Book review

Justice for Laughing Boy: Connor Sparrowhawk – A Death by Indifference

By Sara Ryan
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Justice for Laughing Boy: Connor Sparrowhawk – A Death by Indifference by Sara Ryan is an account of a family's deep plunge into grief arising from the preventable death of 18-year-old Connor Sparrowhawk during July 2013. He had been an in-patient at Slade House, an NHS assessment and treatment unit run by Southern Health NHS Foundation Trust, for just 107 days when he was found unconscious in a bath. The book sets out the stubbornly insensitive sequelae which result from the death of a man who, in his mother's words, "sat beyond definitions of normal". His "magic and eccentricity" were eclipsed by the problem-laden diagnoses of autism, global developmental delay, epilepsy and disability – and services which exhaust credibility.

Connor's family did not foresee his death. They had ideas about the future he might inhabit – he was an assiduous litter-picker, he was absorbed by re-cycling, traffic – most particularly buses, coaches and lorries – and he loved London buses. His focus on favoured activities matched a revelatory imagination and firecracker conversations. Yet in the final months of Connor's life, he and his family were in extremis. He had become agitated and unpredictable, his familiar routines less and less palatable to Connor and distressing events led to the wretched decision that specialist help was required. His experience at Slade House is a bleakly instructive parable of displacement – remote from his family life, comforts and everything that his family wished for him.

The book might have been written by a bewildered archaeologist who is piecing together Connor's life from family albums, the stand-out memories of those who loved him and the damning blind spots of a damaging service. However, it is lined with humour. Readers will not be able to keep a straight face as they think about house security, meet farmers or contemplate visiting caves. The account is also lined with disbelief, anger and dismay. Sara Ryan describes the interventions of specialist services which were unacceptable and inconsistent with her whole family's well-being.

Within hours of Connor's admission to Slade House he was restrained, that is to say, he was pinned to the floor, face down, and he was sectioned under the Mental Health Act 1983; his 13-year-old brother was not allowed to visit him or even visit the grounds with the family's dog; visiting arrangements made by his parents were forgotten; and the tyranny of Connor's "choice" prevailed. Since Connor was 18, it was explained to his family that he had to give them permission to visit each day. Also, it meant that Connor could "choose" not to eat.

The book offers space to the overpowering need to understand how a NHS service could be so indifferent to the distress of a young adult and to the experiential knowledge of his family. The violation of expectations that Connor's family endured – disregarding the implications of changing his medication or even engaging with the fact of his epilepsy, for example – set the scene for the emotional punches which followed.

From the elemental pain of contemplating a young son's funeral and speaking of Connor in the past tense, the collaborative efforts of Sara Ryan's networks of family, friends and colleagues, and those from her blog: https://mydaftlife.com/, melded into a vivid example of a multi-pronged campaign programme. A human rights barrister provided timely and crucial advice; the parents of children and young people at Connor's school, teaching assistants and friends of Connor's siblings created a funeral which reflected his passions; the relatives of people with learning disabilities and autism shared their ideas; and Connor Sparrowhawk's life continues to be honoured in music, quilting, and performance arts.

These networks acquired renewed purpose as Connor's family entered that uncharted space when Trust Board documentation reported that "the [service] user died of natural causes". This implausible statement was a spring board for justice to be heeded. Read about the backdrop to the Serious Incident Requiring Investigation, the CQC inspection, Verita report, Connor's Manifesto, the Mazars review, the 107 days of action, and the coronial processes. In the midst of this lapse from the coherent world, Connor's family marked his anniversaries and birthdays with bus-related activities and memorabilia.

From a single family's grief and disbelief, we have learned that Southern Health investigated less than 1 per cent of deaths of learning disabled people and 0.3 per cent of deaths of older people in mental health services between 2011 and 2015. The Trust had failed to investigate over 1,000 unexpected deaths.

Sara Ryan concludes that "some people do not count, in life or in death".

The best fighting efforts of Connor's family and networks could have been sabotaged by a NHS Trust and its legal teams. The incentives to continue and renew campaigning are hard-hitting: despite the best efforts of the families of people with learning disabilities and autism and those of self-advocates, plus advances in anti-discrimination and human rights, there is eligibility where there should be reciprocity, assessment where there should be curiosity, and mediocrity where there should be connection, not forgetting the shedloads of mother blaming. Surely we can do better than this?

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