Newham
Safeguarding Adults Board

Lilian Marie Modest
(aka Lilian Jenny John-Baptiste former married name)

Safeguarding Adults Review

Lead Reviewer: Angela Neblett

February 2024

Table of Contents

1. Introduction

The case of Lilian Marie Modest (aka Lilian Jenny John-Baptiste) focuses on how effectively multi agency systems in Newham work to support Black people with lifelong mental health diagnoses when their needs change in older age. Intersectionality is an important aspect in this case, specifically relating to age, ethnicity and disabilities. At the request of Lilian's daughter Amanda, we have used her real name throughout this review.

1.1 Intersectionality

1.1.1 "Intersectionality is a distinct concept from the additive disadvantage of race plus gender which is the notion that some people have a burden and others have more burdens, with each new characteristic added on the ones before it, compounding the experience of oppression."

Source : Professor Anton Emmanuel, NHSE[1]

1.1.2 "Intersectionality is a lens through which you can see where power comes and collides, where it interlocks and intersects. It's not simply that there's a race problem here, a gender problem here, and a class or LBGTQ problem there. Many times, that framework erases what happens to people who are subject to all these things."

Source: Kimberlé Crenshaw[2]

Intersectionality

Source: Diversity and Ability (D&A) Ellie Thompson[3]

1.2 Why this case was chosen to be reviewed

1.2.1 The case of Lilian was chosen for review by the Newham Safeguarding Adults Board. Having considered the case details, the multi-agency Safeguarding Adults Review (SAR) subgroup made a recommendation to the Board Chair that a SAR be undertaken. The decision was made in February 2022 as the case met the statutory criteria for a Safeguarding Adult Review under section 44 of the Care Act 2014:

1.2.2 *Local Safeguarding Adults Boards must arrange a Safeguarding Adults Review when an adult in its area dies as a result of abuse or neglect, whether known or suspected,*

[1] Interim clinical lead for the NHS Workforce Race Equality Standard

[2] Kimberlé Crenshaw on Intersectionality, More than Two Decades Later.
https://www.law.columbia.edu/news/archive/kimberle-crenshaw-intersectionality-more-two-decades-later

[3] https://diversityandability.com/blog/what-is-intersectionality-and-why-does-it-matter-in-the-workplace/

and there is a concern that partner agencies could have worked more effectively to protect the adult. (Department of Health, 2020).

1.3 Pen picture of Lilian and summary of the case

1.3.1 Lilian Modest was a Black woman born on the island of St. Lucia in the Caribbean; she came to the UK at the age of 15. Lilian was of Caribbean heritage aged around 75 years at the time of her death. Lilian had a longstanding severe and enduring mental illness dating back to 1977 and was diagnosed with paranoid schizophrenia which by 2018, was changed to schizoaffective disorder. This was a clinical recognition of the mood disorder aspect, and recorded in the CPA by the Consultant dated 6th February 2018. In terms of physical health, Lilian had sickle cell trait, hypertension and suffered with osteoarthritis for which she was treated with medication; by her 70s Lilian had problems with stability and mobility and used a walking stick.

1.3.2 Lilian lived alone in an extremely small one bedroomed flat rented from, and managed by, Newham Council. Lilian lived in cramped and crowded conditions with items that seemed to have accumulated over a period of time; the kitchen was the size of a cubicle.

1.3.3 Lilian lived in the London Borough of Newham for most of her life in the UK and had a number of admissions to Newham Centre for Mental Health under the Mental Health Act 1983. Lilian was a reluctant user of services. Amanda remembers her being admitted as a young girl in care at around the age of 11 years old. Lilian was a frequent in-patient at Goodmayes Hospital in Essex. When unwell, Lilian would self-neglect to the point of emaciation.

1.3.4 On her return from holiday in St Lucia, Lilian attended an outpatient appointment on the 15th July 2019. This was the last time Lilian was seen by professionals and there was no response to any subsequent communication efforts. Lilian's daughter reported Lilian as missing; the date is not recorded.

1.3.5 On 7th July 2021, East London Foundation Trust (ELFT) responded to police enquiries as Lilian had been reported missing. On 17th July 2021 the police attended Lilian's home and undertook a search; she was not found. Police returned to Lilian's home in August 2021 to seize correspondence or paperwork that might support their enquiries. The police opened a missing persons investigation including financial enquiries, local enquiries with neighbours and with ELFT yielding no indication of Lilian's whereabouts.

1.3.5 Amanda has reported that there were frequent exchanges of emails between her and social services at this time. Furthermore, that there were frequent requests from Amanda to the police to revisit her mother's flat; the police warned she could not attend herself as it was a potential crime scene.

1.3.6 Police report that the lack of progress led to a review of the investigation early in February 2022. Police entered Lilian's home for a third time and conducted a systematic search of the premises on 7th February 2022 where sadly Lilian was found deceased on her kitchen floor.

1.3.7 This was almost two years after the first COVID-19 national lockdown; all legal COVID restrictions were lifted in England on the 24th February 2022. It was reported by the police that there was no concern of third-party involvement in Lilian's death.

1.3.8 The coroner concluded that Lilian had been dead for a considerable period of time. Lilian's daughter shared footage of Lilian's home which she had visited after she died. The photos were of a small flat in a state of disarray, strewn with debris and clothing.

1.3.9 The Inquest for Lilian was held on 12th July 2022. The record of the inquest records the medical cause of death as:

- 1a Unascertained owing to advanced decomposition

Conclusion of the Coroner as to the death:

- Open conclusion

The case was referred to the Independent Office for Police Conduct (IOPC) who allocated it back to the Directorate of Professional Standards (DPS) for investigation. As a result of this investigation officers involved in the initial search of the premises were given "learning through reflection". Amanda was informed of this outcome by letter from the DPS.

1.4 Patient Safety Serious Incident Review

1.4.1 Following Lilian Modest (LM)'s death, ELFT led on a Level 2 comprehensive Patient Safety Serious Incident (SI) Review. The scope of the review was as follows (ELFT and LB Newham):

1.4.2 For the review to consider the care and treatment provided by ELFT (the Trust) to Ms LM from 01.01.2018 to 03.02.2020 when she was discharged from its service, with particular emphasis on the following:

a. The appropriateness of the decision for Ms LM's care to be managed on an Outpatient basis, rather than under the Care Programme Approach (CPA);
b. The appropriateness of the decision to discharge Ms LM from the care of the CMHT for Older Adults, taking account of the nature and duration of her mental illness and her relapse patterns;
c. The handling of Ms LM's discharge from the CMHT for Older Adults on 03.02.2020.

1.4.3 For the review to assess whether the Trust's decision in March 2022 not to instigate an SI review into Ms LM's care was appropriate.

1.4.4 For the review to consider LB Newham (LBN) Adult Social Care and Housing involvement with Ms LM from 01.01.2016 to the discovery of Ms LM deceased at her home on 07.02.2022, with particular emphasis on the following:

a. Adult Social Care's assessments with Ms LM and the subsequent care and support plans/ risk assessments and management plans
b. Adult Social Care's consideration of self-neglect and Safeguarding Adult duties
c. Adult Social Care's assessment of Ms LM's mental capacity related to receiving support with managing and maintaining nutrition, maintaining a habitable home environment, being able to make use of the home safely, develop and maintain family or other relationships
d. The application of Section 117 of The Mental Health Act 1983 (updated 2007)
e. Housing's interaction with Ms LM and other agencies in the lead up to Ms LM's body being discovered, and whether additional processes could be implemented in the future from the lessons learnt

1.4.5 The joint East London NHS Foundation Trust (ELFT) and London Borough of Newham (LBN) Level 2 Serious Incident report and action plan were completed on 12th September 2022. This SAR does not duplicate work that has already been undertaken, but draws on the learning regarding safeguarding where there are concerns regarding self-neglect, the importance of recording in relation to mental capacity and communication with Lilian, the lack of s117 aftercare reviews and finally, the importance of interaction and coordination between agencies to deliver care and support.

1.5 Involvement and perspectives of the family

1.5.1 Early discussions were undertaken with family, which consisted of Lilian's daughter and son, in line with statutory guidance, both to understand and agree how they wish to be involved and manage expectations of the scope of the Review with clarity and sensitivity[4]. These requirements are reinforced by the SCIE quality markers.[5] At the time of her death, Lilian had two adult children who were given the opportunity to contribute to the review. Lilian's daughter Amanda played an instrumental role and engaged fully from the outset, advocating for system changes to avoid a repetition of the tragic circumstances of her mother's death. Advocacy was offered to enable independent support with the SAR process.

1.5.2 The reviewer is grateful to Amanda who has illuminated the report with a picture of who Lilian was. Amanda was also able to provide context surrounding Lilian's relationship with and experience of professionals which had led to her mistrust and sometimes hostility towards statutory services.

1.5.3 Amanda recalled that Lilian was a devout Christian lady of strong faith who attended various churches throughout her lifetime. When her children were small and living with her she would take them to church with her or send them to Sunday school at Elim Pentecostal Church.

1.5.4 Amanda described her mother Lilian as a very generous lady who frequently sent drums of clothing, toiletries etc. to St Lucia for distribution to the poor in the local community. Upon her death when her daughter visited her home, there was an empty drum, where Lilian had purchased brand new items to send to St Lucia; sadly, she didn't live to send the drum home. Amanda took the drum to St Lucia and distributed the items on her mother's behalf.

1.5.5 Amanda spoke movingly of her perception that systemic racism was a feature of Lilian's care and support, resulting in neglect and the failure of services to meet her clear needs. This important theme is anchored in the terms of reference for the review and explored in the main body of the report.

1.5.6 The offer to participate in this SAR was not taken up by Lilian's son.

1.5.7 Amanda has been provided with a copy of the report and encouraged to suggest any changes to improve factual accuracy and to prepare a statement for inclusion in the report.

[4] Department of Health and Social Care (2020) Care and Support Statutory Guidance: Issued under the Care Act 2014. London: The Stationary Office (section 14.165-167).

[5] Social Care Institute for Excellence and Research in Practice for Adults (2018) Safeguarding Adult Review Quality Markers Checklist. London: SCIE. Quality Marker 11.

1.6 Terms of Reference and methodology

1.6.1 The SAB decided to use a Learning Together review model (Fish, Munro & Bairstow 2010). This approach supports learning and improvement in the work of safeguarding adults. The model uses systems thinking to develop an understanding of the practice in the individual case and to move towards an understanding of the broader systemic issues that can usefully be addressed. The model also seeks to promote a culture of learning between involved partners. Learning Together provides the analytic tools to support both rigour and transparency to the analysis of practice in the case and identification of systems learning. The model uses 'Research Questions' to identify and frame which areas of the safeguarding system the SAB has agreed will be explored through the case.

1.6.2 The review process involved two distinct groups of participants:

- **Practitioners Group** - Practitioners with direct case involvement and their line managers; who are central to sharing accounts of how the case unfolded in the learning event.
- **Safeguarding Adult Review Panel** - Senior managers with no case involvement who have a role in helping develop system learnings and supporting the case group's representatives if needed. They play an important role in bringing wider intelligence to ascertain which issues are specific to this case only, and which represent wider trends locally.

1.6.3 In addition, for this SAR a **Reference Group** was established, running parallel to the SAR Panel and hosted by Age UK East London (meeting at 655 Barking Road); it included members of the Retired Caribbean Nurses Association. The group provided potential insight to the lived experience of Lilian as a Black Caribbean woman. Further, the Reference Group enabled us to tap into their community expertise and functioned as a sounding board for the system and wider system learning. The reviewer is grateful to members of the Retired Caribbean Nurses Association who contributed richly to findings of this SAR, sharing their, sometimes harrowing, experiences of care and support in Newham.

1.6.4 **Time Period**

The period under review was from Lilian's discharge (from the Newham Centre for Mental Health where she had received inpatient care) in December 2017 until the date she was found deceased in her flat on 7th February 2022.

1.6.5 **Membership of the SAR Panel**

- Independent Reviewer
- Newham Safeguarding Adults Board Business Manager
- Newham Council from relevant range of services and functions
- Metropolitan Police Service
- Named GPs for Adult Safeguarding
- East London NHS Foundation Trust
- Newham Hospital: Barts Health NHS Trust
- The NSAB Business Support Officer provided administrative support.

1.6.6 **Participating Agencies**

The following agencies contributed to this Review:

- Newham Council
    - Adult Social Care

    - Housing
- Metropolitan Police Service
- East London NHS Foundation Trust
- Barts Health NHS Trust
- General Practice
- Voiceability Advocacy
- Age UK

Each participating agency provided an Individual Management Reports (IMRs) or summary of involvement report.

1.6.7 Research Questions

The first SAB chair agreed that the methodology and focus of this Review should complement and not duplicate work that has already been undertaken or is taking place.[6] Accordingly, the Board decided that the SAR would focus on exploring the following practice and system issues:

- Are there mechanisms in place that alert professionals to the fact their attempts to contact older people with a Mental Health diagnosis are not working and prompt them to change course of action? Are there any positive examples of this?
- How well do professionals gather a sense of who a person is? What adjustments do they need to make when someone has a particular collection of protected characteristics: gender, age, religion, disability and ethnicity.
- How well do professionals adapt their tactics when working with someone who is formidable, resistant and private?
- What systems are in place to share information when someone is assessed as lacking capacity for a decision which puts them at risk?
- What is the difference in thresholds and approaches for agencies in:
    a) Deciding to end their involvement with someone?
    b) Judging when to contact another agency to ask advice, share information or consider taking an approach which is multi agency?
- What can this review tell us about how confidently professionals from agencies involved with Lilian approach intersectionality[7] and safeguarding in their work with other older black women with disabilities?
- What confidence can we have that this group of older people who require a coordinated approach are receiving one?
- How confident can we be that the right feedback loop exists when one agency makes a referral to another agency?
- What risk assessment is undertaken when somebody who has previously been known to travel is uncontactable? Are there any mechanisms to pull

[6] Safeguarding Adult Review Quality Markers – March 2022, SCIE. Quality Marker 8

[7] Intersectionality considers power relations and the intersectionality or additive disadvantage faced by individuals when there is more than a single protected characteristic.

the intelligence across agencies? What effect does this have on people's determination to find the missing person?

1.7 Limitations of the review

1.7.1 In the case of this SAR, the commencement and progress of the review following Lilian's death has been delayed. There has been a significant delay between commissioning and completion of this report. Despite the full commitment from partners, the timeliness (agreeing dates for meetings) and quality of responses (delays with the submission and quality of IMRs) to this SAR proved problematic. This is undoubtedly resulting from competing and complex workloads that partners are facing.

1.7.2 Due to limitations in the breadth of available data, there are inevitably implications for the comprehensiveness of the analysis and findings[8].

1.7.3 There remains a gap in what we know about Lilian and how her past may have shaped her behaviour and responses to professionals prior to her death. Little has been learned about Lilian's involvement in the community or her friendships and wider networks.

1.7.4 Fran Pearson was the Newham SAB chair at the commencement of this review; sadly, she died on 24th July 2023, and unfortunately was not able to complete the SAR. Fran was a highly skilled, tenacious and reflective champion of safeguarding. After a period of delay a new Chair (Sola Afuape) took over to progress the production of the draft report to completion.

1.8 Reviewing expertise and independence

1.8.1 This Safeguarding Adults Review has been led by Angela Neblett who is an Organisational Development Consultant and coach with expertise in race and mental health. Angela spent 24 years working across health and social care in leadership roles commissioning mental health, substance misuse and a range of specialist services including forensic provision. Angela has no previous involvement with this case or prior connection to the Newham Safeguarding Adults Board, or partner agencies. Mentoring support was provided by Alison Ridley who is an accredited Lead Reviewer for Safeguarding Adults Reviews and serious incidents.

1.9 Statement from family

I, Amanda Marie Alexander, daughter of the late Lilian Marie Modest make this statement to be included in the SAR report as follows.

I understand the SAR report highlights the ineffectiveness of how multi-agency systems in Newham have not cohesively worked to support Black people with lifelong mental health diagnoses when their needs change in older age. This report is very comprehensive and I sincerely appreciate the author's time and thoroughness in bringing it to final completion.

It is clearly evident that given my mother's long history of paranoia schizophrenia dating back to 1977, (which I understand it's now known as schizoaffective disorder)

[8] SCIE Quality Marker 12 - Analysis

her suffering with osteoarthritis, hypertension and sickle cell, all coupled with mobility and stability issues (hence the use of a walking stick), that my mother's health and well-being was neglected by the respective agencies.

My mother's accommodation was excessively small and was not conducive to her health and mobility problems. She lived on the first floor in a block of flats which required her having to take a lift before accessing her home. There's no evidence to suggest that her home was adapted to take into consideration her health condition and the fact that she was housebound. I currently work as a part-time caregiver, all our clients are housebound, white and live in adapted bungalows to ensure they have a decent quality of life and have the ability to be mobilised whether it's via the use of a wheelchair or walker. Why wasn't my mother afforded such an opportunity? We too have clients who are difficult and there's ways to support their behaviour while ensuring they receive the best care, why wasn't my mother supported in such a way?

Even though my mother declined a care package she admitted she was struggling to cope. Her admission led to a view being formulated without an actual assessment having been undertaken, in my opinion this is neglect by social services. It's clearly evident that my mother did not have the mental capacity to make informed decisions about her care arrangements. Furthermore, Social Services knew my mother's mental health history and tendency to self-neglect and her history of repeated breakdowns with her carers, she was a lady who needed extra help concerning her care.

I'm baffling to still understand why the recommendations of the occupational therapist recommendations were ignored, "a residential accommodation is best suited to meet Ms LM's physical and complex mental health needs. Ms LM as already mentioned can no longer live on her own and does need residential alternative accommodation due to her limited mobility and complex mental health challenges". This was further emphasised by an ASC assessment that stated my mother was of poor mental and physical health, and she required a wheelchair. I'd like to know what led to my mother being disconnected from services and from wider networks of support? What other options were available or efforts made to help, safeguard my mother in light of these breakdown of relationships?

I'd welcome the opportunity to see the Individual Management Reports (IMRs) or summary of involvement report the agencies who participated in this review, Newham Council, Adult Social Care, Housing, Metropolitan Police, East London NHS Foundation Trust, St. Bartholomew's Hospital Health NHS Trust, General Practice, Voiceability Advocacy, Age UK, East London,

In conclusion, the circumstances surrounding my mother's death were extremely tragic to say the least. She was let down and neglected by the very same agencies who knew of her health history and failed to look after her. In addition, the police also failed in their approach of investigating my mother's disappearance, and upon their third visit to her tiny flat found her body on the floor of her cubicle size kitchen. None of these authorities nor the police cared, because at the end of the day my mother was just another black woman, who did not deserve to have any human rights.

There must never be a repeat by public authorities ignoring anyone in particular a black person's health. I do believe that systemic racism played a huge part in how and what type of treatment, care and support, my mother received, which resulted in the neglect and the failure to meet them. Why did it have to take the death of a black woman for authorities to implement practice changes? Surely those who enter these professions should have hearts of compassion in the first place?

Thank you for naming this report in honour of my beautiful mother Lilian Marie Modest.

A. Alexander
Amanda Marie Alexander, LLB - Hons & MATVJ
(Daughter of the late Lilian Marie Modest)
15th January 2024

2. Structure of the report

A brief chronology is provided of what happened in this case is included at appendix one. The case findings clarify the view of the reviewer about the care and support given to Lilian, including where practice was below or above expected standards and explaining why. This appraisal of practice section draws on the full range of relevant information assembled and the input of frontline staff to enable an evaluation and explanation of professional practice in the case. There is transparency about any gaps and limitations in practice and service delivery in this case.

A transition section draws out the ways in which features of this particular case are common to work that professionals' conduct with other individuals and therefore provides useful organisational and systemic learning to underpin improvement.

The systems findings that have emerged from the SAR are then explored. Each finding also lays out the evidence that indicates that these are not one-off issues. Evidence is provided to show how each finding could create risks to other adults in future cases.

2.1 Professional response following Lilian's discharge from inpatient care at Newham Centre for Mental Health (December 2017 – February 2018)

2.1.1 Following discharge from hospital in the period between December 2017 to September 2018, the CMHT for Older Adults team worked to maintain close contact and develop a trusting relationship with Lilian under the Care Programme Approach (CPA).

2.1.2 The Care Programme Approach (CPA) was introduced in 1990 to provide a framework for effective mental health care for people with severe mental health problems. The core elements include assessment, the formation of a care plan and appointment of a key worker (care coordinator) to keep in close touch with the service user and monitor/coordinate care.

2.1.3 Lilian had spent many years under the care of the Assertive Outreach team prior to her time with the Older Adults team as her needs were felt historically to require a more assertive approach.

2.1.4 Lilian was subject to s117 aftercare the Mental Health Act. This provision enables patients who have been detained under specific sections to receive free help and support post discharge from hospital. The 'aftercare' services are those which meet a need arising from or related to the service users mental health problem and which will reduce the risk of deterioration and/or readmission.

2.1.5 A Care Act assessment was undertaken by Newham ASC (Adult Social Care) on 12th December 2017, finding that Lilian was unable to prepare and cook her own meals, was unable to stand as a result of osteoarthritis and was unable to maintain her home environment and relationships with friends and other relationships as she was housebound. A package of care was proposed consisting of 6 hours per week.

2.1.6 Lilian declined the package, instead making private arrangements for a cleaner; this was part of an established pattern of Lilian's behaviour with care packages being declined or quickly breaking down. At the 7 day follow up, Lilian acknowledged that she was struggling to cope and would benefit from carer support; this was arranged privately by Lilian. By February 2018, Lilian had discontinued the carer arrangement and sought social worker input to provide carers from a different agency.

2.1.7 There was no evidence of a formal assessment of Lilian's capacity during the period covered by this SAR; professionals working with Lilian formed the view that she had the mental capacity to make informed decisions about her care arrangements.

2.1.8 All adults should be presumed to have capacity[9] in line with the Mental Capacity Act, however when assessing capacity in relation to self-neglect (a known risk for Lilian) practitioners must remember that capacity also involves the ability to implement those actions. In other words, practitioners should address both a person's decision and executive capacity.[10]

2.1.9 Practitioners were mindful of the need to balance their responsibilities to promote dignity and the principles of empowerment and proportionality[11]with their duty of care to respond to risk and reduce the potential for harm. These are complex and challenging areas of practice.

2.1.10 Lilian's mental health history and tendencies in terms of behaviours that link to self-neglect were known to the team. It was also known that Lilian had a history of repeated breakdowns in her carer relationships which presented a particular risk, particularly given other information that was available to the team at this time.

2.1.11 An occupational therapist concluded in a report on 27.02.17 that: "a residential accommodation is best suited to meet Ms LM's physical and complex mental health needs. Ms LM as already mentioned can no longer live on her own and does need residential alternative accommodation due to her limited mobility and complex mental health challenges".

[9] Mental Capacity Act 2005 – Principle 1

[10] 2011 Social Care Institute for Excellence paper *Self-neglect and adult safeguarding: findings from research* (Braye, S; Orr, D; and Preston-Shoot, M.)

[11] Department of Health, 2011 and subsequently embedded in the Care Act 2014: Six Principles of Safeguarding

2.1.12 A further ASC assessment which included mental capacity dated 16.05.17 further emphasised Lilian's poor mental health and physical health, stating that she required a wheelchair. Given the findings of the assessment, the package of care proposed of six hours per week (2.1.5 above) does not appear to correlate with Lilian's known needs at that time.

2.1.13 In February 2018, it appeared that Lilian had agreed that she did have problems with performance and she also agreed to address those with a care package which she would organise herself; subsequently the relationship broke down. Ordinarily in executive capacity an individual will have overestimated their ability to perform certain tasks.

2.1.14 In this case, Lilian overestimated her ability to have a relationship with the care worker. It is important to note in this context that Lilian was also disconnected from services and from wider networks of support. These multi-layered factors should have been more carefully considered by the team; it was a foreseeable risk that the carer relationship would break down as it fitted with a well-established pattern.

2.1.15 The Reviewer has not seen evidence that the team sufficiently explored options; this was not documented. The Older People's team is more collaborative with patients than may be experienced with the Assertive Outreach Team, wanting to understand the needs of an individual to arrive at more consensual decisions; this is important practice. Getting to know the patient is critical in this context. There is no documentation setting out the efforts to know and understand Lilian in this context.

2.1.16 Given Lilian's history, failing physical health and what professionals observed at points in the clinical notes to be a cluttered living environment, are all factors providing an opportunity for practitioners to actively work with her to encourage her to accept a package and risk assess. Hoarding disorder has been classified as a distinct mental illness since 2017.[12] The team knew at this time that Lilian had a history of hoarding when unwell. It is notable that whilst recording the cluttered living environment, the risks were not explored.

2.1.17 A formal section 75[13] agreement is not in place between the LB Newham and ELFT. Services separated in 2016 but teams are co-located. LB Newham social workers collocating with ELFT staff, were expected to fulfil their duties under the Care Act in terms of Assessment, Review and Support planning using the LB Newham's Care Act documentation.

2.2 Professional response to Lilian's planned trip to St Lucia (March 2018 – September 2018)

2.2.1 By April 2018 the relationship with the carer had broken down and Lilian refused access. In light of this, social care arranged for a Personal Assistant (PA) funded by the Local Authority via Direct Payments. The process was completed but Lilian subsequently declined direct payments. Following a CPA review; adult social care discharged Lilian on 22nd June 2018. No evidence has been provided of alternative

[12] Previously hoarding was considered a type of OCD. On 1st October 2017 the World Health Organisation added Hoarding Disorder as a new distinct category under OCD (Code: 42.3). DSM-5

[13] Section 75 of the National Health Service Act 2006 is used between local authorities and NHS bodies to make joint agreements that can include arrangements for pooling resources and delegating certain NHS and local authority health-related functions to the other partner/s

support being made available to Lilian at this time. Probing and robust intervention would have been expected. It is also a concern that the Reviewer received no evidence of an advanced care and support plan or risk assessment; this is a shortcoming particularly in light of the Occupational Therapy report on 27th February 2017 and the ASC assessment dated 16th May 2017.

2.2.2 By 17th May Lilian confirmed her travel intentions and asked for her injection to be titrated down so that no depot injection would be required when she planned to travel later in the year. Previously when Lilian was relapsing she travelled to St Lucia without informing the team.

2.2.3 Practitioners attending the learning event described how on this occasion Lilian was assertive and gave reasons why she wanted the medication to be reviewed. For example, depot will not be available in St Lucia and that being with family, in the sun and heat, would help her physical state and mental state. On this basis she reasoned that tablets would be better so that she could keep on taking them. It was successful on this occasion.

2.2.4 Practitioners spoke of how the team try to empower services users to say what they want and try to implement. She repeatedly gave the same rational when another consultant reviewed her. The review was carried out by the team and it was agreed that it was a positive risk. From 12th June the depot was progressively reduced and the team liaised with the Trust Pharmacist for a dose equivalent for Lilian once she was no longer on the depot.

2.2.5 On advice from the Pharmacy, the GP issued a six-month supply of Zuclopenthixol oral tablets at 75mg OD. Given the risks of relapse and Lilian's unwillingness to share details of her relatives, the Care Coordinator accessed Rio and was able to contact a friend, Mr A; he was a local friend who helped Lilian with shopping and held the contact details of her brother in case of emergency. This is good practice in terms of trying to reduce risk. However, it was done without Lilian's agreement, leading to the assumption that it was done in her best interests; this raises a question regarding the assertion of professionals that Lilian had capacity. At the learning event, practitioners argued that Lilian had capacity; acting without her consent in the manner set out is at odds with this assertion.

2.2.6 It is notable that Mr A did not, it seems, believe that Lilian would be traveling, advising the team that Lilian's ticket had been cancelled due to non-payment of the balance due for her ticket. Unannounced home visits were conducted in early September 2018 to confirm whether Lilian had travelled. Again, this response from professionals is good practice in relation to a response to perceived risk, but raises questions about whether they were at this point working in her best interests on the assumption that she lacked capacity.

2.2.7 The team listened to Lilian's wishes and worked to ensure that she was prepared for travel to St Lucia without depot medication. Working in partnership with Pharmacy, medication in tablet form was supplied to Lilian. The team supported a change of medication, listening to Lilian's wishes and working as a collaborative team towards a shared goal. The team also made efforts at this time to verify Lilian's travel arrangements with Lilian and others known to her.

2.2.8 There were persistent efforts to engage with Lilian and to ascertain her wishes in line with a person-centred approach. What is less clear from the records is whether there were attempts to engage with Lilian about her response to offers of support.

Concerned curiosity is a core component of best practice but the chronologies do not record her reasoning for declining care packages so her voice regarding her lived experience is silent.

2.2.9 Lilian was characteristically formidable, resistant and private. Yet during this phase of her care, Lilian began to open up to the team, talking about her past experiences of mental health services and of her mistrust. At this time, Lilian cited a specific example of African-Caribbean's being the victims of medical experiments[14].

2.2.10 In the infamous Tuskegee experiments, medical researchers wanted to track the full progression of syphilis. To achieve this, the team provided no care to African American participants, who suffered severe health problems including blindness, mental health problems and death. In response to Lilian, professionals appear to have had no knowledge of this experiment and lacked curiosity; they dismissed Lilian's perspective, assuming that she was delusional:

"28.08.2018 during a CPA Review it is noted that Lilian expressed paranoid beliefs about doctors saying that they tried to poison Afro-Caribbean people with medication and she lacks insight completely."

2.2.11 A further example:

"18th August Lilian was noticeably talkative throughout the hour of the home visit, sharing about her history, divorce from her ex-husband but mainly about how she felt mistreated or let down by services including the police and clinicians; it was difficult to decipher what was accurate/reality and if/what was not.

It is remarkable that none of these important issues were explored with Lilian. The team should have enabled full discussion with Lilian, hearing her voice and addressing her concerns – whether they were perceived by the team as real or not.

2.2.12 Lilian felt that she was being overmedicated and repeated this assertion with anger and resistance to her treatment. Professionals missed windows of opportunity to engage in a meaningful way, on Lilian's terms. The team had built a relationship with Lilian, but there were gaps. It was not known whether Lilian was involved in faith or professional networks. It is a striking feature that very little is known about Lilian's family, friends or ties within the community. Whilst Lilian was perceived as being especially guarded about them, it is also clear from the evidence that opportunities to begin to understand Lilian's connections were missed.

2.2.13 There was a lack of evidence of direct engagement with Lilian in her care and support within the wider context of her protected characteristics. The mental health issues of an individual need to be understood within the context of race, their family, cultural and/or community setting, alongside wider wellbeing outcomes.

2.2.14 To enable meaningful communication and relationship building with the individual, professionals must find time and courage to be curious and ask challenging

[14] La Fleur, J.D. (2018). Improvising Caribbean Medicine in the Age of Slavery. *New West Indian Guide / Nieuwe West-Indische Gids*, *92*(3-4), 285-291. https://doi.org/10.1163/22134360-09203003 Known as the Tuskegee experiments, between 1932 – 1972 Black men with latent syphilis were denied basic antibiotics so that the progression of the full disease could be tracked.

questions, particularly when it comes to sensitive issues relating to race and faith which were explicitly flagged by Lilian.

2.2.15 Professionals acknowledged that they found Lilian difficult to engage. Those attending the learning event focused on her sometimes-volatile behaviour towards practitioners. It was unclear from the limited noted information how much the causes of Lilian's anguish had been explored by the team. There was no evidence of the offer of psychological intervention.

2.2.16 There was also a broad assertion that the very presence of diverse professionals within a team meant that there could be no challenge/lack of engagement/understanding from professionals on race or other protected characteristics; this assertion is not supported by evidence. The presence of diverse staff within a team does not equate to a lack of structural, procedural or systemic racism.

2.2.17 Despite diversity in teams and policies across the system around equalities and inclusion, evidence suggests that persistent challenges remain and the outcomes for particular ethnic minority groups are worse. However, diversity in teams can be a helpful facilitator where there is psychological safety and curious conversations can be had. The Reviewer had an opportunity at the learning event to engage with practitioners; further work on psychological safety and curious conversations are required within the team. The assumptions that prevail are entrenched, historic and systemic – these must be openly discussed, acknowledged and challenged.

2.2.18 The NHS Race and Health Observatory, a health research body, build on evidence of the stark health inequalities faced by ethnic minorities using NHS services. The ground-breaking report analysed the evidence through the lens of racism and found disparities in the access, experience and outcomes of healthcare, rooted in experiences of structural, institutional and interpersonal racism.

2.2.19 In mental health, barriers to seeking help, rooted in a distrust of primary and mental health care providers, were identified. Evidence of persistent inequalities in compulsory admission to psychiatric wards was also found, particularly for Black groups. Evidence was also found of inequalities in access to psychological therapies[15].

2.2.20 Roberts et al (2020) found racial inequality in research following their review of 26,000 empirical articles published between 1974 and 2018. Across the past five decades, psychological publications that highlight race have been rare: in cognitive psychology fewer than 1% of publications highlighted race, 8% in developmental psychology, and 5% in social psychology[16].

2.2.21 Das-Munshi et al (2018) found that compared with White patients, Black patients were more likely to be prescribed depot antipsychotics and were less likely to be

[15] Kapadia, D., Zhang, J., Salway, S., Nazroo, J., Booth, A., Villarroel-Williams, N., Becares, L., & Esmail, A. (2022). *Ethnic Inequalities in Healthcare: A Rapid Review*. NHS Race & Health Observatory. https://www.nhsrho.org/wp-content/uploads/2022/02/RHO-Rapid-Review-Final-Report_v.7.pdf

[16] Roberts, S.O., Bareket-Shavit, C., Dollins, F.A., Goldie, P.D. and Mortenson, E., 2020. Racial inequality in psychological research: Trends of the past and recommendations for the future. *Perspectives on psychological science*, *15*(6), pp.1295-1309.

offered the range of evidence-based treatments for psychosis, including psychological interventions[17].

2.2.22 Sadly the evidence cited is borne out in Lilian's case and voiced through the messages from members of the SAR Reference Group. The overreliance on medication and the difficulty of communicating with professionals (2.4).

2.2.23 The Level 2 SI report led by ELFT enables a connection between health inequalities and Lilian's lived experience. According to the report, Lilian arrived in the UK in 1961 aged 15 from St Lucia and suffered longstanding and enduring mental health issues dating back to 1977 when she was 31 years old; this resulted in 25 hospital admissions over the years. There was a well-established pattern of non-compliance with medication, leading to severe self-neglect which then brought about a relapse in her mental condition and hospitalisation.

2.2.24 Lilian had been brought to hospital under police escort using Section 135, MHA powers on several occasions. Lilian would severely self-neglect, she hoarded and had been considered a fire risk to her neighbours in the block. There is literature examining the associated links between poverty, trauma, migration and hoarding – all pertinent to Lilian's lived experience, coupled with migration from St Lucia and her experience of arriving in the UK with its political and social landscape at that time.

2.2.25 Lilian lived in an extremely small cramped flat located on the first floor of a multi storey block in Newham. Narrative from the SI report is noteworthy, suggesting that whilst tolerant of services at times, Lilian did not accept that she was mentally unwell and was often hostile, paranoid, delusional and difficult to engage.

2.2.26 This narrative provides a lens of how services perceived Lilian, but clearly her life and experience of mental health services, sometimes following police intervention, her experience of not being heard or understood by the teams working with her and her difficult living circumstances are some of the multiple factors that will have impacted on Lilian's presentation.

2.3 Professional responses to the disappearance of Lilian (June 2019 – February 2022)

2.3.1 While in St Lucia, a doctor had reduced Lilian's new oral medication Zuclopenthixol 75mg daily to 30 mg. In June 2019 Lilian initiated contact with the CMHT, confirming that she had returned and would like to discuss her medication which had subsequently changed to Risperidone 4mg tablets BD, wishing to stay on the reduced dose. On 25th June 2019 Lilian independently contacted Voiceability to request advocacy at her future meeting with the CMHT.

2.3.2 Voiceability took Lilian's history at a home visit on 4th July 2019; Lilian set out the details of her previous hospital admission and explained that she was extremely unhappy with her treatment whilst in hospital and was seeking legal advice through a solicitor. In particular, Lilian flagged that police had come to her flat and knocked down her door and that she was given Clopixol injections that had caused her to gain weight. Lilian wanted to ensure that she would remain on her new mediation as prescribed in St Lucia.

2.3.3 On 15th July 2019 Lilian attended the outpatient clinic with her advocate and agreed that she would telephone 3 weeks in advance of the next outpatient appointment.

[17] Das-Munshi, J., Bhugra, D. and Crawford, M.J., 2018. Ethnic minority inequalities in access to treatments for schizophrenia and schizoaffective disorders: findings from a nationally representative cross-sectional study. *BMC medicine*, *16*, pp.1-10.

Voiceability employs multi skilled advocates who can really get to know the client, working alongside them. This is seen from the evidence of how the organisation worked with successfully with Lilian and is to be commended.

2.3.4 On 15th July the Consultant noted that Lilian presented with a stable mental state and had been prescribed different medication and at a lower dose. At this point in time, Lilian had been on the significantly reduced oral dosage since October 2018. On 16th July following the review, Lilian's case was discussed and a decision was made to manage her care on an outpatient basis; Lilian was therefore stepped down from care coordination at this point.

2.3.5 Several factors should have formed part of the review by the team. Lilian's history and risk, reduced medication, the change that will have been experienced on returning from St Lucia where Lilian was surrounded by family and friends, to her flat in Newham where she lived alone and was isolated and finally, that the team had not seen Lilian in her home since August 2018. There was a lack of risk assessment and the decision to step down was made too quickly.

2.3.6 Lilian agreed to be reviewed on 14th October 2019 (3 months' time) in the outpatient clinic but did not attend; subsequent appointments were offered on 21st October 2019, 6th January 2020 and 13th January 2020. The Consultant attempted telephone contact and wrote letters to Lilian on each of these dates. Lilian did not attend a further appointment on 3rd February 2020 or contact the CMHT; at this stage the Consultant wrote to Lilian, discharging her back to the care of her GP.

2.3.7 On the 24th February and 20th March 2020, the GP practice made 2 failed attempts to reach Lilian for her mental health review. On 16th April the practice called and again and were concerned when they could get no response from Lilian. The practice telephoned the CMHT twice, but the line was engaged and no further action was taken. It is of note that by April 2020 the country was in lockdown. The GP notes feature a history of multiple failed appointments and attempts to reach Lilian dating back several years, mainly by telephone/text (by receptionists) and letters.

2.3.8 The IMR completed by primary care acknowledged that there was not the level of GP care that would be expected for a woman of Lilian's age and significant physical health problems. There was little evidence of a joined-up approach across physical and mental health care. Since 2010 Lilian had a total of just 20 contacts with primary care – either face to face or by telephone. Given her age, declining physical health and complex mental health, this is extremely low.

2.3.9 The GP IMR response noted: "…Through her non-attendance due to her vulnerabilities – age, mental health diagnoses, housebound she was unable to access the appropriate healthcare. This was not recognised by primary care as the failed encounters were not passed onto clinicians." The lack of joint mental health reviews to discuss Lilian was also acknowledged as a factor. A policy where multiple failed encounters were flagged to GP's may have helped Lilian.

2.3.10 A GP review would have flagged that she hadn't been seen and this would have increased the level of concern and risk. This should have prompted an MDT approach to contacting the patient. In Newham there are frailty MDT's; surprisingly Lilian was not on this list.

2.3.11 Later on 28th April 2020, housing received a nuisance report regarding rubbish left on Lilian's balcony – the Property Management Officer (PMO) received a referral to

investigate and was unable to establish contact with Lilian. The PMO made further attempts on the 11th May and 2nd June to investigate the complaint and conduct a welfare check in response to COVID lockdown, recording that the telephone numbers on file were not working.

2.3.12 The PMO also attempted to locate alternative contact details or next of kin but was unsuccessful. A planned home visit was never made as the PMO left LBN at this time and the task was not included in the hand over to the newly appointed PMO.

2.3.13 July 2021 housing commenced possession action as the property was assumed to have been abandoned. At this time, a visitor for Lilian reported concerns with concierge; this was escalated to the concierge manager to arrange a police welfare visit. The identity of this visitor is unknown.

2.3.14 On the 16th July 2021 an alert was raised with the police as a missing person and the police contacted the CMHT on 17th July and 10th December 2021, seeking information regarding their last contact with Lilian. The police conducted a search of Lilian's home – Lilian was reported as not being there. A missing person investigation was opened; the bank confirmed that her account was "active".

2.3.15 The IMR from the police confirms that the reason her bank account was deemed "active" was that Lilian's pension income was automatically credited through BACS and all her bills (rent, utilities etc.) were paid in full and on time by Direct Debit. This information was, however, only partially correct; Lilian's rent had not been paid and an arrears was increasing. The IMR from LBN housing confirms that the Rent Officer sent three arrears letters to Lilian's address between 17th September and 30th November 2021 and made repeated attempts to contact Lilian by telephone.

2.3.16 On the 17th July 2021, the Head of Independent Living instructed the Independent Living Team to report Lilian as a missing person to police and asks housing benefits to suspend her claim. Action commenced to repossess the property, which was presumed abandoned and in December the rent officer served notice to quit.

2.3.17 Communication between the housing departments and professionals was disjointed. Information should have been shared with the Rent Team to suspend arrears action, due to concerns around the whereabouts of the Lilian; this would have prevented the notice to quit.

2.3.18 During Lilian's disappearance her daughter Amanda insisted on revisits by the police to her mother's flat. Finally, in early February 2022 a review of the police investigation was undertaken. Given the lack of progress or information coming forward it was decided to revisit all enquiries from day one.

2.3.19 On the 7th February 2022, MPS (Metropolitan Police Service) officers conducted a further systematic search of the premises and found the lifeless body of Lilian, which was partially concealed from view by a significant number of horded articles.

2.3.20 At this early stage, police had the impression that squatters had been in the premises. The MPS revised this position and provided an update at a panel meeting that there was no evidence or indication found to indicate that Lilian's home was occupied by squatters at any time.

2.3.21 There were failings by the police in this case; in particular the failure to listen to Amanda's concerns which were repeatedly raised and the inadequacy of the initial search.

2.4 Age UK East London - Retired Caribbean Nurses Association (the Reference Group)

The Reference Group was established to run parallel to the SAR Panel, providing potential insight to the lived experience of Lilian as a Black Caribbean woman. Further, the group enabled us to tap into their community expertise in Newham.

2.4.1 Two sessions were held with the Reference Group on 22nd April and 22nd June 2023. All six members shared their, sometimes harrowing, experiences of health and social care support in Newham. The key messages were:

a. There is a real challenge for lonely and isolated people in the borough. The state is not good at checking in
b. Many people are in inappropriate housing, with little prospect of change. The importance of people living in poor conditions needs to be focused on; 5,000 in Newham are without a decent roof over their heads and many of those are Afro Caribbean
c. Some services have not been fully reinstated since the pandemic
d. There are a range of services but very few people are getting it; there are so many thresholds, obstacles and bureaucracy
e. African Caribbean representatives are needed within services to provide an understanding to people delivering care and support
f. The medication is not helping people in the long run, yet it keeps on being offered to Black people; there is too much reliance on medication.
g. Professionals must put themselves in others shoes and act with compassion – there is no training that will address this; services lack compassion
h. Communication with professionals is often difficult – they don't understand or hear what we are saying
i. Care must be tailored and monitored
j. Record keeping must be improved
k. Staff must have continuous training

3. Case Specific Findings

3.1 Understanding and connection with protected characteristics and intersectionality

It is crucial that practitioners take steps to understand the history of the individual, such as their culture and past traumas as it can help build a better understanding of how to provide effective support, promoting engagement between resistant individuals and practitioners.

3.1.1 The panel suggested that for patients like Lilian with long histories under mental health services, there is likely to be an additional barrier to staff having the curious conversations in relation to individual experience and in having to overturn an accumulated implicit understanding. In other words, curiosity can wane when professionals have been working with individuals over a number of years, as they had done with Lilian.

3.1.2 Professionals need creativity and courage to work with protected characteristics. Professionals were unable to engage with Lilian regarding her protected characteristics, borne out in the evidence cited in this report. During the practitioner workshop the Reviewer noted repeated assertions that conversations about

protected characteristics are had within the team; beyond assertions, no evidence of this has been provided.

3.1.3 In the IMR, housing acknowledged that adapting or adjusting their approach to address protected characteristics can be difficult if a resident does not engage. However, adaptations when there is engagement can include the method of communication, pairing an officer who is most suited to the resident, providing interpreters and so on.

3.1.4 ASC confirmed that practitioners receive supervision and have the opportunity to attend reflective sessions to discuss their practice. They also receive support from peers and managers. It is important for social workers to be self-aware and constantly reflect in order to not allow their own personal views on a particular situation to affect their work with others. In this context, the issue of psychological safety must be reiterated; without it, professionals will not truly reflect on their practice and the voice of people like Lilian will not be heard.

3.1.5 ELFT reported through their IMR that the staff group is itself diverse. Consideration is given to this in allocating staff to work with service users; in most cases service users are able to see someone to identify with in the team. ELFT has a spiritual and cultural care team available as a resource and is enhancing the data on inequalities to help guide where improvements need to be made. Community mental health transformation work will refocus on engagement with other stakeholders who are involved with this area of community engagement with a clear inequalities perspective. Staff training on cultural competence is planned. This programme of work will be strengthened by the Patient, Carer Race Equality Framework.

3.1.6 Voiceability are thorough in their documentation and work hard to understand and connect with protected characteristics and intersectionality. This is borne out in Lilian's case. Credit must also be shared with the partners across Newham who are commissioning this vital independent service.

3.2 Supporting patient wishes

The team were able to fully engage and listen to Lilian's expressed wishes to travel to St Lucia and have a change of medication to support this. The team were courageous and creative in this aspect of their work and is to be commended.

3.3 Curiosity

It was too readily assumed that Lilian's responses were related to her mental illness and therefore delusional without adequate examination or curiosity. This increased the chances that opportunities to arrive at shared understanding and a genuine building of trust were missed.

3.4 Decision to discharge

The ELFT led Level 2 comprehensive Patient Safety SI Review (see section 1.4.1 above) was critical of both the decision and process of Lilian's discharge from their care. The Reviewer agrees with this conclusion.

3.4.1 ELFT is in the process of updating the Admission, Transfer and Discharge Policy. In undertaking this work, there has been a realisation that policies focused on inpatient scenarios are not readily reframed for community work, where there are different service configurations. The learning from Lilian's case has stimulated work that ELFT has started; momentum must be maintained to complete the policy updates.

3.4.2 Encouragingly, the Newham MHCOP team has updated its processes. All discharge decisions from the team now flow through multidisciplinary meetings for agreement. Notably, in circumstances where there has been no contact from a service user, there is a clear expectation that a face to face visit will happen before any discharge is considered. No assumptions are made in relation to the involvement of other agencies. The team pays additional attention where there might be communication barriers due to language or disability.

3.4.3 ELFT learning events have highlighted the importance of avoiding assumptions about service users who do not attend appointments across all community mental health teams, based on learning from this incident.

3.5 Safeguarding and neglect

The Level 2 SI report addressed the issue of safeguarded and found that a review of Lilian's care records shows that there were no safeguarding concerns raised, despite concerns being recorded on her care notes. Lilian's home environment is consistently noted to be at varying degrees of concern relating to sanitary conditions. There are no references to practitioners utilising the self-neglect and hoarding policy or the safeguarding procedures. There was also no evidence of working with housing colleagues to support and address the known concerns – this is surprising and must be addressed by the teams.

3.6 Mechanisms that alert professionals

Through the IMRs, agencies considered whether there are mechanisms in place that alert professionals to the fact their attempts to contact older people with a Mental Health diagnosis are not working and prompt them to change course of action.

3.6.1 The police use the MERLIN system into the adult Multi-Agency Safeguarding Hub (MASH) to escalate concerns about adults identified as vulnerable.

3.6.2 Housing liaise with ASC to confirm if they are known to service, supporting good outcomes in the past. This was ineffective in Lilian's case as she had been discharged.

3.6.3 ASC use a range of interventions including texts, telephone calls and unannounced visits to ensure residents are safe and well, sharing positive practice examples where the team showed perseverance in the face of hostility, shifting from the usual course of action to ensure the safety of residents. [18] Through reciprocal arrangements, ASC MH staff have access to RIO, which is the patient records system for Health, while health staff have access to Azeus (LBN social care system).

3.6.4 ELFT use multidisciplinary review meetings and team huddles as the review and decision-making space. Staff are allocated to perform the range of interventions including unannounced visits and will work closely with family where this is possible. Discussion takes place after non-attendance at regular clinic appointments or failure to engage successfully. This did not happen in Lilian's case.

[18] For example, a safeguarding concern was received regarding an older Nigerian woman, indicating that she was being financially abused by a family member. Numerous efforts to contact the resident were unsuccessful, but were followed by a barrage of complaints, Members Enquiries, threats and reporting staff to Social Work England by family members. Yet still there had been no communication from the resident. Following liaison with other partners and an MDT meeting, support from the police was sought. Police conducted a visit and ensured that the resident was safe and well.

3.7 Adapting tactics when professionals are working with someone who is formidable, resistant and private

3.7.1 In the IMR, housing described using a variety of approaches to encourage engagement, including exploring different methods of communication or using a trusted intermediary such as concierge staff. Ultimately the formal methods include eviction, a coercive tactic.

3.7.2 ASC practitioners adapt their approach and behaviour in order to engage the person. For example, they will approach family or friends to help them with gaining access to the individual; they will ask for help from a colleague who has similar ethnic origin as the resident or speaks the same language; or liaise with the agency/professional who has an established relationship with the resident. Ethnic or cultural matching is common practice in social work. There us ongoing discourse in the literature regarding effectiveness and outcomes. Staff will also follow the Difficult or Non-engagers guidance; information was not provided on the content of the guidance, whether it was used in Lilian's case or the impact. The guidance should be reviewed in light of this case to address these questions.

3.7.3 ELFT's MHCOP prefer to work to a negotiated individualised approach that considers the person's preferences. This was seen in Lilian's case where the team supported her to travel to St Lucia and acceded to her wish to change from depot medication. Through this is example it is clear that the team will adapt their approach to engage with formidable, resistant and private individuals. More assertive or coercive options are used when needed, for example, the Mental Capacity Act, or imposition of a Community Treatment Order (CTO) through provisions of the Mental Health Act.

3.8 Systems in place to share information when someone is lacking capacity for a decision which puts them at risk

3.8.1 Housing ask ASC to verify any concerns through the Council's Northgate system.

3.8.2 ASC follow provisions of the Mental Capacity Act and make decisions in the best interests of a client who lacks capacity. A multidisciplinary Best Interest Meeting is convened; minutes are captured on Azeus – the resident electronic system. ASC is the lead agency where a risk is identified relating to capacity and safeguarding.

3.8.3 GPs can refer into ASC and safeguarding for advice, in addition to a GP Adult Safeguarding Policy.

3.8.4 Voiceability have a risk assessment on each client and a flag system.

3.8.5 When Lilian was under the care of ELFT, adult social care input was co-located in the team. Whilst there are systems in place to allow information sharing between the agencies, the lack of integration will not make this easier.

3.8.6 The IMR responses regarding the systems in place that enable the sharing of information when someone is lacking capacity for a decision which puts them at risk highlights a set of arrangements that rely on smooth and prompt communication between agencies at a time when service pressures are increasing and resources, including time, are stretched.

3.9 Thresholds and co-ordination in different agencies

3.9.1 ASC operate an all-age model so there is no specific team for Older Adults. The operating model is designed on an asset-based view of communities and close partnership working across agencies.

3.9.2 Housing has a dedicated Independent Living Team in place to provide support and assistance to council tenants. It is unclear what role this team played in Lilian's care.

3.9.3 Where ELFT don't have all the information needed and someone is not engaging; the approach is initially via MDT. The threshold for deciding to end involvement with someone is determined on an individual basis dependent on the level of historical risk and the information available.

3.9.4 ELFT acknowledged in the IMR submitted that a home visit should have been done in Lilian's case as this would have strengthened the information available and was appropriate given the historical risk. In judging when to contact another agency to ask for advice, share information or consider taking an approach which is multi agency, the level of need and certainty about the information held at the time within the team should determine the degree to which they work in collaboration.

4. System Findings and What Has Changed

The learning from this SAR opens a window to wider learning that can be shared and generalised.

4.1 Reaping the benefits of diverse teams

The benefits of a diverse team are well documented; the experience of the SAR Reviewer working with practitioners is that the benefits of a diverse team are not being realised. Everyone in the team must feel psychologically safe, valued and respected as that will impact how they share and receive information – and that flow of information, the open sharing and challenge, will impact patient outcomes and service delivery. Conversations about protected characteristics must be surfaced and supported; we must do so intentionally. They must be part of supervision, team meetings, service away days and so on. In other words, this cannot be achieved through episodic training but must be embedded in practice and documented, driven by persistent and consistent role modelling by leaders. Partners must be intentional about empowering front line staff so that professionals confidently approach intersectionality and safeguarding in their work. Newham SAB must drive a programme of work to embed this in practice.

4.2 Recording

Recording is important; what is recorded is seen and held by the MDT. Where conversations are happening with patients and in the MDTs, they must be recorded. This will lift issues to the surface, enhance patient voice, help to root out the system challenges and support system learning making safeguarding personal provides the opportunity to show evidence of the Care Act 2014 principles being met.

4.3 Self neglect policy

A multi-agency self-neglect policy should be developed, setting out how to manage and escalate risk. The policy should identify who leads and what happens if/when multi agency input ceases. Whilst agencies have their own respective policies, a multi-agency policy would, in cases like Lilian's, prevent risks being overlooked as cases are often complex and falling between agencies.

4.3.1 LBN does not have a “multi agency” self-neglect policy - this should be a multi-agency partnership document. The development of a multi-agency self-neglect policy is a key area of focus of the existing SAB self-neglect sub group as multi agency development in this area is seen as a key priority – momentum is needed to develop the policy.

4.3.2 In 2022 LBN produced the Self-Neglect and Hoarding Procedures for ASC social care workers and the Adult Social Care Operations Hoarding Practice Toolkit. This document updated the multi-agency self-neglect SAB policy dated 2015 which required updating. The operational ASC single agency tools and procedures were designed to support frontline workers navigate the complexity of working with people who self-neglect and hoard. It includes guidance and practice considerations around assessment, risk assessment, the Mental Capacity Act, multi-agency working and escalation for people who are hard to engage.

4.3.3 A multi-agency self-neglect policy will reflect current guidance, practice and service configuration. Delivery should be overseen by the SAB.

4.4 Relevant actions following the Level 2 SI Report

The Level 2 SI report included the following key actions to support system learning following Lilian’s death; these dovetail with the findings of this review:

4.4.1 For a lessons learnt seminar be held, where Lilian’s case is shared, and on the topic of “Safe Management of Patients who we struggle to engage in care”.

4.4.2 All clinicians in the Older Adults CMHT to receive refresher training on the Trust’s CPA policy on their next away day, when this case will also be reviewed, to ensure that their CPA note taking and discharge planning reflects the Trust’s policy requirements**.**

4.4.3 For a joint shared learning session to take place between LB Newham, including Housing, ASC and other relevant services and staff from ELFT’s CMHT for Older People team, led by the reviewers, to consider lessons learnt and promote the need for effective inter-agency working going forward

4.4.4 LBN and ELFT to review with other agencies the use of existing systems and processes to ensure that we identify and respond proactively to those service users who are both not successfully engaged with support services and are thereby left at risk.

4.4.5 The completion date for the actions was 31st December 2022. The Reviewer has received no evidence of completion and stakeholders have not referenced them during the course of this review. Shared responsibility can lead to inaction. The SAB is asked to ensure robust oversight to ensure that lessons are learned and agreed action plans are implemented in a timely manner.

4.5 Practice changes – Metropolitan Police Service

Following this case, the police Missing Persons Unit (a specialist unit) now undertake a systematic search of premises from which a lone adult has been reported missing, regardless of whether another police unit has signed off on it being unoccupied. A full search record is made and body worn camera is utilised.

4.6 Practice changes – GP

Administrative staff within the surgery are now aware of the vulnerable patients on a practice list (through the establishment of a register) and will escalate to the GP if contact is not made. There is a staff team to oversee patients on the complex cases list. The CQC already advise that there must be an adult vulnerable patient list; in this case that information had not been shared with the administrative staff who manage the everyday interface with patients.

4.6.1 The Reviewer recommends that all GP practices should ensure that administrative staff are aware of the vulnerable patients on the practice list and understand the process for escalation to the GP.

4.7 Practice changes – LBN

LBN has introduced two mentoring schemes. A Developing Diverse Leaders Programme is aimed at addressing disproportionality at senior management levels. This has been developed as part of the Council's approach to tackling racism, inequality and disproportionality (TRID).

4.7.1 LBN has also launched a reciprocal mentoring scheme – an opportunity for individuals from across the Council from minority ethnic backgrounds to work with senior colleagues in a partnership. The aim of the programme is to give staff in leadership roles greater insight into the lived experience and development needs of minority ethnic colleagues, whilst offering a mutually beneficial mentoring partnership. Participants will be equal partners, each taking on the role of both mentor and mentee. They will have an opportunity to develop their skills, knowledge and networks through the mentorship of their partner.

4.7.2 Work is underway around hoarding and how service users are discharged from services, with particular emphasis on those people who may be seen as hard to engage. This work is being explored as part of the NSAB self-neglect sub group.

4.8 Practice changes – ELFT

A service user led project has commenced at ELFT engaging more directly with communities including voluntary and community sector organisations. The “Let’s Talk Report” was produced by a service user focus group.

4.8.1 One recommendation highlighted the need for culturally competent staff in order to encourage exactly the cultural curiosity highlighted in this SAR as lacking in some interactions with Lilian. This training was commissioned in the Newham directorate and was delivered for a first cohort in 2023.

4.8.2 The next steps are being reviewed in the directorate Inequalities Group, which continues the focus on the Let’s Talk themes. The imminent availability of the Patient Carer Race Equality Framework (PCREF) linked cultural competence training will be another helpful resource.

4.9 Decision to discharge

ELFT has proposed changes to processes, which are intended to raise the bar in terms of checks completed for someone with Lilian’s history before a decision to discharge is made.

5. Issues for national attention (SAB Chairs group)

i. When a person goes missing, banks will inform relevant police forces that an account is either active or inactive. The terminology ‘active’ can be misleading when related to missing people, especially given that many transactions are conducted automatically in the modern era. In Lilian’s case, the active label led to the wrong assumptions being made. The recommendation is that the issue is addressed at national level. SAB Chairs work with agencies to influence change in the policy and/procedures of the banking sector. The London ADASS hosts a group of all the London Chairs, feeding into a national group which will be well placed to champion this much needed change. This recommendation is based on the thoughts of the former SAB Chair, Fran Pearson.

ii. Research is needed into self-neglect in relation to individuals from Black, Asian and Ethnically Diverse Communities, in particular where there are care and support needs and how these are responded to. Published literature is scarce in this area and will provide much needed resource for practitioners.

6. Appendix 1 Historical context and chronology

Lilian had been an inpatient dated 25.11.16 - 01.07.17 – a readmission occurred approximately 8 weeks later when Lilian was again detained under s3 of the Mental Health Act and was an inpatient from 30.08.17 - 13.12.17; at this time her care was transferred from adult to older adults mental health services. Care management was provided by the Community Mental Health Team (CMHT) for Older Adults under the Care Programme Approach (CPA). Lilian was also subject to s117 aftercare.

Date	Event
December 2017 – February 2018	The Older Adults team maintained close contact with Lilian; depot medication was administered fortnightly. Lilian was subject to s117 aftercare. A Care Act assessment was undertaken by Adult Social Care (ASC) on 12th December, finding that Lilian was unable to prepare and cook her own meals, was unable to stand as a result of osteoarthritis and was unable to maintain home environment and relationships with friends and other relationships as she was housebound. A package of care was proposed. A package of care was proposed consisting of 6 hours per week, which Lilian declined, making her own (privately funded) arrangements for a cleaner. Lilian contemplated travel to St Lucia and first mentioned it during a home visit on 21st February.
May - September 2018	On 17th May 2018 Lilian confirmed her travel intentions and asked for her injection to be titrated down so that no depot would be required when she planned to travel later in the year. From 12th June the depot was progressively reduced and the team liaised with the Trust Pharmacist regarding a dose equivalent for Lilian was no longer on the depot. On 22nd June 2018, involvement with Social Services ended in response to a decision by Lilian to decline Direct Payments and a commissioned service for carers. On advice from the Pharmacy, the GP issued a six-month supply of Zuclopenthixol oral tablets at 75mg OD. In September 2018 Lilian travelled to St Lucia. On 9th October Lilian telephoned confirming that she was in St Lucia and that further medical input in St Lucia had resulted in a reduction of her oral medication to 30mg.
June 2019 – February 2020	Lilian returned to the UK on 17th June 2019 and on 20th June 2019, initiated contact with the CMHT and arranged an outpatients appointment. Lilian was last seen in the Outpatient Clinic on 15th July 2019, accompanied by an advocate from Voiceability. The Consultant noted that Lilian presented with a stable mental state and had been prescribed different medication and at a lower dose. Lilian did not attend any further appointments; the team attempted contact by letter and telephone but received no response. On 20th February 2020 the Outpatient Clinic sent a discharge letter to Lilian and her GP after she had failed to attend outpatient follow ups.

April 2020	On 28th April 2020, housing received a nuisance report regarding rubbish left on Lilian's balcony – the Property Management Officer (PMO) was unable to establish contact with Lilian.
July 2021	On 13th July 2021 a visitor for Lilian reported concerns with concierge; this was escalated to the concierge manager to arrange a police welfare visit. Lilian's daughter was concerned; an alert was raised with police as a missing person and the police contacted the CMHT. On 17th July 2021, the police conducted a search of Lilian's home – Lilian was not found. A missing person investigation was opened; the bank confirmed that her account was "active". Some bills were being paid in full and by direct debit and the pension income was automatically credited by BACS, hence the account was "active". A request was made to suspend housing benefit. Following notification from the Concierge Manager that Lilian had not been seen at her home for approximately 3 months, the Property Management Team Manager commenced action to repossess the property, which was presumed abandoned. In August 2021 police returned to Lilian's home to seize correspondence or paperwork that might support their enquiries.
December 2021	On 3rd December 2021, the rent officer served a Notice to Quit.
7th February 2022	The lack of progress led to a review of the investigation by police. On 7th February 2022, police entered Lilian's home for the third time and on this occasion, conducted a systematic search. Lilian was found deceased in the kitchen of her small flat. The condition of Lilian's flat was cluttered by hording and dirty, contributing to the initial inadequate search.