**Tower Hamlets Safeguarding Adults Partnership Board**

**Safeguarding Adults Review in respect of Mr D**

**Executive Summary**

# Introduction

* 1. Mr D was a 30 year old severely learning disabled (SLD) man diagnosed with sensory defensiveness (SD) cerebral palsy and epilepsy who died in circumstances that were subject to a Coroner’s Inquest held 7th September 2015. Mr D was described by his family and professionals as a happy, contented person. He was a wheelchair user both inside and outside the home that he shared with his mother. He had limited speech but was able to let his wishes be known through gestures and phrases that were familiar to his family and people who knew him well.
  2. Mr D’s death was sudden and unexpected. He was described by his mother as in good health and in regular contact with his neurologist for outpatient review appointments for his seizures. He was last reviewed at the clinic on 22/10/2014.
  3. A post mortem attributed Mr. D’s death to:

1. Gastrointestinal haemorrhage
2. Bleeding peptic ulcer
3. Cerebral palsy
   1. He was in receipt of a personal budget to pay for his care from August 2013 up to his death but continued to use agency workers as he was unable to recruit permanent personal assistants. His care package was assessed and reviewed a month before his death by LB Tower Hamlets Community Learning Disability Service. It consisted of daily assistance with personal care, attendance at a Day Centre five days a week, and regular respite care (78 nights per annum).
   2. A review of adverse incidents about the care of learning disabled people at the Royal London Hospital was convened by the Director of Nursing. It was identified during the review that Mr D’s case may meet the criteria for a safeguarding adult review as there was more than one agency involvement prior to him attending the Accident & Emergency Department at the Royal London Hospital where he died.
   3. A Safeguarding Adult Review (SAR), referral was made to the Safeguarding Adult Board (SAB) in August 2016. It was noted at the SAB panel that the care by the mother was seen as exemplary and the SAR focus would be on the multi-agency input. The SAR report has taken much longer than anticipated due to timeliness of completed Independent Management Reviews, change of Business Manager for the Safeguarding Adults Board and the sudden critical illness of the independent author. All these factors impacted on the expected time frame of 6 months.
   4. Having seen the report, Mr D’s mother commented on it, but did not consider it to have met her expectations, although most points were accepted. Some led to an improvement in the process for relatives. Regrettably she still decided to withdraw from the process, and apologies were given for the length of time and distress caused

# Background leading to the SAR

* 1. Prior to the week beginning 11th May 2015, there was nothing of significance in Mr D’s background or history of care and support from health and social care organisations that might have impacted on Mr D’s safety or the need for safeguarding interventions.
  2. On Tuesday 12th May 2015 during personal care, Mr D’s mother noticed that he (Mr D) had “passed blackened stuff with an unusual odour in the bath water he was sitting in.” His mother arranged an emergency visit to the GP, the same day at around 11.30am. Mr D was seen by a locum GP.
  3. The GP directed all conversation to his mother and did not examine Mr. D. Mr D’s mother discussed the locum GP diagnosis of constipation with a locum pharmacist as she disagreed with it.
  4. Mr D did not return to the day centre until 14th May 2015, when his mother thought that he appeared a lot better.
  5. Mr D had three bowel movements prior to going to sleep on Friday 15th May. These were described by his mother as “loose blackened faeces.”
  6. His mother later began his personal care when he screamed and shouted “bed, bed, bed.” She could not calm Mr D down. His mother telephoned the emergency services using 999 as Mr D was still distressed and she was concerned that he was in pain.
  7. The London Ambulance Service (LAS) call centre sent an ambulance crew and a motorcycle rapid response call. Following their assessment Mr D was transported by ambulance to the Accident & Emergency Department of the Royal London Hospital.
  8. The chronology in the referral for a SAR produced by Barts Health states that the paramedics undertook a patient assessment on route to the hospital which showed abdominal tenderness with guarding. It was challenging for the paramedics to obtain accurate blood pressure and pulse readings and it may have assisted procedures if an analgesic had been administered. The paramedic team took a history from the mother and noted incidents of melena[[1]](#footnote-1).
  9. Mr D was transported to hospital as a non-urgent transfer. LAS placed a priority alert to the hospital. Barts Health IMR chronology notes that Mr D’s eyes were partially open and there was a delay of 19 minutes from his arrival at the hospital to being taken to a cubicle. It notes Mr D showed signs of clinical deterioration and probable circulatory failure.
  10. A Serious Incident investigation concluded that Mr D was left alone with his mother for a period of over 10 minutes without clinical observation after an initial consultation whereby focus was on his learning disability and the mother’s capacity to cope as a carer. When the consultant returned to the cubicle, full cardio-pulmonary resuscitation commenced.
  11. Mr D had arrived at the hospital at 13.36pm and died at 15.25pm.

# SAR Terms of reference

3.1 The terms of reference for the SAR would consider and reflect on:

* Which agencies were in contact with Mr D prior to his death and the nature of their involvement;
* What information was shared between the different agencies involved with Mr D prior to and at the time of his death;
* What information was shared between the different agencies involved with Mr Das part of partnership working to provide health and social care to Mr D;
* The last health and care reviews and any relevant health or social care assessment or reassessment triggered by reviews;
* Risk assessments and other relevant assessments taken by each agency;
* Opportunities taken and missed for assessment and intervention;
* Missed opportunities to raise health issues;
* Critical decision-making and appropriate action in light of assessments;
* Timeliness and effectiveness of actions and interventions;
* Knowledge and understanding of mental capacity and application of the Mental Capacity Act 2005;
* Compliance with guidance on Health Action Plans in particular who held them, how access to them could be gained, and when and how they were updated;
* Compliance with guidance on Hospital Passports and how this was shared with family members and updated;
* Any established Communication Plans i.e. how to communicate with Mr D;
* Issues of training and competence on assessing and communicating with people with learning disabled people;
* Agency values and standards of involving and listening to carers;
* Support to Mr D’s mother and family to work as effective partners;
* Sensitivity to the disability, ethnic, cultural, linguistic and religious identity of Mr D;
* Identify any lessons to be learnt, and recommend how they are to be acted upon and what is expected to change as a result; and include
* Examples of good practice which can be adopted across agencies
  1. Mr D’s mother was invited to be part of the SAR as per the Making Safeguarding Personal agenda. She was offered advocacy under s68 Care Act 2014 and a detailed statement was taken by the author. She stressed that she wanted the SAR to achieve the following outcomes:
* Organisations to acknowledge errors in order that they can minimise the risk of the same errors happening to another family
* Address organisational and individual prejudice towards people with a learning disability that may impact on their access to services
* Organisations to develop an awareness that mistakes happen and that they can learn from them so that Mr D’s death would not be in vain
* Organisations to develop an open culture to complaints and investigations as they are expected within policies and statute.

# Analysis & Findings

**4.1 Assessment, support plans & reviews by CLDT**

* + 1. The process of assessment, support planning and reviewing is the responsibility of the CLDT. The management arrangements were that health staff were accountable to Barts NHS Trust and social care accountable to the London Borough of Tower Hamlets. There are now joint management arrangements with the East London Foundation Trust holding the lead management role for both parts of the service.
    2. Mr D lived with his mother supported by a care package funded by the local authority. He was in receipt of a personal budget to pay for his care from August 2013 up to his death. His care package was assessed and reviewed on 24/04/2015 by LB Tower Hamlets Community Learning Disability Service based at Beaumont House.
    3. The last support plan for Mr D was completed by the CLDT when he was 27 years old, approximately just over 2 years prior to his death. The plan provides a good picture of Mr D, his likes and dislikes, what he wants to get out of life and the challenges that he faces because of his disability. The plan sets out what is needed to meet his daily needs and how to keep him safe. It is well laid out and provided a platform for Mr D to say what he wanted to achieve and the kind of assistance he wanted to maintain his dignity and keep safe but there was no independent advocacy to substantiate this.
    4. Mr D’s reviews were up to date and held with him supported by his mother. The reviews included day care, respite care and domiciliary care. Although Mr D and his mother were keen to employ personal assistants through direct payments, this did not go to plan and the contingency plan was to use agency staff from one provider. His mother provided feedback at reviews about what had worked well and concerns about what had not. There was insufficient detail on the review to say what steps might be taken to assist Mr D to employ his own personal assistants, supported by his mother.
    5. What was lacking in all the documentation however was how the Mental Capacity Act was translated into practice and how practitioners complied with the Act and code of practice in relation to Mr D.

**4.2 Commissioning care through personal budgets**

4.2.1 There are a number of important decision-making points in setting up self-directed support and personal budgets where a person’s mental capacity has to be considered.

* How does the Mental Capacity Act apply to a person who lacks capacity in relation to managing direct payments and their own care?
* How do Personal Assistants ensure that they are competent and give a good standard of care?

4.2.2 Mr D’s support plan included a Person Specification detailed with the knowledge, skills and experience Mr D was looking for. This included safeguarding, manual handling, confidentiality and treating him with dignity. The reviewing process appears to be how personal assistants would be monitored through the funding of Mr D’s care package with the emphasis on Mr D and his mother managing the personal assistants on a day to day basis.

4.2.3 The LB Tower Hamlets in conjunction with five other East London boroughs and with a voluntary organisation supported by Skills for Care have since developed a programme for personal assistants and people wanting to employ them.

**4.3 Clinical examinations**

4.3.1Adults with learning disabilities are people first who have the same rights as other citizens to healthcare, but may have particular health needs. Reasonable adjustments might need to be made to accommodate their needs. For Mr D this was the case.

4.3.2 The GP practice said that they were unable to examine Mr D as there was nothing in place to support people who needed to use a ceiling hoist and a home visit was not requested or suggested. It has since put in place a policy of home visits for people with complex needs.

4.3.3 The possibility of diagnostic overshadowing particularly at the hospital however cannot be ignored. The General Medical Council (GMC) defines diagnostic overshadowing as, “once a diagnosis is made of a major condition there is a tendency to attribute all other problems to that diagnosis, thereby leaving other co-existing conditions undiagnosed.”

**4.4 Values and standards**

4.4.1 Equality, dignity and rights are fundamental principles. There are a number of tools available for agencies to demonstrate and deliver services that embrace these principles in their values and standards. All agencies might consider reviewing their organisational equalities and diversity polices to assure themselves that ‘reasonable’ adjustments are being made, and that there are safeguards against discriminatory practices.

4.4.2 The report by Barts Health and account from Mr D’s mother would suggest that there were elements of diagnostic overshadowing as focus was placed on Mr D’s learning disability and the family capacity to provide on-going care and support which failed to meet the principles outlined above.

**4.5 Communication: With adults with care and support needs**

* + 1. There is evidence that people with learning disabilities are not always able to access mainstream services. Mencap’s report ‘Death by Indifference’ found that people with learning disabilities continue to have poorer experience and outcomes compared to people without learning disabilities.
    2. Dr. Matt Houghton, the lead investigator of the Confidential Inquiry into premature deaths of people with learning disabilities and the medical director of the Royal College of General Practitioner’s Clinical Innovation and Research Centre, emphasises that an important part of the doctor-patient relationship is building trust and rapport. If a patient has difficulty communicating, this process can take more time and effort. But without making this human connection, professionals can fall into the trap of diagnostic overshadowing, and fail to apply the same diagnostic principles that they would with other patients
    3. The London Borough of Tower Hamlets and the CCG has not made a specific local response to the inquiry itself. However this, and the number of local noted deaths did inform its decision to participate in a pilot by the NHS England Learning Disability Mortality Review Programme. The review and work by Tower Hamlets will provide some key learning going forward that the SAB might consider in its deliberations of this SAR.
    4. Culture change in all agencies in the way that they communicate with people is one way to reduce risks to people with a learning disability. The locum GP, locum pharmacist, paramedics and hospital staff all directed conversations to Mr D’s mother who was their only means of understanding Mr D. There was no previous history and rapport with any of the individuals or agencies and there was no means of them knowing the best way to communicate with Mr D directly.
    5. Mr D’s support plan notes his personal difficulties in being touched and yet there was no communication plan or Health Action Plan in place. Mr D had a rare condition which posed challenges to communicating with others, and would certainly have challenged a physical examination.
    6. Neither did Mr D have a hospital passport which may have helped professionals to understand and communicate with him better and have an understanding of his baseline health and abilities. None of the agencies involved noted any particular, skills, knowledge, experience or training for staff in communicating with people with a learning disability.
    7. It is the responsibility of health and social care professionals to ensure that Mr D had an individual health and/or communication plan and support and guidance to obtain a hospital passport which may have helped professionals to understand and communicate with him better. The latter is produced by the North East London Foundation Trust and made available through the CLDT or Hospital Liaison Nurse for Learning Disabilities. As a joint health and care service both clinical and non-clinical staff are responsible for documentation.
    8. For Mr D, the benefit of an annual check might have been:
* Assurance that his general health was good
* Review of his epilepsy (although he did have regular neurology outpatient appointments)
* Review of support from other health professionals e.g. the occupational therapy service
* An opportunity of assessing his life style and discussing preventative medicine
  + 1. Where someone has complex needs it might be helpful to consider a check at the statutory social care annual review to ensure that there is an updated Health Action Plan, communication plan and hospital passport.

**Communication: With Carers**

* + 1. The main source of information about how to communicate with Mr D was his main carer, his mother.
    2. The CLDT offered the mother a carer’s assessment which she declined. Although the Care Act 2014 provides a legal platform for people who might appear to have care and support needs to a carer’s assessment, there is no obligation on the part of the carer to take up the offer.
    3. Mr D’s mother was happy to continue caring and had opportunity for time to herself through regular respite. It would be good practice to continue to explore with carers their experiences of caring, and offer person centred support in the same way that person centred care is advocated for service users. The NHS Five Year View advocates providing support to carers through local community groups but it should be borne in mind that not all carers want or can attend groups.
    4. In this case, there were a number of interactions between professionals and Mr D’s mother where she felt she was not being listened to, initially with the GP.
    5. The London Ambulance Service (LAS) responded to the 999 call and spoke appropriately with the mother. It is not known whether the LAS were aware of the personal needs of Mr D related to his learning disability.
    6. Mr D’s mother felt very strongly about the negative interaction between herself and the hospital consultant. She reported that she was not listened to and that assumptions were made that she was unable to cope with caring, rather than the focus being on Mr D’s medical presentation. Following the death of her son there was uncertainty on the part of the consultant about contacting the family. His mother was later supported by the bereavement counselling service.
  1. **Mental Capacity & Best Interest**
     1. No specific Mental Capacity assessment was located. Support and care assessments from a range of health and social care professionals relating to adult social care reviews, OT assessment and reviews, and a safeguarding concern relating to a provider service in 2012 all refer to Mr D as non-verbal with complex needs.
     2. The GP description of Mr D in his IMR implies that mental capacity was not seen as an issue. “Patient had severe global developmental deficiency and had no speech and he had no mental capacity. I do not think this was recorded anywhere as his Mum had always taken all decisions for him on his care.” The London Ambulance Service said, “Mr D was deemed to not have capacity, a full capacity test was not necessary on this occasion as Mr D was conveyed to hospital.” Such global statements are not compliant with the Mental Capacity Act 2005. (MCA)
     3. Applying the MCA as part of the care of people should not be seen as separate from providing core health and social care services. The MCA is integral to the measures services take to protect and promote the rights of people using its services.
  2. **Safeguarding**
     1. There was a paucity of recording about how each agency translates its commitment to safeguarding, mental capacity and best interest in its training. Agencies in their IMR reports all stated that there were no safeguarding concerns. It should be noted that agencies said that staff were trained in safeguarding and mental capacity but there was no evidence based training documents to support this.
     2. In this case, there was not an s42 Care Act 2014 safeguarding enquiry, although there was an SI investigation. A thematic review of deaths of people with a learning disability led to the SAR, it might therefore be helpful for the SAB to consider how to monitor SI’s and any learning through the local Quality Surveillance Group (QSG).
  3. **Duty of candour**
  4. The Francis Report (2013), concluded that, "insufficient openness, transparency and candour lead to delays in victims learning the truth, obstruct the learning process, deter disclosure of information about concerns, and cause regulation and commissioning to be undertaken on inaccurate information and understanding.” It is welcomed that agencies were keen to learn about improvements. This is summed up by the London Ambulance Service in its IMR, “the Trust has not identified any issues arising from its management of this incident but is fully prepared to take on board any issues that may come to light.”

# Conclusions and recommendations

* 1. There was no evidence of intentional abuse from the health and social care agencies but it could be argued that there was neglect by them, in the failure to make reasonable adjustments for disabled people and the focus on the presenting emergency medical situation. There appears to be some stereotyping of people with a learning disability by a lack of poor communication; understanding of mental capacity; and hidden attitudes affecting the way that professionals dealt with Mr D.
  2. Judgements were made in Mr D’s case with the information to hand to provide medical, health, care and support although the mother’s contribution was not always listened to. If reasonable adjustments were made at the initial GP appointment, the outcome might however have been different. This might include:
* home visits to ensure that people with complex needs like Mr D are more relaxed undergoing physical examination in familiar surroundings.
  1. Gastrointestinal bleeding symptoms can cause serious and even fatal consequences if not diagnosed and treated quickly. A delay from the GP appointment to the A&E assessment is noted. Steps taken by Harford Health to change its policy to ensure that physical examinations are accessible to all patients might helpfully be shared with other health providers.
  2. Ensuring effective information sharing between GP surgeries and the local CLDT by gaining consent from service users to provide a more integrated health and social care approach is strongly advocated. This review highlighted that there are a number of documents held by a range of services that would benefit from a more streamlined comprehensive system. It might be argued that this would improve the chances of people with a learning disability receiving a Health Check, where the national target is 75% and the local figure is 57%.
  3. It is recommended that there is wide promotion and checks on learning disabled people to have annual health checks, Health Action Plans and Hospital Passports. Where people have personal communication needs this should be highlighted in such plans. Furthermore carers who provide day to day support to people with care and support needs, should be included in devising the plans and they should be accessible to them.
  4. Good practice was noted in offering carers an assessment in their own right. An audit identifying take up, themes, might be considered as part of promoting safeguarding prevention and wellbeing.
  5. This review highlighted the need for training and competence testing by agencies providing health and social care to cover:
* an understanding of learning disabilities
* communicating with people who require additional time and support
* understanding the increased health needs of this group
* overcoming barriers in consultations and physical access
* collaborative working with carers
* consent
* Mental Capacity Act
* Equality Act
  1. Training should be aimed at all staff levels to have a minimum of awareness of the issues and good practice. In the event that people manage their own budget and personal assistants, there needs to be assurance that people are adequately trained and have the right set of behaviours as outlined by Skills for Care.
  2. The current SAR SAB protocol requires updating and made accessible for all residents of Tower Hamlets. Guidance on the SAR process might be usefully provided to ensure more consistent quality standards to completing documentation by IMR authors, understanding by agencies, and clarity for adults and their families.

1. Melena: Abnormal dark tarry faeces containing blood (usually from a gastrointestinal bleeding)

   www.vocabulary.com/dictionary/melena [↑](#footnote-ref-1)