

Family statement for Sam's SAR February 2022

The report reflects the events that happened well, and I think we can all agree that Sam's story reads so very sad. The report has taken a long time to get to this stage and I am grateful for all the hard work and effort from everyone involved, especially Kate.

The SAR has brought back a lot of memories, happy and sad and in a way a comfort as Sam's purpose is still lit up, he is not here, and he is still creating a lot of work! When I read the report and I have read it many, many times I can hear him, statements that he would make, sharing his frustrations or looking up who is in charge so he could make a complaint. I have a collection of those type of responses in his files. There were also so many kind and funny things about Sam, he could really make you laugh out loud and could be hugely protective of those he cared for and loved.

There are a few points that I want to take from the report and bring to your attention: -

Sam had many interests, first aid, all emergency services, volunteering to help the disabled, cycling, and DIY but these were not areas focussed upon when offering support, there should be more focus on what makes those like Sam feel valued rather than focussing on what is wrong with them, other activities should be considered when support or intervention is being planned.

Sam's diagnosis of Autism and Asperger's has been disregarded throughout, the diagnosis given by two consultants, working for a trust and whose reports, and diagnosis would have informed many choices around school and residential placements, family support and care plans for many patients has not been valued. Their joint diagnosis was 'unequivocally autism' which has been ignored. Understanding Sam was about understanding his Autism.

There was other diagnosis of sensory integration dysfunction, PTSD, extreme anxiety, low mood, depression – none of which factored in his care plans as a young adult when considering treatment, support, and safeguarding Sam.

I believe the most significant and profound paragraph of the whole report is, 'All organisations who have contributed to this review noted the absence of coordination, of leadership or ownership in Sam's case. This appears compounded by some misunderstanding of others' roles and responsibility, particularly in terms of which teams and organisations are invited to multiagency discussions, and by an absence of escalation when organisations do not undertake crucial actions. The identification and mitigation of risk was particularly impacted by the lack of a lead agency or collaborative working and risk sharing between organisations.' (page 26 section 6.6. 21)

In short, my son was neglected.

The report refers to the importance of person-centred planning, a holistic plan takes time, and they must be informed by that person (page 30, learning point 1), I would also like this to include parent's, carers, families input also, with the person's permission.

We need to understand trauma (page 32 Learning point 6), trauma changed Sam, the nightmares, the demons, the voices, the abuse, the anger and neglect all stem from Adverse childhood experience, (ACES) to make a difference can we make this training mandatory, in all the professions responsible for caring and safeguarding, really get to know the person you are supporting and what makes them 'them'.

Sam's voice was lost in all of this, he was not being listened to or heard. 'With the exception of the plan formulated by Sam and his GP, plans did not involve Sam or his family and may have appeared unfair and incomprehensible to them' (page 35) Learning point 12) The plans did appear unfair and incomprehensible, Sam stated on several occasions that he could not understand the actions of the mental health teams, and the absence of an agreed multi-agency plan meant that other organisations did not understand what other organisations were doing or the rationale for decisions or actions either.

The advocate appointed, Katherine, has been superb and captured Sam just right (Page 10 6.1). The advocate reflects well on his desperate behaviours. Of the eight points listed the ones that would have been most important to Sam would have been – to be seen positively even in the worse moments and to feel safe in his home environment. Sam deteriorated before my eyes, he was getting really quite poorly, and I could not get help, some days were just so desperate. I made Sam a promise in his eulogy – I have had the best and worst times with Sam, the worst being when you cannot make things better or take the pain away for them but one thing I can do and will do, will be to continue to advocate for him, be his voice and hopefully make a difference. I hope and pray that the learning points identified in Sam's SAR will make that difference.

There were so many missed opportunities to put the best support and care around Sam, if only he had not kept falling between the gaps in the services! If only professionals and teams had been on the same page, if only there had been multi-agency meetings when needed. If is such a big word!

S117 did not happened for Sam on more than one occasion, this was a statutory right, how was this able to happen? There is well-documented evidence around the lack of S117 care plans being put in place either in a timely manner or at all, even following other SAR recommendations prior to and after Sam's death. How can we stop this?

If Sam and others had their S117 entitlement the landscape may look very different for them as there would have been an action plan, assigned responsibilities and ownership, a focus on the right accommodation for them, Sam never felt safe in his home.

Instead, the situation spiralled out of control very quickly. I do understand that budgets, resources, and staffing are huge issues for Local Authorities and Clinical Commissioning Groups, but if the model is not working or achievable, then raise it and put pressure on those responsible for a review of S117 process and how it is implemented or not. To me this is a critical action and reflected in Learning Point 3 on page 31.

An example of where things can go wrong is in respect of MAPPA, their input and findings are missing from Sam's SAR. However, I am aware that there is now a separate review of lessons to be learned regarding the MAPPA arrangements concerning Sam and risk management plans made by the organisations working with him, sharing their findings with other organisations would be helpful. I would like to know did those risk management meetings happen, if not why, if they did, what were the actions and the impact?

Is there a robust audit process? Do all procedures get tested to identify the gaps or failings, audit, test and audit again to make sure the processes and procedures work and have an impact that brings improvements to the services.

I see this report as the last chance to do the right thing, Sam did not receive the care due in a statutory, mandatory or legal capacity, he was failed and neglected. I would like for Sam's SAR to be recognised as a mandatory SAR, not discretionary, this matters a lot to me. I have written to the Chair of the Board on this subject, along with a request to see the MAPPA report, be kept updated with the progress of the learning points and action plan, that will eventually be created after a lot of work has taken place. I will also request an explanation as to why S117 is continually not actioned or recognised as required.

My Son died by suicide; he became so desperate, he could not see his life improving, he was scared all the time and could not get help, he felt himself becoming more unwell and dissociated from the world, therefore he chose to do the bravest thing and made the biggest decision of his life, that's it, no more, no more pain, no more fighting and I respect him so much.

Finally, for those who were kind to Sam and I, thank you.