

Meeting with National Autistic Taskforce- 28/10/2019

Notes in italics were added by the review team for our own clarification.

Introductory remarks:

On the whole there is some positive progress.

We like a lot of the language and principles.

However we have concerns about the detail and some of the ways we've approached things.

Major concerns:

1. The move towards a disability model is positive. However the way the review has attempted to actualise the social model in law is problematic.

i) Being recognised as disabled, not just some of the time but all of the time, is important for other laws such as social security.

ii) The attempt has gone too far because autism includes impairment regardless of the environment.

2. What the review has done is to take autism and learning disability out of the definition of mental disorder, then recreate a system by which autism and learning disability can still be the basis for detention.

There is a risk of implementing a change in language with no change in practice.

The review appears to be saying that autism and learning disability on their own still justifies detention in some cases. This is a serious problem and is not compliant with the CRPD.

3. Human Rights Assessment

We have serious concerns about the detail of this.

When the review speaks about proportionality in decision making, it has failed to explicitly factor in the **likelihood** of a rights breach, as well as the consequences or severity of a breach.

An example of a consequence of this could be that deprivation of liberty is authorised on the basis of a faint possibility of a breach to the right to life.

Unless this bias is counteracted it will affect decision making.

Life and liberty are the main rights that will be considered in these assessments.

Right to life will always trump the right to liberty and there are references within case law that evidence this happening.

Under this system it will still be possible for the following to occur:

- Someone with “Autistic impairment” suffers stress or distress
- Therefore they are assessed as having “autistic disability”
- They are offered “care, support and treatment” in an “autism specialist environment” that is the Secure Support Centre
- The treatment given is behaviour modification and medication, to keep other people safe.

Nothing the review has written prevents this from happening.

The culture is too embedded. If we don't make it impossible, the situation now will perpetuate.

It is possible to counteract this problem by incorporating a measure of likelihood into the decision making process. The relationship between likelihood and severity would need to be carefully defined. Likelihood would need to be a significant factor and evidence should be required of likelihood.

Discussion of compliance with Articles 12 and 14

It is not the case that it is not possible to comply with both CRPD and ECHR. There are other legal experts that disagree with the reasons given by the review team for not being able to comply.

With regards article 14, we accept that people may need to be detained for their own or other's safety, but there is no evidence as to why someone needs to be detained without mental illness or criminal conviction.

We think there has been a fundamental misunderstanding of ECHR and the related case law from the European Court of Human Rights on Article 5.

Historically the UNCRPD was created in 2012, compared to the European Convention which dates from 1940s.

The ECHR states that a person should have the right to liberty, except in certain circumstances. Under no circumstances does the ECHR **require** the creation of a mechanism to enable detention of certain groups (i.e. those of 'unsound mind'). What it says is that detention can be justified by some particular factors (e.g. 'unsound mind'), but it is also justified not to do so, it is a choice.

Everyone has a right to liberty. Yes current ECtHR jurisprudence includes autism within the definition of 'unsound mind'. However, this does **not** mean that there has to be a law to allow detention of autistic people. Neither the ECHR, nor related case law from the ECtHR, requires any country to have a system that enables people of 'unsound mind' to be detained. It merely legitimises allowing it if we wish. However, doing so, on the basis of the presence of a disability, is not compliant with UNCRPD Article 14.

Therefore, we disagree that it is not possible to satisfy all committees at present, the review has fundamentally misunderstood the case law on Article 5 ECHR . If the review has received legal advice on this issue, we respectfully suggest that the advice has been misunderstood.

Detention, care and treatment

NAT are not proposing that care and treatment should not be provided, we are proposing that this should not be done with detention.

We would also object to compulsory care and treatment in community settings.

We recommend that the review reads MENTAL CAPACITY REPORT June 2019 Issue 95 commentary on Rooman v Belgium [2019] ECHR 19: *"the current case-law clearly indicates that the administration of suitable therapy has become a requirement in the context of the wider concept of the "lawfulness" of the deprivation of liberty. Any detention of mentally ill persons must have a therapeutic purpose, aimed specifically, and in so far as possible, at curing or alleviating their mental-health condition, including, where appropriate,*

bringing about a reduction in or control over their dangerousness. The Court has stressed that, irrespective of the facility in which those persons are placed, they are entitled to be provided with a suitable medical environment accompanied by real therapeutic measures, with a view to preparing them for their eventual release.”

Essentially, this requires:

- that the level of care required must go beyond basic care: “[m]ere access to health professionals, consultations and the provision of medication cannot suffice for a treatment to be considered appropriate and thus satisfactory under Article 5.”
- deprivation of liberty must be in an institution capable of providing the necessary treatment
- Non-compliance by patient may not be a defence

. Consequently, detentions of autistic people who are merely being ‘contained’ and medicated are likely to be in breach of Article 3, unless genuine treatment **for autism** is being provided. In our view, ‘behaviour modification’ (such as Positive Behaviour Support) may well not constitute ‘treatment’ for autism, since it is aimed at treating ‘dangerousness’ rather than actually treating autism itself

Professionals currently consider things as treatment, for example use of psychotropic medication, which, not only NAT, but the NHS (see STOMP/STAMP campaigns) and the ECtHR (see above) do not consider to be treatment,

Justification of medication

Psychotropic medication should only be used if proven to be **safe** (i.e. on the same basis that any other medication is approved as safe for use on human subjects), not legitimised on the basis that no-one has proved that it does harm (as is written by the review team). The review team’s proposed criteria are a complete inversion of normal criteria for medicines safety.

Consideration of the rights of others

There is a lack of clarity in the report about when, whether or under what circumstances infringements of the human rights of an autistic person (such as their right to liberty) can be justified on the basis, not of a greater risk to the

person's **own** human rights, but on the basis of a greater risk to the human rights of **others**.

The review needs to deal explicitly with this and identify where the balance lies in terms of weighting, otherwise there is a risk of imbalance. For example it could be possible to say "this person might attack one or more members of the public ", that's a risk to more than one person, whereas it is only one person's right to liberty which will be infringed, therefore detention is justified.

Definition of autism and learning disability in the Mental Health Act

NAT are yet to be convinced as to why detention is needed on any basis other than mental illness or criminality. Neither situation requires autism to be a basis for detention.

Therefore, NAT would like to see the exclusion of autism and learning disability from the definition of mental disorder (and any list of justifications for detention of any kind) in the mental health act.

All situations that arise would be covered by mental illness or criminality.

Why is there a need for autism to have anything other than this?

Support in crisis

We accept there will be situations where an autistic person reaches crisis.

In these circumstances there should be access to community based crisis house type support, designed and run by autistic people.

There should also be much better pre-crisis support as intervention earlier on is more effective.

It is positive that the review has offered support for joint crisis planning.

Duties on authorities

The duties outlined in the report are currently to provide health care only.

There needs to be more about social care duties. Most support needed is good low level community support, which is social care, not health. Autism is not an

illness/health problem, it's a disability. Therefore, support from social care is, in most cases, more relevant and appropriate.

The review could look at the statutory eligibility criteria in England (Care Act 2014 – see <http://www.legislation.gov.uk/ukxi/2015/313/contents/made>), which is better than that offered in Scotland. Scotland currently only provides a right to assessment through s.12 Social Work (Scotland) Act 1968 and the law is very weak on actual, enforceable statutory duties to meet an individual's social care needs. Compare s.12 Social Work (Scotland) Act 1968 and Social Care (Self-directed Support) (Scotland) Act 2013 to section 18 of Care Act 2014 in England.

People who commit crime

NAT has sympathy with the desire not to criminalise people who have carried out a criminal act, such as assault, but without intent.

However, we part ways with the review regarding when it is considered that this has occurred, what to do next and who knows best.

At present the proposals are likely to lead, in practice, to essentially what we have now.

The law needs to start from the presumption that this group of people exists, **but that it doesn't need to**. We reference the NAT guide to Quality Care here.

Autism does not **cause** behaviour which violates other people's rights. Such behaviour is an indication of distress. There may be times when intervention is needed, if someone else's rights are being infringed, but this should be done in the community and de-medicalised.

The medical approach effectively treats behaviours of concern as an inevitable part of autism, instead of looking to work with the person to identify the source of their distress, support their understanding of other's rights and support them to live a healthy, functional life in the community in a way which does not infringe the rights of others.

NAT are currently undertaking research projects to provide evidence in practice of how this can be done most effectively.

We would argue that the proponents of the current approach, not only have no evidence that it actually produces anything other than a mass industry of

containing and medicating autistic people. There are any number of individual examples of autistic people who have been detained and medicated for long periods, who have thrived without medication or detention in community placements, simply because they have better quality support.

There is a pernicious assumption that behaviours are **because** of learning disability or autism. Challenging behaviour is looked at as a diagnosis in itself by some professionals. By our own experience in NAT none of us believe this is the case (see <https://www.pavpub.com/learning-disability/challenging-behaviour/ten-rules-for-ensuring-people-with-learning-disabilities-develop-challenging-behaviour>). In our experience, distress-related behaviours are primarily fuelled by:

- Failure to consistently and effectively teach human rights (usually due to an assumption that the person is incapable of learning)
- Failure to support people to effectively meet their needs in ways which do not violate the rights of others (e.g. access to sufficient sensory stimulation opportunities)
- ‘Care’ which (largely through ignorance and under-funding) causes unnecessary stress by failing to meet basic autistic needs (e.g. structure and routine, honesty, provision of information, protection from sensory distress, insufficient downtime and privacy)
- Failure to effectively support the development of functional communication throughout the lifespan

It could be necessary to detain as a short term intervention to protect others human rights, but this should be exceptional and **should only occur where there is evidence (of the same standard that would be required for a criminal conviction) that behaviour which would otherwise be criminal has actually occurred (not just anticipated/possible/feared)**. This is what we believe is necessary for actual compliance with Article 14 UNCRPD, so that disabled people are only being detained on the same basis as non-disabled people i.e. that their actions are actually criminal.

A process for detention could be:

- The application to detain is brought before a judge
- There is evidence submitted to support the application
- There is a strong presumption that detention is not necessary

- The judge should challenge professionals to provide evidence and to justify their application by demonstrating: (1) That behaviour which would otherwise be criminal has actually occurred; (2) That the person cannot be safely and appropriately supported in the community; **and** (3) that actual 'treatment' (more than medication and containment, and not merely 'behaviour modification') is available in the secure setting which includes a plan for re-integration into the community.

It might be possible to do this on a case by case basis with a judge (*as described above*), which is justified by actual evidence and a clear plan put in place about how the person will be able to leave **before** detention is authorised.

There has to be proof of actual evidence that an action would have been considered criminal / could be about to be considered as criminal
This could be similar to the insanity defence in England to determine whether an act was committed on a factual basis (*like examination of the facts in Scotland*)

There is a problem that if decision making is led by professionals it will maintain the status quo.

There is no difference between a hospital and a Secure Support Centre. Who would run the Secure Support Centres? They would be contracted to the private sector and then we would end up with situations such as have been experienced in England with Assessment and Treatment Units. The smaller places are, the more likely they are to go wrong, for example Winterbourne View.

Community based alternatives to detention

'Crisis care' (whether in the community or not) is problematic because a change in environment itself may cause distress.

What is needed is good quality community-based support to prevent crises whenever possible. This needs proper funding and clear, enforceable statutory duties to meet social care needs (not just health needs).

Autistic People's Organisations

If, despite all the above, you are going to go ahead with the plans outlined, we would need to have Autistic People's Organisations involved directly in overseeing, reviewing and critiquing the regimes of places such as Secure Support Centres or any other such place. Such reviews need to have real 'teeth' in order to effectively challenge embedded cultures and practices.

To ensure quality, resources are needed (including sufficient funding to employ and retain skilled staff) and procurement processes have to include the requirement to demonstrate that autistic people have delivered training, created training, are leading training etc. Training should be commissioned from Autistic person's organisations (for example as happened in Leicester).

Human rights training for staff is also important.

Training doesn't work on its own. We need strongly embedded cultural change, through supervision/appraisal and inspection and procurement. And we need to pay enough to get, train and retain the right staff.

Risk to self

If people are hurting themselves, rather than others, this could justify detention under the definition of mental illness, rather than requiring detention on the basis of autism or LD

There are two groups of people:

1. People who self harm or suicidal thoughts – they are analogous to other people who have mental illness without autism. This is likely to indicate the presence of a mental health issue which should be treated as such.
2. Self – injurious behaviour (e.g. head banging): We argue that this isn't inevitable. It's an indicator of distress. There are safe non-harmful ways to address the cause of distress. Detention is **never** necessary and is frequently counter-productive (see <https://www.cqc.org.uk/publications/themed-work/interim-report-review-restraint-prolonged-seclusion-segregation-people>).

Restraint should also never be used unless it would also be justified towards a non-disabled person in the same circumstances i.e. a reasonable use of force to prevent a criminal act is occurring or protect life or limb.

We need to stop the low level of threat on the basis of which restraint is justified i.e. someone is 'bring verbally abusive', 'non-compliant' etc.

Restraint occurs because poorly trained staff are frightened and do not have the basic skills to support autistic people to prevent distress occurring

Restraint can become a pattern. Poor planning can lead to jumping from crisis to crisis.

Staff are trained in responding to challenging behaviour (mainly physical restraint and 'de-escalation' strategies based on a neurotypical view of the world), but not in prevention and how to work with people to prevent distress.

Further minor observations

Suggestions about advocacy are positive, but it is vital that advocacy is funded to ensure advocacy services can afford for advocates to have in-depth, regular training in autism and communicating with people with autism.

Adaptations – need to include the requirement for an interpreter for communications, for example in Makaton. (Equality Act reasonable adjustment)

Procurement – advocacy organisations can't afford to provide in-depth training, so better procurement is needed

We agree there should be separate independent advocates for the carer and the person.

Standards for Accessible Communication – this needs to be made stronger than what we currently have in England.

There is a useful definition in the English Care Act Statutory Guidance – information is only accessible if it is understood by the person receiving the information ('listening' is biased towards oral communication).

Supported decision makingThe 'All Practicable steps' principle in the Mental Capacity Act, which requires all practicable steps to have been taken to support a person to make a decision for themselves before they can be judged to lack capacity, has not worked in practice in England for 15 years!.

Enforcement of a principle of this type is ineffective if the only way to enforce it is for vulnerable adults to seek Judicial Review of failures by public bodies!

Access to tribunals may help. However, it is very likely that merely having such a principle will be insufficient to actually protect the rights of autistic adults to make our own decisions because vulnerable people may not be able to take legal action to challenge the decision.

Concept of 'benefit'

There is a lack of definition of from whose perspective this is from.

E.g. Training people not to bang their head would benefit the person, but this would not address the underlying issue (which might be distress caused by a physical health problem or experiencing abuse).

Disabled people may see aspects of disability as positive and have entirely different priorities to those of non-disabled people. Any external judgement of 'benefit' is akin to 'best interests' and unlikely to actually be compliant with Article 12 UNCRPD.

Positive Behaviour Support

There are concerns from autistic people and autistic persons' organisations about this. They are not concerned about it working, but concerned about its goals (see <https://kar.kent.ac.uk/69268/>). There are equally valid alternative approaches which should be given equal prominence in policy documents:

- Bradley, Elspeth & Caldwell, Phoebe (2013) Mental Health and Autism: Promoting Autism FaVourable Environments (PAVE), Journal on Developmental Disabilities . 2013, Vol. 19 Issue 1, p8-23. 16p.
- National Autistic Society SPELL
<https://www.autism.org.uk/about/strategies/spell.aspx>
- Mills, R & McCreddie, M (2018) SYNERGY: Knowing me – knowing me. Changing the story around 'behaviours of concern'. Promoting self-awareness, self-control and a positive narrative

Psychotropic medication

The report seems to say it is okay unless there is **proof** it causes harm. This is flipped compared to normal medical practice on medicines safety. There needs

to be proof it is safe, and more importantly, safe for this specific population (i.e. autistic people).

This is not suggesting people with mental illness shouldn't get psychotropic medications when they are appropriate to treat that mental illness. However, people with learning disability and autism alone shouldn't be given medication to treat 'behaviour', which is not approved for use to treat autism and which is specifically advised against by best practice.

<https://www.england.nhs.uk/learning-disabilities/improving-health/stomp/professionals/>

Effects of medication for autistic people

There is evidence that shows that autistic people may tend towards adverse reactions to medication.

Dinah Murray suggests this:

<https://researchexperts.utmb.edu/en/publications/treatment-of-autism-spectrum-disorder-in-children-and-adolescents>

Abstract says: Children and adolescents with autism spectrum disorder appear to be more susceptible to adverse effects with medications; therefore, initiation with low doses and titrating very slowly is recommended. Some complementary alternative treatments have been researched as possible treatments in autism, though evidence supporting many of these is very limited.

(Reference submitted after the meeting via email.)

Issues on specific pages

Page 45- Typo- presumption in law, the last 4 words.

Environment- what is the justification for uprooting people in their environment?

Crisis- need for refugee/crisis house

Exceptional circumstances aside, we don't think a person should be uprooted from their environment. Health and social care needs should be met, and support should be provided within a person's home.

Rights to support should be provided by social care, as health only gets involved when things are really bad. Focus on support via Health care only perpetuates perception of autism and learning disability as health conditions.

Page 91- 'Expertise' in learning disability and autism is defined by professionals. There is no mention of understanding of autism in terms of evidenced capabilities (e.g. <https://www.skillsforhealth.org.uk/images/services/cstf/Autism%20Capabilities%20Framework%20Oct%202019.pdf>) or whether autistic people think they're expert. There is a strong need for engagement with autistic people's perspective (note the capabilities framework referenced above is the first produced in genuine collaboration with autistic people).

Page 92- 'Guided by lived experience' is too weak.

Page 93- Under the description of how things are. No requirement for MHOs to have training- needs to include autism specialist training.

Unpublished document- DHSC- sets out core capabilities for supporting autistic people (NAT on steering group), now available at:

<https://www.skillsforhealth.org.uk/images/services/cstf/Autism%20Capabilities%20Framework%20Oct%202019.pdf>