, and I apologise for this mistake. However, I still think the contrast is striking.*

*A page not found*

During the last few days I have been following the live tweets from @JusticeforLBGMC on the General Medical Council's (GMC) fitness for practice hearing for the 'responsible' clinician who was meant to be leading on the assessment and treatment of LB (<http://justiceforlb.org/>) when he was admitted to an Assessment and Treatment Unit (ATU). I do not know much about such hearings and so attempted to learn more by looking them up online. Unfortunately, I was directed to a message stating 'page not found': [http://www.gmc-uk.org/the\\_meaning\\_of\\_fitness\\_to\\_practise.pdf\\_25416562.pdf](http://www.gmc-uk.org/the_meaning_of_fitness_to_practise.pdf_25416562.pdf).

Some of the lowlights that unfolded in the account from the clinician from the hearing including the following:

- LB was not clerked in.
- The assessments carried out were 'in the head' of the clinician and not recorded.
- LB was physically restrained on his first night in the unit.
- The decision to medicate LB with risperidone was taken based on a hunch theory and staff anecdote before the clinician had met LB in person.
- The hunch theory came from the clinicians "*interest in autism*" and suggested that people at the "*milder end*" of the spectrum would upon reaching adulthood see others achieving and getting jobs and will realise that this was "*not for them*".
- The hunch theory also included the assertion that LB was "*complex*" (remember they had not met him at this point).
- That by LB taking the medication he was given and not trying to escape the unit (they were "*told*") "*implied consent*".
- The clinician denies misconduct.

So, the clinician denies misconduct. This is despite running contrary to the Mental Capacity Act (<http://www.legislation.gov.uk/ukpga/2005/9/contents>) and NICE guidance on autism (<https://www.nice.org.uk/guidance/qs51/>), let alone the Royal College of Psychiatry's own guidance on autism (<http://www.rcpsych.ac.uk/usefulresources/publications/collegereports/cr/cr191.aspx>). Although such guidance documentation was published after LB's death, they present a striking contrast to the points laid out above. The latter of these guidance materials is discussed in more depth later in this article.

For reasons I need not go into now, I have been critical of the NICE guidance on autism, yet according to this guidance they state that:

*“Drug treatments have been shown to be ineffective in addressing the core features of autism. They also carry significant potential risks.” (NICE, 2014).*

The clinician stated that LB was not being treated for psychosis or depression, but was *“aggressive and anxious”* (although had not met him at this point). So, what exactly was he being treated for? We don't really know, as the assessments were done in their *“head”*. This is despite the significant risks to the physical and wellbeing of any autistic person treated with such medications. One could only guess that this was in response to some generalised notion regarding 'challenging behaviour'. According to the NICE guidance in relation to the use of medication with autistic people for intervention in such cases, they suggest the following:

*“The first-line intervention for behaviour that challenges should be appropriate psychosocial interventions or interventions to address any identified triggers for that behaviour. In some cases psychosocial or other interventions are not sufficient on their own, or they cannot be delivered because of the severity of the behaviour. In this situation a paediatrician or psychiatrist, working with the person with autism and their family and carers, might consider starting a trial of antipsychotic medication in an attempt to manage the behaviour that challenges. The professional should continue to monitor any subsequent use of antipsychotic medication.”*

So, according to NICE, the first-line of intervention should be to address what is causing the 'challenging behaviour' (or in my view, causing someone distress). I am no fan of PBS models of practice

([http://www.google.co.uk/url?sa=t&rct=j&q=&esrc=s&source=web&cd=4&ved=0ahUKewj\\_keDChdLVAhXhDsAKHdhUBSAQFgg3MAM&url=http%3A%2F%2Fwww.bild.org.uk%2FEasySiteWeb%2FGatewayLink.aspx%3FallId%3D6239&usg=AFQjCNECzQ4ZinRa0lhyL7R79QsD7ncltA](http://www.google.co.uk/url?sa=t&rct=j&q=&esrc=s&source=web&cd=4&ved=0ahUKewj_keDChdLVAhXhDsAKHdhUBSAQFgg3MAM&url=http%3A%2F%2Fwww.bild.org.uk%2FEasySiteWeb%2FGatewayLink.aspx%3FallId%3D6239&usg=AFQjCNECzQ4ZinRa0lhyL7R79QsD7ncltA)), but even if one is following practices such as a functional assessment, this would mean concentrating on the so-called 'antecedents' of the behaviour and not the 'consequences' as a priority (something that I so rarely see in practice). The clinician however, prescribed anti-psychotic medication having not met LB (simply based on his diagnosis of autism, a pet theory, and perhaps a notion that anyone entering an ATU must therefore be 'severely challenging' and thus medicated), and in order so that they could then proceed with psycho-social interventions one might assume, however such interventions were not mentioned once in their account at the hearing. So, LB's behaviour was deemed sufficiently 'severe' based on what? This did not involve any evidence gathering other than staff anecdote. In the whole time LB was in the unit (#107days: <https://107daysofaction.wordpress.com/>), the clinician met with him six times (and was responsible for fifteen patients). As for 'working with families'...fill in the gap there with whatever expletives come to mind.

Last year I wrote a short book entitled *“10 Rules for Ensuring People with Learning Disabilities and Those Who Are On The Autism Spectrum Develop ‘Challenging Behaviour’... and maybe what to do about it.”* with Richard Mills and Simon Jones (<https://www.pavpub.com/10-rules-for-challenging-behaviour/>). Rule one was: *“If you don't understand me, call me complex”*. Rule two stated: *“If I get upset send me to a doctor – they can prescribe medication to control my behaviour”*. Rule three: *“take control of my life, almost as you would a child”*. You get the picture? I should make this clear to this clinician and other psychiatrists that this was not a torture instruction manual and you were meant to look at the sections on *“what to do about it?”*.

*Is this typical?*

Whilst expressing my outrage on Twitter about this situation, I was asked if I thought that this appalling misconduct was typical within psychiatric practice. Another critical academic suggested it was, and a psychiatrist commented that they thought it wasn't. In my own experience, I have met caring and professional psychiatrists, unfortunately not whilst I was one of their (not-so) 'patients' though.

In an article (<http://www.cepip.org/content/becoming-autistic-aut-ethnography>) I wrote in 2014 aimed primarily for an audience of psychiatrists and medical practitioners working with autistic people, I gave an account of my own experiences with the psychiatric profession and the fragmented sense of self-identity that I have experienced. In doing so, I gave what I referred to as an 'aut-ethnography' (<https://theautismanthropologist.wordpress.com/2015/01/19/aut-ethnography-working-from-the-inside-out/>). Unlike auto-ethnography which often seeks to construct a coherent narrative of self over time, to me an aut-ethnography (at least my experience/version) is a fragmented one, where snippets of information are formed into 'rhizomatic' patterns of shifting meanings. Similarly, Melanie Yergeau, an American autistic scholar and activist, refers to an (seminal) essay she wrote in 2013 as an 'autie-ethnographic narrative' (<http://dsq-sds.org/article/view/3876/3405>). This was the approach I took when I wrote a blog essay for the #107days campaign expressing my anger at what had happened to LB and his family and commenting on the common dehumanising of autistic people (<https://107daysofaction.wordpress.com/2014/04/01/day-14-moments-in-time-107days/>). In that blog I commented briefly on my experiences with psychiatrists in my youth:

*"I along with my family were involved in a multi-car road traffic accident. My mother acquired a number of permanent physical disabilities, and I severe psychological trauma. Every psychiatrist who saw me in the years ahead had their own pet theory when they observed my 'behaviour'."*

It would seem that a psychiatrists penchant for pet theories may know no bounds if this hearing is anything to go by. But is it typical of psychiatry? For me, the narrative expressed by the clinician in this hearing suggests that it is. They "*were told*" lest we forget that not trying to escape the unit and compliance "*implied consent*" to medication use. Such a narrative would suggest that such practices are so normal to this clinician to be supported by others as a culture, to have formed part of their 'natural attitude' (<http://www.tandfonline.com/doi/abs/10.1080/09687599.2012.710008>) to those in their 'care'. A sign of an embedded systemic ableist practice. In my reading, it is indicative of the idealisation and reification of normative humanity that runs throughout the field of psychiatry. Of course I may be biased, having been traumatised in my youth by psychiatrists...

#### *Psychiatry and me: a history of trauma*

Following the road-traffic accident I was involved in with family members at the age of 11 I suffered a very high level of mental distress. The way in which this distress manifested would now no doubt be medically termed as PTSD (one would think). At this time though each psychiatrist I came across had their own pet theories (sound familiar?). They did meet me at least, although often by presenting to my perceptions as an imposing and authoritarian presence asking deeply personal questions, and thus constraining much of anything they could have learnt from me:

*"At one consultation, I was taken to Harley Street to see someone who had a plaque of their name outside the building entrance. He was an old man who immediately made me feel intimidated and*

*started asking me questions about 'the accident'. I froze, found myself unable to speak, rocked, and stared at the wall, hoping the whole thing would finish as soon as possible. His report suggested that I was not suffering due to 'the accident', but that I had an underlying childhood disorder of catatonic schizophrenia. He also told my mother after the appointment that, if she pursued the case of psychological damage to me from 'the accident' that he would need to see me several more times. Unsurprisingly, she did not pursue this further. Following a number of sessions with family counsellors and others, I decided very strongly, that I wanted nothing to do with psychiatrists, or 'people who thought they knew what I was thinking better than I did'." (Milton, 2014: <http://www.cepip.org/content/becoming-autistic-aut-ethnography>).*

In a previous essay I wrote for the #7days of action campaign (<https://theatuscandal.wordpress.com/seven-concepts-of-sociological-interest/>) I talked about the othering of autistic people and the 'mortification of self' endured by those entering into 'total institutions' (ala Goffman). In another recent article (<http://www.tandfonline.com/doi/full/10.1080/09687599.2016.1263468>) I utilise the term 'Psychsplaining' when referring to how psychiatrists can undermine one's sense of self through their 'expert knowledge' being projected onto their 'patients', who by default are in a relative position of powerlessness. Indeed, I have been thinking about just how much of the social 'suffering' of autistic people is attributable to this phenomenon. Many critical disability scholars have incorrectly associated the concepts of the neurodiversity movement with 'biological citizenship', but this is rather the internalised oppression of the autism industry and psychsplaining which many within this movement actively resist (<http://www.tandfonline.com/doi/full/10.1080/09687599.2014.1000512?scroll=top&needAccess=true> and <https://madstudies2014.wordpress.com/archive/mad-studies-neurodiversity-symposium-archive/>).

#### *Service abusers, users, survivors, refusers and refusees*

In my work as an academic, I have often heard the phrase 'service user' and calls for having more research being 'user-led'. From the press and from politicians we also often hear of the fantasy of those 'malingerers' trying to play and 'abuse the system'. Although I cannot see how anyone holding such a view has ever had to apply for DLA or PIP! There is a long and rich history of mental health service 'survivors'. Yet, there are also others which are often less attended to. Having survived a few brief scrapes with psychiatry in my youth, I became a firm service 'refuser', which meant that I was not to be diagnosed as being autistic until I was thirty-six years old and only following my son's diagnosis a few years earlier. Still however, I currently 'access' zero services as such for myself. Recently I brought this topic up with some autistic friends and one of them reminded me that there are also those 'refusees' who would like to access mental health services but are denied services, often because they are autistic.

#### *The working group: a visit to the Royal College of Psychiatrists*

A few years ago I was invited to be on a working group to develop new guidance materials regarding autism for the Royal College of Psychiatrists (<http://www.rcpsych.ac.uk/usefulresources/publications/collegereports/cr/cr191.aspx>). Given my personal history, this did not fill me with a sense of glee, but I felt that it was an opportunity to utilise these experiences to some productive effect. Being the only autistic person in the room

discussing autism with lead psychiatrists I cannot say was the most pleasant experience of my work in the field. It was a struggle to even get into the report that some autistic people may have a sense of identity drawing upon concepts such as neurodiversity. Despite the psychsplaining (which boiled up at one point into something of a full blown argument), it is certainly pertinent as to what was advised in this report regarding the use of medication with autistic people:

*“However, where appropriate, medication is only one component of a multi-modal approach that might include psychological therapies, education and environmental change, so it should not be used in isolation.”*

Remember, in the hearing there was no mention whatsoever of any other intervention being considered other than medication and LB was restrained on his first night in the unit. The report continues:

*“It is appears that autism might be a marker for an unpredictable response to psychotropic drugs, with increased and decreased sensitivity in different individuals, as well as more frequent and unusual adverse effects. Drugs should be introduced at a low dose and increased cautiously, with careful monitoring.”*

Careful monitoring does not mean that you prescribe without meeting someone and you see them six times in #107days.

The report also explains how there are two particular circumstances that require medication: psychosis and epilepsy. Yet, we have already established that LB was not psychotic. As for his epilepsy care, the clinician only seems to have recently realised how important this is. To repeat the now common mantra...He died!

Most interesting though is how the report talks of medication use in relation to mental capacity:

*“There are a number of forms of disability associated with autism that may complicate an assessment of mental capacity and thereby the validity of an individual’s consent to treatment.”*

Many factors that could complicate an assessment of consent to treatment, and yet LB was not assessed and the clinician implied his consent by his behaviour being compliant within a total institution. This may not be ‘typical’ of all psychiatric practice, but it is typical of the systemic ableism suffered by autistic people and those with learning disabilities. One only has to take a look at the ‘7 days of action’ campaign to realise that.

This leads me to the question that frames this essay: *So who exactly are those at risk?* Often autistic people are deemed a ‘risk’ to themselves and others. Yet, given the mortality rates of autistic people, it is clear to me that the misconduct of psychiatric professionals is of a much greater risk to autistic people, people with learning disabilities, people in mental distress, and their families.

*I have a dream*

I somehow doubt that autistic people and psychiatrists will ever be able to *“sit down together at the table of brotherhood”*, I do have a dream however, that one day the Royal College of Psychiatrists issues a public statement of apology for all of the abuses endured by those that they have practised upon. At this present moment in time though, such abuses continue.

So a proposal to begin with: a new ten rules book aimed at psychiatrists. To that end, I would like to invite the new lead on autism within the Royal College to be a co-author.

For more information on the hearing see: <https://mydaftlife.com/2017/08/10/writing-trauma/amp/> and <https://markneary1dotcom1.wordpress.com/2017/08/10/too-insignificant-for-the-law/>.