



Norfolk Safeguarding Adults Board

Safeguarding Adults Review: Joanna, Jon & Ben

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Summary

Safeguarding Adults Review concerning the deaths of three Cawston Park Hospital Patients

“...with the closure of long stay hospitals and the campus closure programme, a new form of institutional care developed: what we now know as assessment and treatment units. Not part of current policy, and certainly not recommended practice, these centres have sprung up over the past thirty years. Containment rather than personalized care and support has too easily become the pattern in these institutions.” (Burstow, P. (2012) Foreword to the DH Review. “Winterbourne View Hospital – Interim Report”)

The Background

1. During April 2019, Norfolk’s Safeguarding Adults Board (“NSAB”) commissioned a Safeguarding Adults Review (SAR) concerning the deaths of two adults at a private hospital, Cawston Park (“Hospital”).¹ During December 2020, the death of a third patient was added to the review’s remit. The deceased, Joanna, “Jon” and Ben were in their 30s. They had learning disabilities and had been patients at the Hospital for 11, 24 and 17 months respectively. They died between April 2018 and July 2020.
2. The Hospital is registered with the Care Quality Commission (CQC) for the assessment or medical treatment for persons detained under the Mental Health Act 1983 and the treatment of disease, disorder, or injury. CQC’s website states that it has 57 registered beds across six wards, two of which are locked wards, The Grange and The Lodge. The deceased were placed at The Grange and The Lodge.

The Safeguarding Adults Review

3. The purpose of the SAR was to set out the experiences of the three adults in terms of their care management and the care and support services commissioned on their behalf. In particular, the Review considered the impact of the Hospital’s registration, inspections by the CQC, the Hospital’s governance framework, safeguarding referrals, other alerts and the voice of former patients, their relatives, friends, and the relatives of current patients.

¹ The care provider at Cawston Park Hospital is Jeasal Akman Care Corporation Limited, a Private Limited Company providing “other human health activities.” Sally-Anne Subramanian and Tugay Akman are directors and Tugay Akman is the Responsible Individual

The Challenges

4. The Covid-19 pandemic resulted in six virtual meetings of the SAR Panel. Only the initial meeting was physically co-located. The Panel is made up of representatives from the Hospital, the Care Quality Commission, Norfolk's Adult Social Services Department including its safeguarding team, the Clinical Commissioning Groups (CCGs) responsible for placing the three adults, the ambulance service, the local acute hospital and community care NHS Trusts and the police.
5. As the Review's accounts of Joanna and Jon's circumstances was "coming together" there was another tragedy at the Hospital. It was envisaged that adding Ben's circumstances to the Review would enhance the legitimacy of its findings. A balance prevailed between ensuring that Ben was not shortchanged by being added to a SAR that was reaching its conclusion and ensuring that the SAR should not compromise his inquest.
6. The Review relied principally on the Hospital to provide information concerning the care and treatment of the three adults. It provided partial and incomplete information about their day to day lives.

The Lessons and Findings

7. Joanna, Jon and Ben were admitted to the Hospital under sections of the Mental Health Act (1983). Joanna and Jon originated from London boroughs. Ben was from Norfolk. Their behaviour was known to challenge services and sometimes their families. Joanna and Jon had experienced several out-of-family home placements. Ben had lived with his mother for most of his life. Their placement at the Hospital resulted from personal and family crises. It was the only placement which could be identified by Joanna's CCG which had previously made contact with 38 other services.
8. The relatives of the three adults, and those of other patients, described indifferent and harmful Hospital practices which ignored their questions and distress. They were not assisted by care management or coordination activities. People's families could not value the unsafe grouping of certain patients, the excessive use of restraint and seclusion by unqualified staff, their relatives' "overmedication," or the Hospital's high tolerance of inactivity – all of which presented risks of further harm. In addition, these patients did not benefit from attention to the complex causes of their behaviour, to their mental distress or physical health care.
9. There was no information for (i) 179 days of Joanna's stay (ii) a single day for Jon, and (iii) 450 days for Ben.
10. Families questioned the Hospital's undocumented assumptions concerning patients' mental capacity which appeared to transfer responsibility to patients. For example, Joanna and Ben used Continuous Positive Airway Pressure (CPAP) machines as a result of sleep apnoea. Joanna's inquest heard that in the last 209 nights of her life the CPAP had been used on only 29 occasions and that she did not want to use it. Her parents and all previous placements had prioritised its consistent use and maintenance. Neither her parents, nor her Consultant Neurologist, were advised that

Joanna had ceased to use her CPAP. Similarly, there were 115 documented occasions when Ben declined to cooperate with its use. It does not appear that attempts were made to desensitise either Joanna or Ben to using their CPAPs.

11. Joanna and Ben were obese. Although Ben's weight reduced to 13.3 stones within two months of his admission to the Hospital, two years later, his postmortem revealed that he weighed 18.10 stones. Their CPAP machines would have required adjustments as a result of weight gain. Their protracted physical inactivity increased their risk of obesity, high blood pressure, high blood cholesterol, diabetes and heart disease. They did not benefit from being accompanied to outpatient appointments by support workers who (i) were competent in managing their anxieties and (ii) possessed up to date information concerning their health status.
12. The Hospital did not seek vital information about people's pre-Hospital lives. All that may be reliably gathered from Jon's records is that setting a discharge date is a meaningless activity if no attention is given to planning for this; specialist hospitals which are remote from people's families have unchallenged scope to retain patients; and there are no consequences if Clinical Commissioning Groups responsible for placements are not represented at critical review meetings.
13. There did not appear to be any timetabling discipline at the Hospital in terms of people's daily and weekly activities. Activities in which adults had particular expertise and interests, such as swimming, painting and drawing, for example, were not prioritised.
14. The Hospital is disadvantaged by the absence of accurate and timely information flowing up to managers and directors and down to staff and patients. Although first-person accounts from patients and their relatives are powerful means of establishing the impact of a service and would provide a holistic view of performance, they are absent. Little may be discerned of the Hospital's corporate and financial governance or the extent to which this is intertwined with clinical governance.
15. A CQC report during 2019 stated "The hospital was not working to the model of an assessment and treatment unit and therefore its operation was not in line with the expectations of the Transforming Care Programme." Its subsequent reports indicate that the Hospital was mired in familiar stalemate.

Conclusions and Recommendations

- a) **Norfolk's SAB should write to the Law Commission proposing a review of the current legal position of private companies, their corporate governance and conduct in relation to services for adults with learning disabilities and autism.** Given the clear public interest in ensuring the well-being and safety of patients, and the public sponsorship involved, the Law Commission may wish to consider whether corporate responsibility should be based on corporate conduct, in addition to that of individuals, for example.

- b) **Norfolk and Waveney CCG and Norfolk ASSD should review their commissioning arrangements to embrace “ethical commissioning.”**² This should attend to:

“Ethical employment: Commissioners must be able to distinguish between the workforce practices of different providers and prioritise those acting as ethical employers.³ This might include prioritising those companies that are accredited by the Living Wage Foundation; have effective training, development and supervision; sign up to an ethical care charter; outlaw false self-employment and zero-hours contracts; and encourage staff to participate in collective bargaining.

Tax compliance: The ownership of all companies contracted to deliver public services should be available on public record. At the same time, a taxation test could require contracted private companies to demonstrate that they are based in the UK and subject to UK taxation law.

Transparency: A transparency test could stipulate that where a public body has a legal contract with a private provider, that contract must ensure full openness and transparency with no recourse to the cover of “commercial confidentiality...”

Localism: A focus on smaller and more local commissioning is needed – a challenge for public services commissioners who generally favour dealing with a small number of large organisations with established contracting infrastructures. Smaller organisations hold vast expertise about the precise issues affecting people in their area and can serve very small or isolated communities or specific communities of interest.

Ethical vision: To create change in adult social care, we need a guiding vision, rooted in ethical considerations of promoting good lives well lived, and protecting the wider economic, social and environmental wellbeing of a local area. Procurement legislation in Scotland seeks to promote just such a vision but has no real equivalent in England.”⁴

In addition, a **Community Benefit** test to nurture connectedness to communities would ask potential providers what they will gift to a locality. For example, apprenticeships for local school leavers; opportunities for local businesses and farms to provide goods; the provision of studio spaces for artists; and growing plots for gardeners. This would allow local credit for initiatives to be dispersed and to take root. The test should require the provider to exemplify the community benefit every year, in believable human terms, using people’s own words, for example.

- c) **Evidence of changing commissioning arrangements should be shared with Norfolk’s SAB.**

² <https://socialcarefuture.blog/2019/09/19/adult-social-care-and-ethics-time-for-a-new-relationship/> (accessed 13 April 2021)

³ This should embrace reliable identity and other pre-employment checks. See for example, https://www.cipd.co.uk/Images/pre-employment-checks-guide-dec-2020_tcm18-51572.pdf (accessed 1 April 2021)

⁴ See article by Bob Hudson: <https://www.theguardian.com/society/2018/aug/20/ethics-new-approach-outsourcing-social-care> (accessed 20 March 2021)

- d) NHS – England should ensure that (i) all placing CCGs are proactive in ensuring that they have up-to-date knowledge about the services they commission and how these are experienced.** The “four eyes principle” may be useful, most particularly if the additional “eyes” are those of a parent whose relative has current or recent experience of the assessment and treatment services being commissioned;⁵ and (ii) that when transfers take place between in-patient settings, these cease to be recorded as “continuous inpatient stay ...treatment for the purposes of the one year CTR” [Care and Treatment Review].
- e) Norfolk and Waveney CCG and Norfolk County Council should transfer all its remaining patients from this Hospital.**
- f) Norfolk’s SAB should make representation to the Department of Health and Social Care to ask what additional rights and protections will be afforded to adults with learning disabilities and autism who become vulnerable to detention in the same clinical settings under the Mental Capacity Act (2005).⁶**
- g) Norfolk’s SAB should share this review with NHS – England since it was responsible for Jon’s placement. NHS – England and the CCGs responsible for placing people at Cawston Park Hospital should visit services, host reviews and ask questions** such as:
- how many patients have returned to Cawston Park Hospital for further assessment and treatment?
 - does Cawston Park Hospital have admission criteria concerning patients who have had previous episodes of assessment and treatment?
 - are there periods when the patient we fund is super-busy or are their days characterised by naps, snacking and sitting for hours?
 - are routines such as cleaning teeth, bathing, showering, changing clothes, hair washing and nail cutting, for example, expected and actively supported?
 - does the patient we fund sleep deeply during the night because they are physically tired?
 - how is the patient we fund, who is malnourished and/ or obese, encouraged and supported to make dietary and lifestyle changes?
 - what happens if the physical health of the patient we fund deteriorates because they are resisting essential, prescribed treatment such as CPAP?
 - what happens if the patient we fund refuses to participate in activities?
 - what examples are there of Cawston Park Hospital maintaining and developing the ability of patients to perform daily tasks and promoting their participation in purposeful and valued occupations?

⁵ The requirement that a business transaction should be approved by at least two individuals <https://www.collinsdictionary.com/dictionary/english/four-eyes-principle> (accessed 8 November 2019)

⁶ *The unintended consequences of taking people with learning disabilities and/ or autism out of scope of the Mental Health Act 1983* <https://thesmallplaces.wordpress.com/author/lucyseries/> (accessed 24 March 2021)

- on how many occasions have acute hospital security staff assisted Cawston Park Hospital's support workers to subdue an inpatient during acute hospital admission or attending clinic appointments?
 - where are the service destinations of all former Cawston Park Hospital inpatients?
- h) NHS-England should be invited to provide evidence to Norfolk SAB that these questions have been circulated and incorporated into its own processes.**
- i) Placing/funding Clinical Commissioning Groups are keepers of the public purse. NHS-England is invited to bring forward evidence of strengthened mechanisms for: discharge dates; the stability of accommodation within a service; close attention to an inpatient's physical health needs and experiences, their mental health needs and experiences, and the service's track record in addressing these.**
- j) Norfolk's SAB should propose to the CQC that the legal process of registration cancellation should proceed irrespective of a service's improvements if these are attributable to the ongoing efforts of the NHS, local authority social care employees and Inspectors.**
- k) Norfolk's SAB should set out for CQC's Chief Executive the consequences of Cawston Park Hospital's failure to enable family-centred approaches and engage with the expertise of patients' relatives. This is paralleled in CQC inspections. The inspectors would benefit from including parent "experts by experience" with recent experience of seeking to work with assessment and treatment services and units (see, for example, families' contributions to this Review). To maintain public confidence, CQC may wish to confirm (i) that it has no remit to determine whether patients should remain in such services, not least since this conflicts with national policy; and (ii) what specific actions it proposes to take in relation to locked wards in specialist hospitals and units.**
- l) Norfolk and Waveney CCG and the County Council should rebalance responsibility for Norfolk citizens away from "medical led admissions and social care discharges." The reform of the Mental Health Act (1983) should anchor discussions and agreements between these public authorities concerning ethical commissioning.**
- m) The taboo of addressing the racism of people with cognitive impairments remains to be explicit and made visible in all services. Norfolk's SAB should begin a process of (i) gathering the efforts and experiences of the county's service providers in challenging racism and racist stereotyping and (ii) convening "world café" conversations⁷ with providers and other interested people, including those at the sharp end of injustice.**

⁷ A process for fostering collaborative dialogue, sharing information and discovering opportunities for action. See Brown, J. with Isaacs, D. (2005) *The World Café – Shaping Our Futures Through Conversations That Matter* San Francisco: Berrett-Koehler Publishers, Inc.

16. The roots of private, specialist hospitals reside in business opportunism and profit-driven priorities. These are hospitals in which patients receive neither specialist assessment nor credible “observations” and treatment. The deaths of three young adults must plausibly question the “system response” - CQC’s continued registration of such hospitals and their continued use by CCGs and NHS-England.
17. There is a crucial difference between the health advocacy of patients’ parents and that of staff, regardless of pay scales. Cawston Park Hospital failed to recognise that its interventions were unequal to aiding patients in their physical and mental distress. It neither built nor sustained trust. It did not serve the larger aims of three people’s lives. Joanna was supported by staff who were untrained in the use of her CPAP. They did not begin CPR and a learning disability nurse and two support workers believed that her epilepsy was due to her “playing up and shouldn’t be minded.” The response to Jon’s breathing difficulties was unduly slow even though he had pleaded “I cannot breathe. I am dying.” Ben had ceased to use his already underused CPAP and his low SATS symptoms were ignored. His mother’s insistence that an ambulance should be called had no impact. Unless this Hospital and similar units cease to receive public money, such lethal outcomes will persist.

Acknowledgements

I am indebted to the families of people with learning disabilities and autism who became patients at Cawston Park Hospital, and to former patients. Their experiences have a compelling call on our attention.

Particular thanks are due to the Review Panel members who shared their understanding about events at Cawston Park Hospital. Their aspiration to identify people’s support needs and credibly intervene before they are labelled as challenging will be a fitting, post SAR legacy.

The GP member of the SAR Panel undertook a significant medication review and brought valuable understanding to the Panel’s discussions concerning drugs and other therapies. In addition, Norfolk’s Safeguarding Practice Consultants, who collated summaries of risks and risk concentrations from the Hospital’s many referrals, and the Social Work practitioner who continues to work with the families of Norfolk patients merit sincere thanks for their contributions.

I have been able to count on Walter Lloyd-Smith and James Butler for their assistance and commentary in reading and proof-reading drafts of the Review. They have provided much more than administrative support in seeking out information and exploring its relevance in stimulating discussion.

I hope that this Review, which is dedicated to Joanna, Jon and Ben, provides a further impetus to challenging an obsolescent model of specialist provision.

Section A: Introduction

Background

1. During April 2019, Norfolk's Safeguarding Adults Board ("NSAB") commissioned a Safeguarding Adults Review (SAR) concerning the deaths of two adults at Cawston Park Private Hospital ("Hospital"). During December 2020, the death of a third patient was added to the review's remit. The Hospital is owned by the Jeasal Group. It provides "assessment, treatment and rehabilitation" in six wards for up to 50 patients. Joanna died 17 months after her admission. She was 36. A man ("Jon") died 11 months after his admission to the Hospital. He was 33. Another man, Ben died 24 months after his admission.⁸ He was 32.
2. The NSAB's interest is fivefold:
 - i) Care Management - including the pre-placement assessments, care planning (including health care) and reviewing; how agencies worked together; daily programmes and family support of the three adults, plus those of the nine Norfolk citizens who were patients at the Hospital – some of whom remain there.
 - ii) Commissioning – drawing on the community needs planning and market development in three localities of origin.
 - iii) The Provider/ Jeasal Group – including its history and significant events at Cawston Park; its track record of providing effective treatment and returning people to their localities of origin; the training and professional development opportunities for staff.
 - iv) Quality Assurance – including the provider's governance framework; registration and inspections.
 - v) Adult safeguarding – the volume and characteristics of safeguarding referrals from Cawston Park; the alerts arising from other agencies; and the oversight of both.
3. A related interest of the NSAB concerns the place of specialist private hospitals in the provision of support to adults with learning disabilities and the outstanding systemic issues. Although the scandal concerning assessment and treatment at Winterbourne View Hospital led to Department of Health investing in a Transforming Care programme of reform (costing around £10m), not a great deal has changed. Subsequent scandals at St Andrews Hospital in Northampton, Whorlton Hall in Barnard Castle, Cygnet Yew Trees Hospital in Frinton-on-Sea and Cygnet Woodside in Bradford, for example, do not diminish the anguish of families that their relatives with learning disabilities and autism continue to be treated as if they require long term care and treatment in hospitals. As this SAR attests, these specialist hospitals and units have a poor record in promoting and attending to people's physical health care

⁸ Joanna's father and Ben's mother have given permission for their first names to feature in this review.

and, indeed, in their core functions of assessment and treatment.⁹ During 2019, the British Association of Social Workers (BASW) England promoted a “Homes not Hospitals” work-stream. Its campaign “was created in response to issues with the current system that sees too many autistic people and people with learning disabilities detained in hospital Assessment and Treatment Units or restrictive care arrangements and seclusion units. There is an over-reliance on in-patient care and people can spend too long in hospital before appropriate support is available for them to be discharged...The aim...is to promote preventative approaches in terms of commissioning, human rights based practice, the role of social work and legal literacy to reduce the risk of situations from reaching the point of hospital admission.”¹⁰

The Review Process

4. There were nine sets of activity:

- i) Discussing and agreeing the Terms of Reference with Norfolk’s SAB [August-September 2019] and the Panel brought together for the SAR [see Annex 1]
- ii) Summarising the information provided by the commissioning bodies responsible for placing Joanna, Jon and Ben at Cawston Park and that of the Care Quality Commission; documents concerning Joanna and Jon’s inquests; and the media coverage of these inquests.
- iii) Talking to Joanna’s parents and Ben’s mother, making notes and checking out the accuracy of these with each of them [during December 2019 and January 2021 respectively]
- iv) Summarising and organising information as it became available concerning Joanna and Jon’s experience of treatment at the Hospital [March and April 2020]; and Ben’s [January and February 2021]
- v) Seeking answers to questions arising from organisations [July/August/September/October 2020; February 2021]
- vi) Reviewing emergent findings and progress with the Review Panel via meetings – all but one of which were virtual.
- vii) Reporting the outcome of meetings with patients, former patients and the relatives of patients [December 2020 and January 2021]
- viii) At the invitation of Norfolk’s SAR Group during January 2021, to represent it as an Interested Person at a Pre-Inquest Review Hearings concerning Ben.
- ix) Circulating information summaries, sections of the review and finalizing the review.

The Limiting Considerations

5. The initial meeting of the SAR Panel took place during December 2019. A meeting planned for 31 March 2020 was cancelled due to the Covid-19 pandemic. Virtual panel meetings took place on 25 June, 29 July, 17 November 2020, 14 January, 23 February

⁹ <https://www.learningdisabilitytoday.co.uk/a-decade-on-from-winterbourne-view-where-are-we-now> (accessed 13 April 2021)

¹⁰ <https://www.basw.co.uk/events/basw-england-webinar-homes-not-hospitals-campaign-launch-key-documents> (accessed 16 May 2021)

and 23 March 2021. The minutes and actions arising from each meeting were confirmed at the following meeting and documents prepared by the SAR author in advance of these meetings were the vehicles for Panel members to share their reflections and ideas, ask questions and provide feedback. The challenges of the virtual meetings included poor internet access, different audio and video technologies and less interactive meetings due to the lack of visual cues. The latter was addressed by regular invitations to comment within carefully timetabled meetings. However, some Panel members reflected that, in contrast with physically co-located meetings, collaborative working via virtual meetings is in its infancy.

6. As the Panel's feedback on the trends and themes from the accounts of Joanna and Jon's circumstances was "coming together," there was a further tragedy at the Hospital. It was agreed by NSAB's SAR Group that Ben's death met the discretionary criteria for a SAR (S.44 Care Act 2014). As there was already a well-advanced SAR and a Panel familiar with the ways of the Hospital, NSAB took the view that adding Ben's circumstances to the existing Review had the potential to deepen the legitimacy of its findings.
7. Agencies had pooled information to create a chronology of events covering Ben's detention at the Hospital and this became available at the end of January 2021. The Review's timeframe [see Annex 2] did not allow the relevant agencies to produce their own account of their decision-making concerning Ben. However, an inquest was to be held because Ben was detained, his death was sudden and agencies were preparing information for the inquest. Since the SAR author had summarised the chronology concerning Ben, had met some former patients and their relatives and was in discussion with Ben's mother, she was recommended to the Coroner to contribute to the inquest as an Interested Person. This enabled access to unanticipated information about Ben. A balance prevailed between ensuring that (i) Ben was not shortchanged by being belatedly added to a SAR that was reaching its conclusion, and that (ii) the SAR should not compromise the inquest concerning his death. Although the Review benefitted from the pathologist's recording of Ben's weight, for example, it relied principally on information submitted by the Hospital.
8. Chronologies concerning the three adults were the principal focus of Panel discussions. However, they were based on partial information since the Hospital's chronologies were incomplete. That is, for 179 days, there was no information concerning Joanna. This represents one third of her time as an inpatient. Similarly, for 450 days, there was no information concerning Ben – there is information for just over a third of his time as an inpatient. Necessarily the reviewing process involves questioning and a great many questions were generated by the incomplete chronologies. Although the Hospital requested a generous timeframe within which to answer the many questions [over 30 concerning Joanna, over 40 concerning Jon and over 120 concerning Ben] arising from each chronology, it acknowledged that it was unable to do so because it was without the resources to review its records since many staff had left.

Section B: Joanna

Joanna's parents

9. They described their daughter:

"She was happy and fun-loving. She loved music, loved Michael Jackson, discos, karaoke, going to see musicals and pottery. She hated PE and long walks – physical stuff. She had a learning disability from birth and was "statemented" when she was at school. At 12 years she went to a special needs school. It was when she was 17-18 years that she developed seizures and her epilepsy – it took over her life. She couldn't work.

She saw her brother becoming more independent and she wanted to be independent as well. She wanted to go out on her own and it was not easy. We always had a call from the police. One time they thought she was a victim of a hit and run because she had a seizure crossing the road. We had calls from shops when she had seizures. We had to take her to hospital each time. There was an occasion when the police saw her on CCTV being taken into a park by foreign men. Thankfully they intervened.

She wanted to move out and be independent, but we knew how vulnerable her seizures made her. Whenever we went on holiday, we used to spend hours in A&E with her.

Joanna was a patient of Professor [...] – a neurologist [at a London hospital]. He organised for Joanna to be assessed at the [specialist] Centre for a month. She had scans and was monitored. The assessments confirmed that she had epilepsy and that she also had non-epileptic seizures.¹¹ The two kinds of seizures look alike but it was explained that Joanna was having the non-epileptic seizures as a way of the brain protecting itself from worries and fears. The majority of her seizures were the non-epileptic kind, but she was still having epileptic seizures.

[There was a time when Joanna] was having as many as 20 seizures a day. It meant that we were more or less prisoners. It would get better over time. They got the seizures fairly well controlled. When she was happy her seizures reduced.

One time, Joanna was in hospital for about two months. We were told that she had brain scarring which gave her the seizures and the mental health problems. Then the seizures came back with a vengeance.

She went back to the mental health unit. She kept seeing people and it made her very frightened. Social services were clear that because of her seizures it would be better

¹¹ Non-epileptic seizures (NES) or dissociative seizures may look similar to epileptic seizures, but they are not caused by abnormal electrical activity in the brain... Some NES are caused by mental or emotional processes, rather than by a physical cause. This type of seizure may happen when someone's reaction to painful or difficult thoughts and feelings affect them physically. These are called dissociative seizures. See <https://www.epilepsysociety.org.uk/non-epileptic-seizures> (accessed 3 June 2020)

if she went into a residential home with people of her own age – and not supported living.

Joanna went into [a home in a London borough] in about 2011/12. There was another woman and she and Joanna gelled well. There were six men there. Joanna was there for five years. Although she had seizures, she had a good time there. She enjoyed pottery, the gym, going to the cinema, shopping and going to the theatre. She had a good life there.

There was a time in 2011/12 when Joanna was very sleepy. Her iron was checked – it was ok. They found that she had obstructive sleep apnoea which meant she was not getting any deep sleep. So, she was put on a Continuous Positive Airway Pressure [CPAP]¹² machine. It meant that she had more energy during the day. It was fiddly for her to put the mask on, so the staff used to help her. She had a bell so she could let them know if she was using the toilet in the night. When she went back to bed, they'd help her put the mask back in place. Also, they'd clean it every weekend. It was the same at home. It's what we did.

It was when Joanna's grandma died that she went downhill. Her mental health problems became more apparent and she had more seizures. She used to see the psychiatrist and psychologist every month...then it was every three months. The services were cut. Then two years later her grandad died and she went further downhill. She said she could see them and it made her frightened. She had more seizures. She said "I can't carry on. I need help." Her appointment was put back.

At the [residential home] the staff used to remove the knives from the dishwasher and the girls would unload the crockery. Somehow Joanna got hold of a knife and she took it to her bedroom. She pushed it into her stomach. She was quite large at this time with all the tablets. She went downstairs to the staff and asked them, "Could you take this out. I can't get to sleep with it in." She had to go into hospital to have it removed. Because of her size she had missed all her internal organs. She was sectioned [under the Mental Health 1983] and went to...a hospital... for women with learning disabilities and mental health problems. It didn't do her much good. It was full of fire-starters and ex-Holloway prisoners. They gave her a hard time.

Then Joanna went to... [an NHS] Hospital. They said they couldn't do any more for her because of her challenging behaviour. Social services searched for somewhere and [during late] 2016 she was admitted to Cawston Park. She must have had a terrific scare. She was taken there at night and would have arrived in the early hours.

Joanna would never speak up and would never ask for help...Mentally [she] was like a 6-8 years old and she had autism. She could read but that didn't mean she could understand what she'd read. [Her Care Plan stated that staff should] "use clear sentences because [Joanna's] ability to understand is limited."

¹² This provides non-invasive, positive pressure ventilation.

On one visit Joanna told us that the CPAP had fallen onto the floor. Because we couldn't go into her bedroom, I asked her to bring it down to the Visitors' Room. The machine was working! Other places Joanna stayed in knew they had to assist her with the mask. The police told us that because it wasn't written into the care plan they couldn't prosecute.

We didn't know Joanna wasn't using it. She wouldn't tell us. After she died, we were told that the recordings showed that the CPAP had only been used for an odd night and over the Christmas period for a week in 2017.

The CPA [Care Programme Approach]¹³ meetings of 23 February 2017, 25 August 2017 and 10 April 2018 stated, "Medical concerns: 7 – high risk." It doesn't mean that they did anything. They never mentioned her seizures or the CPAP and social services didn't push much. She was funded by Continuing Health Care¹⁴ – over £1k a day. [One of its team noted that] Joanna will always be one-to-one because of her epilepsy. After she died we were told that she was only on "general observations." A doctor at the Hospital explained that he had discussed this change with Joanna."

Cawston Park

10. The Hospital confirmed that:

- Joanna "had been suspended from several community placements due to episodes of harm to self and others."
- at 21 years, Joanna took an overdose of paracetamol. She was assessed by the Community Learning Disability Team which subsequently discharged her.
- she "came under the care of neurology [due to] her epilepsy and non-epileptic seizures" (NES)
- at 25 years, Joanna was admitted to Hospital 1, where she became an informal patient for eight months. This resulted from "an episode of distressed behaviour...she threatened her father with...scissors [and] a knife."
- following discharge from Hospital 1, she transferred to a rehabilitation unit which could not manage her "distressed behaviours." She was admitted to "an inpatient unit under the MHA" but since "concerns [arose] about her care and treatment at this Hospital... [she returned] to Hospital 1 where she made good progress and was discharged in 2011 to a community residential placement" in a London borough.
- Joanna remained at the London borough unit for four years, at which "she appeared to have made good progress." She saw her parents on alternate weekends.

¹³ A framework used to assess, plan and coordinate care and support: <https://www.rethink.org/advice-and-information/living-with-mental-illness/treatment-and-support/care-programme-approach-cpa/> (accessed 7 April 2021)

¹⁴ People with long term complex health needs qualify for free social care arranged and funded solely by the NHS. This is known as NHS Continuing Healthcare <https://www.nhs.uk/conditions/social-care-and-support-guide/money-work-and-benefits/nhs-continuing-healthcare/> (accessed 14 April 2021)

- She was “later diagnosed with sleep apnoea and...was prescribed a sleep mask for oxygen during nighttime...”
- “Towards the end of 2014 her mood deteriorated.” Joanna described thoughts of suicide and she stabbed herself in the abdomen and required surgical attention [at “Hospital 2” – an acute hospital]
- She was admitted to Hospital 3, at which she exhibited “features of depression...thoughts of suicide...hearing and seeing things...”
- Joanna returned to Hospital 1 during 2015 and, during July 2015, was detained initially under S.2 and then S.3 of the MHA. She had “...reported hearing voices telling her to kill herself.”
- During January 2016, Joanna transferred to Hospital 4, which specialised in supporting women with learning disabilities and personality disorders. However, since she self-harmed, was violent towards others and was “targeted by other patients,” her parents, social worker and CCG sought an alternative provider.¹⁵

11. Joanna was admitted to Cawston Park under S.3 of the MHA during October 2016. On admission she had “a reported history of Moderate Mental Retardation (ICD10-F71);¹⁶ Emotionally Unstable Personality Disorder (ICD 10-F60.3);¹⁷ and epilepsy as well as non-epileptic attacks.”
12. The Hospital states that Joanna “made good progress [with]...improvement in her mental health and associated reduction in...distressed behaviours as well as a reduction in the use of physical intervention, or as a last resort, seclusion...in early 2017 due to the significant nature of Joanna’s distressed behaviours and assaultive behaviour towards staff, she was managed in seclusion on numerous occasions.¹⁸ Her progress was highlighted in internal and external Care Programme Approach (CPA) meetings as well as in Care and Treatment Reviews (CTR)¹⁹...In early 2018, Joanna was [diagnosed as being] on the Autistic Spectrum...[her self-] reported history of traumatic events...resulted in occasional flashbacks...it was reported that [she] became assaultive sometimes in order to gain physical contact with male staff that occurred during physical intervention...[she] reported experiencing flashbacks whenever she was restrained by male staff.”

¹⁵ The [placing] CCG confirmed that Joanna was unhappy and her needs were not being met at Hospital 4

¹⁶ An intellectual disability code.

¹⁷ A disorder characterized by an enduring pattern of unstable self-image and mood together with volatile interpersonal relationships, self-damaging impulsivity, recurrent suicidal threats or gestures and/or self-mutilating behaviour. See <https://www.icd10data.com/ICD10CM/Codes/F01-F99/F60-F69/F60-F60.3> (accessed 3 June 2020)

¹⁸ Joanna’s parents recalled that this Hospital was “...*the only place in which she was put into seclusion. On one occasion she was there for 12 hours*”

¹⁹ There were two CPAs: on 16 January 2017 and 10 May 2018; and three CTRs - Placing CCG. A CTR noted “No Health action plan, no new care plan could be found;” the CTR on the day before Joanna’s death “identified a number of concerns regarding support and care...the action plan included [the expectation that the Hospital would] repair the CPAP machine...”

13. The Hospital's psychology department "introduced a Positive Behaviour Support plan that staff used to help her prevent and/ or manage her distressed behaviours."²⁰
14. Joanna's physical health was compromised. In addition to her epilepsy, she had glaucoma; a "history of anaemia;" she had sleep apnoea, which was associated with her obesity; she had asthma;²¹ an underactive thyroid; constipation; and she was prone to cellulitis. At the Hospital she was taking medication for her epilepsy, anaemia and constipation. In addition, she was prescribed medication "to help with reducing reported voices and behavioural disturbance...[an] anti-depressant...PRN medication²² [for] when she was anxious/more aroused, for asthma...dyspepsia...[and] pain associated with [menstruation]." Joanna "had extensive contact with our physical health nurse at the Hospital...as well as our visiting GP service." During April 2018, Joanna's GP advised staff to "help her with her diet" because blood tests revealed that she was pre-diabetic.²³
15. The Hospital recorded that Joanna "was observed to have experienced 12 query epileptic seizures and a minimum of 20 query non-epileptic seizures...a minimum of 32 recorded seizures over approximately 16 months."²⁴ It does not appear that the Hospital shared the skills of Joanna's parents who were acknowledged as "good at distinguishing the two types of attacks..."²⁵
16. With reference to Joanna's mental capacity, the Hospital stated that she "had the capacity to give informed consent to her medical treatment²⁶...she appeared to have capacity and insight into her particular condition...Joanna was able to differentiate between the two [types of seizures. During the non-epileptic seizures] she was able to hear what people were saying around her..." However, the Hospital noted that "the lack of clarity in the manifestation of these conditions affected the ability of staff to provide appropriate support at all times" [see Annex 3].
17. With specific reference to the CPAP machine, it was noted that Joanna understood its purpose, that is, to reduce discomfort during sleep and tiredness. There was an occasion at the Hospital when "she asked...staff to lock her CPAP machine away" so that she would not break it. "As there was no documented mental capacity assessment in respect of her non-compliance [with the use of the CPAP], it was difficult to appropriately determine her non-compliant behaviour either as an unwise decision (Mental Capacity Act 2005) or a result of lack of capacity to understand the

²⁰ Positive Behaviour Support "teaches alternative behaviour and changes the environment to support the person well." <https://www.challengingbehaviour.org.uk/learning-disability-files/03---Positive-Behaviour-Support-Planning-Part-3-web-2014.pdf> (accessed 14 April 2021)

²¹ The use of Joanna's inhaler is cited in records eight months before she died

²² Administered on a "when required" basis

²³ GP's inquest statement

²⁴ As confirmed at her inquest: <https://www.bbc.co.uk/news/uk-england-norfolk-55106221> (accessed 28 November 2020)

²⁵ Joanna's Consultant Neurologist

²⁶ The GP [surgery commissioned to provide primary care services at the Hospital] advised that "there were no concerns in relation to [Joanna's] capacity to understand [her] care needs" – Norfolk and Waveney CCG

consequences of not using her CPAP machine. She...declined to attend the sleep apnoea clinic at an acute hospital for specialist input.” Joanna’s “lack of engagement” with the clinic was described as, “an area of difficulty...her non-attendance [at] an offered appointment...proved too costly in the end.” Her CPAP machine was not used on the night of her death.

18. The Hospital states that “most patients...are on general observation where staff would record what patients were doing, usually every 15 minutes to an hour. If there are particular concerns regarding patients’ risks, [they] may be placed on enhanced observation...with...1:1 supported observation or in extreme circumstances, 2:1.” Joanna was subject to enhanced observation between November 2016 and August 2017. She “was on general...observation” when she died. During “the night of her passing, the accuracy of the record of her night observation was inconsistent with the CCTV footage...Staff on duty did not commence CPR [cardiopulmonary resuscitation] as expected and the overall management of the incident that night was below standard...staff did not follow relevant policies and procedures – Code Blue assistance was not called; CPR was not applied until the ambulance crew arrived and the record of observation was inaccurate.”
19. The inquest confirmed that a registered nurse and five care workers,²⁷ all of whom were first aid trained, did not attempt resuscitation when Joanna was found unresponsive in her bed. By the time that paramedics arrived she had not been breathing for at least 18 minutes. It was explained that “they hadn’t been trained to do [CPR].”
20. The support workers on duty on the night that Joanna died confirmed that their number hinged on “the number of residents and the type of observations required. The Nurse...in charge of the shift [was] ultimately responsible. [Checks during the night ensured that patients] were safe, asleep and breathing...” However, “there should have been 12 support staff” and there were only ten. One support worker said that Joanna was “on general observations not one-to-one.” Some of the support staff could not recall whether her checks were at 15- or 30-minute intervals. It would appear that hearing Joanna snoring constituted a “check.”
21. The support workers confirmed that there were not enough radios for staff [“in case staff needed help with something or an emergency situation”] because these were being charged elsewhere. When staff became aware of Joanna’s condition, that is, when neither her pulse nor blood oxygen levels could be found, two staff were having a break and were unavailable because they did not have radios. In addition, the absence of Wi-Fi in some parts of the Hospital resulted in delays to entering information to the Hospital’s system. Access to the Hospital’s information system was determined by the status of staff, i.e., core and bank staff had usernames and passwords and agency staff did not. Managers could make minor, corrective amendments to incident reports. However, a manager confirmed in their statement

²⁷ The staff team on duty included a mother and son.

that factual “tidying-up” was commonplace. Several alterations were made to the incident report of the period before and after Joanna became unresponsive.

22. Support workers stated that the Nurse in Charge said that [...] could not do CPR, the nurse did not instruct staff to do so and they could not override this decision. This conflicted with the nurse’s recollection of events.²⁸ Staff on duty during the night of Joanna’s death could not recall reading the “Patient Death Policy” or receiving specific training about this and other policies. They were not trained in the use of a CPAP.
23. The Hospital’s Serious Incident report of 1 May 2018, states that Joanna’s “...post-mortem was carried out on 1st May 2018. The Coroner’s report gave cause of death in the opinion of the Consultant Histopathologist as... 1a. sudden unexpected death in epilepsy (SUDEP); 1b. primary generalised epilepsy. 2. Obesity and obstructive sleep apnoea.” The Coroner concluded that Joanna’s death was due to natural causes. “Whilst the Coroner refused to permit the jury to consider Joanna’s death was contributed to by neglect, the jury found that CPR was not administered...there were inconsistent observations...and her care plan was not accessible to staff...The jury expressed concerns regarding a. The availability of radios and communications b. quality of audits and spot checks c. quality of training and competency including regular follow-ups d. communication, comprehension and understanding e.g. language barriers with staff and patients e. staff shortages f. communicating effectively with family g. training on relevant and patient specific equipment h. fear of blame culture stopping adequate care of patients in response to emergency situation i. management information j. relevant patient information to be accessible to all staff k. governance and control.”²⁹ On 31 January 2021, Joanna’s father reflected on the experience in an article entitled “‘Pathetic’ legal system has failed my daughter” in the Eastern Daily Press.
24. Although no event can be understood in isolation, something of Joanna’s days at the Hospital could be gathered from consideration of her activities, her health and behaviour each month.³⁰ Her transfer to the Hospital then additional transfer within the Hospital after four days was associated with epileptic seizures and behaviour requiring staff intervention, and specifically, her aggression. Over the following weeks Joanna made threats to abscond, she rang 999 to complain about the Hospital, she removed her clothes and she self-harmed. Joanna favoured sleeping on the lounge sofa rather than her bed. She was “on 1:1 constant observations”³¹ which changed over time. The rationale for the change is not clear.
25. It is difficult to discern a plan to Joanna’s activities even though they were circumscribed and mostly sedentary. She engaged in “self-directed activities” on over 25 days; there are records of 17 grounds walks; 10 bus trips; visits to the farm plus

²⁸ The nurse’s [adult child] was working on the same shift.

²⁹ <https://www.inquest.org.uk/joanna-bailey-close> (accessed 16 May 2021)

³⁰ For a period of seven months – March-September 2017, the Hospital’s notes are incomplete.

³¹ This was stated on 13 November 2016.

some “ward-based activities.” During September 2017, one of the months when the Hospital’s records are unaccountably inadequate, the records state that “Joanna spent the majority of mornings in bed asleep.” A CPA during March 2017 highlighted Joanna’s “wish to be involved in more activities...[she] attended one out of four [educational skills development] sessions. The reasons were one was cancelled due to her behaviours and the rest was due to her being asleep.” A member of the Review Panel recalled that, in relation to other patients, the Hospital had inappropriately cited their personal care as an example of activity.³²

LEARNING IDENTIFIED

Physical activity is an important determinant of physical and mental health with clear links between activity levels and mood. However, the quantity of Joanna’s unstructured days at the Hospital underline research findings which conclude that the population of adults with learning disabilities is “incredibly inactive [hence] the crucial need to increase [their] physical activity...”³³

26. Responses to Joanna’s behaviour included physical intervention or restraint, seclusion, medication – which she occasionally declined, activity sessions, including education and skills development and psychology sessions. There were over 10 occasions when Joanna was subjected to seclusion and at least one of these was overnight. (The duration of these is not revealed.) There were over 40 references to Physical Intervention and over 30 references to the administration of PRN³⁴ medication, some of which were intramuscular.
27. During December 2016, Joanna attended hospital for an electroencephalogram (EEG). She experienced seizures which lasted for over an hour. As Joanna and “support staff were leaving...she reported feeling confused and asked to sit down...she fell to the floor, hitting her head and had another seizure, she became incontinent of urine. [Subsequently she had a nosebleed and because she became agitated, she was taken to A&E. Once she was determined to be fit for discharge] she became severely agitated and security staff were called to assist. Intramuscular Olanzapine was administered “to aid calming.”
28. Joanna had over 30 sessions with a trainee psychologist; over 20 sessions with an Occupational Therapist, including sessions which focused on Activities of Daily Living. She had five with a social worker. Given that such sessions were the only activities cited in records, it appears that Joanna’s days were typically unstructured.
29. Annex 4 provides a sample of the Hospital’s response to questions arising from information it provided concerning Joanna, Jon and Ben.

³² Virtual Panel Meeting of 14 January 2021

³³ <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4929079/> (accessed on 20 November 2020)

³⁴ Pro re nata: the administration of “when required,” prescribed medication.

LEARNING IDENTIFIED

Although Joanna's parents recalled meetings during 2017-18, at which medical concerns were rated as "high risk," the Hospital acknowledges that "the management of [Joanna's] physical health complications revealed a gap in service delivery that needed to be urgently addressed." The Hospital confirmed Joanna's,

- refusal to attend an appointment with an NHS Consultant.
- refusal to use the CPAP machine.
- deliberate damage to the CPAP

as capacitated decisions, albeit without documented assessments or discussion with her parents or Consultant Neurologist concerning her specific healthcare support needs. It cannot be determined from the documentation how much information was given to Joanna, when and whether it was understandable to her. Similarly, it is not clear whether the Hospital adjusted the CPAP due to Joanna's increased weight;³⁵ or what steps were taken to encourage Joanna to use the CPAP. Joanna's parents had prioritised the consistent use and maintenance of her CPAP to address her obstructive sleep apnoea. Their experience confirmed its necessity because when Joanna used it, she benefitted from having more day-time energy. It had not been unduly problematic for her parents or for staff when Joanna was supported at a residential home during 2011/12. Her parents believed that the CPAP was being used on a regular basis since they had not been advised that its use had ceased. A Consultant Neurologist advised the coroner that the risks of not using the CPAP over time included, "...evidence that it may increase...high blood pressure...also...sudden unexpected death in epilepsy probably through an increased risk of nocturnal seizures...[Joanna] knew how to use the CPAP but undoubtedly would have required encouragement and supervision..."

Professional values and fact finding are critical. Joanna's history of cooperation with using her CPAP was relevant to considerations about her mental capacity and would suggest that her reported decision not to use the CPAP was compromised rather than "unwise." It was an assumption that recalls the faith of professionals in the "choices" of adults with learning disabilities before the introduction of the Mental Capacity Act 2005. That is, a prejudicial assumption which set no boundaries, regardless of the likely consequences. While no service supporting adults with learning disabilities advertises its aims in terms of 'adopt an attitude of non-interference...promote unfettered independence,'³⁶ for example, effectively this resulted when 'choice' was advanced as a rationale for setting aside a duty of care. Joanna's circumstances would suggest that it results too when a determination of an "unwise decision" without

³⁵ Cited in Hospital records on 6 January 2017.

³⁶ See for example, Keywood, K., Fovargue, S. and Flynn, M. (1999) Best Practice? Health Care Decision-Making By, With and For Adults with Learning Disabilities Manchester, Institute of Medicine, Law and Bioethics and the National Development Team; and Flynn, M., Keywood, K. and Fovargue, S. (2003) Warning: Health choices can kill. *Journal of Adult Protection*, 5, 1, 30-34

reference to her parents and their management of the CPAP, or her Consultant Neurologist, is not part of a defensible process.

People with learning disabilities experience a greater variety, number and frequency of health problems than those of the rest of the population - and they use the NHS much less than they need to. As a result, many have undetected health problems that cause unnecessary suffering and which limit the quality and length of their lives. Yet Joanna was a patient at a hospital that was unskilled in addressing patients' physical health care needs. She was proactive in telling staff when she was unwell, in pain or discomfort, including when she self-harmed – bringing about physical damage and pain - and she experienced mental distress.

It is not known whether there was an over-reliance on security staff when Joanna attended an acute hospital for an EEG or what proactive consideration was given to the likelihood of her distress. Although she was accompanied by Hospital staff, their presence did not preclude security staff intervention which resulted in distress sufficient to complain about the manner in which she was handled. In addition, Joanna acknowledged that the memory of her handling by security staff was a deterrent to returning for further treatment.

Finally, the coroner was advised that “the death of this 36-year-old woman with a known history of epilepsy and recent seizures is attributed to her known epilepsy.” Joanna’s Consultant Neurologist acknowledged that “...over the years her parents had been good at distinguishing the two types of attacks, enabling appropriate adjustments to be made to her treatment.” Although the Hospital’s Consultant Psychiatrist was aware of the two forms of Joanna’s epilepsy, on the night she died, two support workers referred to Joanna’s “seizures.” The learning disability nurse and two support workers believed that Joanna had “non-epilepsy //pseudo seizures// [and a seizure] but she was playing up and shouldn’t be minded.”

The Placing CCG

30. The CCG acknowledges that, before Joanna’s admission to the Hospital, it should have ensured “and agreed to a clear rationale for...admission with clear expected outcomes...an anticipated length of stay and a preliminary discharge plan...in place from the point of admission.” However, it has been unable to locate any evidence that these processes occurred and acknowledges that CTRs should be undertaken every 12 months. Joanna’s CTR was delayed by two months.³⁷

³⁷ NHS England (2017) “These reviews will focus on the safety, care and future planning for those people who remain in specialist inpatient assessment and or treatment services...for adults in secure settings this will be at 12 months” (p36)

LEARNING IDENTIFIED

The placing CCG cites NHS England (2017) the Care and Treatment Reviews (CTRs): Policy and Guidance³⁸ and specifically the following (which is unchanged from the 2015 version):

“Where a transfer is taking place between inpatient settings as part of the planned care and treatment pathway, for example a move from high to medium secure services, this is to be treated as a continuous inpatient stay and would count as continuous treatment for the purposes of the inpatient CTR” (p15).

Arguably this accounts for the difficulty in determining the chronology and duration of events from information provided by the Hospital. Crucially, it downplays the disruptive impact of (i) being evicted or expelled from services which can no longer manage and (ii) being physically re-located on the individuals concerned and, on their families, and other relationships. As her parents recalled, *“on 28 October 2016 she was admitted to Cawston Park. She must have had a terrific scare. She was taken there at night and would have arrived in the early hours.”* Nighttime transfers to unfamiliar settings are remote from the promise of a care and treatment pathway. Similarly, Joanna’s move within the Hospital after only four days downplays the experience of disruption and disorientation in transition. It is not surprising that Joanna feared discharge from the Hospital. For example, when encouraged to think about her future she stated that “she would not like going somewhere new.”³⁹

Were Joanna’s pre-Hospital circumstances so dire and extreme that there was no alternative to planning her arrival in the early hours and in the dark? Did the Hospital have an opportunity to challenge an arrangement which is likely to exacerbate a prospective patient’s distress and disorientation? This echoes the notorious practices of acute hospitals discharging elderly and confused patients during the night without reinstating the support required.⁴⁰

Admission times require attention, most particularly if they occur after 17.00 hours, during weekends and Bank Holidays. The CCGs associated with such shortcomings should be known and challenged to stipulate transfer expectations if the practice is to be halted.

31. The placing CCG confirms that the “CTRs and CPAs suggest that [Joanna’s] mental capacity, wishes and feelings were taken into account.” It does not specify how or what consequences resulted. It confirms that there is no available copy of a CTR which took place during May 2017.

³⁸ <https://www.england.nhs.uk/wp-content/uploads/2017/03/ctr-policy-v2.pdf> (accessed 14 June 2020)

³⁹ 9 February 2017

⁴⁰ See “National Health Service Provision” in Mandelstam, M. (2009) *Community Care Practice and the Law* 4th Edition, London: Jessica Kingsley Publishers

32. It confirms also that the CCG had weekly contact with Joanna's parents concerning their daughter's care. Separately, Joanna had "regular telephone contact" with the same CCG Director.
33. Joanna was known to have been "deeply unhappy" at her penultimate placement where she had alleged staff bullying. She was described by the placing CCG as "very hard to place with 39 placements refusing to accept her after the placement at [the previous hospital] broke down."

LEARNING IDENTIFIED

Place-hunting prevails in the context of crisis. This is exemplified by the 39 potential placements contacted by Joanna's placing CCG (Newham) - regardless of (i) the close contact the placing CCG had with Joanna's parents and, to a lesser extent, with Joanna (ii) escalation to the attention of NHS England's responsible commissioner for secure services, and (iii) the ambition of the Transforming Care Programme. Since the needs of a minority of adults with learning disabilities are interpreted as exceeding the capacity of community services, the familiar refrain "There are no community services which can manage people with challenging behaviour" – means that once people have been sectioned under the Mental Health Act 1983, spaces in neo-institutions provide choice for commissioners, albeit typically "Out of Area." Such trans-institutionalisation is outwith the spirit of Human Rights and has barely been touched by the Transforming Care Programme.

Depending on commissioning practice and within-county service provision, localities may be construed as "importers" or "exporters" of people with learning disabilities.⁴¹ Although Joanna was from north London, the Review Panel was advised that the South London Mental Health and Community Partnership has a "Complex Care" programme which merits duplicating. It hinges on "...improving recovery closer to home for patients typically with complex mental health needs and multiple, long-term conditions, including challenging behaviours, who have often experienced high lengths of stay in restrictive settings."⁴² It is ensuring less fragmentation in the management of a combined £50m+ commissioning budget. Its Clinical Commissioning Team has initiated the repatriation of patients to less restrictive accommodation closer to their homes and families. It notes that "Improved care goes hand in hand with better use of commissioning budgets. We are working to reduce inconsistent and expensive use of independent sector accommodation – often more restrictive than clinically needed – and reduce high lengths of stay. System level savings will be reinvested into local specialist services."⁴³

⁴¹ See for example, Barron, D.A., Hassiotis, A. and Paschos, D. (2011) Out of area provision for adults with intellectual disabilities and challenging behaviour in England: policy perspectives and clinical reality. *Journal of Intellectual Disability Research* 55, 9, 832-843

⁴² <https://www.swlstg.nhs.uk/about-the-trust/striving-for-better-quality-mental-health/slp> (accessed on 20 November 2020)

⁴³ <https://www.slpmentalhealth.com/AnnualReview201819/#12> (accessed on 20 November 2020)

34. Norfolk County Council confirmed that its remit at the Hospital involved “recording...safeguarding concerns and raising S.42 enquiries [Safeguarding Adult Review] when necessary, when an incident involved [Joanna] ...the safeguarding incidents raised prior to Joanna’s death concerned [her] either as a victim or perpetrator and involve either [her]...physical or verbal abuse by other residents (9) ...by staff (3) or by Joanna to another resident (1). There were no safeguarding incidents reported concerning Joanna’s treatment or support plans. One of the incidents of physical abuse occurred when 1:1 support is reported to have been in place on 24 April 2017.”
35. Norfolk’s Adult Social Services’ Emergency Duty Team was notified of Joanna’s death on 28 April 2018. The notification did not suggest that a S.42 enquiry was indicated. On 31 December 2018, the placing CCG requested information from Norfolk concerning a Safeguarding Adult Review referral. On 21 February 2019, Norfolk Police made the referral:
- “There is to be an inquest with a jury. Issues have arisen since receiving statements, namely [Joanna] wasn’t wearing her sleep apnoea mask and CPR had not been initiated until the paramedics arrived.”
36. With reference to patients’ physical health care, Norfolk and Waveney CCG confirms that although the Hospital “employs General Medical Council registered doctors...[they] do not deal with physical health and therefore GP services are required. A weekly clinic is held at the Hospital every Friday morning...either as a ‘drop-in,’ for those requiring a consultation that day or as advised to the surgery the evening before as a ‘prepared list’ so that the visiting GP is aware of the history and background of the patient.”
37. Joanna’s annual Learning Disability health checks were undertaken by GPs. The CCG states: “It is of note that prior to being registered at the surgery in 2016, [Joanna] was last registered with a GP in 2009. This may be because she was registered with a surgery where a different electronic clinical system is used and the two cannot talk to each other, or she was not registered...Gaps of this nature prompt the surgery to double check the paper records...but as the notes are archived it is not possible to comment further.”
38. Norfolk and Waveney CCG were alerted to Joanna’s death via NHS England.
39. Joanna had limited contact with the Norfolk and Norwich University Hospital. “There were three attendances...due to Joanna having placed foreign objects into her ear...On the second...attendance a small...stone was seen in the right ear...the attempt to remove this failed...it was agreed that the duty doctor [at the Hospital] would make a referral to ENT.” The onward referral could have been made also by the Minor Injuries Unit. This did not appear to have happened since “on the third attendance...the stone is recorded as having been in situ since the last...attendance.”

It was noted that, “Further information is required to understand the rationale behind the cancellation of Joanna’s referrals to different...clinics.”

LEARNING IDENTIFIED

It is not clear whether the advice arising from Emergency Department attendance was followed at the Hospital. This adds weight to the Hospital’s acknowledgement that there was a “gap” in its management of Joanna’s health care.

It is not known what, if any, steps were taken to (i) prepare Joanna for hospital appointments in terms of seeking to reduce her anxiety – perhaps by inviting a parent to accompany her, or a member of staff known to work well with Joanna – and/ or adjusting her medication or (ii) address the implications of Joanna failing to attend clinic appointments. It does not appear that the resulting healthcare risks were perceived as such by the Hospital.

40. Prior to Joanna’s death, Norfolk Constabulary received six reports of incidents involving Joanna. The records concerning the initial incident are insufficiently specific, that is, the police did not note whether a staff member or a peer was the subject of an assault by Joanna. The second and third incidents stated that Joanna “does not have capacity” but does not set out what this is in relation to. The fourth incident refers to Joanna assaulting a staff member, having been “encouraged by another patient”⁴⁴ for which the restorative justice process was invoked – yet this is not cited in the Hospital’s chronology. The final two incidents concern verbal abuse and physical abuse respectively. The former included a threat of rape. It was noted that Adult Social Services was “satisfied that safeguarding measures were in place.” The latter concerned Joanna being slapped on her arm. Joanna died before the police could attend.
41. Norfolk Constabulary states that Joanna’s death “should have resulted in a Duty Detective Inspector being notified and a Crime Scene Investigator attending the Hospital... [Although her death was unexplained and there were anomalies⁴⁵] there was a breakdown in communication...between the attending officers and the Duty Detective Sergeant.”
42. Subsequently, the Crown Prosecution Service “advised that...no further action” was merited since “it cannot be proved when Joanna died...staff didn’t offer first aid or CPR to Joanna when she was already deceased.”
43. Joanna’s inquest concluded that she died from “natural causes” as a result of Sudden Unexpected Death in Epilepsy.⁴⁶ The inquest heard that Joanna had 60 seizures

⁴⁴ From Police Incident Details of 3 May 2017

⁴⁵ Including amended accounts of events on the night of Joanna’s death; the absence of staff alarms and ‘phones (which were being charged); and a perception that her seizure the evening before her death was the result of her “playing up.”

⁴⁶ The pathologist also cited primary generalised epilepsy, obesity and obstructive sleep apnoea as contributory causes.

during the 18 months in which she was detained, including one on the day before her death.

44. A Consultant Neurologist reported that in the last 209 nights of Joanna's life, the CPAP's data showed that it had only been used for 29 nights. The failure to ensure its regular use increased her risk of SUDEP. It was noted that Joanna "knew how to use CPAP but undoubtedly would have required encouragement and supervision to have actually used it." The Hospital did not advise Joanna's parents or Respiratory Consultant that she was not using the CPAP.⁴⁷ Although the Coroner refused to permit the jury to consider neglect by the Hospital,⁴⁸ it was confirmed that there were inconsistent accounts concerning the actions of night staff; the 30 minute observations as directed in her care plan (which was inaccessible to the staff) did not happen; and although a registered learning disability nurse and the five care workers on duty had received first aid training, none of them attempted CPR or accessed the unit's defibrillator; the 999 paramedics commenced CPR. The Hospital's "barrister made submissions that Joanna's father should not be permitted to give oral evidence as he did not have any "facts" only "opinions" to share."⁴⁹

LEARNING IDENTIFIED

There does not appear to be a shared perspective across the safeguarding partnership concerning Joanna's contact with Norfolk Constabulary. It is not clear what a determination of mental capacity means in terms of police investigations at the Hospital. In fairness, the context is the Hospital's information shared at the safeguarding strategy meetings. Although the process of assessment, its recording and descriptions concerning allegations and their context are crucial, they do not appear to have been credibly documented at the Hospital.

A single assault was reported as resulting in the restorative justice process – a means of constructive learning via mediation between a victim and the offender. The outcome was twofold: "words of advice [and] letter of apology."

The Barrister's submission concerning Joanna's father was experienced as hurtful and offensive. It perpetuates the discredited perception of professionals possessing unique, rational expertise and disembodied knowledge which keeps relatives in their muted, marginal place.

⁴⁷ An inquest witness stated that "the fact that [Joanna] refused to use [the CPAP] wasn't documented anywhere. Cawston Park were not good at documenting refusals."

⁴⁸ <https://www.ukinquestlawblog.co.uk/rss-feed/153-admitted-failings-art-2-inquests> (accessed 29 December 2020)

⁴⁹ <https://www.simpsonmillar.co.uk/media/jury-concerned-over-death-of-woman-with-learning-disabilities/> (accessed 29 December 2020)

Summary of record availability

45. Finally, the records concerning the duration of Joanna's inpatient stay at the Hospital are incomplete. The following table shows that there are records for 68% of the time that Joanna was at Cawston Park, that is, 377 days out of the 556.

Year	Month	Days in residence	Days for which some records are available	Days with no records
2016	October	12	12	-
	November	30	30	-
	December	31	31	-
2017	January	31	31	-
	February	28	20	8
	March	31	12	19
	April	30	6	24
	May	31	7	24
	June	30	4	26
	July	31	7	24
	August	31	26	5
	September	30	2	28
	October	31	14	17
	November	30	30	-
	December	31	31	-
2018	January	31	31	-
	February	28	28	-
	March	31	27	4
	April	28	28	-
	18 months	556 days	377 days	179 days

Section C: Jon

The records

46. Since the review could not gather the perspective of Jon's family it has relied solely on records. From these it may be gathered that Jon was placed at Cawston Park Hospital under S.3 MHA by a London CCG to which he was known as "a complex patient with complex needs...[His] capacity, dignity, wishes and feelings were difficult for commissioners to ascertain, not least because of his diagnosis of learning disability and the reports of Jon's challenging behaviours." Jon's mother was not informed of his transfer to Cawston Park Hospital. Jon rang to tell her. He had regular contact with his mother by telephone. The Hospital's records reveal little of Jon's early life other than that he "...had a long history of aggressive behaviour and temper tantrums, going back

to his childhood...His aggressive behaviour also extended to...deliberate self-harm.” He was “taken into care...and later moved through various care homes...before moving into adult residential placements.”

47. The Adult Mental Health service responsible for Jon’s placement funding stated: “It was not necessary at the time, for the care coordinator to specify the placement provider, nor demonstrate their suitability to address the client’s needs, to the satisfaction of the Panel. Once placed, the care coordinator’s role included ongoing support to the service user, ensuring the placement provider continued to meet their needs. In the event this was no longer the case, the care coordinator would present a new case to the Panel for a more appropriate placement... [The Adult Mental Health service’s] role...was that of a funding authority...[it] does not systematically maintain individual patient case files.””
48. Jon’s penultimate placement was a private hospital providing specialist services to adults with learning disabilities and complex mental health problems. The Adult Mental Health service was advised by this hospital that it was no longer suitable for Jon and the hospital suggested that he should be transferred to a psychiatric intensive care unit. A subsequent assessment by the South London Partnership recommended admission to a Low Secure Unit. This did not happen and NHS England effected the transfer to a “locked rehabilitation inpatient setting” at Cawston Park Hospital.⁵⁰ The latter revealed that the team at Jon’s penultimate placement “felt that Jon needed a robust environment with the option of a seclusion room in order to manage him safely...He was sensitive to peers moving on and he wished to do so...It had become difficult to establish boundaries...incidents had become severe and prolonged requiring patients to be moved from the area for their safety and Jon’s dignity.” The Adult Mental Health service responsible for Jon’s placement funding reported that “Difficulties arose from the lack of a suitable placement provider. Jon was placed outside of the borough which necessarily stretched communication lines between Jon and his supports, including his family and the CLDT.” Cawston Park Hospital’s assessment of Jon led it to believe that that it “could meet Jon’s needs.” When admitted, with an “estimated discharge date [of] six to nine months,” he] had a diagnosis of mild to moderate learning disability and an autistic spectrum disorder. It was also queried whether Jon had a major mental illness, but this was uncertain.” Jon had “poor sight and hearing problems.”
49. The Adult Mental Health service responsible for Jon’s placement funding “sought advice on Jon’s ongoing care and support from NHS England [which, in return, commended] a London-based, adult social care provider “to develop an alternative care/ support plan... [Jon died] before this alternative plan could be completed.” Jon’s stay as an inpatient was a few days short of 12 months.

⁵⁰ This was six months after Cawston Park had received a “requires improvement” rating by CQC.

LEARNING IDENTIFIED

It is regrettable that there is no account of Jon's childhood and pre-Cawston Park Hospital life, even though he had some contact with his family as an inpatient. Given the unknown number of placements prior to transferring to the Hospital, there is no doubt that vital information concerning Jon exists in other organisations' systems. Crucially, it was not instrumental in assisting the Hospital's understanding of his biography or the origins of some of his behaviour. All that may be reliably gathered from records is that:

- setting a discharge date is a meaningless activity if there is no attention given to planning for this
- specialist hospitals which are geographically remote from people's families have unchallenged scope to retain patients
- there are no consequences if professionals responsible for "placement management" are not represented at either CTR or CPA meetings
- Jon's behaviour speaks of distress.

History

50. When Jon became a Cawston Park Hospital inpatient, staff were advised of the "main triggers of [his] distressed behaviour: high anxiety levels; not being listened to or understood; jealous of peers; altercations; boredom; over-stimulation; unable to have 1:1 time; when he doesn't get what he wants; and to gain response."
51. Although Jon's medical history was unremarkable, from the point of his admission to Cawston Park Hospital he reported stomach aches, painful limbs, headaches, chest pains and non-specific pains.⁵¹ On separate occasions he reported that his optic nerves were damaged, he had a broken arm and a broken toe. He requested a bandage for the former. Subsequently he requested a sling, acute hospital admission and occasionally "demanded" to see a doctor. Typically, he was offered Paracetamol (on 30 occasions).⁵² There were a few occasions when he (i) "dropped to the floor" and separately, (ii) when he appeared to have seizures. It is not known whether investigations concerning possible epilepsy commenced. On one such occasion the records stated "care eliciting histrionic behaviour. Non epileptic episode." On another occasion, Jon received Buccal Midazolam. When he experienced three fits, it was recorded that these were "likely secondary to Acuphase."
52. Jon's sleeping pattern was haphazard. He reported that he did not feel safe sleeping in his room and even described it as "dangerous." He moved his bedding and at

⁵¹ It is possible that some of these were the side effects of Jon's prescribed medication which included Clozapine, Sodium Valporate, Lamotrigine, Clonazepam, PRN Promethazine and Lorazepam

⁵² The number derives from the chronology provided by the Hospital. However, these numbers do not tally consistently with information set out in the Hospital's management review.

different times favoured sleeping in the lounge, the quiet room, the seclusion room, corridor and a dining chair, for example. He was funded to have two rooms and moved his belongings between these and other rooms. There were occasions when Jon's behaviour was suggestive of sleep deprivation. He was up a great deal during the night and this increased the likelihood of him sleeping during the day, e.g. "slept until late morning...spent most of the day in bed...spent most of the day in bed area (x2) ...slept until after lunch...asleep for most of the afternoon...after breakfast returned to room and slept...sedated presentation...it was reported at handover that Jon was often sleeping through the day. [An assessment of Jon's quality of life noted] Jon feels he does not have enough energy at all as he is always tired and falls asleep during the day." On at least two occasions Jon missed telephone calls from his mother because he was sleeping. When Jon was tired it was noticeable that his speech became unclear and he became frustrated at having to repeat himself.

53. Jon's death resulted from swallowing part of a plastic cup. His self-harming was known to include head banging (this is recorded in the Hospital's chronology on 21 occasions), tying a ligature around his neck (three occasions) and swallowing foreign objects (three are recorded, including the fatal ingestion). Jon was known to have swallowed screws, parts of zips [and] batteries." The swallowing incidents did not result in changes to Care Plan or Risk Assessments. "It was decided that Jon remained at low risk of swallowing." Other features of Jon's behaviour included: kicking, typically staff, doors and windows (there were 70 recorded occasions); spitting at staff (c.50 occasions); hitting others, mostly staff (50 occasions); and being racially abusive (almost 30 occasions).

Incidents and restraint

54. Cawston Park Hospital describes "a fairly unsettled man...[who] was more settled when actively engaged with staff and in activities... [There were] significant periods when Jon presented as being highly aroused, when we saw incidents of distressed behaviours which generally involved the destruction of property or physical aggression directed at others...we made some significant changes to Jon's psychotropic medication without over sedating him...From our incident records...Jon was involved in 333 incidents. The majority...were assaults on others...The incidents were of an average duration of almost two hours...over time...we saw a gradual improvement in his overall presentation...a reduction in staff having to use seclusion as a very last resort..." Jon was usually apologetic and remorseful after his outbursts, most particularly when he had physically attacked staff.
55. Jon was restrained on over 90 occasions and at least 35 of these were supine. Separately, he is described as receiving "Physical Intervention" – on 25 occasions. The distinction between these interventions is not clear. For example, the records cite "full supine restraint...seated restraint...prone restraint...restrained then supported to the floor for full PI...restrained with the intention of asking him to spit out the lens." Jon was placed in seclusion on over 65 occasions. It was recorded that on one occasion

he was placed in seclusion “to avoid prolonged restraint.” Jon himself requested access to seclusion on a further 25 occasions. He suggested that the police could put him in a cell. Jon received 110 doses of sedative PRN medication, at least 40 of which were administered by injection. On one occasion Jon was commended for requesting PRN medication. Although Jon told a psychologist that he did not like “kicking off,” this behaviour persisted. It was noted by the Hospital that “Jon’s aggressive behaviour may make it difficult for him to attend as many activities as he would like.” During Jon’s penultimate visit to the acute hospital, where he was diagnosed with a chest infection, he became agitated and destructive and was restrained by Cawston Park Hospital staff and the acute hospital’s security staff.

Activities and aspirations

56. Reference to Jon’s recorded activities reveals over 120 occasions when Jon went on “walks.” These were largely referred to as “grounds’ walks.” Although Jon was described as “overweight,”⁵³ it is not known whether walking featured prominently in his care plan. He watched films and DVDs, went to the farm and went on bus rides. The records state that Jon had 18 sessions with a psychologist; seven art sessions; and 17 creative skills sessions. Swimming did not feature in Jon’s activities even though he was known to be a “strong swimmer.”
57. Jon had aspirations. He made it clear that he did not want to be at the Hospital, he wanted to be near to his family and to live in a bungalow with a computer room. He sought purpose. Within days of arriving at the Hospital he “walked around in his police uniform informing staff he was in charge” and he was given a bag of belongings to sort through. Jon was known to like wearing uniforms and badges. On another occasion he wanted “something important to look after.” His desire to be occupied involved “continually requesting items he can fiddle with.” On one occasion he was provided with Halloween decorations. He was described as making “demands on staff.” He stated that as an employee he required equipment for the job. On another occasion Jon “presented as pushy in boundaries saying he’s a member of staff.” When he was recorded as being “agitated and demanding” he wanted a belt, a phone and access to restricted areas, “as he is security staff.” These requests were made as he banged and kicked glass in his bedroom and paced the unit’s communal areas. After a successful session of picking leaves in the Hospital grounds, Jon was “promoted to senior security man” but it is not known what this entailed. Similarly, in the midst of another aggressive outburst he stated that he was “busy working as a maintenance man.” There was an occasion when Jon requested “a session” with the psychologist in which he explained that the lights in the seclusion room made his head “fuzzy.” He pointed to the angry and sad faces among his emotion cards “saying this was how he felt.”
58. After seven months at the Hospital Jon announced that he was leaving. Subsequently, he packed his bags and told staff that he was looking forward to moving closer to his

⁵³ This was not confirmed by his postmortem.

mother. He made cards for peers and staff to sign wishing him good luck. During the month before his death Jon was pleased at the prospect of leaving the Hospital and moving into the community. It was noted that he had “limited understanding as to the timetable of this event.” The credibility of Jon’s belief is not revealed in the records. He planned his leaving party and discussed party food. When it appeared that Jon had swallowed part of a plastic cup he asked for, and received, a Get Well Soon card from his art tutor.

Inquest

59. Jon’s inquest reported⁵⁴ that he had complained about difficulties with breathing a few hours before collapsing...medical director said “I would have expected a quicker response. The response could have been different. I wasn’t there at the time, but I would have done things differently. The inquest...was previously shown footage of [Jon] collapsing...and staff performing CPR while waiting for the emergency services to arrive. It heard that [Jon] was “pale,” “struggling” and “rolling around the dining room before that.” At around 7.25pm...the inquest heard the 33-year-old told staff “I cannot breathe. I am dying.” In response to the CCTV [the Coroner] said “The staff are standing there. Nobody appears to be doing anything. There seems to be a long time before any definitive action was taken to assist him. They [the Hospital staff] appeared to be milling around.” The inquest heard that a staff nurse got oxygen for [Jon] but it took “several minutes for the defibrillator to be used in the so-called code blue emergency situation. During live questioning, family barrister...revealed two members of Cawston Park staff who helped [Jon]...were not-up-to date with their first aid training.”
60. The day before Jon was taken to hospital, the statement of a staff member noted that “...Jon had wanted to go to hospital, but the doctor had said it wasn’t necessary because of his clinical observations.” Jon died of hypoxic brain injury following a cardiac arrest, acute laryngeal obstruction, and aspiration of a plastic cup. The Record of Inquest concluded death by “misadventure.”

LEARNING IDENTIFIED

The listing of “triggers” to Jon’s aggressive behaviour are wide ranging and yet do not take account of the trauma of transitions. Having had many placements since his childhood it is likely that his behaviour reflected familiar adjustment symptoms such as anxiety, sleep problems, hostility and anger about apparently minor frustrations. Although sedative medication may bring such behaviour under control, it appears to have been continued without considering and evaluating Jon’s pre-medicated behaviour and its history.

⁵⁴ <https://www.edp24.co.uk/news/response-criticised-after-man-collapses-in-hospital-1426334> (accessed 20 December 2020)

“Spent time in communal areas... Spent time roaming around unit in a settled mood...talked to peers and staff...spent the day on the unit...walked in communal areas...tidied bus...remained in quiet lounge.” Although Jon enjoyed art sessions, these did not appear to have been frequently or regularly timetabled. Boredom was identified as a “trigger” to Jon’s distressed behaviour and yet his days are not suggestive of a programmed treatment plan.

Understanding Jon’s biographical history does not appear to have been prioritised at the Hospital. He became an inpatient in a context of crisis. There were many occasions when Jon’s behaviour was unmanageable, however, dependence on the accounts of others is a principal feature of reviews. The skills and insights proceeding from experience of working with people described as challenging services may have assisted in understanding the variety of its forms, the impulses and incentives, the social and environmental contexts of Jon’s behaviour. In addition, accounts of responses to a person’s aggressive behaviour may become complicated and conflicting when they are drafted by staff who have been physically and mentally harmed.

One element of Jon’s behaviour merits critical exploration. Although Cawston Park Hospital was not explicitly tolerant of racism, it did not address the fact that Jon targeted BAME employees. Hospital staff were not protected from their injurious encounters with him.

Racism has been closeted in health and social care services for people with cognitive challenges for too long. The aversion to dealing with it parallels the long and persistent history of racism itself. It suggests denial and/ or uncertainty about whether to challenge the perpetrator. Arguably this leaves BAME employees torn between a service’s custom and practice and the wretchedness of their own experience.

Section D: Ben

Ben’s mother

61. She described Ben:

“Ben had Downs Syndrome. He was a happy little boy. He spent all his life with me and with his dad until he was 12... There was nothing would come between me and that boy. I’d do without myself for him to have quality of life. He was so rewarding. He had cheeky ways about him. He’d make you laugh like you couldn’t laugh no more. I knew him inside out. A lot of the time he was a pleasure to have. He loved his dog, the birds and the garden. He was a joy because he loved life and people... The shame of losing Ben...he was always so close to me. As a little boy he was very hard work but very caring which is why I found it so difficult when he got aggressive. He’d never been like that.

Ben had to go in a home. I had no one and I was poorly. I told the social worker even before I went to the doctor... The day he was taken from me, he didn't know where he was going or why. It really stressed him out because everything changed. He was taken to [a residential care home] in the evening. One of his Mencap workers went with him and said, "Please let me stay the night with him." They wouldn't let him.⁵⁵ Ben was no angel, but I'd always managed him by myself, and then, when he was an adult, we had the help of his two Mencap workers who would take him out in the day. One had known Ben for eight years and one for six years. Because Ben smashed the home up, they called the police, he was sectioned and taken to Cawston Park Hospital... [The care home] didn't tell me about this, even though I rang them first thing the following morning. They told me that he was fine and sitting on a bean bag! Later I got a call from them to say he'd been taken to Cawston Park. He was my everything. I was ill...It was heart breaking to watch what was happening to Ben...

To see him deteriorate was terrible...They're too free and easy about sectioning people.⁵⁶ He shouldn't have been at Cawston Park Hospital. Sometimes you'd have to restrain Ben if he got iffy. But it was like they were happy to put him there. Ben was who he was. If they'd talked to me about how to manage him, he wouldn't have needed all that restraining...They weren't doing the important things. [For example] Ben had cataracts when he was born. He was partially sighted in one eye and needed his glasses. I used to ask about them. He never wore them at Cawston Park and he needed them.

For the first eight months Ben was upset. At the beginning, me and his Mencap staff started taking him out. We did things like get new clothes for him and we'd be out all day. I could see that the staff at Cawston Park Hospital didn't like it with us there every day. Over time, Cawston Park Hospital wouldn't let me or the Mencap staff take Ben out because of his behaviour. It was a punishment and a big change.⁵⁷ I carried on visiting and, before the Mencap staff stopped being funded, the Hospital staff carried on telling us things like "Ben has had a bad morning so he's not coming down." It was hard when the funding stopped because Ben missed them and he missed going out. I was going there to see Ben and it meant that they had to get him off the unit and have staff with him. It deteriorated from there. Even the cleaning stopped. Ben didn't seem to be doing anything and I asked the staff "Can he go out?" He was supposed to be constant care all the time, 1:1, that's a lot of money a week... It wasn't just Ben - others weren't...either.

I was concerned because there is nowhere in Norfolk that could cope with Ben – it would mean him having to go away. I could see the whole place was deteriorating.

⁵⁵ This is confirmed by a Mencap support worker.

⁵⁶ Although Ben was not diagnosed as having a mental illness, a month after his admission to the Hospital he was detained under S.3 of the MHA 1983 (as amended)

⁵⁷ A Mencap support worker recalled "We used to walk him around a lot. Sometimes we'd be out for 10 hours with Ben. At Cawston Park Hospital, they'd only go out for about an hour on the bus. He wouldn't understand why they weren't out for longer. When they cut the hours, he would have issues on the way on the home – being out for say, 1.5 hours rather than all day."

Ben wasn't going out at all and he wasn't getting any better. He was worse. He had always been on Ritalin and they decided to take him off it.⁵⁸ He got to being withdrawn and aggressive. In all the time he was at home he'd never hit me, but at Cawston Park Hospital I took some punches on the face. When I was punched no one asked me "Are you alright?"

In February [2020] I was told by Dr [...] not to go because of Covid restrictions. I was phoning up and checking on Ben every day. I rang every day to speak to Ben and, one time, I rang them back to say "Ben's voice is husky. Has he seen a doctor?" They said that Ben had a chest infection. Then, when he had Covid, I didn't see him for several months. Ben used a CPAP machine. He needed help to put it on.

There was one time at the Grange when he had eyebrows shaved off. I took a photo of it. He'd shaved his pubes as well. This is when he was supposed to be 1:1 – and they left him with a razor. Ben wasn't a self-harmer, but they left him with a razor!⁵⁹

I would take up snacks for Ben – grapes, strawberries, tangerines, bananas and breakfast bars. I never took him chocolate or crisps. The first time I was able to visit, I hadn't seen him for four months, I was horrified to see the weight he'd put on and it began when he was no longer being taken out by the Mencap staff. He wasn't even walking to his activities on Tuesdays and Wednesdays when he used to do art and woodwork. He started putting a lot of weight on in those four months when he was coming off the unit less and less. They'd say that it was because of his behaviour... I didn't recognise my son when I saw him. He could barely walk and his head was touching his chest. He didn't have a neck. I couldn't get the clothes to fit him. I used to ask them for his diet plan. I never saw it. Same with monthly reports. They never shared them. They tried to blame me because I was taking food in for him. I wanted to make sure that he was getting fruit. He only had treats when it was his birthday and at Christmas. When he died the funeral director, who took his body, found it difficult to find out where they could put him because he was so big. Ben was never a skinny little boy, but he was always on the go. He'd always walk his dog and he was a swimmer – he was like a goldfish in the water.⁶⁰ They're letting people get overweight and they're not stopping it... I'm a bit of a fighter and I'd have got the weight off Ben and he'd have been alright. I'd always prayed I'd outlive him and I have.

Ben was diagnosed with Covid [during] May. They told me he had "very mild Covid symptoms." What happened was he became withdrawn. It had a big impact on him. Always, he was coming home. He was not going to stay at Cawston Park Hospital. His bedroom is still the same. I've not changed it. He was my life. Every day that boy would

⁵⁸ A Mencap support worker recalled "I went to a meeting where Ritalin was discussed. The doctor asked, "Who are you?" to [his mother]. It was out of order. He didn't believe what we said. When Ben stopped taking the Ritalin it was dangerous and, suddenly, Ben's behaviour got worse and he was shaking. Ritalin had kept him on a steady keel. We asked them to put him back on it, but it was never done."

⁵⁹ This was confirmed by a Mencap support worker.

⁶⁰ The Mencap support worker recalled "I remember going swimming with him when he was at home. I was struggling as I was swimming and Ben was laughing his head off and swimming fast."

ask me “When am I coming home?” And I would always say “When your section is finished and they say so. Then you’ll be back home with me.” Before I started visiting again, he had a Covid test that came back negative. He had to have it because he’d always kiss and hug me when I visited. I started visiting again in early June when he had recovered.

CQC were too slow [in responding to reported events]. They didn’t do anything. Even when Cawston Park Hospital was in special measures. Why did they have to wait until they killed Ben before it did anything? Two days later, when I’m visiting, I bumped into Dr [...] says “Hello...we’ve just had a big meeting about Ben. I have told the night staff that when his SATS⁶¹ drop, they’ve not to call an ambulance. The paramedics wouldn’t take him in.” I said “Well I hope for your sake nothing happens to my son. The paramedics wouldn’t take him in if there was nothing wrong with him.”

I phoned...and when Ben came to the phone he said “Mummy my side is hurting...” I asked him to give [the support staff] the phone and I said... “I’m coming up. Ben has a pain in his side.” He said, “He’s only saying it because you have phoned him.” I rang...that night and asked “How is he? How’re his SATS?” They told me that the SATS machines weren’t working... [When I visited] I had Ben’s fruit and bits and pieces. They said “Ben is not well at all. I’d like you to see him, it might lift his spirits...” I waited outside for an hour... and a nurse came by. I asked, “What are they doing with Ben?” She said, “Ben is really unwell.” I said, “tell that effing Dr [...] to call an ambulance.” I don’t know whether [they] did.

They carried Ben out, one on either side of him and put him on a bench. He could barely stand. They were holding him up. To my horror he was nearly falling over. I got on the floor. I could see he was blue lipped, gasping for breath and a grey colour...The staff stood about... Dr [...] came and I said “I’m not leaving him like this. He needs an ambulance.” Dr [...] said “We’ll perhaps try and clear his airways. I was called out to Ben last night. I didn’t ring you... because you need your sleep.” It’s all over his records – ring me if Ben is unwell! One staff said, “Do you think Ben’s got hay fever?” I thought –really? Ben took his shoes off and threw them at Dr [...]. I don’t know how he found the strength to do it. Any other person would have been onto an ambulance. Ben was sitting out there. I had no reception on my phone. I didn’t know what to do. He was begging me to take him home. I said, “Listen - I will take you home – please go in for mummy because mummy’s got to go.” I didn’t get a chance to say goodbye to that child. That’s my last memory of him. He tried to run to me in the car as I was driving away. I’d decided I was going up there tomorrow and just taking him. He’d only got one day left on his section. I phoned on Tuesday evening and they said, “Ben’s temperature has gone up.” I asked about his SATS and was told “I don’t think the thing is working properly. I’ve done it visually.” So, early Wednesday morning I rang again and was told, “Ben’s had a reasonable night. His temperature is 36.5.” I asked about the SATS and was told to “ask Dr [...]” and I said “No, I’m not waiting for Dr [...] I’m

⁶¹ Oxygen saturation of blood

asking you because you've been on all night." They put the phone down on me. Ben had gone into cardiac arrest. Dr [...] rang and said "...you need to get up to the Norfolk and Norwich Hospital..." [It turned out that Ben's] SATS were 35%⁶² and they left him.

It's all down to money. Ben was costing [thousands] a week not to be looked after. I only got £67 a week and he was healthy, well and safe. He was robbed of the rest of his life. It's soul breaking because he loved life that little boy... when he was with me, I got £67.00 a week for being Ben's carer and I'd do it again. I'd do it for nothing. That's the difference. Now I have no family. My world has been broken. Cawston Park Hospital has learned nothing. It let staff sleep on duty after my boy died."

The funeral car drove through Cawston Park Hospital because I wanted Ben to know that he was being taken out of there... I'm fairly strong but I'm not the person I was and I never will be. Ben didn't deserve this. Even when I did get myself in the unit for his things, they gave me someone else's clothes and half of his stuff is missing... Some days it's too hard to carry on. The thought of never hearing Ben laugh again. He was always telling me that he loved me – always. Why did they get rid of [the two Mencap support workers who continued to support Ben when he was transferred to Cawston Park Hospital]? It broke his heart. They stopped funding them. It was as though they thought, "He's costing a lot. We can leave him there." Even now, there are lot of places who would say they can't have Ben. I looked after Ben like a diamond in cotton wool. I protected him all those years to the best of my ability. I feel like someone's flipped a switch on me."

Cawston Park

62. There are entries in the Hospital's records for 40% of the time that Ben was a patient.

Summary of record availability

Year	Month	Days in residence	Days for which some records are available	Days with no records
2018	July	23	17	6
	August	31	10	21
	September	30	6	24
	October	31	3	28
	November	30	5	25
	December	31	3	28
2019	January	31	3	28
	February	28	7	21
	March	31	3	28

⁶² On 23 February 2021, the GP member of the Panel noted, "...generally if SATS levels fall below 92% then guidance would be to think about calling an ambulance. For a patient with Chronic Obstructive Pulmonary Disease (COPD), a clinician might let it go down to 87% before calling an ambulance."

Year	Month	Days in residence	Days for which some records are available	Days with no records
	April	30	5	25
	May	31	5	26
	June	30	7	23
	July	31	12	19
	August	31	6	25
	September	30	8	22
	October	31	8	23
	November	30	9	21
	December	31	16	15
2020	January	31	23	8
	February	29	28	1
	March	31	27	4
	April	30	30	-
	May	31	28	3
	June	30	13	17
	July	29	20	9
	25 months	752 days	302 days	450 days

63. In the absence of any information concerning 60% of Ben's experience as an inpatient, it is not clear that there was any timetabling discipline in terms of his daily and weekly activities and the formal separation of specific tasks. Before Ben's admission to the Hospital, he was known to be a fast swimmer and a dog walker who could be persuaded to walk long distances. In contrast, information shared with the Coroner noted that "He would often be sitting in the Quiet Room under 1:1 supervision;" and "Needs a lot of encouragement to move about and will chose (sic) to sit in his chair all day without hardly moving." There is no record of Ben swimming or having long walks. He gained a great deal of weight irrespective of weight loss during his first three months at the Hospital - he was 100kg/ 15.7 stone on admission and he lost 16kg/ 2.5 stone within two months. The Hospital cited Ben's weight-loss as "one of our main aims." It is not known when this ceased to be an aim because in the month that Ben died, an acute hospital Consultant wrote "...the carer told me that his weight is now 106kg" [16.6 stone].⁶³ The postmortem revealed that Ben weighed 115 kg [18.10 stone]. Had the Hospital's goal been sustained, tracking Ben's weight would have been necessary to determine its success.

⁶³ Correspondence shared with the Coroner.

LEARNING IDENTIFIED

There is very little information concerning Ben's activities at the Hospital. His protracted physical inactivity increased the risk of obesity, high blood pressure, high blood cholesterol, diabetes and heart disease. Ben required knowledgeable support to access and receive health care. He did not benefit from being accompanied to an outpatient appointment with a support worker with up-to-date information about his health status and weight, for example.

64. When Ben was admitted to the Hospital the Consultant Psychiatrist noted that he had “no clear mental illness.” However, the following month he was detained under S.3.⁶⁴ There is a single reference to anti-psychotic medication in the records available. It is not known for how long this was administered [see Annex 3 - prepared by GP member of the SAR Panel]. Ben was prescribed Promethazine during May 2020 as part of a two-week trial. It is a sedating antihistamine which is licensed for short term use only. It does not appear that the prescriber set out the rationale for its continued use after the two-week trial or whether it was discussed with Ben's Respiratory Consultant. NICE guidance concerning Obstructive Sleep Apnoea⁶⁵ states that patients should be given lifestyle advice including the reduction of sedative use.
65. The Hospital's records reveal inconsistencies. For example, during July 2018 Ben was described as being at risk of “severe aspiration.” Seven months later, the records noted that he had “No issues with eating and drinking.” Ben's severe respiratory problems and obstructive sleep apnoea pre-dated his admission to the Hospital. In view of this, the Hospital recorded that staff should “...avoid restraint...if required use seclusion room as last resort.” Its records show that Ben was restrained during August and November 2018, January 2019 and March 2020.
66. Ben's intermittent tolerance of a CPAP pre-dated his admission to the Hospital. It appears that he did not like the noise and sensation of air pressure “up his nose.” The Hospital's efforts to encourage its use had limited success since there are 115 occasions recorded when Ben declined to tolerate it. Although obesity is a reversible risk factor for obstructive sleep apnoea, during May 2019 Ben's Respiratory Consultant confirmed that weight loss in itself would not treat his condition. He required the CPAP.
67. Ben wanted to return home to his mother. He became tearful when speaking to her on the phone and at the end of her visits. A month after his admission, the Hospital acknowledged that “a lot of Ben's distress is driven by his want to be with mum and

⁶⁴ S.1 of the MHA 1983 (with amendments) states that a mental disorder is any disorder or disability of the mind. Except for admission under S.2, a person with a learning disability will not be considered to be suffering from a mental disorder unless it is associated with abnormally aggressive or seriously irresponsible conduct. Two psychiatrists determined that treatment was necessary for Ben's health and safety or for the protection of others and that appropriate medical treatment was available at the Hospital.

⁶⁵ <https://cks.nice.org.uk/topics/obstructive-sleep-apnoea-syndrome/#!diagnosissub> (accessed 8 March 2021)

people he knows...keeping Ben separate from his mum is perpetuating his behavioural distress.” However, it formulated this as “attachment problems...issues” and planned “...to reduce the amount of time mum and Mencap [support workers] see Ben,” and to limit the calls he made to his mother. Although Ben’s care plan does not reference this, it does cite an “appropriate relationship with mother” as an “outcome and success measure.” The rationale is not stated. However, the formulation suggests the ascendancy of professional dominance over (i) protecting family integrity (ii) Ben’s sense of belonging and (iii) learning from the established behaviour management/ problem-solving skills of his support workers and mother.

LEARNING IDENTIFIED

There is a dynamic interplay between the characteristics of individuals, their families and the environments in which they live. Ben assertively expressed his feelings and frequently stated that he wanted to be with his mother – and towards the end of his life – that he wanted to go to [the acute] hospital. Mother and son had developed a valued and collaborative relationship with two Mencap support workers. However, within weeks of being an inpatient, when the Hospital had no appreciation of this mother and son’s life, family functioning and problem-solving, it prioritised Ben’s “attachment problems” as a matter of significance. It did not seek to understand his mother’s goals or work with her and Adult Social Care⁶⁶ to determine Ben’s future.⁶⁷ At best, family-centred approaches are active and enabling and yet were absent when Ben had to leave the home he had shared with his mother for 30 years.

68. Ben refused to sleep on a bed and his mother advised that he preferred being upright and sleeping in a chair at home. Since he yearned to be at home with his mother, she advised that his bedroom should not be too home-like. At the Hospital he favoured being on a mattress on the floor and slept with the windows open, regardless of the weather.
69. Ben had seven out-patient appointments at the acute hospital between July 2018 and July 2020. These mostly concerned his respiratory and urology problems. With reference to his respiratory outpatient appointments, it does not appear that the detailed recording concerning Ben’s tolerance of the CPAP was shared with his Consultant.
70. The placing CCG attended and received copies of Ben’s Care and Treatment Reviews and Care Programme Approach meetings. (The latter required the Hospital to complete a template.) Fifteen months after Ben’s admission, the CCG made recommendations concerning Ben’s care plan. That is, the Medical Director was to liaise with the acute hospital’s specialist team to agree a CPAP management plan which involved the family; a treatment and management plan concerning sleep

⁶⁶ A LA social worker was at the Hospital most weeks with the specific brief of identifying post Hospital supports for Norfolk patients. This investment is barely reflected in the Hospital’s chronology.

⁶⁷ In June and September 2019, it was noted that there were no discharge plans for Ben; a Care and Treatment Review in February 2020 determined that Ben was “ready for discharge”.

apnoea; “*clinically meaningful*” SATS checks, sleep and other health checks; and the clinical signs that night nurses should be attentive to, for example. During December 2019, a CCG quality visit recommended: “revised observation training and competency booklet to be introduced and then evaluated... [clarity concerning] level of observations [and] in relation to capacity...a programme of organisational development related to instilling a recovery philosophy amongst the clinical teams.” During April 2020 the CCG contacted the Hospital seeking assurance concerning person-centred planning and crisis planning during the pandemic; evidence of staff training concerning physical health care, “vital signs and when to escalate” for example, confirmation that all MCA assessments had been completed and documented; and, in the light of visiting restrictions, information from families concerning means of contact in emergencies. The outcome of a Best Interests meeting the following month is not recorded.

71. A Care and Treatment Review during February 2020 required an outpatient appointment with the Respiratory Consultant; a record of staff training concerning the CPAP; a carer’s assessment for Ben’s mother; and evidence of an annual health check.
72. Ben was one of five inpatients who developed Covid-19 during May 2020. The Hospital stated that “at one point about 10% of nursing and care staff were Covid-19 positive and away from work. Activities were reduced in the service...This severely impacted on the ability of patients like Ben to move around the Hospital...He was isolated from the rest of the patients [and because he used a CPAP] staff had to wear full Personal Protective Equipment... and had to be trained to support him. [Ben became] lethargic once he had recovered...”
73. During the early part of the month that Ben died (July 2020), the Hospital informed the CCG that he had been admitted to the acute hospital. The CCG attended a virtual meeting with Cawston Park Hospital. The latter was required, *inter alia*, to plan SATS monitoring; identify “when hospital admission is required;” ensure that all staff were “trained in basic life support;” confirm that there was “no underlying health issue causing [low] SATS [in addition to] sleep apnoea. Dr from [the Hospital] on the call reported they were aware of this possibility hence the recent transfer to [acute] hospital for a review.”
74. During 2020, CPAP became a viable treatment option for Covid-19 respiratory failure with the potential to reduce lung damage.⁶⁸ Yet in the weeks preceding Ben’s death, and regardless of his dangerously low blood oxygen levels, staff ceased to encourage Ben to use CPAP. His history of non-compliance and the potential spread of contaminated droplets would appear to have shaped this decision.

⁶⁸ <https://www.gmjournals.co.uk/cpap-used-at-earlier-stage-helps-save-lives-of-hospitalised-covid-patients> (accessed 8 March 2021)

LEARNING IDENTIFIED

The recorded evidence is inadequate concerning this critical feature of Ben's care. His Respiratory Consultant prescribed the CPAP due to Ben's compromised respiratory system and obstructive sleep apnoea. Ways of promoting its use, perhaps through desensitisation for example, were not explored with the NNUH's Learning Disability Liaison Team.⁶⁹ The fact that it was under-used did not feature prominently in correspondence and discussions with the funding CCG until the final weeks of his life.

75. When the CCG was advised of a S.42 [adult safeguarding] referral in July 2020, a "quality visit" took place. This reviewed Ben's records and requested "a care plan [reflecting SATS] monitoring;" Ben reported "some abdominal pain" so [Hospital] Dr was reviewing [him]. The CCG drew attention to Ben's "weight management etc. to improve sleep apnoea."
76. Two days later, a safeguarding visit to the Hospital sought copies of Ben's health care plan and his clinical care record. The health care plan was out of date and "contained conflicting information." It recommended an updated care plan which reflected "any recommendations from the consultant regarding management of...sleep apnoea;" and a copy of the "current physical health plan to be forwarded to CCG Adult Safeguarding Nurse." The CCG's request included information concerning "...when to call for medical assistance depending on clinical need [re] oxygen saturation etc." Ben died before this information was received.
77. Within a month of Ben's admission, he was noted to spit at staff and, on at least one occasion, at a peer. His spitting was noted on 14 occasions. Ben placed a burden on staff by urinating and defecating "on the floor" and/or on his clothes. He engaged in rectal digging and on at least six occasions, threw faeces at staff. He also smeared faeces on himself, walls and furniture and occasionally threw soiled clothing and towels. This behaviour was associated with acute distress and posed such challenges for staff as the management of visceral disgust,⁷⁰ infection avoidance, hypervigilance and the reduction of physical contact with a man who required daily assistance with his personal hygiene and grooming.
78. Ben was dying and his soiling was a potent trigger for one staff member. The CCTV footage during the hours preceding Ben's death was scrutinised by the police. Ben had been cleaned and moved to his second bedroom, having defecated on and around his bed at approximately 4:00 a.m. and 5:50 a.m. The footage reveals that at 6:00 a.m. that morning, this staff member "approached (Ben) who was awake in his lounge/second bedroom" and "rough handled him by pushing him roughly and dragging him down by his arms before hitting his head area with an open hand." The carer "...then looked up to make sure that there was no one looking and hit (Ben) again in the head area with the back of his hand." The Hospital's senior managers

⁶⁹ The local acute hospital's liaison team reported that it has very little contact with the Hospital.

⁷⁰ Miller, W.I. (1998) *The Anatomy of Disgust* Boston: Harvard University Press.

have access to CCTV recordings, but these are sampled rather than viewed continuously.

LEARNING IDENTIFIED

Ben was deprived of elementary decencies just hours before his cardiac arrest. The CCTV freeze-framed a dying man being rough handled and assaulted at a hospital.

Section E: Concerning patients and ex-patients' circumstances

79. Meetings with current and former patients and their relatives revealed several patterns prior to admission to Cawston Park Hospital. In addition to their diagnoses and the description of “challenging behaviour,” the current and former patients were described as “complex,” “very complex,” prone to “kicking off,” “pushing boundaries,” exhibiting “distressed behaviour” “histrionic” or “tricky.”
80. There is no life-long perspective for children and young people with learning disabilities and autism. The short-term perspective of the commissioning to which they are subject arose due to their families having two options: cope yourselves or hand over responsibility completely:
- “[They] left school... and was at [college] for two years. But [they] was misunderstood. [They'd] throw a wobbly because [they] doesn't understand situations...It was because of the mood swings that we couldn't cope.”
 - “You have to put the support into the family when they need it...There are no choices. They go where the bed is. Your worst fear is an out of county place. How can anyone know it's the right place? It's terrifying...The care we have experienced...hasn't learned anything from me or [my child].”
 - “[When our child returned home] we had a very bad time... finding it really difficult... [my partner] called social services and said ‘I can't cope anymore. I'm going to make us a drink and put all our tablets in.’”
81. Three adults remained with their birth families as children. One set of parents was assisted by grandparents who shared responsibility for caregiving until incidents of violence became unmanageable and [they] were admitted to a children's home. Others sought their [child's] admission to a long stay hospital for people with learning disabilities due to their own support needs.
82. As children and young people, some were traumatised by rape and/or physical cruelty and their families are attuned to the continuing destructive impacts of these assaults:
- *It was hard for everyone...There was insufficient evidence, he was given a verbal warning. [Now, my child] is terrified of seeing [the person responsible]*
 - *...hunched rocking*
 - *They'd take their clothes off and walk around.*

83. They were exposed to lies, “secrets” and active developmental harm in their early lives when their understanding was limited and they had neither the vocabulary or wherewithal to report these crimes. Some learned to soothe their anguish by hurting themselves – biting their penis, inserting objects into their vagina, for example, and/or appearing to engineer ways of offering their bodies to adults, including staff:
- [They] *was found online with a stranger. She was exposing her breasts.*
 - *...very sexualised behaviour.*
84. The consequences of these harms go beyond individual suffering and impact on the victims’ families, most particularly their parents:
- *It’s hard. [They] has no understanding of relationships...*
 - *...was placed on a mixed sex ward even though [they] had been sexually assaulted.*
85. One child was terrorised by [their] father. [They were] subjected to frequent, enraged beatings, sexual assaults and bore witness to the brutality experienced by [their] mother. [Their] mother was benign but ineffectual in protecting her child. She remained an important constant in [their] life.
86. Another was removed from the care of [their mother] as an infant. The child had been beaten and [their] care neglected. [They] received inadequate nourishment, warmth and attention when it was most needed.
87. Several embarked on an odyssey of foster homes and children’s homes. For one person, admission to foster care was pivotal because it heralded more harm and assaults. When intervention halted this ordeal, it took the form of another foster placement and then adoption.

LEARNING IDENTIFIED

It is not clear that as children and young people these patients and former patients:

- received professional, therapeutic input that recognised the harm that so many had endured, so that they were no longer at the mercy of the destructive dynamics of others
- benefitted from any acknowledgement of the gravity of being removed from all that was familiar, regardless of the harrowing early lives of some
- were helped to make sense of their abandonment and losses – of loving relatives and of kind staff, during subsequent removals and transfers to other holding environments.

Descriptors such as “complex, challenging behaviour,” “very complex challenging behaviour,” “kicking off,” “histrionic” and “tricky” are not diagnoses. They have reduced people’s educational and occupational opportunities. They are not assets in terms of the support services offered or experienced.

88. There is no evidence of families being acknowledged or involved as equal partners – even though they know their relatives best. As two parents stated:

“I feel for the patients who haven’t got anybody because they’re in a sausage machine that turns them into patients that become institutionalised. It’s made me think about the MHA and the assumption that a S.2 automatically becomes six months on S.3. It’s not right.”

“I was let down by the system way back. We both were. I don’t want this to happen to anyone else. I protected [them] from services... The whole system is appalling. [When they went to] day care [they] always knew [they] was coming home at the end of the day. When it closed, I was left a year with no respite or day care and in that time not a soul looked in on me. Some days I had gone days and days with no sleep...”

89. Investment in sustaining the contact that adults with learning disabilities had with parents and siblings was not consistently evidenced at the Hospital. This source of sustenance from significant early attachments and natural support systems was even in danger of being devalued:

One patient’s “social worker rang the ward...and ‘warned of parental over-involvement [which] in the past was a trigger for [the patient’s] distressed behaviour.”

How would adults with learning disabilities know that they were loved and worth loving – most particularly those whose families could not cherish them?

90. One parent recalled a pivotal event:

“One Xmas [our relative] was supposed to come home. [They’re] not good in the mornings and [a clinician] decided that [they] shouldn’t be allowed to come home. It was awful because we had everything ready here for the family.”

91. Patients’ relationships with their parents was a feature of the Hospital’s therapy:

“[Our relative] was told that she should not hold hands with [their parent.]” The patient was reminded of this during a visit from [their] family.

“What can you do if the Head of Unit is telling you what you can and cannot do and they told me not to visit? There were times when I said I want to see [them] but didn’t want to stress [them] out anymore. Even [friends] had seen for themselves what we were up against. [They] wasn’t an angel – [they] was hard work. I never feared [them] when [they] was with me - but I got to a point where I feared [them].”

92. Another patient’s parent was the only constant in a life characterised by a slew of “placements.” It was because [they] sought to be geographically nearer to [their parent] that they moved to the Hospital where [they] remained for many years. With the encouragement of families, two former patients are currently being supported to use public transport so that they may visit their relatives independently.

93. A parent recalled the distress arising from home visits:

"It's the hardest thing ever. I hated returning [them] every single time. [They'd] be quiet in the car going back to the Hospital. I had to put the child locks on. It started on a Saturday night when [they] knew [they] was going back. In the end we reduced it to [them] staying at home for one night – they'd drop [them] and we'd take [them] back. We tried to make it pleasant with the family coming to see [them] at home and not telling [them] so it was a surprise. Returning [them] was always hard."

94. Visits to and by relatives and phone contact with them are highly valued:

"[Their parent/ my partner] is very concerned for [them]. At review meetings they talk a load of codology and [they] can't cope with it so...doesn't go any more."

"I want to live nearer to my [sibling.]"

"The daily phone contact is so important."

"There was one man whose family lived a long way away. He looked a mess a lot of the time but on the days that his mother visited they made sure than he was nicely dressed and shaved."

[Back home, here with the family, they get their] *own breakfast and cooks with [sibling]... unsure [they do this at the Hospital.]*

Changes to visiting routines are upsetting. For example, when a patient who was accustomed to visiting a sibling was admitted to an acute hospital [they] were very distressed because being visited was too unfamiliar.

LEARNING IDENTIFIED

Family diversity is the norm. With a few exceptions, families seek to sustain relationships with their relatives. There is no sense of partnerships with families being nurtured, regardless of their profound contribution to the lives of their members. Understanding the contexts and values of each patient's family and drawing on their experiential knowledge of bringing out the best in their relatives was not prioritised.

95. Some families became frustrated as they sought to persuade the Hospital of the relevant histories, interests and skills of their relatives:

"The Hospital didn't seek copies of [their] Care and Treatment plans or copies of risk assessments specific to [them] ... Because the Hospital hadn't requested information, [the previous placement] sent information directly to them – which they didn't read...there was a wealth of information... and yet the Hospital wasn't interested."

"[Our relative] used to love art⁷¹ - [they] have not done any for ages. At the Hospital there was too much self-directed time or they had the right to decline activities."

"[They] used to be a fantastic swimmer. It didn't make any difference [they] was never taken."

⁷¹ There are framed examples of their paintings in the family home.

96. The promises of the Hospital were misleading:

“The ... sales pitch included the promise of rehabilitation, treatment and the opportunity to learn and practise independent living skills were not realised. There was no sense of personalisation even though [they] was commissioned to receive 1:1 observations. [They] has such a lot of potential and yet it was as though [they] slept through [their] time at the Hospital... did nothing meaningful... and there was an over-reliance on medication... [They] put on a great deal of weight and in the view of professionals [they] was going backwards.”

“They couldn’t even get the paperwork right. I was sent papers about [their] S.3 when [they] was on a S.2.”

“[Our relative] has always had a calendar so [they] know what is [happening], how many sleeps before events. We’ve told them lots of times and they say the same thing, “We’ll look into it.”

“... [they] took part in the special Olympics. [They] is a very good swimmer. We wanted [them] to swim at the Hospital - there’s a private swimming pool close by. The Hospital did a risk assessment and decided that the carers who would go with [our relative] should all get a lifeguard qualification – even though the pool has its own lifeguards. You’d think they’d encourage [them. Our relative] never went to the pool... The Hospital had been members of the private pool, but they let it lapse. They used to have a sports person but when he left he was not replaced. [Our relative] doesn’t have the activity – there’s boxing and a bit of art [mostly it is] just watching TV or playing cards. We got [them] a bike as a Xmas present. We brought it home because they just put in the shed.”

97. A former patient recalled undertaking “a lot of sessions” at the Hospital:

“I was hardly on the ward some days. Any other people wouldn’t do their sessions and they’d always come to me so I could do them – woodwork, drama... mostly art... I’ve got some certificates...I’d have at least four to five sessions a day.” However, a downside was described *“When I went to sessions they would be asking “When are you coming back?” It was more rigid. I felt rushed...They carried walkie talkies. They were always on and loud...The Hospital say they’ll do things and they don’t do them – like “We’ll post any belongings asap” and they haven’t...I used to wash all the company vans and I’d wash the staff cars. They just let me get on with it.”*

Another former patient stated *“I don’t really want to talk about [the Hospital], it makes me anxious. I don’t want to look back, I want to look forward and I am in a happy place now.”*

98. A parent was dismayed at their relative’s inactivity:

“[They] didn’t seem to be doing anything and I asked the staff “Can [they] go out?” [They] was supposed to be constant care all the time, 1:1, that’s a lot of money a week. The staff said, “We’ve got no diesel for the bus.” I offered to give them £20 to get diesel to take [patients] out...others weren’t going out either... I could see the whole

place was deteriorating. [They] wasn't going out at all and ...wasn't getting any better. [They] was worse."

99. A patient who has developed dementia has had their favourite activities painted on the walls of their living space. However, he is deteriorating because he has spent less time with his family because of Covid-19.

LEARNING IDENTIFIED

The contrast between the lives of the Hospital's patients and those of their siblings, for example, is stark. If accountability of the Hospital to individual patients and to public agencies to provide care and treatment is to be realised, tolerance of long-term under-occupation requires attention. Patients' relatives do not regard daytime hours spent in bed, tolerance of patients declining to exercise and/or participate in "sessions" as exemplifying self-determination or "unwise" choices. They perceive it as a failing service in which inattention to (i) patients' histories, (ii) their health (iii) risk assessments and (iv) Care and Support Plans is endemic.

100. Families understand the challenges and disappointments their relatives face as they seek to find their place in a world defined by achievement. They acknowledge too that the resistance of their relatives to elements of their support – such as staff rotation and departures - render their behaviour increasingly difficult to manage.
101. One family struggles to understand why services themselves have no insight into the impacts of their decision-making and practices. For example, as a teenager, one young person became close to a housemother. The latter understood this young person and encouraged them to develop skills and interests. However, this woman left without notice and without explaining her imminent departure to their relative. Although necessary, this member of staff's rapid replacement meant that this young person *"lost it a few times [and] they couldn't cope with [their] behaviour."* Transfer to another service also failed this young person because *"the staff there weren't really trained."* Over time, this young adult *"lost [their] speech"* and began to attack relatives. On an occasion when the police were called, they too were attacked.
102. An ex-patient valued one worker in particular because of his interest and kindness. *"My key worker would come in on his day off to take me out...none of the others bothered...My key worker changed...Some of the other staff are just in it for the money... [one] took the mickey. He'd say, "I'm in charge. You do as I say. As long as you live here you're not going to have your phone" ... He was bossy – too sarcastic. When I left he said, "Bye, see you back here in six months."*
103. A parent recalled the *"...staff coming in and you think to yourself "They must be trained." I saw all kinds of things. Some staff were just trying to get through the day. There was no interacting with patients. They wouldn't be talking to the patients. They'd just stand there on their phones all day. [My relative] didn't like the staff very much but*

there were certain ones [they] did like. A handful of the staff are good but more of them are not. There are some who seemed loyal to their job. Others couldn't care less...

[I remember my first visit] I went into a waiting room [and] there was a lady... in there. She handed me a piece of paper with the phone number of solicitors. She said "Once people are in Cawston Park Hospital you can't get them out." I didn't keep the number because I thought, "It's a hospital and hospitals are supposed to make people better."

104. Another parent stated, *"I don't rate the staff there... [our relative] was terrified and kept asking "Why can't I go home?"*

105. Another noted that one staff member was *"very good [with their relative] but they change them every hour...keep [patients] busy throughout the day and [they're] too tired to kick off."*

"[Our relative] was put on increased observations and was over-medicated. One time [they] came home on S.17 leave... had put I mac on the front of [their] head and had no hair. [They] had cut and scratched self; was filthy; fingernails and toenails had not been cut; and was not wearing [underwear]. I complained and the complaint was upheld."

106. Before one man transferred to the Hospital, he was described as aggressive towards people and property. Key professionals had left this service – including a psychologist with whom he had developed a positive relationship.

107. A parent recalled a time their relative was returned to the Hospital. *"There was a member of staff asleep in the sitting room. I was horrified – it was the middle of the day... I went in search of other staff, yet the manager was unbothered There's a lack of people in the right positions... Do they ever answer the phone at the Hospital? The switch just goes round and round."*

108. One family stated, *"They tell [them] to go to their bedroom so they don't restrain [them.] "[They] enjoy having something to do and going out..."*

109. Another person's violence has increased in frequency and intensity and he struggles to cope with unfamiliar people. Although the Hospital has identified a core team of staff for him, his life is highly circumscribed and for a period of several months, there was no legal justification for his physical segregation.

110. One family described its distress when their relative *"was in the Hospital with her hair matted and her eczema [untreated] – she looked like she'd been in a bath that was too hot because her skin was weeping. There was a CPA meeting and we wondered, "Who is going to talk to her for her views about this?" She wants to go to college, to get married and have children – and yet there she was looking so neglected. We were horrified when we saw her. She looked so poorly. They said "She doesn't want us to help her. She's not funded for 1:1." That was the state she came home in. I showered her and covered her with cream. I know how to cajole her along, but they didn't and didn't seem interested. The SALT was the exception. She did some work with staff to*

help them to improve communication. [However] a care plan is only useful if it's read...She is not the only person who has been ill-served..."

"[You have to take] account of moving from [the penultimate placement which provided] 24 hour 1:1 to a mixed setting. [How can they not] have problems? At the Hospital [they] witness violence, verbal aggression and self-harming – and [they]... imitate this. Staff were always busy with their phones and red alerts."

111. Two parents recalled the apparent disinterest of the Hospital in caring for patients' private spaces and their belongings. *"...her clothing disappeared; she wore other people's clothes and even men's clothes. I have LPA⁷² and she left the Hospital without any of her money. I chased it up, asking where it was. They had £293.00..."*

"Cawston Park Hospital's owner has many homes apparently. I see them in their big guzzling motors – getting a lot of money for old rope."

"One time we went to her bedroom and she'd said it was in a bit of a state. Usually, we didn't see the untidiness, but she had piles of wet washing in there. We asked her about it, and she said, "I don't know – they just put it there." Her mattress didn't fit the bed properly – it was on an angle and there was no bedding on it. She said, "They keep saying it's in the cupboard but it's not mine." They said "the washing machine's broken" but it wasn't true – it was the carers who didn't help her. At home she is tidy..."

"They'd say, if she had anything new, that they'd always add to the inventory in the office. They'd never see the light of day again – CDs, walkmans – and then they'd reimburse but it took forever to get the money back! She had some Ugg boots – they're expensive and she never got them back. The woman who was supposed to be responsible for the inventory said she didn't know anything about it."

112. Families are distressed by the Hospital's use of medication, restraint and seclusion and its failure to change.

"It's been a struggle to get the right medical help for [them]."

"[They] even has to ask for toilet paper."

"The Hospital has such a simplistic understanding of behavioural antecedents..."

113. A former patient recalled *"It's not nice being restrained. It's painful. Some staff went over the mark. One he used to put my fingers on my wrist. They take the mickey... It depends on the staff what they do [during restraint]. They shove you on the floor with your hands behind your back. Your head's on the floor and they put it sideways. There's one on each leg and two holding arms for however long they think is necessary. It's painful. It hurts. It depends on the patient how long. At the Hospital it was sometimes an hour on the floor. [What about medication? PRN?] They don't piss about – they just do it. They pull your trousers down and just do it then they leave you in seclusion for four hours. It's horrible. They stand outside the door until they think you're safe to get out. They just push you back in. They don't care about me. They*

⁷² A Lasting Power of Attorney

make it that uncomfortable. They make you get on your knees and put you to the floor. When I've been restrained there, I didn't come out of my room for days because I'd be so annoyed. Most of the time it's over the top what they do. When they bend your wrist, it hurts and I couldn't draw or do computer games for four days. The staff are in control of [the psychiatrist] I never had the [psychiatrist's] number... When I asked, they'd say, "He's busy - in a meeting – in the office." They didn't ever ring him. It's a long time ago. Then you'd see him and he hadn't been in a meeting!"

114. Covid-19 is responsible for delaying the transfer of some patients from the Hospital. These delays became very stressful for the patients concerned. However, one patient was sustained by video calls with the new provider. *"Now [they're] doing really well, engaging with the staff, enjoying walks, going shopping and learning how to use public transport...Seen as an individual [with their] own flat...becoming familiar with the location."* In contrast, *"the Hospital had a very narrow view of [their] support needs."*
115. Another patient has become so unsettled by the postponed discharge that [their distressed] behaviour has escalated. *"It is as though a fortress is being built around [them.] Now, the Hospital is asserting that [they] are unfit for discharge."*
116. A parent stated:
"They all need a little bit of TLC. They don't get it in there. They don't need to be there."
117. The family of a former patient recalled that *"There was no discharge paperwork sent to the community team – it was down to me to follow things up...I'm impressed with what's been picked up so far [at the new service] ... Now, [they're] brighter, cheerful, joking with staff and [they] look relaxed... [They] talks about what [they've] done and where [they've] been..."*

LEARNING IDENTIFIED

Although families are experienced problem-solvers, there is a persistent thread of criticism in their testimony. Neither relatives nor patients were supported during meetings at the Hospital. With reference to patients, perhaps this was because, inadvertently, the crises which triggered their detention had ceased. Too often, MDTs relied on in-house clinicians and staff. What is perceived as the excessive use of restraint and seclusion by unqualified staff, the "overmedication" of patients and their weight gains trouble families because they are remote from the healing implied by being in a hospital. Families have no faith in a service which puts troubled people together without advancing their individual or collective interests; and responds inadequately to the complex causes of people's behaviour. Their relatives have been stuck in a system in which the question "What is the mental illness that requires inpatient treatment?" is not answered.

Families understand that the conditions and means of participation vary for people with learning disabilities and autism and that this requires specific attention to making participation possible. Patients and their relatives know which staff are approachable, knowledgeable, insightful and kind. They judge individual staff members and services by how they have assisted with support needs and what they have achieved with and on behalf of their relatives.

Section F: The Hospital

Ownership and history

118. Companies House reveals that the care provider at Cawston Park Hospital is **Jeesal Akman Care Corporation Limited**, a Private Limited Company providing “other human health activities” (SIC code 86900). Tugay Akman is a director and the Responsible Individual. Sally-Anne Subramanian is the other director.
119. **Jeesal Residential Care Services Ltd** provide “residential care activities for learning difficulties, mental health and substance misuse.” Sally-Anne Subramanian is the director. This and three other companies make up the Jeesal Group. “The ultimate parent company is **Jeesal Holdings Ltd**⁷³ [and] the ultimate controlling parties are J and SA Subramanian.”
120. The Group Strategic Report for the year ended 31 March 2016 acknowledged “the continuing growth of the group, not only in financial results, but also in the provision of the services provided...The director and key management are keen to provide a high level of service for all tenants living at the numerous homes throughout the county, and as such, continue to invest in the onsite facilities. The Company has recently been awarded a rating of Good from CQC within all its residential homes, with an Outstanding achieved in the caring assessment for three homes.” In terms of “principal risks and uncertainties...the company requires management to continually monitor the key risks...the Board formally manage this process on a regular basis and ensure that necessary processes are in place to help to mitigate any potential risks which are identified via the continuous improvement plans to deliver the highest care provision to the tenants.” The report identifies three principal risks
- Local competition – Reputation and strong relationships with referrers together with the good level of service provision provided at the homes across the

⁷³ JEESAL RESIDENTIAL CARE SERVICES LIMITED, 04062939 - Incorporated on 31 August 2000
JEESAL AKMAN AYSEL CARE LIMITED, 10413898 - Incorporated on 6 October 2016
JEESAL AKMAN CARE CORPORATION LIMITED, 07200632 - Incorporated on 24 March 2010
GO SMART CARE LTD previous names: JEESAL AKMAN SERVICES, 10413918 - Incorporated on 6 October 2016
JEESAL SUPPORT SERVICES LIMITED, 08331750 - Incorporated on 14 December 2012
MEDICAL EXCHANGE LIMITED, 08219439 – Incorporated 18 September 2012

county, ensure that the business is at the forefront of Learning Disability services.

- Dependency on revenue streams – Local authorities are facing well publicised budget cuts...there are currently no indications that this revenue source is in any way threatened. However, the Board are continually developing and evaluating new ideas for revenue streams in other geographical locations, to help deliver new and existing care services.
- Key personnel – Management seek to ensure that key personnel are appropriately remunerated to ensure that good performance is recognised and that the core team is maintained, together with new links with local specialist staffing agencies to reinforce the compassion and dedication from care staff” (p1).⁷⁴

121. These statements were repeated in the Group of Companies Accounts of 27 October 2017 and 1 August 2018. The Group of Companies Accounts dated 5 August 2019 repeat the principal risks concerning “Dependency on revenue streams [and] Key personnel.” The risk concerning “Local competition” is no longer cited.
122. The company Jeasal Akman Aysel Holdings Ltd was succeeded by Jeasal Akman Anafarta Holdings Ltd which was incorporated on 27 September 2016.⁷⁵ The nature of the business was “other letting and operating of own or leased real estate.” This company “applied to be struck off and dissolved” on 28 May 2020. Its dissolution date was 13 October 2020.
123. An agency support worker confirmed in a statement for Joanna’s inquest that [they were] working for “Medical Exchange Agency” – which is owned by Tugay Akman one of two directors of Jeasal Cawston Park.
124. “The Jeasal Group was established over 30 years ago by Jeeva and Sally Subramaniam...a long-established health and social care organisation with great traditions, caring for some of the most vulnerable and marginalised people in our society since 1984...it was in 2010 that the Jeasal Group acquired Cawston Park.”
125. Cawston Park was a flagship - a privately-run hospital, opening in 2003 to help people with complex psychiatric needs and adding a state-of-the-art doughnut shaped building in its 115 acres of grounds that used to be Cawston College independent school.⁷⁶ Jeasal purchased the site in 2010, after the previous owners went into administration following a collapsed fraud trial.⁷⁷
126. The acquisition of the hospital was not based on a local population needs assessment. Jeasal claim “that many of the people they supported were prone to long term hospital treatment and... acquired Cawston Park with the aim of being

⁷⁴ Group of companies accounts 28 November 2016 <https://find-and-update.company-information.service.gov.uk/company/08896891/filing-history> (accessed 9 October 2020)

⁷⁵ <https://find-and-update.company-information.service.gov.uk/company/10397063/filing-history> (9 October 2020)

⁷⁶ Eastern Daily Press, 17 March 2010

⁷⁷ DB Double Blog, 19 June 2009

able to provide clinical care and treatment and supporting people as quickly as possible back into the community.”⁷⁸ Assessment and Treatment for adults with learning disabilities, autism and mental health problems for whom placements were difficult to find was a business opportunity to meet a need identified by the provider. The directors that were removed and then exonerated as part of the investigation prior to the closure in 2009 said the hospital was thriving had a good reputation and was profitable.

The Hospital’s Governance Framework

127. During December 2015, the CQC stated that the Hospital had “governance systems in place.” Although the elements of these systems were not described, insights may be gathered from this and all subsequent reports. For example, the December 2015 report states that the Hospital’s “electronic system...allowed senior staff to monitor compliance with mandatory training,⁷⁹ supervision and appraisals...staffing levels were determined based on the information provided by this system.” Thus, the Hospital’s Responsible Individual had readily available information about the workforce and, having identified staffing shortfalls at the weekends, introduced an incentive for weekend working.
128. The **professional development of the workforce**, including the Hospital’s managers, is a feature of CQC’s reports:
- “Staff received supervision every two months, supervision covered topics such as patient cases, workload, development and training... (May 2017)
 - “Managers had not ensured all staff received specialist or mandatory training for their role. We requested training figures from the provider. We found managers inconsistently provided training to all staff regardless of their role... The training figures included available Continuous Professional Development modules for each staffing role but not figures for who had completed this training... (September 2019)
 - “... we were not assured that the quality of clinical observations was consistent and sustainable due to new staff not receiving observation training⁸⁰ from March to September 2019...” (January 2020).
129. Beyond mandatory training, it is not clear what specific training goals were identified by the Hospital. The reporting of challenging behaviour may be explained by differences between staff and their attributions of responsibility for behaviour. Did the training advanced and fostered by this Hospital address, for example, capacities for shaping emotional and cognitive responses to patients’ behaviours?

⁷⁸ <https://jeesal.org/who-we-are> (accessed 21 March 2021)

⁷⁹ Also cited in reports of May 2017 and February 2018,

⁸⁰ Also cited in April 2020; other training cited by the CQC included recording restraint positions [April 2019]; the use of a “defibrillator...signalong...Makaton...writing easy-read care plans... [September 2019]

130. In addition, the **auditing** undertaken by the Hospital's managers addressed many themes:

- "...clinical audits, such as incident records, patient treatment engagement and file checks... records audits (May 2017)
- clinical audits, such as incidents, therapy led and patient engagement (February 2018)
- documents concerning the use of restraint (April 2019)
- The provider did not have an effective audit process to provide assurance or review the quality of the care provided at this hospital. There were poor governance arrangements in place to review audit processes. External stakeholders found issues that were not identified by the provider's internal or external audits (September 2019).
- ...managers had not identified which care records had been audited...Staff had carried out recent audits in staff training, environmental cleanliness, hand hygiene and the Mental Health Act. However, managers could not provide evidence that staff were working cohesively together to ensure a co-ordinated approach to quality improvement and audit across the hospital (January 2020)
- The service did not have effective systems and processes, such as regular audits of the service provided, to assess, monitor and improve the quality and safety of the at the hospital (April 2020).
- The provider had worked to make improvements to the process of audits however many scheduled audits were not completed... we saw that the cleaning audit for the clinic room confirmed the environment was clean when there was enough dust on the emergency medicines bag to indicate it had not been cleaned for a significant period of time. This cast doubt on the validity and quality of the audit." (August 2020).

131. There is a single reference to the Hospital's "Clinical Audit Effectiveness Committee" in CQC's August 2020 report. However, "Managers acknowledged that audits were currently not being used to drive change at the hospital. During our most recent three inspections of this service in 2019 and 2020, we highlighted concerns regarding audits and a disconnect between audit and governance processes."

132. The Hospital's **internal reviewing** was highlighted by CQC:

- We saw evidence of hospital wide actions taken in response to findings, and progress updates reported in the quality improvement review (February 2018)
- ...the hospital still had vacancies for registered nurses which remained an area of concern and had been escalated up to the corporate risk register and was reviewed with commissioners through Care Quality review meetings and the hospital Clinical Governance group (April 2019)
- Monthly reviews were absent of any useful information which can be used in the evaluation of effectiveness of the support plan and made it almost impossible to track the patient's progress (September 2019)

- Staff had not fully discussed what audits and reviews needed to be prioritised. And we observed staff working on separate projects without management oversight or actions being taken. For example, one person working on quality improvement had reviewed incidents relating to patients swallowing objects... [completed during August 2019]. However, managers had not discussed the review, drawn up an action plan or put into place any of the recommendations made. The provider had reported further incidents of patients swallowing objects since the time of the review (January 2020)
- we saw evidence that managers were undertaking quality and safety reviews at ward level, but it was unclear how these fed into the overall governance processes as the reviews had been returned to the Director of Nursing who was no longer in post (April 2020)
- Managers did not have sufficient oversight of the management of serious incidents, including completing reviews of serious incidents and sharing learning with staff... Managers told us of plans to implement a Patient Safety and Quality Review Committee to improve patient safety, discuss root cause analysis, serious incidents and lessons learned from incidents" (August 2020).

133. CQC's scrutiny of the Hospital's decision-making, procedures and practices that should assist directors and managers to achieve its stated purpose confirms that the Hospital has a limited ability to sustain improvements. The Hospital's internal efforts to monitor and manage the risks to which its patients are exposed, for example, are static problems. During 2020, the CQC was "maintaining enhanced engagement" with the Hospital with "various other stakeholders...such as Clinical Commissioning Groups, local safeguarding authorities and NHS-E." The August 2020 inspection highlighted the Hospital's still fragmentary system of incident recording and reporting: "Incidents that were subject to a Root Cause Analysis (RCA) were recorded on a separate database. An RCA is an investigation led by the provider following a serious incident and reported to the Clinical Commissioning Group (CCG). When we requested a record of the provider's serious incidents, we were informed that these had been extracted separately from the provider's electronic recording system and it was unclear how the service distinguished serious incidents from all other incidents that occurred at the service. Incidents on the RCA database did not match the serious incidents information that we were provided with."

134. During September 2019, the CQC stated that the Hospital "must ensure governance meetings are effective in identifying areas for improvement and sufficient priority is set for these meetings to take place regularly." During January 2020, it stated that "Managers were not acting on concerns and reviews with sufficient coordination and urgency which had an impact on patient safety." By August 2020, the CQC noted that "...it did not appear that any improvements had been made to align priorities identified from governance meetings. It was not evident what the provider's priorities... were...it was still not clear how the provider measured patient progress...also unclear how these reviews fed into the provider's overall governance or quality processes."

135. It does not appear that the Hospital developed or maintained a successful risk culture. It is disadvantaged by the absence of accurate and timely information flowing up to managers and directors and down to staff and patients. It is mired in familiar stalemate. Although first-person accounts from patients and their relatives are powerful means of establishing the impact of the Hospital and would provide a holistic view of performance, they are absent. Little may be discerned of the Hospital's corporate and financial governance or the extent to which this is intertwined with clinical governance.

Commissioning and care management

136. The CCGs responsible for placements at the Hospital arguably believed that they were purchasing a bespoke service. There was no evidence of overall leadership among commissioners. Individually, they did not press for, or receive, detailed accounts of how the Hospital was spending the weekly fees on behalf of its patients or whether agreed levels of observations were being honoured. They did not request information concerning the destinations of former patients. For example, did they return to their pre-placement addresses or were they transferred to other Jeesal facilities? Even though the Hospital was not meeting its contractual requirements in terms of the levels of supervision provided to individual patients, commissioners continued to place people there. Neither patients nor the families whose relatives were in crisis could influence the decisions of the Hospital's clinicians concerning medical treatment, health care and, specifically, prescribed medication. It strayed far from its stated purpose of assessment, treatment and rehabilitation. The Hospital's management was discontinuous, its staff were unskilled and staffing levels were inadequate – all of which rendered its patients under-protected.
137. Care management and coordination are at the sharp end of commissioning and trusting relationships reside at the heart of these. The purpose of care management and its variant, care coordination, is to ensure continuity, accountability and efficiency of individual care. The core functions typically include assessing a person's needs, developing a comprehensive care plan, arranging services and reviewing progress by checking that the service is adhering to the care plan, for example.
138. Care management is familiar across health and social care since it is concerned with aspects of a person's care over time. Patients' relatives reasonably expected that care management would be based on familiarity with a person's history and would be given expression in guidance, advocacy, interpreting behaviour and monitoring the individual's service, for example. However, this was not supported by the Hospital's information sharing across professionals, services and families or its records. People's relatives raised pivotal questions in relation to medication, diet and inactivity and yet their profound knowledge of people's histories, including their medical treatment was barely acknowledged. Although families have a great deal to contribute to patients' care and the impact of the latter on them is profound, they were not perceived as credible partners.

139. The CQC reports between September 2019 and October 2020 cite that it received feedback from Norfolk safeguarding authority, West Norfolk CCG. The reports of August and October 2020 state that, “various other stakeholders are also monitoring the provider such as Clinical Commissioning Groups, local safeguarding authorities and NHS – E.” CQC reports glimpse the circumstances and experience of individual patients.

- “We were concerned that there was a patient identified as being cared for in a single service who would be more appropriately described as being in long term segregation.⁸¹ The patient lived alone in one of the self-contained flats and did not mix with other patients, or the public, at any time due to risk to others. We were satisfied he was being well cared for and this was the most appropriate setting for him. We do not recommend that he is moved from his current setting...” [April 2019]
- “Shortly prior to the first inspection visit, the provider alerted us to a significant error in which a patient received the wrong dose of medication for a four-week period. This was not initially identified by the provider’s internal or external audits but by an outside stakeholder...” [September 2019]
- “Managers had not ensured nursing staff were trained to communicate effectively with patients.” [September 2019]
- “We reviewed multiple easy read care plans for two patients. Based on the information present in the patients’ communication plans the patients would not be able to understand their easy read care plans.” [September 2019]
- “Managers had not prioritised the oversight of patient observations despite a high number of safeguarding incidents directly related to this concern...” [January 2020]
- “...managers have engaged with the advocacy service to work towards patients being able to contribute towards clinical governance in a meaningful way...the Chief Operating Officer had made changes to the membership of the clinical governance meetings to include the ward managers and the independent advocates.” [April 2020]
- “...the service reported...incidents where a patient was caused harm, or was exposed to the risk of harm, due to observations either not being completed...or where staff did not have sufficient skills and experience to understand the meaning behind a patient’s behaviour.” [April 2020]
- “Stakeholders raised concerns that a patient was on a maximum weekly dose of an anti-psychotic medication despite not having been diagnosed with a psychotic illness. Another patient was prescribed a sedative medicine to be given as required with a maximum dose within BNF limits. The patient had been

⁸¹ In CQC’s September 2019 and January 2020 reports, long-term segregation is defined as “a situation where, in order to reduce a sustained risk of harm posed by the patient to others, which is a constant feature of their presentation, a multi-disciplinary review and a representative from the responsible commissioning authorities determines that a patient should not be allowed to mix freely with other patients on the ward or unit on a long term basis. Four patients were in long-term segregation at the hospital at the time of our inspection.” By April 2020 there were three patients in long-term segregation

receiving 1mg of this medicine for several weeks at the discretion of the nurses in charge. From 20 January staff increased the dose more often to 2mg without a rationale for this being recorded.” [April 2020]

- “A patient in long-term segregation experienced deprivation of access to normal daytime clothing...” [April 2020]
- Another patient in in long term segregation had a leather settee which they often slept on. As this patient experienced night-time urinary incontinence at times...the settee was urine-sodden and the lounge and entrance smelled strongly of urine.” [April 2020]

140. The form and complexity of individual care plans vary depending on the level and type of services involved. A member of the Hospital staff described a care plan: “It would say what a patient was allowed to do or not i.e., if they could go out [and use a] metal or plastic fork. Staff would read the care plans to know what they were doing. [They included] the basic information.” This review has shown that there is nothing assured or contingent about the Hospital’s attention to care plans, no matter how detrimental the consequences of not reading them.
141. There were three placing CCGs: Great Yarmouth and Waveney CCG, Norwich CCG, North Norfolk CCG, South Norfolk CCG and West Norfolk CCG, which became Norfolk and Waveney CCG; Waltham (sic), Newham and Tower Hamlets CCG⁸², which also operates within the NHS North East London Commissioning Alliance; and Merton and Wandsworth CCG, which became Merton CCG. The latter, in relation to Jon described itself as “a funding authority rather than a case manager.” His transfer to Cawston Park Hospital “was effected by NHS England.” Merton CCG acknowledges that Jon’s placement “outside of the borough...necessarily stretch [ed] communication lines between Jon and his supports, including his family and the CLDT.” The Waltham, Newham and Tower Hamlets CCG acknowledged that a CTR review concerning Joanna, which took place 14 months after the previous CTR, “identified a number of concerns...the action plan included an action for Cawston Park Hospital to repair the CPAP machine, unfortunately the patient died the next day after the CTR was conducted.” With reference to the CPA, Waltham, Newham and Tower Hamlets CCG note “...there is a lack of evidence/ documents about the frequency of the patient’s CPA.” Norfolk and Waveney CCG report that the deaths of Joanna and Jon during 2018 resulted in a change from quarterly contract meetings to monthly meetings. During June 2019, “...the North/ South CCGs commissioned additional support to oversee [the Hospital] and undertake an extensive quality review...a report to the Quality Surveillance Group chaired by NHS England requested the [Hospital] was added to enhanced surveillance...” Following Joanna and Jon’s deaths, Norfolk’s CCG liaised with NHS England “...and contact was made with the other responsible commissioners [since the Hospital] had contracts with over 10 other CCGs...”

⁸² On 22 June 2021, the Panel was advised by the North East London Commissioning Group that the correct name at the relevant time was WEL CCGs, that is, Newham, Tower Hamlets and Waltham Forest CCGs.

142. During January 2021, NHS England published guidance concerning the responsibilities of host commissioners.⁸³ The key roles, which were undertaken by Norfolk and Waveney CCG, included: being a point for contact for all commissioners, most particularly when “issues of concern” arise; creating a means of sharing information between commissioners and the safeguarding adult board; working with colleagues in contracting and quality teams and being the point of contact with the provider “for issues relating to quality and safety” and for “developing actions that will deliver required quality improvements;” and “taking a lead role in coordinating the response required if there are serious and/ or multiple concerns identified...”

Registration and Inspections

143. Cawston Park Hospital is registered with CQC for the assessment or medical treatment for persons detained under the Mental Health Act 1983 and the treatment of disease, disorder, or injury. CQC’s website states that it has 57 registered beds across six wards: **The Grange** – a 15 bedded locked ward for male patients only; **The Lodge** – a 14 bedded locked ward for male and female patients; **The Manor** – a 16 bedded ward for both male and female patients. **The Manor Flats** – has six individual living flats; **The Yew Lodge** - has three self-contained flats; and **The Manor Lodge** – has three self-contained flats. In all the flats and **The Manor Lodge** patients are supported to live independently.⁸⁴
144. CQC’s website contains 15 inspection reports. The key features of each are summarised:

An inspection of the Grange⁸⁵ published on **24 January 2013**⁸⁶ was based on an inspection on 19 December 2012. It noted that action was required in the “care and welfare of people who use services.” It reported “...gaps in care planning and delivery, which could impact on the health, safety and welfare of patients...two plans contained outdated information about where the patient was being nursed and their level of observations. Failure to update care plans created a risk of inappropriate care being delivered...One patient was considered to have a medium risk of self-harm. A written management plan was in place to reduce the risk and protect the patient, but this had not been communicated to all staff...we found that some of the records of restraint were not completed in full...(p8-9.) The service was judged to be meeting standards concerning “respecting and involving people who use services, cleanliness and infection control, staffing [and] complaints.”

⁸³ <https://www.england.nhs.uk/wp-content/uploads/2021/01/Host-commissioner-guidance.pdf> (accessed 1 April 2021)

⁸⁴ This information is from the CQC inspection published during October 2020.

⁸⁵ Providing a “Care home service with nursing”

⁸⁶ [https://www.cqc.org.uk/sites/default/files/old_reports/1-\(197770593_Jeesal_Akman_Care_Corporation_Limited_1-217058056_The_Grange_20130124.pdf](https://www.cqc.org.uk/sites/default/files/old_reports/1-(197770593_Jeesal_Akman_Care_Corporation_Limited_1-217058056_The_Grange_20130124.pdf) (accessed 15 February 2020)

An **inspection of the Grange** published **11 June 2013**⁸⁷ confirmed that the standard “care and welfare of people who use the service” had been met. That is, patients at the Grange “...experienced care, treatment and support that met their needs and protected their rights.”

An inspection **across the Hospital** published **22 August 2014**⁸⁸ stated that it met all assessed standards. Based on a visit on 2 July 2014, CQC noted that “current safeguarding concerns for this service were being addressed through the relevant statutory agencies. We found that the previous concerns about reporting and ward-based practice had been addressed by the provider with the support of an external specialist. Improvements had been made to the provider's safeguarding systems and protocols. Further work was taking place to ensure that these improvements were being embedded through the service” (p10).

An inspection **across the Hospital** published **10 March 2015**⁸⁹ was based on an inspection on 16 January 2015. This determined that the Hospital met all assessed standards, that is “Care and welfare of people who use services, meeting nutritional needs, safeguarding people who use services from abuse, cleanliness and infection control, management of medicines, safety and suitability of premises, requirements relating to workers, staffing, supporting workers, assessing and monitoring the quality-of-service provision.” It noted “People who use the service told us that they felt safe living at Jeasal Cawston Park. Staff were able to give examples where people's safety had been considered and suitable plans had been put in place to prevent any potential abuse. We were told on one ward that a patient was placed on enhanced observations to safeguard them from any potential harm from others and from themselves. Staff were able to describe the different types of abuse and the provider's reporting procedures should they need to raise a concern. We looked at staff training records and saw that 84% of staff had completed safeguarding training” (p8).

An inspection **across the Hospital** published **16 December 2015**⁹⁰ and based on an inspection of 22-23 September 2015, received consistently “good” ratings in response to the questions, “Are services: safe, effective, caring, responsive [and] well-led?” With reference to safeguarding, it was noted that “81% of staff had completed mandatory training and 95% of staff had completed safeguarding training (p7). [They] recognised and reported abuse appropriately from this... Robust systems enabled staff to report safeguarding concerns...In the past 12 months, there were 38 serious incidents, which senior management have investigated to reduce the risk of reoccurrence. The serious incidents included a patient absconding, and staff failure to report an injury of a patient.

⁸⁷ https://www.cqc.org.uk/sites/default/files/old_reports/1-217058056_The_Grange_INS1-592603266_Responsive_-_Follow_Up_11-06-2013.pdf (accessed 15 February 2020)

⁸⁸ https://www.cqc.org.uk/sites/default/files/1-217058056_Jeesal_Cawston_Park_INS1-1568968789_Scheduled_22-08-2014.pdf (accessed 15 February 2020)

⁸⁹ https://www.cqc.org.uk/sites/default/files/1-217058056_Jeesal_Cawston_Park_INS1-1605981588_Responsive_-_Concerning_Info_10-03-2015.pdf (accessed 15 February 2020)

⁹⁰ https://www.cqc.org.uk/sites/default/files/new_reports/AAAE8230.pdf (accessed 15 February 2020)

(p15). Hospital policies, including those relating to safeguarding, observations and complaints procedures, were current and reviewed regularly” (p19).

A report published on **31 March 2017**⁹¹ concerned two units **Yew Lodge and Manor Lodge**.⁹² The report presented the findings of a “focused inspection...in response to concerns identified by a member of the public to the Care Quality Commission [concerning two wards. It] ...focused on three domains, safe, effective and caring” (p5) and noted that: “Both [Yew and Manor] lodges had blind spots where staff could not observe all areas. Staff mitigated risks to patients by updating patient risk assessments, carrying out one-to-one observations and escorting patients at all times. Managers reviewed these risks during monthly multidisciplinary meetings (p1) ... Ninety-three per cent of staff had completed safeguarding training. Staff knew what should be reported under the safeguarding procedures. We saw records where staff had dealt with a potential safeguarding issue...The provider had systems in place for the reporting and investigation of incidents. Action plans were in place following incidents” (p12).

An inspection report **across the Hospital** published on **17 May 2017**⁹³ resulted in a “requires improvement” rating. The domains found wanting were, “Are services safe? Are services effective?” “Training records inspected showed 83% of staff had completed mandatory training. This included, safeguarding (p13) ...In the last 12 months there were three serious incidents, which senior management had investigated to reduce the risk or reoccurrence. The serious incidents included patient absconding and an injury to a patient” (p14). In relation to services being caring, responsive and well-led, the Hospital was judged to be “Good.”

An inspection report **across the Hospital** published on **16 February 2018**,⁹⁴ based on an inspection of 12-13 December 2017 determined that the service was “good” overall. “The provider’s patient safety and quality report showed that 93% of staff had received safeguarding training. Staff knew what to report under the safeguarding procedures. We saw records where staff had appropriately dealt with potential safeguarding issues...The hospital had 32 serious incidents in the last twelve months. Senior management had investigated all serious incidents and produced a subsequent investigation report (p15).

Joanna died during April 2018. She had been admitted to **The Manor** and transferred to **The Lodge** within days of her admission. **Jon died during November 2018.** Jon was admitted to **The Lodge** where he remained as an inpatient.

An inspection report **across the Hospital** published on **23 January 2019**⁹⁵ was based on an inspection on 12-13 November 2018. It did not provide an overall rating. It resulted from, “Notification of an unexpected death of a patient, Complaints [and]

⁹¹ https://www.cqc.org.uk/sites/default/files/new_reports/AAAG3520.pdf (accessed 15 February 2020)

⁹² These units had two and three self-contained flats respectively in 2017

⁹³ https://www.cqc.org.uk/sites/default/files/new_reports/AAAG4601.pdf (accessed 15 February 2020)

⁹⁴ https://www.cqc.org.uk/sites/default/files/new_reports/AAAH0857.pdf (accessed 15 February 2020)

⁹⁵ https://www.cqc.org.uk/sites/default/files/new_reports/AAAH9796.pdf (accessed 20 February 2020)

Information shared from other external agencies” (p4). It identified the following “areas for improvement: The seclusion room did not meet the standards of the Mental Health Act Code of Practice and staff had not fully completed seclusion records. There were ligature risks on **The Lodge** and courtyard that had not been identified. Where risks had been identified actions to mitigate the risk posed to patients had not been carried out. There had been an increase in the number of restraints across the hospital. Where prone restraint had occurred, staff did not accurately record this within patient notes and physical observations following restraint had not taken place. Medication was not stored safely or securely. Daily checks of equipment within the emergency grab bag were not recorded on **The Manor**. Not all ward areas were clean and tidy. The provider did not deploy sufficient numbers of staff to safely maintain patient observation levels. Not all reportable incidents were notified to the Care Quality Commission and managers did not routinely share and discuss learning from incidents with staff” (p6).

“Between 1 October and 31 October 2018, there were 29 incidents where staff had placed patients in seclusion at the hospital. Nine records had missing or inaccurate information and did not include observation records and two records had been created in error. This meant that the electronic records did not reflect patient observations by staff during seclusion episodes or the decision staff had made to begin or end the seclusion” (p10).

“Between 1 July 2018 and 30 September 2018 there was a total of 696 restraints across the hospital. **The Lodge** had the highest number of restraints with 255 episodes. This compared to a total of 546 restraints between 1 April 2018 and 30 June 2018. **The Lodge** had the highest number of restraints between 1 April 2018 and 30 September 2018. This ranged between 67 to 103 episodes in a month. There were 18 occasions when staff restrained patients in a prone position (face down) between July 2018 and September 2018 across the hospital. Eleven of these were for one patient. we reviewed 10 of these restraint reports. Eight showed that staff had not updated the patient’s notes following the restraint. Seven of these did not include a record that physical observation of the patient had taken place following the restraint” (p10-11).

“The provider’s patient safety and quality report dated October 2018 showed that 99% of eligible staff had received safeguarding training. Between 1 August 2018 and 12 November 2018, a total of 15 safeguarding reports had been made to the local authority. Two of these reports had not been notified to the Care Quality Commission as required by regulations. Incidents resulting in serious injury required notification to the Care Quality Commission. However, we found one incident that had not been notified...The number of incidents across the hospital had increased. Between 1 April and 30 June 2018 there was a total of 1805 incidents across the hospital. This compared to a total of 1946 incidents between 1 July 2018 and 30 September 2018. Of these 1946 incidents, 849 had occurred on **The Lodge** and 490 on **The Manor**. The provider told us the number of incidents had increased due to a deterioration observed in one patient and new patients admitted with distressed behaviours...following a serious incident, managers noted on a serious incident record

that plastic cups would be removed from the hospital. However, we found plastic cups on **The Lodge** during our visit 13 days later” (p11).

An inspection report **across the Hospital** published on **1 April 2019**⁹⁶ was based on an inspection on 5-6 February 2019. This determined that the service required improvement, most particularly concerning its safety and leadership. It noted that “Staff did not ensure that patients in seclusion were having the required medical and nursing reviews to meet the standards outlined in the Mental Health Act (1983) Code of Practice (2008). Staff did not ensure that the recording of seclusion was complete and accurate. Managers did not have sufficient oversight of seclusion and restraint recording, despite seclusion recording being identified at a previous focused inspection and in the hospital’s own internal audit. The seclusion room did not meet all the required standards of the Mental Health Act (1983) Code of Practice (2008). Staff did not consistently and accurately fully record incidents involving restraint and the management of violence and aggression. Staff did not ensure that all patients in long term segregation were reviewed by an approved clinician every 24 hours and that all paperwork relating to long term seclusion was in place. Staff did not ensure consistent recording of Section 17 leave for patients including risk assessment, clothing notes and details of patient engagement and behaviour whilst on leave” (p2) “Managers had not ensured that seclusion recording was completed to a satisfactory standard with adherence to the Mental Health Act Code of Practice. This was a requirement notice from the last focused inspection in November 2018 and although the hospital recorded actions in this area as complete or ongoing, we could not see sufficient evidence of improvement. We observed inconsistency in the recording of incidents, particularly relating to the management of violence and aggression and restraint. Managers had not ensured that staff across all wards were providing full details of incidents, correct recording of restraint positions and physical observations” (p10).

“Staff were trained in safeguarding, knew how to make a safeguarding alert, and did that when appropriate. The provider’s patient safety and quality report for the period 1 October 2018 to 31 December 2018 reported that 99% of eligible staff had received safeguarding training. Between 1 October 2018 and 31 December 2018, a total of 66 safeguarding notifications had been made to the local authority. There has been a substantial increase in the number of safeguarding notifications made since the first quarter of the year when there were 24 notifications. 13 of these involved allegations made against staff and the organisation. Norfolk Safeguarding Team have been informed of this and are currently carrying out an investigation to identify the reason for trend. An external stakeholder told us that they felt the hospital did not always identify, and proactively consider, the antecedents to behaviour that could lead to a safeguarding referral, e.g., incidences of patient-on-patient assault. Safeguarding notifications were being sent appropriately to CQC, at the time of the incident. However, the safeguarding lead at the hospital told us that CQC were notified of a

⁹⁶ https://www.cqc.org.uk/sites/default/files/new_reports/AAAJ1338.pdf (accessed 20 February 2020)

safeguarding issue only when the safeguarding team had advised it was an appropriate referral. We were concerned that there was confusion about this process... The number of reported incidents had increased. Between 1 October and 31 December 2018 there were 2177 incidents across the hospital. This compared to 1946 incidents between 1 July 2018 and 30 September 2018. Of these incidents, 594 occurred on **The Lodge**. The most common behaviour displayed during these incidents was non-person directed aggression, followed by aggression towards others. The provider reported that the number of incidents had increased due to a number of new admissions to the hospital during this time period, including the admission of one particularly unsettled patient. Between 1 December 2017 and 30 November 2018, 59 serious incidents were reported via the Strategic Executive Information System. A serious incident is an incident that has resulted in serious physical or emotional injury or damage to property essential to the security and effective running of the unit. The most common type of incident reported was disruptive, aggressive and violent behaviour meeting the criteria for a serious incident” (p18).

An inspection **across the Hospital** published on **16 September 2019**,⁹⁷ based on inspections on 20-21 June, 5 and 16 July determined that the service was “inadequate.” It noted that: “The hospital was not working to the model of an assessment and treatment unit and therefore its operation was not in line with the expectations of the Transforming Care Programme. The service was not proactive in enabling patients to leave hospital and return to life in the community. Some patients who had been resident at the hospital for some years had no discharge plan. The provider had not ensured there were sufficient staff with the appropriate skills and training to deliver safe and effective care and treatment to patients. A high proportion of staff were unqualified support workers and, because of a high number of vacant posts, a substantial proportion of shifts were filled by bank or agency staff. Managers had not mitigated the risk this posed by ensuring that all staff had the training essential to provide high quality care to patients with complex needs in specialist setting. Also, the provider had not ensured there were sufficient staff on duty to complete patient observations in accordance with their policy. Staff did not always ensure that patients nursed within long term segregation were nursed in accordance with the Mental Health Act Code of Practice guidelines. Staff did not consistently complete physical observations of patients following restraint. Staff carried out weekly emergency bag checks but there was no assurance or system in place that the emergency bag would be checked after each use or between these times. Clinic rooms were not all fully equipped. Staff had not accurately checked the emergency equipment. We found no cleaning records in any of the clinic rooms or a clinic room audit in one of the clinic rooms. The service had not considered and responded to the needs of patients with autism in the ward environment. The service did not have any sensory rooms for patients and sensory equipment was minimal and not readily available for patient use.

⁹⁷ https://www.cqc.org.uk/sites/default/files/new_reports/AAAJ5248.pdf (accessed 20 February 2020)

Staff did not ensure care and treatment records contained information on the patients' mental capacity. We found no individualised assessments of capacity for specific decisions within patient records with the exception of the use of medication. Managers were not proactive in identifying and responding to issues within the service. Managers responded to issues when identified by external stakeholders and then did not do so promptly. Managers were not consistently responsive to patient needs. Managers did not have a good understanding of the service they managed. The provider did not have an effective audit process to provide assurance or review the quality of the care provided at this hospital. There were poor governance arrangements in place to review audit processes. External stakeholders found issues that were not identified by the provider's internal or external audits" (p3). "Managers had not ensured all staff were compliant with safeguarding adults training, in accordance with their own target of 90%. We were particularly concerned around required training for bank staff. At the time of inspection, the compliance with training for permanent registered nurses was 87.5%, and 74% for permanent support workers. The provider had not ensured bank staff or therapy staff were suitably trained. The compliance for bank nursing staff was 71.4%. The compliance for bank support workers and senior support workers was 39.2%. The compliance for the therapy team was 67.7% at the time of our inspection. This was of concern due to the high levels of bank staff working across the hospital" (p18). The service's overall rating was "Inadequate." In terms of its responsiveness and leadership it was "inadequate," with reference to safety, effectiveness and caring, it "requires improvement." The hospital was issued with a warning notice for a breach of Regulation 17⁹⁸ of the Health and Social Care Act (2008) and was placed in special measures.

A "quality report" **across the Hospital** was published on **14 January 2020**.⁹⁹ It was based on an inspection on 13-14 November 2019. It was "...an unannounced, focussed inspection to follow up on the warning notice and to assess whether the provider had made the required improvements. During the inspection period, we found significant concerns that required urgent action. We have taken further enforcement action against the provider to require that, with immediate effect, the Registered Provider must not admit any patients to any ward at Jeasal Cawston Park hospital without prior written agreement of the Care Quality Commission. We found some areas of improvement. However, we found that further improvements were required, or it was too early to judge whether the measures the provider had put in place had an impact or were sustainable. We did not re-rate this service at this inspection. We found the following areas required improvement: There had not been a consistent senior leadership team in place since July 2019. Whilst some members of the leadership team had been with the organisation for some time, there was evidence of changes in roles which affected the stability of the leadership team. The registered manager left in July 2019 and an interim appointment was made to cover this vacancy who

⁹⁸ Concerning good governance - see <https://www.cqc.org.uk/guidance-providers/regulations-enforcement/regulation-17-good-governance> (accessed 20 February 2020)

⁹⁹ https://www.cqc.org.uk/sites/default/files/new_reports/AAAJ7782.pdf (accessed 20 February 2020)

unfortunately was on long term sick. This meant that other senior managers had to fulfil the role. There had been a restructure of the quality improvement team. We were not assured that there was the stable, robust leadership in place in order to embed and sustain the quality improvements necessary to ensure effective and safe patient care. The provider did not demonstrate that governance systems were sufficiently embedded to be assured of the impact and sustainability of these systems. For example, we were not assured that the quality of clinical observations was consistent and sustainable due to new staff not receiving observation training from March to September 2019. Managers had not prioritised the oversight of patient observations despite a high number of safeguarding incidents directly related to this concern in the six months prior to this inspection. Managers had not implemented recommendations made by an external nurse consultant relating to patients swallowing foreign objects as a matter of priority. Recruitment and retention of qualified nurses remained challenging and staff we spoke to described difficulties in meeting the demands of their roles. We spoke to 16 members of staff. Three members of staff told us that the wards could be short-staffed and sometimes staff were unable to escort patients on trips out of the hospital because of this. One member of staff told us that because of a high number of incidents the previous day, general observations had not been completed as per the observation and engagement policy. This could have an impact on patient safety. Staff did not have a co-ordinated approach to the completion of audits or the implementation of quality improvement work. We spoke to senior managers and four members of staff who were involved in quality improvements and audit and we observed staff working on separate projects without management oversight or actions being taken. For example, one person working on quality improvement had reviewed incidents relating to patients swallowing objects. However, managers had not discussed the review, drawn up an action plan or put into place any of the recommendations made. The provider had reported further incidents of patients swallowing objects since the time of the review. Managers were not acting on concerns and reviews with enough co-ordination and urgency which had an impact on improving patient safety” (p2).

“Staff did not ensure care and treatment records contained information on the patients’ capacity. We found no individualised assessments of capacity for specific decisions within patient records except for the use of medication. During the inspection we found an infection control issue on **The Manor**. We also found poorly written lessons learnt bulletins. Managers acknowledged our findings at the time of inspection. The provider’s internal audits and governance processes had not identified these concerns. There were ineffective systems in place to assess and monitor the quality of care which was a concern at the last inspection” (p3).

“During the inspection we found an unbagged stool sample in the medication fridge on **The Manor**, which had been there since 9 September 2019 [the inspection spanned 13-14 November 2019] ... We were not assured that the quality of clinical observations was consistent and sustainable... Recruitment and retention of qualified nurses remained challenging and staff we spoke to described difficulties in meeting the

demands of their roles. We spoke to 16 members of staff. Three members of staff told us that the wards could be short-staffed and sometimes staff were unable to escort patients on trips out of the hospital because of this. One member of staff told us that because of a high number of incidents the previous day, general observations had not been completed as per the observation and engagement policy. This could have an impact on patient safety. An incident occurred during the inspection where a patient broke a toilet seat and swallowed a screw. Staff had reduced the patient's level of observations due to lack of staff" (p9).

"In the three months prior to the inspection, the Care Quality Commission and safeguarding authorities were notified of six incidents involving patients where staff had failed to carry out observations as prescribed in the patient care plan. In response to these incidents, the provider had engaged a nurse consultant who had undertaken a review of staff observations which had been completed at the beginning of November" (p14-15).

Inspectors found significant concerns that required urgent action. CQC took further enforcement action [in November 2019, the time of the inspection] against Jeessal Cawston Park [JCP] requiring that it must not admit any patients to any ward at the hospital without prior written agreement of the Care Quality Commission.

A "quality report" **across the Hospital** published on **13 April 2020**,¹⁰⁰ based on an inspection of 11 and 12 February 2020 determined that the service was "inadequate" overall and specifically concerning safety, care and leadership. A letter from the Chief Inspector of Hospitals stated "This service was placed in special measures in September 2019. Insufficient improvements have been made. The rating from this inspection remained Inadequate and the service has remained in special measures due to the lack of sufficient improvement. Therefore, we are taking action in line with our enforcement procedures to begin the process of preventing the provider from operating the service" (p3).

The Hospital was issued with a Notice of Proposal to cancel the Hospital's registration as a provider in respect of the regulated activities, a) Treatment of disease, disorder and injury; and b) Assessment of medical treatment for persons detained under the Mental Health Act 1983.

"Staff did not manage risks to patients well. In the month prior to the inspection, and the two weeks following inspection, the service continued to report incidents where patients were harmed, or exposed to risk of harm, due to observations not being completed correctly. The service had not addressed the risk of fire. We saw fire risk assessments for all areas of the hospital which indicated there was a moderate to substantial risk to life from fire. We requested evidence of any actions that had been taken to address these risks, but managers were unable to provide these. The service did not have enough nursing and support staff to ensure that it could meet patients' care and treatment needs. Staff described difficulties in meeting the demands of their

¹⁰⁰ https://www.cqc.org.uk/sites/default/files/new_reports/AAAJ9290.pdf (accessed 8 May 2020)

roles because of staff shortages. Staff did not provide enough activities for patients. There was a lack of activities particularly at weekends and evenings, including for patients in long-term segregation. Staff did not use processes to safely prescribe, administer, record and store medicines. Staff recorded as required medicines (PRN) reviews inconsistently. Staff had not effectively monitored patients on high dose anti-psychotic therapy and had not clearly documented the rationale for giving a patient in long term segregation the maximum dose of anti-psychotic medicine. Staff did not always respect patient's privacy and dignity. Staff left patients in long term segregation in undignified situations. The provider had not ensured that all staff were trained in Makaton or Signalong to communicate with patients whose main form of communication was Makaton. There was a lack of effective leadership and governance. There had not been a consistent senior leadership team in place at the hospital since July 2019. Staff told us they were not always clear about their roles and accountabilities, and changes in leadership made it difficult to be confident about processes and procedures and their responsibilities in relation to these. Managers did not have effective oversight of staff management of patient risk and the service did not have effective systems and processes, such as regular audits of the service provided, to assess, monitor and improve the quality and safety of the patients at the hospital and to manage performance effectively. At the time of inspection, a new Chief Operating Officer (COO) had been appointed and had been in post for four weeks. We spoke with the COO during the inspection and they demonstrated a good understanding of the challenges that the service faced and had begun to make a plan to manage them. However, it was too early to say whether these changes would be effective and sustainable" (p3-4).

"Staff did not ensure that all patients had adequate physical health care. An external stakeholder raised a concern about a patient who had begun to experience a health problem which had an impact on their dignity. There was no evidence that staff had attempted to address this or investigate if there may be an underlying cause" (p11).

"The design, layout, and furnishings of long term segregation environments did not create a therapeutic environment. This had previously been raised as a concern. Long-term segregation environments were bare and sterile and did not meet patients' needs" (p12).

"Between 31 December 2018 and 31 December 2019, the Care Quality Commission received 156 safeguarding notifications from this service. This is similar to the 155 notifications reported at the last comprehensive inspection. The Safeguarding authority for Jeasal Cawston Park has established there were approximately 18.5 safeguarding concerns per month being raised by the hospital over 2019. We sought feedback from the safeguarding authority prior to the inspection and the safeguarding authority confirmed there was an ongoing section 42 enquiry for the organisation which is chaired by the Director of Social Work... The section 42 enquiry had reported serious concerns regarding this service due to a high number of safeguarding referrals being received and multiple concerns which independently have not all necessitated a

safeguarding enquiry. The themes identified by the safeguarding authority related to long term concerns around observations on patients being reduced, staff not correctly carrying out observations, incidents of alleged physical abuse by staff, and concerns about physical healthcare needs not being met” (p21-22).

“Between January and December 2019, 32 serious incidents were reported via the Strategic Executive Information System. A serious incident is an incident that has resulted in serious physical or emotional injury or damage to property essential to the security and effective running of the unit. Of the total number of incidents reported, the most common type of incident was disruptive/ aggressive/ violent behaviour and apparent/actual/suspected self-inflicted harm. The number of serious incidents reported during this inspection was lower than the 59 reported at the last inspection” (p23).

Ben died during July 2020. He had been admitted to **The Grange**. He transferred to **The Lodge** in the final days of his life.

An **across the Hospital** inspection report published on **11 August 2020**¹⁰¹ arose from an inspection visit on 27 May 2020 and resulted from “two incidents relating to patient safety.” The inspectors noted that “Enhanced patient observations were still not completed in line with the provider’s observation policy, despite the provider implementing strategies to address this concern...One to one observations are designed to support patients who are deemed as a higher risk of harm to themselves or others...We were not assured that all serious incidents were investigated, reviewed and that lessons learned were shared with staff. The provider did not have an established forum to discuss serious incidents and the Registered Manager and Head of Communications and Quality were unable to tell us who had oversight of the quality of patient care...The governance systems in place were not sufficiently embedded to provide adequate oversight and monitoring of the quality and safety of the service...Staff did not notify CQC of all reportable safeguarding incidents in a timely manner...The provider could not provide assurance that they could deploy enough registered nurses and support staff with the right skills and competence to meet the needs of the people using the service and to manage patient risks.”

An **across the Hospital** inspection report published on **9 October 2020**¹⁰² resulted from a visit on 27 and 28 August 2020. Its overall rating was “inadequate” and it remained in “special measures.” It noted that “...inspectors found further incidents where patients were placed at risk of harm due to observations not being completed correctly...Staff who witnessed colleagues sleeping on duty did not challenge this poor practice and accepted this behaviour...The leadership team had not effectively addressed the issues outlined above despite being aware of these for over ten months. Managers had initially attributed the issue of staff sleeping to the use of agency staff; indicating it was agency staff who engaged in this practice. However, seven out of the

¹⁰¹ <https://www.cqc.org.uk/location/1-217058056/reports> (accessed 15 October 2020)

¹⁰² <https://api.cqc.org.uk/public/v1/reports/3ca2c84d-7a03-4975-89cc-5d8d9eca5988?20210112225753> (accessed 13 March 2021)

eight staff members noted on the CCTV footage were permanent employees at the hospital...Staff did not sufficiently encourage patients to maintain a healthy lifestyle, for example to manage their weight by eating a healthy diet and do sufficient exercise...Staff had not taken all actions necessary to reduce the spread of infection.” The report stated of the use of restraint, “The use of restraint had decreased. Between June and August 2020, there were a total of 489 episodes of the use of restraint across the hospital... [and] 15 incidents of rapid tranquilization.... There were 14 patients in the hospital at the time of inspection...The provider is now open for admissions and can provide regulated activities for a maximum of 12 patients. This has reduced the capacity of the hospital from 57 to 12 beds.”

Adult Safeguarding at the Hospital

145. Cawston Park Hospital has exercised Norfolk Adult Social Services Department (ASSD) since 2013. It does not commission any services at the Hospital. Its powers and duties (S.42-47 Care Act 2014) hinge on its lead coordinating responsibility for adult safeguarding with CCGs and the police. With reference to the Hospital, Norfolk SAB has a duty to enquire, to commission SARs and to share information, not least concerning all safeguarding referrals at the Hospital.
146. The purpose of safeguarding has been subverted to setting out (a) what it is that providers, service commissioners, contract monitors and inspectors should be doing anyway, and (b) reminding these organisations of their remit, powers and enforcement resources.
147. During 2013-2014, an overview of the risks safeguarding activities highlighted included: waking night staff sleeping on duty; an insufficient number of staff (often from agencies) providing 1:1 support and differing perceptions of what this entails; failing to refer safeguarding incidents; medicine mismanagement; and poor information sharing and recording within the Hospital. “Significant working with a number of other LAs and CCGs to ensure their service users were reviewed and [their] care managed appropriately” led Norfolk ASSD to have low expectations of the NHS organisations responsible for placing and funding patients.
148. Joanna and Jon were funded by two London boroughs. They were placed at **The Manor** and **The Lodge** respectively. Joanna featured in 13 referrals, typically having been subject to “physical or verbal abuse...by other residents (x9) or staff (x3).” On an occasion when Joanna was physically assaulted, “1:1 support is reported to have been in place.” On another occasion Joanna was either physically or verbally abusive to a peer. On five occasions Jon was subject to either physical or verbal abuse by his peers and on an occasion when he was physically assaulted, “1:1 care was in place.” On two occasions Jon was verbally abusive and, separately, he alleged that he had been physically assaulted by a staff member. The “failure to manage known risks” featured in the referrals concerning Joanna and Jon. These included the medical events associated with their deaths during 2018.

149. During December 2018, ASSD, the CCG and NHS England reviewed the circumstances of four patients at the Hospital. This identified weaknesses in, *inter alia*, treatment and support planning; staff guidance concerning 1:1 support; seclusion documentation; post restraint observations; supporting patients with declining cognitive capacity; and risk assessment processes.
150. Norfolk ASSD regards the Hospital as a “high referrer of safeguarding incidents over a very long time.” During 2019, there were 227 safeguarding referrals with an “average referral rate [of...] 18.9 per calendar month.” It appeared that most referrals originated from **The Manor**. However, the referral information does not reflect the movement of patients between the Hospital’s wards. From the period 1 April 2018 to 31 March 2021, Adult Safeguarding received 126 safeguarding referrals from the Hospital which progressed to S.42 enquiries. During the same period, there were “310 safeguarding concerns where abuse or neglect was reported under S.42(1) but not taken to a S.42 (2) enquiry.” Although there are caveats concerning the accuracy of address records and case note recording, which may depress these numbers, they point to a single S.42(2) enquiry every week for three years and an additional two referrals a week that did not progress to an enquiry. This constitutes a great deal of safeguarding activity for a single provider.
151. Norfolk ASSD has drawn on its referral data to identify the conditions associated with safeguarding incidents at the Hospital. Some are reminiscent of findings at Winterbourne View Hospital and Whorlton Hall. For example: the scale of referrals becoming “normalised;” the hospital’s interpretation of “1:1” support or observations; multiple incidents associated with the same person; inattention to known risks; poor physical healthcare; inconsistency in referring altercations between patients; patients withdrawing complaints; the Hospital beginning investigations prior to a police investigation and/or a S.42 enquiry; and now, the trustworthiness of the Hospital’s (i) recording and (ii) scrutiny of CCTV footage.
152. Despite action-planning and promises arising from adult safeguarding activity – of which there is a great deal - it appears that what is achieved is soon eroded. Overall, Norfolk ASSD notes “There is ongoing S.42 enquiry for the [Hospital] chaired by...Director of Social Work. [In spite of] serious concerns regarding this provider [Norfolk ASSD] cannot take any enforcement action – this is the role of the CQC...a repeated pattern of limited improvement followed by a decline in standards which has led to difficulty in identifying the point when more robust action should be taken.”
153. The expectations on LAs to assume post-Hospital responsibility are disproportionate. For example, “Provider to liaise with social care to move discharge plans forward...Person ready for discharge but no discharge destination found at present by the Local Authority.”
154. The mood of fatigue associated with “learning lessons” reviews is not new because Safeguarding Adult Reviews are not resolving anything in a permanent way. They are dependent on information which organisations are prepared to put in the public

domain. In contrast, the legal inquiries of Coroners, independent judicial officers, may gather more detailed information which is pertinent to a SAR. Reviews which hinge on “learning lessons” are not the most effective ways of solving the problems which are associated with wretched events and tragedies. No amount of hectoring recommendations and action planning can remedy the long-established inclination to express solutions to historical events in individualistic, local and partial terms.¹⁰³

¹⁰³ Flynn, M. and Citarella, V (2020) Connecting people’s lives with strategic planning, commissioning and market shaping. In S. Braye and M. Preston-Shoot (Eds) *The Care Act 2014* London: Sage Publications Ltd

Conclusions and Recommendations

155. The Department of Health's Transforming Care Programme which ended in March 2019, has not delivered the promised reduction in reliance on inpatient care following the Winterbourne View Hospital scandal.¹⁰⁴ During February 2021, the Health and Social Care Committee began an inquiry into the limited progress concerning the treatment of people with autism and learning disabilities. It is considering restraint, "sectioning," the use of seclusion, human rights and the implications of the reform of the Mental Health Act for these population.¹⁰⁵ Its work is a significant backdrop to this Review.
156. Criticisms of hospitals for adults with learning disabilities and autism are numerous and persistent. Scandals contributed to the persuasive agenda which led to the closure of most of the UK's long-stay hospitals for people with learning disabilities in the 1980s and 1990s. Scope for rethinking how people should be supported to have ordinary lives heralded the possibility of radical change premised on inclusion, interdependence and insight in the place of services in family and community life. This is a critical backdrop to the creation of a private, specialist hospital in Norfolk which is entirely dependent on NHS contracts. There is no incentive for commercially provided inpatient care to discharge patients and retain empty beds. Scrutiny of safeguarding's direct work and decision-making typically highlights flaws in structures and whole systems, and this Review is no exception. Since adult safeguarding is a wide-ranging subject which spans prevention to remedial action, references to local and national implications are apposite.
157. Such questions are the basis and rationale behind the following recommendation. This, and succeeding recommendations, does not specify dates by which actions should take place. This matter requires the considered opinion of the Norfolk's SAB and its partners.
- a) **Norfolk's SAB should write to the Law Commission proposing a review of the current legal position of private companies, their corporate governance and conduct in relation to services for adults with learning disabilities and autism.** Given the clear public interest in ensuring the well-being and safety of patients, and the public sponsorship involved, the Law Commission may wish to consider whether corporate responsibility should be based on corporate conduct, in addition to that of individuals, for example.
158. It is unlikely that the Norfolk families of infants and children with learning disabilities and complex neuro developmental disabilities envisage Cawston Park Hospital as part of their waiting future. The life-course of families who juggle their caregiving with other careers is relevant to service commissioning. Typically, the biographies of people with

¹⁰⁴ <https://www.learningdisabilitytoday.co.uk/a-decade-on-from-winterbourne-view-where-are-we-now> (accessed 13 April 2021)

¹⁰⁵ <https://committees.parliament.uk/work/1026/treatment-of-autistic-people-and-individuals-with-learning-disabilities/> (accessed 16 May 2021)

learning disabilities integrally involve their families. Understanding the life stage of an adult - what is known about their history, including their physical and mental health history – is as critical as engaging with families’ knowledge about what has worked in terms of supporting them and what is likely to work for them.¹⁰⁶

159. Are Norfolk’s supports to families competent and trustworthy? Does Norfolk pay enough attention to the families with high stress levels with children and young people whose behaviour challenges professionals as well as the families who appear unwilling to seek professional help? Such questions are pertinent to Norfolk and Waveney CCG and Norfolk ASSD purposefully addressing the obstacle cited by so many, that is, “there are no community services that can manage people with challenging behaviours.”

b) Norfolk and Waveney CCG and Norfolk ASSD should review their commissioning arrangements to embrace “ethical commissioning.”¹⁰⁷ This should attend to:

“Ethical employment: Commissioners must be able to distinguish between the workforce practices of different providers and prioritise those acting as ethical employers.¹⁰⁸ This might include prioritising those companies that are accredited by the Living Wage Foundation; have effective training, development and supervision; sign up to an ethical care charter; outlaw false self-employment and zero-hours contracts; and encourage staff to participate in collective bargaining.

Tax compliance: The ownership of all companies contracted to deliver public services should be available on public record. At the same time, a taxation test could require contracted private companies to demonstrate that they are based in the UK and subject to UK taxation law.

Transparency: A transparency test could stipulate that where a public body has a legal contract with a private provider, that contract must ensure full openness and transparency with no recourse to the cover of “commercial confidentiality”

Localism: A focus on smaller and more local commissioning is needed – a challenge for public services commissioners who generally favour dealing with a small number of large organisations with established contracting infrastructures. Smaller organisations hold vast expertise about the precise issues affecting people in their area and can serve very small or isolated communities or specific communities of interest.

Ethical vision: To create change in adult social care, we need a guiding vision, rooted in ethical considerations of promoting good lives well lived, and protecting the wider economic, social and environmental wellbeing of a local area. Procurement legislation

¹⁰⁶ See, for example, <https://www.skillsforcare.org.uk/Documents/Learning-and-development/Qualifications/Commissioning-for-wellbeing/L5-Certificate-in-Commissioning-for-Wellbeing-with-a-Learning-Disability-and-Autism-Focus-v4.pdf> (accessed on 13 April 2021)

¹⁰⁷ <https://socialcarefuture.blog/2019/09/19/adult-social-care-and-ethics-time-for-a-new-relationship/> (accessed 13 April 2021)

¹⁰⁸ This should embrace reliable identity and other pre-employment checks. See for example, https://www.cipd.co.uk/Images/pre-employment-checks-guide-dec-2020_tcm18-51572.pdf (accessed 1 April 2021)

in Scotland seeks to promote just such a vision but has no real equivalent in England.”¹⁰⁹

In addition, a **Community Benefit** test would nurture connectedness to communities would ask potential providers what they will gift to a locality. For example, apprenticeships for local school leavers; opportunities for local businesses and farms to provide goods; the provision of studio spaces for artists; and growing plots for gardeners. This would allow local credit for initiatives to be dispersed and to take root. The test should require the provider to exemplify the community benefit every year, in believable human terms, using people’s own words, for example.

c) Evidence of changing commissioning arrangements should be shared with Norfolk’s SAB.

160. The deaths of three adults age 32, 33 and 36 within 27 months is an indictment of a Hospital providing assessment, treatment and rehabilitation. It challenges its credibility as a service. The behaviour of Joanna, Jon and Ben was eloquent enough. They did not want to be there and they did not thrive. Their lives mattered. They did not benefit from discernible assessment, treatment or time-discipline at the Hospital. There did not appear to be any evidence of willingness to segment their inpatient days into units devoted to specific tasks or topics. Jon in particular yearned for purpose and the external discipline of work. The Hospital surrendered to interrupted night-times, mornings spent in bed and “self-directed” inactivity. Necessarily the Hospital sought to create a predictable environment by allocating staff to particular tasks, for example. However, if the staff allocation of “one-to-one observations” is considered, the standard procedure hinged on watching the designated individuals rather than doing things with them. This is dull and unrewarding - most particularly if the subjects of such observations are inactive.
161. The release of inquest statements to the SAR author (representing NSAB’s SAR Group) provided a significant additional resource to the information provided by the Hospital. However, little is known about the lives of the three adults at the Hospital since the information shared with the Review Panel is so partial. It is troubling that shortly after Joanna’s death, the Hospital’s records were amended. The altered text made it appear that staff commenced CPR which was not corroborated by CCTV evidence. However, not even CCTV protected Ben from being assaulted in the final hours of his life. Had there not been a police investigation it does not appear that his assault would have been detected by the Hospital’s managers. These discrediting facts are suggestive of duplicity.
162. Trust in placing CCGs’ is eroded by tragedies and scandals. Mental health crisis interventions for adults with learning disability and autism should be characterised by

¹⁰⁹ See article by Bob Hudson: <https://www.theguardian.com/society/2018/aug/20/ethics-new-approach-outsourcing-social-care> (accessed 20 March 2021)

brevity (if a placement is required) and the maintenance of people's relationships and local ties. The personal impact of transferring to other services should not be administratively downplayed.

- d) NHS – England should ensure that (i) all placing CCGs are proactive in ensuring that they have up-to-date knowledge about the services they commission and how these are experienced.** The “four eyes principle” may be useful, most particularly if the additional “eyes” are those of a parent whose relative has current or recent experience of the assessment and treatment services being commissioned;¹¹⁰ and (ii) that when transfers take place between in-patient settings, these cease to be recorded as “continuous inpatient stay ...treatment for the purposes of the one year CTR.”

163. Ethical commissioning would not rely on high cost, out of area, independent hospitals. Indulging this obsolescent model of specialist service provision does not pretend to pay lip service to person-centered working. There is nothing in the information shared with this review, most particularly the feedback from ex-patients and relatives, to show that this Hospital's services enhanced its patients' lives or their life chances. Services must be judged by the impact they have on people's lives.

- e) Norfolk and Waveney CCG and Norfolk County Council should transfer all its remaining patients from this Hospital.**

164. Discharge dates were not identified at the point of admission to Cawston Park Hospital. The Hospital was not required to describe what it did to keep adults with learning disabilities physically and mentally healthy or what outcomes it had achieved for its ex-patients.

165. The reform of the Mental Health Act is welcome – most particularly the Department of Health and Social Care's proposal to reduce reliance on inpatient services for people with learning disabilities and autism.¹¹¹ The three deaths at Cawston Park Hospital underline the necessity of this major reappraisal of the MHA's legally mandated restrictions. However, the potentially perverse outcome of shunting responsibility from the MHA to the Mental Capacity Act requires the attention of all agencies associated with the adults whose circumstances feature in this review.

- f) Norfolk's SAB should make representation to the Department of Health and Social Care to ask what additional rights and protections will be afforded to adults with learning disabilities and autism who become vulnerable to detention in the same clinical settings under the Mental Capacity Act.**

¹¹⁰ The requirement that a business transaction should be approved by at least two individuals <https://www.collinsdictionary.com/dictionary/english/four-eyes-principle> (accessed 8 November 2019)

¹¹¹ *The unintended consequences of taking people with learning disabilities and/ or autism out of scope of the Mental Health Act 1983* <https://thesmallplaces.wordpress.com/author/lucyseries/> (accessed 24 March 2021)

Norfolk's SAB should engage with the subtle pressure faced by CCGs. That is, they are commissioning assessment and treatment and they are associated with addressing the consequences of poor and neglectful care. It is possible that they are therefore inhibited in taking action against those providing poor care,

g) Norfolk's SAB should share this review with NHS – England since it was responsible for Jon's placement. NHS – England and the CCGs responsible for placing people at Cawston Park Hospital should visit services, host reviews and ask questions such as:

- how many patients have returned to Cawston Park Hospital for further assessment and treatment?
- does Cawston Park Hospital have admission criteria concerning patients who have had previous episodes of assessment and treatment?
- are there periods when the patient we fund is super-busy or are their days characterised by naps, snacking and sitting for hours?
- are routines such as cleaning teeth, bathing, showering, changing clothes, hair washing and nail cutting, for example, expected and actively supported?
- does the patient we fund sleep deeply during the night because they are physically tired?
- how is the patient we fund, who is malnourished and/ or obese, encouraged and supported to make dietary and lifestyle changes?
- what happens if the physical health of the patient we fund deteriorates because they are resisting essential, prescribed treatment such as CPAP?
- what happens if the patient we fund refuses to participate in activities?
- what examples are there of Cawston Park Hospital maintaining and developing the ability of patients to perform daily tasks and promoting their participation in purposeful and valued occupations?
- on how many occasions have acute hospital security staff assisted Cawston Park Hospital's support workers to subdue an inpatient during acute hospital admission or attending clinic appointments?
- where are the service destinations of all former Cawston Park Hospital inpatients?

h) NHS-England should be invited to provide evidence to Norfolk SAB that these questions have been circulated and incorporated into its own processes.

166. Joanna's death did not lead the Hospital to invest in training concerning sleeping problems or to develop expertise in exploring ways in which the use of a CPAP and other measures¹¹² might be proactively promoted. Joanna, Jon and Ben had too many nights without sleep and were permitted lengthy lie-ins. Their sleep did not provide

¹¹² See for example: https://britishsnoring.co.uk/shop/mandibular_advancement_devices_MADs.php <https://link.springer.com/content/pdf/10.1007/s11818-018-0179-z.pdf> <https://sleepunlimited.co.uk/> (accessed 12 March 2021); and Halstead, E., Sullivan, E., Zambelli, Z., Ellis, J.G. and Dimitriou, D (2021) The treatment of sleep problems in autistic adults in the United Kingdom *Autism* Short Report, 1-6

respite from days which were neither busy nor active. Jon and Ben spent many hours hauling their mattresses around and altering their bedrooms. Joanna and Ben's sleep-related breathing disorders were not managed. Although neither complied with their essential and prescribed CPAP therapy, the Hospital's principal response was to document their non-compliance. Joanna and Ben's sleep was neither safe nor restful and the failure to track and report their weight gain in order that adjustments could be made to their CPAP equipment compromised both. Since the Hospital did not acknowledge that it was failing these patients it did not source relevant expertise. Joanna's loud snoring appeared to signal to night staff that "checks" requiring them to enter her room were unnecessary. The Hospital's Consultant Psychiatrists were gatekeepers to emergency services. They took no account of Ben's considerable weight gain, his plummeting SATS, or the pleas of his mother to get an ambulance. Paramedics and acute hospital clinicians are reliant on people's relatives or support staff to "explain" and interpret the communication and behaviour of people whose communication is not readily understandable. The persistent advocacy of families originates from being attentive to and acting on changes to their relatives' bodies and demeanor. This was not matched by health advocacy at the Hospital.

- i) **Placing/funding Clinical Commissioning Groups are keepers of the public purse. NHS England is invited to bring forward evidence of strengthened mechanisms for: discharge dates; the stability of accommodation within a service; close attention to an inpatient's physical health needs and experiences, their mental health needs and experiences, and the service's track record in addressing these.**

167. Since December 2015 CQC has rated the Hospital as "Good... Requires Improvement... Good... Requires Improvement... Inadequate... Inadequate [and] Inadequate." It is not clear why its "...enforcement procedures to begin the process of preventing the provider from operating the service" [in April 2020] ceased. It is speculated that:

- CQC has a high tolerance of this Hospital's repeated shortcomings.
- The prospect of identifying alternative providers for the current inpatients is too difficult.¹¹³
- If the Hospital was a care home the CQC would be less tolerant of its inability to prevent repeated failings.

- j) **Norfolk's SAB should propose to the CQC that the legal process of registration cancellation should proceed irrespective of a service's improvements if these**

¹¹³ On 22 January 2020 the *Health Services Journal* reported that "the poor standard of inpatient facilities is one of the most pressing issues facing mental health and learning disability services." Just prior to the Hospital agreeing to a voluntary embargo on new admissions, when CQC inspectors reported "serious concerns," NHS England sent a patient there, regardless of its "Inadequate" rating. "Jeesal said the new patient is an "exceptional case" and its clinical team "felt the admission was in the best interest of the patient."

are attributable to the ongoing efforts of the NHS, local authority social care employees and Inspectors.

168. The combined apparatus of CQC and CCGs' oversight was unequal to the task of uncovering the fact and extent of failing practices at this Hospital, most particularly those occurring within its locked wards. An ostensibly compliant service may disguise a host of operating problems and fail to identify the necessity of urgent intervention. The CQC's reports acknowledge that the Hospital has an array of processes and managers whose positions involve: attention to risk registers; corporate risk management meetings; patient risk management; clinical governance groups, meetings and annual reports; lessons learnt bulletins; ward managers' reports; daily, weekly and monthly ward audits; Red, Amber and Green (RAG) rating systems; performance management processes; independent advocacy; staff workbooks; a safeguarding tracker; action plans; Root Cause Analyses; Patient Safety and Quality Review Committee; fortnightly quality and safety reviews re medication, seclusion, environment risks, safeguarding referrals, staffing and care records; Covid-19 meetings; Quality Assurance and Audit Manager; and Patient-Led Assessments of the Care Environment (PLACE).¹¹⁴ Their claims on credibility cannot be assumed merely by their existence. What is the point if they are not actively enhancing patients' lives and there is little or no movement towards individuals' treatment goals? Leadership, stewardship, accountability, challenge, values and partnership working should be exemplified in the ways in which a Hospital demonstrates and verifies its effectiveness. The means by which this Hospital identifies and acts on the need for change should inform the judgement of the CQC. It discredits the CQC to assert of a man in long term seclusion, "We were satisfied he was being well cared for and this was the most appropriate setting for him. We do not recommend that he is moved from his current setting..." [April 2019].
169. Of the 15 CQC reports available online, 12 concern the Hospital as a whole with occasional reference to specific wards. The two inspections during 2013 concern **The Grange** and one of the two inspections during 2017 concern **The Yew Lodge** and **The Manor Lodge**. The CQC report of 23 January 2019 noted that of 1946 "incidents" which occurred during July and September of 2018, 849 occurred at **The Lodge** - a locked ward - and 490 occurred at **The Manor**. A key recommendation of the Serious Case Review of Winterbourne View Hospital concerned the scrutiny of specialist mental health services. It stated: "The mental health arm of the CQC should have characteristics akin to HM Inspectorate of Prisons. The hospital managers as defined by the Mental Health Act 1983 have the primary responsibility for ensuring that all requirements of the Act, including all safeguards to ensure detention is necessary in the first place...needs to continue..."¹¹⁵

¹¹⁴ These "are undertaken from a patient's perspective and focus on what matters to the patient based on a visual assessment" (CQC, October 2020)

¹¹⁵ <https://www.southglos.gov.uk/news/serious-case-review-winterbourne-view/> (accessed 29 March 2021)

170. The CQC delivered *Registering the Right Support* (2017) as policy guidance on registration and variations to registration for providers supporting people with a learning disability and/or autism. It covers the new and changed registrations of care homes, specialist hospitals and supported living. It serves to regulate the types of services required in the community as result of closing inpatient hospital beds. It is based on principles for commissioning good services which include “quality of life, keeping people safe, and choice and control.” These were the fundamental standards in the applicable regulations. Its presumption of small services, “usually accommodating six or less,” appears to be the primary impact. It is leading some providers to switch to other younger adult provision such as mental health and physical disability. Significantly, there is no such consideration of the possible benefits of small group living for older adults who are often required to seek accommodation and care in increasingly large institutions. However much strategic planners promote good design and positive values these continue to be trumped by the economies of scale and the pull of cutting costs. This makes it harder for both practising commissioners and providers to keep people safe. What will it take to de-register the wrong support? Oversight systems remain to be clear of duplication and mixed messages. The commissioner is responsible for checking the service to an individual and the inspector for regulating the whole service. The provider is responsible for supplying what is contracted for in the care plan within the law and regulations under which they are governed.

k) Norfolk’s SAB should set out for CQC’s Chief Executive the consequences of Cawston Park Hospital’s failure to enable family-centred approaches and engage with the expertise of patients’ relatives. This is paralleled in CQC inspections. The inspectors would benefit from including parent “experts by experience” with recent experience of seeking to work with assessment and treatment services and units (see, for example, families’ contributions to this Review). **To maintain public confidence, CQC may wish to confirm (i) that it has no remit to determine whether patients should remain in such services, not least since this conflicts with national policy; and (ii) what specific actions it proposes to take in relation to locked wards in specialist hospitals and units.**

171. The critical task of all LAs dealing with people residing in residential and nursing homes and specialist hospitals is to dovetail the procedural arrangements of adult protection/ safeguarding with inspections, professional regulation, law enforcement, complaints, clinical governance and internal disciplinary procedures. In congregate settings a lot hinges on the perceptions of Registered Managers and staff about what constitutes an abusive act. Such perceptions are shaped by prior experience and understanding of adult protection procedures. The boundary between good and less than good practice challenges safeguarding practitioners because it draws them into the distinction between poor practice and neglectful practice.

172. Norfolk ASSD is investing a lot of safeguarding resources at the Hospital and yet its personnel and activities have had no discernible impact. For example, action-planning

cannot feasibly remedy the repetition of promises of reform and scenarios such as: staff sleeping on duty; poor recording and information sharing; the high use of agency staff; and the poor alignment of patients' care and treatment plans with their daily lives. In addition, it is anomalous for Norfolk ASSD's practitioners to focus on the Hospital's clinical failures when the placing CCGs do not proactively engage in scrutinising the experience of the patients they fund. The principles and practice of adult safeguarding do not permeate through the whole system. The principal quality assurance activities are those undertaken by the Hospital, the CCGs and the Care Quality Commission on behalf of the public.

173. Norfolk ASSD is currently in the position of identifying support services for this Hospital's Norfolk patients – even though it was not involved in the decisions concerning their placements. Low investment in social care results in higher costs for the NHS. It is speculated that the support needs of these patients have not diminished as a result of being at Cawston Park Hospital.

l) Norfolk and Waveney CCG and the County Council should rebalance responsibility for Norfolk citizens away from “medical led admissions and social care discharges.” The reform of the Mental Health Act (1983) should anchor discussions and agreements between these public authorities concerning ethical commissioning.

174. Ignoring behaviour, which is prohibited by law, disadvantages the people responsible, erases the experience of services' employees and ignores contexts. Although there are no quick fixes, questions hinge on how to reduce racism and how to respond when it occurs. The principles of restorative justice have promise in learning from the people involved and those who have a positive influence on offenders. Services advancing values-driven and person-centred approaches must credibly further the rights of minority groups and adopt an active remit since equal treatment demands the sustained engagement of their collective power.

m) The taboo of addressing the racism of people with cognitive impairments remains to be explicit and made visible in all services. Norfolk's SAB should begin a process of (i) gathering the efforts and experiences of the county's service providers in challenging racism and racist stereotyping and (ii) convening “world café” conversations¹¹⁶ with providers and other interested people, including those at the sharp end of injustice.

175. This is less a matter of focusing on the moral rehabilitation of individuals whose utterances are offensive than one of drawing attention to structurally countering the ways it is expressed in interactions and in contracts, for example. The transformation of taken for granted racism requires consistent, informed and critical interpersonal challenge and the conspicuous support of directors, professional bodies, trade

¹¹⁶ A process for fostering collaborative dialogue, sharing information and discovering opportunities for action. See Brown, J. with Isaacs, D. (2005) *The World Café – Shaping Our Futures Through Conversations That Matter* San Francisco: Berrett-Koehler Publishers, Inc.

associations, shareholders and trustees, for example. However, it is the collective intelligence of “conversations that matter” that will begin to focus attention on ways of responding to overt racism in Norfolk’s services and communities.

176. Finally, the roots of private, specialist hospitals reside in business opportunism and profit-driven priorities. These are hospitals in which patients receive neither specialist assessment nor credible treatment. The deaths of three young adults must plausibly question the “system response” - CQC’s continued registration of such hospitals and their continued use by CCGs and NHS-England.
177. There is a crucial difference between the health advocacy of patients’ parents and that of staff, regardless of pay scales. Cawston Park Hospital failed to recognise that its interventions were unequal to aiding patients in their physical and mental distress. It neither built nor sustained trust. It did not serve the larger aims of three people’s lives. Joanna was supported by staff who were untrained in the use of her CPAP. They did not begin CPR and a learning disability nurse and two support workers believed that her epilepsy was due to her “playing up and shouldn’t be minded.” The response to Jon’s breathing difficulties was unduly slow even though he had pleaded “I cannot breathe. I am dying.” Ben gained almost six stones in weight at the Hospital. He had ceased to use his already underused CPAP and his low SATS symptoms were ignored. His mother’s insistence that an ambulance should be called had no impact. Unless this Hospital and similar units cease to receive public money, such lethal outcomes will persist.

Postscript

178. On 14 April 2021, Norfolk’s SAB received the following statement from Jeasal Group.

“The Board have reluctantly taken the decision to close down it’s Hospital Service. The hospital was placed in special measures in September 2019 and the Management team at the hospital have been committed to making the necessary quality improvements, however further operational and financial challenges has meant that the hospital service is no longer viable.

Furthermore, the Jeasal Board reaffirms their commitment to our Community Services.”

Annex 1: Membership of the SAR Panel

Agency	Meetings attended
Independent review author	7 out of 7
Adult Social Services, Norfolk	7 out of 7
East of England Ambulance Service NHS Trust	6 out of 7
Jeesal Group – Cawston Park Hospital	7 out of 7
Merton CCG – placing authority for Jon	6 out of 7
Newham CCG – placing authority for Joanna	6 out of 7
Norfolk and Waveney CCG – host CCG, placing authority for Ben	7 out of 7
Norfolk and Norwich University Hospitals NHS Trust	4 out of 7
Norfolk Community Health & Care NHS Trust	6 out of 7
Norfolk Constabulary	7 out of 7
Norfolk Safeguarding Adults Board	7 out of 7

Please note that:

- 1) the Care Quality Commission received all SAR Panel correspondence and advisory input was provided by its National Advisor Safeguarding Children and Adults at 3 out of 7 meetings;
- 2) some agencies provided more than one representative e.g. from different departments;
- 3) due to the duration of the review, some representatives left their agencies and were replaced on the SAR panel (see Annex 2);
- 4) the Covid-19 pandemic and resulting lockdown led to the cancellation of the planned second panel meeting of 31 March 2020;
- 5) panel meetings resumed virtually from 25 June 2020;
- 6) the response to the Covid-19 pandemic required some panel members to reprioritise their time at short notice to meet operational needs.

Annex 2: The Review's Timeframe

This table provides key dates pertinent to the review process.

Date	Activity
16 December 2019	SAR Panel meeting 1 – review formally opened
24 February 2020	Master chronologies and IMRs for Joanna and Jon circulated to SAR Panel for review and feedback
16 March 2020	SAR Panel meeting 2 postponed (originally scheduled for 31 March) due to Covid-19 lockdown
09 April 2020	SAR Panel process formally placed on hold, as agreed by statutory Safeguarding Adults Review Group and Independent Review author, to allow partners to prioritise response to the pandemic
27 May 2020	Independent Review author and NSAB Board Manager agree plan to resume the review
01 June 2020	Month-by-month summary of Joanna's experience at the Hospital circulated to SAR Panel for review
24 June 2020	Change in representation of Cawston Park Hospital on the SAR Panel
25 June 2020	SAR Panel meeting 2 – virtual meeting focussing on Joanna's experience at the Hospital
01 July 2020	Month-by-month summary of Jon's experience at the Hospital circulated to SAR Panel for review
29 July 2020	SAR Panel meeting 3 – virtual meeting focussing on Jon's experience at the Hospital
20 August 2020	Independent Review author, NSAB Board Manager and Norfolk social worker responsible for Norfolk's patients at the Hospital agree a way to include their stories in the Review. These included people who were resident at the Hospital at the time the Review was commissioned
28 August 2020	Letters sent to former patients at the Hospital (from Norfolk), as well as their families, inviting them to participate
20 October 2020	Change in representation of Newham CCG on the SAR Panel
26 to 29 October 2020	Planned face-to-face interviews with the former patients at the Hospital (from Norfolk) and family members postponed due to pandemic restrictions
13 November 2020	Emerging narrative and learning identified for Joanna and Jon's circumstances circulated to SAR Panel for review

Date	Activity
17 November 2020	SAR Panel meeting 4 – virtual meeting focussing on emerging narrative and learning
02 to 05 December 2020	Independent Review author in Norfolk for interviews with former patients at the Hospital (from Norfolk) and family members
14 December 2020	NSAB SAR Group reviews referral for Ben and agrees that the criteria for a discretionary SAR is met. The group decides that his circumstances should be considered alongside those of Joanna and Jon
18 December 2020	Decision to include Ben's case communicated to SAR Panel, agency chief officers, Coroner's Office and NSAB members; agency chronologies commissioned
14 January 2021	SAR Panel meeting 5 – virtual meeting focussing on identified learning from Joanna and Jon's cases and December interviews
29 January 2021	Master chronology for Ben circulated to SAR Panel for review
31 January 2021	Norfolk and Waveney CCG's Named GP for Safeguarding Adults joined the SAR Panel
18 February 2021	Month-by-month summary of Ben's circumstances at the Hospital circulated to SAR Panel for review
23 February 2021	SAR Panel meeting 6 – virtual meeting focussing on Ben's time at the Hospital and learning identified
11 March 2021	Medication reviews for Joanna, Jon and Ben circulated to SAR Panel, completed by GP member of SAR Panel
15 March 2021	First draft report circulated to SAR Panel for review
18 March 2021	Change in representation of Newham CCG on the SAR Panel
23 March 2021	SAR Panel meeting 7 – virtual meeting to review first draft report
07 April 2021	Deadline for submission by SAR Panel members of additional information pertinent to Ben's circumstances
19 April 2021	Final draft report circulated to SAR Panel members for review, Chief Officer briefing and sign-off; report circulated to NSAB's SAR Group
27 April 2021	NSAB's SAR Group considers recommending the report for sign off by NSAB

Date	Activity
10 May 2021	Deadline for forms confirming sign-off by SAR Panel members' agency Chief Officers
12 May 2021	Final draft report and confirmation of Chief Officer sign-off circulated to NSAB members
02 June 2021	Independent Review author presents final report to Extraordinary NSAB meeting
c. 07 July 2021	Anticipated publication date (subject to change)

Annex 3: Medication Review by GP member of SAR Panel

This annex considers the medication prescribed for Joanna, Jon and Ben. It is based on partial information. The rationale for the medication prescribed by the Hospital's Consultant Psychiatrists is not revealed in the information available. A medicines optimisation professional observed that "There does appear to be an over reliance on promethazine for sedation, that isn't best practice... Lactulose isn't a particularly useful laxative to prevent clozapine induced constipation. A PEG based laxative and/or a stimulant would be more appropriate."

Joanna's Medication Review

Although there are no copies of the medication charts used at the Hospital to review, the Coroner's office identified a letter from Consultant Psychiatrist [...] which lists Joanna's medication:

- clozapine "to help reduce reported voices and behavioural disturbance".
- gabapentin "as an anti-epileptic medication"
- fluoxetine "as an anti-depressant /anxiolytic"
- ferrous sulphate "given the history of anaemia".
- laxido "to help with constipation which may be associated with clozapine".

The correspondence states "[Joanna] was also prescribed PRN medication including medication to help with times when she was anxious /more aroused".

The correspondence does not name these medications; however, the Hospital's chronology indicates promethazine and olanzapine being used "as needed" at these times.

Promethazine is a sedating antihistamine. The British National Formulary (BNF) states an indication for promethazine use as sedation, for short term use at a dose of 25-50mg. The dose prescribed for Joanna is not stated. NICE guidance (NICE CKS Obstructive Sleep Apnoea 2015) states to give patient lifestyle advice on weight loss, exercise and reducing sedative use.

The BNF states **olanzapine** is an antipsychotic licensed for control of agitation and disturbed behaviour in schizophrenia or mania. There is no record stating that Joanna was diagnosed with schizophrenia or mania.

Regarding the use of CPAP and epilepsy, the letter of Consultant Neurologist [...] in the bundle from the Coroner's office indicates that "For more lengthy periods, not having CPAP does carry some risks....it could also increase the risk of sudden unexpected death in epilepsy probably through an increased risk of nocturnal seizure."

Jon's Medication Review

Jon had a diagnosis of mild learning disability, autistic spectrum disorder, dysexecutive syndrome and epilepsy.

The medication prescribed by his GP consisted of lactulose 15ml twice a day for constipation, epilim chrono (sodium valproate) for epilepsy, cholecalciferol 100units

daily (vitamin D supplement) and nystatin oral suspension for oral thrush. The GP surgery did not prescribe any of the specialist medication prescribed at the Hospital.

The medication prescribed for Jon at Cawston Park Hospital appears to vary over the time of his admission. The medication charts are for 2018 and indicate that Jon was prescribed, in addition to the above, clozapine twice a day 150mg mane and 250mg nocte. The indication for this is not recorded on the drug chart. Clozapine is an antipsychotic licensed for schizophrenia in patients unresponsive to, or intolerant of conventional antipsychotic drugs.

Jon was prescribed lamotrigine 100mg twice a day. The indication for this is not recorded. However, lamotrigine is used in epilepsy.

Jon was prescribed clonazepam three times a day at a dose of 1mg, 2mg, 2mg. The indication is not recorded. The British National Formulary (BNF) states clonazepam is indicated for all forms of epilepsy.

Jon was prescribed lorazepam 2mg IM (intramuscular) twice a day as needed for “severe agitation”. Lorazepam is a benzodiazepine. The BNF states intramuscular administration is licensed for acute panic attacks.

Jon was prescribed promethazine 25-50mg IM daily as needed for “agitation”. Promethazine is a sedating antihistamine. The BNF states promethazine is licensed for sedation (short term use).

Ben's Medication Review

Name of medication	Prescribing instructions	Date commenced	Date stopped/recommended	Comments/analysis
Promethazine hydrochloride 25mg	Initially prescribed at 25mg half an hour before applying CPAP mask to "hopefully maintain his sleep and desensitisation. Once a trial period of 2 weeks have been completed it will be added to his body of this care plan."	25/05/2020	Stopped on 09/07/2020 (Coroner's office records) following review by Dr [...], restarted 09/07/2020 and continued on as "as needed" basis with indication "to aid calming" and for "agitation/procedure" (Coroner's office records).	<p>Promethazine is a sedating antihistamine. It is licensed for sedation for short term use only at a dose of 25mg-50mg once daily. (British National Formulary). This medication was administered at Cawston Park Hospital on a "when required" basis. A maximum recorded dose of 25mg at night was administered.</p> <p>The records received from the Coroner's office state "He has severe sleep apnoea and has difficulties which put him at risk if given PRN medication/sedation." The author is not recorded.</p> <p>I cannot find any rationale for continuing the promethazine after the 2-week trial initiated on 25/05/2020 or that discussion took place with the Respiratory specialist regarding initiation of or continuation of this medication in the light of Ben's diagnosed obstructive sleep apnoea. NICE CKS (Obstructive Sleep Apnoea April 2015) advises that patients should be given lifestyle advice which includes reducing sedative use.</p> <p>The GP records indicate that the surgery were aware that Promethazine was being administered at Cawston Park Hospital however it was never prescribed by the GP surgery with a consistent entry "do not issue; hospital item only"</p>
Cetirizine	10mg once daily	15/07/2020	27.07.2020	Cetirizine is a non-sedating antihistamine. It was prescribed short term to treat hayfever symptoms.
Gaviscon	10ml twice a day as needed for "heartburn" and "abdo pain"	03.06.2020	Not known	Gaviscon is a medication used to treat acid reflux symptoms (dyspepsia). It was prescribed because Ben reported longstanding (abdominal) pain "in his side." This was discontinued as was not helping.

Name of medication	Prescribing instructions	Date commenced	Date stopped/recommended	Comments/analysis
Paracetamol	1g four times a day as needed for "query pain"	02.06.2020	Last dose given 28.07.2020 at 1335	Paracetamol is licensed for mild-moderate pain and pyrexia (fever). The records indicate that Ben reported longstanding lower abdominal and flank pain.
Salbutamol inhaler	"2 doses for wheeze-use spacer and mask"	28.07.2020	Last dose given 28.07.2020	Salbutamol acts to relax the smooth muscle of the airways thereby relieving wheeze and breathlessness.
Methylphenidate	30mg twice a day (in reducing regimen)	Not known	Not known	<p>Methylphenidate is initiated under specialist supervision for Attention Deficit Hyperactivity Disorder (ADHD). There is one entry indicating Ben was on this medication in the documentation from the Coroner's office - when Ben's capacity to make treatment decisions was assessed at the Hospital. The date of this assessment and the author is not apparent. The dose is as recorded as 30mg twice a day. This is inconsistent with the dose prescribed on repeat from the GP records (see below). I cannot find any further entries for methylphenidate being prescribed at the Hospital or the rationale for stopping this medication.</p> <p>The GP records indicate that methylphenidate on repeat prescription at a dose of 10mg three times a day and 20mg twice a day was last issued on 02.07.2018.</p> <p>Common listed side effects of methylphenidate include aggression (or hostility); anxiety; arrhythmias; arthralgia; behaviour abnormal; depression; diarrhoea; dizziness; drowsiness; dry mouth; gastrointestinal discomfort" (British National Formulary)</p>
Aripiprazole	10mg twice a day	Not known	Not known	Aripiprazole is an anti-psychotic medication. There is one entry for use of this medication on admission to Cawston Park Hospital in the records received from the Coroner's office. There is no subsequent record of this being administered again.

In addition to the above, Ben was prescribed the following at the Hospital:

Zerobase 11% cream as a moisturiser for dry skin behind the ears

Sudocrem- as a barrier cream

Savlon cream – antiseptic cream for head and groin area twice a day

Movicol one sachet a night for constipation relief commenced 15/07/2020.

Duraphat 2800ppm for prophylaxis of dental caries

Omeprazole 20mg once daily for abdominal discomfort/reflux symptoms was prescribed on 27/07/2020

Fexofenadine 120mg once a day which is a non-sedating antihistamine was prescribed on 29/07/2020

The GP records evidence that circadin 2mg modified release tablets once a day was on repeat prescription and last issued 02.07.2018. This is indicated for insomnia in patients with learning disabilities (where sleep hygiene measures have been insufficient (initiated under specialist supervision) as per British National Formulary. The documentation from the Coroner's office does not state (i) whether circadin was prescribed at the Hospital or (ii) the rationale for stopping this medication.

Annex 4: The Hospital's Response to Questions

The Hospital's responses to almost 200 questions generated by the Panel were partial. The following is a sample:

- What is the remit of the "Speciality Doctor" at Cawston Park? *Specialty doctor is a job title which refers to a medically qualified doctor who is neither in training nor a consultant (previously referred to as middle grade doctors)*
- What was the rationale for moving Joanna within days of arriving at Cawston Park? *Following assessment at her previous hospital it was felt that Joanna could be managed safely on The Manor. The Manor is a ward with a fairly open feel and is the least restrictive environment across the site. Following admission there were several risky incidents and prolonged NES on The Manor which lasted late into the night. There was significant risk and disruption posed to peers. Joanna herself stated that she did not like The Manor and that comments from peers had caused her distress.*
- What was the outcome of the [...] referral of 28 October? *This information would have been sent to [...]’s GP [...] and any actions required eg with respect to medication changes etc would be actioned by the GP*
- How did Cawston Park Hospital (i) promote the use of the CPAP machine (ii) support Joanna's understanding of its necessity? *From the outset Joanna told us about her CPAP machine, what it was for (to aid sleep) and possible consequences of not using it. Joanna appeared to be particularly interested in her various health problems and also her medication*
- When was [...]’s mental capacity assessed and what decisions did the assessments relate to? *Assessments of mental capacity are decision and time specific and would occur if there is a concern lacks capacity (one starts at the point that one assumes a person has capacity) Such assessments took place for example with respect to...medication, financial matters and Care and Treatment Reviews*
- What did mental capacity assessments reveal? *That [...] was on assessment to have capacity with respect to... prescribed medication and also to the sharing of... information at Care and Treatment Reviews. However, [...] found financial matters stressful and difficult and [...] had a Lasting Power of Attorney in relation to this area.*
- What less restrictive / escalation techniques were documented / used before administering IM medication or placed on increased observations? *De-escalation training is provided to all staff and is used in the first instance in all cases of patients presenting with distressed behaviours. In the case of [...] due to...emotional dysregulation and difficulties relating to autism [...] found it very difficult to recognise and process emotions... This often led to [...] appearing very calm and then without any apparent trigger suddenly appearing very*

distressed and moving to assault others or throw furniture or other risky behaviours. Occasionally when an individual escalated very suddenly without warning there is no opportunity for using less restrictive de-escalation techniques before physical intervention is required to prevent harm to the individual or others.

- How did Cawston Park Hospital address [...]’s request – via the police – to be moved to another hospital? [...]’s external care coordinator was informed of this and it was explained...this was not our decision to be made.
- What is the remit of the “responsible clinician”? *The responsible Clinician is the consultant psychiatrist with overall responsibility for... care and treatment.*
- Was there any formal review to ascertain how this new placement was progressing which included the Family and the placing commissioning officer or Social worker? *Yes through Care and Treatment Reviews which occurred every 6 months as well as Care Programme Approach meetings that also took place every 6 months i.e. 4 formal reviews per year where all the above were present*
- What debrief / reflective practice was used following each restraint, incident / seclusion with [patients] & for Staff? *Need to check.*
- What does “had a settled day” mean? *Within the limits of what can be documented for each patient on a given day by referring to someone as ‘settled’ it can be inferred that they have not had any incidents (or that they have had fewer less intense incidents relative to the individual’s baseline). That they have not presented with symptoms of major mental illness and have gone about their Activities of Daily Living with no or few issues arising.*

Annex to the Safeguarding Adults Review

Margaret Flynn

31 July 2021

“Autistic people and people with learning disabilities have the right to live independent, free and fulfilled lives in the community and it is an unacceptable violation of their human rights to deny them the chance to do so. It is also more expensive to detain autistic people and people with learning disabilities in inpatient settings and this takes up resources that are not then available for more humane community care. We are therefore deeply concerned that community support and provision for autistic people and people with learning disabilities, and financial investment in those services, is significantly below the level required to meet the needs of those individuals and to provide adequate support for them in the community...”¹

Following a series of Pre-Inquest Hearings, Ben’s Inquest spanned ten days and concluded in early July 2021. Article 2 was engaged and the inquest was heard with a jury. The jury’s conclusion was based on the evidence of witnesses and Ben’s experience of detention at Cawston Park Hospital. The Senior Coroner for Norfolk, Jacqueline Lake, drew the jury’s attention to his weight management, his prescribed sedative medication, his three attendances at the Norfolk and Norwich University Hospital during July 2020 and events on the day of his death.

The medical cause of Ben’s death was “1a Acute type II respiratory failure; 1b obesity hypoventilation syndrome and use of sedative medication; 1c obesity; 1d Downs syndrome; obstructive sleep apnoea.” The circumstances by which Ben came by his death were described: “On 29 July 2020, at Norfolk and Norwich University Hospital, Ben...died due to inadequate weight management and failure to diagnose obesity hypoventilation syndrome and inadequate consideration of the use of promethazine.” The jury concluded that to these failures was added a “failure to identify the seriousness of a life-threatening situation.”

The Coroner emphasised that the purpose of an inquest is not to establish who was responsible for a death. The Coroner has a critical role in seeking to prevent future deaths if the circumstances creating risks continue to exist. Accordingly, these are reported to those with the power to take action. Ten matters of concern were identified in relation to Jeetal Akman Care Corporation Ltd, Jeetal Holdings Ltd and Jeetal Residential Care Services Ltd:

1. “Jeetal Akman Care Corporation (Directors: Tugay Akman and Sally-Anne Subramanian) was the care provider for JCP [Jeetal Cawston Park] and closed

¹ House of Commons Health and Social Care Committee (2021) *The treatment of autistic people and people with learning disabilities*. Fifth report of session 2021-2022; HC 21 published 13 July 2021

in May 2021. However, Jeasal Holdings Ltd (JHL) and Jeasal Residential Care Services Ltd (JRCSL) and possibly other linked companies with the same Directors, continue to provide residential care to persons with mental health illness, learning disabilities, complex needs and physical disability. The concerns raised at the inquest could apply to residential care offered by these companies and unless such concerns are addressed there is a risk that future deaths may occur. It is not known if the Directors of these companies namely Tugay Akman and Sally-Anne Subramanian are Directors of any other companies providing care for persons with learning and other disabilities.

2. CCTV was shown at the inquest which revealed Ben... had been assaulted in the hours prior to his death and also that 1 to 1 observation was not carried out in accordance with the Observations Policy. CCTV is a reliable means of ensuring that staff comply with Policies and residents are treated with dignity. CCTV is not available in many if not all of the residential homes owned by JHL and JRCSL.
3. Basic dietary advice and guidance provided was not followed by staff.
4. The use of the Dietician in training of staff was reduced in 2017 from one day's training to an hour's power point presentation
5. Important records were not completed by staff, eg Food intake, Exercise, Weight and vital observations
6. Evidence was heard that exercise was not regularly offered to Ben... and when the Sports Instructor was absent for lengthy periods of time, there was no replacement
7. Multi-Disciplinary Team (MDT) Meetings were not held every 4 to 6 weeks as required. At MDT meetings which did take place, out of date weight measurements were recorded and relied upon for Ben. His increasing weight gain was not discussed at these meetings and weight loss was not set as a desirable or essential goal
8. JCP used the Pandora software system, (company Directors for Pandora are the same as for JHL and JRCSL) which is still used at the residential homes owned by JHL and JRCSL. Concerns were raised at the inquest in respect of this software system in that not all policies and documents were available to staff on the IPads provided, some of the documents were unwieldy and difficult to read (eg Personal Healthcare Plan), the Dietician recommended use of paper records in respect of Food and Fluid intake as these would be more accessible to staff and encourage the documents to be completed or in the alternative providing for the records on I-pads to be more easy to access and complete
9. The internal investigation carried out following ...Ben...'s death did not capture the concerns raised at inquest
10. Evidence was heard that no substantive changes have been made at the residential homes owned by JHL and JRCSL following the death of Ben... and the closure of JCP to deal with these concerns."

Six concerns were highlighted regarding Norfolk and Norwich University Hospital:

1. "Guidance was sought by Emergency Department (ED) when Ben... attended on 10 July 2020 from a Respiratory Consultant, who was not made aware that Ben... had attended some 6 hours earlier with the same symptoms.
2. The Respiratory on call consultant was not contacted when Mr... returned to NNUH two days later on the 12 July 2020 with the same symptoms.
3. At the time of Ben...’s attendance at NNUH, Ben... was under the Respiratory Team and had been seen a few days earlier, on the 3 July 2020. The Respiratory Team was not made aware of Ben...’s attendances at ED on 9, 10 or 12 July 2020 with respiratory problems
4. Advice given on discharge appears to be unclear and contradictory. The expert Respiratory Consultant referred to the advice as being "inadequate, unclear and inaccurate". On the Discharge Form provided on 9 July 2020 it is noted "Plan – home as Ben is back to normal, self, red flags and safety netting covered, to return in the event of any difficulty." On discharge from ED on 10 July 2020 (second occasion) the hospital record states that Ben... is to return home, encouraged to lose weight, fluids are to be encouraged and "with no need to monitor his sats unless clinically unwell with sats in 60s%". Not all of this information was included in the Discharge Form on 10 July 2020: The Discharge Form provided under "Other" - "seen by respiratory team, they are happy to send him home, they have clerked their advice on the paper. Cpap and O2" On 12 July 2020 the Discharge Plan provided "Home". The advice from the Respiratory Consultant seen on 3 July 2020 was for CPAP to stop. Evidence was heard from the Care staff at JCP that they were unclear as to what the plan was with regard to Ben and specifically as to when Ben was to be returned to Hospital. One of the Doctors at JCP contacted the ED, NNUH to try to ascertain what the advice was and was unable to get any substantive response. Email contact was made with the Respiratory Team but no response was received until after Ben...’s death on 28 July 2020
5. The section headed "Drug History" was not completed on the Discharge Form on Ben...’s attendances on 9 or 12 July 2020. On 10 July, it states "nil significant". This is despite Ben... being prescribed Promethazine, a sedative medication, affecting the respiratory system. Evidence was heard that not all prescribed medications could be expected to be included in "the small space" provided. That this is a medication where consideration would have been given to a risk vs benefit analysis but there was no evidence of any such analysis. Regulation 28 evidence was that not all medication can be listed; only "pertinent" medication. Promethazine would appear to be such a medication
6. Arterial and venous blood gas samples were taken from Ben... on his attendances on 9 and 10 July 2020, which the Respiratory Consultant said in evidence were incomparable (although this was not the evidence of the Expert Respiratory Consultant). No blood gas samples were taken on the 12 July 2020."

The Interested Persons have 56 days within which to respond, setting out the actions that have or will be taken. Although, this cannot be enforced, this Prevention of Future

Deaths Report is apposite. Crucially, the Coroner acknowledges the interconnectedness of companies and their directors. The directors of Cawston Park Hospital remain the directors of several companies providing care to people with life-long support needs. The “voluntary deregistration” of Cawston Park Hospital, the deaths of three young adults and the end of Ben’s inquest present yet another occasion to reflect on the high cost of multi-level failure in the business of outsourced healthcare and the widespread harms that result.

It is ten years since the Panorama broadcast *Undercover Care: the Abuse Exposed* about Winterbourne View Hospital. The review’s recommendations were checked out with the principal agencies involved. For example, “Commissioners responsible for funding placements should be proactive in ensuring that patients are safe...Adult Safeguarding Boards, CQC and all stakeholders should regard hospitals for adults with learning disabilities and adults with autism as high risk services i.e. services where patients are at risk of receiving abusive and restrictive practices within indefinite timeframes...the mental health arm of the CQC should have characteristics akin to HM Inspectorate of Prisons...the CQC and commissioners should ensure that a service is providing care that is consistent with its *Statement of Purpose*, i.e. in the care of Winterbourne View Hospital, assessment and treatment and rehabilitation...the CQC should consider including pharmacist led medication reviews in future inspections.” Politicians’ promises to transfer more than 3000 patients out of assessment and treatment units by July 2014 were not met – primarily because there is no incentive for commercially provided inpatient care to discharge patients. There remain more than 2000 people in these services. I regret giving coverage to the recommendations of the contributing organisations since it obscured the commissioning challenge: “Commissioners ought to use their best endeavours [to return patients] home...This will require more than keeping tabs on where they are now – political support, the engagement of generic mental health services...capable managers and staff are essential if competent and humane forms of local provision are to develop.” The recommendations set out in this Safeguarding Adults Review have not been negotiated.² It is clear that a progressive, non-sectored and long term solution is necessary, from which Assessment and Treatment units and hospitals are excluded.

The overarching **failure of governance** in evidence at Winterbourne View Hospital persists with gaps in powers and fragmentation. Safeguarding Adults Boards have no more power than coroners to apportion failures to individuals. SABs may identify the “lessons learned” for future application from its referrals. In addition, its commissioned SARs may make recommendations, but there are no consequences if provider

² During June 2019, the North and South Norfolk CCGs commissioned “additional support to oversee” Cawston Park Hospital, “the result of which produced a report with 94 recommendations.” At the same time, “a report to the Quality Surveillance Group [a non-statutory body] chaired by NHS-England requested [that Cawston Park Hospital] was added to enhanced surveillance.”

services fail to act on these. There is no evidence that Cawston Park Hospital was able to sustain change as a result of the persistence of similar safeguarding enquiries, the fact that these were cited in the CQC's inspection reports or even the oversight of the regulator. It is not certain that this Hospital would have closed had there not been three patient deaths. The failure to commission community-based services which prevent hospital admissions and are responsive to crises has a long history. It overlaps with commissioners' failure to oversee the care they buy. Not even weekly meetings advanced Joanna's, Jon's³ or Ben's hospital discharge.

Commissioners have powerful obligations to build the capacity of their organisations and to earn legitimacy for taking conscientious and effective actions. Given the duration of Joanna's, Jon's and Ben's stay at Cawston Park Hospital (18, 12 and 25 months respectively) they shared the experience of their peers as administrative orphans since their commissioners were unfamiliar with patients' day to day lives at the Hospital and did not appear to be pressing for their hospital discharge.

It matters that the explicit coercion expressed as "No other service can manage their challenging behaviour...we wish we didn't have to offer this service but nowhere else will take these people" is met with a decisive public commissioning response: a locally agreed proposal for service provision that is subject to regular local scrutiny. People with learning disabilities and autism, their relatives and social care professionals should have a persuasive voice in deciding how the funding for their support should be spent. Ben was admitted to Cawston Park Hospital with no clear mental illness and was determined by a Care and Treatment Review to be "ready for discharge" five months before he died. The local authority was seeking a bespoke service for Ben to complement his mother's care. Tenacious emails from the local authority during 2020, questioning, *inter alia*, the frequency with which night time observations took place received no reply; and when "urgent" confirmation was sought by the local authority that Ben was "medically fit for discharge," a clinician replied, "In answer to your question, what's the plan? If you get the wrong environment/ support he can be very challenging." Thus delayed discharges from hospitals, including Assessment and Treatment units, are a whole system problem that requires all agencies to work together to identify solutions. This is particularly pertinent when individuals have been admitted and funded by the NHS to such services without the agreement of the relevant local authorities.

It is possible to discern in the sum of such failures the role of the much delayed and vital reform of social care in England and Wales.

³ During February 2020, Merton CCG (now part of South West London CCG) informed the SAR Review Panel that NHS-England had "effected" and "directed" Jon's placement at Cawston Park Hospital. On the 27th August 2021, NHS-England informed the Norfolk Safeguarding Adults Board that it did not commission this placement.

The **deficiencies in the private sector business model** include corporate structures which undermine accountability and responsibility. Weekly fees of many thousands of pounds, paid for by the NHS, are unaffected by failures in service delivery, even those that result in hospitalisation and death. One of the consequences of Cawston Park Hospital “ceasing to trade” was that Jeesal Akman Care Corporation Ltd had no funds for former employees to be legally represented at Ben’s inquest. This is despite the indefensible levels of profit associated with “assessment and treatment” services.

Corporate governance codes are based on the principles of accountability, fairness, transparency and probity and may be given expression, for example, in the appointment of non-executive directors. Crucially however, they do not apply to private, non-listed companies, that is, the majority of health and social care providers in England and Wales. Section 172 of the Companies Act 2006 is the closest the legislation comes to advancing corporate social responsibility provisions. It states:

(1) A director of a company must act in the way he considers, in good faith, would be most likely to promote the success of the company for the benefit of its members as a whole, and in doing so have regard (amongst other matters) to–

(a) the likely consequences of any decision in the long term,

(b) the interests of the company's employees,

(c) the need to foster the company's business relationships with suppliers, customers and others,

(d) the impact of the company's operations on the community and the environment,

(e) the desirability of the company maintaining a reputation for high standards of business conduct, and

(f) the need to act fairly as between members of the company.

Having “regard” is hardly a bugle call for the proper alignment of means and ends. The Act makes no reference to businesses commissioned by the health and social care sectors to provide care, including healthcare to residents and patients with lifelong support needs. The absence of a parallel, business regulatory model enables companies to move money around and beyond UK jurisdiction and begs such questions as:

- why should the liquidation of one company protect all companies with the same directors from liability?
- why is there no equivalent to “the fit and proper person test” for company directors?
- why is “assessment and treatment” provision for people with learning disabilities and people with autism enabled to place ever greater strain on NHS budgets?

The directors of organisations registered with the Care Quality Commission must meet “fit person” requirements. Regulation 5 of the Health and Social Care Act 2008 (Regulated Activities) Regulations 2014 extends the requirement of a “fit and proper person” to anyone with authority in a providing organisation. That is, they accept responsibility for the overall quality and safety of the care provided. An executive or non-executive director may therefore be held accountable if the standards of care provision for their organisation do not meet legal requirements.

Are leaders in health and social care assured that the people who are directors of companies and hospitals in their local areas are “fit” to do so, even if they claim to be detached from the operational performance of their organisations? Are their organisations meeting their purpose? The custodian of “purpose” in registered health and social care is the Care Quality Commission. If there are questions concerning adherence to mandated purpose, leaders in health and social care should call on the CQC. Does the CQC establish that a person is “unfit” because they are a director of an undertaking that has lost sight of its mandated purpose and has caused harm and neglect? This is a crucial question for regulators. If the answer is “Yes,” then arguably that person should be deemed “unfit” under the Company Directors Disqualification Act 1986 and barred from Trustee roles in charities and public appointments. Companies receiving public monies may only be perceived as reliable stewards of the public good when they serve more than the interests of company directors and shareholders. There is no proper prudence concerning the registration of interconnected companies, including holding companies, shadow directors⁴ and phoenix-type companies with previous involvement in the health care sector. Similarly, there is no due diligence with reference to companies’ fees or for the terms and conditions of service they impose. For example, Jeasal Akman Care Corporation directly employed staff to work at Cawston Park Hospital and it created Medical Exchange Agency which, *inter alia*, supplied agency staff to the Hospital. Since limited liability corporations providing health and social care services enjoy important advantages, their justification can no longer be defended.

Failures in individual care and in professional practice were in evidence at Cawston Park Hospital. Ben’s mother was most powerless when she stood up to the Hospital’s psychiatrists. The micro-exchange of her pleading for an ambulance within 24 hours of his death is a compelling inducement to securing change in existing commissioning, complaints and inspection arrangements.

The private distress of people with learning disabilities and autism, and that of their families, reveals itself in their experience of mental health legislation and their unacceptable physical health care. Parents and relatives are more likely to be dismissed as “overprotective” than perceived as stubborn advocates with relevant

⁴ The Companies Act 2006 defines a “shadow director” as a person “in accordance with whose directions or instructions the directors of a company are accustomed to act...” that is, a person who makes decisions behind the scenes

expertise. They cannot effect change and yet they are likely to know their relatives' health support needs better than a service's employees. The principles of personal budgets and self-directed care, albeit compromised by social care spending constraints, are far removed from the reality of Joanna's, Jon's and Ben's experiences as patients at Cawston Park Hospital. There is growing awareness of the economic benefits of investment in social care. However, the powerful hold of the private sector on specialist and very separate NHS budgets has rendered transformation elusive in the lives of adults with learning disabilities and autism who are detained under mental health legislation or are vulnerable to being detained.

The written records concerning the nights on which Joanna and Ben died were wholly inconsistent with the CCTV evidence. This is not a reporting or IT glitch that may be fixed. It is a culture. There was no case for recording Joanna's and Ben's non-compliance with their CPAPs because it did not result in any credible intervention. Understanding the ways in which the directors responsible for health and care services think, feel and act cannot be ignored in any consideration of the culture and values that exist among a service's clinicians, managers and employees. The Cawston Park Hospital families have learned the hard way that norms at this specialist provider were wrong in principle and practice.

The existence of policies and procedures reveals nothing about their application. For example, the Hospital's Managing Conflict of Interest Policy had no impact on the mother and son who were on duty on the night of Joanna's death. The Supportive Observations Policy which had failed Joanna during 2018, also failed Jon and Ben. The inquest heard that most patients at Cawston Park Hospital were obese and yet its Nutrition Policy was not adhered to. The multi-disciplinary team meetings barely engaged with the absence of detailed recording of Ben's dietary intake; his visits to fast food restaurants; his weight gain (he was 13.41 stones/ 85.2 kilos during May 2019 and by July 2020, he was 16.7 stones/ 106 kilos) or the fact that the advice of a nutritionist was not known to staff with the most frequent contact with Ben. The Hospital did little to prevent people from putting on weight and attributed patients' underactivity to the pandemic and their poor motivation. Cawston Park Hospital had no procedure authorising psychiatrists to act as patients' gatekeepers to secondary care. Although "diagnostic overshadowing" is associated with generic healthcare clinicians, it also prevailed at this specialist hospital.

Safeguarding Adults Boards include professionals with critical powers:

- the police have duties to protect members of the public and prevent crime
- the CQC has registration and health and safety duties
- CCGs have commissioning and contracting duties
- CCGs and local authorities have shared duties to organise, coordinate and contribute to Mental Health Act assessments and to provide aftercare.

Many SAB members are professionally registered – doctors, nurses and social workers – all of whom are registrants with duties to alert their professional bodies if

they are aware of practices which breach standards of conduct, performance and ethics. What are the consequences of health and social care professionals authorising the detention of an adult with a learning disability in a hospital in the absence of a “clear mental illness”?

Finally, there was a **failure of professionals to rearrange and redirect resources** to meet agreed goals and reject the default placement of specialist hospitals for unresolved personal distress. A witness at Ben’s inquest confirmed that Cawston Park Hospital had not sought contact with Community Learning Disability Teams because “it was more likely that they would seek help from us. It’s a very specialist service.”

The Safeguarding Adults Board shared with the inquest’s Interested Persons a summarised chronology which was based on the partial information shared by Cawston Park Hospital, plus a Medication Review written by the GP member of the SAR Panel. The submissions of Interested Persons revealed how short-changed Norfolk’s SAR Panel had been. It is possible that the Hospital assumed that its submissions for the purpose of Ben’s inquest would be reflected in the SAR because of the Reviewing author’s access to witness statements. However, the SAR Panel’s experience exemplifies the frustration of many Safeguarding Adults Boards facing corporate providers with regard to information requests. They appear to be perceived as an irritation at odds with business self-interest.⁵

Joanna, Jon and Ben had no say in their placement at Cawston Park Hospital. The pervasive programmes of medication, seclusion, restraint, “observations” and inactivity have ever decreasing legitimacy. These chronic treatments, ostensibly for their behaviour, left the crises which gave rise to their admissions unaddressed. Such a mental healthcare model is without promise in advancing valued lives and sustaining trust. It is regrettable that the eloquence of Joanna’s, Jon’s and Ben’s protest behaviour was treated as “challenging.”

Thanks are extended to James Butler, Vic Citarella, Aled Griffiths, Richard Humphries, Joan Maughan and Walter Lloyd-Smith for the ideas and discussions which led to this annex.

⁵ Section 45 of the Care Act 2014 states, “If an SAB requests a person to supply information to it, or to some other person specified in the request, the person to whom the request is made must comply with the request...”