

Experiences as an autistic in-patient in psychiatric care

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This Talk

WARNING: Potentially triggering content. We will be discussing issues relating to mental health, distress, suicidal, self-harm, and mental health services

- My story and personal experiences
- The general problems with crisis support and inpatient care for autistic people
- What needs to change



My Story: A Poem

What led me to crisis

- I have co-existing mental health difficulties, including Bipolar, anxiety and traits of OCD
- I was diagnosed late and tend to mask my traits a lot
- Balancing employment and socialising often leads me to 'burn out'
- I'm very sensitive to medication changes, and these had been happening regularly in the lead up
- Lots of changes and transitions in my life



My experiences of accessing crisis care

- I struggle to make phone calls and most urgent crisis care involves phoning crisis lines
- The people you see and speak to are always different, so you never get to know anyone and there is always that anxiety of who will you speak to this time and will they understand me
- It is difficult for me to identify and describe my feelings
- Many do not have autism training, so do not adjust for my needs
- Referral to Home Treatment Team hadn't been successful – they refused to see me and referred me back
- I don't present typically when in mental health distress and so often am not believed or my experiences are invalidated



My experiences as an inpatient

Acclimatising and transitions:

- Loss of community team support
- Unknown wait time for a bed and where it will be
- Being searched and stripped of belongings
- No one shows you around the ward or explains what's going to happen
- Uncertainty over when you will be able to leave



My experiences as an inpatient

Sensory overwhelm:

- Loud environment – patients and staff
- No control of heating – either too hot or too cold
- Strong smells
- Hospital food
- Not being allowed sensory/stimming objects
- Plastic mattress and thin sheets
- People entering room unannounced



My experiences as an inpatient

Social aspects:

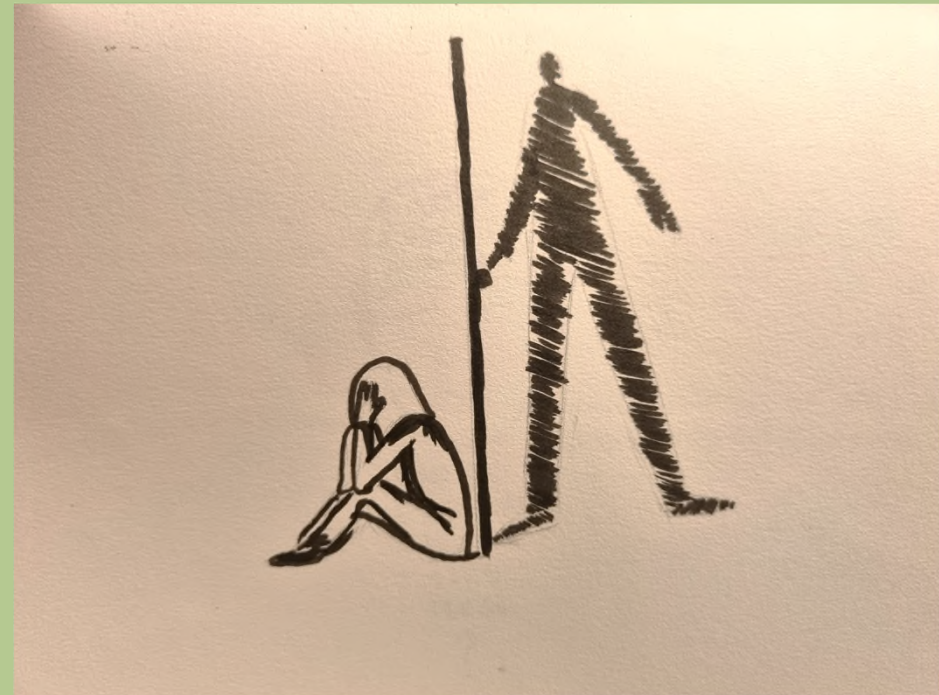
- Community with other patients
- Constantly being around others – social burn out
- Some became friends whilst others were quite threatening or took advantage
- Only avenue for discussing feelings and concerns



My experiences as an inpatient

Staff:

- Inconsistency of staff – mostly agency staff (especially at night)
- Lack of therapeutic support – no staff available to talk to
- Over reliance on sedation and giving medication with no explanation of what it is
- Heavy handed
- Lack of mental health training, let alone autistic training
- Misunderstanding and mismanagement of meltdowns
- Frequently made sudden changes to routines/rules



A Wider Problem

Autistic people and risk to mental health

- **Autistic people are at an increased risk of mental health problems**
 - Autistic vs non-autistic: General Anxiety Disorder (11.8% vs. 4.4%) and depression (15.8% vs 2.3%)¹
 - Increased experiences of bullying, harassment, stigma, and needing to mask autistic traits
- **Autistic people are more likely to experience suicidality**
 - 66% of adults diagnosed with Asperger's Syndrome experienced suicidal ideation²
 - Autistic people are 7.55 times more likely to die from suicide than non-autistic people³
 - 'Elevated autistic traits are significantly over-represented in those who die by suicide'⁴
- **Many autistic people are undiagnosed or have been diagnosed late**
 - Lack of support growing up for differences and so more likely to mask autistic traits⁵
 - Misdiagnosed with other mental health conditions and therefore received incorrect care⁶
 - More likely to be women with an atypical presentation of traits⁷

Autistic people and risk to mental health

Autistic people likely experience and present mental health crises in different ways to non-autistic people, and therefore strategies used to support non-autistic people in crisis may not be effective, or worse, cause more harm:

- More autistic women die by suicide, whilst in the general population more are men₃
- Depression and anxiety aren't necessarily predictors of suicidal behaviours in autistic people – suggesting a different route to suicidality₂
- Masking autistic traits and unmet support needs are significant risk factors for suicidality in autistic people but not in non-autistic people₈

Autistic people in crisis care

- In 2015 autistic people made up 38% of the number in hospital in the UK, in 2022 this had risen to 58%⁹
- Autistic children are 6 times more likely than non-autistic children to be hospitalised in the USA¹⁰
- By 25 years, 22.1% of autistic females and 10.9% of autistic males (compared with fewer than 4% non-autistics) had been hospitalized¹¹
- The average length of stay is around 5 and a half years⁹

Lack of autism awareness contributed to Essex teen's death - inquest

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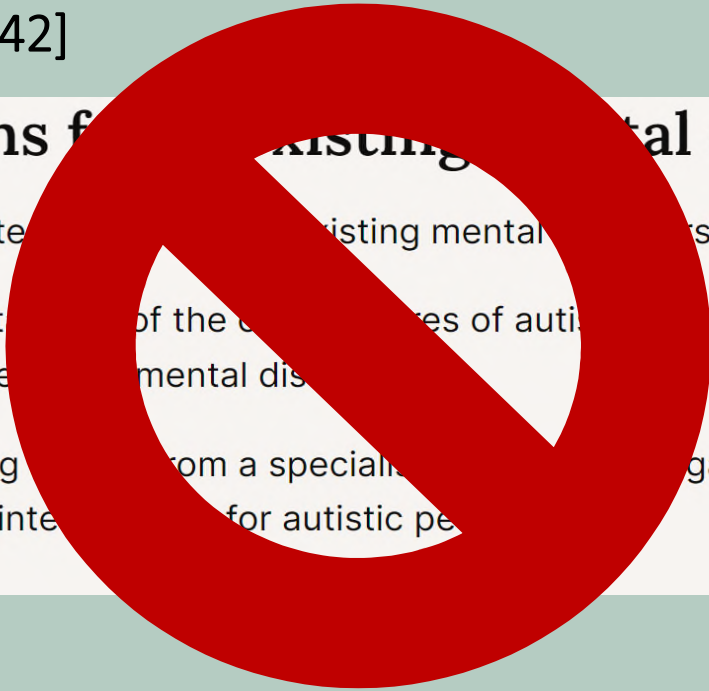
Chris Nota was failed by a "fundamental misunderstanding" of vulnerable people with autism

A lack of awareness about the "increased" risk behaviour in people with autism contributed to the death of a teenager, a coroner has concluded.

Autistic people in crisis care

NICE (2021): Autism spectrum disorder in adults: diagnosis and management.
Clinical guideline [CG142]

1.6 Interventions for existing mental disorders

- 1.6.1 Staff delivering interventions for existing mental disorders to autistic adults should:
- have an understanding of the characteristics of autism and their possible impact on the treatment of coexisting mental disorders
 - consider seeking advice from a specialist regarding delivering and adapting these interventions for autistic people
- 

What needs to change?

1. Prevention of hospitalisation

- Earlier autism diagnoses and more adapted community based mental health support and care, especially for girls.
- Longer term adult mental health support for autistic people, which is adapted to our needs and easier to access.
- Reforming the Mental Health Act so people can't be hospitalised just for being autistic – where hospital is needed this should for a short a time as possible and in an adapted environment to meet specific needs.

2. More 'autism friendly' environments

- Reasonable adjustments need to be made to the hospital environment – Things like bright lights, excessive noise and overwhelming smells need to be reduced to avoid further distress.
- Ensuring autistic patients' routines are not disrupted and reducing unpredictability and change.
- Sensory rooms that are quiet and feel safe and are away from other patients.
- Continuity of staff responsible for care.

3. More 'autism aware' staff

- Training is needed on how to spot a 'meltdown' or 'shut down' and how this differs from a mental health crisis for autistic people – restraint and seclusion should be avoided and staff should be trained in how to deescalate and help autistic patients feel safe again.
- Awareness of the increased risk of suicide in autistic patients and how this may manifest differently.
- Better understanding of communication differences and the difficulties autistic patients may face in explaining their experiences and emotions.

For more information

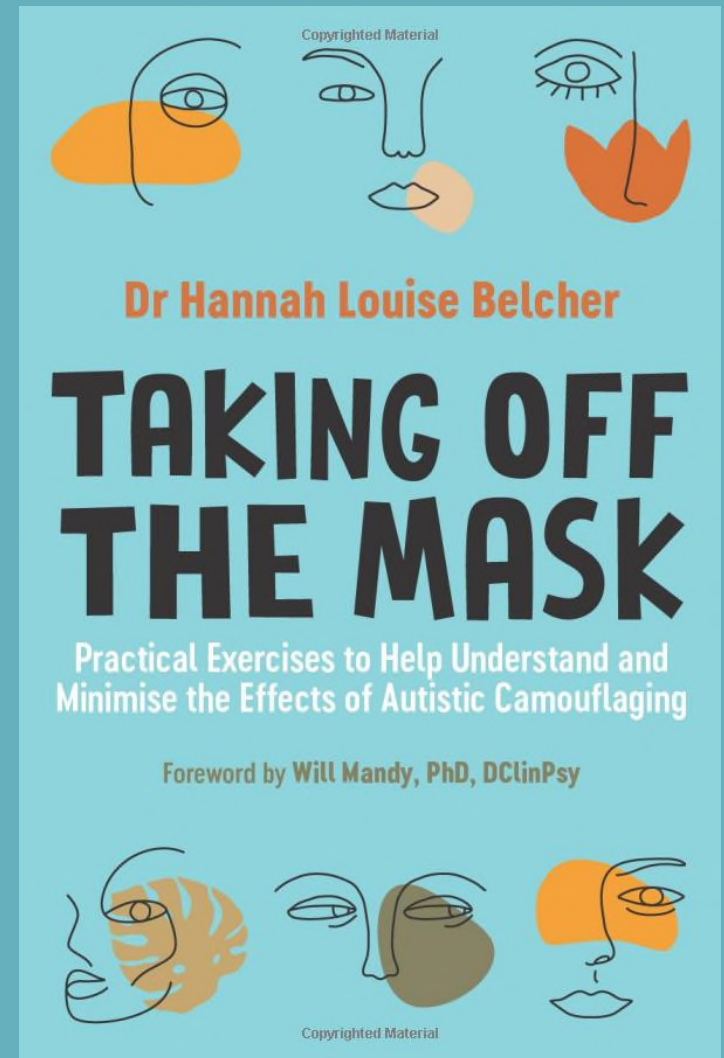
- Hannah L. Belcher. **On Being Autistic and in Mental Health Crisis Care.** Autism in Adulthood. Sep 2022. 179-182. <http://doi.org/10.1089/aut.2022.0044>

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- 'Taking off the Mask: Practical Exercises to Help Understand and Minimise the Effects of Autistic Camouflaging' <https://www.amazon.co.uk/Taking-Off-Mask-Understand-Camouflaging/dp/1787755894>

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