

Written evidence submitted by The Challenging Behaviour Foundation (ADL0007)

Case studies Illustrating the impact of the lack of appropriate and timely care provision for people with Learning disabilities and their families

NB we had aimed to include an additional case study which the family were keen to share due to the issues it highlights but have been unable to include it at this point due to concerns that it may compromise a very complex situation. We may be able to provide it at a later date.

Case study 1 – Anonymised case study of a young man with learning disabilities and autism who spent a long period in inpatient units and is now living in the community.

“Aged 18, my son was sent to an inpatient unit, where he stayed for nearly 2 years. He has learning disabilities and autism, but was detained in a psychiatric unit, with much older patients who had a range of different psychological conditions, as a result the staff struggled to cope with and understand his needs. I travelled the 80 miles there and back with my family to see him each weekend, but sometimes we were only allowed to see him for a few minutes, or not at all. My son’s consultant said that he should be moved somewhere more suitable.

It was heart-breaking to have to leave my son at the hospital. He was covered in bruises and gashes from where he had hit himself from being anxious. He was put on six anti-psychotic drugs, two of which were for epilepsy, even though he has no diagnosis of psychosis or epilepsy. When we arrived he was so drugged that he fell asleep when he sat down with us. The long-term effects of sedation mean that my son has now lost the little speech he had.

My son was then moved to a specialised autism unit in a secure hospital, 78 miles away from home. The new hospital was not a success- his medication was still very high and had been increased despite a CTR recommendation to lower it. My son had also been bitten and received other injuries including a broken clavicle that went untreated for three weeks.

A house was bought for my son in the community, but delays with funding and building work meant he remained in hospital as his discharge date was pushed back every month. In the meantime, my son’s self-injurious behaviour became more severe due to the frustration of being in the unit and being forced to take so much medication.

After six years, my son finally came home and was totally overwhelmed with anxiety. He has panic attacks, and will only access the bedroom and bathroom and still wants to sleep on the floor as this is how he slept at the ATU. After 6 months of being out we have seen great improvement, but he is still overly medicated because the doctors here not sure what to do about it.”

Case study 2 – Anonymised case study of family of an adult with learning disabilities and/or autism in an inpatient unit, during the pandemic.

“Our daughter has been locked away in inpatient units for nearly 15 years now. We were finally looking forward to her being discharged into a community placement with 24-hour care in March, when the coronavirus crisis struck, and everything was put on hold. This came as a devastating blow

to our family. We had been planning for her next stage of life, for her to finally achieve a level of independence, and her freedom was almost in grasp.

“This has had a massive impact on my daughter. Not knowing when she will be coming home has led to her anxiety levels increasing. Lockdown has also meant that we haven’t been able to visit her, and we haven’t been told when we can next see her. Throughout lockdown, she has been confined

within the inpatient unit with only walks in the small courtyard; although she will be able to go out for limited walks with one of the support staff soon.

“We were worried sick that our daughter might contract COVID-19 while she is still locked away. Being trapped in an inpatient unit can make people physically vulnerable; I know from our daughter’s experience that it is difficult for patients to get regular physical exercise, eat healthily and people are often overmedicated. That kind of lifestyle takes a serious toll on the body. I was also worried about whether she would get the medical treatment she needs at the right time if she fell seriously ill.

“Our worst fears were realised when our daughter started displaying COVID-19 symptoms. We felt completely helpless because we couldn’t do anything to care for her while she was unwell. Although she was never tested, she was treated by the inpatient unit as being positive and was isolated for eight days. Thankfully, she is over the worst of it now but other people in her hospital are also suspected to have had it.

“What is the hardest thing for my daughter and our family during the coronavirus crisis is not having a discharge date that we can look forward to. We hope that she will be out before her next birthday so that we can celebrate together, that’s all we can do to help keep us going.”

“Our daughter’s discharge is now being affected by a delay in provider visits. Provider visits were suspended for a while during Covid and then went online. They have now restarted although our daughter has not really had the community exposure we would have wished.”

“The refurbishment of our daughter’s apartment has been delayed and she has not been able to visit it as we would have wished.”

“We have not been able to see our daughter since 23rd December 2020 for a short visit in a family room. We are really concerned that when she comes out of the inpatient unit, we will not be able to visit her. After such a long time being detained her discharge will be a major change particularly for someone with autism. She will need support from her loved ones.”

Case study 3 – Anonymised case study of an adult with learning disabilities and/or autism experiencing repeated unmet needs

Our son has a significant acquired brain injury as a result of complex, challenging neurosurgery and immediate post-operative meningitis. He presents as severely autistic, has a severe intellectual disability, suffers from epilepsy and has no speech. Following a reasonably successful 365 days a year school placement he has churned through a number of adult services which were incapable of meeting his needs. All failed and he experienced some degree of neglect and abuse in all of them. At one point he was being bullied and subjected to prolonged periods of restraint and seclusion. He was badly traumatised, declared to be mad by the owner of the service and admitted to an ATU. He was found to be suffering from a chest infection and a UTI. No psychosis was present and a better understanding of his difficulties and specific needs was established. He was then discharged into the care of a specialist provider which eventually recognised that the placement was inappropriate and that a single person service was needed. In spite our efforts to have the situation reviewed, no action was taken to remedy the problem. Inevitably the placement failed. Because of the failure to respond to the identified difficulties it created an emergency situation as there was no possibility of

establishing a single person service for him at short notice. He was admitted to an NHS specialist rehabilitation service.

In adult care he has always expressed his distress by presenting behaviour described as challenging. The response to those behaviours over time has been the use of physical and chemical restraint, sometimes alongside aversive or punitive responses and seclusion. At times he was so distressed that he indulged in self-injurious behaviour. This needs to be viewed in the context of the fact that at nineteen years of age challenging behaviour was not a significant issue. The greatest cause for regret is the fact that at that stage he was incapable of deliberately hurting another person. His current situation is the consequence of the damage caused by years of inadequate, inappropriate settings in which he was mismanaged.

The rehabilitation service was staffed by a neuropsychiatrist, a senior clinical psychologist, psychological therapists, occupational therapists, a speech and language therapist, LD nurse managers, LD nurses and health support staff.

The unit in which our son was placed was a congregate setting containing some very challenging, complex, extremely troubled individuals. Housing five such individuals who had little, if any ability to make allowances for each other and adjust their own behaviour to live together in a bungalow would seem to be unlikely to result in a responsive, therapeutic environment.

Our son moved into the unit in September 2007. It was planned that his stay should be between twelve and eighteen months. In 2008 we began to seek to have him discharged into a suitable service. A long period of fruitless negotiations followed. There seemed to be no appetite on the part of commissioners to facilitate his discharge.

In the latter part of 2010 we discovered, by virtue of an FOI request, that a whistleblower had revealed the presence of significant abuse in our son's unit in the latter part of 2009.

The abuse described was of a patient being kned in the groin and incidents of verbal abuse. There was also a problem around hygiene in the unit. Our initial review of the available records revealed numerous incidents of aggression and violence and we also found evidence that our son was being sexually abused by another patient. We found that, within the unit, there were a number of unexplained injuries deemed to be 'minor'. In our view categorizing all of them as minor was not accurate and that the description probably meant that external scrutiny was not triggered. It was most concerning to note that there seemed to be quite lengthy gaps in the records.

An independent report, undertaken by a clinical psychologist who had experience of managing specialist challenging behaviour services, concluded that the service did not meet our son's needs. The report identified that our son was regularly subjected to restraint and was also vulnerable to assault by other residents. It also stated "It is not unreasonable to consider that he would have been stressed, anxious and may have been frightened".

Because our son cannot speak and the report formed part of evidence that would be presented in court, any views expressed had to take into account the possibility of legal challenges. In our opinion and that of others currently involved in our son's care, he has been psychologically damaged by his experiences and is almost certainly suffering from complex PTSD.

That an NHS service set up with the level of clinical expertise that was in place in our son's rehabilitation unit should fail so utterly offers irrefutable evidence that patients cannot thrive in fundamentally flawed environments. That an abusive culture developed that was very much akin to what was revealed at Winterbourne View, Atlas Care, Whorlton Hall, Mendip House and many other

institutional/congregate settings is a stark message that people with complex needs are hugely damaged in such environments. The system is unprofessional and largely poorly regulated and monitored.

It was not that long ago that brutal, hugely damaging and clearly unethical neurosurgery which removed parts of the frontal lobes of the brain was deemed to offer the possibility of a 'cure' for socially unacceptable/challenging behaviours. It is to be hoped that the current, often cruel, damaging mismanagement and traumatisation of people like our son will, in the future, also be regarded as unethical. They are not children of a lesser god without feelings and needs yet the system continues to fail to recognise their vulnerability and fundamental innocence. Their human rights are all too often totally disregarded.

It is both depressing and alarming to report that the funding authority, last year, questioned the validity of our son's current single person, supported living service. How is it possible that the evidence available from twenty years of failed services and traumatic inpatient stays can be so readily ignored? In his current service, hard won progress has been made and neither physical nor chemical restraint feature in his daily life. Astonishingly, during discussions about his care and support, a nurse 'helpfully' suggested that psychotropic medication would be a useful addition to his care plan!

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