Brent Safeguarding Adults Board

Safeguarding Adult Review: Adult B (Cassie)

July 2018

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SAFEGUARDING ADULTS REVIEW
Introduction

1. This Safeguarding Adults Review (SAR) concerns Cassie,[1] a Black woman in her mid-fifties, who has lived in services for people with learning disabilities and autism since she was a child. She was found to be HIV positive during 2016. Since information about Cassie is primarily based on:
    (i) the clinical classifications of *pervasive developmental disorder, unspecified; severe mental retardation; bi-polar affective disorder;* and *autistic spectrum disorder*, and
    (ii) records held by health and social care services, including the Independent Provider, the autism specialist residential home at which she has lived since 1990,

2. Brent's Safeguarding Adults Board acknowledged the limited benefits of relying solely on such records. All that the classifications suggest is that Cassie has intense intellectual, physical and behavioural limitations and that, without direct instruction, she would have learned slowly and might have struggled to perform such basic tasks as: communicating her needs and feelings and understanding those of others; and eating and exercising bowel and bladder control. The classifications might indicate that she may engage in behaviour which appears to have no constructive purpose. However, they do not imply the absence of such familiar and positive behaviour such as determination, sociability and humour for example.

3. At a safeguarding meeting arising from Cassie's diagnosis it was:
    (i) Confirmed that the HIV infection was sexually transmitted and that Cassie *did not have the capacity to consent to having sexual relations.* The Infectious Diseases Team which made the diagnosis proposed that Cassie *was infected at some point between 2007 and 2015 while resident with the independent provider commissioned by the local authority,* that is, Brent Adult Social Care; and
    (ii) *Agreed that a police investigation and a safeguarding enquiry would be an appropriate response and it was agreed that these enquiries would run concurrently*.[2] *On discharge from hospital, Cassie was moved to alternative accommodation at a different home, also managed by the independent provider.*

4. At a subsequent safeguarding meeting a referral was made to the Case Review Group which subsequently commissioned this SAR. It was agreed that a police investigation[3] and a safeguarding enquiry *would run concurrently*.

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[1] A fictitious name

[2] During March 2017, the Safeguarding Adults Board formally received notification that the police investigation had closed

[3] That is, to *formally advise on the outcome of their investigation of whether Cassie was the subject of a serious sexual assault;* and determine *whether there is a record of any involvement with Cassie prior to the sexual assault investigation*

5. **The Purpose** was to review the health and care and support provided to Cassie from January 2007 – March 2016; and to identify good practice and shortcomings in practice highlighting lessons to be learned. The Safeguarding Adults Board sought specific information concerning:
   (i) *the determination of Cassie's mental capacity as appropriate*
   (ii) the assessment of Cassie's *capacity to enter into sexual relationships*
   (iii) consideration given to Deprivation of Liberty Safeguards and
   (iv) learning arising from *the safeguarding investigation and protection planning since March 2016.*

6. The **methods** were *traditional* insofar as the five agencies with experience of supporting Cassie provided chronologies and their own reviews. The agencies were:
   - Brent Adult Social Care (Commissioning, Reviews, Safeguarding)
   - Willow Tree Surgery
   - The Independent Provider
   - Central & North West London NHS Foundation Trust
   - London Northwest Healthcare NHS Trust

7. In addition, Brent Adult Social Care provided *a pen picture of Cassie* with the expectation that this would be supplemented by Cassie's mother.

The Findings

8. It is remarkable that Cassie's many years of residing in long stay hospitals and latterly, at the Independent Provider, reveal so little about her. Whatever the names of the hospitals she has lived in, observers and some former residents have commented on the bleak and unstimulating environments of large institutions. There were no opportunities for children with severe learning disabilities to learn functional skills, including basic communication skills, or to prepare for life beyond the institutions. It is noteworthy that the single sign which Cassie was consistently encouraged to use was "Thank you."

9. Knowledge of Cassie is primarily based on clinical interpretation and classification and these do not help in deciphering the ways in which she engages with others or with objects. There is neither a simple nor consistent description of her. Yet support staffs' understanding of Cassie determines how she spends her days. The challenges Cassie faces in figuring out the world are unfamiliar since so little is known of her developmental path. The records suggest only partial accounts of her behaviour or aspects of particular actions. How her interest in paper tearing is defined is critical. During her adulthood, Cassie began to create scatterings of torn paper. The Independent Provider notes that she becomes distressed when she is required to pick up and put the pieces of paper in the bin. This prompts the question: Is this the only possible intervention? It is clear that Cassie can communicate intention. For example, she takes people to the kitchen when she is hungry and she gets her coat when she wants to go out. It is known too that she needs a lot of help in terms of her personal and intimate care. This does not preclude her having unique forms of communication, demonstrating awareness

of others and desiring to belong and participate. For example, she enjoys her mother's visits and she likes to sit with staff.

10. The records suggest that during the weeks prior to Cassie's HIV diagnosis, her world experience appeared to be confined to her bedroom and the living room and, specifically, the sofa.

A Mother's Perspective

11. *Cassie was happy and outgoing. She wants to be up, dressed and out there. She becomes very frustrated when she can't go out…She will play with a button or her belt. Paper tearing seems to give her comfort – just as when she's with me she takes a leaf off a plant. She has always picked things up from the floor, even when she was very small. The paper tearing – I don't know when it started. Same with pulling threads from curtains – she does that now. She's bored. She's got pictures in her room – her special photographs and her holiday pictures. There's one of her drinking a pint! She enjoys being part of things. She doesn't like disorder and likes to tidy things away – out of sight. At the day service she liked the music room. She'd jump up and down. She was happy – you could tell when she slapped her legs she was happy. I want the people who look after her to see her as a person and not a meal ticket.*

12. She is concerned that Cassie's world has narrowed during the time that she has been supported by the Independent Provider:

    When Brent closed its day centres I was told, "We'll make a programme for her so she can go out, meet people, walk around – we'll put a programme together that includes shopping and visiting you." Nothing materialised. The residents in the house were there all day. She would sometimes run out of the house when I visited. I was told that one place Cassie could go to – the Independent Provider's Day Centre was "being repaired." She got a place there but it didn't last long. I had a letter saying that Brent had cut the grant and she didn't go back anymore. She's bored. It was better when she went to the centre…Now they just sit in the living room with the music channel on the TV. There are only three of them and that's what they do.

13. Cassie's HIV diagnosis was devastating:

    As long as the law is what it is, this will always happen. There are people who work with people with autism who only do it for the money or for what they can get. There are early shifts and late shifts and at night they will have a man and/or a woman working depending on shifts at Independent Provider. The HR person at the Independent Provider said that this must have happened at night.[4] *This is all I know. This rape, which I can't talk about or tell anyone about, this rape happened. Cassie has no control over her body and this man takes over her body. You can't get them to take tests because of their human rights. What chance have you got? I asked the police if they could offer a reward. They said "no" because people tend to close ranks. They don't want to be seen as a grass. One time in the very bad weather the staff stayed*

[4] Cassie's mother met with the HR lead after Cassie's diagnosis

and got drunk. I was told this at the hospital by one of the care workers who was looking after Cassie. This is in a service where people can't speak.

The police can't offer a reward. They said that staff "all join ranks…no one wants to be seen as a grass. They work and socialise together." So – it's a service – like all services for people who can't speak – where, when they were asked if they've noticed any changes in Cassie's behaviour, they said "No!" They drink and get drunk together – the people who are responsible for a service where people can't speak. They noticed nothing? That's not right. I don't know who monitors them or who checks them at weekends. They use agency staff who don't know them. They use carers who are not originally from the UK. Do they get references for them? One Saturday I was there and a girl arrived saying how difficult it had been finding the place Cassie's in now. She hadn't been there before! When I visited last Saturday, I was told that Cassie was in hospital. I am her mother. I did not know and they didn't know which ward she was on. Her liver and her kidneys are damaged now – it's the medication she's taking for HIV.

Cassie had been poorly [before her diagnosis] *and she fell. She had a bad tooth and because she wouldn't let the doctor take blood she went to Guy's Hospital. She had a low blood count and the tooth couldn't be removed until she'd built up her blood count. I asked, "Why are her legs like sticks?" They didn't take any notice of me. Her legs were so thin.*[5] *I think they probably had an inkling. Then one day she fell down and she couldn't get up. She was in the hospital for eight days. It's only when she collapsed – she was not strong. She slept a lot. She was ill. She had to go back to the hospital and the doctors do everything but nothing worked. I was told that they'd tried everything but Cassie was not responding. Then they did an HIV test and it was positive – so they did another one. Then we had a meeting with everyone.*

Cassie was in hospital for three months – they were trying everything and then the social worker became involved. Are there no background checks on staff? Maybe people get their friends, people with no experience? If they had had a caring nature they would have done more. They're supposed to be specialists. I trusted them. It's only since Cassie's rape that I've realised they're not specialists. If they'd done more when we believed they were then Cassie would be able to do more now. When Cassie was at the Independent Provider she could go to the toilet by herself and because she became sick she soiled herself. I discovered that she was wearing disposable pads and she's still wearing them a year later. I think this has set her back. Now she is wearing a pad all the time and she can't take it off. She didn't used to have it on all the time. When I asked how often it is changed they said it was put on at 2.00pm so not until 6.00pm. That's four hours so I rang the social worker. She checked and was told that they shouldn't have said this because it is changed four times a day! At her review in August 2016 it was said that she should be going to the toilet every hour.

They work to order – it's all tasks. You think they're doing the right thing. When a particular unnamed member of staff worked with her, she cared and Cassie seemed happier back then.

[5] Cassie's mother shared some distressing photograpof her daughter when she was in hospital

Very few of them seem to enjoy what they do and treat them like real people. Some are ok but it's only a few that really stand out. At Cassie's reviews, rarely anyone from head office came down. Sometimes the social worker comes.

When Cassie took sick, the manager at the Independent Provider didn't phone me. After I asked questions at the hospital, the manager rang me at home and said "You've complained that we're not taking care of Cassie." I said to her that there are only two staff on duty and Cassie has a room upstairs and she won't manage the stairs. Then I was told by a key worker from the Independent Provider that I had "had words with a particular unnamed member of staff!" I said that I hadn't and that a particular unnamed member of staff had rung me. Cassie got a black eye and I never knew how she got it. They said she'd scratched herself! Cassie's key worker was asked if she had seen any changes in Cassie and she said "No!" So nothing - in 10 years? It is distressing that they gang up.

The previous Chief Executive at the Independent Provider offered counselling but when I discovered that [Male Worker 1] *was the supervisor at weekends, I became even more distressed and worried for my daughter because I don't know what goes on there at nights so I went to see my GP and she offered counselling for six weeks. The family have been offered nothing. I am upset in my head. I don't know what's going on. It's really painful for a mother to think that there's a man there at night – so crafty and it's not reported. Men should not be working with her. It rests on my mind, heavily and constantly. I want her to move. I didn't have much choice - only the Independent Provider. I want to get somewhere good with women staff and then move her.*

14. Her recall of Cassie's deterioration confirms her belief that services have no understanding of how bad things are and how they prioritise their reputation over compassionate care:

On Cassie's birthday [in] *2014, I mentioned to her key worker that I would like to make a birthday party for Cassie and she agreed. I asked her to invite some of the service users from other houses and I gave £50.00 to help buy food and I also bought balloons, streamers to hang up and ordered a cake for her. On the evening of the party lots of people were there. Some were in the kitchen and I heard* [Male Worker 1] *say to his friend/work mates "are you hitting on Cassie's mum?" I didn't respond because I thought that was not a proper thing to say. It was not until Cassie was diagnosed in 2016 that it all came back to me.*

Cassie was sick for a long time in 2015 and no one knew what was wrong with her. Her neck was down and she was dribbling all the time. She went to the doctor who thought she had osteoporosis. She was given physio then given neck braces. It was then discovered that she had bad teeth so she was sent to Guy's hospital. They could not take out her teeth because she had a low blood count and she needed anaesthetic to remove them.

On 28 January 2016, Cassie collapsed and was taken to hospital and she returned home on 4th February. An appointment was made for her to see the doctor on 11th February and no one

took her and no reason was given. Another appointment was made for 1st March. She didn't attend and no one let me know. On both occasions I was waiting to meet her at the doctor's surgery. I went up to the house and no one said anything to me. Cassie went back to hospital on 5th March. I went to see her on 6th March. She had two big scratches on her forehead. I asked what happened and I was told they took her for a walk and she fell over. One carer went with her. The scratches were already healing. I visited her every two days.

On 28 January 2016, when Cassie was taken to hospital, I visited her on 30 January and saw that she had a black eye. When I asked what happened, I was told that Cassie had scratched herself. Doctors referred this incident to Safeguarding.

15. Her aspirations hinge on finding safe accommodation and a team of all women support staff, most particularly to assist Cassie during the night:

The social worker tried to get Cassie somewhere else for her to move to but it was not suitable. The Independent Provider had a new place and it had a ground floor room. Cassie was very weak and her room was on the third floor so I asked for a transfer but I was not happy with her staying with the Independent Provider. I wanted her in a new environment – wanted her to be transferred from this Provider. *I was not happy with her staying* [with the] *Independent Provider because I was still trying to figure out how she got HIV. Then when Cassie was leaving hospital to go to the new place,* [Male Worker 1] *from the old place, the Independent Provider, was sent with a car to meet us at the hospital. I was so upset I couldn't say anything. It was raining and I didn't feel like we had any choice. It was distressing. On one occasion at the Independent Provider, Cassie saw* [Male Worker 1] *and she got up from one chair and moved away to the furthest chair. She didn't want him near her! I do not know who raped her. You can't get them to take tests. There's one who shouted my name and I didn't want to speak to him. I said that and now he is silent. He's the one who's advising the agency staff. He says he is the supervisor at weekends. He likes to offer his services but not in a good way. I don't want to interact because I don't know who raped my girl. They might still be there – allowed to work. I don't want men to work with Cassie at night.*

As I get older and my body deteriorates, I think of Cassie and this makes me tearful as she not only has to deal with her autism but now has to deal with HIV as well. I worry about what will happen to her when I am not here anymore.

The perspective of two current support workers and a former support worker

Cassie understands everything. She has days when she's really challenging and other days when she is calm. When her mother comes she is calm, afterwards she is screaming. She hates being told what to do. She's outgoing and she likes being outdoors. She likes to hold onto you. She links arms – she doesn't need to. Sometimes she taps her hand on the table and she slaps her legs really hard sometimes. She gets angry – not every day. She's not violent. She's pleasant. She jumps and claps when she's happy like when she's sitting and tearing paper or walking.

In the last house, she used to smear – sometimes it would take two hours to clean it. If you don't watch her the bathroom floor looks as though there's been a snowfall because she tears up toilet paper. There are some things she doesn't like doing and she makes a noise. Even putting her socks on she makes this noise. She gets angry when she has to pull her trousers down or do something she doesn't want. She's very slow to eat but fast if she knows she's going out! Very slow when she doesn't want to do something, it's as though she thinks "I'm going to make mischief!"

She's a nice, noisy person, happy and a lovely lady. She's friendly and cheeky. She slowed down a lot when she was ill. She didn't want to eat. Now, she has put weight on. She loves her cooked breakfast. She's not as keen on cereal and toast.

She used to throw her clothes out of the window until we had safety catches put on. She has a sign for "thank you" but she didn't use it much.

She goes out to lunch once a week – depending on the weather. We're trying to work out what best fits her. Cassie likes a day out with a packed lunch. She enjoys going to Nandos. She hasn't needed to wear her neck brace while she's been here. She has a lot of attention here. She likes her routine. She only sits on this dining chair and on that armchair and she doesn't like it if someone else is using them. She stands over them.

She's in hospital now. It took seven people to hold her down. They had to do a blood test – the last time blood was taken was December 2016. She fine in 2011 then she became very weak. She couldn't even hold a cup. She was so noisy in hospital. Now she wears pads all the time. The District Nurses provide them. She doesn't like taking her medication – she takes a lot more now than she used to.

There are two staff to three people and one waking night.

16. The majority of the Independent Provider's Risk Assessments date from the month of Cassie's diagnosis. There are many gaps in the "monthly reports" and other information shared by the Independent Provider. Their notes convey only biographical fragments. The monthly reports contain a lot of repetition and evidence of "cut and paste." This renders problematic the claim that these will be subjected to "trend analysis."[6]

A Primary Healthcare perspective

17. General Practitioners have known Cassie over many years. They described their reaction to her HIV diagnosis and outlined the challenges they encountered. Additionally, they set out the role of their experiential knowledge in making sense of Cassie's health status:

It was shocking when the Infectious Diseases Team made their diagnosis because Cassie is so very vulnerable. As a patient, she is sometimes compliant but there are a lot of barriers to

[6] As stated in the Independent Provider's IMR

investigating what is wrong. She had anaemia [a low blood count]*. We didn't have a context. We assume that she's being cared for by people who are skilled.*[7] *We know she doesn't have Continuing Health Care funding since there has been no documentation.*

Cassie was always accompanied for her checks. However, there were a lot of "cut and paste" requests that we should undertake blood tests as though this is straightforward! [Pre-HIV diagnosis] *she was taking less medication than a lot of people who are being cared for. Some of her carers were very caring. Cassie's cooperation was clearly related to the calmness of the carer. Some were better than others in helping to calm her. We're obviously interested in her diet and exercise and her activities but we don't have information about this.*

18. The GPs' records confirm the importance of credible briefing from her carers and something of a "trial and error" approach in determining what may/may not be the source of her discomfort prior to identifying a course of treatment.

19. The GPs' records show that since **2007**, Cassie has been treated for skin problems, most particularly for skin dryness, rashes and bruising. These are recurring themes throughout the 2007 - 2015 timeframe. As recently as **2015**, a carer accompanying Cassie explained that Cassie had *no known injury,* noting that, although *one of the other residents can lash out,* nothing was *seen or reported*.

20. Medication reviews likewise characterise Cassie's contact with Primary Care. Terms such as *restlessness, agitation* and *no consent,* feature in her medical notes. Since Cassie has a very slight build, concern about her weight prompted the observation that *carers should be educated to provide more regular snacks and fluids.*

21. Cassie resisted blood testing. One GP noted that: *she's agitated, pacing around and cannot be stilled. When she saw the blood bottles she roared and stood up and started pacing noisily.*

22. On another occasion, it was noted that the *carers brought her because the day centre wouldn't accept* Cassie…*wanted to exclude infectious diseases.*
23. Regarding women's health, during **2011**, it was noted of cervical screening that this was*, not wanted, not possible.* This chimes with observations during **2013** and **2015** stating, *contraception not needed.*

24. The GPs' **2012** records highlight the challenges of securing urine samples from patients whose mentally capacity is ostensibly compromised; who are intermittently incontinent of urine; and of establishing the meaning of successive upper respiratory tract infections, for example. The GPs' experiential knowledge was a valuable source of information: *seems unhappy and quieter than usual…looks miserable…she can't tell me…never sits down…consistently walking…looks like she's in pain…crying. No idea where pain is – moaning but not holding any*

[7] One record noted that *Cassie has a cough…carer does not know for how long…could not examine throat…carer does not know why appointment was booked…really not enough information* [2011 record]

part of her body. Ears ok, throat not red…ate a couple of sweets I gave her…managed to get a little bit of blood.

25. Cassie's health deteriorated. During **2013**, her appetite was diminishing and her intermittent cooperation with invasive medical treatments persisted: *did not consent for blood pressure check, kept pulling the cuff away despite the carer's help.* Regarding Cassie's bruising, the GPs were advised that she *does hit self and head on things.* During **2014**, Cassie's familiar health problems were unchanged. On one occasion the GP noted, *no need for blood test as traumatic.*

26. During **2015**, Cassie was frequently brought to see a GP. Her notes state, *inter alia,* that she was *making grunting noises but carer says normally does that…cannot be persuaded to open mouth today…very poor dental hygiene…gums sore and red.* It is noted also that the Independent Provider staff contacted the surgery to express concern about Cassie's tablets and that they were *not allowed to crush* [these] *because they'll get into trouble with the CQC.*

27. Regarding muscular-skeletal issues, the GPs' notes state that Cassie *will not be able to cope with exercises.* Cassie's ongoing health checks hinged on how cooperative she appeared, for example, *didn't co-operate. Could not keep still for blood pressure check…tried to take blood, too distressed…unable to check BP either…quite distressed today…blood sample taken…a little tricky but obtained at first attempt…minimal distress, was bribed with a chocolate.*

28. Cassie's anaemia was pronounced during **2015**, not least because it appeared to be, *consistent with poor nutrition*. The GPs' notes record that on one occasion, Cassie *was quite distressed today…flu vaccination consent given…blood sample taken but only managed a smaller amount this time. Hopefully will be enough.* Cassie's bruising exercised her GPs since: *no known injury* [was] *reported.*

Service contributions

29. Cassie did not benefit from yearly reviews. Reviews were not undertaken during 2008, 2011, 2013 and 2014. A review during 2012 resulted in Cassie's attendance ending at the Independent Provider's day service. There was an (unchecked) expectation that the day service would *be replaced by a timetable provided by residential staff*. Adult social care became more visible with Cassie's admission to hospital during January 2016 and the subsequent HIV diagnosis. Contributors to the safeguarding Strategy Meeting *agreed that a sexual assault had occurred (on balance of probability) …and the nature of Cassie's mental disorder meant that she could not have consented to sexual relations.*

30. Cassie's contact with the Learning Disabilities Community Health Team involved *on-going psychiatric and a brief episode of specific, physiotherapy support…Cassie has been known to the psychiatry service since 1990 for management of fluctuating levels of behavioural disturbance in the form of agitation, screaming, poor sleep, slapping herself and property destruction…she continues to be reviewed in outpatients' clinic every 6 months…Her mental*

state and behaviour continues to be characterised by fluctuating levels of agitation of low intensity which is managed effectively by a combination of behavioural approaches and medication. In view of the stability of her presentation her medication and dosage have not been changed for the last 5 years. The service regularly requested that Cassie's GPs undertook blood tests.

Determining best interests

31. Before the Mental Capacity Act 2005 came into effect, the principle of acting in the best interests of the person who lacks capacity was well established and the concept had been developed by the courts in cases relating to incapacitated adults, which were typically concerned with the provision of medical treatment. Since it is not possible for statutory guidance to provide an exhaustive account of what is in a person's best interests, the *best interests' checklist* may be broadly summarised as:
    - Equal consideration and non-discrimination
    - Considering all relevant circumstances
    - Regaining capacity
    - Permitting and encouraging participation
    - Special consideration for life sustaining treatment
    - The person's wishes and feelings, beliefs and values
    - The views of others.

32. There is no reference to the MCA in relation to Cassie's care and support. Although the Independent Provider cites "best interest meetings"[8] there are no documented examples of any such meetings.

33. Section 5 of the MCA makes provision to allow health and social care professionals to carry out certain acts regarding the treatment of a person lacking capacity to consent to treatment. These provisions protect professionals from liability since they could be performed as if the person concerned had capacity and had given consent.

34. Irrespective of the seriousness of Cassie's HIV diagnosis, no individual or agency has undertaken to determine her best interests in relation to achieving a consensus approach to decision-making concerning invasive treatments or even essential treatment. The courts have established the common law *principle of necessity* setting out the circumstances in which actions and decisions could lawfully be taken on behalf of adults who lack capacity.[9]

Deprivation of Liberty

35. Deprivation of Liberty (DoLs) provisions were introduced to address shortcomings in relation to the detention and restraint of people lacking capacity where detention or restraint amounts to deprivation of liberty for which the state is responsible. In order to reduce the

[8] "As Cassie lacks capacity in most areas of decision making in her life, best interest meetings would be held where required" - IMR

[9] *Re F (Mental Patient: Sterilisation)* [1990] 2 AC 1, at 75

risk of a deprivation of liberty, the Code[10] sets out the steps to be taken. These include: decisions and their reasoning should be recorded; good practice concerning care planning should be followed; and a proper assessment is required to determine whether or not a person lacks capacity to accept proposed treatment. A DoLS authorisation was sought on Cassie's behalf when she was in hospital at the time of her diagnosis. The law and practice concerning DoLS are complex and the broad interpretation a matter of concern in terms of overloading the Court of Protection. However, it is possible that a social work-led, annual reviewing process might have sought an authorisation of Cassie's living circumstances.

Consenting to sexual relations

36. The capacity to consent to sexual relations is a vexed issue, that is, is it act-specific or person-specific? Is the relevant information for the purposes of S.3 (1) of the MCA solely relevant to the sexual act and its consequences or does it also include information about the proposed sexual partner? However, unlike many questions concerning a person's capacity, questions concerning a person's capacity to consent to sexual relations largely provide a yes/no answer. Section 27(1) (b) of the Mental Capacity Act provides no ability to consider whether it is in a person's best interest to have sexual relations.[11]

37. The Infectious Diseases Team was of the view that Cassie could *not consent to sexual relations* since they referred her to safeguarding and to the police.

Lessons

38. It would appear that the Learning Disabilities Community Health Team underestimated the challenges associated with its regular requests for Cassie's blood testing. There is a case for such teams assuming leadership in terms of (i) assisting professionals across agencies to assess mental capacity and review best interests decision making; (ii) making sense of Cassie's wants and preferences, irrespective of a determination of (in) capacity; (iii) and in being persistent advocates for improved health for people with learning disabilities in the light of "diagnostic overshadowing."[12] Until the months before Cassie's HIV diagnosis, her tearful distress was seen as behavioural rather than as an undetected health problem.

39. The absence of a credible life story is stark, that is, one which goes beyond setting out Cassie's likes, dislikes and challenging behaviour, for example. Without the account of Cassie's mother and her GPs' descriptions of what they have learned from supporting her, Cassie's life-long history of being supported by services is reduced to a dishearteningly short list of home based activity. Although it is known that Cassie loves to walk, and her impulse to get out is

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[10] *Deprivation of Liberty Code of Practice* para 2.7

[11] *X City Council v MB, NB and MAB* [2006] EWHC 168 (Fam), [2006] 2 FLR 968 and *Local Authority X v MM and KM* [2007] EWHC 2003, (Fam), [2009] 1 FLR 443. See also, Roderic Wood J in *D County Council v LS* [2010] EWHC 1544 (Fam), [2010] COPLR Con Vol 331; [2011] EWHC 101 (COP), [2011] COPLR Con Vol313; *LB Tower Hamlets v TB* [2014] EWCOP 53

[12] The tendency to attribute physical symptoms to an individual's learning disabilities and/ or autism

undiminished, at the Independent Provider this is given expression in her fast paced restlessness. Cassie's life story is not known. That is to say, the relevant parts of her past and present have not been recorded. The services to which Cassie is known appear not to have any processes for eliciting stories about her and her family as a means of connecting her life to her present circumstances and the people who are significant.[13]

40. Since Brent's commissioning did not ensure that the Independent Provider established the necessary conditions to support Cassie, this is an opportune time for Brent to initiate a fresh approach to the support of people with autism. What "autism specialism" is Brent seeking? It cannot be credible that faith is invested in a service which advertises itself as specialist. Brent has a responsibility to identify and monitor the tasks required to address Cassie's considerable support needs and those of others with autism and learning disabilities. What arrangements are in place in Brent to provide support to the families of people with autism at times of transition and to ensure that workforce planning, training and retraining arrangements are effective? The test of such investment will be in the improvements they bring to the lives of people with autism and learning disabilities.

Good Practice

41. Cassie's GPs learned a great deal about Cassie during the years she was registered with their practice. Although she has no readily understandable language the practice was attentive to her behaviour, especially her avoidance behaviour. The GPs expected the staff who accompanied her to the practice to be well briefed, in terms of sharing accurate and credible information and competence.

Conclusion

42. Cassie has been failed by services. Exposing her to sexual abuse by a third party, if appropriate steps – through care planning and risk assessment - were not taken, is professionally negligent and possibly a breach of the duty of care. The evidence suggests a possible breach of the right to respect for private and family life and potentially a breach of the right to protection from inhuman or degrading treatment.

43. It is disappointing that the Independent Provider's IMR states: *The organisation is unable to comment on the assertion in the terms of reference that Cassie was infected as a result of a sexual assault as we have seen no evidence of this. The same applies to the second assertion in the terms of reference that Cassie was infected between 2007–2015*. Although these claims are supported by the statement that *Cassie had consistent female key workers and female wake night* (sic) *staff*, the documentation does not support the assertion that Cassie was solely supported by women staff.

[13] See for example, Kaiser, P. and Eley, R. (Eds.) *Life Story work with people with dementia: ordinary lives, extraordinary people* London: Jessica Kingsley Publishers

44. Cassie has remained within the purview of the Independent Provider, albeit in different accommodation, since her discharge from hospital during 2016. Her mother is unhappy with arrangements and wants urgency in seeking an alternative placement for Cassie. Thus far, there is no evidence of attentive external scrutiny of her post-diagnosis care plan. Since the documentation shared by the Independent Provider and service reviewers is limited it is possible that these are systemic matters.

45. There is a great deal of work to undertake in Brent concerning the use of the Mental Capacity Act 2005 and the DoLS, (which have been criticised for being overly complex and bureaucratic[14]). Cassie's health is compromised and is vulnerable to deterioration. It is not clear what "practicable steps" were taken to support Cassie's decision-making in advance of a determination of incapacity.

46. The long-term treatment of Cassie's *bi-polar affective disorder* by the Learning Disabilities Community Health Team is wanting because it does not appear to engage with the possibility of (i) trauma and suffering or (ii) underlying physical pain or discomfort. The Team knew nothing of Cassie's life even though she has received publicly funded services since she was a child.

Recommendations

1) Since there is cause for concern and uncertainty concerning the HIV status of five residents at the care home, Brent requests the Court of Protection to give direction in this matter
2) Cassie should be provided with additional interim support until she moves to another service. Such support should be informed by the principles and management of care as set out by NICE guidance[15]
3) Brent's Safeguarding Adults Board seeks reassurance that:
   - The Transforming Learning Disability Services' initiative of the CCGs, permits and establishes with Brent's Adult Social Care an ambitious path which promotes greater attention to individual support needs which credibly involves (i) self-advocates and (ii) engagement with the families of people with complex support needs, most particularly in ensuring that account is taken of people's life stories and their future aspirations
   - Future changes (that result in discontinuities of personnel and functions) in respect of reviewing and monitoring long-term placements must ensure that (i) people funded by public services are better off or at least not worse off, (ii)

[14] http://www.lawcom.gov.uk/wp-content/uploads/2017/03/Mental_Capacity_Report_Summary.pdf (accessed on 6 July 2017)
[15] NICE (2012) *Autism spectrum disorder in adults: diagnosis and management* (CG142)

reviewing is annual and (iii) goals or "ends" for people receiving services are not displaced by undue attention to "means"

- The Transforming Learning Disability Services' initiative adopts a proactive and questioning approach to the scrutiny and oversight of all placements. Critical skills should be evidenced such as: collaborating with people with autism and their families; knowledge of effective care planning; knowledge of safeguarding and, specifically, how to record safeguarding concerns; identifying potential community collaborators; and because several medical conditions are significantly more prevalent among people with autism compared with people who do not have autism,[16] ensuring that medical appointments are prioritised
- The operational competences and track records of specialist providers are known to service commissioners in term of the recorded outcomes realised for individual people with autism
- The Learning Disabilities Community Health Team and specialist providers can provide evidence that they are (i) instrumental in working with GPs in detecting health problems which would otherwise result in unnecessary suffering; (ii) make it possible for residents to develop health routines such as accessing health screening and health promotion activities; and (iii) are persistent and creative advocates for people's improved health and health care – paying particular attention to the challenge of "diagnostic overshadowing"
- The Learning Disabilities Community Health Team assumes a lead role in promoting positive practice in the use of the Mental Capacity legislation
- The signs being taught to people with compromised communication skills include the sign for "No!"

4) Brent's Safeguarding Adults Board may wish to consider advising service commissioners that questions must be asked about the mechanisms in place to ensure the safety of people with limited articulacy, in particular those who are supported by male workers

[16] Treating Autism, Taking Action (2013) *Medical Comorbidities in Autism Spectrum Disorders: A Primer for Health Care Professionals and Policy Makers* England: Treating Autism Publications