

AT-Autism conference - Autism and Mental Health-Who Cares:

- **Learning from the lived experience of autistic people, families, and frontline professionals**

Jeremy - Bethany's dad.

The father to Bethany, a young autistic woman who spent several years locked in a seclusion cell in a secure hospital.

A former college tutor, I now use Beth's story to inform various parts of "The System" regarding the impact of inappropriate care.

Former Co-chair of NHSE's CAHMS Quality Improvement Taskforce's Parent Council, I currently work on Care Treatment Review panels, and am the parent/carer rep for the HOPES programme's Clinical Reference Group - work aimed at ending long-term seclusion/segregation.

A champion for the parity of the lived experience voice - I despise box-ticking inclusion!

[#ATAmentalhealth.](#)

“With all due respect Mr Harris.....”

- The impact of not equally valuing the family or carer voice

#ATAmentalhealth.

“with all due respect.”

- Used as a polite or formal way of saying that you disagree with someone.
- ‘due respect’ – an acknowledgement of the reverence that the person deserves.

Our journey

#ATAmentalhealth.





#ATAmentalhealth.

The System's approach

1. Blame the parents!
2. Remove from the home & place in appropriate settings.
3. Threaten parents with a CARE ORDER if they disagreed or didn't comply.
4. Blame Beth when placements inevitably broke down.

#ATAmentalhealth.

The placements – 19 in 6 years – not one truly ASD specific (all claimed to be!)

- Pheasey Park Farm School
- Phoenix EBD School *
- Jane Lane School
- Alpha Hospital – Bury (PICU)
- High Grange School – Derby *
- Huntercoombe Hospital - Stafford
- Kingfisher Residential
- 2 x “Bespoke” Placements
- Laurel Farm - Redditch
- Ashton Old Road – Manchester
- Penn Road - Wolverhampton
- The Flat - Dudley
- Butterflies Respite Centre
- Mountwood Academy – Preston
- Ty Coryton - Cardiff
- St Andrews Hospital – Northampton
- Huntercombe Staffordshire 2nd time!
- Llanarth Court – Raglan/Abergavenny

Demand Avoidant Profile – our lightbulb moment.

- 1 Obsessively resists and avoids ordinary demands and requests.
- 2 Complains about illness or physical incapacity when avoiding a request or demand.
- 3 Is driven by the need to be in charge.
- 4 Finds everyday pressures (e.g. having to go on a school trip/ visit dentist) intolerably stressful.
- 5 Tells other children how they should behave, but does not feel these rules apply to him/herself.
- 6 Mimics adult mannerisms and styles (e.g. uses phrases adopted from teacher/parent to tell other children off).
- 7 Has difficulty complying with demands unless they are carefully presented.
- 8 Takes on roles or characters (from TV/real life) and 'acts them out'.
- 9 Shows little shame or embarrassment (e.g. might throw a tantrum in public and not be embarrassed).
- 10 Invents fantasy worlds or games and acts them out.
- 11 Good at getting round others and making them do as s/he wants.
- 12 Seems unaware of the differences between him/herself and authority figures (e.g. parents, teachers, police).
- 13 If pressurised to do something, s/he may have a 'meltdown' (e.g. scream, tantrum, hit or kick).
- 14 Likes to be told s/he has done a good job.
- 15 Mood changes very rapidly (e.g. switches from affectionate to angry in an instant).
- 16 Knows what to do or say to upset specific people



#ATAmentalhealth.

Nobody listened

- Accusations of Munchausen by Proxy.
- Mum labelled as “seeking to justify behaviours”.
- Parents excluded from all “professionals meetings” as we were constantly asking for Demand Avoidance to be considered.
- Local Authority now in a vicious circle of placement collapse, followed by hastily arranged new provision, followed by another collapse.
- They continued to enforce boundaries, timetables and routines. They saw these as the ‘treatment’ of autism.

#ATAmentalhealth.





RE: Beth H.

Sent: 17 August 2018 13:34

To:

Cc:

<J

Subject: Re: Beth H.

CAUTION: This email originated from outside of the council. Do not click links or open attachments unless you are sure the content is safe.

Hi.

I understand that Beth has pushed the entire refill insert of a ball point pen into her right arm? Apparently it is still there buried in her arm?

This happened on weds but nobody from St Andrew's contacted either Julie nor myself.

I only found out when I visited her yesterday evening. This was very upsetting.

The staff member looking after Beth could not give me any information at all.

Please could you tell me what is being done about this?

Jez

Get [Outlook for Android](#)

#ATAmentalhealth.

The inpatient units

Health Care Assistants with no autism training..... Just security guards.

No staff knowledge or understanding of Demand Avoidance.

Incredibly noisy environments not designed to avoid sensory overload.

Boundaries and Demands to behave. Behaviour Modification

Complete ban on Beths self-soothing tools – Ipads/Ipods, CD's – even cuddly toys

A warehouse for Local Authority 'Problems'

#ATAmentalhealth.

We were not involved in care planning.

We were not listened to.

“with all due respect Mr Harris....we are the experts – we know what needs to be done.”

#ATAmentalhealth.

The Horrors

- Restraint - longest recorded was for 236 minutes.
- Assaulted 3 times by staff
- Routinely stripped naked by groups of men
- 19 Police Officers responded to an incident - they used pepper spray, handcuffs and leg straps.
- Kept In seclusion (solitary confinement) for over 3 years.



#ATAmentalhealth.



#ATAmentalhealth.



- The Legislation that should have shielded Beth
- Human Rights Act
- Children and Families Act
- Mental Health Act
- Autism Act
- Care Act
- Equality Act
- Seni's Law

#ATAmentalhealth.

→ [Coronavirus \(COVID-19\)](#) | Guidance and support

[Home](#) > [Health and social care](#) > [Public health](#) > [Mental health](#)

Independent report

Serious incident investigation report excerpt: Secretary of State case review into Beth

An excerpt from a report looking at the care and management of Bethany, a Looked After Child (LAC).

Parents as Partners

- “Beth’s parents were never seen as partners in the care of their daughter and over time have moved to a combative position as a consequence of lack of involvement, acknowledgement and voice”

Parents as partners

There are reports from parents of an absence of meaningful involvement in decisions relating to the care and management of their children. Development of a parental rights-based approach is needed to ensure that wherever possible no decision about their child without their involvement or the involvement of the young person is made. This should be enhanced with the introduction of a programme of parental peer support for hospital admissions. Introduction of patient ambassadors for each region will develop networks to facilitate support and advice for parents with children entering inpatient care.

And now?

- As a direct result of the media coverage Beth was moved to a bespoke setting in Lancashire – part of Merseycare NHS Trust.
- A No Force First approach – staff trained in de-escalation not restraint
- The HOPES model – looking at the barriers in the system to providing the right support.
- Family as equal partners in care. (Beth chooses what I get to know!)

And now - continued

- All staff are fully trained in autism.
- The environment is right for Beth – reviewed by Anne Memmott
- Demand Avoidance is the main formulation used to underpin all support for Beth.
- All new staff have training from me.



It was all avoidable.

- The system just needed to value my voice equally

- When it comes to our children, we, the parents, are the experts.
- We are the ones who don't need to search through reports. We hold the information in our hearts and in our heads.
- We are the database of the omissions and inaccuracies, and the positives
- We are the lifelong witnesses to what works and what doesn't.

- “With all due respect Mr Harris” damaged my daughter for ever.