

Beth

Beth's Dad Jeremy tells the devastating and disturbing story (trigger warning: this case study includes details of self-harm, restraint and abuse) of how Beth was 'failed by the system'.

Jeremy covers Beth's early years, her 19 placements in 6 years, her first section aged 11 and her fateful move to an ATU. Despite PDA being recognised relatively early in the process, none of her care was PDA-informed, leaving Beth's anxiety and distressed behaviours to escalate and escalate over many years. Jeremy embarked on a high-profile media campaign, but despite this and the high-level meetings and reviews that ensued, her situation worsened. Eventually a review involving an autistic advocate led to a happy ending, with Beth finally being well-supported in a bespoke community placement.

Beth was a much-wanted and much-loved daughter, the first girl in the family for many years. As a baby, however, she was hard to settle, slept little and wanted to feed constantly. The social and sensory demands of toddler group proved tricky for Beth, and we felt like 'meerkat' parents constantly on edge, looking out for potential triggers.

As soon as she started at nursery school, her behaviours escalated considerably – she was very controlling towards other children, physically aggressive at times, didn't like timetables or transitions and really didn't understand why the teachers were in charge. And so started a series of exclusions, starting at nursery and ending in a permanent exclusion from infant school a short time later.

Despite our older son not presenting with any difficulties at all, social services blamed our parenting, sent us on multiple parenting courses and placed Beth in an EBD (education and behavioural difficulties) school. Here she mixed with children who had sadly suffered all sorts of abuse and trauma, and being a natural mimic Beth acquired a new toolbox of undesirable learned behaviours.

The one positive was that Beth's autism was first identified at this school. But like so many parents, we found that there was no post-diagnostic support and we were just left to try and muddle our way through. We tried all the recommended approaches we could find on the internet, though nothing seemed to work and in fact seemed to make everything harder.

A member of staff at the school knew about PDA and suggested that it should be included on Beth's EHCP – this could have been a game-changing moment but sadly the powers that be were too blinkered, they said PDA wasn't 'in the manuals' and stuck with 'standard' autism approaches. At home, however, we fully took PDA on board and the difference in Beth once we changed our approach was dramatic.

Sadly, the opposite was true outside the home.

Beth went through a series of 19 placements in 6 years. None of these placements acknowledged or adopted strategies to support her demand avoidance. Beth was 'tormented' with boundaries, timetables and expectations to behave and act in the way 'neurotypical' people did – everyone kept trying to bash poor Beth's square peg into their round holes. Beth felt rejected and angry, and reacted in the only way her brain allowed her to, by becoming extremely anxious. And when Beth is anxious that is displayed in incredibly distressed behaviour.

Many of these placements were set up in a rush, with no proper planning or transitions. Some lasted just a few days. The one that lasted longest (18 months) was a special school where one member of staff was familiar with PDA. She supported Beth well and trained all the rest of the team working with her. Sadly she moved on and very shortly afterwards the placement broke down, prompting highly escalated behaviours that resulted in Beth being sectioned for the first time at just 11 years old.

Because of the lack of understanding and support, Beth was permanently in a highly aroused, distressed state and constantly sought ways to escape the anxiety-provoking settings she was in. She learned that some behaviours resulted in the police being called: she would be taken away to a quiet, calm police station, be given a hot chocolate and a caution (her PDA meant she could 'role play' the appropriate response to hide her lack of ability to properly process this) and be taken home by her parents. This became a predictable pattern that met her needs, so Beth would do this regularly.

Our greatest fear was that this would ultimately lead to a life behind bars. So, when a team of professionals, who we trusted 'knew best' and had Beth's best interests at heart, suggested that a short term admission to an ATU (assessment and treatment unit) would provide a calm, safe, therapeutic environment where her vast array of medication could be assessed and she would be cared for by an expert team, we sadly agreed. She was admitted at 15, and we were told that she and we were incredibly lucky to secure this placement.

Little did we know.

What follows has been widely documented in the media – you may like to have a look on my Twitter feed [here](#).

Beth was on a ward with ten other distressed young people in an environment that could best be described as **sensory hell**: bright fluorescent lighting, alarms, staff radios, shouting, banging doors, rattling keys, screaming ... Here she witnessed self-harm and learned how to ligature. All this overloaded poor Beth and unsurprisingly her behaviours escalated.

This was dealt with by placing Beth into 'seclusion': a room designed for short-term containment, 10 foot by 8 foot, with nothing but a mattress on the floor; a cell with one small, opaque high-up window where she was fed through a hatch and watched whilst on the toilet or washing; a place where Beth displayed her newly learned skills of self-harm, using her underwear as neck ligatures and inserting a biro into her arm. Groups of staff, up to 8-10 at a time, would burst into her room, alarms going off. They would restrain Beth, place her on the floor, remove her clothing leaving her naked, injected with sedatives until, exhausted, she'd fall asleep.

Far from being a therapeutic environment, the ATU triggered extreme distress and Beth's 'treatment' equated to abuse. And yet, shockingly, there was no incentive for anyone to try and move Beth to a more suitable community setting. Whilst in the ATU, the local authority weren't financially responsible, the NHS was. And the ATU was privately-run, so they were happy to keep their 'cash cow'.

Horrified by how Beth was being treated, I turned to the media, and was interviewed on a Radio Four programme about the failure of the government's 'Transforming Care' policy. I discovered to my further horror that Beth's experience was far from unique and many other autistic young people and adults were being similarly harmed by the 'care' system.

The media coverage led to a whole host of high level meetings with the Health Secretary, MPs, the Children's Commissioner, the Care Quality Commission, the Joint Select Committee for Human Rights, the Equality and Human Rights Commission together with a full thematic review into the use of seclusion and restraint in in-patient settings and an NHS England serious case review into Beth's case from first contact with services to the current day (which concluded she had been 'failed by the system').

And yet, all this didn't bring any benefit or change for Beth for a long time to come.

The first 'next step' was a very rushed community placement, which was sprung on Beth with no notice and no prior planning. Beth was extremely institutionalised after 2 years in the ATU and was completely overloaded by this abrupt change. It lasted 3 days. She was moved to an adolescent psychiatric intensive care unit and was once again heavily medicated. However, the psychiatrist here did start to work with Beth in more positive ways, involving us as a family more. But then she turned 18, and so had to leave this unit.

Again, a rushed transition ensued, this time to a 'medium secure unit' with no understanding of autism and even more restrictive practices than in the ATU, where Beth was treated like a kind of rabid animal and was re-assessed, incorrectly, as having a personality disorder with the only approach being medication-based. Predictably, Beth's distress escalated, the unit wasn't able to cope with the resulting behaviours and the responsible clinician recommended that Beth be moved to a high secure unit (usually reserved for dangerous criminals!).

Fortunately, this triggered a care treatment review by an independent panel. We managed to have an autistic advocate included on this panel, and their insights (relating to Beth's sensory experience, her demand avoidance and her crippling anxiety) and input (including the fact that there was a potential breach of Beth's human rights and that they feared for her life) finally made people sit up and listen and bring about long-awaited change.

As a result, Beth was moved to her current placement – a calm, bespoke environment with highly trained staff and a responsible clinician with expertise in PDA and low arousal approaches. Everything is focused on keeping Beth's background anxiety as low as possible.

She now lives in an open-plan flat, carefully designed to reduce sensory overload and which Beth had a hand in decorating. She has her own pets and enjoys gardening, fishing and walks in the countryside. She can do all the things you'd expect a 20 year old to do. She has her hair dyed, cut and styled how she wants it. She can experiment with clothes, she's mad on shopping. We're closely involved, not only in seeing Beth regularly and having normal family outings, but in training the team around her about her and her PDA.

Beth uses drama as a way of controlling her anxiety – she'll assign roles, create the script, direct people's behaviours, there's a lot of fantasy involved ... but it's something that works, and that's the only thing that matters in the environment, because what works reduces anxiety, what works reduces the triggers and thus challenging behaviours. The team around Beth uses these role play opportunities to model behaviours that Beth can observe, respond to and develop, and being a social mimic as she is, she goes on to mimic those behaviours and thus learn new skills.

Beth is off all the horrific medications she was on – there are no anti-psychotics, there are no sedatives, there are no mood stabilisers, there is just Beth.

Beth said to me that the thing that changed everything for her was that professionals stopped trying to drag her into their world and instead they came into her world and finally got to meet, understand and support the real Beth.

What a transformation. This photo says it all.

