

### **Written evidence from Rosemary Tozer**

I am pleased to have the opportunity to submit evidence to the Justice Committee as the bereaved parent of a 36yr old man Daniel (Danny) Tozer. He died in September 2015 following an unsupported & unwitnessed epileptic seizure while living in a supported living house run by Mencap, commissioned by City of York Council and partial NHS funding. Danny had autism and a learning disability and epilepsy and could not use speech to communicate. He had been left alone awake in his bedroom for 35 minutes. However his support plans stated that he should be checked every 5-10 minutes and an ambulance called if a seizure lasted more than 5 minutes.

After being found in cardiac arrest by staff, his heart was restarted by paramedics and he was rushed to hospital but after failing to revive after sedation on life support, he was brain dead by the following evening. Danny was a healthy young man & he subsequently donated his organs to help 5 people. At that time ICU consultants agreed that a seizure had preceded his death and if put in the recovery position he would probably have survived.

#### ***Contact with Coroners and staff***

- The ICU consultant contacted the deputy Coroner to gain permission for organ donation which precluded a post-mortem. We understood that a post-mortem would not provide further useful evidence, but the coroner asked the consultant if we thought there was foul play; we responded that did not think that he had been deliberately killed but neglected. We had raised numerous concerns about the care he was or wasn't receiving during the previous 2 years of this placement.
- Some initial legal advice suggested we write to the coroner to ask him to open and adjourn an inquest pending an independent investigation (and the CQC advised we should write letters of complaint to York council & Mencap). The Coroner replied that initial inquiries did not suggest malpractice (though no one had spoken to us) and he was not obliged to do so as Danny was not under a DOLS (legally he should have been but there was a backlog of cases at CYC). He also said he could not speak to us or 'he would have to speak to the others' - ie CYC, Mencap etc. Later it was obvious that other organisations had had direct contact with the coroner's office which in York is housed in the council offices alongside Social services, Health & Police departments.
- In following months we anticipated that, in line with the Care Act 2014, the CYC would instigate an independent Adult Safeguarding Review which they refused to do without valid explanation. Instead 9 months later they commissioned an independent management review, a largely paper exercise which criticised both CYC and Mencap which had not done an internal investigation.
- In the months following Danny's death the CQC also did an inspection of York Mencap supported living services which found regulation breaches and 'requires improvement' in all areas, though no reference to Danny's care could be included. These responses strengthened our view that an inquest was essential to uncover what had happened & safeguard other vulnerable people. A year later, and after it was concluded, the CQC told us they had investigated whether Mencap should be prosecuted but had only spoken to Mencap to do this not CYC or anyone else. Their reasoning was that because it was not known when Danny had a seizure in the 30+ mins he was unobserved he might not have survived anyway!

- In the meantime INQUEST found us an inquest solicitor who would petition the coroner with further legal arguments. It took over 2 years for the 3<sup>rd</sup> coroner who had looked at this to open an inquest following advice from counsel and an opinion from the ICU consultant.
- Our contact with coroner's office staff was very limited during and before the inquest and they only communicated directly with our solicitor, even eg when I asked to be told the date and venue of a PIR as I anticipated having to rearrange an outpatient appointment to suit the Mencap barrister. At the inquest their volunteers sat & chatted with Mencap and other witnesses though when I left the room just before the end of proceedings, it was a friend who came to find and support me.

### ***The Inquest***

- The case was later passed to a 4<sup>th</sup> Assistant Coroner who held 3 PIRs before an 8 day Article 2 inquest was held in April 2018. The Coroner seemed to have little experience of the purpose of an article 2 inquest, limiting his brief to the who, where and how of all inquests which, was held without a jury (as urged by Mencap). Important witnesses were not called eg the Assistant Director of Adult Social Care, and NHS staff including one who had written his epilepsy support plan & a family member who knew Danny well and had observed care at the Mencap house.
- The proceedings which were supposed to be investigative rather than adversarial felt stage-managed largely by the Mencap barrister who we felt bullied some witnesses and who managed to halt the inquest for a day because of a perceived slur on social media, thus adding delay and extra costs. He also frequently interrupted discussions between us and our barrister, which then made us feel we had not had adequate preparation between witnesses. It seemed like a contest between barristers and the inquest format seemed to prevent the truth being established.
- The Coroner seemed unable or unwilling to prevent a contest between barristers and to lack professional curiosity about the evidence presented. He was intent on finding 'natural causes', and even asked a neurologist whether one could recover from a sudden death in epilepsy. Although no doubt a perfectly pleasant person, he seemed to prefer not to not challenge questionable practices such as staff shortages and hours of support not provided or to rock the boat with establishment bodies. His final statement was an hour's summary of what he had heard without any analysis which shocked all parties who were expecting identification of failures, with a one sentence verdict.
- As there were no recommendations from the Coroner the verdict allowed all agencies to abandon any changes they might have made to improve support for people with Danny's profile who have epilepsy. Though inquest lawyers & social care professionals and campaigners have expressed astonishment and disappointment at the inquest (which was live tweeted @TozerInquest) we feel an opportunity was missed to improve support for others as a meaningful legacy for our son. Alistair Burt, one time Disability Minister, had previously urged us to push for scrutiny 'to help other families' less able to do so.
- The Coroner did say communication between the family and Mencap and CYC was not satisfactory but that keeping an eye on Danny to ensure his safety would have been too difficult, though we managed to do so on his visits home and his health funding was partly for his epilepsy support. We felt this comment displayed a complacent attitude towards the lives of people with learning disabilities and an assumption that nothing can be done to protect

people with autism, LDs and epilepsy from early death, fewer than half of whom reach their 40<sup>th</sup> birthday [Autistica 2018].

- After the inquest I sent the Coroner a covering letter & some information & research papers about preventing deaths connected with epilepsy of people with learning disabilities, as epilepsy charities have tried to improve knowledge amongst coroners. I did not receive any reply or acknowledgement.
- We understand that we could have asked for a judicial review of the outcome of the inquest within 3 months which might have cost a further £15,000+. At that point we did not have the emotional strength to undertake this and had lost much most of our confidence in the legal system. We had already spent around £14,000 on legal fees as our application for legal aid was refused although this was an Article 2 inquest.
- We were asked questions about Danny at the start of proceedings but then could only speak through our barrister asking questions of key witnesses who then were able to say they could not remember or didn't know. It would perhaps be better if families could give their own summing up later on all the evidence they have seen or heard which may only be produced at the inquest.
- Overall, apart from the poor practice and disregard exposed at the inquest which only confirmed our suspicions of how Danny had been supported during his placement, it was the most traumatising experience we have ever had, after Danny's death and that of our younger son 15 years previously. Our MP Julian Sturdy who supported our quest to get an inquest for Danny said we had a right to expect good quality care for him.
- Our contact with coroner's office staff was very limited during and before the inquest and they only communicated directly with our solicitor, even eg when I asked to be told the date and venue of a PIR as I anticipated having to rearrange an outpatient appointment. At the inquest their volunteers sat & chatted with Mencap witnesses and when I left the room just before the end of proceedings, obviously unhappy, it was a friend who came to find and support me.

### ***Comments and Suggestions***

- Clearly inquests are unique events depending on the circumstances of a death and the practice of the Coroner. Article 2 inquests would suggest the need for thorough training for Coroners in conducting what is frequently a difficult process especially for families, with public bodies motivated to preserve their reputations. Bereaved family members who have experienced an inquest need to have input into induction and training and attitude screening to ensure that officials believe in an equal 'right to life' for everyone.
- We believe a jury might have demanded more scrutiny in Danny's case and local citizens need to know what is happening in their area and have input into the process. In addition where expertise and experience in a particular area such as mental health or maternity is required, a panel could be involved with more than one person to officiate including independent experts.
- However it could be argued that the coronial process is fundamentally archaic and does not best reflect the way that vulnerable people can die today. After 3 PIRs we felt their format might have been a better way to conduct the inquest – more of a round table discussion where everyone can have an equal voice, competently chaired by a Coroner. At the second

of our PIRs the room (at the council offices) was packed with over 20 people, my husband and I the only ones who had ever met Danny.

- York like many other towns and cities does not have its own corner's court despite many ancient buildings. There was discussion about holding the inquest at Selby 15 miles away and a difficult journey for many involved. It is very important that Coroners are seen as independent but local so that members of the public can attend if they wish. In another case a family had to travel daily to Harrogate – an hour's journey. The combining of coronial areas is likely to make such distances common.
- There need to be clearer criteria for financial support for families involved in inquests; but we suggest that legal aid should be offered to families as a matter of course in a lengthy Article 2 inquest as public bodies receive unlimited public funding to cover legal costs. In our inquest we knew that to have our solicitor present would cost a further £1000 per day so we opted for a paralegal to be present who was new to the case.
- Families are usually asked to talk about their deceased relative at the start but have no further opportunity to comment themselves on the evidence presented. This is very frustrating when they have knowledge that would challenge or add to the evidence of subsequent witnesses. Perhaps an opportunity to comment on what had been heard could be included in proceedings, rather as impact statements are heard in criminal proceedings.
- It needs to be recognised that, in contrast to those living within health or residential settings, people with learning disabilities and autism living in the community have very little legal protection in their lives to ensure their safety and the way they are supported. This is particularly important following austerity when budgets have been cut within services and regulatory bodies. For example, care and support plans appear to have no legal basis & staff can ignore best interests under the Mental Capacity Act 2005 without fear of sanction, and there is little scrutiny or reprisal if plans are not followed.
- Those who cannot speak for themselves and with little access to independent advocacy are largely dependent on the goodwill and humanity of staff and the support of any family they may have but without a clear legal framework, although a 'duty of care' is often mentioned. In our scenario, giving health and safety powers to the CQC instead of the Health & Safety Executive in our view led to an inappropriate response. Likewise legal definitions of 'neglect' need to be clarified or redrafted as it seems almost impossible to achieve this at inquests. This creates serious risk for vulnerable people and can end in tragedy as it did for Danny.

*August 2020*