BOOK REVIEW

Sarah Ryan. (2018). Justice for the Laughing Boy Connor Sparrowhawk - A Death by Indifference. London: Jessica Kingsley Publishers. ISBN 978 1 78592 348 7

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Introduction

Connor Sparrowhawk, also known as Laughing Boy or LB, was an 18-year-old with learning disabilities, who drowned in a bath in a residential unit in a hospital with four "specialist" staff and five patients. Within this book, his mother, Sarah Ryan, describes her struggle for legal justice to identify the clinical failings by staff working in the hospital unit at the time of his death.

The title of the book emphasises the word *Justice*, which implies that some injustice has been done to the "laughing boy". This suggests that the health and social services and/or the family of this 18 year old boy had failed in some way. It is a very important story for people working with people who have learning disabilities. It is also essential reading for families with a learning disabled member. The book illustrates that time spent campaigning can bring rewarding results, though this requires tremendous resilience and courage and, through its encouraging conclusion, provides a noteworthy example of accountability and democracy in action.

How the book is organised

The volume consists of 13 chapters and 2 appendices. Chapter 1, entitled 'What a wonderful world'and Chapter 2 entitled 'Dog days, Holidays and Life Rafts' detail Connor's early years. We learn that Connor developed a close relationship with a Jack Russell puppy who joined the family and that he liked the everyday stuff that did not involve 'disability' and was just about life. After being ejected from a dental surgery for biting the dentist's finger when she tried to X-ray his teeth, he was smuggled back to the surgery and was assigned a new, young and enthusiastic surgeon. He enjoyed bus rides in London with his parents.

Chapter 3, entitled 'Nudging Adulthood', describes the secondary school years when Connor was easing into life and finding ways of largely managing things that generated distress and anxiety. He would spend hours in his room utterly engrossed with his bus and lorry models. On a sunny day he would lie on a blanket in the garden with his favourite books. The author describes a "lack of an imagined future" when Connor approached 18, though Connor himself had ambitious plans to own a haulage company and marry a beautiful, brown-eyed woman. "A taste of the future" described within this chapter, explains that when Connor was 16, the outlook for his future remained limited. He did not have friends to hang out with and, apart from activities arranged by school, his peer social life revolved around his brothers and sister and their friends. The "Downturn" came when returning to school after the summer holidays in September 2012. Connor became uncharacteristically unhappy and anxious. He threatened a teaching assistant and a fellow pupil, who he accused of having stolen his toolkit. By March 2013 Connor was often off school in a state of agitation and unpredictability. At six feet tall, he had developed surprising strength. After attacking a support worker he was sectioned under the Mental Health Act and was admitted to a learning disability Short Term Assessment and Treatment Unit.

Chapter 4, entitled 'The Fallout', describes the nature of Connor's death and the decisions that his parents had to take. Connor's heart valves were removed for children's heart surgery. The section on "post-death work" explains that the cost of legal representation at Connor's inquest would be £20,000. Chapter 5, entitled 'Death of a Service User', explains that the family had no idea that Connor's death would generate a ground breaking social movement and lead to the uncovering of a systematic failure to investigate the deaths of other patients in the UK. The discussion on 'Mother-blame' within the chapter, deals with the new discredited research which claimed that autism was caused by cold, unfeeling and rejecting mothers. The chapter includes very tragic discussions of 'Death by Indifference' within the sections 'Criticisms of Southern Health and its Responses' and 'Dirty lenses and

human rights' documenting the series of organisational failures.

Chapter 6, entitled 'The Seeds of Justice for LB' describes how nearly four months after Connor died, the Trust commissioned an independent investigation into what had happened. Chapter 7, entitled 'The Waiting Game', charts the elapse of time. Chapter 8, entitled 'A very Adversarial Affair' describes how, following a report of a death, the State Coroner must decide if it is necessary to hold an inquest to determine the cause and circumstances of the death. The inquest is a key moment or event in finding out how and why someone died and an essential step in gaining justice. On 1 October 2015, the week before the inquest, Southern Health were still disclosing records which they should have provided two years earlier. The family knew that a determination (verdict) that did not capture how deeply Connor had been failed would forever haunt them.

Chapter 9, entitled 'The Inquest' describes how the inquest was scheduled to take place in the last two weeks of October 2015. The family room was large with settees and armchairs off a corridor behind the courtroom. There was some relief in leaving the intensity of the courtroom by the back door, for somewhere they could breathe deeply, be still and wait for what they described as the next "battering". Connor's mother writes that; "Looking back, the inquest gave me the impression of revolving around two main arguments as to why there was no wrong-doing on the part of the Trust or some of the staff members". There was no evidence that Connor had seizure activity while in the Unit and therefore his mother was somehow to blame. Discounting seizure activity functioned to remove the responsibility of staff to provide basic care and portraying a mother who was impossible to engage with further diluted this responsibility.

The discussion of 'The locked door and continued seizure denial' focussed on whether or not the bathroom door was locked when Connor was having a bath there. One thing that was never elucidated during the inquest was what actually happened on the morning Connor died. Staff evidence exhibited a mix of remorsefulness, defensiveness, reflectiveness and the downright offensive.

Chapter 10, entitled 'Taking the Stand' reviews an earlier death and the whole process of giving evidence, the retirement of the jury and the determination itself. Chapter 11, entitled 'Stumbling into Scandal' is followed by Chapter 12, entitled 'Crime and Justice'. On 10 December 2015, two months after the inquest, Jeremy Hunt, Secretary of State for Health, was called to answer an Urgent Question in the House of Commons. The BBC published a leaked version of a review earlier that morning. This had the aim of identifying the level of investigation into the expected deaths of learning-disabled people and people with mental ill health in the care of Southern Health Trust. The replacement of Southern Health Board Chairman Mike Petter with Tom Stuart was announced in May 2016. In July 2016, a story about Southern Health Trust and contract irregularities was revealed. Connor and the campaign became increasingly known about in the worlds of health and social care. Jazz performances, blog post extracts and a play with "A mother's Song" were all organised in Connor's memory and a Professor in the University of Warwick, UK organised a memorial performance of Tippett's moving spirituals form *A Child of Our Time* - a free performance open to all. The campaign of Justice for LB also spread beyond the UK in 2016.

Conclusion

This is an extremely harrowing account of a mother's struggle to understand why her son died while in NHS care. A range of medical decisions are questioned. At the heart of the story contained in this book is love. We read about a young man whose story managed to mobilise a social movement in a Society in which people labelled with learning disabilities and autism are too often sidelined or ostracised. It features a Scania truck and two red double-decker buses and a world-leading human rights team. Importantly, the case was discussed by the Secretary of State for Health in the House of Commons and describes a campaign that was marked and celebrated by hundreds of people in the UK and beyond. The success of this campaign is an encouraging conclusion to this tragic story and a noteworthy example of accountability and democracy in action.

Conflicts of Interest

The author declares no conflicts of interest.