

A family carer's story

Rosemary's Lived Experience of Statutory Advocacy

I am the proud Mum of a fine young man called James who is 28 years old. He has severe autism, a learning disability and other complex needs which means he can, when distressed display behaviours that can most definitely be described as challenging. I have fought his corner for decades to do whatever I could to make his quality of life better and asking me not to do this would be like asking me not to breathe.

James received zero transition planning from children to adult services and a total lack of adequate support resulted in him being sectioned under the Mental Health Act and placed in a local Assessment and Treatment Unit. The premise originally was for it to be a 28 day assessment of need to set him up for his adult life. That 28 day assessment turned into 5 ½ terrible years.

My first experience of statutory advocacy happened when James was injured during a floor restraint. James had never experienced restraint and punitive regimes in his life. In fact I recall having to ask what the term "restraint" meant, it was totally alien to me. Needless to say I quickly learnt as my son went on to be restrained on an almost daily basis. These prone restraints would last hours and after one such episode my son's front two teeth were broken. He hadn't even had a filling up to that point in his life. After this episode there was the first of a great many safeguarding referrals and an advocate/IMHA got involved.

The IMHA was funded by the placing authority and represented the majority of patients on the ward. She set up a meeting with my son's legal representative and invited me along. I arrived and met the solicitor but was asked to leave the meeting before my son came in. The reason I was given for this was my son was 18 now and had his own right to represent himself. I protested that due to his complex needs he wouldn't be able to express himself and would get very distressed, but I was quoted policy again and James was brought into the meeting with 2 bank workers, the advocate and the solicitor who he hadn't met before. None of them had any understanding of his communication difficulties.

A Serious Case Review was later published into my son's abusive care which revealed a staggering number of safeguarding referrals in that hospital alone. Some I had been told about, some I had not. None of these ever resulted in a positive outcome for James. It was my experience that as long as policy and procedures were followed that was all anyone cared about.

I found it completely overwhelming to attend a meeting with a large group of professionals all with impressive titles sometimes 13 or 14 people and just me, I rarely was ever called by my name simply referred to as "Mum". I am a gentle non-confrontational person by nature, but I was regarded as difficult and demanding because I couldn't sit quietly and watch them destroy my son.

At 19 years my son was sent to a Castlebeck Hospital 100 miles from home. It was supposed to be an autism specific service. I enquired before he went about advocacy and this time it was funded by the provider so hardly "independent". This advocate represented every patient at the hospital, and she told me she had very little to do with families as it was an "adult service". This advocate did not warn me when I spoke to her about the serious safeguarding enquiry that was on-going at this service that had stopped admissions, that was only revealed to me years later via the Serious Case Review.

I decided that because this was after Winterbourne View to employ a local independent social worker to be the advocate for James and the family. He successfully visited James every fortnight and he built up a rapport with him and was welcomed but suddenly after 6 months he was "banned". A week previously he had made a safeguarding referral to the placing authority about lengthy floor restraints. This ban from the hospital came under the pretense that this man couldn't advocate for James and the family despite there being no conflict and that he lacked capacity to consent to this man visiting. This hospital later got my son arrested and on the same day removed his autism diagnosis and told police he was "culpable and needed to be dealt with".

Whilst all this turmoil was happening I became an Expert by Experience for the CBF when they were responsible for recruiting and training family carers to participate in CQC Inspections. The knowledge and contacts I gained from that role changed the dynamics completely. My instincts were right..... There was another way other than over medication, restraints and seclusion.....I learned about Person Centred Plans, Positive Behaviour Support and Trauma Informed Care and what should be happening for my son and those like him.

James was then sent to a third hospital where thankfully they knew how to support his complex needs. They worked closely with us - his family - and other external organisations. The advocate in this hospital simply told the Ward Manager that he couldn't represent James as James couldn't give him his instructions. He recommended an IMCA for James, but she wouldn't get involved as James had a parent who was willing to speak up for him.

I applied to be James's Health and Welfare Deputy and eventually after appointing a Solicitor and Barrister at the cost of £5,000 I won on appeal at the Court of Protection in London. Every professional attached to James's case supported my application and I now could no longer be excluded as I had a legal right to speak up for my son.

This brought about positive, genuine, partnership working and discharge planning between NHS England, every professional, family, friends, a housing association, solicitors and it included involving a local self-advocacy group being commissioned to facilitate a Person-Centred Plan. All of this happily resulted in my son now living for 5 years in his own self named "magic" house with zero restraints or restrictive practices. He says he is "as free as a bird"!!

At the end of James's 5 1\2 years of detention I too had gained several more titles, "Expert by Experience", "Human Rights & Disability Campaigner", "Keynote Speaker", "Health & Welfare Deputy", "Property & Finance Deputy", "Nearest Relative", and "Litigation Friend" but I believe it should not have been THAT difficult. It would have made such a profound difference to be respected for the most impressive title of all.....

"James's Mum"