

# **Building Rights**

**A report to the Keeping  
Bristol Safe Partnership  
Board.**

**Review of Bristol's policies and actions  
for people with learning disabilities and  
autism**

**Sir Stephen Bubb May  
2021.**

# Building Rights

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## Acknowledgments from the Author

In presenting this report to the Keeping Bristol Safe Partnership, I would like to thank the individuals and organisations that I have spoken to over the course of the last year whilst collecting information for it. I have welcomed their views, and I hope some of their insights have made it into this report, though the report is mine. I was asked to undertake this review as an independent person with experience in this area in policy and governance terms, though I am not a professional social or care worker. I particularly want to acknowledge the help and support provided by staff at Bristol City Council, especially Noa Hagan.

I have witnessed a willingness from Bristol City Council and partners to acknowledge failings (and that there have been was clear to me) and to do better in the future. I believe Bristol City Council and the agencies represented on the Keeping Bristol Safe Partnership Board have the ability to make the changes that would establish the city as a leader in the provision and support for people with learning disabilities and autism, but there remains a long way to go.

I hope the recommendations in this report will be followed, and that improvements are made to the way Bristol City Council and the Keeping Bristol Safe Partnership agencies support some of Bristol's most vulnerable citizens.

## **Background**

In September 2019, I was asked by the Keeping Bristol Safe Partnership (formerly the Bristol Safeguarding Adults Board) to investigate three cases of individuals with autism and/or learning disabilities. I regret that there has been a considerable delay in producing the final report and this has led to great frustration by the 3 families concerned which I understand and regret.

The origin of this review lies with a request for a Safeguarding Adult Review (SAR) on behalf of AB and his parents (identified further below), submitted by the Associate Director for Statutory Delivery for Avon and Wiltshire Mental Health Partnership NHS Trust (AWP). This request for a SAR was rejected by the Bristol Safeguarding Adults Board (BSAB) on the grounds that it did not meet the statutory requirements for multi-agency working, though this was subsequently challenged. However, following a formal complaint submitted by the parents of AB, Bristol City Council and BSAB subsequently agreed to examine the circumstances surrounding AB and two other cases where there had been failings in support and provision. It was discerned that there would be opportunities to learn wider lessons regarding the treatment of individuals with autism and learning disabilities in Bristol, particularly as Bristol claimed to be an 'autism friendly city'.

Whilst this review has been hampered by the exigencies of the COVID-19 pandemic, I have been able to meet and speak to a wide range of individuals and organisations. I recognise that I have not been able to speak to as many organisations and individuals in the third sector or those that work directly with people with learning disabilities and autism, but I believe my recommendations will win support from that broader constituency.

In agreeing to conduct this independent review I was keen to stress I would be looking for recommendations for improvement for the future, rather than investigating errors or past practices.

## **Overview**

As noted above, the starting point of this review was the request for a SAR for one young man with autism ('AB'). At the request of the Partnership, two other cases ('John' and 'SF') were also considered as part of the Review.

In all three cases I discovered a history of inappropriate placements, ineffective multi agency support and lack of understanding of the problems faced by the families. In some cases, the individuals report that this has resulted in emotional and psychiatric harm to the people concerned. It is abundantly clear that the claim that Bristol was an 'autism friendly city' can be challenged by this evidence. Indeed, Bristol City Council's 2015 Autism Strategy is accepted to be out of date and is now under active review.

In my meetings I was heartened by the acceptance from the key statutory agencies that in the three cases I looked at, there were failings, and that change was needed. I was particularly struck by the fact that three key individuals, the Chief Executives of the Mental Health Trust and the Clinical Commissioning Group, together with the Director of Social Services are relatively new to their posts and yet are keen to drive change.

I observed from a meeting with the Governor of Bristol Prison and the Chief Constable of Avon and Somerset Police that they understood that change was needed and had taken steps to improve the way they interact with people with autism and learning disabilities. These leaders accepted that much remains to be done to improve further.

Regrettably, my interactions with the British Transport Police and the Independent Office of Police Complaints (IOPC) have been less than satisfactory. Indeed, both the heads of these organisations felt unable to meet with me.

The families of the three individuals concerned say that they have been emotionally scarred by their experience with the many agencies involved in the care of their loved ones. I was struck by their resilience and determination to do right for their sons. It was interesting to note that as result of discovering that their experience was not unique the parents of AB set up the campaign group 'Autism Injustice'. (More information can be found on [the Autism Injustice website](#))

One of the lessons I have drawn from this review, (and indeed I have found this borne out in other cases in the country that have been drawn to my attention), is that agencies often failed to provide effective support and advice for families. As a result, these families found it extraordinarily difficult to challenge decisions being made about their loved ones. For some of our most vulnerable citizens, it is their families who bear the major burden in advocating for their loved ones and securing effective care and support. This is unacceptable, and my recommendations will address the heart of this problem.

Re-balancing the level of influence between families and service providers is crucial to securing more effective care. Families need more support, but this must be underpinned by strengthening their rights to speak out, to be listened to and to challenge. In these three cases, the families have been strong advocates, though often at great expense to their own health and wellbeing. How much more difficult must it be for people with learning disabilities and/or autism who do not have that effective family support?

Bristol's agencies act within the context of a national system of care and support for people with learning disabilities and autism that is wholly inadequate. I reflect on how little has changed since I wrote my report on the Winterbourne View scandal in 2016. Therefore, although this report is directed to Bristol and its agencies, I also make further recommendations for national policy and practice.

My report and recommendations draw on the meetings and discussions I have had with organisations, as well as the accounts from the families, which are presented in the following section.!

## **Accounts from families**

In the following accounts the names of the individuals have been changed to protect their privacy. What follows below are the accounts of the families as told to me. I was not asked to undertake a full scale investigation of the very long and protracted history of care (or often lack of it) , though I spoke extensively to the families and I met with the agencies involved. I was tasked with a report that drew conclusions for the future from the experiences of the past. I believe it is important that the voices, views and opinions of families are heard. That is why I reproduce their accounts. Those involved in the care and

support of people with autism, and the wider community, need to hear these voices in order to help them understand the impact that their interventions can have, for good or for otherwise.

The voices of families are often so little heard. I want these stories to be told so that in working to make lives better for our most vulnerable people, we can put individuals and families centerstage.

## **John**

John's case is unique and complex. John's mother Sue was born in the UK but was forced to move to the Yemen at an early age. She lived in the Yemen for 17 years and endured two forced marriages, as well as several traumatic life changing events throughout her time in that country. John was born in the Yemen, along with his two brothers and two sisters.

At age 18 months and while living in the Yemen, John suffered a serious brain injury. This was not diagnosed correctly, and the treatment provided was insufficient for the severity of what occurred. This incident and the lack of correct management are pivotal in John's development and have been hugely significant in his engagement with various services in the UK. The family fled Yemen in 1992 under extremely difficult circumstances and began the process of re-building their lives in the UK.

At a very early stage, John was recognised as not developing as expected and although it was acknowledged he had a learning disability, his needs went unmet. John demonstrated challenging behaviour and early professional assessments suggested that he was experiencing mental health problems. At this stage John did not receive enough support for his complex mental health problems, learning disabilities or brain injury, resulting in detrimental consequences including John entering the criminal justice system.

As John entered teenage years his hidden impairments had an increasingly negative impact on his engagement with various authorities, particularly the Police. His behaviour drew him to the attention of the Police, but he did not have the skills to deal with the conflict this inevitably brought about. His vulnerability made him an obvious target for manipulative people within the community and this took him into the world of drug and alcohol use and petty crime.

In 2001 (aged 13), John suffered a second brain injury following a car crash whilst joy riding. John was transferred to a young offenders' institute funded by the Local Authority rather than to a brain injury rehabilitation unit for follow up care. Subsequently John would attend further young offenders' institutes up and down the country. This had terrible long-term consequences for John because these young offender units were not equipped to care for people with traumatic brain injury. John did not receive adequate care following his brain injury or following the physical injuries he also received from the car accident. In 2011 John (now an adult), was sectioned under the Mental Health Act for a period of three months.

Over the period December 2011 to February 2012 John was detained in Callington Road Hospital, Bristol, which provides in-patient care and treatment to adults with a mental

illness. This was another extremely difficult time for John's family as this was the first time John had ever been sectioned. They felt that the care provided was inappropriate as it failed to recognise the impact of John's brain damage nor his learning disabilities. John's family had specific concerns about the alleged practice of 'over-drugging' BAME patients and those with a brain injury or learning disability. John's inpatient experience had an even greater detrimental impact on his overall long-term mental health. John's family reported their concerns to the management at the unit; however no meaningful dialogue took place and no action was ever taken, despite official reviews indicating wrongdoing, and John continued to be drugged whilst at the hospital.

In May 2012, John was targeted by a group of local youths in the St Paul's area of Bristol. The youths shaved a swastika into the back of John's head and encouraged him to commit robbery. John was subsequently arrested. Not for the first time, John was apprehended by the police and interviewed without an 'Appropriate Adult' present, nor even a solicitor: a direct breach of the Police & Criminal Evidence Act (PACE).

John's family provided the Police with ample documents and reports proving that John was an extremely vulnerable man who did not have the capability to stand trial. Despite this, the Avon & Wiltshire Partnership (AWP), without a face-to-face assessment with John, produced a Computerised Assessment and Referral System (CARS) screening report that stated there were no mental health issues that needed consideration at John's trial. The report failed to identify any aspect of John's mental health or physical disability, and as a result John was deemed fit to serve a prison sentence instead of a hospital order.

Whilst in prison, there were no accurate reports produced of John's needs. Whilst serving his sentence, John was abused by prisoners and staff resulting in him receiving multiple injuries and attempting suicide. John was transferred to several different prisons around the country. **John's experience in prison highlights concern for the way inmates with autism, learning difficulties, brain injuries and/or mental health issues are treated in prisons within Bristol and throughout England.**

The human rights organisation Liberty took on John's case against the Ministry of Justice challenging the inhumane treatment of people with disabilities in prisons.

Upon his release from prison, John's family experienced major difficulty in organising a suitable care plan to prevent relapse. Principal responsibility for identifying alternative care plans and treatment methods was placed on John's mother Sue as his primary care giver, with little support provided by AWP nor other services. **This highlights the lack of appropriate services in Bristol for individuals like John who are highly vulnerable and have complex care needs.**

John's condition deteriorated quickly, and he returned to Callington Road hospital. The same issues of inappropriate treatment and the over-use of drugs were repeated. Sue felt that she was intentionally isolated from her son's care, and that staff resented her involvement. However, Sue continued to advocate for her son, and consequently the Clinical Commissioning Group (CCG) agreed to fund a specialist hospital placement. John was placed in Chalkdown House hospital in Swindon: a hospital that specialises in treating people with both mental health and brain injury conditions. However, this placement failed

quickly, and the family were left confused. No report was produced to clarify what care John received whilst in the hospital, nor the cause of the placement breakdown.

Several incidents occurred after this, including in 2015 when John's care in the community broke down yet again and he was arrested after accidentally setting fire to the curtains in his bedroom. This time a specialist hospital placement was not found for John and once again he was sent into prison for three months, awaiting assessment and treatment. This happened despite John's doctors and care team acknowledging that prison was not appropriate for John and that he needed to be in hospital instead. Once again, the prison authorities failed to obtain John's previous medical history or share critical information between themselves to properly identify or treat his health care. John was not properly safeguarded by the prison authorities, including from acts of self-harm.

John was eventually transferred to St Andrews: a private 110 bedded medium secure assessment and treatment unit in Northampton, funded by NHS England. Here also John experienced abusive and neglectful treatment by staff and patients, with no one stepping up to take responsibility when Sue reported the abuse to various authorities. There was a change in staff and job moves which distracted and hindered the investigation into the abuse. John was denied his basic human rights, such as exercise or walks in the grounds. John became obese and developed diabetes and high cholesterol. John was eventually transferred to a private, locked secure hospital in the Priory Group.

The placement at the Priory Group hospital was funded by Bristol CCG and accepted by John and his family as they were told that it was a specialist learning disability hospital. Sue was dismayed to find out that the Priory hospital was neither an LD hospital, nor able to meet John's needs. Instead, like many other organisations unable to care for patients with dual diagnosis, the hospital punished patients who could not follow hospital 'rules'. Sue told the hospital she was concerned that they were failing to properly safeguard John and she intended to submit an urgent safeguarding referral. Upon hearing this, the hospital gave John 28 days' notice to leave. Sue registered a formal complaint with the Priory. They acknowledged her complaint but then suddenly closed the hospital. She has heard nothing back from them to date.

John's discharge in July 2019 was disorganised and chaotic. He had no discharge coordinator and his discharge was unsafe. Up until this sudden discharge, John had spent four years in hospital under section. John's physical and mental health had deteriorated, and he needed more care and support than before he went into hospital in 2015. John's mother Sue questions the way NHS England and CCGs fund hospital placements in private hospitals but then fail to oversee the care and treatment of their patients once they are placed. She questions NHS England, CCG, Care Quality Commission (CQC) and other authorities' ability to challenge private hospitals when it has been proven they are abusing and neglecting patients. Sue also questions why private hospitals lead the investigation themselves when a complaint is submitted against them.

John did not receive the treatment or rehabilitation he needed in hospital and consequently his return to the community was problematic. On discharge John's community placement broke down within weeks, and although John is entitled to a full package of support from Bristol City Council (BCC) under section 117 of the Mental Health Act 1983 and the Care Act 2014, he was left homeless.

At his Multidisciplinary Team (MDT) discharge meeting from hospital, John and Sue had been told John should present to Jamaica Street as homeless if his placement broke down. This had been the only contingency plan put in place by his care team, contrary to AWP's promises to always have a contingency plan for anyone who is deemed a 'complex case'. This raises concerns for how Bristol cares for their most vulnerable, and Sue questions "how BCC expects someone with John's cognitive disabilities to survive in Jamaica Street is beyond my understanding."

John was classed as 'homeless' for months while BCC sought accommodation. Sue believes the housing sector in Bristol is also not set up to help those returning to the community from secure hospitals. Sue was unwilling to allow her son to become homeless as he had been beaten and taken advantage of in the past. Sue took John home to sleep on her couch. She feels that BCC takes advantage of the fact that she steps in and looks after John, even when it's detrimental to her own health and the health of the rest of her children. BCC know Sue has health issues but continue to ignore her and her family's needs.

John was eventually given emergency accommodation but was shocked to find it was a single tiny room in an old Victorian house that had been turned into multiple flats. Unbeknown to the family, this property had come to the attention of the Bristol Post before it was offered to John. It was in appalling condition, and exposed John to more danger. However, John had no other choice but to accept the accommodation. Whilst in this accommodation, John was exploited by other residents and drug dealers for their own gain. He also experienced 'cuckooing' and was often in A&E after receiving injuries from being attacked. Sue tried to complain to BCC who funded the property but felt that nobody was listening, so she contacted the lead for housing to complain about the condition of the whole property.

John's accommodation is far away from his family home which makes it more difficult for Sue to keep an eye on him. Even though he's mobile and active, he self neglects and needs daily help and prompting to do basic tasks like taking his medication, washing, changing his clothes, cleaning his room, and eating. The distance of his accommodation from the family home is problematic because his mother is his full-time carer when John is not engaging well with his care team. Sue feels that she must step in as she is constantly being told by social services that they are 'under financial pressure' and there is very little more they can do to help. Sue believes that Bristol City Council's Social Services department has not acted appropriately in response to several safeguarding referrals submitted by professionals who have registered concerns about John's welfare.

John is unable to successfully navigate the complexities of living in the community, which inevitably bring him into frequent contact with the police. This contact never turns out well for him and he often ends up injured. John has a great sense of humour and is often telling jokes. Unfortunately, his jokes are not always 'appropriate' for the situation he's in and the police have no patience with him.

After his placement in the emergency accommodation, John eventually moved into supported accommodation. John had some good support workers around him for a few months that were patient, understanding and knowledgeable in how to meet his needs.



Social services told John and Sue this placement could assess John and any advice from the staff around extra support needed for John would be given. However, when the placement put in their request it was denied. John was eventually evicted and once again there was no contingency in place, so he was told to present as homeless.

John was back home with Sue since the beginning of October 2020. Not only is he without his own home, but he has no daily support. Sue is now John's only support, needing to take him to all his appointments as well as looking after all his care and health needs. Sue's request for John to have a capacity assessment has been ignored since last year, along with her request for a personal budget for John so she can source her own support package for him. However, John is currently on remand to prison awaiting an assessment to determine his sentence.

John's family say that for many years they have attempted to work alongside various services to share their views and experiences of mistakes where John has come to harm. The family say that on more than one occasion they have accepted an apology and a promise from these organisations that lessons would be learned, and that services, policies and guidelines would be reshaped for the future. Sue is now concerned that the phrase 'lessons will be learned' is repeated too many times and has no meaning. She acknowledges that budgets are tight and also understands that we are all human and mistakes can be made but asserts that for John too many mistakes and 'near misses' have been made and his life is being put in danger. Sue also feels that one reason budgets are tight is because money is being wasted on services which don't work for the population they are trying to serve. Regardless of the reason, John is being failed because BCC has failed to put in place good community services.

Sue states that many of those who have worked in John's care team agree that services need reshaping. She says that even though they may not be in the position themselves to act or to 'whistle blow', these carers have also expressed their dismay at how John and the whole family have been treated.

Sue feels that there has been a lot of bias and discrimination against people with autism and learning disabilities displayed by agencies when they are deciding on John's care, whether this has been intentional or not.

## **AB**

AB has the benefit of an anonymity order from the court in respect of his current civil law claim against British Transport Police; hence he will be referred to as AB throughout this report.

Now 29 years old, AB is a young man with Autism Spectrum Disorder (ASD). AB is now a resident of Cardiff but at the time of the incidents described below) regularly travelled by train from Cardiff to Bristol for study, and latterly Bath where he lived and worked. .

AB has profound anxiety about traveling on public transport that sometimes results in sensory overload and psychological meltdown. One of the ways that AB tries to control his anxiety is by 'stimming', in his case, fiddling with any material within his reach, as this has

a calming effect. This may include unconsciously touching other people's (men's or women's) clothing, bags, etc. When challenged, AB doesn't have the language to explain or apologise. These features of AB's ASD are compounded by poor 'proprioception' and 'theory of mind'. Contact that AB would perceive as harmless can be misperceived by others who do not understand stimming, sensory overload, theory of mind and poor proprioception.

Having successfully travelled daily to university and then work by train for four years without any incident, on two occasions, two and a half years apart (in 2011 and 2014), AB's stimming resulted in him being apprehended by the police after being accused of unwanted touching by two women passengers.

As a result of his 2011 apprehension by the Police, AB was cautioned. This caution was later quashed because of several irregularities, particular breaches of the Police and Criminal Evidence (PACE) Act and failure to recognise his right to an 'appropriate adult'. Following his 2014 arrest, AB was again not charged as it was judged that the Police and health professionals who assessed him failed to recognise his vulnerability and his protected characteristics. Also, appropriate and reasonable adjustments that are required by law and national guidance were not made during his detention, nor subsequently. As well as failures by both police forces involved, failures by custody nurses employed by Avon and Wiltshire MH Partnership NHS Trust (AWP) were acknowledged in a letter of apology to the family by the Trust's former Chief Executive.

However, subsequent enquiries by AB and his family discovered that explicit and erroneous allegations of sexual assault remained on police databases in relation to both incidents. Despite extensive and complex complaints being made to the relevant agencies, those made to the British Transport Police (BTP) and Independent Police Complaints Commission remain unresolved, and AB and his family have grave concerns about the lack of governance and compliance with required standards demonstrated in the handling of these complaints. These are currently the subject of a civil claim which AB has taken out against British Transport Police for breaches of the Data Protection Act and Human Rights Act.

The trial hearing for this civil claim was postponed from May 2020 to February 2021 and then again to September 2021 due to the coronavirus and together with an aborted mediation process in which the BTP confirmed their intention to retain the erroneous allegations until AB's 100th birthday (even though BTP have acknowledged that the allegations are inaccurate), these factors have compounded the psychiatric harm already suffered by AB. This harm has been documented by five consultant psychiatrists and in a Section 42 Safeguarding Enquiry report from Bristol's Safeguarding Adult Team. That report also identified the false allegations on BTP databases as the cause of his ongoing anxiety disorder and depression.

Prior to, and after the first incident, AB was studying for a BA (hons) degree at Bristol, travelling daily to Bristol by train from Cardiff. Prior to the second incident, he was working and living full time in Bath. However, his experiences, and in particular the failure to remove the false allegations from police databases, have resulted in serious impairment of his health and development with significant increase in anxiety and impact on his functioning. This had been predicted by a consultant psychiatrist who assessed AB in

December 2015. This decline in health resulted in him having to move back home to be supported by his parents, the loss of his employment, and caused an inability to travel independently on public transport.

As a result of AB and his parent's experience and frustration, in December 2017 a director of AWP and AWP's representative on Bristol City Council's Safeguarding Adults Board (BSAB) put in a request to the Safeguarding Adults Review (SAR) subgroup of the BSAB for a referral. Unfortunately, the SAR subgroup decided that the criteria for SAR were not met due to a variety of reasons even though the Bristol Safeguarding Adult Team subsequently accepted a Section 42 referral, the outcome of which acknowledged abuse and neglect.

The parents of AB submitted a complaint and request for the case to be re-examined by BSAB. Although BSAB took the decision not to accept or re-examine the SAR, the conclusion of Bristol City Council was that there were opportunities for wider thematic learning around the treatment of individuals with ASD and learning difficulties, how Bristol functioned, and whether the city lived up to its claim to be an 'Autism friendly' city.

## **SF**

SF struggled all through nursery and primary school and in 1997 at the age of seven SF was assessed as being behind his classmates with difficulty concentrating. However, SF received no official diagnosis until 2015.

For the majority of his early life, SF lived with and cared for his father, who has significant health needs due to Multiple Sclerosis (MS). However, at the start of 2014 SF's behaviour began to deteriorate as his father became frailer. At the same time, SF began to associate with others, and he was introduced to drugs and alcohol. This caused an argument between SF and his father and resulted in the involvement of the Police. At that stage SF became involved in the criminal justice system.

SF's psychologist produced a report for the courts that concluded that SF had an IQ of 61 and low levels of comprehension. Testing results showed age seven. The report also identified neuropsychological problems that required further assessment. It concluded that he should be accompanied by an 'appropriate adult' when interviewed. Police agreed to drop the charges against SF if a restraining order was put in place to prevent SF from contacting his father. This resulted in a housing placement being found for SF by South Gloucestershire local authority in The Forecastle, which is a supported housing scheme.

Unfortunately, use of drugs and alcohol by other residents of The Forecastle influenced SF and there were a series of minor incidents that brought SF to the attention of the Police again. These were largely petty theft and taking the remains of cigarettes from bins from the local hotels. A staff member at the hotel accused SF of strange behaviour and the police brought a harassment case against SF.

The Forecastle was a disastrous experience for SF, and the family felt that it was the wrong place for him to be placed. It has since been gutted and had a complete make over.

The Forecastle was advertised as somewhere that offered support and building skills. In reality, the majority of residents were addicts and/or had criminal records and the family felt it was not focused on providing support that SF needed. SF's autism resulted in him not fitting in and feeling isolated and scared. SF's mother was trying to get SF the assessment he needed to get the right support. Due to NHS delays, this took too long and left SF vulnerable in the wrong environment and with inadequate support.

The police failed to consider this context when he was arrested and pushed SF through the criminal justice system. From their experience, the family feel that the police continue to make the same mistakes and then make the same promises for improvement, such as increasing training and awareness of the needs of vulnerable people. However, they feel that until the police and all the agencies demonstrate real care about what happens to vulnerable people and not look at them first and foremost as criminals, there will be no change. In their view, the police act as if they are reluctant to support vulnerable people and would prefer to put people through the justice system without having to meet their responsibilities.

From their experience the family of SF felt that the police acted as if they were seeking to 'tick all the boxes' to cover themselves regarding providing 'appropriate adults', and placing vulnerable people in specially designed cells, etc.

In December 2014, new residents at The Forecastle attacked SF, resulting in his arrest and his eviction. Similar to John and AB, SF is interviewed without an 'Appropriate Adult' despite previous psychologist reports. It came to light that the person accusing SF of assault had lied about his injuries and had convictions for fraud and violence. The family feel that the Crown Prosecution Service (CPS) and the police underplayed or disregarded this and other important evidence to plough on with their case against SF.

After his arrest, SF returned to live with his father but remained unwell and without any support. Other attempts to live in alternative accommodation failed for SF. After an incident at his father's house, SF was taken on remand to HMP Bristol. Whilst he was originally only supposed to serve three weeks awaiting a psychiatric evaluation, this period was extended to six weeks because the psychiatric evaluation was not ready in time. This had a severe impact on SF's mental health, who found his stay in prison in the Brunel hospital wing isolating. He was locked up for 23 hours a day, which was very distressing, and he was traumatised after being assaulted by prison guards. Eventually in April 2015, SF went to court and was sentenced to twelve weeks, with half his sentence to serve before he could be released. The solicitor directed the judge to ensure the sentence handed down was appropriate to the number of weeks SF had been on remand, to ensure he would not have been held on remand longer than the sentence imposed, or inadvertently sent back to prison, due to a miscalculation.

On his release, SF was housed in supported accommodation provided by Maples. This accommodation was also not equipped to support vulnerable people with autism. The Maples had many support staff that come from agencies. There were failings with continuity or communication on shift hand overs and new staff would be introduced with little awareness of the needs of the residents. This resulted in mistakes often being made and bad decisions resulted. These are the worst circumstances for an autistic person.

In August 2015, Police were called to the Maples after SF was found trying to climb to his friend's flat to have a drink with him, and accidentally cracked a window by standing on the ledge. CCTV shows that SF was non-combative but scared and tried to run away when the Police tasered him, causing him physical and psychological trauma. Later, there were false allegations from the police that SF had assaulted them, although these were found untrue by video evidence obtained by SF's mother. The police later apologised for failing to seize the CCTV and making mistakes.

As a result of his treatment from the Police, SF's family requested a review by the IPCC (later IOPC) to investigate the evidence that her son had been the one assaulted by the police officers who went on to make false allegations against him. Had the false allegations had been believed, it is likely that this would have resulted in a prison sentence for SF. Not satisfied with the outcome of the IOPC two-year investigation, SF's mother released the video evidence to the media.

After a two year wait for a second report, the IOPC revealed it would not share it with SF or his family for legal reasons. They quoted Regulation 13 of the Police (Complaints and Misconduct) Regulations 2012 that includes provisions to withhold information where it is (a) required on proportionality grounds; or (b) otherwise in the public interest. This meant that SF's family could not appeal the report in judicial review, even if they felt it unsatisfactory.

The IOPC admitted that there had been unacceptable delays and mistakes. They agreed that what SF needed was appropriate care and support. The full investigation report however has still not been released, with the IOPC insisting it is not their job to overturn records of conviction. The only option open to the family is Judicial Review.

Ever since, SF's family have been trying to get a response from Michael Lockwood of the IOPC to ensure the IOPC recognise police failings and hold the police to account. The family feel that this is crucial in order to restore not only their confidence in the system, but public confidence also. Similar to 'John', SF's family have fought to get the correct information on police data systems. The family have no confidence in the IOPC and consider them to be a safety shield to protect the police and keep the public in the dark about what is happening within the police force and about the systemic problems that affect many families.

Due to his experiences, SF is too anxious to go out and he feels safer at home. For the past three years it has been a challenge to get him to leave the house although he will on occasion go to the shops or to McDonalds with his mother in the car. SF says he has been attacked and feels safer at home.

## **Main recommendations**

I make several recommendations for action by Bristol City Council and the Keeping Bristol Safe Partnership (KBSP). I recognise these will take time to implement, particularly as I think that it is important that they are subject to discussion and consultation. I have highlighted three main recommendations which I believe are crucial to putting Bristol agencies and multi-agency working at the forefront of good practice in this area. These are as follows.

1. Establish a 'Charter of Rights'
2. Ensure a Right to Challenge and
3. Establish an Independent Commissioner for people with learning disabilities and autism.

I would urge the City Council and those key agencies of the KBSP to implement these recommendations. I expect that they will wish for further deliberation and discussion. It is important that families and organisations that represent those working in this area, as well as individuals with learning disabilities or autism themselves are involved in developing these proposals and taking them forward after a full consultation.

## **Recommendation 1: A Charter of Rights**

Bristol City Council, in conjunction with key agencies, should draw up a 'Charter of Rights' for people with learning disabilities and/or autism and their families which should underpin all commissioning and provision.

We have heard, loud and clear, the message from people with learning disabilities and autism and their families that the system needs to do a better job of respecting and upholding their rights and listening to what they have to say. This is about doing what is fundamentally the right thing, respecting people's human rights as a point of principle. But it is also about empowering people who could help change the way the system works for the better, but who struggle to make themselves heard. In the context of the problems described in this review, it is about empowering the agents of change.

People with learning disabilities and autism and their families have an array of rights in law and central/local government policy guidelines. For example, human rights law, the Equalities Act, the NHS constitution, the Mental Health Act, the Care Act, the Autism Act, the Mental Capacity Act, the UN Convention on the Rights of Persons with Disabilities, and so on.

In my engagement with the families over the course of my work, I heard that too often the lived experience of people with learning disabilities and/or autism and their families is that they feel powerless and that their rights are unclear, misunderstood or ignored.

In some cases, I suspect people may not be aware of the rights they already have or may not have access to the support they need to exercise those rights. For instance, their right to access an 'Appropriate Adult' during a crisis, at the point of admission, or when in an inpatient setting. In other cases, there are doubts over whether the rights of people with learning disability or autism are being respected in practice as originally intended.

To make the rights that people with learning disabilities and/or autism and their families already have feel real, I recommend establishing a charter and then requiring the agencies in Bristol and commissioners to shape local services around those rights.

In developing a charter, the City Council and key agencies should work with experts and practitioners, the third sector, as well as families and individuals concerned. Any such

charter should build on existing work such as the ‘We Have the Right’ statement put together by people with learning disabilities, or the Challenging Behaviour Charter drawn up by the Challenging Behaviour National Strategy Group. The Charter of Rights should clarify the rights people already have and the support they can access to exercise them. It should clarify how professionals (commissioners, clinicians and others) should respect those rights.

To give the Charter of Rights ‘teeth’, local commissioners should base their local commissioning plans on it, and to set out how they will make those rights real. For instance, by

- Ensuring information is accessible and available in a range of formats (including easy read) and adapted for individual needs.
- Commissioning high-quality independent advocacy services, brokerage support, and supporting self-advocacy and family advocacy groups. This can be particularly important for individuals who do not have family, or do not have a supportive family.
- Agencies should consider offering personal budgets and strong support for people with learning disabilities and autism and their families to use them.
- Ensuring that at key moments (such as prior to admission to clinical settings, local authority care, or immediately following contact with the police) people with learning disabilities and autism and their families know their rights, know what support they can access and know that they have a right to challenge.

## **Recommendation 2: A Right to Challenge**

One of the most serious challenges faced by people with learning disabilities and autism and their families is a decision to admit to an inpatient facility, particularly when this is an institution. It is my view that institutional care is an inappropriate placement and should be replaced by community care facilities. This was sadly the case in John’s admission to St Andrews hospital: an institution that has been subject to critical Care Quality Commission reviews and in my view should be closed. Any decision to admit to institutional care can have profound implications, not just for an individual’s current care but also for their future development, and it is therefore vital that families are fully involved in such decisions and are able to challenge them.

In addition to making existing rights feel more ‘real’, I propose extending the rights of people with learning disabilities and/or autism and their families, starting with a ‘right to challenge’. This would allow a person with learning disabilities and/or their family to challenge a decision to admit them to hospital or keep them there, should they so wish. Such a right should be accompanied by free support from an independent advisor.

The aim of this would be to review whether it was necessary for the assessment, treatment, or safeguarding intervention to be undertaken in an inpatient setting rather than in the community. The independent support would help individuals and families understand what community-based alternatives might be possible: the presumption should always be that people remain in their communities. The review triggered by this ‘right to challenge’ would only recommend admission/continued placement in hospital if it concluded that the

assessment, treatment, or safeguarding intervention could only be effectively and safely carried out in an inpatient setting.

I recognise that many individuals with learning disabilities and/or autism will not feel able to challenge the decisions taken regarding their care, particularly if they are in inpatient settings. In these cases, it is essential that the commissioners paying for their care take the responsibility to challenge the appropriateness of their admission or continued placement in inpatient settings.

The independent commissioner (recommended below) would monitor and ensure compliance with these new provisions.

### **Recommendation 3. An Independent Commissioner for people with autism and learning disabilities.**

I recommend the establishment of an independent commissioner ICALD. This independent commissioner would have the task of promoting, enhancing and protecting the rights of people with learning disabilities and/or autism in Bristol, and for brokering a systemwide consensus on how to deliver better services and support.

Role responsibilities:

- To monitor and review the policies and actions of the agencies involved in providing services and support.
- To ensure effective compliance with the proposed Charter of Rights and Right to Challenge.
- To conduct reviews either on request or independently.
- To be consulted by the Keeping Bristol Safe Partnership on issues arising in safeguarding, including decisions on whether to implement a statutory review.
- To ensure effective support for the families of people with learning disability and autism.
- To investigate individual cases of concern.

I recognise that this list may not be exhaustive and should be subject to change. I would hope that the Council and the Keeping Bristol Safe Partnership would accept the principle of such a post and then consult on its remit and functioning. The post must operate within its ethical remit and not be accountable to any individual organisation.

In establishing this new post, it might be useful to set up an advisory board to help select the individual and then to provide support for the new function. Such an advisory board should be drawn widely from agencies, families, and the voluntary sector. It is crucial that in establishing this post it is seen as independent, and it is therefore important that the many voluntary agencies, families and people with learning disabilities and autism themselves have confidence and trust in this new office.

In conducting this review, the families have stressed to me how they felt that there was a lack of transparency and accountability in the system. I have commented on the power imbalance between the state and its agencies and families and individuals. The agencies



involved in this review need to consider how their processes and systems can be more transparent and this would be an early task for the new commissioner.

## **Further recommendations**

### **Support for families**

My review has convinced me that the system needs to provide more support for families who are trying to navigate the system for their loved ones. At present, families find the system problematic, and the constant battles that they have to engage in are draining on them. For people with learning disabilities and autism, the role of families is particularly crucial.

I recommend that The Council consider how advocacy and legal support can be given to families to help them navigate the system.

## **The Criminal Justice System**

There are serious concerns about the treatment of people with learning disabilities and/or autism by the criminal justice system, and whether their rights are being properly upheld. I discussed this with the Governor of Bristol Prison and the Chief Constable of Avon and Somerset Police, though sadly not with the British Transport Police (BTP) as previously stated. In the cases I have reviewed, issues relating to the prison service, the criminal justice system and the police have loomed large. Two of the cases I reviewed (John and SF) illustrate why the police should not always be the first line of response for people with autism and learning disability when in a mental health crisis. As the College of Policing Guidelines on Mental Health state: *“Decision making concerning health care matters should be made by clinically trained professionals and not police officers.”*

This goes to the heart of Lord Bradley’s recommendations that “street triage ... offers a more humane crisis response”, yet there was no evidence in any of the three cases reviewed that such a service existed or could be deployed. In fact, when John’s mother recently challenged probation officers about the way John was being responded to by police, she was told that probation staff had never heard of either ‘street triage’ or ‘liaison and diversion’.

My review also identified that following arrest, statutory provisions of the Police and Criminal Evidence Act (PACE) were ignored, including the provision of an ‘Appropriate Adult’. Medical evidence was also ignored, as were families who were pushed out of the process. There were failures to complete assessments to determine fitness to be detained and interviewed, in reasonable adjustments, and in the interview process itself.

It is an indictment of local joint service provision that police are still often the first response for people in a mental health crisis, and that they so often get it wrong. This identifies the need for a comprehensive review of crisis response and a realignment of budget provision to fund these services. If there is collaboration between agencies, this should be financially cost neutral and have significant benefits in terms of the human cost of crisis response.

The Police have accepted the need for effective training in the special needs and circumstances of these vulnerable adults.

The history I have outlined is not a happy one. People with autism and learning disability face significant difficulties, and what happens to them in the system can have profound implications for their futures. In the case involving the British Transport Police the actions taken have been life and career changing for AB. That is one reason why I was so disquieted by the refusal of the BTP to engage with my review. I very much hope that the Chief Constable will reflect on my report and consider whether he is providing the leadership necessary in this area of his responsibility. In the police and prison service my discussions with the Chief Constable of Avon and Somerset Constabulary and the prison governor indicate an understanding of past failures, and I saw evidence of changes that have been made since some of the incidents outlined in the family histories. But there is still so much to be done.

In terms of national action, the Bradley Report of 2009 described a widespread lack of awareness of the issues faced by people with a learning disability and communication difficulties in the criminal justice system. Since then there has been progress, but the 'Bradley Report: Five Years On', found still more needs to be done, and it made further recommendations for action. This area was outside my remit to explore in detail, but I am clear how fundamentally important it is. I believe that the Government must implement in full the recommendations of the Bradley Report and his subsequent recommendations.

However, all the agencies represented on the KBSP could themselves review the Bradley recommendations to see what aspects they are able themselves to implement. This could form part of an updated Bristol Autism Strategy.

My report stresses the importance of the right to challenge. In this area the ability of families to make a complaint about police actions and behaviour is important.

## **Community Provision**

It is accepted that the provision of community support for people with learning disabilities and for autism is inadequate. I have seen how the lack of community provision can lead to placements in inappropriate facilities. Often the placement itself leads into further problems for the individual with serious consequences, including police intervention and then involving the prison and courts system.

In my report on the Winterbourne View scandal in November 2014, I recommended that all institutions for people with learning disabilities be closed in favour of community provision. This recommendation was widely supported and accepted by Government. However, the number of people with learning disabilities and autism still in institutions remains stubbornly high with levels not dissimilar to those in 2014 when I recommended closure. In one of the cases I reviewed, the individual concerned had been placed at St Andrews Hospital, and this placement had been both inappropriate and unsuccessful.

The Care Quality Commission has recently reported that too many people with learning disabilities or autism are receiving 'undignified and inhumane care' in specialist hospitals. The report highlights the use of seclusion and physical restraint, practices that I saw were too common when I undertook my review of Winterbourne View.

Over the course of my review, I have been in contact with other families who have had similar experiences to the three families involved in this review and I have further evidence of the abusive nature of institutional care and failures to provide effective support to some of our most vulnerable citizens. This is a continuing scandal.

In discussions with the Chief Executives of the Clinical Commissioning Group and the AWP Mental Health Trust there is agreement that community provision must be enhanced. This will require new build and new provision with new and existing providers. I have proposed that social finance can be used to facilitate such development and have signposted to providers in this area such as Big Society Capital and Social and Sustainable Capital. There are others, including some local provision.

The changes in the commissioning system to move away from the artificial provider and commissioning split into a new collaborative approach is very welcome and should be used as a spur to build new community provision more tailored around the individual. I am confident that the Mental Health Trust will use these new arrangements to work with the City Council and the proposed LD/Autism Commissioner to look at a new approach and bring in new providers who could discuss what is needed and then build and provide it in Bristol.

In developing these new community facilities, it is important to work with families and individuals with autism and learning disability. Too often provision has been 'top down' and designed by commissioners who feel they know best and ignore the client base, their carers and families.

In the time available to me in this review I was not able to look at the economics of provision in this area. However, it is clear to me from this work and work previously that the cost of community provision is significantly lower than the cost of institutional care. In the broader context the economic and social costs of inappropriate placements would almost certainly amount to significantly higher costs than if effective investment had been made in community provision. There is a question of 'double funding' which is why I have recommended the use of social finance. It is recognised that Council funding in particular is hugely constrained but there are long term savings for the public purse, in addition to better care. Some of these issues are national policy decisions, for example we still await Government action on social care reform, and it is clear that the division between health and care spending adversely affects social care.

I accept that the financial strains that agencies are experiencing because of the pandemic and general austerity measures will lead to questions about whether such an expansion can be achieved. However, this is an area where medium and long-term savings can be secured. I believe the potential savings are significant. If decisions to expand provision are continually put off because of current financial problems, then the future savings that could occur will not be realised.

I recommend that the AWP Trust, the Bristol Clinical Commissioning Group and the City Council establish a panel to review the options to expand community provision, including social finance providers, community providers and clients and families in the discussion.

I further recommend that no further placements of people with learning disability or autism be made to institutions (inappropriately named 'assessment and treatment centres') such as St Andrews. Any proposed placement in such an institution should only occur if the proposed LD/Autism Commissioner has accepted this is the only option available at the time.

## **An Autism Friendly City?**

It is estimated that there are some 4,000 individuals with autism in Bristol. That may be a conservative estimate.

Bristol can no longer claim to be an 'autism friendly city' and should stop using this slogan. This is not to suggest that changes and improvements have not been made, but it is not appropriate to use the slogan when the evidence to support it is lacking. I believe it is widely accepted that Bristol's Autism Strategy (published in 2015) needs review and improvement. I recommend establishing a working group comprising of the Council, other statutory agencies, providers and third sector organisations, as well as people with autism and their families and carers. The Council needs to review how it complies with the Autism Act (2009), as it would appear that many of the provisions of this legislation are not being observed.

Alongside the review of the Bristol Autism Strategy there should be a strategic review of approaches to learning disability. I understand that both streams of work have begun, and I would urge those involved to give both strategic developments priority. A recent example of good practice was the development of a new strategy for autism by Hackney Council which was conducted with the voluntary organisation 'Hackney Citizen'. This was a strategy developed by the Borough, health bodies, residents and voluntary organisations and produced a wide range of document covering the 'whole life course' of autistic people. There will be other examples and discussions in consultation which will enable Bristol to develop its own strategy and to aim to reclaim its title as an autism friendly city.

## **Independent Office for Police Conduct (IOPC)**

When the Police and those commissioned by them fail to follow due process such as the breaches of PACE that are identified in this report, clear consequences should follow. There is little point in the police having clear guidelines to follow if they are either unaware of them or ignore them. The experiences of those whose cases I reviewed was not only that the police themselves failed to properly investigate complaints, but that when these complaints were escalated to the IOPC there was likewise a failure to properly investigate. The process was also far too lengthy and difficult for people with autism and learning disability to access and navigate.

In investigating these matters, I did not find my interactions with the IOPC to be very satisfactory and the Director General refused to meet me, but I have not had time to pursue these cases further. My observation is that the systems and process for complaints

involving people with learning disabilities and autism leaves much to be desired. I recommend that they review their handling of such cases and work with appropriate third sector organisations and advocates, particularly involving the views of people with learning disability and autism.

It must be recognised that vulnerable citizens and their families will find it especially difficult to navigate the complexities and legalities of a complaints system. Any system of complaints about the police must be made more accessible, otherwise significant numbers of very vulnerable citizens are effectively disenfranchised from the complaints process.

## **The Third Sector**

Working with and through the Third Sector is often a highly effective way of engaging with families and this client group. The Third Sector often provides more effective service provision that is better tailored to the client. Bristol has a vibrant Third Sector, with numerous charities, social enterprises and voluntary organisations. These should be fully integrated into discussions on the rollout of provision and the development of strategy. They should be closely involved in the development of provider collaboratives. They should also be involved in the formulation of proposals for an independent commissioner, the right to challenge and the Charter of Rights.

I was not able to meet and discuss with many of the Third Sector organisations in Bristol because of the pandemic. However, the role of the sector as a provider of client-based services as well as an advocate for families and clients is crucial to the development of Bristol's strategy, and the sector should be used effectively.

## **Bristol Autism Spectrum Service (BASS)**

The AWP Mental Health Trust is reviewing its support and strategy around learning disability and autism. Bristol Autism Spectrum Service (BASS) is a specialised service which is supported financially by the Local Authority to employ social workers. BASS told me they would be able to help hundreds more adults every year if they had more resources. Future support by the Council could be provided in the shape of funding a small number of embedded specialist social workers. An example of this could be the funding a 'social prescribing' post, to signpost and accompany individuals on the ground to a variety of 'autism friendly' events happening in the city.

BASS has one social prescriber post shared across the four authorities of Avon. It is suggested that two or three social prescribers across BCC area would be required to begin to offer a more comprehensive service helping isolated adults start to construct less lonely and unfulfilled lives.

BASS also suggested to me that an 'awareness campaign' is needed. I believe this would be an important aspect of introducing a revised autism strategy, as my work has shown a broader context of people not understanding autism. This was particularly demonstrated in the case of individual AB where several agencies including the British Transport Police failed to understand the context of his autism.

The BASS team should also be enhanced to provide input into the Street Triage Service when responding to autistic people in crisis.

## **British Transport Police (BTP)**

My interactions with the former Chief Constable of the British Transport Police was unsatisfactory. I regret that the opportunity was not taken by the Chief Constable to examine and review past failures with a view to making changes in the way the BTP interact with people with autism and learning disabilities. My review of AB demonstrated the need for an urgent review by the BTP of their handling of cases involving people with autism and learning disability, and such a review should look at strategy and policy as well as effective training of officers. Leadership in this area must be demonstrated. The Keeping Bristol Safe Partnership will wish to review this matter.

## **Avon and Wiltshire Police**

As can be seen from the accounts of the families, the role of the police has been particularly problematic, and has led to significant difficulties for the individuals concerned in ways that were avoidable. This highlights the need for the police to thoroughly review their response to individuals they encounter who have autism and learning disabilities and their families. The accounts I have been given are extremely disturbing and unsatisfactory and I recommend the police review their processes in the light of these findings.

There were several specific suggestions that I discussed with the chief constable. These included the following.

- Wider promotion and use of the Safer Places scheme
- The expansion and availability of street triage
- The expansion and availability of liaison and diversion services
- A review of the police risk assessments process to include specific questions on autism and learning disability

## **Recommendations to Government**

In delivering this report I am conscious of the 10-year anniversary of the screening of the panorama programme which exposed the abuse that was taking place at the Winterborne view home for people with learning disabilities. I was asked by Government to review actions taken by the Authorities and to report with recommendations for future policy and practice, which I did in 2014. Progress has been made, for example the proposal to limit powers of detention under mental health legislation announced in the recent Queen's Speech. This is much to be welcomed.

But progress has been patchy, and the fact remains that when I looked at this matter in 2014 there were over 2000 people with learning disabilities and/or autism in institutions and that figure remains roughly the same now seven years later. Progress has been made in providing care plans for individuals to ensure their treatment in the community rather than in an institution but the reality is there is a "revolving door" whereby once a bed in the institution becomes available it is filled. There will be no progress until institutions close and there is a major investment in community provision.

However, it is now 10 years since the Panorama programme that exposed systematic abuse of people with learning disabilities in Winterbourne View. I made recommendations for change following my pendant review commissioned by NHS England. In particular I recommended that all institutions like Winterborne should be closed. There is a revolving door in institutions which accounts for the fact that placements remain at a high level. Despite considerable efforts to review the placements of people with learning disabilities and autism who have been in such institutions for some time and the success of these reviews, the fact remains that if a place becomes available in these institutions it is quite quickly filled. It is time to accept that this type of institutional care by its nature is abusive and must end.

I recommend that the Government make a clear commitment now to closing all such institutions and the transfer of resources into the community. A deadline of 2024 should be established for this closure programme. Major program of investment in community facilities should be set in train, particularly using social finance which helps tackle the problem of double funding whilst institutions remain open.

In my discussion with Avon and Somerset police we discussed how the public often can treat people with autism with hostility and the potential for making the recognition and reporting of autism as a separate and distinct form of hate crime. I recommend that the government give consideration to this proposal.

**Stephen Bubb**  
**May 2021.**