This is Elliot

By Rebecca Davis – Elliot’s sister
Elliot was sectioned April 2018 due to increase in self injurious and challenging behaviours. He was 23.

No beds locally were available, he was placed on a PICU ward 50 miles away and remained there for 8 weeks until an LD bed was available.

PICU ward is not an ideal environment for patients with Autism or Learning disabilities but its all they had. Seclusion was used majority of the time he was there.

6th June an LD bed was sourced, and he moved. He was agitated for the first few weeks and eventually he began to settle.

Elliot has severe Autism, a learning disability and challenging behaviour. He’s labelled as “complex” by professionals. To family, he’s misunderstood by the systems in place.
**Contributing factors to admission**

| Lack of understanding from education – expelled early on. Schools fighting for funding and resources. |
| Lack of support from Local Authorities |
| Clinical commissioning groups having lack of knowledge and poor communication from Mental Health services for individuals needs. |
| Community mental health teams not having enough time or resources to provide support and prevent hospital admission |
| Not enough housing options for bespoke or supported living or help to stay in familiar settings with families. |
Barriers to discharge

- Psychiatrists insist on a “stable” period to be fit for discharge.
- Restrictive interventions add to patients anxiety and leads to an increase in challenging behaviour which contributes to them being unstable.
- Housing not ready or available for patients to be allowed to discharge.
- Clinical commissioning groups allocate the minimum amount of time for case managers to work on the cases. This also goes for social workers. We’ve had 4 different social workers in 2 years.
- Struggles with funding, rent/housing benefit within the local authorities. For example, they argue over who’s responsibility it falls under.
- Insufficient support in the event of a crisis - when crisis planning, no back up plan is available. For example, if the placement breaks down.
- Lack of expertise across mental health trusts around autism. Specialist autism units have a minimum of 3 years waiting list and there are only a few in the UK.
- No positive risk taking or compromise within ATU settings.
What can we do to improve quality of life for people with Autism and learning disabilities?
Working together

- Clinical Commissioning Groups need to think differently. They need to partner with provider organisations to look at new service specifications that mean when people with LD are in crisis, there is more available to them than just hospital or respite facilities that won't meet their needs. They need to work with housing providers who can source a property that can cater to all needs including challenging behaviour. Having quality providers who can provide support immediately and continued assessments which then commissioners can block funding for hospital beds.

- This would mean the person could stay there until an alternative was ready or they could keep the individual and provide them with a placement internally to their organisation. This prevents the trauma of being far away from home and the lack of understanding on ATU wards.
Lack of crisis support

The problem faced time and time again, is that family members, carers and the patients themselves contact the local crisis team in an emergency situation and there is nothing available. Time is spent finding appropriate accommodation, hospital beds, recruiting more staff into a package or using an agency etc. We need places that are ready at any time.
Listening to individuals and families.

• Mental health services and providers need to make sure staff are curious and compassionate first. Training is great but I think being curious and wanting to listen is the thing that seems to make the difference.

• “Aims” need to be developed together. Families need to be listened to as they have known the person their whole life. This is often ignored and causes extreme distress for the person which could have been avoided.

• Having a focus on the person and what is important to and for them, rather than what services usually do. Flexibility and creativity rather than this is the ‘normal’.
Expertise in learning disabilities and Autism.

Making sure the people presented as ‘experts’ actually know what they are doing and that people who are finding/commissioning services have enough knowledge to understand whether what they are paying for is the right thing, the quality thing. Ask them what their experiences are, what qualifications they have so we know they are good enough to support.
Early intervention

Many parents describe the process after diagnosis as “they are thrown in the deep end”.

Elliot went to a special needs school. Once he reached puberty, Elliot’s behaviours changed. The school expelled him as they expressed they were unable to support him. He wasn’t in education from 2011, he was 16 years old.

In 2012, he got a college placement. He really enjoyed it. The second year, they wouldn’t accept him back as there was no funding and he wasn’t ever going to get a qualification. The college knew this when they first accepted him. This is what education was like however, there has been some progress but these are still some of the issues.

- Early intervention at a young age is key.
- It’s a postcode lottery, if they receive the best support for SEN in mainstream schools.
- There is a huge need for teaching assistants who are specially qualified to support challenging behaviours and learning difficulties in mainstream schools.
- More funding and resources to be available to support the individuals.
What a good life would look like for Elliot

- Discharged from hospital
- A home, with everything he needs and a support team who go the extra mile.
- Family to be involved throughout.
- To feel like he's succeeding.
- To be encouraged and supported to do the things he wants to do, not others.
What needs to work for this to happen?

- Keep pushing discharge and planning.
- Fresh mindset – how can we make this work rather than it's not going to work.
- Giving individuals “hope” that discharge is near.
- Listening to the individuals and families.
- Positive risk taking.
All parts of the system working together helping build a picture of the whole person from all angles.

Creating a life that is quality for each and every individual with Autism, Learning disabilities and challenging behaviours.

#Homesnothospitals