

Less than the sum of the parts

Lived experience of ATUs and mental health in-patient settings in the SELTCP region

Three Cs August 2020

BIG words



A word on words

SELTCP means South East London Transforming Care Partnership

ATU means Assessment and Treatment Unit

Co-production means planning and designing services alongside those who experience them

Lived experience is when somebody has been in a service or has experienced a loved one in a service

System culture is about how people behave in a sector, service or organisation

The Cs in Three Cs stand for control and choice in the community



About Three Cs

Three Cs is a charity supporting people with learning disabilities, autism and/or mental health challenges.

Involving people we support and families is at the heart of our approach.

We are the co-production partner for the South East London Learning Disability and Autism programme.



About the authors

The report was written by Jo Clare, Alison Love and Miren Cerezo

Anna Snowling assisted with the research



Thank you

The authors thank South East London Clinical Commissioning Group for being committed to transforming care and learning from lived experience of ATUs



We also thank everyone who contributed to the research, and the South East London Transforming Care Forum for their feedback.



South East London Clinical Commissioning Group responded to the report.

They said that the views in the report would help inform development and commissioning.



What is the research about?



Three Cs was asked by CCGs in South East London (SELTCP) to interview people about their experience of Assessment and Treatment Units (ATUs)



59 ATUs were asked to take part but none of them responded

11 people with lived experience were involved in interviews and focus groups



8 were family members and 3 were people with autism and/or learning disabilities

9 ATUs and 16 admissions were referred to



Evidence from other public sources was used

The South East London Transforming Care Forum also gave feedback



What were the findings?



System culture and human rights



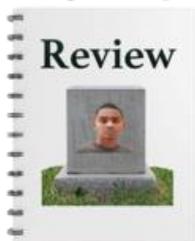
Most ATUs:

- Do not understand autism and cannot communicate with patients
- Cause 'challenging behaviour' and mental illness by their methods
- Do not involve patients and families in decisions
- Deprive children and adults of things in ordinary life that keep us all well
- Fail to assess or treat patients successfully



Most ATUs breached human rights because:

- People felt punished and said ATUs felt like prisons
- Restraint caused injury and threatened life
- There is lack of dignity, privacy or respect for people's things
- Personal care and hygiene of patients was neglected
- Healthcare is poor and risks death or harm from things which can be treated





Battle of the Experts



Most family witnesses said:

- They valued competent doctors and staff
- Successful treatment can be a matter of life or death
- When ATUs respect and involve families as experts treatment is more successful
- When professionals know best, misunderstand patients, exclude families it is least successful
- Families were blamed
- Some were threatened and silenced



There is a hierarchy of experts and those with lived experience are still at the bottom

Hospitals sometimes exclude other professionals too



Crisis: transitions and funding battles



The reason for admission to ATUs is almost always crisis caused by:

- No planning for ordinary life changes or events which cause distress
- Families left to cope without support
- There was no crisis support in the community
- There was nowhere else to go



Funding battles and delays:

- Cause or make crisis worse
- Delay referrals
- Delay discharge



Witnesses also said:

- Families have to fight for funding
- The way funding works is not fit for purpose
- Blanket funding policies are not personalised



Things that worked well were:

- Individuals who did their best to make it work
- Co-operation on joint funding and 50/50 splits



Witnesses and Forum members had good ideas about what would improve crisis response

- A support register of children at risk of crisis
- Crash pads in the community
- Pre-planned crisis responses direct to people's homes
- Police and professionals being aware of adults at risk under Mental Health Act
- ATUs should be last resort and only to (rare) good ATUs

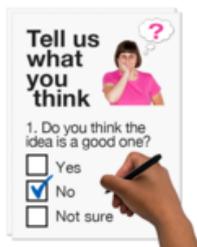


There was lots of evidence that good ordinary lives were possible, including:

- Fun, learning, social life, work
- Personalised and ordinary daily support, not always specialised
- The right school, home, or residential accommodation
- Appropriate Deprivation of Liberty Safeguards (DoLs)
- Deputyship by parents
- Good practice in autism
- Behaviour support plans
- Pro-active support from the MDT i.e. psychology, psychiatry, speech and language therapy



	<p>Navigating the system</p>
	<p>The system is very difficult for people with learning disabilities and/or autism and their families to understand:</p> <ul style="list-style-type: none"> • It is full of laws and rules that people don't know about. • Professionals often disempower families • Families are treated like the enemy • Bad experiences cause trauma to the patient and to their families • Information and guidance is difficult to find if you are not 'in the know'
	<p>What were the conclusions and recommendations?</p>
	<p>There is a whole system problem which is letting people down</p> <p>Only the closure of ATUs will stop abuse of human rights</p> <p>It is the wrong model and the wrong treatment and it does not work</p> <p>Its methods cause 'challenging behaviour', injury, mental illness and threat to life</p>



It is recommended that the South East London Learning Disability and Autism programme:

- Speed up and get people out of hospital
- Make it more difficult to detain people
- Plan ahead for changes in the Mental Health Act
- Treat families as human rights defenders
- Notify families of all incidents of segregation, seclusion and restraint
- End referrals to ATUs outside the region
- Pre-plan transitions like puberty and adulthood to prevent crisis
- Use 'proxy measures' to assess the risk of abuse in ATUs
- Use feedback from people they trust not just NHS and CQC data
- Make a reality of homes not hospitals and increase options
- Fit places to people not people to places
- Support patients and families to know their rights
- Do not refer children or adults to any ATU or hospital with an inadequate rating
- Get people out of all ATUs with a history of inadequate ratings

The report finished with recommendations about co-production.