

**Safeguarding Adults Review**

**Tower Hamlets Safeguarding Adults Board**

**Title**: Mr Z

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Making reasonable adjustments for people with learning disabilities in the management of constipation. Public Health England August 2016

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Acknowledgements:

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The Head of Safeguarding Adults, Bart’s Health NHS Trust The Safeguarding Lead for the care provider

# Summary

* 1. This is a Safeguarding Adults Review (SAR) commissioned by the London Borough of Tower Hamlets Safeguarding Adults Board. The Care Act 2014[[1]](#footnote-1) sets out a clear legal framework for how local authorities and other parts of the system should protect adults at risk of abuse or neglect.
  2. When someone with care and support needs dies as a result of neglect or abuse, or it is suspected and there is a concern that the local authority or its partners could have done more to protect them, the Safeguarding Adults Board can commission a review to identify learning.
  3. This review primarily focuses on the care and support Mr Z received for the 10 months prior to his death (July 2015 to April 2016) but does include relevant information from before that time, to assist in giving a wider context to the events.
  4. Mr Z was described by a long-term support worker as a quiet man who often seemed nervous and didn’t like to mix. Other staff where he lived had a different view, that he was more out-going, able to be involved in projects and group activities. Professional staff characterised him as lonely. However, in the past he had been married and had a son. He looked forward to the visits his son made to him. Mr Z’s sister describes his son as having a learning disability.
  5. Mr Z had a learning disability, a history of being depressed and could get frustrated at times. He also had epilepsy and a diagnosis of paranoid psychosis.
  6. While there was little evidence of assessments of capacity, it was apparent from case file recording and the interactions of staff that Mr Z was deemed to have capacity.
  7. Mr Z had a number of physical health needs. His care plan noted an ‘eating disorder’ and he was often incontinent of urine and faeces. From time to time this was investigated, or plans were made to investigate it.
  8. Mr Z was very anxious about visiting doctors and hospitals, some care staff even said he “hated” doing so, although he did attend his GP from time to time and was willing to have x-rays. Staff where he lived, and who supported him, knew they had to convince him of the need to visit a doctor or seek medical help.
  9. Mr Z lived in sheltered accommodation and received care and support from two other providers which the London Borough of Tower Hamlets (LBTH) funded. Mr Z received daily support including help with: personal care,

cooking, cleaning, shopping, and also to monitor his health and wellbeing and medication. He also attended a day centre twice a week.

* 1. Mr Z died in April 2016 at home. The post mortem report indicated that the cause of death was peritonitis, which was due to bowel ischemia, which related to faecal loading ischemia. The secondary cause was hypertension and hypertensive disease.
  2. There was no one safeguarding incident that led to Mr Z’s death. The Safeguarding Adults Review (SAR) report evidences a lack of curiosity and focussed intervention over a number of years to:
     + understand Mr Z’s eating difficulties and put a treatment plan in place;
     + understand Mr Z’s incontinence and put a treatment plan in place;
     + assess Mr Z’s capacity to make decisions and to plan interventions accordingly; and
     + recognise that what were seen as his choices should have been seen in the wider context of self-neglect.
  3. The report makes recommendations for partners on:
     + health and social care needs being reviewed;
     + record keeping and information sharing;
     + assessments and reviews of capacity;
     + training around the Mental Capacity Act 2005;
     + advocacy for people with a learning disability in supported or residential care setting;
     + advice and information around constipation;
     + learning events on self-neglect; and
     + ensuring effective communication with emergency services.
  4. While there is learning around person centred support; professional curiosity and contact with the 999 London Ambulance Service the key areas for learning from this report are around:
     + constipation and healthy eating; and
     + capacity.
  5. Constipation can kill people. Constipation is more of an issue for people with a learning disability than the general population. Constipation can be treated.

# Background

* 1. Mr Z was a 59-year-old man. He had a number of physical health and mental health conditions and was supported by his GP, district nurse, social workers and consultant psychiatrist and other professionals from the Tower Hamlets community learning disability service. His day-to-day support was jointly

provided by the on-site care provider and also from a local domiciliary care agency.

* 1. Mr Z lived in Tower Hamlets, and moved in to sheltered accommodation in August 2012 shortly after the unit opened. It is a modern building made up of self-contained single flats and double flats.
  2. The London Borough of Tower Hamlets commissioned this housing service. When the service was taken over by a different provider from the previous provider; a number of staff transferred to the new provider allowing a reasonable degree of continuity of care. Mr Z also received additional support from a local care agency.
  3. Mr Z received support from Bart’s Health NHS Trust (Bart’s Health). This NHS Trust provided a significant range of inpatient and community services in Central and East London. Bart’s Health provided community learning disability services to people in Tower Hamlets and Mr Z received care from this service.
  4. There was a GP Enhanced Service to offer an annual Health Check for adults with Learning Disabilities. Mr Z was offered appointments for his annual health check at his GP surgery but he did not always attend.
  5. Sometimes Mr Z’s behaviour was seen as ritualistic and he became frustrated when his routine had to change. He often didn’t seem to be aware of the dangers of everyday life, for example while using a hot iron or cooking a meal. Physically he was able to walk and was able to travel independently.
  6. Mr Z died in April 2016 at home. The post mortem report indicated that the cause of death was peritonitis, which was due to bowel ischemia, which related to faecal loading ischemia. The secondary cause was hypertension and hypertensive disease.
  7. At the time of Mr Z’s death he received support from an external provider and another on site. The external support was mostly around escorting and going to the bank and in a 2014 review was noted as seven hours per week. In the Integrated Commissioning IMR this support is described as:
     + Personal Care x 1 hour
     + Escort x 2.5 hours
     + Shopping 2.5 hours per week
  8. However the primary personal support provided to Mr Z was 16.25 hours per week from the other provider to support with personal care, cleaning, laundry, managing tenancy and bill payment. From the Provider log sheets this consisted of:
     + 45 minutes each morning for personal care, help with breakfast and flat tidying;
     + 15 minutes at lunch time to help with lunch and change of continence pad;
     + 15 minutes in the early afternoon to change continence pads;
     + 15 minutes (30 minutes on a Thursday) each day to support him making supper;
     + 15 minutes in the early evening (19.00-19.15) to change continence pads and help to get into night clothes;
     + Once a week on a Monday an hour for a ‘deep clean’ of the flat and laundry;
     + Once a week on a Thursday 45 minutes to help with correspondence, chat and play board games; and
     + Medication administration during each day.
  9. Mr Z had also attended a day centre two times a week.
  10. The care management record was incomplete and it was difficult to get a complete picture of the level of care and support Mr Z received during the time he was in his sheltered accommodation.

# Purpose and Terms of Reference

* 1. The purpose of a Safeguarding Adults Review (SAR) is neither to investigate nor to apportion blame. It is only relevant when professionals can learn lessons and adjust practice in the light of lessons learnt. It therefore requires outcomes that:
     + Establish what lessons can be learnt from the particular circumstances of a case in which professionals and agencies work together to safeguard adults;
     + Identify what those lessons are, how they should be acted upon and what is expected to change as a result;
     + Review the effectiveness of procedures, both of individual organisations and multi-agency arrangements;
     + Improve practice by acting on the findings (developing best practice across organisations);
     + Improve inter-agency working to better safeguard adults; and
     + Make a difference for adults at risk of abuse and neglect

## The Terms of Reference of this Safeguarding Adult review included:

* + 1. Areas for consideration:

The 6 Principles of Safeguarding:

* + - * **Empowerment** - People being supported and encouraged to make their own decisions and to have informed consent;
      * **Prevention** - It is better to take action before harm occurs;
      * **Proportionality** - The least intrusive response appropriate to the risk presented;
      * **Protection** - Support and representation for those in greatest need;
      * **Partnership** - Local solutions through services working with their communities. Communities have a part to play in preventing, detecting and reporting neglect and abuse; and
      * **Accountability** - Accountability and transparency in safeguarding practice.

And:

* + - * The care arrangements in place for the individual;
      * If any of the care or support contributed in any way to the individual’s death or their significant harm;
      * If all appropriate practices and professional standards were followed by staff assigned to the individual’s care;
      * If there was sufficient co-ordination amongst all agencies involved;
      * Any learning from this situation, and to make recommendations to improve future working practices;
      * How the agency held Making Safeguarding Personal at the centre of the services provided to SD; and
      * How and when MCA and DoLS were applied and how this was documented.
    1. And specifically:
       - Consider if there were missed opportunities to prevent the death of Mr Z by agencies involved in the days before his death;
       - To consider whether the basis of judgments made by those involved such as GP, LAS and A&E were within guidelines;
       - To consider issues of training and competence on assessing people with a learning disability;
       - To particularly consider the understanding of ‘consent’ within the Mental Capacity Act and consideration of use of advocates;
       - Check to see if guidance followed a Health Action Plan, if Mr Z had an Individual Health Action Plan, Communication plan and Hospital Passport;
       - To consider if any agencies could have done anything differently to identify Mr Z’s health need earlier;
       - To consider whether there was a multi-agency issue on sharing information;
       - To consider how agencies considered ways of communication with a person with Learning Disability and good practice guidelines at the time;
       - To consider if there were any commissioning and contact monitoring issues for health and social care;
       - To provide recommendations for learning and development to support people with learning disabilities; and
       - To consider any learning for The Learning Disability Mortality Review (LeDeR) Programme.

## The Purpose (outcome)

* + 1. To reduce premature mortality and health inequalities for people with learning disabilities and to develop learning for: commissioners; providers; health and social care staff. And to reduce premature mortality by improving access to health services, education and training of staff, and by making necessary reasonable adjustments for people with a learning disability and/or autism.

(NHS Operational Planning guidance 2017/18).

* + 1. The author of this report had a useful and detailed conversation with Mr Z’s sister after she received a copy of the final draft report. A number of changes and additions were made to the report following this conversation. However it should be noted that Mr Z’s sister would have liked to have been involved earlier in the process.

# The review process

* 1. The methodology applied for this SAR combined formal individual management reports and a chronology from each agency with discussion at multi-agency panel meetings.
  2. The main focus of this review was on the 10 months preceding Mr Z’s death. However where relevant, references are made to information prior to July 2015.
  3. The Independent Author and Chair met with agency authors at the beginning of the review to discuss the terms of reference.
  4. The reports were reviewed and discussed in detail at meetings between the panel and authors.
  5. The Independent Author and Chair were supported in the review by a panel. The panel members were from the NSAB partner agencies and brought a further level of expertise and scrutiny of the individual agencies’ reports. The panel membership included:
     + SAR Panel Chair
     + Independent Overview Author
     + Joint Safeguarding Adults Strategy and Governance Manager (Interim), LBTH
     + Head of Safeguarding Adults, Bart’s Health NHS Trust
     + Safeguarding Lead, Care provider
     + Quality, Governance and Assurance Manager, London Ambulance Service
     + Delivery, Transformation and Independence Service Manager, LBTH
     + Service Manager, Community Learning Disability Service
     + Team Manager, Community Learning Disability Service
     + Service Director, Care provider
     + Extra Care Manager
     + Registered Area Manager, Care provider
     + GP
     + Safeguarding Adults Board Coordinator, LBTH
  6. Organisations that had significant involvement with Mr Z prior to his death completed a chronology of events outlining their involvement. These were collated into an integrated chronology.
  7. Internal management reviews (IMRs) were requested from all of the organisations that had significant involvement with Mr Z and were received from:
     + The care provider
     + Bart’s Health NHS Trust
     + GP Practice
     + The London Ambulance Service
     + LBTH Integrated Commissioning
     + LBTH Community Learning Disability Service
  8. Further reports were received from the current Community Learning Disability Service and the LBTH commissioning service.
  9. The panel met on four occasions in 2017 to consider the IMR reports. The IMR authors presented the reports to the panel, answering questions and contributing to discussions.

# Who was Mr Z – a description

* 1. Describing himself (with help from staff) in his support plan in May 2013 Mr Z said:
     1. ‘I am a 56 year old man with Learning Disabilities of Asian origin. I have a history of depression and can get very frustrated at times; I also have a diagnosis of paranoid psychosis. When I am on my own I hear voices and sometimes see ghost at night, these experiences can make me upset and angry at times. I have a very ritualistic pattern of behaviour and change can cause me extreme anxiety and agitation.’
     2. ‘I have many health issues which are longstanding: high blood pressure, epilepsy, abdominal discomfort, constipation and haemorrhoids. My GP has informed me that my cholesterol remains very high and I am at a high risk of developing a heart attack. I attend a lot of medical appointments as well as take medication. I find it difficult to take my medication, sometimes my hand shakes and I drop my tablets, other times I just mix the medication together which can be fatal. I have an eating disorder, I can't help myself rushing around therefore I rush to eat, stuffing food into my mouth; sometimes I'll choke and throw up. I have difficulty keeping to a healthy eating strategy.’
     3. ‘I tend to shout and sound aggressive sometimes when communicating with others even though it is not my intention do so. This has caused problems with other tenants and members of the public. Sometimes when I do not have anything to do I'll wander around other service user's flats, or walk the street, where I get targeted by local youths who call me names. I have stopped attending a disability arts programme and I am looking forward to starting a day service. I am occupying myself with in house activities but do get bored easily.’
     4. ‘I have brothers and sisters who live outside Tower Hamlets. I lived in the area with my son whom I brought up as a single parent; my son now lives with my brother. Now I live in sheltered accommodation where I hold my own tenancy. I see my brother every Tuesday and my son visits me on Thursday.’
     5. ‘I like watching basketball, cricket, football and sports in general.’
     6. ‘I would like to live near my family and live a healthy lifestyle. I want to be able to go to bed at night without hearing voices or seeing ghosts.’

# Narrative chronology of events concerning Mr Z

* 1. There are medical records for Mr Z dating back to 1981. Reviewing the history from relevant records the Bart’s Health IMR noted that in May 2006 Mr Z was seen by a colorectal surgeon having been referred by his GP for assessment into a change in his bowel habit and increasing constipation. Mr Z refused examination and investigation. The surgeon offered to undertake the examination of Mr Z under general anaesthetic but this was refused. A CT scan was performed.
  2. He was further seen by a gastroenterologist in March 2007 who noted that Mr Z had been carefully assessed by the colorectal surgeon. The scan that had been undertaken showed faecal loading. The advice given was to keep Mr Z free of constipation and use a regular laxative.
  3. Subsequent records show appointments for assessment of chest pain but nothing further relevant to this review.
  4. At the beginning of February 2014 Mr Z’s care coordinator asked for an emergency review saying that his health was deteriorating and he had become incontinent of faeces. She said Mr Z was denying this and was hiding his clothes and insisting that he washed them himself.
  5. The community learning disability service reviewed Mr Z in February 2014 as a response to the request for an emergency review. This review highlighted a range of health issues that had an impact on his life and included constipation; haemorrhoids and bloody stool. It was reported that most of his health conditions were linked to what was referred to as his eating disorder and poor diet management, with Mr Z not having the capacity to stop eating all the food available to him, and not digesting food adequately. It was noted he had a habit of eating all his food in one go. However it should be also noted there is no evidence of any formal diagnosis of an eating disorder although this term is used in case records.
  6. His care co-ordinator was concerned about his health and that he was becoming incontinent of faeces. As above it was reported that he was asking to do his own washing and was hiding his clothes. A range of concerns and issues were raised by Mr Z’s sister (who was not present at the review), which included no support being offered to Mr Z to manage his post; his medical appointments; nor his financial requirements. This had resulted in benefits being stopped and his rent being in arrears, and his sister subsidising his food shopping. His sister noted that while she helped with the shopping, she felt that Mr Z was then left to potentially eat a week’s shopping once she had left. She felt there was management of his food by the support services.
  7. The review notes contained quite graphic comments from the care coordinator who said their main concern was Mr Z’s incontinence which had reached a point where he was smearing faeces in his flat and on door handles in the building. It was also noted that he had been asking for food from other residents. Mr Z’s sister noted that the family were asked to manage his laundry as his clothes were soiled. She believed that some staff saw the incontinence as ‘behavioural’ and that led to an element of blaming Mr Z. by some staff.
  8. The review clearly noted that there had been a problem with his receipt of benefits. It was also noted that he missed two appointments with the CLDS psychiatrist.
  9. The review minuted that Mr Z was reluctant to discuss his health needs. It was agreed that an appointment would be made for Mr Z with his GP for a full health assessment and further to rule out any psychological reasons for the incontinence and to request the GP to make a referral for him to a district nurse for a continence assessment. Mr Z was seen by a GP on 20 February 2014.
  10. In March 2014 when followed up by the CLDS it was noted he was still
  11. ‘bothered by double incontinence which may be related to constipation’. He was doubly incontinent and it was noted that faecal incontinence was likely to be due to constipation and overflow and that the urinary incontinence may be due to a prostate problem. It was further noted that there had been no investigation of these issues and that Mr Z takes no medication for them. Mr Z was encouraged to attend a GP appointment and was referred to district nursing. There was professional concern about Mr Z’s non-attendance at his GP practice. It was also noted that his family wanted another placement and were concerned about his health. He attended his GP later in the month.
  12. In April 2014 there were a range of discussions noted about welfare benefits for Mr Z, and someone to act as an appointee, and a request for a washing machine to assist with his laundry. Later in the month following the review the Consultant Psychiatrist wrote to the GP for advice around Mr Z’s incontinence.
  13. In September Mr Z was seen by the continence team at Bart’s Health. The assessment found urge urine incontinence and occasional faecal incontinence. This assessment took place not because a referral was received, but because the team was undertaking an audit of people using incontinence pads in the community. It was described as a ‘symptom assessment’ not looking at any causes.
  14. In November another doctor in the mental health team noted they would contact the GP to discuss Mr Z’s incontinence.
  15. In March 2015 (over a year after the first record of incontinence of faeces) there was a discussion between the CLDS team members and Mr Z’s carers about him accessing health appointments and investigations. Possible constipation with overflow and the suggestion that a prostate issue had not been investigated, was noted.
  16. In June 2015, three months later, Mr Z was allocated to a student in the CLDS and there was again a discussion about Mr Z accessing health services. The student contacted the GP for health information, and the student also contacted Mr Z and tried to contact his sister to find out why he didn’t attend GP appointments. At the end of June a meeting took place to look at the reasons why Mr Z was not attending GP appointments. The reasons noted included staffing and communication problems at his sheltered accommodation in addition to Mr Z’s anxiety. It was also noted at this meeting that Mr Z had some new behaviours of arm rubbing and lip- smacking. Additionally it was fed back that there was blood present ‘on wiping’.
  17. The meeting agreed that there would be an investigation into possible medication side-effects and there would be a nursing assessment.
  18. At the beginning of July 2015 Mr Z had an appointment with his GP. His son was also present and shared some family history with the GP. However, it should be noted that Mr Z’s sister describes Mr Z’s son as having a learning disability and believes any support he was able to give was limited. There are no records showing that issues with incontinence were discussed at this appointment.
  19. A nursing assessment was undertaken on 10th July where it was noted that

Mr Z was doubly incontinent probably due to constipation overflow and urine incontinence due to prostate problems. A high roughage diet with increasing fluids and increased mobility was suggested. It was also requested that care staff support him in attending GP appointments and concern was raised

that his refusal was taken on face value without any further discussion. It was also suggested that pictorial aides were used to assist him to understand the importance of attending. Mr Z’s sister says she was left with the impression that some staff blamed Mr Z for his constipation; poor eating; and incontinence.

* 1. In July there were further appointments and discussions and it was agreed following an examination that the presence of blood on wiping was the result of piles. Other issues were discussed such as road safety awareness. There was no record of incontinence being discussed further at this time.
  2. It was noted on 23 July that a Health Action Plan and Hospital passport were in place and this was reviewed with his son. It was suggested substituting bran and fruit for usual cereals. Plan was to continue monitoring.
  3. The provider care plan of 5 August 2015 noted:
     + use of pads is an improvement in his life;
     + he was self-neglecting if not prompted;
     + psychologist thinks incontinence is behavioural and nonphysical; and
     + appointment is being followed up in the New Year with the incontinence clinic.
  4. Later in August there are further discussions around Mr Z’s incontinence with care provider staff reporting there was a smell of faeces and staining on his carpet. It was noted that this was a long-standing issue and hasn’t changed recently. It was also noted that there was no laxative listed on regular medications. However there was encouragement to attend the GP for a review of leg pain.
  5. In late August there was a note of an email exchange between the CLDS and the continence service asking if the continence service knew Mr Z. The continence service replied that they did not know him. There was no record of any action following this email exchange.
  6. On 19/10/15 Mr Z’s health action plan was reviewed. Much of the document was blank and it was unclear who was involved in the process of planning or updating / reviewing the plan.
  7. A provider risk assessment was completed on 20/10/15.
  8. The GP’s IMR noted that Mr Z had a care plan completed on 29/10/15 and all his needs were identified, discussed and a thorough care plan was identified.
  9. In November 2015 the original support provider changed with another organisation becoming the support provider. Later that month the carers supporting Mr Z said he had become depressed and agitated and asked for a social care review.
  10. The care provider IMR noted that a review took place in January 2016 (attended by two CLDT doctors and a specialist nurse) where it was deemed Mr Z had capacity. It added no further information about this assessment or what (if anything specifically) capacity had been assessed in relation to. The review also agreed there should be no change to his medication. A further review was arranged to take place in five months’ time. It was also reported that there was no longer a smell of faeces and Mr Z reported that he slept well and was no longer disturbed at night. His mental-health was noted to be stable.
  11. On 20 April an appointment was made with Mr Z’s GP because he was complaining of stomach ache and pain in his legs. However Mr Z later refused to attend and so the surgery was contacted again and a home visit appointment was made for the next day. This visit did not take place. There was no documentary evidence to indicate why the GP did not attend or that anybody from care provider contacted the GP practice to follow this up.
  12. On 20 April 2016 a letter to the GP from CLDS noted that Mr Z’s mental health had been reviewed. It described that Mr Z was in a lot of pain in his lower back and right knee. Mr Z was noted to have put on a lot of weight around his middle and was feeling unwell. The letter requested forms to be completed so that a blood test could be undertaken. A telephone consultation was requested to take place next day. The letter states that a home visit may be necessary. Staff at the provider were encouraged to offer Mr Z paracetamol for pain relief.
  13. The GP practice noted that the request for a consultation from the provider had been received but that it was not urgent and there were no more slots available for consultations that day. The care provider was informed that a telephone consultation would take place the next morning. They were told the GP would ring back on the 21st after 12 noon. However, the providers’ hand-written handover notes recorded this on 21st “GP is coming b/4 9-12 2 day to see…”.
  14. The GP practice notes say that they contacted the provider on the 21st but there was no reply. It was documented as a ‘failed encounter’ by the GP surgery.

On 22nd April staff supported Mr Z according to his care plan and usual routine. It was recorded that Mr Z was seen walking around and touching his belly. At 14.45hrs he refused to accept personal care and said that he had a stomach ache. He was asked if he wanted to see the doctor but he refused saying it was just ‘bellyache’. It was recorded that he was to be monitored by the care provider staff hourly. No attempt was made to contact family members who may have been able to support Mr Z in visiting his GP.

Later in the day there was a call from the community nurse who rang to enquire about the GP visits and Mr Z’s stomach ache. The support worker told the nurse she wasn’t aware of the appointment, as nothing had been passed to her at handover. The support worker said she would try and find out and would ring back. The support worker checked the notes again and tried to contact staff from the previous shift but she could not contact anyone.

* 1. It should be noted that Mr Z’s sister recalls being told by the Community Nurse after his death that she, the community nurse, had called to see Mr Z and was very concerned about his health.
  2. The nurse called back to check Mr Z’s pain levels and whilst on the phone it was reported that Mr Z had started to lean to the left. It was agreed to call an ambulance. The provider IMR records a call to LAS at 18.54hrs and the LAS IMR records a call at 18.55hrs.
  3. The final version of LAS IMR provided to the SAR noted that a 999 call was received in the Emergency Operations Centre (EOC) at 18:55:

*It was reported that a 59 year old male was experiencing abdominal pain and was unable to stand/sit. It is further documented that the caller was the*

*patient’s carer who had spoken to a community nurse who had advised to request an ambulance.*

*The caller was informed that based on the information provided an emergency ambulance was not needed but a further assessment from NHS 111 was needed and that they were to ring them.*

*The call taker asked the caller who they had spoken to before the ambulance service to which the caller replied 'The Community Nurse’. The caller was asked if they were a carer to which they responded ‘yep I am one of the*

*carers’ and that the Community Nurse had advised that is was an emergency.*

*The call handler informed the caller that based on this information they would instruct one of our clinicians to ring back to obtain a more enhanced assessment, based on the information provided the call was categorised as a C3 priority (telephone assessment commences within 20 minutes or a response arrives within 30 minutes).*

*It is documented that at 19:22 a member of staff from our Clinical Hub pressed a flag to ring back the caller to start a clinical assessment, however whilst the ring back was being processed an ambulance was dispatched which meant the ring back was not undertaken and was not needed as a resource had been dispatched.*

* 1. The provider IMR noted that the staff member was told that the ambulance service was quite busy and would call back in 20 minutes as the case was not considered a priority. The staff member told the operator that as far as she was concerned it was urgent. A call back was not received and this is confirmed by the LAS have record above. Instead an ambulance was

dispatched at 19:26, (31 minutes after receiving the call) arriving at the address at 19:34.

* 1. Because of the number of staff on site, and the needs of other tenants, it wasn’t possible for a staff member to stay with Mr Z for the whole time between the call to LAS and the arrival of the paramedics.
  2. At 19.40hrs paramedics arrived and entered Mr Z’s flat. On being shown to Mr Z’s room he was found lying on his back on bed with his legs hanging over the edge. Mr Z was in cardiac arrest. Mr Z was moved from the bed to the floor and CPR was commenced.
  3. At 19.43hrs a second ambulance was requested to assist and arrived at 19.49hrs. CPR continued throughout.
  4. The LAS record noted that on examination Mr Z’s airway was obstructed with vomit, which was manually cleared. An Electrocardiogram (ECG) indicated that Mr Z’s heart rhythm was in asystole (no electrical activity present). Mr Z’s breathing was assisted via a bag, valve and mask, oxygen was administered.
  5. Intravenous (IV) access was unsuccessful, Intraosseous Infusion (IO) (to enable the administration of drugs directly into the marrow of the bone) was gained and a full drugs protocol was administered.
  6. CPR was continued throughout. Reversible causes were considered, Mr Z remained in asystole. Following a consultation with all ambulance staff on scene, CPR was terminated and Verification of the Fact of Death was recorded at 20:35.
  7. The police were contacted as Mr Z’s death was unexpected. Mr Z was left on scene in care of the police, in accordance with the LAS policies and procedures.
  8. Mr Z’s family were contacted after his death. They had not been contacted during the day nor alerted that he was unwell nor that an ambulance had been called. They arrived after midnight and found Mr Z’s body, naked on the floor as they assumed it had been left by the London Ambulance service. There had been no attempt to cover the body or move the body to the bed.

# Analysis

## The Care arrangements in place for Mr Z - Person centred approach

* + 1. Mr Z was well known to support services in Tower Hamlets. He received support from Bart’s Health – which had the contract to provide Community Learning Disability Services in the borough. Amongst others, the service included registered nurses, social workers and therapy staff. Clinical psychology and Consultants psychiatry were also part of the service.
    2. The day to day management of the team was by a team manager who was jointly appointed by both Bart’s Health and LBTH. They reported to senior managers in both organisations. The local authority discharged its statutory duties through this team and the social work staff remained employed by the local authority
    3. Mr Z had a health action plan, a health passport and a care plan. There was evidence that reviews did take place and that if an additional or ‘emergency’ review was required this would be held. However, Mr Z’s sister says she was never shown his care plans, despite asking staff when she visited.
    4. There was evidence that the care plan included statements by Mr Z about who he was (see para 1.5) but it was also clear that this probably was not in Mr Z’s own words. It was hard to tell if this had just become an automatic statement appended to the beginning of each review or whether time had been spent with Mr Z before each review to write and consider what he wanted from the meeting.
    5. Mr Z was seen at least five times a day by support staff at the sheltered accommodation. He was also seen by a social worker, nurse and other team members from the CLDS. He was in contact with his son who visited regularly and there was evidence his son played a part in his care planning, although Mr Z’s sister suggests this would be limited.
    6. There was no evidence that an advocate had been offered to Mr Z or was assisting in helping his voice to be heard.
    7. However Mr Z had a long standing issue with diet, food and, perhaps as a consequence, constipation. There was limited evidence that there was a plan in place around his eating. There was no reference to a dietitian being involved. There was no reference to Mr Z having been seen by or referred to an eating disorder service. There was no assessment nor formal diagnosis of an eating disorder, although his care plan documents clearly use the term eating disorder. Although not evidenced, investigations may have been considered and even been actioned in the past, but there was no plan or intervention in relation to his eating disorder in place at the time of his death.
    8. Mr Z’s support documentation also evidenced that Mr Z could be anxious, depressed and become frustrated. It also clearly identifies an issue with receiving medical and health support and interventions. This had been a longstanding issue. There was no evidence of any desensitization plan or behaviour plan to address this issue. The only intervention seems to be encouragement to attend appointments, which he then often missed.
    9. It was noted over a number of years that Mr Z was incontinent both of urine and faeces. It seems to have been accepted that he used incontinence pads although there was no information as to how and when this started. There was some limited contact with the continence service but that was not pursued and came to nothing.
    10. The nursing assessment in July 2015 specifically followed up his constipation and the IMR noted:

‘Double incontinence probably due to constipation overflow and urine incontinence due to prostate problems’

But no consideration of laxatives were noted. No plan was put in place to help Mr Z attend his GP on a regular basis and there was no consideration of his capacity. However he did attend the GP the next day but there was no record of incontinence or overflow being discussed.

* + 1. The IMRs also note, as do support plans and reviews, that at some stage it was suggested that Mr Z’s incontinence had a psychological reason rather than a physical cause. This observation seems to have been repeated in a number of documents, but there was no evidence to suggest that this hypothesis was ever fully tested. Likewise there had not been any recent investigations into physical causes.
    2. Mr Z was on a range of medications. These were considered at each of his reviews. The consultant psychiatrist reviewed the medication listed on 19/10/15:
       - Aripiprazole – an anti-psychotic medication
* Procyclidine – used to treat involuntary movements due to the side effects of certain psychiatric drugs
* Carbamazepine – an anticonvulsant used to treat seizures
  + - * Ramipril – for high blood pressure
      * Atenolol – a beta blocker used to treat angina
      * Simvastatin – a statin used to lower ‘bad’ cholesterol
      * Omeprazole - decreases the amount of acid produced in the stomach
    1. There was no laxative prescribed and there was no evidence that an over the counter laxative was being used despite use of a laxative having been suggested.
    2. Checking the medication listed on 19/10/15 to see if any would have an impact on causing constipation the consultant psychiatrist noted:

Ramipril and Aripirazole - constipation not listed

Atenolol and Simvastatin - gastrointestinal disturbance listed Omeprazole - constipation and diarrhoea listed for all proton pump inhibitors

Carbamazepine - constipation common Procyclidine - constipation is listed side effect.

* + 1. There was no evidence from the review documentation that prescribed medication was considered in relation to Mr Z’s constipation. There was no evidence from the IMRs that a pharmacist was involved in these discussions despite Mr Z himself identifying issues he had with medication:

I find it difficult to take my medication, sometimes my handshakes and I drop my tablets, other times I just mix the medication together[[2]](#footnote-2)

* + 1. From the IMRs there was evidence of a number of discussions about Mr Z’s incontinence and potential for constipation. Psychological causes were discussed. But no one consistently or tenaciously followed up the causes of his incontinence or any treatment options. Laxatives were suggested but none were prescribed or offered.
    2. On the day of Mr Z’s death he was seen to be holding his stomach and had been complaining of stomach ache, he had also refused personal care. Staff at the accommodation asked him if he wanted the GP but he refused. Later that day when the ambulance was called it appears no one stayed with Mr Z until the LAS arrived. The notes from LAS IMR indicate that Mr Z was alone in his room and lying on the bed with his legs over the side. There was no indication that anyone else was with him.
    3. There was much guidance on care planning. Many papers and good practice documents have been produced over the last 30 years. Much of this was drawn together in the Care Act 2014 and associated guidance[[3]](#footnote-3). Chapter 10 paragraphs 1 and 5 of the guidance states:

(10.1.) Care and support should put people in control of their care, with the support that they need to enhance their wellbeing and improve their connections to family, friends and community

(10.5) Ultimately, the guiding principle in the development of the plan was that this process should be person-centred and person-led, in order to meet the needs and achieve the outcomes of the person in ways that work best for them as an individual or as part of a family.

* + 1. Mr Z was involved in his care planning. However given the causes of Mr Z’s death, his care planning was clearly not effective. The lack of professional curiosity and investigation around both his eating disorder and his incontinence must give rise to questions about the multi-agency working of his care team and his care planning.
    2. Mr Z’s incontinence was not a secret. The IMRs make reference to constipation, incontinence of urine and faeces and even at his nursing assessment they reference overflow. Support staff noted that he left faeces on door handles and was hiding his soiled clothing. But no one in his care team consistently and over a period of time ensured that this was investigated and that he accessed the correct medical investigations and interventions. While it was impossible to say that if they had, Mr Z would still be alive, it is possible to say that Mr Z lacked someone to champion his best interests and to ensure he fully understood the consequences of his actions.
    3. In that regard the co-ordination of Mr Z’s supports, information sharing and joint decision-making was flawed.

## The Mental Capacity Act and self-neglect

* + 1. There was very little reference to capacity in the IMRs. It seems to have been decided at some point that Mr Z had capacity for a range of decisions and no further documented discussions took place.
    2. But the assessment of capacity is not a single event. As the General Medical Council guidance makes clear[[4]](#footnote-4):

You must assess a patient’s capacity to make a particular decision at the time it needs to be made. You must not assume that because a patient lacks capacity to make a decision on a particular occasion, they lack capacity to make any decisions at all, or will not be able to make similar decisions in the future.

* + 1. There was no evidence of an assessment of Mr Z’s capacity in respect of his ability to make a decision about his medical treatment, nor comprehensive assessments of his capacity to make decisions about his eating. The judgement appears to be that these were unwise decisions that he had capacity to make. As the Bart’s Health IMR noted:

There is reference to mental capacity assessment for consent to his psychiatric and social assessments as well as decision making about eating out of date food, however there is no record of a thorough capacity assessment undertaken in relation to his decision not to engage in medical assessment.

* + 1. The CLDS serious incident response says that there was a presumption of Capacity to Consent by CLDS and formal capacity assessments are not routinely carried out with all clients. This is in line with the Mental Capacity Act 2005. The GP as the decision maker in relation to investigations and/or treatment concerning constipation would have to conduct their own Capacity. Assessment, and if Mr Z was assessed as not having capacity, to take a lead on a Best Interest decision.
    2. The assessment dated 20/10/15 noted Mr Z had an eating disorder. There was no text under the section headed ‘Risk awareness / Capacity’. On the risk check list which identifies 44 risk areas only 6 areas of risk are ticked in respect of Mr Z: 2 high risk; 2 medium risk; and 2 low risk. Self-neglect was rated as a medium risk.
    3. The Department of Health commissioned research on self-neglect and the SCIE report 695 ‘Self-neglect policy and practice: building an evidence base for adult social care’ was published in November 2014. This document defines self-neglect as:

Self-neglect for definitional purposes then includes both adults with and without capacity, and centres on:

* + - * lack of self-care – neglect of personal hygiene, nutrition, hydration, and/ or health, thereby endangering safety and wellbeing, and/ or
      * lack of care of one’s environment – squalor and hoarding, in the context of refusal of services that would mitigate risk of harm.
    1. Using this definition an assessment could be made that even though Mr Z was living in supported accommodation, and received over five face-to-face support interventions a day, he was self-neglecting. This had been identified as a risk on his risk assessment.
    2. There was no evidence from the IMRs that the concept of self-neglect was discussed or that Mr Z’s behaviours were seen in the context of self-neglect. It was as if the risk assessment was separate to the day-to-day support Mr Z received.
    3. The research in the SCIE paper highlighted the challenge self-neglect poses to health and care workers and the conflict between a duty of care and promoting choice and control. This dilemma is also present in the Care Act guidance, which says any concerns about self-neglect “do not override” the principle, set out in section 1 of the Act, that any restriction on an individual’s rights should be kept to “the minimum necessary”.

5 Braye, S.; Orr, D.; Preston-Shoot, M., (2014). “Self-neglect policy and practice: building an evidence base for adult social care”. SCIE report 69, London (commissioned by DH)

* + 1. It was impossible to tell what the outcome of a full and regular discussion around capacity, self-neglect, self-determination and the ability to made poor decisions might have been, but it would have meant there was an explicit

MCA based judgement made in relation to Mr Z making his own decisions about whether to access medical support or not.

* + 1. As it was, it left frontline care staff in a position where they would suggest and offer appointments with the GP knowing these would often not be taken up by Mr Z.
    2. Conclusion

There was no evidence of recent discussions about Mr Z’s capacity to make the various decisions he was making in this life. There should have been.

Front line staff were often left to cajole Mr Z to attend GP and hospital appointments. Everyone knew he was very anxious about having investigations or attending the GP surgery although he did from time to time. But no one developed an effective plan, which may have involved use of the Mental Capacity Act (MCA), to enable Mr Z to have his health needs fully met.

## Working with people who have a learning disability including effective communication

* + 1. Much has been written over the years about working with people who have a learning disability. In an area that is much written about and debated, it is perhaps useful to go back to the core value that people with a learning disability articulated: Nothing about us, without us.
    2. Mr Z had a complex set of needs, one of which was his learning disability. However there was no evidence that services defined him by his learning disability. It was significant to note that discussions in reviews and from case note entries referenced in the IMRs spent very little time considering how Mr Z’s learning disability impacted on his life. To some extent it was the physical needs and behaviours that were focused on.
    3. There was no clear evidence that reviews explicitly discussed Mr Z’s learning disability and how this impacted on his ability to make decisions or care for himself. There was however some evidence that use of easy read and pictures were discussed in relation to visiting the GP. It was not clear whether these were solely about the practical aspects of how to get there, or whether they were used to help Mr Z gain a better idea of the reasons for visiting, having tests undertaken and the consequences of not attending.
    4. There was no evidence that any discussions around constipation or incontinence used easy read or pictures to help discuss with and ensure that Mr Z understood what was happening to his body and the need for further investigation and assessment. Although at the nursing review, a suggestion was made that to help Mr Z feel empowered there should be use of pictorial aids. There was no evidence that this was followed up or undertaken.
    5. Most people find discussing going to the toilet difficult. We often don’t know what words to use. We have a range of words used in family settings, different words when talking to friends and again more formal or technical words for discussing with professionals. Even then we find it embarrassing and often difficult. For someone with a learning disability living in supported accommodation and receiving support from paid carers it must be even more difficult, and if support staff have not agreed a set of words with the person they are working with, and are fully confident that both they and the person being supported understands what is being discussed, no progress can be made.
    6. Following two Safeguarding Adult reviews in Suffolk6 - Amy and James - the Suffolk SAB commissioned a short publication: ‘notes on constipation7’ to be read in conjunction with the two Safeguarding Adult Reviews. In August 2016 Public Health England8 published: ‘Making reasonable adjustments for people with learning disabilities in the management of constipation’9.
    7. Under the Equalities Act 201010 public sector organisations have to make changes in their approach or provision to ensure that services are accessible to disabled people as well as everybody else. ‘Making reasonable adjustments for people with learning disabilities in the management of constipation’ is the twelfth in a series of reports looking at reasonable adjustments in a specific service area. The aim of these reports is to share information, ideas and good practice in relation to the provision of reasonable adjustments.
    8. The report notes on page 10:

‘Prevalence rates of constipation vary… An unpublished study reported rates from 17% to 51% among adults with learning disabilities living in varying types of supported accommodation in the UK. A European study of adults with learning disabilities living in institutions found that almost 70% of them had constipation compared to 15% in the general population.’

And page 13:

‘Chronic constipation can lead to a plethora of negative impacts on quality of life. In addition to the physical aspects described above, there are also

6 <http://www.suffolkas.org/safeguarding-adults-reviews/>

7 <http://www.suffolkas.org/assets/Safeguarding-Adult-Reviews/Notes-about-constipation.pdf> 8 With The Public Health England Learning Disabilities Observatory (PHELDO) a collaboration between PHE, the Centre for Disability Research at Lancaster University and

the National Development Team for Inclusion. The observatory is operated by PHE and is also known as Improving Health and Lives (IHaL)

9 Making reasonable adjustments for people with learning disabilities in the management of constipation PHE August 2016 <https://www.ndti.org.uk/uploads/files/Constipation_RA_report_final.pdf>

10 UK Parliament (2010) Equality Act 2010. Available on-line at [www.legislation.gov.uk/ukpga/2010/15/pdfs/ukpga\_20100015\_en.pdf](http://www.legislation.gov.uk/ukpga/2010/15/pdfs/ukpga_20100015_en.pdf)

psychological impacts. These include embarrassment, social isolation and anxiety. Long-term constipation is also associated with urinary and faecal incontinence, which in turn can increase social anxiety.’

* + 1. Conclusion

While there were changes in provider and support staff this did not seem to impact on the day to day support Mr Z received. However it was unclear what level of continuity Mr Z received from his whole support team.

* + 1. There were issues of communication between Mr Z, his support staff and his wider support team and also between the teams.
    2. It was really unclear from the IMRs what Mr Z really understood about his conditions, what level of capacity he had and how he wished to be communicated with. There was no evidence of a communication plan, no evidence of the use of advocates, no evidence of any easy read documents or the use of video. On this basis the conclusion has to be that there was not effective communication between support staff, the wider team and Mr Z.
    3. Likewise given the evidence of care planning, assessments and some discussion having taken place between staff supporting Mr Z around his incontinence, that he did not receive the investigations and treatments required, one has to conclude that communication between the relevant team and individuals was not effective.

## Professional standards and practice

* + 1. Mr Z had no one to advocate for him, or who had a consistent overview of his care. There were a range of agencies involved, with a range of professionals involved all of whom played a part in Mr Z’s care, and while it was hard to say explicitly if any professional standards were breached, what was evident was that person centered support did not enable Mr Z to receive the care and treatment he needed and was entitled to.
    2. A lack of professional curiosity and tenacity meant that concerns were not seen through to a conclusion. It was often left to the staff supporting Mr Z on a day-to-day basis to manage his incontinence as best they could.
    3. The Mental Capacity Act was not seen as, nor used, as a tool to support Mr Z to get the outcomes he needed. Professionals need to be aware of statute and how the law can assist in decision making and planning – this is

sometimes referred to a ‘legal literacy’.

* + 1. The GMC identifies on their website11 that while no doctor intends to discriminate against his or her patient, and we can take that more widely for

11 <https://www.gmc-uk.org/learningdisabilities/200.aspx#207>

all health and social care staff, the evidence12 shows that people with learning disabilities have poorer health outcomes than the rest of the population.

* + 1. The GMC goes on to explain:

In the context of learning disabilities this means that ‘symptoms of physical ill health are mistakenly attributed to either a mental health/behavioural problem or as being inherent in the person's learning disabilities’.13

* + 1. This is often referred to as ‘diagnostic overshadowing’ and the GMC notes a range of ways to help detect and prevent diagnostic overshadowing14. The National Institute for Health and Care Excellence (NICE)15 also holds a range of guidance and advice in this area especially for GP and general hospital settings.
    2. The LAS was called at 18.55 and dispatched an ambulance 31 minutes later having said that a call would be received from the clinical hub. Having reviewed the transcript of the call the call taker is clearly concerned that even though the Community Nurse had requested a 999 call the system was indicating ‘it is not for an emergency ambulance from the information you have given me’ and says ‘I can’t bypass the system’ and ends the call by saying, ‘Alright then they will ring you as soon as possible.
    3. It is unclear if an ambulance had been dispatched and arrived sooner what impact that may have had. It is also unclear that if Mr Z’s condition had been described differently, or if the LAS call taker had asked different questions what the outcomes may have been.
    4. The care provider noted that staff did not stay with Mr Z after calling 999, and were clear that this was a mistake and have put in place procedures to enable this to happen in the future. This will of course impact on their staffing levels.

## Commissioning

* + 1. The commissioning team were responsible for commissioning both the sheltered accommodation and the domiciliary care agency involved. The IMR noted that responsibility and accountability for domiciliary care spanned three areas within Commissioning and Health, with no overall Commissioning Manager.

12 Confidential Inquiry into premature deaths of people with learning disabilities (CIPOLD) <http://www.bristol.ac.uk/media-library/sites/cipold/migrated/documents/fullfinalreport.pdf> 13 Emerson, E., and Baines, S. (2010) Health Inequalities and People with Learning Disabilities in the UK : 2010

http://webarchive.nationalarchives.gov.uk/20160704153130/http://www.improvinghealthandliv es.org.uk/uploads/doc/vid\_7479\_IHaL2010-3HealthInequality2010.pdf

14 <https://www.gmc-uk.org/learningdisabilities/200.aspx#207>

15 [https://www.nice.org.uk](https://www.nice.org.uk/)

* + 1. The IMRs evidence that through the Contract Monitoring and Quality Monitoring of both the providers concerns raised about them were managed by the Monitoring Officers in a timely way. There was evidence that monitoring visits took place and complaints and concerns were followed up by the team.
    2. It was unclear on what basis the support was split between the two providers. If the external agency had been providing advocacy, or a different form of support that was commissioned to provide different outcomes, that would be understandable – but they weren’t. They provided some escorting, and a small amount of personal care and shopping. It was unclear how this split between providers benefitted Mr Z or what outcomes were hoped for.
    3. It was clear from the care plan that Mr Z received some 15 minute calls. These may have been appropriate to check on his wellbeing or that he had taken medication. There has been much national discussion about 15 minute calls and the National Institute for Clinical Excellence (NICE) 16 advise that carers must spend a minimum of 30 minutes during visits to help keep people well. Mr Z lived in his own home; he should not have been receiving 15- minute visits.

7.5.5. There was evidence that the commissioning team reacted in a timely manner to the request for additional funding to support Mr Z.

7.5.6 It was not possible to say what impact the transfer of the management of the on-site provide had but there was certainly a loss of some of the history of support.

## Good practice

* + 1. Good practice:

That incontinence had been identified as an issue that some attempts were made by various professionals to explore the causes and treatment requirements.

* + 1. Mr Z received a good level of personal support and welcomed the support he received.
    2. That the Community nurse followed up her concerns about Mr Z on 22/4/17 and was proactive and clear about the need to call for an ambulance.
    3. That when LAS staff arrived on the scene they acted quickly and robustly.

16 <https://www.nice.org.uk/guidance/NG21>

## Learning

There are two main areas for learning:

* Capacity
* Constipation
  + 1. Better consideration should have been given to Mr Z’s capacity in relation to his decision-making around medical assessments and interventions. While Mr Z did go to his GP and did undergo assessments from time to time the evidence was that this was not consistent. An agreed plan could have been developed to investigate further Mr Z’s eating issues and his incontinence and the MCA should have been explicitly considered as a tool to enable that plan to be implemented. Alternatively, the MCA could have been used to determine that Mr Z fully understood the consequences of his decisions.
    2. This report also highlights the issues of constipation for people with a learning disability. All staff working with people with a learning disability need to be aware of the potential consequences of unmanaged and untreated constipation.
    3. In addition to these two overriding learning points, further learning is highlighted around:
       - Person centred support;
       - Professional curiosity;
       - Contact with 999 LAS around a person with a learning disability; and
       - Contact with 999 LAS around people living in supported accommodation.

# Conclusions

* 1. There was no one incident that led to Mr Z’s death. But there were missed opportunities that might have led to a different outcome. However if Mr Z had not had a learning disability it is possible his incontinence would have been investigated more fully, seen as a serious symptom and the physical causes investigated more systematically. It is hard to tell how Mr Z was

seen by health and care workers, and to what extent he was ‘overshadowed’ by his disability or behaviours.

* 1. There needed to be a better understanding of Mr Z’s eating disorder. While this was referred to in care plans and support plans there was no evidence about how this was being treated or managed. This should have been fully investigated and a plan put in place to assist Mr Z to manage his eating.
  2. There needed to be a better understanding of Mr Z’s incontinence. While there was evidence of some historic investigations, and there was more recent references to incontinence; a prostate issue; blood on wiping; haemorrhoids; and even a question about his faecal incontinence being to do

with ‘overflow’, no one took responsibility for co-ordinating the necessary investigations and then implementing any treatments. It was not possible to say what impact the suggestion that the causes may have been psychological had on further physical investigations, but a physical cause or contribution should have been completely discounted before investigation stopped or were seen as less important.

* 1. As previously recognised, talking about bodily functions: ‘poo’ is difficult, and providing direct personal care to someone who is incontinent of faeces is unpleasant. Mr Z recognised this himself and was clearly embarrassed by it – he tried to hide his clothes and wash them himself. But employed staff at all levels needed to be comfortable to talk to Mr Z in language he understood about his incontinence. There was no evidence this happened.
  2. Potential physical causes of Mr Z’s incontinence should have been fully investigated and a plan put in place to manage Mr Z’s incontinence and where possible to solve the problems that were causing it.
  3. The assessment of Mr Z’s capacity to make decisions was poor or even non- existent. There was no evidence of any written assessments of capacity. Without an assessment of his capacity to make specific decisions (e.g. around medical interventions) it was not possible for staff to plan appropriate interventions.
  4. Because the issues of capacity were not explored and fully assessed, his eating, his self-care and his refusal to attend GP appointments were seen as his choices. They should have been considered in the wider context of capacity and self-neglect.

# Recommendations

* 1. LBTH and the CCG need to ensure that all 18+ adults with learning disabilities and complex support needs have been considered for a named care

co-ordinator and that their health and social care needs are jointly reviewed on at least an annual basis.

* 1. LBTH needs to ensure that care coordination is supported by record keeping and information sharing across professionals and services and that people’s families or representatives are regularly consulted.
  2. LBTH adult social care and its commissioned providers need to ensure that that regular assessments and reviews of capacity are undertaken when someone receiving support is refusing medical assistance.
  3. The CCG should set targets and have systems in place to ensure commissioned annual health checks take place.
  4. LBTH adult social care, CCG commissioners and partners need to ensure that that they have in place appropriate training on the Mental Capacity Act 2005 that is accessible, understandable and covers day to day decision making such as diet, and more complex medical assessments and interventions, including how such decisions are recorded and collated and when these should be escalated for further clinical and professional assessment.
  5. The Learning Disability Partnership Board (LDPB) should discuss access to advocacy for all people with a learning disability in supported or residential care settings.
  6. LBTH adult social care and partners with the LDPB should develop a programme of advice and information around healthy eating and constipation for the whole learning disability community in Tower Hamlets.
  7. LBTH adult social care and partners should put in place with the LDPB learning events for all staff on the issues for people with a learning disability around:
     + diagnostic overshadowing
     + healthy eating
     + constipation

This training should be on-going and updated as new research and learning is published and should include all staff working with, or commissioning services for, people with a learning disability.

* 1. LBTH and CCG commissioners should ensure that contracts with providers of learning disability services should require staff to have regular training and development around the risks associated with constipation and the appropriate response to encouraging healthy eating and treating constipation.
  2. LBTH adult social care and partners should put in place with the LDPB learning events for all staff on the issue of self-neglect. This training should be on-going and updated as new research and learning is published.
  3. LBTH adult social care and the CCG should ensure that care co-ordinators, managers and senior clinical staff are up-to-date with current practice around the use of the MCA, and the MCA and neglect. They should have access to good legal advice where necessary.
  4. LBTH and CCG commissioners should ensure that providers have in place protocols to ensure a member of staff stays with a resident when an emergency ambulance is called and have some level of basic first aid training and know when it is appropriate to use the ‘recovery position[[5]](#footnote-5).
  5. Given the national changes in November 2017, the London Ambulance Service should consider if there are any further changes to their systems required in light of their response to this 999 call.
  6. LBTH should ensure there is an easy read summary of the finding and recommendations of this report and that the report is presented to the LDPB.

1. <http://www.legislation.gov.uk/ukpga/2014/23/pdfs/ukpga_20140023_en.pdf> [↑](#footnote-ref-1)
2. 5.1.2 above [↑](#footnote-ref-2)
3. Care Act 2014 Statutory Guidance: Care and support statutory guidance - Updated 28 June 2017 Department of Health

   <https://www.gov.uk/government/publications/care-act-statutory-guidance/care-and-support-statutory-guidance> [↑](#footnote-ref-3)
4. GMC Consent guidance: Assessing capacity para 71:

   <https://www.gmc-uk.org/guidance/ethical_guidance/consent_guidance_accessing_capacity.asp> [↑](#footnote-ref-4)
5. <https://www.nhs.uk/conditions/first-aid/recovery-position/> [↑](#footnote-ref-5)