

Case Study

Trapped

The story of a family that lived at home for 3 years.

An Independent Complaints Advocates reflections authorised by their complaint partner. This has been written to share the complex nature of the processes that have ultimately left the complainant with some reassurance about the potential learning.



Flamingo family story

In October 2018, the Flamingo family were out shopping, when Damian, who had been diagnosed with autism spectrum disorder (ASD) 10 years previously, had an autistic meltdown. The police were called, and he lashed out, they pinned him to the floor, and he was arrested. Taken to the police station aged sixteen, he felt scared, confused and away from the safety of his family. He was left in a cell for a few hours and then released.

To this day this event has had a profound effect on his mental health and the Flamingo family.

As a result, Damian's attachments issues intensified, he would not let his mother out of his sight, he would not leave the family home and even slept next to his parents.

The family needed support and Aspens and their intensive planning team, started working with Damian, however this was only one hour, once a week.

Damian's mum described in a statement the feeling of being trapped in her own home, she could not leave the room without Damian following her, and Damian would self-harm to show her how bad he felt about himself; this was in the form of head banging objects closest to him.

October 2019, Damian was seen by Children Adolescent Mental Health Services (CAMHS), and he was diagnosed with Post Traumatic Stress Disorder (PTSD), and needed trauma counselling but as Damian was nearly 18 years old, he needed to be transferred to adult treatment services (ATS), and this is when normal life for the family declined further. ATS rejected the referral, and the family were signposted to Mind, Time to Talk, Lifelong Services, but nobody would help due to Damian's autism and PTSD. Damian would not leave the side of his mum; she could not even go to the bathroom without him sitting on the floor by the door. The GP submitted numerous referrals to ATS, but each one was rejected.

Finally in July 2020, Damian was assessed by ATS, they suggested medication, but the diagnosis of PTSD and the offer of trauma counselling were both removed. Months of chasing resulted in a letter saying Damian had been discharged from the service and the only suggestion was for the GP to send in a new referral. In December 2020, Damian started taking medication, this helped, but Damian still was very scared to leave the house. The family were supported by Lifelong Services and again the GP wrote to ATS in December 2020 asking for support. In March 2021, Damian started working with Venture People, they were trying to get him outside, the family social worker suggested an NHS complaint, and a new referral from the GP.

On 27th April 2021, ATS wrote to the family and confirmed the diagnosis of PTSD was excluded and they considered pharmacological and psychological intervention for Damian's condition and discharged him again.



Damian's sister needed her immunisations, and Mum could not take her to the GP surgery on her own, so instead they all went to the surgery, including the support worker. Damian had a meltdown outside and as a result, Marie stripped her daughter to her nappy, whilst the two nurses gave her the immunisations in the car park. The health visitor had to make home visits to the family, Marie's daughter did not even know what a play park was, as they never really went outside, she never socialised with other people. Marie then fell pregnant and was unable to attend midwife appointments, so they came to the house:

"It was a nightmare trying to get to the hospital for my scans, I had to have a home birth, and it was agreed with the neighbours that when I went into labour, Damian would cut the grass to distract him. I went into labour at 1am.

Moving forward, my oldest daughter needed to start pre-school, she had never been away from me, as we were trapped at home.

I would have to run up the road with her to drop her off at pre-school, all the time Damian would stand at the front door watching me, she struggled to settle in, as she had not really socialised with other children."

After contacting her local Independent Health Complaints Advocacy Service (IHCAS) team and working with her advocate, the formal complaint was submitted in August 2021. When the response was received, it was not satisfactory to the family, there was still no support for Damian. A local resolution meeting was arranged but it had to be online at lunchtime. It was planned this way so Marie would sit the two girls away from the camera as they were not used to seeing strangers faces and, she would feed them and talk at the same time. Having a meeting like this was also extremely challenging for Damian, being autistic and speaking online.

The meeting happened in May 2022. The staff from the mental health trust were surprised to see the family and how they were living, trapped for over 3 years, and there was an apology and an offer of a home visit to assess Damian's needs. Damian had an assessment in September 2022, and started Eye Movement Desensitization and Reprocessing (EMDR) treatment, however, he has still not been formally diagnosed with PTSD, but he has been told that he would not have received all the treatment if he did not have PTSD, it is just the staff working with Damian were not qualified to diagnose. After a year of trying to get all the action points completed, including the stand-alone apology letter that had been promised, the Trust wrote to the family in July 2023 and closed the complaint at the local level.

The complaint was then submitted to the Parliamentary Health Service ombudsman (PHSO) in August 2023, and when the case worker was allocated after 7 months the PHSO decided to time out the complaint as the family had received an apology and Damian had started treatment.

Damian is now being support by Barnardo's children charity, they have teamed up with community retailer Co-op in an ambitious partnership to support 750,000 young people, after research found just 62% of young people feel positive about their future. Damian has even joined an online support group for young people, which has helped him to socialise outside of his family. The family recently made a trip to Disneyland in Paris which was a huge step forward for the whole family.



Feedback from advocate

It has been a pleasure to advocate for this wonderful family since April 2021, it has been a lengthy process, that finally resulted in Damian getting the support that he so desperately needed. The family have finally been able to leave their home, and I wish them all the best moving forward.



Feedback from Flamingo family

We were very unsure about making a complaint against the NHS as they have a huge, important job to do, that they usually do so well. Sadly, in this case, they failed us, which then affected our family.

We were put in touch with an amazing advocate who helped us through the complaint journey. She kept us updated and informed throughout the whole process.

She was easy to talk to and never made us feel that we could not talk to her or ask her about anything that we did not understand or needed clarifying.

We would like to say a huge thank you to our advocate, she has been so helpful, kind, and caring.