



All Party Parliamentary Group on Autism

Thursday December 14th

Virtual Meeting on Mental Health

Time	Item
12:00 – 12:05	Opening remarks from the APPGA Chair – Sir Robert Buckland MP
12:05 – 12:15	Speaker – Sam Forrester (National Autistic Society) – An update on the Mental Health Bill
12:15 – 12:25	Speaker – Zaynab Sohawan and Lindsey Bridges – Autistic people's two experiences of the mental health system.
12:25 – 12:55	Open to the public to provide their own experience and thoughts about what changes they would like to see.
12:45 – 12:55	Reflections from MPs and Lords in the meeting.
12:55 – 13:00	Closing Remarks from Sir Robert Buckland
	Meeting ends

Welcome from Sir Robert Buckland MP (Chair of the APPG on Autism)

Sir Robert welcomed everyone to the APPG meeting and introduced the first speaker.

Sam Forrester: Policy & Parliamentary Officer (Mental Health) at the National Autistic Society

Sam gave a presentation on the current state of the mental health bill and the context behind why the legislative change is needed.

The full presentation will be shared with all along with the minutes.

Action: Share slide with the minutes

Zaynab Sohawan – Emotion Dysregulation in Autism & NAS Young Ambassador

Zaynab talked about her experience of being in a mental health setting.

- From when they were 14 – 18 years-old Zaynab was in eight different units – as an in-patient

- She experienced restraint, and saw other patients being restrained for up to six hours at a time.
- Was injected with sedatives
- The whole environment was chaotic, in one case she was “spat at for being brown.”
- Ended up having to be re-admitted three times
- The whole experience was traumatic. She still experiences flash backs from being restrained.
- Zaynab is now a mental health campaigner and has set up charity to help people leaving mental health units
- She has had a number of opportunities including, handing in an open letter to Downing Street with the National Autistic Society and speaking in front of the Crown Princess of Denmark

Lindsey Bridges – Campaigner and parent

Lindsey spoke about her daughter Lauren's (Lolly) tragic experience of mental health hospitals

- Lauren passed away while in a mental health hospital, six hours away from their home.
- From a young age Lauren always suffered anxiety. She lost her brother when she was six years old and at secondary school she was often mute
- At 17 – at the advice of CAMHS, Lauren was admitted into an adolescent mental health hospital. Lindsey was advised this would ensure they got the help they needed. But Lindsey says :“We regret the day we asked for help”
- Lauren was put in solitary confinement and physically and mentally abused and was threatened by members of staff
- Lauren was scared of other patients.
- Lots of professionals didn't accept her autism diagnosis
- Lauren's family put in daily requests were made to bring her home.
- Lauren was suicidal and died in February. On the day she died there were requests for her to be watched which she wasn't.
- A 4 week inquest showed a number of failures in Lauren's care including, a lack of record keeping, lack of communication between agencies and it was revealed there were beds available in Lauren's home area of Bournemouth Lauren didn't mean to lose her life the inquest agreed. It was a cry for help.
- Lindsey is now campaigning for “Lolly's law” which would mandate all psychiatric staff to be retrained and for all doors in mental hospitals to be anti-ligature doors

The floor was opened to members of the public on the call to share their own experiences.

Paul Ridley

Shared the experiences of his two children, and the multiple times the system has failed his nonverbal son.

- Wants to see specific training for supporting nonverbal autistic people.
- Stressed that being nonverbal does not mean that someone doesn't have capacity.

Sir Robert Buckland echoed these sentiments

Simone Aspis

Leads a campaign by people with lived experience

- Spoke about the people without family or parents to speak up and advocate for them.
- Their big issue is the Mental Health Bill, it needs to be seen from a human rights perspective.

Caroline Hearst (AutAngel)

- Spoke about the work of small organisations.

Sir Robert Buckland agreed with the need for small organisations to work with the larger organisations.

Action: NAS to discuss with other relevant organisations potential for a meeting with smaller autism advocate groups working on this topic

Simon Buckingham

Spoke about the comparisons between the UK and New Zealand where they had previously lived.

- Wants to know if the Human Rights Act can be imbedded into the mental health legislation.
- Looking to take the discussion about a rights-based approach offline.

Julia Caro

Spoke about the experience of campaigning and advocating, and of the bereavement of her family members through failures of the system.

- Stressed the need for more help and support and how children are failed from the very start.
- Some families have to fight to get their children admitted to mental health units.
- It should always be safer inside the units than outside.

Sir Robert Buckland stressed that the experiences of people on this call are important, and that people are not alone – Support is so important.

Simon

- Simon spoke about his experiences with autism and ADHD – being pushed around in a circle between services that fail to support him and the impact it has had on both him and his family. There was a pathway to get diagnosed but not a pathway to get treatment.
- Hasn't been able to reach his full potential
- The cost of what's been happening has to be less than the cost of putting it right.

Jaki

- For many years local mental health services have been using their autism diagnosis as a reason that they cannot provide the support for their PTSD.
- Has been refused treatment in other places because they are technically 'under the care of' already.
- Where there is a primary care need, could PTSD be considered a primary health need?

Sir Robert Buckland MP

Thanked everyone for attending and for sharing their stories,

Understood that lots of people wished to speak who couldn't, and some raised complex issues.

Suggested people email with more information to APPGA@NAS.org.uk

Meeting ended.