

Statement on behalf of Sasha's family

1. We have been invited to respond to the draft Hampshire Safeguarding Adults Board report. The report is lengthy and, while we agree with some of its findings, we strongly disagree with others. In preparing this response we have not addressed every point of disagreement or factual inaccuracy. Instead, we focus on certain key issues below.

Events immediately prior to Sasha's death

2. The events on the day of Sasha's death are not the central focus of the report and have been examined in other forums including at Sasha's inquest. We therefore do not address them at length here, except to make the following points regarding factual inaccuracies and omissions at paragraph 5.15:
 - a) It was common ground between the parties at Sasha's inquest that when Sasha attended our local hospital on 31 March 2017 she did not ask to see a particular member of staff; rather she simply asked to be attended by the psychiatric team. Her request was refused.
 - b) The extent and effect of the confusion surrounding Sasha's crisis plan at the time of her death is not acknowledged in the report. The evidence at Sasha's inquest was that, at a Multi-Disciplinary Team Meeting on 28 March 2017 at which crisis planning was discussed, Sasha and her family were led to believe that the PLS remained an available source of crisis support. The Coroner ruled that there was evidence upon which a jury could properly find a failure in care planning which resulted in the PLS reaching a decision not to see Sasha on 31 March 2017 which was inconsistent with the care/crisis plan in place at the relevant time.
 - c) It is incorrect to say that the decision not to telephone the police when Sasha absconded from another local hospital was in accordance with the inter-agency care plan. Again, it was common ground at Sasha's inquest that police should have been called when Sasha absconded from the hospital (she was by that stage believed to have taken an overdose).

Diagnosis EUPD

3. We strongly disagree with the assertion at paragraph 6.14 that Sasha had a confirmed diagnosis of Emotionally Unstable Personality Disorder ('EUPD'). It is well known that we as a family do not believe that Sasha had EUPD; however, neither was it the view of professionals that Sasha had a full diagnosis. Sasha's consultant psychiatrist in the community, gave evidence at Sasha's inquest that he considered Sasha had "traits" of EUPD rather than a full diagnosis. The expert evidence was that "I do not think that she fulfilled the diagnostic criteria for EUPD but it is likely she had some traits of EUPD". The expert warned in her evidence about the risks associated with a lack of clarity around diagnosis and of misrepresenting or misrecording a diagnosis of "traits" as a full diagnosis, such that this became "the new truth".

4. We felt that professionals could not see past the perceived EUPD diagnosis, and did not question the presumed narrative or “new truth”, even when their instincts told them otherwise. Sometimes we felt staff members did not feel brave enough to stand up to more authoritative figures on this issue.
5. We believe that the perception that Sasha had EUPD and a resulting tendency to see her as “attention seeking” affected tremendously the way she was treated by services. Sasha’s sense, and ours, was that there was an unyielding focus on a “boundaried” approach that was just not right for her and did not help her condition to improve. For instance, the emphasis on police using their powers of arrest, rather than their Section 136 powers, when in contact with Sasha (a change that was introduced without consultation with her) was a source of great distress and we believe demonstrates a real lack of understanding of the mental health challenges she faced, complicated by her autism.
6. Professionals often described Sasha as someone who “picked which service” she used, or “attempted to evade” some services in order to attract attention or cause disruption. Having lived with Sasha through the period we know that this simply was not the case. The hospital or service Sasha attended was influenced by a range of factors including the restrictions arising from her OCD, what I, her mother was able to facilitate and what mental health services required of her.
7. Sadly, we as a family found that our attempts to challenge the presumption that Sasha had EUPD and, importantly, the way the perceived diagnosis affected how services treated Sasha were simply dismissed or misconstrued.

OCD

8. Paragraph 6.14 states that Sasha disagreed with the diagnoses of OCD and PTSD. This is not correct; Sasha accepted these diagnoses.
9. Sasha’s OCD was complex; it affected all aspects of her life and became debilitating. Unfortunately we felt there was a reluctance by Sasha’s CMHRS to recognise that perhaps they did not have the expertise to deal with the condition. Indeed, we were bemused and despairing at the suggestion by some professionals that Sasha changed her OCD rituals at will, to suit her convenience. To us, this suggested a profound lack of understanding about OCD and the way it morphs.
10. When, in an effort to access support, we sought advice privately we found the community mental health recovery services team very reluctant to accept any opinions or recommendations from OCD experts. Indeed, our desperate attempts to get Sasha the expert help she needed appear to have often been regarded as our being ‘difficult’ or interfering.

11. We welcome the acknowledgment at paragraph 6.19 that an earlier Autism Spectrum Disorder diagnosis would have made a difference to the treatment offered to Sasha, with which we agree.

Crisis planning

12. As mentioned above, we regard failures in crisis planning at the time of Sasha's death to be an important feature of her case which is not fully acknowledged in this report. The refusal of the psychiatric team at our local hospital on 31 March 2017 to see Sasha shows how chaotic and dangerous this had become.
13. More broadly, as is recorded at paragraph 6.52, we disagree that Sasha was properly involved in care and crisis planning. Plans were often not communicated to Sasha or us, her family, let alone discussed with her in a way that would enable her to provide input.
14. We agree that the points referred to at paragraph 6.59 would have improved the care planning process. With regard to recommendation 3a) we consider that a review of care/crisis plans should be triggered where a person's risk significantly increases (as was the case for Sasha in the period before her death) as well as where there is a change in diagnosis.

Section 17 leave and the process when Sasha was AWOL

15. We welcome the acknowledgment at paragraph 6.24 of the flaws in the process that was applied when Sasha was granted Section 17 leave and then became AWOL. The Trust's practice of not providing transport to return Sasha to the ward meant that we often had to struggle alone to seek to return her when she was at high risk.
16. It is a source of grave concern that Sasha's Section 17 leave was not formally revoked on the day of her death, despite her being in crisis.
17. We think it is of the utmost importance that lessons are learned from this aspect of Sasha's case and that adequate training is provided to professionals regarding the Mental Health Act ('MHA'), Mental Capacity Act ('MCA'), and Mental Health Act Code of Practice.
18. Two Prevention of Future Deaths reports were prepared by HM Coroner which address these issues. We note that, as a result of those PFD reports, a decision has been made by the report writer not to make specific recommendations regarding these issues.

Community-based care

19. Paragraph 4.4 of the report refers to Sasha having been offered "intensive support at home". It is a matter of deep regret to us that intensive support was in fact not offered to Sasha in the community, despite repeated requests. Indeed, it was only shortly prior to Sasha's death, at the MDT

meeting, that a package of intensive community-based support began to be seriously considered by those treating her.

20. Prior to this, our experience of Sasha's community-based treatment was that she would be offered an appointment every couple of weeks. We found that there was a worrying willingness of community-based services to give up when Sasha was perceived to "refuse to engage". So many times we hear of youngsters who refuse to engage. While we recognise absolutely that young people cannot be forced to engage with services, it is our firm view that professionals should consider looking at alternative ways to engage people like Sasha. We believe that, had professionals spent more time speaking with Sasha as an individual and questioned *why* she struggled to engage to such a great extent, then perhaps there would have been some progress made in her treatment or perhaps her autism diagnosis might have been reached more quickly.
21. The advice we repeatedly received was that Sasha should not be helped whilst in crisis and instead needed to emotionally regulate herself before she could access support. This was incredibly difficult to work with in practice given the severity of her self-harming. It put us in an impossible situation as we tried both to follow the advice of professionals whilst trying to keep Sasha safe. The approach also did not help Sasha; as she frequently said herself: *"If I could help myself, then I wouldn't need their help."*
22. Nevertheless Sasha did try to follow the advice of professionals. However, despite our protestations that she was trying her very best, as we were too, we found there was never any questioning of why she made so little progress; often her efforts were ignored or disbelieved. Importantly, despite the lack of progress, the approach to her treatment was not modified by professionals.
23. As a result, for long periods we felt we were left to try to help Sasha, including seeking to protecting her from the risk she posed to herself, largely alone.

Communication with Sasha's family

24. There are various references in the report to our approach as a family to supporting Sasha. We do not propose to address these in detail, save to say that our motivation was always to try to act in Sasha's best interests including by seeking to get her the treatment she needed.
25. We welcome the acknowledgment at paragraph 6.75 of inadequacies in the communication of the professionals with us as Sasha's family. Unfortunately as a family we did often feel misunderstood and at times even vilified; it was an unhelpful aspect of this dynamic that criticism of us was often not made openly, in a way that we could address or challenge. Rather there was a degree of 'gossip' and rumour. Reading through Sasha's medical records after her death, it struck us that at times the language referring to Sasha and her family was judgmental, dismissive, defensive and even unkind. We

believe this approach exacerbated the misunderstandings and half-truths that acted as barriers for the constructive treatment of Sasha.

26. We appreciate how difficult professionals found it to treat Sasha. However, in the context of this report which seeks to draw learning from Sasha's case, we wish to make clear that greater empathy from professionals regarding the impossible and desperate situation we found ourselves in would have made a real difference to us.

Learning

27. It is of the utmost importance to us that lessons are learned from Sasha's death.
28. To that end we would like to see:
 - a) Better communication between services in relation to care and crisis planning;
 - b) Clearer formulation of diagnoses and review of diagnosis where appropriate;
 - c) Improved training regarding the Mental Health Act, Mental Capacity Act and Mental Health Code of Practice;
 - d) Improved communication between family and professionals;
 - e) An approach of not presuming that all high intensity users have EUPD;
 - f) An approach of never presuming a potential suicide is unavoidable;
 - g) A willingness among professionals, where a treatment plan is demonstrably not working, to review the approach in a way that is sympathetic to the needs of the individual patient.
 - h) The availability of an independent appeals/advocacy process for families, to facilitate challenging treatment/care plans and diagnosis.