Service feature

A family’s battle to understand “challenging behaviour”

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Abstract

Purpose – This is about the authors’ son James’ life. The purpose of this paper is to share a story of misfortune and a battle to find answers in which the greatest enemy was ignorance. Such experiences are not uncommon. It is the authors hope that sharing this will make some small contribution to bringing about change.

Design/methodology/approach – The authors discuss the experiences of care placements, and the battle to understand “challenging behaviour”.

Findings – Reflecting upon James’ experiences of the care system, it is clear that the system is fragmented and operates in silos that do not work together. Decision makers were all too often individuals not qualified to assess James’ needs and therefore implement appropriate solutions. The outcome was repeated failure which resulted in the view that he was a lost cause.

Originality/value – Such cruelty as James has experienced should be recognised and banished forever.

Keywords Learning disabilities, Intellectual disability, Challenging behaviour, Abuse, Restraint, Transforming care

Paper type Case study

This is about our son James’ life (see also Jack, 2010). It is a story of misfortune and a battle to find answers in which the greatest enemy was ignorance.

As young parents, we had no professional understanding of autism, learning disability and the consequences of an acquired brain injury (ABI). As a result, we were not equipped to manage the seemingly incomprehensible behaviours presented by James. We also had no idea how to plan for the future in terms of education and subsequent adult care. No support was provided for us as a family. We very much regret our own initial ignorance which prevented us from ensuring James received appropriate care and support.

Early childhood

James was a somewhat irritable infant but soon matured into a delightful, engaged, happy normal child. At two-and-a-half years of age James developed treatment-resistant epilepsy. It took the form of tonic-clonic seizures occurring every couple of hours. Generous doses of anticonvulsants failed to achieve any significant control of the seizures. At the age of five a CT scan revealed a tumour close to the amygdala in the left hemisphere of his brain. At that point he was extremely ill and surgery was necessary to offer a chance of survival.

Subsequent to the surgery, he contracted meningitis in the post-operative period. Miraculously, he was seizure-free but he was desperately emotionally distressed. He screamed non-stop and the only way to console him was to carry him and walk along the corridors of the hospital. This continued for three weeks.

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The consequences of the frequent seizures, the medication, the surgery and the meningitis were profound. James recovered well physically but was effectively an infant again and presented as autistic, hyperactive and non-compliant. He slept for no more than four hours a night. He lost his ability to use speech soon after the onset of the seizures and this never returned. Withdrawing the anticonvulsants proved very difficult for James, causing emotional upset and mood swings. It was necessary to proceed very slowly and the process took five years.

James was clearly not the child we knew prior to his illness and we had little understanding of how to support him, help him to learn and how to contact and build a relationship with him. He seemed isolated and to exist in a world of his own. A request for professional guidance elicited the response that we seemed to be doing well and to continue what we were doing. We needed to understand the issues around interrupted and delayed development, the likely consequences of his ABI and autism. Most importantly, we needed to know that he was most likely to learn by modelling and the establishment of patterns of behaviour and responses. Augmentative communication strategies should have been explored. We were never supported or trained to attempt any of those strategies. By chance we did instinctively use something like intensive interaction to some extent. It was obvious to us that his intellectual disability was such that the rest of the family simply had to function around James’ needs and accommodate his limitations.

We never punished him. The fact that we were unable to teach him the skills that would have helped him to avoid extreme frustration and anger did result in the development of behaviours that were challenging. These behaviours included destruction of the environment and, rarely, minor self-injurious behaviour. Families need to be supported to be part of an early intervention strategy. Simply waiting for a crisis to occur before investing in additional support seems counterproductive. Surely, early intervention must bring benefits both in terms of the wellbeing of the individual and their family and the savings achieved if admission to a 52-week residential school is avoided.

Family life became a matter of survival and, after five years of little change, we were exhausted and very concerned about his lack of progress. James was desperately unhappy and under threat of exclusion from the local special school. We sought help from social services and their advice was that he should be admitted to a mental health ward. That ward was a large room full of cots, one of which would have been allocated to James. There was no indication of how he would have had his needs met or have an opportunity to learn the skills he needed. The quality of life on offer in that environment was utterly appalling and we could not contemplate condemning him to such an existence. When we refused to have him admitted to a hospital we were told to find a residential school because no such option was available locally.

Off to school

We identified the Rudolph Steiner philosophy as a holistic approach which might be able to support James. An agreement was reached locally to pursue that option. Sadly, the first school excluded James, without notice, after two weeks. The second Steiner school proved able to meet his needs, successfully integrating James into their community and he remained there until he was 19 years of age. It did not use punitive or aversive strategies, he was loved and respected and for the most part enjoyed being part of the communal activities. The predictable rhythm of life in the school and its essential structures clearly suited him. It was about 100 miles from the family home, so it was not easy to visit frequently. We did manage to build and sustain a good relationship with James and he was always pleased to see us. Prior planning was always necessary but we could take him shopping, enjoy a meal in a Chinese restaurant, and go for walks in a local park, often enjoying a picnic there.

At 19 years of age, James was deemed to be an adult and we were informed that no suitable care placement was available near the family home. We were told to identify a suitable placement which our local authority (LA) would then assess. It is appalling to reflect that there was not even a superficial assessment of his likely needs on the part of the LA. Regrettably, we did not understand the essential truth that James had not changed significantly in terms of his ability to adapt and live in a family or communal care home environment. We failed to recognise the capacity of the school to manage the environment and his support in a way that his difficulties and
limitations did not present a significant problem for him or those living with him. We sought advice from the school and they too failed to recognise that it would require a very particular environment and degree of understanding for any service to successfully support James.

**Adult services**

We entered the world of care provision “roulette” in 1993, opting for a provider and particular home which was recommended by the Steiner school. It was a heart breaking experience to move James from what had been his home for nine years. Not long after he moved in, we were horrified to be told by a member of the care staff that James would have to learn to hit people in order to successfully survive in the home! Shortly afterwards we were helping him to change into walking boots and socks and found his heels rubbed raw, bleeding and dirty. We demanded to see the owner of the home in order to express our grave concerns about what we had discovered. The explanation offered was that the deputy manager of the home presented some “problems”. The owner, without any sign of regret or concern, said that the individual concerned had a problem with alcohol, smoked “pot” and stole from the clients! For such an excuse to be offered in order to explain an incident of very poor care was astonishing. It clearly indicated that the home operated within the context of an unacceptable culture. We complained to the officer responsible for care home standards in that area and also to our LA. A conversation with another family elicited the information that clients had been locked in their rooms at night. Subsequent investigations revealed that there were problems with hygiene, inadequate heating and insufficient food on the premises. Promises were made by the provider that changes would be made but we remained unconvinced and insisted that James should be moved. Once again it was left to us to find alternative provision, being told by our LA that no suitable service was available in their area. Commissioners aware of the failings that had caused our concerns about the home recommended another care provider in that area. We visited one of their homes which resembled a four-star hotel with no sign of any residents present. We were refused permission to view any of the bedrooms and when we asked about how any problematic behaviour might be managed the response was “Oh that can be managed with medication, it is not a problem”! Even in our state of relative innocence and considerable ignorance we were alarmed by the model of care on offer and continued to search for a new placement.

Eventually, James’ second care home was identified with the help of a social worker from our LA. We very much regret that we still failed to understand that the model of care would never be able to provide the sort of support James needed. We soon observed that James was looking pale, unwell and showing signs of pain in the area of the oesophagus. He had also lost a considerable amount of weight. When we expressed our concerns about his condition we were ignored and had to threaten to report the home to the authorities in order to have James examined by a doctor. He was found to be suffering from a bleeding stomach ulcer. James continued to be extremely stressed in the environment and began to show signs of great distress, doing his best to tell everyone that he was frightened of certain individuals. This he did by moving their chairs away from his space, throwing paper over them and refusing to come out of his bedroom at night. All of those obvious signs were ignored and he eventually attacked a resident who was bullying him. James was declared to be mad by the manager of the home and thioridazine was prescribed. He was subsequently admitted to an assessment and treatment unit (ATU).

Initial assessments revealed that James was suffering from both chest infection and urinary tract infections. He was clearly in a highly anxious state because of what he had experienced but the conclusion was that there was no underlying psychosis. The ATU assessment was thorough and confirmed that he was autistic and had a severe learning disability as well as the problems associated with his ABI. It was recommended that specialist support was needed and a care provider was identified with the help of the ATU and a social worker.

The specialist provider claimed expertise in autism and learning disability but failed to learn the lessons of the past and placed James in a group care home. By this stage James had learned that punitive and aversive responses, including prolonged periods of restraint, might well be the order of the day. As a consequence he arrived in his third adult residential placement with a repertoire of unacceptable behaviours which he used to try to gain some control over his life. He suffered abuse by neglect and ended up spending much of his time perseverating in his bedroom.
which was devoid of furniture save for a mattress on the floor. At that stage he began to indulge in significant self-injurious behaviour, banging his head on the wall. Prior to reaching this point we had recognised that James needed a single person placement and the LA had promised to commission such a placement. At the 11th hour plans for the promised service were abandoned and by the time the third placement had failed the only option was to have him admitted to an NHS rehabilitation unit.

Rehabilitation?

James was effectively abandoned in the rehabilitation unit for six years. Three years into that period we became concerned about the disappearance of a number of staff and the suspension of some clinicians. A Freedom of Information request submitted to the Care Quality Commission revealed that there had been significant abuse and neglect in James’ unit. A safeguarding investigation failed to inform us of the concerns raised by a whistle-blower which were confirmed by the subsequent investigation. Upon examining the unit’s records, we discovered that there were a number of patients who had unexplained injuries and bruises over a period of time. We also learned that James was being subjected to inappropriate sexual behaviour and violence by other patients. Of course it has to be said that James responded with aggressive and destructive behaviours which resulted in his being subjected to frequent restraint including the use of pain pressure points.

We engaged a solicitor, raised our concerns with the Trust concerned and pressed for his discharge into a single person service close to the family home. Fortunately it had been concluded in a Best Interests meeting that James would need such a service in order to meet his needs.

Prior to his admission to the NHS unit, James was funded by the LA and the Primary Care Trust (PCT) and we were told by the PCT that it had been agreed that the previous arrangement would be resumed upon his discharge. The LA took the view that James should be funded through continuing health care and, after some debate, this was agreed. The commissioning PCT eventually became engaged in the process of planning James’ discharge but subsequently decided that responsibility lay with the receiving PCT because “James had decided to move to be close to his family”. It took two years to work through the process of identifying the responsible commissioner. We had to take the lead in identifying a suitable provider and solving the problems of obtaining a suitable property and modifying it.

A fresh start

After 20 years of inappropriate, inadequate, poor quality support and care (see Table I), James finally moved into an environment designed to meet his needs. Sadly the transition process was poorly managed. The different agencies involved in the transition process seemed to be constrained by the rules that applied to their separate “silos”. No one seemed to “own” the problem. The whole process was completed without the engagement of a social worker or care manager. Only the discharging NHS unit and the provider worked together but even here communication was not entirely adequate. In our view, the initial support offered by the provider was insufficient because they failed to understand, for whatever reason, how distressed James would be by the move. Everyone underestimated how terrified James would be as a result of being placed in a strange environment even though he was familiar with some of the new staff team.

Two weeks after moving into his new home it was suggested that he move out so that some of the damage could be repaired. The only way that this would have been realistically achieved would have been to section James and place him in an ATU. A psychiatrist was sent to the house and fortunately he phoned us to discuss the situation and we agreed that a further move would make matters even worse and result in a prolonged stay in an ATU. The two frontline care workers were given the option of declaring the situation to be unmanageable. Those two caring and generous individuals were determined to help James stay in his new home. The day was saved not by us, the manager of James’ service or anyone else volunteering to go into that extremely challenging environment, it was saved by those two men. It has to be said that we were fortunate that the attending psychiatrist took a long-term view. It was his opinion that psychotropic medication should be used to minimise the risks associated with the behaviour being presented.
Unfortunately, James experienced serious side effects associated with the medication prescribed, including tonic–clonic seizures that had been absent for 35 years. Withdrawing that medication has proved to be very difficult and it may take further two years to complete the process. We are concerned that a problem associated with the withdrawal process might prove to be enduring.

It is now nearly three years since James moved into his new home. Having given him a break from the psychotropic medication reduction process, he is very clearly responding positively to the environment and model of care now in place. In previous placements, including the specialist NHS placement, prone restraint was often the response to behaviour described as challenging and there could be several such incidents in a day. On one occasion that we are aware of, he was held down by five people for 20 minutes “until calm”. There have been very few instances of behaviour described as challenging in the last six months in his current service. Prone restraint has never been used and he is gradually learning that his care staff are not going to hurt him. It has to be recognised that James has learned that the exercise of physical enforcement is how matters are resolved. It will take a long time for him to appreciate that this is no longer the default position.

It is difficult to be absolutely certain because James is unable to speak but it is likely that he is suffering from post-traumatic stress disorder (PTSD). We know from patient records provided by the NHS unit that he was subjected to verbal abuse, physical assault and inappropriate sexual behaviour by other patients. He urinated in the sink in his bedroom rather than leave his room to use the toilet in the corridor. When the sink was boxed in to prevent the behaviour, he used the corner of the room. He had also resorted to this behaviour in the residential care placement where

<table>
<thead>
<tr>
<th>Age at entry and departure</th>
<th>Nature of placement</th>
<th>What happened</th>
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<tbody>
<tr>
<td>Entry 1984 aged 10</td>
<td>52-week Rudolph Steiner residential school, 35 miles from family</td>
<td>James was excluded due to school’s inability to cope with problems he presented</td>
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<tr>
<td>Departure 1984 aged 10 (2 weeks later)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Entry 1984 aged 10</td>
<td>52-week rural Rudolph Steiner residential school for children with a broad range of needs, 100 miles away from the family</td>
<td>Successful placement. Eventually had to leave to move to adult provision</td>
</tr>
<tr>
<td>Departure 1993 aged 19</td>
<td>Relatively isolated rural residential care home for 6 clients. Recommended by the Steiner school and approved by social worker, 130 miles from family</td>
<td>No assessment before entry. We reported evidence of neglect. LA investigation found a culture of neglect, inadequate food and heating, and poor hygiene</td>
</tr>
<tr>
<td>Entry 1993 aged 19</td>
<td>Large rural residential care home – main house plus smaller houses in the grounds. Claimed expertise in autism. Recommended by the Steiner school and approved by social worker, 150 miles from family</td>
<td>Excessive use of restraint and inadequate support. James suffered physical and mental health wellbeing problems. He acquired more inappropriate behaviours, was bullied by some residents and became extremely distressed and anxious. He was declared to be “mad” and admitted to an ATU. This home no longer exists</td>
</tr>
<tr>
<td>Departure 1995 aged 21</td>
<td>ATU for assessment</td>
<td>150 miles from family. He was found to be suffering from chest and urinary infections and in a highly anxious state. No underlying psychosis was identified. It was established that specialist skilled support was required</td>
</tr>
<tr>
<td>Entry 1999 aged 24</td>
<td>Autism and learning disability specialist provider. A group care home for 12 autistic clients. TEACCH programme in use. Recommended by ATU, approved by social worker, 70 miles from family</td>
<td>James’ behaviours resulted in restrictive responses. It was suggested that a single person placement was required</td>
</tr>
<tr>
<td>Departure 2000 aged 24 (6 months later)</td>
<td></td>
<td>A downward spiral of worsening behaviour problems and ever-increasing restrictions followed. He suffered abuse by neglect, had an impoverished life and began to present self-injurious behaviour Placement failed. Only suitable, available placement was a rehabilitation unit The service was initially based on positive behaviour support but there was a change of clinicians and a return to a more traditional rehabilitation model. James suffered physical, verbal and sexual abuse. He undoubtedly found the environment oppressive and frightening. It was extremely damaging and we believe restraint was inappropriately used. A Best Interests meeting established the need for a single person placement. However, his discharge was delayed. Finally, James was discharged into his own home with a specialist provider near his family home</td>
</tr>
<tr>
<td>Entry 2000 aged 24</td>
<td>Specialist rehabilitation unit, only placement available. Admitted informally, an exit plan was in place and discharge was expected to be in 18 months. Approved by social worker, 150 miles from family</td>
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<tr>
<td>Departure 2007 aged 33</td>
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<td>Entry 2007 aged 33</td>
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<tr>
<td>Departure 2013 aged 39</td>
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</table>

Unfortunately, James experienced serious side effects associated with the medication prescribed, including tonic–clonic seizures that had been absent for 35 years. Withdrawing that medication has proved to be very difficult and it may take further two years to complete the process. We are concerned that a problem associated with the withdrawal process might prove to be enduring.
he was subjected to significant bullying. As an autistic person who is unable to predict events, outcomes and consequences he must have found life extremely frightening and oppressive in such environments. Given that he has no internal mechanisms for managing high levels of anxiety whilst living in such unpredictable environments, as well as having no therapeutic support, it would not be surprising if he is suffering from PTSD. He finds it difficult to settle at night and will often delay going to bed until he has worked through his anxieties.

Why did things go so wrong?

Our experiences were of a fragmented care system with different components stuck in silos that did not work together. Decision makers were all too often not qualified to assess James’ needs nor implement appropriate solutions. The outcome was repeated failure which resulted in James being viewed as a lost cause. For frontline staff in services a lack of progress or improvement results in poor morale. This is compounded when there is no effective oversight and leadership which in turn results in a poor culture and an absence of humanitarian values. In such circumstances the cared-for individuals are regarded as children of a lesser God, not to be valued. They are blamed for the difficulties being encountered. Individuals become thought of as unmanageable or treatment-resistant with the only options being physical and chemical restraint. Punitive and aversive responses are employed and abuse and neglect seem to inevitably follow. It is sad to reflect that these problems have often been identified in supposedly specialist services.

There seems to have been little understanding of what represents an appropriate model of care. An interdisciplinary, holistic approach is surely needed. The situation is not helped by financial constraints which result in the assumption that barely enough is good enough. For individuals with complex needs such an approach inevitably results in placement failure and significant damage to the individual. This is likely to lead to ever escalating costs associated with their care.

It is hard to understand why it seems to have been assumed that James would not be offended or frightened by the unpleasant experiences he has had to endure. For many years his care has not extended beyond meeting his biological and physical needs and at times some of those have not been met. He has on occasions, gone hungry, been cold and deprived of sleep. His safety needs have rarely been consistently met. “Belongingness” and “love” needs have probably never been considered in most of his care environments (his school being a notable exception). We now observe that he seeks reassurance that he will not be criticised and is pleased to be praised. He clearly now is enjoying feelings of self-worth and self-esteem. Such cruelty as James has experienced should be recognised and banished forever.

Reference


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