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

**Tower Hamlets Safeguarding Adults Partnership Board**

# Acknowledgements

# I am indebted to Mr D’s mother whose care throughout his life enabled him to live in a meaningful and contented way. Much of her time was devoted to Mr D’s wellbeing and her generosity in sharing her thoughts and personal papers have added value to the understanding of who Mr D was. He was first and foremost a son and brother who was much loved and cared for by his family.

# My thanks to the Tower Hamlets Safeguarding Adults Board Executive together with those of Mr D’s mother whose comments and extensive feedback has been accepted. I would also like to extend thanks to the IMR authors and organisations who contributed to the report and the panel members who provided valuable insights into improving outcomes for people with care and support needs.

**Glossary and abbreviations**

**Individual Management Review (IMR):** An IMR is a document that provides an account of the decisions made, actions taken and services provided by an agency about an adult who is subject of a Safeguarding Adult Review.

**Making Safeguarding Personal (MSP):**is a sector led initiative which aims to develop an outcomes focus to safeguarding work, and a range of responses to support people to improve or resolve their circumstances. It is about engaging with people about the outcomes they want at the beginning and middle of working with them, and then ascertaining the extent to which those outcomes were realised at the end

**Safeguarding Adults Board (SAB):** All Local Authorities must establish a SAB as set out in the Care Act 2014. The Act (Schedule 2) gives the local SAB three specific duties including, to decide when a Safeguarding Adult Review is necessary, arrange for its conduct and if it so decides, to implement the findings.

**Safeguarding Adults Review (SAR):** Section 44, the Care Act 2014 stipulates that SABs must arrange a SAR when an adult in its area with care and support needs dies as a result of abuse or neglect, whether known or suspected, and there is concern that partner agencies could have worked more effectively to protect the adult. SABs must also arrange a SAR if an adult with care and support needs, in its area has not died, but the SAB knows or suspects that the adult has experienced serious abuse or neglect.

**Serious Incident (SI):** An event or circumstance which could have resulted, or did result in unnecessary damage, loss or harm such as physical or mental injury to a patient, staff, visitors or members of the public.

**Serious Incident Framework (SIF)** The Framework seeks to support the NHS to ensure that robust systems are in place for reporting, investigating and responding to serious incidents so that lessons are learned and appropriate action taken to prevent future harm.

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# 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. Individuals with SLD characteristically have little or no speech, have difficulty learning new skills and require total support with daily living activities e.g., dressing, eating, washing toileting etc. These activities can pose great difficulty and can take longer than usual. Mr D was hypersensitive to sensory input, e.g., when touched he may have felt stressed and threatened therefore would scream, struggle and may tense up in such situations.
	3. 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. His mother, reported that Mr D first experienced seizures when he was 13 years old. He had two hospital admissions in 1997 and 1998 for seizures and since this time his seizures were well managed by medication [carbamazepine].
	4. There was no side effect noted by W’s use of long term carbamazepine, but there have been rare instances of blood in the stool and urine of some users.

(<https://www.drugs.com/sfx/tegretol-side-effects.html>)

* 1. A post mortem attributed Mr D’s death to
1. Gastrointestinal haemorrhage
2. Bleeding peptic ulcer
3. Cerebral palsy
	1. At the inquest, Mr D’s mother raised questions that are elaborated on in section 4, and are included in the scope of this Safeguarding Adult Review (SAR).
	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.

1.8 A Safeguarding Adult Review (SAR), referral was made to the Safeguarding Adult Board (SAB) in August 2016 and accepted a SAR should be completed to see what lessons could be learnt to prevent such situations reoccurring. 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.

1.9 Section 44, of the Care Act 2014 stipulates that SABs must arrange a SAR when an adult in its area with care and support needs dies as a result of abuse or neglect, whether known or suspected, and there is concern that partner agencies could have worked more effectively to protect the adult. SABs must also arrange a SAR if an adult with care and support needs, in its area has not died, but the SAB knows or suspects that the adult has experienced serious abuse or neglect.

1.10 The SAB decides when a SAR is necessary, arranges for its conduct and if it so decides, implements the findings. The criteria are met when:

* An adult at risk dies (including death by suicide) and abuse or neglect is known or suspected to be a factor in their death; or
* An adult has sustained a potentially life threatening injury through abuse, neglect, serious sexual abuse or sustained serious and permanent impairment of health or development through abuse or neglect; and one of the following:
1. Where procedures may have failed and the case gives rise to serious concerns about the way in which local professionals and/or services worked together to safeguard adults with care and support needs;
2. Serious or apparently systematic abuse that takes place in an institution or when multiple abusers are involved;
3. Where circumstances give rise to serious public concern or adverse media interest in relation to an adult/adults with care and support needs.
	1. The SAR process is not intended to provide forensic answers to what went wrong or place blame on individuals or organisations. “SARs should seek to determine what the relevant agencies and individuals involved in the case might have done differently that could have prevented harm or death. This is so that lessons can be learned from the case and those lessons applied to future cases to prevent similar harm occurring again. Its purpose is not to hold any individual or organisation to account. Other processes exist for that, including criminal proceedings, disciplinary procedures, employment law and systems of service and professional regulation, such as the Care Quality Commission (CQC), the Nursing and Midwifery Council, the Health and Care Professions Council, and the General Medical Council.”(DH, 2016)
	2. This 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. Sincere apologies are offered to Mr D’s family for any distress that this may have contributed to.
	3. 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 his safety or the need for safeguarding intervention.
	2. Mr D living 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. His care package included daily assistance with personal care, attendance at a Day Centre five days a week, and regular respite care. His mother acknowledged that she was always present at personal care times, as she had found the care and support variable from support workers. The social worker had spoken to her about not allowing the support workers to undertake the tasks in the care plan unsupervised. The provider had met with the mother and social worker, and discussed at social care reviews the concerns about the care provided which resulted in the request for a personal budget.
	3. On Monday 11th May 2015 Mr D’s personal care did not indicate anything unusual. His bowels were opened as normal with no abnormalities noted. The weekend prior he had been at respite and his mother was not informed of any unusual bowel motions or any other health concerns, except that Mr D would not eat his lunch and she subsequently visited to encourage him to do so.
	4. On Tuesday 12th May 2015 during his personal care, Mr D’s mother noticed that he had “passed blackened stuff with an unusual odour in the bath water he was sitting in.” His mother took the decision that Mr D should stay at home, cancelled his day centre and arranged an emergency visit to the GP, the same day at around 11.30am.
	5. His mother took Mr D to see the GP and had to wait as there was no pre-booked appointment, Mr D attended the surgery as an emergency patient. The family doctor was not on duty and Mr D was seen by a locum GP. The family had a good relationship with the surgery, and the mother said that the regular GP knew that she did not bother the surgery unnecessarily, and this was the first emergency appointment that had been requested.
	6. At the appointment Mr D was not spoken to and the locum GP directed all conversation to his mother. She was asked if there was red blood being passed and whether Mr D was constipated. She reported that Mr D had been to respite and queried whether or not there would be an adverse effect if Mr D took his epilepsy medication on an empty stomach. His mother said that the locum GP confirmed that the particular medication Mr D was on would not cause Mr D difficulties.
	7. Mr D’s mother said that she raised this question with the GP because “when he goes to respite it has always been problematic for many years.” (amended notes). There were however no reports of difficulties from the respite service who had a good relationship with the mother.
	8. Mr D’s mother said that the locum GP wanted to examine Mr D but was unable to do so as Mr D was unable to stand. The GP was unable to undertake a physical examination and Mr D was diagnosed with constipation. He prescribed Anusol cream[[1]](#footnote-1) to be applied rectally.
	9. Mr D’s mother said that she was advised to see if there was any “overgrowth pile and use the ointment for seven days.” His mother said that she was not satisfied with the diagnosis and that her description of “black blood clots” did not change the medical opinion.
	10. On the way home from the GP surgery, Mr D and his mother stopped at a local pharmacy to have the prescription filled. The mother discussed the locum GP diagnosis with the pharmacist and said that she disagreed with it. The pharmacist was not the usual pharmacist, who knew Mr D’s medical history. The mother noticed that Mr D may have soiled himself and the same offensive smell she had noted earlier when supporting his personal care and promptly left the pharmacy.
	11. Mr D did not return to the day centre until 14th May 2015, when his mother thought that he appeared a lot better and that the locum GP may have been right in his diagnosis. Mr D also attended the day centre the following day 15th May 2015 without any reported concerns.
	12. 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.”
	13. On Saturday, 16th May 2015 Mr D is said to look a little pale and tired but his mother was not unduly concerned as he was smiling. Mr D ate breakfast, took his medication, asked to watch television and for his door to be closed. This is how Mr D communicated that he was not ready to get up.
	14. His mother later began his personal care with some coaxing, using the ceiling hoist to assist in transferring him from the bed to the toilet when he screamed and shouted “bed, bed, bed.” His mother could not calm Mr D down and transferred him to a warm bath hoping that the water would do so. A short while later (estimated by the mother as10 minutes) his mother telephoned the emergency services using 999 as Mr D was still distressed and she was concerned that he was in pain.
	15. The London Ambulance Service (LAS) call centre sent an ambulance crew and a motorcycle rapid response call.
	16. Mr D was transported by ambulance to the Accident & Emergency Department of the Royal London Hospital.
	17. 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. This is usually indicative of someone guarding against their stomach being touched as they are in pain. It may also in Mr D’s case have been symptomatic of his sensory defensiveness.
	18. 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.
	19. The paramedic team took a history from the mother and noted incidents of melena[[2]](#footnote-2) in the past week. The LAS crew documented that obtaining clinical observations was difficult due to Mr D’s presentation and disability; his mother stated she could tell that he was in obvious discomfort.
	20. Mr D was transported to hospital as a non-urgent transfer and joined the queue for emergency assessment. LAS in its IMR stated that, a priority alert was placed with the hospital to enable the hospital staff to be prepared for Mr D’s arrival. The ambulance arrived at the hospital at 13:36 where a handover of care was given to the hospital staff.
	21. The Barts Health 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. Concern is noted in the chronology that Mr D showed signs of clinical deterioration and probable circulatory failure and it is likely that his condition was now critical with severe circulatory compromise.
	22. There is some discrepancy in the account of Mr D’s mother and the Accident & Emergency consultant about how long Mr D was left alone in the cubicle, between the initial consultation by the consultant and the subsequent emergency action taken when he returned. This discrepancy was highlighted by the mother at the coroner’s inquest and investigated under the NHS Serious Incident Framework. Given the two different times proffered by the consultant in the Serious Incident investigation, both of which are different to that of the mother, the conclusion was reached that Mr D was left alone with his mother for a period of over 10 minutes without clinical observation.
	23. When the consultant returned to the cubicle, full cardio-pulmonary resuscitation commenced. Mr D was also intubated, auto pulse attempted and central access blood transfusion commenced.
	24. Mr D had arrived at the hospital at 13.36pm and died at 15.25pm.

# Terms of reference and methodology

* 1. “The SAB should be primarily concerned with weighing up what type of ‘review’ process will promote effective learning and improvement action to prevent future deaths or serious harm occurring again. This may be where a case can provide useful insights into the way organisations are working together to prevent and reduce abuse and neglect of adults. SARs may also be used to explore examples of good practice where this is likely to identify lessons that can be applied to future cases.” DH, 2016.
	2. To assist with the process a ‘scoping meeting’ was convened on 31st January 2017 by the then Safeguarding Adult Board Manager, chaired by the independent Safeguarding Adult Board chair to identify:
* The agencies to be involved in the review
* The Lead/Author for each agency
* The period to be reviewed (date from – to)
* The Terms of Reference for the review
* Standards for anonymisation and confidentiality
* Engagement and involvement of family
* Timescales
* Dates for Authors Briefings
* Communication strategy with clear leadership and co-ordination to include
1. Family liaison
2. Publication
3. Media
4. Learning events
	1. A SAR independent chair, an independent overview report author and panel membership for this SAR was determined as follows:

|  |  |
| --- | --- |
| **Name & Job Title** | **SAR Role** |
| Deputy Director Mental Health & Joint Commissioner. Tower Hamlets CCG | Chair Overview Panel  |
| Independent Safeguarding & Social Care Consultant | Overview Report Author |
| Joint Safeguarding Adults Strategy & GovernanceManagerLB Tower Hamlets | Governance of SAR policy and procedure |
| Safeguarding Adults Board Co-OrdinatorLB Tower Hamlets | Administration |
| Deputy ManagerThe Camden Society | IMR AuthorHotel in the Park (Respite Service) |
| GP PartnerHarford Health Centre | IMR AuthorHarford Health Centre (GP Surgery) |
| Head of SafeguardingLondon Ambulance Service | IMR AuthorLondon Ambulance Service |
| Safeguarding LeadNHS Barts Health | IMR Author Barts Health |
|  | IMR AuthorTower Project New Dawn Day Centre |
| Service Manager – Access to ResourcesLB Tower Hamlets | Background papers held by CLDT |
| Matron/Clinical Nurse SpecialistEast London NHS Foundation Trust | Panel Member |

* 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. The scoping meeting agreed to keep the focus on whether there are lessons to be learned about how individuals and agencies worked together to safeguard Mr D. The questions to be answered are:
* Did Mr D suffer abuse and/or neglect because of multi-agency failings?
* Could anything have been done to identify health needs earlier?
* What are the multi-agency issues in relation to information sharing?
* Did services comply with each agency’s professional standards and relevant policies, procedures, protocols and clinical governance, particularly those relating to safeguarding, mental capacity and best interest?
* What training did frontline staff have to know how to communicate with people with a learning disability?
* How effectively did agencies communicate with Mr D and his mother?
	1. An Individual Management Review (IMR) and chronology was requested from each of the following agencies:
* Barts Health (The Royal London Hospital Accident & Emergency Department)
* London Ambulance Service
* Harford Health Centre (GP surgery)
* Tower Project New Dawn (day care service)
* Hotel In the Park (respite service)
	1. The SAR included the history of care and support through a chronology of records held by the Community Learning Disability adult social care team responsible for funding Mr D’s adult social care support package.
	2. Agencies submitted in support of their IMR and chronology the following evidence where appropriate and available:
* Key assessments
* Reports
* Reviews of patients/ service users/ services
* Links to relevant policies and guidance
* Details of expectations and requirements as outlined in service specifications and contracts
	1. It was noted that other NHS processes had taken place to review and scrutinise decisions and actions via its complaint procedures, an SI investigation in addition to a coroner’s inquest. Reports and information from other processes were used to help build up an overall chronology of events leading up to Mr D’s death. Those agencies who were involved in these processes also used this information in their IMR submissions.
	2. Mr D’s mother was invited to be involved in the SAR and provided a detailed statement taken by the author in a meeting held on 19th January 2017. She also shared her papers and records with the author for the purpose of ensuring that this review heard the voice of the family. This is commented on further in section 4.
	3. A communication strategy with the family was agreed by the scoping meeting. The SAB manager would maintain contact with the family and make an open offer of support to enable involvement in the SAR and keep them informed of progress. This would ensure that the family had a named person to contact in the event of any queries. It was also agreed to offer bereavement counselling.
	4. The SAR start date was agreed as from 1st May 2015 as Mr D had been on planned respite the weekend of 11th May 2015 and it was important to establish Mr D’s usual health baseline and routines.
	5. Tower Hamlets Safeguarding Adults Board Partnership policy and procedure was reviewed with the introduction of the Care Act 2014. The Act itself does not stipulate how SABs should conduct a SAR or who the report should be made available to. The current draft protocol reflects some of the guidance but would benefit from further review and best practice guidance under the Making Safeguarding Personal agenda
	6. At present the protocol states that the full report is made available to the SAR panel, Tower Hamlets Safeguarding Adults Board, the family and others upon request. The Board is keen to maintain the confidentiality and dignity of adults, family and friends. An executive summary is made available on the LB Tower Hamlets website[[3]](#footnote-3). On conclusion of a SAR, an action plan is drawn up to ensure the recommendations of the findings are implemented monitored by the Executive SAB. This includes feedback from family and friends to support learning for all agencies and individuals.
	7. The overview report collates and analyses the information contained in the IMRs and any other reports/ information presented at the SAR meetings with reference to relevant research/guidance. It highlights lessons learned and draws overall conclusions in terms of key issues for the safeguarding partnership. It makes recommendations on what actions the safeguarding partnership might take following the SAR.
	8. The Tower Hamlets Safeguarding Adults Partnership Board will determine the type of learning event(s) that will take place to ensure that practitioners and strategic leads focus on the key messages.

# Making Safeguarding Personal – family views and outcomes

* 1. The impact of the Care Act 2014 places adult safeguarding on a statutory footing and protects the rights of people who use services and those of their family and friends who provide unpaid care and support.
	2. There has been a gradual culture shift in adult safeguarding practice under the Making Safeguarding Personal agenda, to put the adult with care and support needs in the driving seat, by supporting them to determine the outcomes that they would like from their own safeguarding enquiry.
	3. The DH Guidance, 2016 emphasises that, “early discussions need to take place with the adult, family and friends to agree how they wish to be involved.” Whilst there is no specific guidance on how adults, family and friends might be involved in SAR’s, the ‘Making Safeguarding Personal’ agenda advocated in chapter 14 of the DH Guidance stresses the importance of the adult (or their representative) remaining central to all decision making.
	4. The Tower Hamlets Safeguarding Partnership Board has adopted the London Multi-Agency Safeguarding Adults Policy and Procedures, (2015). It states that, “Communication should be established at the earliest opportunity and advocacy provided to support the adult. Information should be given about how the SAR will be conducted and how they [adults] can be involved or, in the event that the adult has deceased, how nominated people can be involved.”
	5. Following the first meeting with Mr D’s mother, typed notes were sent to her to review the content and make any amendments. She made amendments and stressed that she wanted the SAR to achieve the following:
* Organisations to acknowledge errors in order that they can minimise the risk of the same errors happening to another family

 It is noted that Barts Health and LAS met and offered apologies to Mr D’s mother for any errors following their internal investigation. Any SAR learning event and SAR action plans are vehicles for all agencies to determine how lessons can be learnt from Mr D’s death to minimise risk to other adults.

* Organisations to develop an awareness that mistakes happen and that they can learn from them so that W’s death would not be in vain

The Care Quality Commission (CQC) report ‘Learning Candour and Accountability’ in 2016, describes what the CQC found when it reviewed how NHS Trusts identify, investigate and learn from the deaths of people under their care. The CQC research resulted in National Guidance on Learning from Deaths published by the National Quality Board in March 2017. The Learning Disabilities Mortality Review Programme Annual Report (December 2017) notes that “the guidance emphasises the importance of learning from reviews of the care provided to patients who die, and that this should be integral to a provider’s clinical governance and quality improvement work. It requires providers to have a clear policy for engagement with bereaved families and carers, and an updated policy on how they respond to, and learn from, deaths of patients who die.”

 At a local level Tower Hamlets has signed up to the ADASS commitment to support any activity that promotes learning and future prevention of inequality. Plans in progress to strengthen this commitment include:

* universal health services awareness and skills development of their staff so they can better support adults with learning
* funding for a learning disability nurse for a year to train general practices about health checks for adults with learning disability
* the CLDS now helps make sure everyone has an annual health check and a health action plan.
* A plan to improve support for adults with learning disability admitted to hospital with mental illness has been developed and is being implemented.

Tower Hamlets joined a national pilot and carries out local reviews of deaths of adults with learning disability. The learning is used to improve care and support to people with a learning disability.

* Address organisational and individual prejudice towards people with a learning disability that may impact on their access to services.

 Contributors to the Tower Hamlets Learning Disability Strategy 2017-20 echoes the outcomes expressed by Mr D’s mother. The strategy is to address that health staff communicate well with people and give them easy to understand information after each contact.

* Organisations to develop an open culture to complaints and investigations as they are expected within policies and statute.

 Mr D’s mother experienced difficulties in finding out who to contact and raise concerns to about the treatment her son received. She was ultimately supported by the bereavement service. All CQC health and social care registered organisations must comply with Regulation 20 – Duty of Candour. “The intention of this regulation is to ensure that providers are open and transparent with people who use services and other 'relevant persons' (people acting lawfully on their behalf) in general in relation to care and treatment. It also sets out some specific requirements that providers must follow when things go wrong with care and treatment, including informing people about the incident, providing reasonable support, providing truthful information and an apology when things go wrong.”

* 1. The family’s desired outcomes combined with the focus of the enquiries of the SAR (3.7 above) are considered in the analysis and recommendations of this report.
	2. Section 68, of The Care Act 2014 requires that a local authority must arrange, where appropriate, for an independent advocate to represent and support an adult who is the subject of a safeguarding enquiry or SAR where the adult has ‘substantial difficulty’ in being involved in the process and where there is no other appropriate individual to help them. DH (2016)
	3. Any testing for ‘substantial difficulty’ was not undertaken with the mother representing the family as there was pre-agreement that the local authority would offer advocacy and/or any support to ensure that the voice of the family was heard. Mr D’s mother was offered advocacy and support and it is noted that she was supported through the SI process by the bereavement counselling service which she was appreciative of, she declined advocacy during the SAR process.
	4. The scoping meeting agreed that support would remain an open offer if at any time the mother changed her mind. It was further commented on by Mr D’s mother that she was well practised in advocacy and had played a major advocacy role with Mr D.

# Mr D the person

* 1. Mr D was born on 21st October 1984. He was the youngest of three children. His brother and sister are both university educated as is his mother. They are a close knit family and Mr D was well loved. The family did not view him as a disabled person but as a son and brother. Mr D’s support plan states that, “My family is very important to me and my mum is my main carer.” He also said, “I should really list my disabilities, even though that is only part of who I am.”
	2. Mr D liked to be called the Boss or the Director within the family. His mother described him as happy and always smiling. She rarely sought GP appointments as Mr D was generally well.
	3. Mr D was born in the Tower Hamlets and lived there all his life. His mother gave up paid work to care for Mr D and her two older children.
	4. Mr D moved house three times but remained with the same GP and knew the surrounding area well, and was well known in the community.
	5. Mr D was assessed by children’s social care services and special educational needs. He had a transition plan to transfer to adult social care when he reached 18 years old. Mr D, therefore had a long history with the local authority as he was known to education, children and adult social care. For Mr D it was important that he built up trust with people because of his sensory defensiveness.
	6. Mr D’s sensory defensiveness meant that he found it difficult to be touched in certain ways as he was hypersensitive to sensory input. His care plan lists this as a major concern as he experienced some care as threatening and stressful which made him scream and tense up. This is summarised as, “Living with Sensory Defensiveness is hard work for me as well as those that support me.” (Taken from LB Tower Hamlets Support Plan undated)
	7. Mr D used a ceiling hoist for all transfers to meet his personal care needs. He was also a wheelchair user both indoors and outdoors. There were regular reviews from an Occupational Therapist (OT) to consider any change to his needs, and that equipment was regularly serviced as per the manufacturer specifications. The last OT review was recorded as November 2014.
	8. The day care provider and worker who worked consistently with Mr D indicates in written records that Mr D could let his likes and dislikes be known, indicate if he did not want to eat or do something by gestures and body language.

5.9 Mr D’s mother said that he was in tune with how she was feeling and was a caring son who would say ‘phone’ indicating that she should telephone friends and family as Mr D knew that this made her feel better. He also let it be known if he wanted to watch television or remain in his room by the use of simple words.

# Analysis & Findings

**Assessment, support plans & reviews by Community Learning Disability Team (CLDT)**

* + 1. The process of assessment, support planning and reviewing are 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. All adult social care assessments should embrace the principle of wellbeing. Wellbeing relates to:
	+ personal dignity (including treatment of the individual with respect)
	+ physical and mental health and emotional wellbeing
	+ protection from abuse and neglect
	+ control by the individual over day-to-day life (including over care and support)
	+ participation in work, education, training or recreation
	+ social and economic wellbeing
	+ domestic, family and personal relationships
	+ suitability of living accommodation
	+ the individual's contribution to society

6.1.2 Good adult social care assessments are:

* Person centred
* Involve the person and/or advocate
* Multi professional
* Identify strengths of service users
* Identify risks
* Notes conflicts (conflicts between carers and the service user)
	+ 1. Person-centred care emphasises the importance of choice and control for the service user. In D’s case, all professionals tended to focus on the mother as the decision maker. There is no indication that D’s best interest was not served through this approach but neither was there any indication that D’s views or alternative options were explored to see if he had views independently of his family as no Best Interest documentation was available.
		2. A person-centred approach puts people, families and communities at the heart of health, care and wellbeing. It means people feeling able to speak about what is important to them and the workforce listening and developing an understanding of what matters to people.
		3. Staff in health and social care services are often working under intense pressure and severe time constraints which may impact on practice and behaviour. However, the values and behaviours of being person-centred is a fundamental approach. It should also be recognised that professionals especially the emergency services have to act quickly and put patient safety above all else.
		4. An assessment of need is the basis for a support plan. All service users should have a personal support plan. The plan contains personal information about their history, needs, preferences and what care they have agreed to. The Care Act 2014 sets out the legal responsibility to ensure support plans meet the adult's needs and outcomes.
		5. Support Plans should be:
	+ Current
	+ Outcome focussed:
	+ Take an integrated approach
	+ Aim to meet basic needs (daily living)
	+ Aim to safeguard the service user
	+ Aim to improve the quality of life
	+ Aim for the service user to achieve their full potential
		1. 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.
		2. Service User Reviews should note who was invited to reviews and whether information was available either in person or by report. Reviews conducted by report and from a limited number of people are less likely to be holistic than those that include a range of inputs from professionals, informal networks and advocates. Direct contact with the service user is essential for measuring the effectiveness of outcomes from services. Efforts should be made to engage service users and provide them with a voice placing them at the centre of the reviewing process. Where there are no changes in circumstances that require a change in the support plan these should always be noted.
		3. Good practice indicates that the essential components of a Review should focus on:
* Whether the agreed outcomes of the support plan are achieved
* If not, is there a satisfactory explanation
* Action identified to achieve outcome
* Service user evaluation of what has worked well and what needs to be done differently
* Carers views about their role and feedback on services
* Significant changes since the last review
* Clear allocation of responsibility and timescales
* Safety and safeguarding risks
* Contingency plans
	+ 1. 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.

**Commissioning care through personal budgets**

6.2.1 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. A person who lacks mental capacity to manage a direct payment may still receive one if a ‘suitable’ person is available to manage it for them. Where a person is assessed as lacking capacity to either choose a direct payment or manage a personal budget, local authorities must make a best-interest decision about how the person’s support will be managed.

6.2.2 Some key questions to consider are:

* 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?
* How do Personal Assistants work with other organisations to keep a person in their care who lacks mental capacity safe?
* How will the effectiveness of direct payments be monitored in meeting the persons changing needs and ensure their health and well-being?

6.2.3 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.

6.2.4The nature of the relationship between the employer (the service user) and the employee (the PA) is such that there will be occasions when the employer’s priorities in choosing a PA may not include the range of training that would be compulsory for CQC registered care providers. In such instances a risk assessment that underpins the decision about providing a Direct Payment, particularly if there are specific medical conditions that require ongoing management, or other specialist requirements should always be undertaken and discussed with the service user.

6.2.5The LB Tower Hamlets in conjunction with five other East London boroughs and with Real (and supported by Skills for Care), the new PADE UP website <http://www.real.org.uk> which once fully live will provide a suite of online training modules covering all of the basics (and linked to the knowledge requirements of the Care Certificate).

6.2.6The aim of the website is to give easy access to a range of learning by making it accessible from PC, tablets and smartphones so modules can be completed at times and places convenient to the PA. PAs will then be able to ‘advertise’ the modules they have completed (and any specialist training they have done in addition) on the PA register. This is a positive step forward for people like Mr D to have person centred care, specific to their needs.

6.2.7 Skills for Care provide some useful guidance for both personal assistants and people employing their own personal assistants that might be helpful for managers to consider. <http://www.skillsforcare.org.uk/Employing-your-own-care-and-support/Resources/Working-as-a-PA/1.-What-is-a-PA/Being-a-personal-assistant/Being-a-personal-assistant.pdf>

**Clinical examinations**

6.3.1 Adults with learning disabilities are people first, who should be valued and respected for their differences. They 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 W this included communication, physical and functional needs.

6.3.2 At the surgery, the locum GP was 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 by the surgery. The surgery has now put in place reasonable adjustments for the benefit of adults with physical disabilities who cannot be assessed at the surgery.

6.3.3 It would be assumed that there would be equipment at the hospital to enable an examination but it appears that the issue of diagnostic overshadowing might have taken place.

6.3.4 The General Medical Council 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.”

6.3.5 The GMC quotes the research by Emerson and Baines, (2010) “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.”

6.3.6 In short, diagnostic over shadowing describes the tendency healthcare professionals have to attribute to symptoms and behaviours associated with illness to the learning disability, and for the illness itself therefore to be over looked and routine investigations not being undertaken. This can be a particularly problematic when someone with a learning disability is in pain and can only communicate distress through behaviour such as screaming.

6.3.7 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.

**Values and standards**

6.4.1 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.

6.4.2 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.

|  |  |
| --- | --- |
| **Equality** | * Communicate in the way that best supports the individual to make their own decisions
* Find ways to include and involve individuals to access services
* Acknowledge and embrace personal preferences
 |
| **Dignity** | * Support individuals in a respectful manner
* Respect and listen to individuals wishes and choices
* Support individuals in their decisions
 |
| **Rights** | * Ensure that the voice of the individual is heard
* Support individuals to be in control of their own lives and work with others for what is in the best interest of the individual
* Comply with the Mental Capacity Act 2005
 |

6.4.3 The IMR from Barts Health Trust and account of Mr D’s mother at the A&E department suggest that there were elements of diagnostic overshadowing. The consultants’ emphasis on the fact that Mr D required on-going care and support because of his learning disability set the tone and accent of care which failed to meet the principles outlined above.

**Communication:**

**With adults with care and support needs**

6.5.1 There is evidence that people with learning disabilities are not always able to access mainstream services whether this is in respect of general health promotion, disease prevention, screening or treatment. Mencap’s report ‘Death by Indifference’ exposed poor quality and unequal care for people with a learning disability compared to the general population over ten years ago, which remains of concern. The main finding from Mencap was that people with learning disabilities continue to have poorer experience and outcomes compared to people without learning disabilities, including:

* 22% of people with learning disabilities were under 50 when they died, compared with 9% of people without learning disabilities.
* The most common reasons were delays or problems with diagnosis or treatment, and problems with identifying needs and providing appropriate care in response to changing needs.
	+ 1. In July 2013 the government responded to the Confidential Inquiry into premature deaths of people with learning disabilities (CIPOLD). This research was funded by the Department of Health. Its aims are to improve the health and well-being of people with learning disabilities by carrying out an inquiry into their death.
		2. 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.
		3. 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.
		4. 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.
		5. The General Medical Council (GMC) provides a wealth of training information for GP’s drawn from the work of Dr. Matt Houghton. The top tips from the GMC includes:
* Taking time
* Communicate with the individual first involving them as much as possible
* Use language that the patient understands using aids e.g. pictures and symbols
* Demonstrate procedures before undertaking them
* Make reasonable adjustments to mainstream health care
* Investigate as early as possible as people with a learning disability often present late with serious symptoms
* Avoid diagnostic overshadowing
* Ask and look for signs of pain and distress regularly as people with a learning disability do not have higher pain thresholds
* Involve people in decisions and understand the law around capacity and consent
	+ 1. It was the responsibility of health and social care professionals to ensure that Mr D had an individual health and/or communication plan. He also did not have a hospital passport which may have helped professionals to understand and communicate with him better. The latter are 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.
		2. Annual health checks are aimed at those people with a learning disability thought to have the greatest need. In England it is estimated that 240,000 people with a learning disability should be eligible for an annual health check (Glover 2014). They are only offered to people whose GP has registered them as being learning disabled.

6.5.9 The benefits of an annual health check are:

* Overcomes the difficulties for people to recognise illness or ailments
* Enables people to communicate their needs in accessible personalised ways
* Provides early treatment
* Supports prevention strategies
* Enables individuals to build up a rapport and trust with clinicians

6.5.10 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

6.5.11 Mr D had annual statutory adult social care reviews carried out by the CLDT. Some agencies took part in reviews but the GP was not part of this process. Where someone has complex needs it would be helpful to consider a check at the annual reviews to ensure that there is an updated Health Action Plan, communication plan and hospital passport.

**Hospital Passports**

6.6.1 National estimates indicate that more than two per cent of the adult population have a learning disability, which according to the LB Tower Hamlets Local Account (2016) equates to almost 5,000 people in Tower Hamlets.

6.6.2 Whether or not a hospital passport would have helped in this situation is debateable. How to communicate with Mr D might however have helped professionals to understand his usual baseline and that during the week of 11th May 2015, this was not his usual presentation, even though his mother was very clear about this. Unfortunately his mother’s views and knowledge were not given sufficient regard by some professionals.

**Carers**

6.7.1The main source of information about how to communicate with Mr D was his main carer, his mother. The NHS Five Year Forward View, 2014 states that there are 1.4 million unpaid full time carers in England, and the Care Act 2014 policy emphasises the importance of understanding history and relationships in building up knowledge about the individual and their carer.

6.7.2 Carers have important roles in protecting people who may be unable to protect themselves.Recognition of risk of harm or harmful behaviours is critical to prevention and protection of people with care and support needs.

6.7.3 Research by ADASS (2011) cites that the risk of abuse increases where:

* The person being cared for has high complex needs that have increased but support has remained the same
* Assessments have not included the health and wellbeing of the carer
* The carer is ignored by professionals
* The carer has refused help
	+ 1. The CLDT offered Mr D’s mother a carers 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 carers assessment, there is no obligation on the part of the carer to take up the offer. It was not made clear to Mr D’s mother the possible benefits of a carers assessment An assessment provides the opportunity for carers to consider their own needs and to assess whether or not they may need support to continue in their caring role.
		2. Mr D’s mother made it clear she was happy to continue caring and had opportunity for time to herself during the week and when Mr D went to respite (78 nights per year). It was not made clear to Mr D’s mother the possible benefits of carers assessment. It is however good practice to explore with carers their experiences of caring, and offer person centred support in the same way that person centred care is advocated for those who are cared for.
		3. Mr D’s mother was a member of a local carers group. 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 can be supported through or can attend groups
		4. There were a number of interactions between professionals and Mr D’s mother in the lead up to his health deteriorating, where she felt she was not being listened to. The first being with the locum GP. She was not satisfied with the diagnosis and continued to raise her concern with the locum pharmacist.
		5. The London Ambulance Service (LAS) responded to the 999 call and spoke appropriately with the mother. They made attempts to assess Mr D and noted the history given by his mother as possible malena. It is not known whether the LAS were aware of the personal needs of Mr D related to his learning disability.
		6. His mother was dismayed that the ambulance did not use the emergency siren or blue lights when transporting Mr D to hospital and it is not known how decisions about blue lighting were communicated to her.
		7. 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. The conversation as reported by her implies that there might have been some prejudice in dealing with people with a learning disability which she has taken further through the complaint procedures.
		8. Dr. Houghton acknowledges that, “Doctors can discriminate against patients. I think normally it’s not done consciously. I think it mainly happens through indifference.” To combat against this he recommends being polite and respectful to carers, acknowledging the information that they are giving and then focus on the patient, as this will give reassurance that the situation is being taken seriously.
		9. 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.

**Mental Capacity & Best Interest**

6.8.1No specific Mental Capacity assessment was located by the reviewer. 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.

* + 1. 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.”

* + 1. 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)
		2. 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.
		3. In 2013, Sir David Behan, Chief Executive of the Care Quality Commission said, “Understanding the Mental Capacity Act and the way it is applied is critical to good quality, safe care. Those providing services, must ensure that their staff understand the Act and what it means for the care and treatment of people.”
		4. A review of London SAR’s, Braye & Preston-Shoot (2017), found that there was a fundamental flaw in understanding the MCA and applying it to practice. All agencies need to ensure that there is a means of competency testing for all staffing levels, their knowledge and practice of the MCA.

**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.
		2. 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. Checks on the CQC available reports for those agencies that are CQC registered were compliant with the standard regulations.
		3. In this case, there was not a s42 Care Act 2014 safeguarding enquiry, although there was a SI investigation. A thematic review of deaths of people with a learning disability by Barts Trust led to the SAR referral, 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).
		4. The QSG provides an open forum for local supervisory, commissioning and regulatory bodies to share intelligence and give the opportunity to co-ordinate actions to ensure improvements in services. Its purpose is to ensure quality by early identification of risk, and; reduce the burden of performance management and regulation on providers. The strategic links with the SAB provides further opportunity to escalate concerns and share risks, and take a sub region view of quality concerns.
		5. Going forward it may be helpful for learning from SI’s to be shared with the SAR sub-group of the SAB. Taking a strategic approach to learning and disseminating learning from SI’s, near misses and SAR’s, and where learning effects people with a learning disability to ensure that the Learning Disability Partnership has oversight.
		6. The Tower Hamlets CCG Quality Performance Framework (2016-2018) is to be reviewed. Included in the review might be the arrangements to work with local authorities through the SAB to ensure that there are strong strategic links from the local QSG to the SAB and in particular the SAB SAR sub-group.

**Duty of candour**

6.10.1 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.”

6.10.2 There is now a legal duty on providers of health and social care to act in an open and honest way with patients who experience incidents that cause them harm. 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.”

**7** Conclusions and recommendations

7.1.1 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.

7.1.2 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
* increasing the face to face GP allocation time for people with complex needs
* earlier referral to hospital specialists
	+ 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. The lack of a communication plan, Health Action Plan and hospital passport and their known benefits for people with a learning disability might have proved helpful to Mr D to increase his access to services.
		3. 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.
		4. 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%.
		5. Finally, how training is monitored for its effectiveness in practice, with particular reference to the MCA, safeguarding and communication skills were not sufficiently documented.

# Recommendations

**1. Plans and reviews**

7.2.1 This report has been finalised sometime after the events under review. During that time, there has been some major national initiatives for people with a learning disability. Some of these changes and the relevance to the matters under review are referred to within the report.

7.2.2 Good practice was noted in the assessment, support plan and review process by the CLDT. Person centred assessment and planning were well documented. The OT service monitored changing needs and ensured that equipment was maintained in their reviews.

7.2.3 There is scope to improve the planning and reviewing process by a shared joined planning and reviewing strategy between social care and health in particular closer working with general practitioners. In particular there needs to be close attention paid to mental capacity and ensuring that all practitioners from health and social care are competent in understanding and translating the Act and code of practice into their work. The work Tower Hamlets are undertaking to improve services to learning disabled people is a good starting point.

**2 Health Checks & Health Action Plans**

7.2.4 It is further 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.

7.2.5. The Learning disabilities national enhanced service requirements 2016/17 summary below provides a helpful checklist:

**Health checks**

Practices should invite all patients on the health check register for a review of physical and mental health annually. As a minimum the health check should include:

* A collaborative review with the patient and carer (where applicable) of physical and mental health including: health promotion, chronic illness and symptoms enquiry; physical examination; epilepsy, dysphagia, behaviour and mental health and specific syndrome check.
* Accuracy and appropriateness of prescribed medication checked
* A review of co-ordination arrangements with secondary care
* A review of transition arrangements (where appropriate).
* A review of communication needs
* A review of family and carer needs
* Support for the patient to manage their own health and make decisions about the health and healthcare

**Health action plans**

* These can be created at the time of the health check via an electronic template or provided to the patient as a written plan following the review.
* Practices need to ensure the plan is provided in the best possible format for the patient to maximise their understanding.
* The focus of the plan should be the key action points discussed and agreed in the health check.
* It should highlight any other relevant information.
* If the patient has a personalised care plan in place, this should form part of the health action plan.
* If a patient is mentally competent to provide their consent the health action plan should be shared with other relevant professionals.

**3. Carers Assessments**

7.2.6 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.

**4. Training**

7.3.1 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
* the Mental Capacity Act
* the Equality Act

7.3.2 Training should be aimed at all staff levels to have a minimum of awareness of the issues and good practice.

7.3.3 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.

**5. Safeguarding Adult Board governance**

7.4.1 The current SAR SAB protocol requires updating and made accessible for all residents of Tower Hamlets.

7.4.2 Guidance on the SAR process might be usefully provided to ensure a more consistent quality standards to completing documentation by IMR authors, understanding by agencies, and clarity for adults and their families.

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[6.2.5] <http://www.real.org.uk/getsupport/padeup>

[6.2.4] Guidance for PA’s and employing your own support can be found at the Skills for Care website <http://www.skillsforcare.org.uk/Employing-your-own-care-and-support/Resources/Working-as-a-PA/1.-What-is-a-PA/Being-a-personal-assistant/Being-a-personal-assistant.pdf>

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[6.7.11] Matt Houghton <http://www.rcgp.org.uk/learningdisabilities/>

[6.8.6] Michael Preston Shoot & Suzy Braye (2017) Learning from SAR’s A report for the London Safeguarding Adults Board

[6.9.5] CCG Tower Hamlets Quality Performance Framework (2016-2018)

[6.10.1] Robert Francis QC (2013) The Report of the Mid Staffordshire NHS Foundation Trust Public Inquiry

1. Anusol cream is used for the relief from the pain and discomfort associated with haemorrhoids and other related anal conditions. [↑](#footnote-ref-1)
2. Melena: Abnormal dark tarry faeces containing blood (usually from a gastrointestinal bleeding)

www.vocabulary.com/dictionary/melena [↑](#footnote-ref-2)
3. Please note, since the SAR commenced the SAB decided that in principle all SAR reports should be published in full with the executive summary on the website [↑](#footnote-ref-3)