City and Hackney Safeguarding Adults Board

FINAL REPORT

Safeguarding Adult Review into Death of Jo-Jo

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Contents:

Safeguarding Adults Review.
Jo-Jo:
Date of Birth: 9 June 1978
Date of Death: 10 March 2017

1. Introduction

1.1 Jo-Jo was a 38 year old woman who had been known to the London Borough of Hackney's Adult Social Services since March 2007. She had a diagnosis of learning disability/Downs Syndrome. Jo-Jo had care and support needs including personal care, nutritional support, prompts to dress, managing her finances and maintaining her personal relationships. Jo-Jo lived with her mother who was her main carer and her step-father.

1.2 Jo-Jo had a history of childhood eczema. She continued to have severe eczema into adulthood on her whole body but it was particularly acute on her feet, hands, scalp and head.

1.3 Jo-Jo was diagnosed in August 2013 with probable crusted scabies by the dermatology out patients department at Homerton University Hospital NHS Foundation Trust. This diagnosis was confirmed in September 2013 and in December 2013 the whole family received treatment for this highly infectious condition. Jo-Jo's history of eczema led various GPs to diagnose eczema and it appears that scabies was not considered, although scabies was queried twice by the GP practice in July 2015.

1.4 Jo-Jo's support plan of 25 July 2016 stated that she needed support to maintain her personal care. This support was provided by her mother. Jo-Jo needed full support with personal care especially in relation to her skin condition(s) including being moisturised after bathing with medicated creams. Her condition also necessitated the use of medicated shampoos to prevent deterioration of her skin condition.

1.5 The London Borough of Hackney's Integrated Learning Disabilities Services (ILDS) funded a package of care for 6 hours per week to support Jo-Jo to access the community. This was divided into two mornings per week on a Monday and Wednesday 10am -1pm and was provided by Goldsmith Personnel (during the period in scope).

1.6 Jo-Jo died on the 10 March 2017 in the Royal London Hospital after being taken there by an ambulance for an emergency dermatology out-patient appointment arranged by the GP who had visited the family home on 9 March (the previous day).

1.7 As this was an unexpected death, Barts Health NHS Trust raised a Safeguarding Adults Review referral with the City and Hackney Safeguarding Adults Review Panel and the local Learning Disability Mortality Review (LeDeR) Programme.

1.8 The London Ambulance Service (LAS) crew that transported Jo-Jo to the dermatology department on the morning of 10 March also raised a safeguarding referral within an hour of Jo-Jo arriving at the hospital about Jo-Jo’s living conditions and concerns about her deteriorating condition.

1.9 Following Jo-Jo’s death, a post mortem was carried out which indicated the cause of death as being:

1a Subarachnoid haemorrhage with underlying hypoxic brain injury
1b Right lateral sinus thrombosis
1c Severe scabies with superimposed bacterial infection

1.10 There was no Coroner’s Inquest into the cause of Jo-Jo’s death.

1.11 The SAR Case Referral identified:

- The post mortem stated that Jo-Jo’s body was in a very neglected state.

- Concerns that a number of different agencies could have worked better together resulting perhaps in avoidance of death, but at least providing a better analysis of pain that Jo-Jo may have been in and possibly seeking clinical engagement sooner

2. About this Safeguarding Adult Review (SAR) and LeDeR Review

2.1 This SAR was commissioned by City and Hackney Safeguarding Adults Board (SAB) and managed by a SAR Panel.

2.2 Terms of Reference for the review were agreed by the SAR Panel on 24 May 2017. The Terms of Reference are set out in Appendix B.

2.3 The Panel decided that in addition to the SAR, a Learning Disabilities Mortality Review (LeDeR) should also be carried out as this was an unexpected and premature death. A LeDeR is a national programme to address the premature deaths of people with learning disability. This was completed by a LeDeR trained reviewer and considered health issues relevant to the case. A summary of the national LeDeR programme is given in Appendix C.

2.4 It was agreed that the LeDeR review would examine the unexpected death of Jo-Jo and the major relevant background regarding her health care. Following this the SAR review would consider the findings of the LeDeR and other elements of the case relevant to the SAR especially the care arrangements and evidence of joined up support to both Jo-Jo and her mother as the main carer.

2.5 In summary the agreed process was:

- LeDeR review completed

- The SAR author to consider issues related to Jo-Jo's care from information provided by agency chronologies and Independent Management Reviews (IMR)

- IMR from agencies and LeDeR findings to be integrated by the SAR author to inform a collaborative review facilitated by the SAR author to identify recommendations

2.6 This report is based on information provided from:

- Jo-Jo's General Practitioner
- Homerton University Hospital: hospital dermatology outpatient's attendance and adult community nursing
- Integrated Learning Disability Services (London Borough of Hackney)
- Goldsmith Personnel – providers of Jo-Jo's community outreach support commissioned by the local authority

Objective of the Review

2.7 The objective of this Review is to establish:

a) Through the LeDeR, if Jo-Jo's health could have been managed differently

and

b) Through the SAR process, consider the impact of

i. Neglect

ii. Service Offer/Refusal
iii. How Jo-Jo's mother was supported to look after her daughter
iv. Understanding the relationship between Jo-Jo, her mother and her family
v. How Jo-Jo's Mental Capacity was understood, addressed and risks managed
vi. If Jo-Jo's voice was heard
vii. Bringing together the findings from the LeDeR and the findings from the SAR to inform learning
viii. Consideration of all relevant use of legislation and national/local policy and practice guidance.

Scope of the Review

2.8 It was agreed that the scope of this Review should be events from 1 April 2016 to 31 March 2017, although account should be taken of earlier incidents that might provide relevant background information.

2.9 The full outline of scope and objective is set out in Appendix B.

3. Family Involvement

3.1 Jo-Jo's mother met with the author of the LeDeR review (Julie Willison) on 29 June 2018 as part of the LeDeR process. The Review was submitted to NHS Learning Disabilities Mortality Review Programme on 6 July 2018.

3.2 As part of this review Jo-Jo's mother was invited to meet with the independent SAR author to share her views on the support that both Jo-Jo and the wider family received from the agencies involved in her daughter's care and to raise questions that she might have about the review and its outcome.

3.3 A meeting with the independent author and Jo-Jo's mother was held at the Hackney Service Centre on 10 September 2018. A follow up meeting with the family was held on 7 January 2019 when the SAR author gave feed back and discussed the main findings of the review. This meeting was also attended by Dr Nicole Klynman, the SAR Panel Chair. It was agreed at that meeting that the report should be published to support wider learning and that throughout the report the name Jo-Jo would be used.

3.4 Mother gave a very detailed account of Jo-Jo since her birth in 1978. She was diagnosed with Down's Syndrome at 6 weeks and mother recalls that a consultant paediatrician said that perhaps she should be "put away". Mother would not have that. Jo-Jo's father did not accept her condition and her mother was determined to care for her daughter and did so consistently throughout her life.

3.5 Jo-Jo crawled at the age of 2 and started walking in a rather ungainly fashion at 2½ (mother described her as walking something like Buck Rogers).

3.6 Jo-Jo went to the Ickburg School from the age of 3 to 19. She mainly got on well with other children. She went to dance school which was an activity she loved. Her academic skills were limited: she could copy writing although she only understood some specific words.

3.7 Mother described how the transition from the school setting to college was a bit difficult as Jo-Jo sometimes responded with panic attacks if it was a new setting or she felt uncertain.

3.8 Jo-Jo watched TV avidly (often watching recorded shows over and over) and enjoyed music on CDs and would often sing along. To a significant extent she liked routine and was sometimes unsettled by new places or experiences. She could be stubborn but more frequently was loving and gentle.

3.9 When Jo-Jo's mother and father divorced, her mother cared for Jo-Jo on her own for 4 years. Mother has two younger further daughters, who are now grown up, with whom Jo-Jo had a very good relationship.

3.10 Mother reported that Jo-Jo had eczema from an early age and suffered it recurrently. Jo-Jo had first had scabies diagnosed in 2008.

3.11 Jo-Jo's skin conditions were generally less virulent in the winter, but in recent years mother described the main attacks as seeming to be worse each year.

3.12 Mother described treatment as sometimes successful, commenting that when Jo-Jo's skin condition was at its worst she did not want to go out or be seen in public. It was at these times Jo-Jo's mother cancelled the care agency sessions as she believed the main purpose of those sessions was taking her daughter out.

3.13 In this regard mother stated that she found the GP service not to be supportive as they would not do any home visits and Jo-Jo did not want to have to sit in the surgery waiting room in her condition.[1]

3.14 Mother recalled that social workers were first involved with Jo-Jo about 8 years ago and described some workers who were consistent and supportive. She particularly liked knowing who the social worker was and whom she could contact. It felt to her as if there was an individual supporting her and taking an interest in Jo-Jo.

3.15 Mother did not recall any consistent social work visiting or support over the last 3 or so years. She did not like the duty system as it meant that she constantly had to go over all the old ground with social workers who seemed to know nothing of the past, or of Jo-Jo.

3.16 Mother said she did not believe she had ever been "assessed", though a couple of years ago she was asked "how she felt" by a social worker.

3.17 Mother described some supportive workers from the Goldsmith Personnel care agency but referred to one exception to this.

3.18 Mother was under the clear impression that the care agency was only engaged to go out with Jo-Jo, so when that proved impossible because of Jo-Jo's skin condition she did not think there was any alternative but to cancel the service.

3.19 It is obvious that Jo-Jo's mother had made significant attempts, in her own way, to treat Jo-Jo's eczema, though as the condition worsened Jo-Jo was increasingly resistant to any treatment. There were inevitable inhibitions in mother attempting to treat sensitive body areas. Mother confirmed that she had never received any advice or specific guidance in applying the treatment. She was adamant that Jo-Jo had not had scabies since 2014 on the basis that:

i. Scabies had not been diagnosed
ii. The treatment plan was for eczema but not for scabies
iii. No other family member had been infected after 2014

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[1] The GP surgery have commented that they had never stated that they would not do any home visits and indeed the assessment on 9 March 2017 was a home visit. Any previous requests for medical advice/home visits were assessed first on the phone with a clinician and a decision made based on that assessment. Requests for home visits in the practice would never be refused but would be assessed on the phone and a clinical decision reached about the request.

4. Summary of main issues and agency responses

Year	Issue/Event	Service Provider Response	Social Care Response	Health Involvement	LeDeR findings
2013	Scabies diagnosed 2013	N/A This was before Goldsmith Personnel started to provide community care	Not known	Referred to dermatology and treated for scabies. No follow up on DNA on last appointment (due Feb 2014)	
2015	Repeated contact with GP due to problems with feet in 2015	Service provision started in October 2015. Two cancellations due to skin condition reported to ILDS Duty Team	Service cancellations logged by ILDS Duty Team	Referred to podiatry (May 2015) Crusted scabies queried (July 2015) Referred to dermatology at Homerton for eczema (July 2015)	
2016	Repeated contact with GP for continuing and worsening eczema on hands, face and feet Jan – March 2016	Services cancelled 8 times by Mother between 15 February and 9 March 2016. Reported to ILDS Duty Team	Cancel services from 9 March 2016 until further notice from Mother This service cancellation was not made known to the GPs	Not made aware of service cancellations by ILDS or local authority commissioning Referred to podiatry (Jan 2016) Antibiotics, Epaderm and steroids prescribed (Jan 2016). GP notes Mother has only limited understanding of the skin condition Notes that house had been fumigated but	Mental capacity assessment of Jo-Jo should have been considered Unclear if any blood test investigations were undertaken since July 2015 It was known that prescriptions were not been collected so Jo-Jo was not receiving the treatment prescribed There was no risk assessment of Jo-Jo's Mother's capacity to provide the care required

2016				that the “bed bugs are back”. Permethrin prescribed (March 2016)	
	FACE Overview Assessment. Home visit in April 2016 and paperwork completed in June 2016	Not involved	Home visit involving Mother and Jo-Jo. Restates known needs; notes eczema is the main health concern for Jo-Jo and the GP is treating it. FACE form progresses process for continued support package. Case notes of 5 April report that service should be suspended until further notice.	Not involved	
	Visit to A&E – 14 July 2016	Care support worker rings ambulance because Jo-Jo in pain and cannot walk.	Not aware	Jo-Jo examined for shoulder pain and discharged from A&E for care at home with analgesic.	
	Period of improving health: 28 June 2016 - December 2016	Twice weekly visits recommence from 28 June to provide 6 hours of community opportunities a week.	Home visit by Social Worker June 2016. Jo-Jo’s health has improved. Request made to reinstate services and arrange respite care in August.	No contact	

2017	Jo-Jo's mother cancels service on numerous occasions due to skin condition – December 2016 – 23 January 2017	Service cancelled 11 times as Jo-Jo is too unwell to go out. ILDS informed of cancellations on 6 occasions. Email raising concerns about the cancellations sent to ILDS on 23 January. Service provider cannot find the email that they sent. No response received and no follow up attempted	Service cancellations logged. There is no record of an email being received from the service provider that raised concerns On 3 February ILDS ask service provider to confirm the last day of service. GPs not informed of service cancellations Brokerage team suspend service on 7 February.	Not made aware by social care of service cancellations by Mother GP not informed by social care.	There was no follow up to understand why services were cancelled and what was really happening.
2017	Mother finding managing Jo-Jo's condition difficult. Mother seeks assistance from GP – 24 and 25 January 2017	Unaware - last contact with Jo-Jo and her mother was 5 January 2017.	Unaware	Case referred to District Nurse. District Nurse visits and states there is agreement that Jo-Jo will try and apply the creams to herself. Case is closed and Mother to raise any further concerns with GP. District Nurse's letter to GP states Jo-Jo's refusal to apply cream was due to pain. No pain management action considered.	Mental capacity assessment of Jo-Jo should have been considered. There was no risk assessment of Jo-Jo Mother's capacity to provide the care required.
	Mother seeks further assistance	n/a	Unaware	GP phone consultation: Jo-Jo not allowing anyone	

2017	from GP – 16 February 2017			to put cream on her body or to shampoo her hair or apply anything to her scalp. Scalp has lots of crusts that she picks off, some are bleeding. No action recorded.	
	Mother seeks assistance from GP– 9 March 2017	n/a	Unaware	Home visit carried out. Norwegian scabies diagnosed. GP considers admitting Jo-Jo to Royal London Hospital dermatology department as an emergency. Mother does not want this so GP arranges urgent dermatology referral for 09.00 the next day.	Need to understand why the GP did not remove Jo-Jo immediately after noting her poor condition and the environment in which she was being cared for. There was no risk assessment of Jo-Jo Mother's capacity to provide the care required.
	Admission to hospital – 10 March 2017			Ambulance arrives at 09.00 to transport Jo-Jo to Royal London Hospital. Ambulance arrives at 09.15. Jo-Jo taken to dermatology department but goes into cardiac arrest within 6 minutes. Initial resuscitation successful but fails on 2nd attempt before	

				Jo-Jo can be transferred to ICU. 10.13 Ambulance crew log a safeguarding referral referring to concerns about the home environment and Jo-Jo's worsening condition.	

5. Summary of Findings from the LeDeR

LeDeR Findings

5.1 The LeDeR concluded that the care that Jo-Jo received fell short of current best practice in one or more significant areas which resulted in the potential for (or actual) adverse impact on Jo-Jo.

5.2 Findings from the LeDeR are summarised below and concerned:

Mental Capacity Assessment

5.3 It was considered that a mental capacity assessment would have been relevant to Jo-Jo but that there was no evidence that such an assessment had taken place in the past 2 years.

5.4 There were a number of occasions when mental capacity could have been considered, particularly in light of her mother appearing to have a limited understanding of Jo-Jo's condition.

5.5 The District Nurses visited on 25 January 2017. There is no evidence that they took account of Jo-Jo's learning disability, specifically her understanding of the need to apply the prescribed creams. No planned follow up was made to ensure treatment was being followed.

Impact of delays in care/treatment

5.6 The LeDeR concluded that there were delays associated with Jo-Jo's care and treatment.

5.7 As a part of the home visit by the GP on 9 March 2017, Norwegian scabies was diagnosed in consultation with a colleague GP who also recalled a Norwegian scabies diagnosis from 2013, though this was contrary to the diagnosis from the dermatology clinic at the hospital in September 2015[2].

5.8 It was clear that the topical creams were not being applied as prescribed as evident from the lack of repeat prescriptions and Jo-Jo's mother reporting that Jo-Jo did not want/would not allow the creams to be applied.

5.9 Jo-Jo was not sent to hospital on 9 March 2017 although the GP noted her poor condition and the environment in which she was being cared for[3].

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[2] Norwegian scabies is an extremely rare diagnosis in General Practice (prevalence approximately 2/3 per 1,000 population). Previous GPs who had seen Ms Z after her last dermatology attendance were following a plan outlined in a letter regarding treatment of chronic eczema which was the principle and only diagnosis mentioned. Information of the history of Norwegian scabies had been mentioned in the letter referring Ms Z to dermatology and it was therefore assumed that the diagnosis had been considered and ruled out by the specialist. The GP discussion directly in conjunction with the home visit on 9 March 2017 correctly diagnosed the condition and an immediate, urgent referral was made for a consultant dermatology appointment for 09.00 the next day.

[3] This area was considered in detail during the SAR and is set out at paras 7.30-7.37

Was the death attributable to abuse or neglect

5.10 The LeDeR concluded that Jo-Jo’s death might have been attributable to abuse or neglect. The Coroner’s report references that Jo-Jo’s body was “*in a very neglected state”*.

5.11 It was the LeDeR author’s view that some of the decision making (or lack of it) from health and social care professionals might have contributed to Jo-Jo’s death. In particular, there was never any approach to risk assess Jo-Jo’s mother’s capacity to competently look after Jo-Jo’s complex skin condition which would have include providing a clean environment, ensuring adequate personal hygiene and regular application of topical medications.

Poor/Negligent standards of care indicative of problems with organisational systems and processes

5.12 It was considered that Jo-Jo did experience poor or negligent standards of care, including the co-ordination of her care, that might indicate problems with organisational systems and processes.

5.13 There was no coordinated approach about what the ongoing risks were for Jo-Jo, how these were to be managed and by whom.

5.14 There was no evidence of a Multi-Disciplinary Team meeting or Best Interest meeting taking place in the 2 years leading up to Jo-Jo’s death to discuss a way forward for her especially considering her chronic skin condition that was not improving and her vulnerability as a person living with a learning disability.

5.15 Jo-Jo no longer had a regular social worker in the latter half of 2016. Her case was not passed over to another regular social worker. All the issues were dealt with by the 'Duty' system.

5.16 When the community service was terminated by Jo-Jo's mother in January 2017 there was no follow up by ILDS to understand why and to evaluate what was happening.

5.17 There was no policy/protocol for what should happen when a family member terminates a care contract for a vulnerable adult.

5.18 Jo-Jo saw a number of GPs at her practice, there does not appear to be one named GP who had overall responsibility for her ongoing needs.

Gaps in service provision

5.19 The LeDeR concluded that there were gaps in service provision that may have contributed to Jo-Jo's death.

5.20 On 4 September 2015 Norwegian scabies was missed when Jo-Jo was seen at the dermatology clinic. The diagnosis was eczema.

5.21 There were no safeguarding alerts raised.

5.22 There was no follow up by ILDS when the care contract was cancelled by Jo-Jo's mother in January 2017.

5.23 There was poor continuity of care, including health monitoring. The health and social care provision fell short of basic standards which meant that inherent system 'safety nets' did not protect Jo-Jo, such as:

- Annual Review of care needs by IDLS. This was a poor quality review with no analysis of Jo-Jo's living conditions.
- Carers Assessment (under the Care Act) – there is no evidence of consideration of Jo-Jo's mother's needs as a carer.
- Primary Care Health Assessment - there is evidence that GP surgery sent an invitation for this assessment (Annual Health Check) but it did not occur during this 2.5 year period.

5.24 There were no triggers concerning the failure to pick up repeat prescriptions.

5.25 It appears that there was no GP follow up from March 2016 to January 2017

5.26 There were no mental capacity assessments carried out.

5.27 Jo-Jo was not removed to hospital on 9 March 2017 despite knowing that she was very ill, incoherent, unable to stand, incontinent, that it had been impossible to take vital blood pressure or pulse recordings and that it was recorded that she had been "floppy" since 6 March.

5.28 The key recommendations from the LeDeR were:

i. Further exploration and understanding of why blood test screenings did not take place after July 2015 as this should have been part of Jo-Jo's annual health check.

ii. Further exploration required to understand why the GP did not organise for Jo-Jo to go to hospital on 9 March 2017.

iii. Further understanding of the process of handing social care cases to "Duty" needs to be explored especially with regards to risk management and continuity of care.

Moving from the LeDeR to the SAR

The findings of the LeDeR are extremely important.

The overall aim of the LeDeR programme is to drive improvement in the quality of health and social care services delivery and to help reduce premature mortality and health inequalities.

Its' approach, primarily directed at health and clinical activity, is based on formatted questions that have been carefully developed to specifically examine what lessons need to be learned.

As the LeDeR was conducted by an independent reviewer and was carried out separately to the SAR process it is important that the key findings of the LeDeR have been set out here so that they can be considered in conjunction with the SAR findings.

The bringing together of these reports is critically important as the LeDeR findings on their own are potentially limited, while the additional examination by the SAR gives depth, breadth and context to what happened with Jo-Jo and her family.

That is why these findings have been brought together. This enhances the learning and the opportunity for development, though it is important to acknowledge that the LeDeR findings are presented through a narrower and rather prescriptive lens.

The SAR sets the LeDeR findings in a wider context that engages across the spectrum of services and all the individuals who have had a role.

This wider context is important so that the long term and sustainable lessons can be embedded in the whole system focused towards the benefit of adults who, in this instance, have a learning disability.

It is not for any SAR author to gainsay LeDeR findings, though it is important to set out the comprehensive findings against the original scope and set the experience of Jo-Jo and her family in a robust, balanced, effective and meaningful way that will lead to improvements in current services.

6. Summary of Findings and Learning Presented in the Independent Management Reviews (IMR)

6.1 This section sets out each agency's report through the IMR responses that they have recorded. It demonstrates considerable learning and development work in the respective agencies, much of which is being put in place.

6.2 Part of the purpose of conducting an IMR is for the individual agencies to reflect on their role in events and to identify areas of learning and development, either for their own organisation or as part of the wider safeguarding partnership. To a significant extent this has already commenced.

6.3 In this review IMRs were produced by:

a) London Borough of Hackney's Integrated Learning Disability Service (ILDS)
b) Goldsmith Personnel Limited (the community care provider)
c) Jo-Jo's GP practice
d) Homerton University Hospital NHS Foundation Trust – for Homerton Hospital and the Community Nursing Service

6.4 Set out below is a summary of the learning and development action identified in the four IMRs. The full details can be seen in the respective IMR documents. It is very positive to note that all the IMR indicate a significant level of development and learning, much of which has already been actioned. It is clear that agencies used the challenge questions set out by the SAR author in the IMR preparation papers to both structure their responses and indicate good progress on learning lessons with some practical outcomes. Copies of the IMR support papers are at Appendix F.

6.5 As indicated in the recommendations, there is still a good deal to do as some of the patterns in relation to Jo-Jo are recurring themes in the care of people with learning disabilities.

6.6 There will need to be follow up by individual agencies, commissioners and the Adult Safeguarding Board Partnership to ensure there are sustainable changes.

Integrated Learning Disability Service

Suspension of Care Arrangements

6.7 There was a history and pattern of the service being suspended and re-instated by Jo-Jo's mother:

- ILDS (and the commissioner) should not have suspended the package solely on the basis of a phone call or email from the service provider.

- When the agency stopped the services on the 3 February 2017 the duty worker should have made contact with Jo-Jo to check her situation and to confirm her agreement that the package be suspended.

- A welfare check could have been carried out. A face to face home visit would have been preferable to a telephone call. Had this taken place it may have been evident to the social worker that Jo-Jo's mother was finding it difficult to effectively care for Jo-Jo and that she needed support or advocacy herself to gain the right support from medical professionals.

- ILDS should have explored options with the support agency supporting Jo-Jo to undertake indoor activities at home instead of going out. This would have ensured consistency for Jo-Jo as well as ongoing contact and additional stimulation for Jo-Jo.

Action taken by ILDS

6.8 There are no policies in place regarding the suspension of services other than those relating to financial processes. This is being reviewed in the department to ensure robust responses are provided in similar future situations.

6.9 The process relating to risk management of calls dealt with by the ILDS duty worker is being reviewed to ensure there is a risk matrix which will evidence decision making in situations such as this.

6.10 The role of a Welfare Officer as piloted in the wider Adults Team is being considered. This role could be used to carry out welfare checks in situations similar to Jo-Jo. Ways of utilising this role within the restructure of the ILDS and the Social Care 'front door' to meet the needs of service users are being considered.

Mental Capacity

6.11 There should have been better consideration given to the Mental Capacity Act (MCA) in relation to Jo-Jo's ability to make choices regarding her care arrangements. Jo-Jo was not spoken to regarding changes to her care including suspension of the package. It was assumed that:

- Jo-Jo did not have capacity to make these decisions even though an assessment did not take place.

- Jo-Jo's mother was acting in her best interests regarding the suspension of care arrangements.

6.12 Had a mental capacity assessment been carried out, it is considered likely the outcome would have been the same and that Jo-Jo's mother would still have been deemed an appropriate advocate for Jo-Jo. However, the social worker would have documented more clearly the wishes and views of Jo-Jo during the assessment and review process and specifically the issues regarding Mental Capacity, Best Interests or the use of an independent advocate.

Action Taken by ILDS

6.13 Issues around MCA are now more clearly documented throughout the assessment and review processes and are built in to the checklist used prior to any funding panel submission.

6.14 Significant training has been offered to staff, including agency social workers, and will be part of the core training offered on a rolling programme.

Multi-Agency Working

6.15 Communication between the agencies involved in the care of Jo-Jo could have been better:

- Regular contact with the GP would have provided an overview of Jo-Jo's health conditions and allowed services to be adapted to meet any change in need. ILDS could have made contact with the GP to alert them to the fact the care package had been suspended.

- The social worker should have referred Jo-Jo to the ILDS specialist LD nursing team for additional support.

- A GP liaison nurse could have assisted in the communication between ILDS and the GP.

- The social worker could have had a Multi-Disciplinary Team (MDT) discussion with health colleagues (the nursing team) to gain additional professional advice regarding Jo-Jo's eczema and the need to suspend social support when it worsened.

- MDT discussion may have helped establish if Jo-Jo was receiving an Annual Health check.

Action Taken by ILDS

6.16 ILDS is currently being reviewed with the intention of incorporating more MDT approaches throughout a service user's pathway within the service. This includes the introduction of a new MDT management tier.

6.17 The provision of a GP liaison nurse is being considered as part of the ILDS review to improve relationships between the service and GPs.

Record Keeping

6.18 Some dates on records seem to be inaccurate as a result of errors. These errors should have been picked up.

Action Taken by ILDS

6.19 Senior Social Care Practitioners to carry out regular case audits of service user records to ensure case notes and documentation are accurate and of the quality required.

Carers Assessment

6.20 Jo-Jo's mother should have been offered a Carer's Assessment by the local authority.

6.21 <u>Recommendations set out in the ILDS IMR</u>

i. The ILDS to urgently review the decision-making processes used by duty workers. A new risk matrix to be implemented.

ii. Consideration to be given to the use of a Welfare Officer to carry out welfare checks.

(Both of these recommendations are being reviewed as part of the wider ILDS review and will be implemented by early 2019.)

iii. Social workers must have an MDT discussion when the health needs of a service user are impacting on the delivery of their care and support package.

<u>Goldsmith Personnel Limited (GPL)</u>

Response to repeated service cancellations

6.22 Cancelled visits were not escalated all the time to social services as part of the reporting procedures. There should have been more phone calls and follow up emails to the LD Team or Duty Desk.

6.23 An email sent in January 2017 to social services regarding cancelled visits was not followed up which was not in line with the reporting procedures for raising concerns.

6.24 A welfare call visit should have been conducted to check on Jo-Jo's condition during the prolonged absence. Welfare visits might have:

- picked up on any concerns relating to personal neglect.
- identified if Jo-Jo's mother might need more assistance to sign post and contact the GP.

Action Taken by GPL

6.25 Reporting and escalation procedures to be improved and monitored by senior staff in Goldsmith Personnel.

6.26 High frequency cancellations will now be escalated, and safeguarding alerts made where relevant.

6.27 All visits cancelled by the client or their family are documented and reported to social services by email within 24 hours so that the local authority can investigate or review.

Multi-Agency Working

6.28 A joint review by the agency and social worker should have been carried out which would have inquired further if Jo-Jo's mother needed more support within the home.

6.29 Communication from the care agency to the social worker could have been improved and this would have triggered an urgent follow up to non-contact issues which resulted from Jo-Jo's cancellation of support.

Action Taken by GPL

6.30 Arrangements will be put in place to provide alternative arrangements for support in the home if the client is not able to go out for any reason. This will be done in conjunction with the family and what would be the best for the individual service user.

Assessment of Care Needs

6.31 Care agency assessments were based on the commissioned support package for access into the community. There was no inquiry into the full medical history as this was not a full care package involving personal care and medication administration and it was noted that Jo-Jo's mother and family were responsible for medication and personal care.

Action Taken by GPL

6.32 In future a holistic assessment will be conducted on <u>all</u> LD clients. This will:

- Help to stipulate responsibilities and raise awareness of early warning signs of physical health of deterioration.

- Prompt carers to report on signs of physical health deterioration.

- Ensure that the client receives further support where the responsible person is not available or is incapable of providing support due to other factors.

Record Keeping

6.33 Phone calls and emails were sent to the Integrated Learning Disability Service but there is no record of a reply or the agency pursuing a response.

Action Taken by GPL

6.34 All senior staff issued with a management instruction to escalate and follow up on all significant emails sent to social services, in particular with regard to non-contact and cancelled visits.

GP Practice

Ensuring accurate diagnosis

6.35 The surgery needs to take extra caution and be extra vigilant regarding diagnoses and treatments for those with learning difficulties.

6.36 Absence of a DNA letter from dermatology in February 2014 (Homerton hospital) meant that there was no re-referral or consideration of further clinical assessment, therefore there was no trigger for follow up by the GP.

6.37 Jo-Jo was seen five times at the surgery with a severe hyperkeratotic rash during the period 30 November 2015 and 7 March 2016. It may have been appropriate to refer Jo-Jo back to the dermatology outpatient department.

6.38 A review of clinical notes when Jo-Jo’s mother telephoned on 16 February 2016 about managing Jo-Jo crusting scalp would have highlighted the previous diagnosis of Norwegian scabies. This would have prompted the GP to consider referring Jo-Jo to dermatology.

6.39 It was assumed Mother would bring Jo-Jo for review if her skin condition was deteriorating. When Jo-Jo did not present for a GP review for her skin condition after 7 March 2016 it would have been appropriate to call her for a review appointment given the seriousness of her skin condition.

6.40 If Jo-Jo had been allocated a named GP:

- Mother would have been encouraged to make this doctor her first point of call for GP appointments and telephone consultations. This could have been a link to follow up and annual reviews.

- All incoming correspondence from hospitals and outside agencies would have been directed towards this GP.

- The GP would have been able to have an ongoing over-view of her care.

- Clinical and non-clinical staff at the practice would have addressed any concerns or questions they had to this GP.

Action taken by GP

6.41 Training has been given during serious event analysis (SEA) regarding clinical diagnosis, significance and treatment of Norwegian scabies.

Pain Management

6.42 There should have been consideration given to referring Jo-Jo to dermatology outpatients given the pain that she was reported to be in.

Mental Capacity

6.43 Given Jo-Jo's known reduced capacity, all treatment and care issues were discussed with her mother who made decisions on her behalf. Mother had been Jo-Jo's consistent carer throughout her life and also successfully brought up other children. All the indications were that this approach was appropriate, however as Jo-Jo's condition worsened and evidently became much more difficult to manage there was an over reliance, or a lack of recognition of the carer burden that was being expected by the key agencies in light of Jo-Jo's Capacity.

6.44 If Jo-Jo had been highlighted as someone at significant risk of neglect then safeguarding procedures would have been initiated, ensuring that Jo-Jo was reviewed on an ongoing basis for her severe skin condition. It is recognised that mother needed support with this as she may not always have been able to be aware of when Jo-Jo needed medical input/review.

Annual Health Checks

6.45 Jo-Jo received Annual Health Checks by the GP in 2014 and 2015 but failed to attend in 2016. This was not followed up. A system should have been in place to ensure Jo-Jo was invited for annual chronic disease and annual LD health check and that she attended those appointments.

6.46 <u>Recommendations from GP IMR</u>

i. Need to ensure that all patients with learning disabilities have a named doctor involved in their care because of their increased vulnerability.

ii. Follow up of clinical conditions: Where it is deemed imperative that a patient be reviewed clinically for a particular condition a system is in place to ensure that this happens. Ms. Z was not put on recall for appointments as she had been attending regularly as needed. The surgery has discussed increasing the frequency of routine follow up appointments and reviews for this patient group.

iii. A review of systems to ensure that LD patients are recalled for chronic disease and annual health checks and are followed up if they do not attend.

Homerton University Hospital NHS Foundation Trust

6.47 There was no follow up of Jo-Jo's non-attendance for her dermatology outpatient's appointment in February 2014. Standard practice would be to send out a follow up appointment after the first non-attendance and to then discharge back to the GP if that appointment was not kept. This did not happen.

Action by Homerton hospital

6.49 Although this was outside the review period it has highlighted the need for the hospital to ensure it quality assures its' follow up system for "Did Not Attend".

Access to medical records

6.50 In September 2015 the dermatologist did not have access to Jo-Jo's previous dermatology records. If the old notes had been chased the decision by dermatology to discharge Jo-Jo might have been reviewed. This was not recognised as a problem at the time. In retrospect dermatology should have been asked if Jo-Jo's past history had been considered and a follow up appointment requested

Action by Homerton hospital

6.51 In June 2016 the hospital moved to electronic patient records (EPR).

Multi-Agency Working

6.52 Staff should use a multi-agency approach when dealing with patients who have complex needs. Jo-Jo was already known to the ILDS and it would have been good practice for the community nurse to liaise with that service.

6.53 Specialist support from a learning disability practitioner ought to have been sought when it was clear that Jo-Jo would not let her mother apply the prescribed creams so that she could have received specialist and multi-disciplinary care. Jo-Jo was not referred to the ILDS team which has learning disability nurses, occupational therapists and physiotherapists who could have developed a tailored care plan to manage her situation.

6.54 The community nurse's discharge letter to the GP stated that Jo-Jo's refusal to apply her medicated cream was due to pain. It is unclear if the GP acted on this to institute a pain management plan.

Action by Homerton hospital

6.55 The NHS Improvement Benchmark for Learning Disability has been signed-up to.

6.56 The Learning Disability strategy is being reviewed.

6.57 A Learning Disability policy and pathway is under development.

6.58 Information on making reasonable adjustments and providing easy read materials are available for staff on the intranet.

6.59 Learning disability awareness training is delivered twice monthly during trust induction.

6.60 A simulation based mental capacity training to increase staff confidence in completing mental capacity assessments has started to be delivered.

6.61 <u>Recommendations from Homerton University Hospital NHS Foundation Trust</u>

i. Training:

- Raise staff awareness on how to support service users who are not engaging with services.
- Enable staff to know what other agencies or services people with learning disability could be referred or signposted to.

ii. Multi-agency working:

- Promote effective communication between hospital services and specialist community services for patients with learning disability.
- Discharge checklist (acute and community) should include a section for liaison with the ILDS for patients with learning disability.

iii. Mental Capacity Assessment

- Increase staff confidence in carrying out mental capacity assessment and documenting the assessment correctly on the appropriate forms.

7. Key Findings from the SAR process

7.1 This section sets out the main findings from the SAR process drawing information from the IMR reports and related material including the LeDeR.

Key Findings and Comments

1) Use of the Mental Capacity Act

7.2 There were many points at which there could have been consideration of the Mental Capacity Act in relation to Jo-Jo, particularly within the period in scope of this review. Assumptions were made about Jo-Jo's capacity probably by relying on knowledge of her condition (Down's Syndrome), mother's descriptions of her reasoning ability and so on. However, assessment using the Mental Capacity Act was never considered.

Comment

7.3 An assessment would have clearly placed Jo-Jo's capacity in the context of both her health and care situation and helped to inform visiting professionals and the care agency of her needs. It may well have assisted the mother had it been explained to her.

2) Specific assessment or support to Jo-Jo's mother

7.4 Jo-Jo's mother had a right to be assessed as the main carer under the Care Act 2014. This would not only have explored the impact of caring for Jo-Jo but also examined if mother had support needs in her own right, had such an assessment been carried out there would have been a realistic understanding of the impact of being a carer given Jo-Jo's deteriorating skin condition and of the quite understandable difficulties that Jo-Jo's mother was facing. In this context Jo-Jo's mother was let down by the assumption from social care and general expectation from the health services that she was managing.

Comment

7.5 Both health and care agencies had unrealistic expectations of Jo-Jo's mother in the very specific and consistent care that Jo-Jo needed for her skin condition. This despite the impact of Jo-Jo's condition being known about by the care agency, GP, hospital, community nursing service and social care services. Of particular note was the missed opportunity to provide effective and sustainable treatment and support following the visit of the community nursing service in January 2017. It is inexplicable why this one-off visit was not followed up.

3) Joined-up/integrated assessment of care and treatment plan

Comment

7.6 Throughout this review and the key findings of the LeDeR there was a failure by the agencies to set out:

- An integrated assessment of Jo-Jo (or her mother)
- A realistic treatment plan for her condition (based on a diagnosis that did not appear to have considered her history)
- A commissioned care service that was matched to an assessment, ie based on a care plan

7.7 This area is of particular concern as it goes to the heart of the role and function of the local authority in its services to people with a learning disability. Detailed consideration of the information presented shows some flaws in system and approach which are unacceptable and contribute to the key failures to support Jo-Jo and her mother.

Outline of the “FACE” Assessment of 26 June 2016

Comment

7.8 The assessment completed by Adult Social Care dated 26 June 2016 (FACE Assessment form) seems to relate directly to the request from Jo-Jo’s mother for 2 weeks respite care. Presumably the completion of this form is required to justify the respite care.

7.9 As an assessment form to fulfil the requirements of a personalised approach or the requirements of the Care Act, it is an inadequate document.

7.10 It has been stated that this was also used as the joint carer’s assessment and the Annual Review as such:

i. The requirements of the form are not adequate for this task.
ii. The information in the form is somewhat perfunctory
iii. There was no integrated assessment or planning
iv. The support plan was inadequate

7.11 It is difficult to justify having an integrated service if outcomes for individuals are seemingly ignored and assessment is reduced to a somewhat simplistic/mechanistic process apparently to justify whether expenditure on services can be authorised. The starting point is the care and outcome for the individual not the bureaucratic demand of the system.

7.12 The function and requirements of social care should not be diminished to a purchasing equation only.

7.13 It is also unclear how the assessment form and the subsequent support plan were drawn up. It appears that the assessment form of 26 June 2016 was based on the home visit on 5 April some 2 ½ months earlier. Although there was a home visit on 28 June 2016 the record of that visit does not refer to the assessment or the support plan being discussed. It appears this was a visit to confirm Jo-Jo’s mother’s request to restart the community support after her cancellation of services in March 2016. This sequence is set out over the page.

<u>Sequence of contact with Jo-Jo and her mother and completion of assessment form and support plan</u>:

Date	Activity and record	Comment
5 April 2016	Home visit by Social Worker. Contemporaneous record states: *"Review carried out today 05/04/2016. Outcome of review. Carer/Mother said Jo-Jo has severe eczema on her feet, legs and head. Jo-Jo is very unwell to go out in the community. She has had this condition since 9 March 2016. Action Needed: To complete CA4 to suspend the services. Carer will contact the Learning Disabilities Services to reinstate the services when she is well*."	This visit is described as an Annual Review in the ILDS IMR and was also a joint carers assessment. This is inadequate as an Annual Review.
26 June 2016	FACE Overview Assessment form.	ILDS IMR refers to this as the Community Care Assessment and indicates that this documentation was based on the visit on 5 April. There is no signature by the carer but that area of the form is dated 19 July 2016. This form is not sufficient to carry out the requirements of the Care Act 2014.
28 June 2016	Home visit by Social Worker. Contemporaneous record states: *"Home Visit I carried out a home visit this afternoon. Met with Mother and Jo-Jo. Jo-Jo had made a lot of improvement. Mother stated that Jo-Jo's package of 6 hours community day opportunities can be reinstated as from tomorrow. I made a telephone call to Goldsmith Personnel to reinstate the services. Mother also requested for 2 weeks despite from 6 August to 20 August. Action Needed: Social Worker to find respite*."	This hardly constitutes a social work visit from a multi-disciplinary service. It seems centred around one small part of the care and is narrow and limited.
25 July 2016	FACE Support Plan	Discussed in supervision. Plan sets out continuation of support by the care agency and 2-week respite. Plan is not signed by either Jo-Jo or her mother, but that area of the form is dated 25 July 2016. This is not a complete plan, it does not have any multi-agency or multi-disciplinary context despite this being done by an Integrated Learning Disability Service.

4) No functional links between service provision and commissioning

7.14 There were a number of occasions when the care agency or Jo-Jo’s mother cancelled services because of Jo-Jo’s skin condition.

7.15 This was used by commissioning who presumably saw it just as a contractual/finance arrangement. There was no functional link between commissioning and the ILDS which would have indicated to social care that the arrangement were not functioning.

5) Incorrect diagnosis of Jo-Jo’s skin condition

7.16 This is set out in the LeDeR review. The diagnosis at the dermatology clinic in 2015 set in train a sequence of assumptions about the nature of the treatment required which was essentially incorrect. The underlying and fundamental condition of Norwegian scabies, though rare, is a treatable condition given the right circumstances and expertise. Because of the incorrect diagnosis this was not put in place.

7.17 As a consequence Jo-Jo’s skin condition persisted between November 2015 and March 2017 with what was inevitably ineffectual and inadequate treatment. During which time the impact of her condition was set out by the care agency and Jo-Jo’s mother and, in extremis, when she asked for help. Better co-ordination from ILDS underpinned by even rudimentary care planning could well have called in to review Jo-Jo’s health condition, her care situation and adequate support for her mother as the main carer.

6) No pain management

7.18 One particular issue in Jo-Jo’s treatment relates to pain management. It is clear that Jo-Jo did not have an understanding of her skin condition and did not have the skills and ability to articulate how this made her feel. It is clear not least from the findings in the post mortem, that the nature of her infection would undoubtedly have caused very considerable discomfort, irritation, pain and frustration. Mother’s own account about her attempts to treat Jo-Jo’s condition confirmed that this caused distress and pain.

7.19 It is unacceptable that this situation was not resolved. Jo-Jo and her mother were left carrying this very painful burden for over a 16-month period with little support.

7) Unrealistic expectation on Jo-Jo’s mother (to manage Jo-Jo’s ongoing condition)

7.20 As set out at para 7.4, there was no formal assessment of Jo-Jo’s mother, nor was there any meaningful contact or engagement with the mother to either understand her needs or the impact of her caring role. Both health and social care failed to support Jo-Jo’s mother. Moreover, they made unsubstantiated and untested assumptions about her own understanding and abilities to do these tasks.

8) Lack of clarity of the role of the care agency

7.21 Putting the care agency services in place to provide an outlet for Jo-Jo and a short break for her mother was a positive step. However, because this care arrangement was not based on any substantive assessment, it was too limited and somewhat simplistic, especially when Jo-Jo was unable to go out for social contact.

9) No overall case management or appropriate reviewing function

7.22 Responses by the main agencies to Jo-Jo's needs and any ongoing understanding of the changing circumstances of her condition throughout the period February 2016 to March 2017 were inadequate.

7.23 One of the fundamental problems here was that there was no bringing together of the issues or coordination of responses.

7.24 No-one considered Jo-Jo as a complete individual. This should be covered by the activities of:

- Case reviewing
- Case management
- Case coordination

7.25 There are quite specific requirements in relation to individuals with learning disabilities laid down in guidance and practice reviews and in any event the aspects set out above should be the very corner stone of social care practice and should be the basis of an integrated learning disability service.

7.26 While individual practice in health and social care may vary, the frameworks that are set out are based on good practice and personalised approaches designed to help achieve consistency, avoid disruption through organisational changes, take account of changes in personnel and give carers a point of contact. The most fundamental point is that the coordination and exchange of information did not happen for Jo-Jo or for her main carer.

7.27 Notwithstanding the lessons now set out in the IMRs by the agencies, there was a failure to use any kind of consistent framework of case management, coordination or review.

10) Failure to identify key risks to Jo-Jo's care or health

7.28 No risk assessment was carried out of Jo-Jo's care and health situation during the period in scope for this review.

7.29 There a number of points at which Jo-Jo's risks should have been assessed and responded to. There are no recorded attempts to support Jo-Jo's mother to understand those risks.

7.30 In accordance of the requirements of the SAR, the scope requirements are drawn more widely than the LeDeR. The LeDeR concluded that there was a need to understand why the GP (who conducted a home visit on 9 March 2017) did not remove Jo-Jo immediately and cited elsewhere in that report some of the factors that needed further consideration.

7.31 Within the context of the SAR this event and GP engagement more generally was considered in much more detail using both the IMR prepared by the GP practice, follow-up correspondence and a face to face meeting at the GP practice involving the SAR author and relevant GPs. This enabled a thorough exchange of information, some key challenges and helped to reinforce learning.

7.32 Prior to 9 March 2017, the GP practice had not been informed of any significant changes in Jo-Jo's care or the role of the care agency by social care. This is set out at page 10 and 11. Nor had there been any clinical information suggesting areas of concern or need for follow up following the District Nurse's visit to Jo-Jo and her mother in January 2017. The background was that the care and support seemed stable, confirmed by the occasional opportunities when the family requested help or clinical involvement.

7.33 The events of 9 March 2017 involving the GP visit to the family home did in fact include a careful weighing up or balancing of the most appropriate option at that time, namely seek emergency admission via A&E that afternoon or a planned admission that next morning at 09.00 via outpatient appointment with the consultant dermatologist. This was considered even more likely in light of the diagnosis of Norwegian scabies and the need for urgent treatment.

7.34 In any event a hospital admission via A&E was by no means a certainty; it is possible there would have been considerable delays in that process and could well have been unsuccessful and resulted in Jo-Jo being returned home that same evening[4]. In consequence there was careful consideration of the safest approach resulting in the hospital appointment the next morning. This was also influenced by Jo-Jo's mother resisting emergency admission. A subsequent telephone call later that afternoon between the GP and mother helped to prepare the way for Jo-Jo's likely admission the following day. The GP also noted that there should be a referral to social care regarding Jo-Jo's living situation.

7.35 During the home visit on 9 March 2017 the GP was unable to take Jo-Jo's heart rate or blood pressure as, despite the GPs approach, Jo-Jo physically resisted the GP's attempts. To some extent the strength of this resistance seemed to mitigate Jo-Jo's condition.

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[4] It is important to note that the Homerton Hospital A&E Department had in place a fast track approach for individuals with a learning disability which may have obviated undue delay. Subsequent information indicates that there has been a good deal of success in reducing waiting tomes in this regard. However, following discussions at the time, and responding to Jo-Jo's mother's views it was agreed that direct access to the dermatology service at Royal London Hospital (where Jo-Jo had been before) was on balance the best option.

7.36 As is often the situation, the visiting GP had not met Jo-Jo or her mother before, but the GP sought to mitigate this by discussion with a colleague in the practice. This led to the firm diagnosis of Norwegian scabies and the discussion of the most appropriate course of action.

7.37 In this context, and while trying to avoid the bias of hindsight, the GP made very considerable efforts to ensure an appropriate outcome based on a personalised clinical approach that met the needs of Jo-Jo and responded to her mother.

11) No understanding of the lived experience of Jo-Jo

7.38 There is no evidence in either the LeDeR or the material provided to this SAR, that Jo-Jo's whole lived experience was understood. The provision of support for her to go out was relevant and important to her socialisation and support for her mother. It is disappointing that this service arrangement was never joined-up in any holistic way with an overall assessment of her needs.

12) No provision of advocacy or support to hear Jo-Jo's voice

7.39 There is no doubt that Jo-Jo's mother had been a strong advocate for Jo-Jo and her needs throughout her life. There is no evidence to suggest that Jo-Jo's mother did not do her best for her daughter. However, the over reliance of the main agencies on Jo-Jo's mother to fully advocate for her daughter and meet all her care needs was not sufficient.

7.40 Had the full context of an integrated learning disability service been brought to bear and had there been a better understanding and use of personalised services or a putting people first approach then the use of advocacy could well have been an option.

7.41 In any event the requirements of the Care Act 2014 were ignored in this regard. The substantive responsibility for this rests with the local authority. The Social Care Institute for Excellence is useful in this regard.

13) No consideration of safeguarding referral as a means of achieving a coordinated action orientated approach

7.42 This is a difficult area. In ordinary circumstances there is nothing to indicate that Jo-Jo was not cared for appropriately nor are there any indications at all that her ordinary needs were not being met or that she was subject to any unnecessary risks in her day to day life.

7.43 However, in many ways her health condition and its treatment shifted that balance. Safeguarding should not only be about things that are done to others but may, on rare occasions, be to do with those things that that are not being done or not done completely. As set out elsewhere in the review, Jo-Jo's mother provided care for her daughter in her own way, according to her experience and her own understanding and abilities. In much of this she was unsupported. Though it is evident from the LAS safeguarding referral on 10 March 2017 and the post mortem report that there was some neglect of Jo-Jo evident, there are no indications that this neglect was deliberate but more likely due the almost overwhelming complexity and scale of Jo-Jo's increasingly rampant skin condition.

7.44 Risks to Jo-Jo were not considered. The corollary to these considerations should have been at least whether safeguarding was a factor: it is stated that the care agency raised a concern on 23 January 2017 and the circumstances of Jo-Jo on 9 March 2017, although neither ILDS nor the care agency can find a record of this.

7.45 The only agency that responded appropriately in this regard was the London Ambulance Service who raised a safeguarding referral on 10 March 2017 after transporting Jo-Jo and her mother to the Royal Free Hospital for her emergency dermatology appointment that had been organised by the GP the day before. It is inexplicable why the concerns raised by the London Ambulance Service were not picked up during the GP visit the previous day.

7.46 It is worthy of note that this response was based on a single visit to the home and observation of Jo-Jo that lasted approximately 15 minutes.

14) Failure to consider key policy frameworks

7.47 There does not appear to have been any consistent consideration of any of the key policy, good practice or legal frameworks. This includes:

- The Care Act 2014
- Mental Capacity Act 2005
- Learning from other LD reviews e.g. Death by Indifference

7.48 A summary of the key areas that should have been considered are shown at sections 10 and 11.

8. Bringing Conclusions Together from the LeDeR and the SAR

8.1 The key objectives of this review are set out in the Terms of Reference at Appendix B and are referred to below. The findings of the LeDeR and the findings of the SAR form a comprehensive picture of the lessons that need to be learned regarding Jo-Jo.

8.2 The IMRs written by the agencies concerned set out learning/development that has already taken place, though progress on all these must be monitored and maintained.

8.3 The original Terms of Reference includes:

a) Through the LeDeR report, review if Jo-Jo's health could have been managed differently

b) Through the SAR process, consider the impact of:

  1) Neglect
  2) Service offer/refusal
  3) How was Jo-Jo's mother supported to look after her daughter?
  4) Understanding the relationship between Jo-Jo, her mother and her family
  5) How was Jo-Jo's mental capacity understood, addressed and risks managed?
  6) Was Jo-Jo's voice heard?
  7) Bring together the findings from the LeDeR and the findings from the SAR to inform learning
  8) Consider all relevant use of legislation and national/local policy and practice guidance

8.4 Many of these areas have been covered in the preceding sections of this report but the main findings of both the LeDeR and SAR are brought together here and form the basis of recommendations and learning.

8.5 From the LeDeR the conclusion is that Jo-Jo's health should have been managed differently and so too should her wellbeing needs (social care and personalised opportunities).

8.6 Both from the SAR and in the read across to the LeDeR report, one of the primary lessons to be learned was the failure to provide joined-up assessment, services and risk management over many months that should have diagnosed and treated her condition and worked with Jo-Jo as an individual person. Support to Jo-Jo's mother was woefully inadequate.

8.7 Taking the main activities or the gaps in service that had a major impact on the care of Jo-Jo, the LeDeR and SAR reports come to very similar conclusions, though they consider the impact on Jo-Jo and her main carer from different perspectives.

8.8 The following sets out these key areas as set out in the Terms of Reference and links the various elements of the agencies' responses.

Neglect

8.9 The direct care of Jo-Jo (by health) was impacted by the failure to diagnose her condition and put in place an adequate, and supported, treatment plan which should have been underpinned by pain management. The support from social care was uncertain and inadequate.

8.10 Jo-Jo's mother supported her daughter as best she could but was very much left to get on with it. There is no doubt that a number of separate but linked elements contributed to a difficult, unmanaged, undiagnosed and unsupported situation culminating in the events of 10 March 2017. All of which could and should have been addressed in the preceding months.

8.11 The major contributing factors are grouped below so that their key activities read across to the original Terms of Reference.

System and Process Gaps and Omissions and Practice Shortfall

8.12 These are exemplified by:

- There was no case management or case coordination.
- Jo-Jo's condition and circumstances left her in a neglected state.
- Significant problems with organisation systems and processes contributed to poor care.
- There were gaps and missed opportunities in service provision with little regard for good practice guidance, policy or lessons from the past.
- There was a failure to provide proper annual reviews of Jo-Jo in either social care or health.
- There were no functioning links between the commissioning of care and service provision causing a failure to follow up cancelled services.
- Jo-Jo's mental capacity was never considered.
- All this culminated in the situation that any risks in either health or social care were not considered.

8.13 The following section sets out these points and links the LeDeR and SAR.

	Covered in	
Main Findings	**LeDeR**	**SAR**
There was no case management or case coordination	-	y
Jo-Jo's death was attributable to abuse/neglect	y	-
Significant problems with organisation systems and processes contributing to poor care	y	y
There were gaps and missed opportunities in service provision	y	y
There was a failure to provide proper annual reviews of social care or health	y	y
There were no functioning links between the commissioning of care and service provision (failure to follow up cancelled services)	-	y

8.14 Targeted and appropriate services and support to Jo-Jo and to her mother would have been present if joined-up/linked assessment(s) had been done. These are all cited in the LeDeR and SAR reports.

Incomplete or Inadequate Assessments

8.15 Specifically:

- Failure to use any risk assessment in either care or health
- No Mental Capacity Act assessment
- Significant impact on Jo-Jo's health and social care because of delays in health treatment and no comprehensive assessment from social care
- There were no joined up assessment or integrated care arrangements
- There was no specific assessment or support to Jo-Jo's mother
- There was no adequate health care treatment plan

	Covered in	
Main Findings	**LeDeR**	**SAR**
Failure to use any risk assessment in either care or health	y	y
No Mental Capacity Act assessment	y	y
Significant impact on Jo-Jo's health and social care because of delays in health treatment and no comprehensive assessment from social care	y	y
There were no joined up assessment or integrated care arrangements	y	y
There was no specific assessment or support to Jo-Jo's mother	y	y
There was no adequate health care treatment plan	y	y

8.16 As a direct result of the above the actual services provided or available to Jo-Jo (and her mother) were inadequate. Although some elements of services did carry out their tasks (as designated) eg the care agency, the fundamental commissioned brief and follow up, especially when services were cancelled, was inadequate.

Service Inadequacy

8.17 The areas of service inadequacy are below:

- There was a failure to diagnose Jo-Jo's condition
- There was no pain management
- There was a lack of clarity of the role of the direct care service agency

	Covered in	
Main Findings	**LeDeR**	**SAR**
There was a failure to diagnose Jo-Jo's condition	y	-
There was no pain management	y	-
There was a lack of clarity of the role of the direct care service agency	-	y

Was Jo-Jo's voice heard

8.18 Throughout both reviews it is demonstrated that the voice of Jo-Jo was not considered or even heard. Her lived experience, her right to personalised care should have shone through, but this did not happen.

	Covered in	
Main Findings	**LeDeR**	**SAR**
No understanding of the lived experience of Jo-Jo.	y	y

Use of Policy and Practice Guidance

	Covered in	
Main Findings	**LeDeR**	**SAR**
Little recourse to policy or practice guidance by either health or social care	y	y

8.19 Good practice is underpinned by both statute and ensuing policy. This provides a framework for consistency and a touch stone for managers, commissioners and Elected Members to be assured that appropriate and high-quality services are in place.

8.20 In January 2012 Hackney's Scrutiny Commission reported on a major review following the implementation of new service model for Learning Disability Service that was tailored to suit individual needs. The new model was expected to address the implementation of "Personalisation" in Adult Social Care Services aimed at giving service users more choice and control over their care. The purpose of the scrutiny review was to understand the journey being taken by Hackney's Learning Disability Services to become a service of excellence. It was an important development. It is difficult to relate this aspiration to Jo-Jo's experience set out in this LeDeR and SAR.

8.21 The findings of the LeDeR and SAR show that for Jo-Jo the fundamental requirements of the Hackney Learning Disability Service did not work. The basis of multi-agency working/communication was not evident. Much of this has been acknowledged in ILDS' own report and reinforced by the findings of this SAR and LeDeR. The key issues are:

- It would have been good practice for the community nurse to liaise with the ILDS (who already knew about Jo-Jo). The social worker should have referred Jo-Jo to the ILDS specialist LD nursing team for additional support.

- Regular contact with the GP by the ILDS would have provided an overview of Jo-Jo's health conditions and allowed services to be adapted to meet any change in need. ILDS could have alerted the GP to the fact that the care package had been suspended. A GP liaison nurse could have assisted in the communication between ILDS and the GP. A Multi-Disciplinary Team discussion between social care and health colleagues (the nursing team) would have provided additional professional advice regarding Jo-Jo's eczema and the need to suspend social support when it worsened. It would also have established if Jo-Jo was receiving an Annual Health check.

- A holistic assessment should have been conducted on all LD service users. This would:
    - Help to stipulate responsibilities and raise awareness of early warning signs of physical health of deterioration.
    - Prompt carers to report on signs of physical health deterioration.
    - Ensure that the client receives further support where the responsible person is not available or is incapable of providing support due to other factors.

The Care Act 2014

8.22 The Care Act 2014 had relevance to Jo-Jo and to her mother. It should have been considered in its requirements for assessments of both Jo-Jo and her mother (as her main carer) and the requirements in relation to the protection of vulnerable adults.

8.23 There is no evidence that the Wellbeing test set out in the Care Act was considered in relation to either Jo-Jo or her mother. The lack of comprehensive assessment of Jo-Jo or carer assessment in relation to her mother (her main carer) was in breach of this Act. So too was the lack of any consideration of advocacy to support Jo-Jo. The key requirements are set out in section 6 of this report.

Mental Capacity Act 2005

8.24 The Mental Capacity Act (MCA) was not formally considered in the support offered to Jo-Jo. Nonetheless, assumptions were made about her not having mental capacity. The principles and requirements of the MCA should have been the basis of services and the support offered.

8.25 The Mental Capacity Act is designed to empower and protect an individual who may be unable to make a decision because of the way their mind or brain works and is affected, for example, by illness or disability. Jo-Jo was not properly considered.

8.26 There should have been better consideration given to the Mental Capacity Act (MCA) in relation to Jo-Jo's ability to make choices regarding her care arrangements. Jo-Jo was not spoken to regarding changes to her care including suspension of the package. It was assumed that:

- Jo-Jo did not have capacity to make these decisions even though an assessment did not place.

- Jo-Jo's mother was acting in her best interests regarding the suspension of care arrangements.

Valuing People

8.27 The principles outlined in *Valuing People: a new strategy for learning disability for the 21st Century* (Department of Health, 2001) and *Valuing People Now* (Department of Health, 2009) apply to the provision of health and social care for people with learning disabilities in England.

8.28 The purpose of that body of work was to establish the key principle that people with learning disabilities want to be able to make choices and decisions about the things that affect their lives. Having good support enables them to do this. The key aspects of what Valuing People sets out are summarised here.

What does good care and support looks like

8.29 People with learning disabilities should be valued equally, participate fully in their communities and be treated with dignity and respect. In developing good support organisations should work in partnership to provide holistic and person-centred services. In order to achieve this, support should uphold a number of basic principles and values:

Rights

8.30 The rights of people with learning disabilities are protected by law, and particularly by the Human Rights Act (1998). People with learning disabilities, their families and carers have an important role in promoting and upholding these rights.

Choice and control

8.31 People with learning disabilities need to have a wide range of options and information, knowing the advantages and disadvantages of each and are able to decide for themselves which ones best suits and that this choice is respected.

Independence

8.32 Although people with learning disabilities are taking more control over their own lives, they are still often on the receiving end of other people's decision making and planning. In promoting independence, the individual should be empowered to make choices and have more control over their own lives.

Inclusion

8.33 This is being able to participate in all aspects of life from work and education, to accessing services, to going out and meeting people. It also requires that people have the right support to be able to do this.

Guidance from Valuing People Now For Individuals Living with Their Family Carers

8.35 When an adult with learning disabilities lives with family carers, services should work in partnership to ensure that the needs of the whole family are met, recognising the important contribution that family members have. This was particularly the case for Jo-Jo as her mother was recognised and expected to be her main carer and give significant health and care overview.

8.36 This good practice enables family carers to be equal partners in care and recognise the expertise and knowledge of their family member. By definition if there are aspects that a main carer finds more difficult this should be supported. When beginning this process, services should agree the best ways to work with and involve families, and how this will be reviewed and evaluated on a regular basis.

8.37 The expectation of Valuing People is that any assessment should include consideration of the range of support services available to be provided. It further states that some people may have a support worker to help them access the local community; home or domiciliary care; or short breaks services. The individual with a learning disability may also receive a personal budget that can be used to provide tailor-made support. Access to all of these services is dependent upon an assessment of the person’s needs, which is provided via the local learning disability team or local authority social services department.

8.38 Adults with a learning disability and family carers may get support from a number of different health care or social care workers. These can include:

General Practitioners

8.39 GPs are the first point of contact for most people and have an extensive knowledge of medical conditions to be able to assess a problem and decide on the most appropriate course of action. Their role includes assessment, treatment, preventative work, education and signposting. They have an important role in making sure that individuals and their families are provided with the right support and will refer on to appropriate professionals.

Learning Disability Nurses

8.40 People with learning disabilities often have a wide range of physical and mental health conditions. Learning disability nurses have an extensive range of skills and work in partnership with individuals and their family carers to provide specialist healthcare. They aim to improve or maintain health and wellbeing, enabling people to participate in their local community. By reducing barriers to participation, they enable people with a learning disability to lead fulfilling lives.

Social Workers

8.41 Social workers support individuals and families to help improve the quality of their lives. They aim to develop strong relationships with the people they support and help them to find solutions to their problems. Social workers work closely with the other members of the multi-disciplinary team to protect people from harm and abuse and to support them to live independently.

8.42 This summary guidance is repeated here in full as a reminder to all those working with individuals with learning disabilities and their carers.

9. Concluding Statement

9.1 The scope of this SAR covers the period of Jo-Jo's life from April 2016 to March 2017 when she was 37 to 38 years old.

9.2 There is of course much more to her life before that when her main carer throughout childhood and into adulthood was her family with her mother as primary carer. As set out in Section 3 there was a strong bond between mother and daughter and her younger sisters. Jo-Jo was loved as an equal part of the family and involved in activities.

9.3 Jo-Jo's mother cared for her according to her own skills, abilities and understanding. It is not for this review to make a judgement on that care. There is no evidence that Jo-Jo was badly or differently cared for in the family because of her disability. Indeed, it is clear that she was unconditionally loved for the person she was.

9.4 The evidence and information gathered in this review and the LeDeR process outlines the ways in which both Jo-Jo and her mother, as the main carer, were let down by a succession of gaps and omissions by health and social care agencies on many occasions. Many simple straightforward communications/basic activities were not carried out, no one sought to coordinate care, good practice was ignored, policy and current learning was ignored, and unrealistic and untested assumptions were made about Jo-Jo's mother, who was left virtually unsupported to provide daily care for her daughter's undiagnosed skin condition.

9.5 Jo-Jo was let down by the agencies that should have supported her health and care, and so too was her mother.

9.6 Jo-Jo's care was not impaired by the lack of resources, rather she (and her mother) were left isolated by poor and ineffective use of resources.

9.7 It is difficult not to conclude that her learning disability played a part in these gaps and omissions, so too perhaps the assumed social standing of her mother.

9.8 Jo-Jo's voice was not heard. There was no advocacy, contrary to the requirements of the Care Act 2014, and the key tenets of Valuing People. Her mother inevitably struggled to penetrate an unfathomable and disconnected health and social care system.

9.9 It is not enough to state that "lessons will be learned". There are some fundamental issues of practice and process that must be addressed from this SAR. The primary issues are covered in the recommendations.

9.10 While some good progress has been made by agencies in their own analysis in the IMRs, senior managers and the Adult Safeguarding partnership will need to demonstrate commitment and challenge to put in place a sustainable action plan with clear requirements and monitored timescales to ensure that this constellation of circumstances does not happen again.

Recommendations and Learning

9.11 The following recommendations and learning are based on discussion with the SAR Panel at the meeting on 29 October 2018. Ultimately it is the responsibility of each agency to work through and implement the findings from their own Independent Management Reviews and the subsequent findings from the LeDeR and SAR reports. Though a good deal of this has been done there is still much to do.

9.12 The following recommendations are specific to the role of the LSAB and follow up the primary areas from this report. These will provide the basis for ongoing action plans.

9.13 To reiterate the following statement made at para 9, “it is not enough to state that “lessons will be learned”. There are some fundamental issues of practice and process that must be addressed from this SAR.”

Recommendations for the LSAB

LSAB 1. The LSAB should seek updated progress on the actions that have resulted from each agencies’ IMR report.

LSAB 2. The LSAB should establish an overarching SAR Action Plan covering individual IMR progress and the recommendations set out here.

LSAB 3. Ensure that agencies carry out annual health and social care reviews and have put in place adequate methods for checking on progress and outcomes of these reviews.

LSAB 4. Each key agency should be asked to demonstrate how they are supporting staff to use the Mental Capacity Act at a practice level in their assessments and ongoing practice. Any training and development should be practically based.

LSAB 5. Under the heading of Making Safeguarding Personal, the key principles of Valuing People Now and the Care Act 2014 should be reinforced particularly the focus on the needs of people with learning disabilities and their carers.

LSAB 6. The current Neglect Strategy for adults in Hackney should be reviewed to consider neglect concerns on a wider basis than self-neglect and hoarding.

Recommendations for Health Commissioners

HC 1. Health Commissioners should work directly with the GP surgery to ensure that the findings of the LeDeR are fully considered and that the IMR action points are put in place and monitored.

HC 2. Where appropriate these findings should also be shared more widely with health care providers to support good practice in all aspects of care.

HC 3. The GP surgery should be supported to review its use of practice meetings, specifically the best ways of ensuring that, where there are complex/high needs patients, their situation can be systematically considered.

Recommendations for the ILDS

ILDS 1. The document called FACE Overview Assessment form should be urgently reviewed to ensure that it meets the needs of personalised/individualised care for people with learning disability. It must give opportunity for the consideration of risk and safeguarding concerns. Specific consideration should be given to the "voice of the individual". It should be assessed to confirm that it meets the requirements of the Care Act 2014.

ILDS 2. When services are commissioned by the ILDS there should be clarity about:

- i. The purpose of the commissioned service.
- ii. Ways in which the service will be monitored using a personalised approach.
- iii. Clear expectations of the provider agency particularly in terms of information sharing about changes in key circumstances of the individual or their situation.
- iv. Where any significant changes are made in services, especially cancellations, these should be followed-up (in light of the original purpose) and where necessary communicated to other key agencies who may also be working with the individual or their family.

ILDS 3. As a practice standard, when setting up reviews the ILDS team should ensure that all other professionals (e.g. GP, community health, specialist staff and all those working with the individual or their family) are made aware and invited to attend or provide reports.

ILDS 4. Any review should ensure that a carer's needs are also fully considered in line with the Care Act 2014.

10. Legal Framework

10.1 There are relevant parts of legislation that should have been used to underpin and shape services to Jo-Jo.

Care Act 2014

10.2 The Care Act 2014 had relevance to Jo-Jo and to her mother. It should have been considered in its requirements for assessment of both Jo-Jo and her mother (as her main carer) and the requirements in relation to the protection of vulnerable adults.

10.3 The Guidance states that safeguarding is necessary for any adult who:

- has needs for care and support (whether or not the local authority is meeting any of those needs)
- is experiencing, or at risk of, abuse or neglect
- because of those care and support needs is unable to protect themselves from either the risk of, or the experience of, abuse or neglect.

10.4 Safeguarding, an additional responsibility on top of an institution's normal duties, is defined as:

> "*Protecting an adult's right to live in safety, free from abuse and neglect. It is about people and organisations working together to prevent and stop both the risks and experience of abuse or neglect, while at the same time making sure that the adult's wellbeing is promoted including, where appropriate, having regard to their views, wishes, feelings and beliefs in deciding on any action. This must recognise that adults sometimes have complex interpersonal relationships and may be ambivalent, unclear or unrealistic about their personal circumstances*."

10.5 According to the Guidance, an effective safeguarding environment should:

- facilitate multi-agency communication and be able to stop abuse where possible
- focus on preventing the likelihood of abuse occurring: this can be achieved by raising public awareness, providing information about potential safeguarding issues and addressing any underlying cause of abuse or neglect. For the latter, the Guidance states that it is necessary to reduce the risk of social isolation through provide mainstream community resources.
- have clear guidance for staff about their responsibilities and cultivate a positive working environment "to help break down cultures that are risk-averse and seek to scapegoat or blame practitioners".

10.6 The six principles underpinning the above are:

- empowerment (allowing individuals to make their own decisions)
- prevention
- proportionality (taking the least intrusive actions)

- protection (“Support and representation for those in greatest need”)
- partnership (working with communities)
- accountability

10.7 Set at Appendix I, with the permission of the London Borough of Barking and Dagenham, are extracts from their publication “Quick Cards: an introduction to the Care Act 2014” that provide a useful summary guide of key operation points introduced by the Care Act. These were written by the author of this SAR.

Mental Capacity Act 2005

10.8 The Mental Capacity Act was not formally considered in the support offered to Jo-Jo. Nonetheless, assumptions were made about her <u>not</u> having mental capacity. The principles and requirements here should have been the basis of services and support offered.

10.9 The Mental Capacity Act is designed to empower and protect an individual who may be unable to make a decision because of the way their mind or brain works and is affected, for example, by illness or disability.

10.10 The five principles of the Mental Capacity Act

1. **Presumption of capacity** – You must presume that the person you are working with has capacity for the particular decision unless you have evidence to the contrary. Assumptions about capacity should not be made on the basis of appearance, age or disability. Every adult has the right to make his or her own decisions and must be assumed to have capacity to do so unless it is proved otherwise.

2. **Maximise decision making ability** - A person must not to be treated as being unable to make a decision unless all practicable steps to help them to do so have been taken without success. Examples may include the use of interpreters, supporting people to communicate in their own language, using pictures or using a speech and language specialist.

3. **Unwise decisions** – If a person appears to be making unwise decisions this is *not* evidence of a lack of capacity. Just because an individual makes what might be seen as an unwise decision, they should not be treated as lacking capacity to make that decision.

4. **Best interests** – an act done or decision made under the Act for or on behalf of a person who lacks capacity must be done in their best interests.

5. **Less restrictive option** – anything done for or on behalf of a person who lacks capacity should be the least restrictive of their basic rights and freedoms.

10.11 In assessing a person’s capacity to make a decision, the principles of the Mental Capacity Act 2005 should be followed.

10.12 A person lacks capacity if at a specific time they are unable to make a specific decision because of a temporary or permanent impairment of, or disturbance in, the functioning of the mind or brain.

10.13 A person is deemed as unable to make a decision if they are unable to:

- understand information relating to the decision, or
- retain the information, or
- use the information as part of the process of making the decision, or
- communicate the decision.

10.14 Every effort should be made to find ways of communicating with someone before deciding that they lack capacity to make a decision based solely on their inability to communicate. Family, friends, carers or other professionals will need to be involved.

Record keeping

10.15 What and when to record will vary. Although as a general rule, there is no need to record assessments of capacity to take day-to-day decisions, in order to have protection from liability when providing care or treatment, staff must have a reasonable belief that the person they care for lacks capacity to make relevant decisions about their care or treatment (see section 5 (1) MCA).

10.16 In these circumstances, it is useful to be able to describe the steps taken and have a written record.

10.17 Professionals are subject to higher standards in terms of record keeping and a formal record will be required to be kept, for example in the patient’s clinical notes if a doctor or a healthcare professional is proposing treatment for someone who lacks capacity.

Human Rights Act 1998

10.18 It is difficult to find any underpinning considerations of the Human Rights Act or application of the Equality Act in relation to the services and support in both health and social care services.

10.19 The Human Rights Act 1998 bolstered the rights of children and vulnerable adults. Human rights are now at the very core of Person-Centred Planning, which aims to give people with learning disabilities the right to be treated and live life with the same rights, choices and opportunities as everybody else.

10.20 There are several specific rights that are particularly relevant to people with learning disabilities. Some of these include, but are not limited to Article 2, 3 and 14.

Article 2 – the right to life

10.21 This is a universal and limitless right. Those with severe and profound learning disabilities therefore have the right to life-saving medical treatment, to treatment that prolongs life. However, it also calls into question the right to life and the right of the individual to choose to die, through euthanasia. As expected, this is an extremely controversial and sensitive subject that continues to divide opinion throughout the public and professional services.

Article 3 - everybody has the right not to be tortured in an inhuman or degrading way

10.22 For people with learning disabilities, this means that they are legally protected from both mental and physical abuse, protected from living in poor conditions in institutions, with the right to be protected from any form of neglect, such as not being dressed, fed or receiving appropriate care and treatment. The Human Rights Act 1998 also means that public authorities can be prosecuted should they fail to protect people with learning disabilities from abuse or neglect.

Article 14 – the right to not be discriminated against in the enjoyment of your other rights

10.23 This has a particular relevance to those with learning disabilities. Along with certain legislation such as the Disability Discrimination Act, this right helps to ensure that people with learning disabilities are not discriminated against because of their disability, in all aspects of life, including healthcare, job opportunities, the right to independent living, the right to services and support in the community.

10.24 Article 14, strengthened by the legal effect of the Human Rights Act, also helps to ensure that people with learning disabilities officially have equal rights and opportunities as everyone else.

Equality Act 2010

10.25 The Equality Act brought together all the major reforming legislation into one statute but was not simply a consolidating Act. It expanded the anti-discrimination law applying to race, sex and disability, and applied the same principles to age, gender reassignment, marriage and civil partnership, religion or belief, sexual orientation, and pregnancy and maternity – the nine “protected characteristics” covered by the Act. It is a major piece of legislation designed to protect and promote the interests of some of the most vulnerable members of society

10.26 The Equality Act 2010 says that an individual must not be discriminated against because:

- they have a disability
- someone thinks an individual has a disability (discrimination by perception)
- they are connected to someone with a disability (discrimination by association)

11. Learning Disabilities and Safeguarding

11.1 There is a long catalogue of failings directly related to health and social care support to adults with a learning disability set out over many years.

11.2 Some refer to deliberate harm, but many refer to failures in practice, assessment and review and joined-up approaches. Many have failed to ascribe the same rights for care and treatment to people with a learning disability as are expected and mostly received by people without a learning disability.

11.3 Numerous initiatives such as Putting People First[5] etc. have made significant inroads into these problems but still there are continuing difficulties in accessing and receiving health and social care and support.

11.4 Jo-Jo was an adult suffering from a significant and debilitating skin condition that was not diagnosed and consequently not properly treated. Her main carer was left to manage this essentially on her own.

11.5 The failure to diagnose and treat Jo-Jo is laid out in the LeDeR and has been recognised by the health agencies in their IMR.

11.6 The failure to provide support and coordinated care to Jo-Jo and support to her mother has been set out straightforwardly by the local authority learning disability services.

11.7 Had the required assessment of need and risk and review requirements been followed it is likely that the health diagnosis and care arrangements would have been challenged.

11.8 Had an advocate to support both Jo-Jo and her mother been arranged this too could have added weight to this challenge.

11.9 As it happened, Jo-Jo's voice was not heard, nor was her mother as her main carer.

11.10 It is very difficult not to conclude that these gaps and omissions were linked to Jo-Jo's learning disability, though not as a conscious act by anyone; had the required safeguards of good practice and process been in place (as developed for people with a learning disability) then Jo-Jo's condition would have been treated and her considerable pain and suffering would have been greatly reduced.

11.11 Jo-Jo had long history of eczema. Below is a table summarising the sequence of Jo-Jo's diagnosis and treatment with comments:

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[5] Putting People First was published by the Department of Health in December 2007 and set out an approach to ensuring independent living for all adults through a joined-up partnership between local and central government

Date	Diagnosis/Treatment	Comment
2013 (Aug to Dec)	Jo-Jo and family diagnosed and treated for scabies by dermatology outpatients	
July 2015	Scabies is queried twice by GPs Topical cleansers and moisturisers prescribed Referral to dermatology	This does not appear to be a treatment for scabies, rather eczema
September 2015	Diagnosis of moderate eczema and hyperkeratosis. Prescribed topical treatments	This diagnosis, which did not include any reference to scabies, was then relied upon as a basis for future treatment until 9 March 2017
November 2015	Flare up of eczema with hyperkeratosis Not using creams prescribed as no repeat prescriptions. Mum said *'it's a problem getting the creams onto her*"	Indication that Jo-Jo's mother is struggling to apply the creams and therefore that Jo-Jo is not receiving the treatments as prescribed
5 January 2016	Review of hands and feet, needs referral to podiatrist. Had difficulty extending fingers, 'crusty areas come off in the bath'. Palms are hyperkeratotic, and deep fissures. Antibiotics prescribed.	
21 January 2016	Consultation follow up - Terrible hyperkeratosis, scaly rash on hands, glove size changed. Only using Epaderm on face not hands, encouraged to continue. "*Not sure what else to do as mum only has a very limited understanding of her condition".*	Epaderm is a brand of emollient which is used for the treatment of dry skin, including conditions such as eczema Missed opportunity to consider Jo-Jo and the impact her skin condition was having on her day to day life and possible appropriate action
1 February 2016	GP follow up - hands slowly improving, scalp itchy/scaly, nails dystrophic, continue with current treatment. Prescribed topical medications	
7 March 2016	"*Ongoing rash over face and trunk, and abdomen, re-infected with bed bugs. Council fumigated house but have noticed bugs are back."* Dry eczema over hands and erythema on hands	Bedbugs had not previously been mentioned. Permethrin would be suitable for treating bedbugs (and scabies

	Prescribed steroids and permethrin	also). It would need to be applied to the entire body from head to the soles of the feet and washed off after 8–14 hours. One treatment can be curative.
24 January 2017	Mother seeks help in managing Jo-Jo's skin condition. Referred to district nursing	
25 January 2017	District Nurse attends. Assesses that Jo-Jo will apply the creams herself with prompts from mother.	No feedback given to GPs. Insufficient consideration of whether this was manageable by the family. Pain was the noted reason for Jo-Jo not allowing creams to be applied. The District Nurse referred to this in the discharge letter to the GP but did not discuss pain management with Jo-Jo or her mother. No evidence of assessing the likelihood that Jo-Jo would apply the creams. GP took no action in relation to pain management
16 February 2017	Telephone consultation. Jo-Jo not allowing anyone to put cream on her body or to shampoo her hair or apply anything to her scalp. Scalp has lots of crusts that she picks off, some are bleeding. Mum suggested applying olive oil, to soften the crusting, then maybe accepting of the Nizoral shampoo	Nizoral shampoo is a powerful anti-yeast treatment which is often used if eczema scaling does not improve after using a medicated shampoo for a few weeks
9 March 2017	GP home visit at Mother's request. GP unable to get close enough to Jo-Jo to take her vital signs. Diagnosed with Norwegian scabies. Urgent appointment made for dermatology the next day.	This was a considered approach discussed in detail at paras 7.30-7.37
14 March 217	Coroners post mortem report states that the GP said Jo-Jo had been treated for scabies	This is incorrect. Scabies had only been diagnosed the day before Jo-Jo died. Permethrin had been prescribed in March 2016

		(a year before Ms's death) but the diagnosis at this point was "Dry eczema over hands and erythema on hands". Prior to that scabies had been treated in 2013 (over 3 years before she died)

Health Inequalities

11.12 Detailed evidence reported by the Public Health Observatory shows there to be five discernible determinants of the health inequalities commonly experienced by people with learning disabilities:

- Social determinants
- Genetic and biological determinants
- Communication difficulties and reduced health literacy
- Personal health behaviour and lifestyle risks
- Deficiencies in access to and quality of health provision

What Health Checks Should be Done

11.13 Public Health England cites the following significant health problems for people with a learning disability:

- Obesity
- Epilepsy
- Severe mental illness
- Dementia
- Diabetes
- Gastrointestinal problems e.g. constipation, gastro-oesophageal reflux disorder, dysphagia
- And many others

11.14 Slides prepared by NHS England in 2017 on the Annual Learning Disability Health Check explain that under the Learning Disability Direct Enhanced Service practices should invite all patients on the health check register for a review of physical and mental health annually.

11.15 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.

Appendix A

Safeguarding Adult Reviews (SAR) National Requirements

The Care Act 2014 came into effect from 1st April 2015. Under section 44:

> “(*1) A Safeguarding Adults Board must arrange for there to be a review of a case involving an adult in its area with needs for care and support (whether or not the local authority has been meeting any of those needs) if—*
>
> *(a) there is reasonable cause for concern about how the Safeguarding Adults Board, members of it or other persons with relevant functions worked together to safeguard the adult, and*
> *(b) condition 1 or 2 is met.*
>
> *(2) Condition 1 is met if—*
>
> *(a) the adult has died, and*
> *(b) the Safeguarding Adults Board knows or suspects that the death resulted from abuse or neglect (whether or not it knew about or suspected the abuse or neglect before the adult died).*
>
> *(3) Condition 2 is met if—*
>
> *(a) the adult is still alive, and*
> *(b) the Safeguarding Adults Board knows or suspects that the adult has experienced serious abuse or neglect.*
>
> *(4) A Safeguarding Adults Board may arrange for there to be a review of any other case involving an adult in its area with needs for care and support (whether or not the local authority has been meeting any of those needs).*
>
> *(5) Each member of the Safeguarding Adults Board must co-operate in and contribute to the carrying out of a review under this section with a view to—*
>
> *(a) identifying the lessons to be learnt from the adult’s case, and*
> *(b) applying those lessons to future cases.”*

The Care Act 2014 Guidance explains that the purpose of a review is to:

i. Develop learning that enables the safeguarding adults' partnership future.

ii. Ensure that lessons are learnt and lessons are applied to future situations to improve local practice, procedures and services together with partnership working to minimise the possibility of circumstances similar to this happening again.

iii. The purpose of the review is not to apportion blame or 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, the Nursing and Midwifery Council, the Health and Care Professions Council, and the General Medical Council.

The City and Hackney Safeguarding Adults Board will ensure recommendations and actions from Safeguarding Adults Reviews are implemented to ensure that learning from these are not lost but used to improve services and prevent further harm, abuse or neglect.

The following principles apply to all reviews:

- there must be a culture of continuous learning and improvement across the organisations that work together to safeguard and promote the wellbeing and empowerment of adults, identifying opportunities to draw on what works and promote good practice;

- the approach taken to reviews must be proportionate according to the scale and level of complexity of the issues being examined;

- the individual (where able) and their families will be invited to contribute to reviews. They should understand how they are going to be involved and their expectations should be managed appropriately and sensitively;

- the City and Hackney Safeguarding Adults Board is responsible for the review and must assure themselves that it takes place in a timely manner and appropriate action is taken to secure improvement in practices;

- reviews of serious cases will be led by individuals who are independent of the case under review and of the organisations whose actions are being reviewed and

- professionals/practitioners will be involved fully in reviews and invited to contribute their perspectives.

Appendix B: Terms of Reference

Objective of the Review

The objective of this Review is to establish:

Through the LeDeR, if Jo-Jo's health could have been managed differently

Through the SAR process, consider the impact of:

1) Neglect
2) Service Offer/Refusal
3) How was Jo-Jo's mother supported to look after her?
4) Understanding the relationship between Jo-Jo, her mother and her family
5) How was Jo-Jo's Mental Capacity understood, addressed and risks managed?
6) Was Jo-Jo's voice heard?
7) Bring together the findings from the LeDeR and the findings from the SAR to inform learning
8) Consider all relevant use of legislation and national/local policy and practice guidance.

Methodology

The chosen methodology is the most appropriate approach that will enable the learning objective to be met in a way that is proportionate to the needs of this case review. The approach will be flexible, if in the course of the process, it needs to be adapted to the findings to better inform learning.

The methodology combines the LeDeR to interrogate the unexpected death of Jo-Jo, and the SAR overview process that considers the findings of the LeDeR and other elements of the case relevant to the SAR.

Jo-Jo's family will be informed of the SAR process and offered involvement.

The Process will be as follows

- LeDeR (a national programme to address the premature deaths of people with learning disability) will be completed by LeDeR trained reviewer and consider health issues relevant to the case.

- The SAR author will consider issues related to care through chronologies and IMRs.

- IMRs and LeDeR findings are integrated by the SAR author to inform a collaborative review facilitated by the SAR author to identify recommendations.

- The draft report is produced and considered by the Panel and recommendations agreed.

- The draft report is circulated to agencies involved and amended with agreement by Panel and Panel Chair.

- The draft report is presented to the SAR subgroup of the CHSAB and amended where relevant.

- Final draft review report to be presented to the CHSAB.

Membership of SAR Panel

The Panel will consist of:

- Chair: Dr Nicole Klynman
- GP
- CCG
- Homerton University Hospital
- LBH Integrated Learning Disabilities Service (ILDS)
- Pain Management Nurse/LD liaison nurse (as an advisor to the panel)

The CHSAB Business Support Team will provide administrative support and, where possible, circulate documents at least five working days in advance of meetings.

Agencies to be involved in Review

The following agencies are to be asked to contribute to this Review:

- London Borough of Hackney: Adult Social Care, Integrated Learning Disability Services
- Goldsmiths Care Agency
- Health Services

Agencies to be involved in LeDeR Review

The following agencies are to be asked to contribute to this Review:

- General Practitioner
- Homerton University Hospital – District Nursing
- Any Health Services identified as having provided services and where referrals were made and refused for Jo-Jo

Links to other Reviews or Processes

There are no further Coroner or Police investigations currently known to be linked to this case.

The LeDeR process applies to this case due to the fact that this was an unexpected and premature death. The findings of the review will be integrated into the findings of the SAR.

The Panel chair has agreed that the methodology of this Review complements and does not duplicate these ongoing processes.

Appendix C: LeDeR Review Programme

The Learning Disabilities Mortality Review (LeDeR) Programme has been established in response to the recommendations of the Confidential Inquiry into the premature deaths of people with learning disabilities (CIPOLD). It has been commissioned by NHS England and is managed by the Healthcare Quality Improvement Partnership (HQIP).

Since the 1990s there have been a number of reports and case studies that have consistently highlighted that in England people with learning disabilities die younger than people without learning disabilities. CIPOLD reported that people with learning disabilities are four times as likely to die from preventable causes compared with the general population (Disability Rights Commission, 2006). More recently, analysis of data from the Primary Care Research Database suggested that the all-cause standardised mortality ratio for people with learning disabilities was 3:18, and that people with learning disabilities had a life expectancy 19.7 years lower than people without learning disabilities.

The LeDeR Programme has been set up to contribute to improvements in the quality of health and social care for people with learning disabilities in England. It will do so by supporting local areas to carry out local reviews of deaths of people with learning disabilities. Through an agreed local review process, it aims to firmly embed the responsibility for conducting the reviews and implementing any recommendations and plans of action into the hands of regional and local services.

In addition to supporting the programme of local reviews of deaths of people with learning disabilities, the LeDeR Programme is also undertaking four additional projects. The focus of these is to:

- Support data linkage techniques to provide national data about the mortality of people with learning disabilities

- Map the provision of reasonable adjustments for people with learning disabilities across England

- Improve the consistency of death certification in relation to people with learning disabilities

- Establish a repository for anonymised reports pertaining to people with learning disabilities, e.g. Serious Case Reviews, Ombudsman Reports

The purpose of the Learning Disability Mortality Review programme

The main purpose of the LeDeR of a death of a person with learning disabilities is to:

- identify any potentially avoidable factors that may have contributed to the person’s death and
- develop plans of action that individually or in combination, will guide necessary changes in health and social care services in order to reduce premature deaths of people with learning disabilities.

Source: Guidance for the conduct of local reviews of the deaths of people with learning disabilities Published by University of Bristol and NHS England

Appendix D: Summary Chronology of agency involvement

Date	Event
2013	
June	Jo-Jo referred to dermatology OPD in view of severe widespread eczema
31 July	Treated in outpatients for widespread infected eczematous eruption
28 August	Reviewed in outpatients – no improvement. Treated for possible crusted scabies
9 September	Reviewed in outpatients – probably crusted scabies, responding to treatment
25 September	Reviewed in outpatients – continue treatment for Norwegian scabies. Increased treatment for sub-erythrodermic eczema
9 October	Jo-Jo much improved. GP suggests treating whole family
4 December	Reviewed in outpatients – Jo-Jo has active scabies and treatment for all in family recommended
2014	
15 January	Reviewed in outpatients – skin much improved; may need one more treatment. To be reviewed in one month. This did not happen. GP practice did not receive a Did Not Attend letter
20 February	Vitamin B12 deficiency noted
27 March	Cervical neoplasia screen (negative)
28 April	Chronic Disease monitoring appointment
28 May	Invite for annual review appointment
18 July	Did not attend for chronic disease, bloods and initial review
29 July	Was seen for chronic disease, bloods and initial review
19 September	Consultation re rash and skin eruption: query infected, prescribed antibiotics
5 November	Vitamin D deficiency noted
2015	
23 March	GP Consultation re painful feet
8 May	Consultation re infected feet - referred to Podiatry Adverse reaction to Penicillin documented
11 May	Follow up consultation on foot sores
1 June	LD Annual Health Examination
25 June	Invite to annual review appointment
30 June	Foot Health Clinic letter - Mother states current creams not effective, proposing a referral to dermatology.
7 July	Consultation re skin sores, query scabies, Prescribed topical cleansers and moisturisers. Mum asking to go to GPwSI (GP with Special Interest) (out of area) for dermatology review.
9 July	Telephone consultation with mother, feet swollen and very uncomfortable, advised to call CHUHSE (out of hours GP).
16 July	Chronic Disease monitoring
2015 continued	
24 July	Coeliac Disease Screen - Abnormal

27 July	Consultation, Inflammation of feet, Foot Health Clinic said needs a dermatology referral. Query crusted scabies Continue on current treatment
30 July	Referral to dermatology completed.
19 August	Chronic Disease follow up Vitamin B12 injection schedule, Vitamin D booster prescribed.
4 September	Homerton Hospital dermatology Clinic letter. Diagnosed with moderate eczema and excessive hyperkeratosis especially on her heels. Prescribed topical treatments and advised needs a podiatrist for toe nail clipping. Discharged.
17 September	Did not attend for B12 injection
21 September	Seen by GP for B12 injection
Weds 14 October	Goldsmith Personnel (GPL) Community escort service started twice a week (6 hours in total). Overview Assessment & Care and Support Plan and the GLP Needs and Support Plan notes Mother is main carer and supports Jo-Jo in expressing her needs and providing personal care in the home
Mon 19 October to Wed 4 November	5 GPL community outreach support visits
Mon 9 November	Jo-Jo's mother cancels the service from GPL due to Jo-Jo's skin condition (not well enough to go out). Hackney Social Services notified of cancellation
Weds 11 November	Jo-Jo's mother cancels the service from GPL due to Jo-Jo's skin condition (not well enough to go out). Hackney Social Services notified of cancellation
30 November	GP Consultation re flare up of Eczema with hyperkeratosis, query not using creams prescribed as no repeat prescriptions. Mum said *'it's a problem getting the creams onto her'*.
Mon 14 December 2015 to Mon 4 January 2016	GPL carer informs GPL that Jo-Jo has gone to Blackpool on holiday with family till the end of the month. Hackney Social Services notified of cancellation
2016	
Tues 5 January	GP Consultation review of hands and feet, needs referral to podiatrist. Had difficulty extending fingers, 'crusty areas come off in the bath'. Palms are hyperkeratotic, and deep fissures. Antibiotics prescribed
Weds 6 January	Referred to Podiatry
Fri 8 January	GP Consultation follow up - needs to apply creams or won't improve, advised to use regularly
Sun 10 January to 20 January	4 GPL community outreach support visits
2016 continued	
Thurs 21st January	GP Consultation follow up - Terrible hyperkeratosis, scaly rash on hands, glove size changed. Only using Epaderm on face not hands, encouraged to continue. "*Not sure what else to do as mum only have a very limited understanding of her condition*".
Mon 25 January	GPL community outreach support

	Did not attend GP review, but seen a week later
Weds 27 January	GPL community outreach support
Mon 1 February	GPL community outreach support GP Consultation follow up - Hands slowly improving, scalp itchy/scaly, nails dystrophic, continue with current treatment. Prescribed topical medications
Tues 2 February	Homerton Hospital Letter Inviting to Foot Health Clinic appointment
Mon 8 February	GPL community outreach support
Weds 10 February	GPL community outreach support
Mon 15 February	Jo-Jo's mother cancels the service from GPL due to Jo-Jo's skin condition
Weds 17 February	Jo-Jo's mother cancels the service from GPL due to Jo-Jo's skin condition. Hackney Social Services notified of cancellation
Mon 22 February	Jo-Jo's mother cancels the service from GPL due to Jo-Jo's skin condition. Hackney Social Services notified of cancellation Did not attend Homerton Hospital Foot Health Clinic
Tues 23 February	Jo-Jo's mother cancels the service from GPL due to Jo-Jo's skin condition. Hackney Social Services notified of cancellation
Mon 29 February	Jo-Jo's mother cancels the service from GPL due to Jo-Jo's skin condition. Hackney Social Services notified of cancellation
Weds 2 March	Jo-Jo's mother cancels the service from GPL due to Jo-Jo's skin condition. Hackney Social Services notified of cancellation
Mon 7 March	Jo-Jo's mother cancels the service from GPL due to Jo-Jo's skin condition. Hackney Social Services notified of cancellation Jo-Jo sees the GP. This is the last GP appointment in 2016. Notes show the house had been fumigated "Ongoing rash over face and trunk, and abdomen, re-infected with bed bugs. Council fumigated house but have noticed bugs are back. Dry eczema over hands and erythema on hands, prescribed steroids and permethrin."
2016 continued	
Weds 9 March	Hackney Social Services issue a CA4 to GPL to cancel the service to Jo-Jo until further notice
Mon 4 April	Hackney Social Services contact Jo-Jo's mother to arrange a review
Tues 5 April	Social Worker has a face to face annual review meeting with Jo-Jo's mother at home. Notes state that Jo-Jo has severe eczema on feet, legs and head and that advises Jo-Jo has had condition since 09 March 2016. Jo-Jo very unwell and can't access community. Action to suspend services and carer to contact ILDS when Jo-Jo is improved. Views of Jo-Jo are not recorded

Weds 8 April	Social Work discusses case in supervision with Senior Practitioner 1. There are no notes of this supervision Social Worker sends request to Brokerage to suspend the services
Sun 26 June	Paperwork of FACE Overview Assessment (a joint assessment of Jo-Jo and her mother).
Tues 28 June	Home visit by Social Worker. Jo-Jo has improved. Request made to reinstate 6 hours of community access per week. Social Worker phones GPL to resume services to Jo-Jo "Re-instate of services 28/06/16 and request for respite for 2 weeks 6-20 August 2016"
Mon 4 July to 11 July	3 GPL community outreach support visits
Thurs 14 July	GPL provide community outreach support to Jo-Jo but carer noted that Jo-Jo was in a lot of pain and could not walk, therefore she called the paramedics who checked Jo-Jo and was transferred to Homerton A&E in an ambulance. GPL carer stayed with Jo-Jo till her mum arrived at the hospital and left Jo-Jo at the hospital with her mum. A&E notes describe Jo-Jo as experiencing pain in her shoulder and is discharged with analgesic cream
Mon 18 July	GPL community outreach support
Tues 19 July	Social Worker initiates Community Care Assessment. Respite care identified. Mother agreed to continue to provide personal care.
Thurs 21 July	GPL community outreach support
Fri 22 July	Community Care Assessment is completed. Outcome is 2 weeks respite care with budget of £2,000
Mon 25 July	GPL community outreach support Social Worker sends completed Support Plan to Senior Practitioner 1 to authorise
Tues 26 July	Supervision session between Social Worker and Senior Practitioner 1. Outcome: Social Worker to send letter re respite and close case, suspend services whilst in respite
Thurs 28 July	GPL community outreach support Z
Fri 29 July	Social Worker sends letter to Jo-Jo/Mother. Confirming respite and cessation of package for period.
Mon 1 August	GPL community outreach support
Thurs 4 August	GPL community outreach support
Mon 8 August	Care cancelled – no reason given in GPL chronology
2016 continued	
Thurs 11 August	GPL community outreach support
Fri 12 August	Social Worker sends Support Plan to Linton Lodge
Sat 13 August	Jo-Jo attends residential respite care from 13 to 27 August.
Mon 15 August	Care cancelled – no reason given in GPL chronology
Thurs 18 August	Care cancelled – no reason given in GPL chronology
Mon 22 August	Care cancelled – no reason given in GPL chronology

	There is contact internal to GPL where an admin worker is given confirmation that services had been reinstated from 28 June
Thurs 25 August	Care cancelled – no reason given in GPL chronology
Sun 28 August	Senior Practitioner 1 tells Social Worker that the support plan needs to be recalculated to include respite - respite needs to be added before authorisation at panel
Mon 29 August	GPL text mother to check if Ok to provide service. Mother says it is and service is provided
Tues 30 August to 5 September	3 GPL community outreach support visits
Weds 7 September	ILDS Panel Meeting - Support Plan agreed – Social Worker informed Did not attend GP for Vitamin D injection
Thurs 8 September	Support Plan sent to Brokerage Officer GPL provide community outreach support to Jo-Jo
Mon 12 September to Thurs 22 December	27 GPL community outreach support visits.
December	No specific date. LeDeR report says as Jo-Jo became unwell again she took to her bedroom and did not want to do anything. There was no discussion about support workers still having 1:1 time with her at home
Mon 26 December	Jo-Jo’s mother cancels the service from GPL due to Jo-Jo’s skin condition
Tues 27 December	Jo-Jo’s mother cancels the service from GPL due to Jo-Jo’s skin condition
Fri 30 December	Jo-Jo’s mother cancels the service from GPL due to Jo-Jo’s skin condition
2017	
Mon 2 January	Jo-Jo’s mother cancels the service from GPL due to Jo-Jo’s skin condition
2017 continued	
Thurs 5 January	GPL community outreach support
Fri 6 January	Jo-Jo’s mother cancels the service from GPL due to Jo-Jo’s skin condition. Hackney Social Services notified
Mon 9 January	Jo-Jo’s mother cancels the service from GPL due to Jo-Jo’s skin condition. Hackney Social Services notified
Weds 11 January	Jo-Jo’s mother cancels the service from GPL due to Jo-Jo’s skin condition. Hackney Social Services notified
Thurs 12 January	Jo-Jo’s mother cancels the service from GPL due to Jo-Jo’s skin condition.
Sun 15 January	Jo-Jo’s mother cancels the service from GPL due to Jo-Jo’s skin condition. Hackney Social Services notified. Email sent to Social Services about the cancellations
Mon 16 January	Jo-Jo’s mother cancels the service from GPL due to Jo-Jo’s skin condition. Hackney Social Services notified
Mon 23 January	Jo-Jo’s mother cancels the service from GPL due to Jo-Jo’s skin condition. Hackney Social Services notified. Email sent to Social Services raising a concern (this email cannot be found on the ILDS files or the GPL records)
Tues 24 January	Mother contacts the GP asking for help in managing Jo-Jo’s skin condition as she was refusing to have cream applied to her back and head. GP refers to District Nursing
Wed 25 January	District Nurse sees Jo-Jo. Jo-Jo declined to apply cream to her skin because of the pain. No open wounds visible

	The outcome was to discharge Jo-Jo from the service as there was an agreement for Jo-Jo to apply the creams herself with prompts from Mother. No further District Nurse involvement required – if it was contact to be made with GP
Fri 3 February	Email from GPL to ILDS saying that Jo-Jo's mother had cancelled the service "as no longer needed" from the beginning of January 2017. Senior Practitioner 2 (ILDS Duty) emails GPL asking them to confirm the last date of service provision
Mon 6 February	GPL email Senior Practitioner 2 (ILDS Duty) advising that the last service provided was 5 January 2017
Tues 7 February	Brokerage Team suspend service
16 February	GP telephone consultation with Mother – Jo-Jo not allowing anyone to put cream on her body or to shampoo her hair or apply anything to her scalp. Scalp has lots of crusts that she picks off, some are bleeding. Mum suggested applying olive oil, to soften the crusting, then maybe accepting of the nizoral shampoo.
Mon 6 March	Mother told LeDeR author that Jo-Jo stopped eating and drinking at this date
Thurs 9 March	Mother phones GP and a home visit is carried out. Jo-Jo had become incontinent in the past few days and could not stand to get to the toilet. Has refused to get up since 7 March, is not eating but drinking well. GP was unable to get near enough to Jo-Jo to take her vital signs. "Diagnosed Norwegian scabies. Jo-Jo lying on the floor, afebrile, unable to take HR or BP as pulling away, said sorry but otherwise unable to understand. Could not stand up, old skin covering the floor. On examination she had large crusty plaques 1cm thick on her scalp, all her skin was red but not hot. Crusting all over her body. Feet almost completely covered with crusts 0.5 mm thick. On her right upper thigh and buttock 12 cm diameter that is dark brown/black. Surrounding erythema but not hot, mum said she had noticed it today. She didn't want her to go to hospital and that Social Services would be called and didn't want that. House needs a blitz clean and Social Services need to be involved. Urgent appointment made for dermatology at RLH next day." Urgent referral to dermatology department at the RLH for the next day (10 March)
2017 continued	
Fri 10 March	GP writes to RLH dermatology - there is a concern that there is a recurrence of Norwegian scabies. GP stated that Jo-Jo would probably need admission as she was declining the use of topical treatments, (for what was thought to be eczema). A single room was advised so Mother could stay Ambulance arrives at home at 09.00 to take Jo-Jo to the hospital. They arrive at 09.15 Jo-Jo taken to dermatology department but within 6 minutes of arriving goes into cardiac arrest. After an initial successful resuscitation, she arrested again and died in the department before being transferred to ITU.

	AT 10.13 the Ambulance raise a safeguarding alert with the local authority because of their concerns that Jo-Jo's condition could deteriorate due to the home environment GPL had conversation with carer regarding appointment today. Text received later that day [from Mother] saying Jo-Jo had died. GPL emailed Senior Practitioner 2 (ILDS Duty) to inform them. Senior Practitioner 2 (ILDS Duty) requests phone number for carer [Mother] from GPL GPL provide the phone number for Mother. Senior Practitioner 2 (ILDS Duty) phones Mother - who advised that "Jo-Jo wasn't herself last night" [9 March] and GP called. Urgent dermatology appointment arranged today and Jo-Jo went by ambulance. Jo-Jo went to Royal London Hospital in the morning. When doctors left room to take samples, Jo-Jo died.
14 March	Learning Disability Lead Nurse at Barts Health NHS Trust makes a referral to LD mortality Review and advises LB Hackney's Head of Service Safeguarding Adults
	Chronology prepared by SAR Author

Appendix E: Agencies Involved

Agency
London Borough of Hackney : ● Adult Social Care, Integrated Learning Disabilities Service ● Adult Social Care Duty Team
District Nurse Service
GP Practice
Goldsmith Personnel Limited – provider of community outreach workers
Homerton University Hospital ● A&E ● Foot Clinic ● Dermatology Clinic
Royal London Hospital

Key to Acronyms/Abbreviations:

ASC	Adult Social Care
CHUHSE	City and Hackney Urgent Health Care Social Enterprise (out of hours GP)
GPL	Goldsmith Personnel Limited
GPwSI	GP with Special Interest in dermatology and skin care. Now referred to as GPwER (GP with Extended Role)
HUH	Homerton University Hospital
LAS	London Ambulance Service
ILDS	Integrated Learning Disabilities Service
MCA	Mental Capacity Act

Appendix F: Specific areas of enquiry raised with agencies as part of the IMR process

LB Hackney's Integrated Learning Disability Services

Analysis of and reflection on your agency's involvement:

- What significant actions were taken or not taken during your agency's involvement, and the reasons you have been able to identify for the actions taken or not taken.
- How do the actions taken or not taken measure up against legal requirements, policy and procedures, contractual requirements, codes of practice and good practice standards (nationally and locally).
- What approach was taken to the individual's capacity, dignity, wishes and feelings, issues of diversity and equality.
- Inter-agency collaboration: what good practice or difficulties were experienced, how did these affected your agency's involvement and how did your agency attempt to address difficulties.
- Has your agency already identified practice/improvement issues and changes it may have made as a result.
- What management oversight and scrutiny was given to the case within your agency; were any issues of concern escalated by staff.

In the narrative of your involvement and engagement please consider:

1. Were there any significant events/changes and how did your agency respond
2. Give evidence of this in terms of any reports, reviews etc
3. Support any practice and decision making with your own existing policy or guidance documents

All agencies are asked to comment specifically on some key questions. Please address these, build them into the narrative referring if necessary to information given in the section above.

a) How was Jo-Jo's voice or views heard. What attempts were there to engage with her to obtain her views

b) What multi-disciplinary discussions or analysis were asked for. What discussions took place

Please also consider the following issues relating to your service(s):

Assessment, Planning and Decision Making

- Did any worker form a relationship with Jo-Jo or her Mother. Give details if possible.
- Were any safeguarding concerns raised.
- What was the specific commissioning request to the care provider for care that started in October 2015. How was the service reviewed from a commissioning perspective and from a service perspective. What were the outcomes of any reviews.
- Was advocacy considered/offered
- Does the record keeping show evidence of decision-making, case work and risk analysis.

- Was consideration of the care agency (or anyone else) giving support to Jo-Jo's care in the home ever done.
- Clarify who carried out/organised the fumigation of the house in March 2016. What does the record say, who was informed etc
- With regard to the 5th April 2016 review meeting by the social worker with Jo-Jo (Mother):
  - Was Jo-Jo present at the review or seen at all?
  - Was the cancellation of services discussed
  - Was treatment programme for skin condition discussed
  - Was there any involvement of other agencies eg GP, GPL

- With regard to the 8th April 2016 supervision discussion of Jo-Jo, what was the outcome.
- Was Mother ever considered for payment as a significant carer.
- Was Mother ever assessed as a carer or as an individual (under the Care Act) and if so what was the outcome/action taken
- Did the home have the capacity and resources to provide practical responses to Jo-Jo's condition (eg laundry, cleaning, separate facilities)
- With regard to the Community Care Assessment on 19th July 2016, did the support plan only refer to respite care. It is not clear if respite happened or when it was for – may have been around 12th August 2016 at Linton Lodge – please clarify and provide any details from Linton Lodge
- With regard to the 26th July 2016 record of supervision that says "sent letter re respite and close case, suspend services whilst in respite", what was the rationale for closure. What is the policy for case closure. Was there any involvement of other agencies in risk analysis or safeguarding considered.
- On the 7th September 2016 a support plan was agreed. Was Jo-Jo or her Mother involved.
- Did Jo-Jo have a nominated named social worker through whole or part of the process. If not, why not and did this comply with guidelines or policy.
- Can you give particular detail about the action taken following the care agency's email on 23rd January 2017 raising a concern about Jo-Jo

Risk Analysis

- Please give details of any risk analysis at any time over the period April 2016 to February 2017

Cancellation of Service

- How did ILDS respond to the cancellation of services from November to December 2015.
- There were further cancellations of service by the Mother in February and March 2016. Was anything done about this before the 9th March 2016 when Hackney cancelled the service until further notice
- What was the response to the cancellation of services by the mother on a running basis in August 2016 and then in December 2016.
- What was the response to the email on 3rd February 2017 from the care agency notifying that the Mother had cancelled services from the beginning of January. What consideration was there that the cancellation was not being made by the client. What reason for the cancellation was recorded. What were the views of Jo-Jo.

- Were missed appointments to Jo-Jo’s case noted/recorded. What response(s) were made.

Legal

- How and when was Jo-Jo’s metal capacity assessed
- How were Jo-Jo’s best interests ensured.
- How was the Mother assessed either as a carer or in her own right (in accordance with the Care Act). What was the outcome
- How were equality/reasonable adjustments considered and what action was taken.
- Was consideration ever given to pursuing a Continuing Healthcare assessment.
- Is there any record of Human Rights Act considerations

Goldsmith Personnel (GPL) – Care Provider

Analysis of and reflection on your agency’s involvement

- What significant actions were taken or not taken during your agency’s involvement, and the reasons you have been able to identify for the actions taken or not taken.
- How do the actions taken or not taken measure up against legal requirements, policy and procedures, contractual requirements, codes of practice and good practice standards (nationally and locally).
- What approach was taken to the individual’s capacity, dignity, wishes and feelings, issues of diversity and equality.
- Inter-agency collaboration: what good practice or difficulties were experienced, how did these affected your agency’s involvement and how did your agency attempt to address difficulties.
- Has your agency already identified practice/improvement issues and changes it may have made as a result.
- What management oversight and scrutiny was given to the case within your agency; were any issues of concern escalated by staff.

In the narrative of your involvement and engagement please consider:

1. Were there any significant events/changes and how did your agency respond
2. Give evidence of this in terms of any reports, reviews etc
3. Support any practice and decision making with your own existing policy or guidance documents

All agencies are asked to comment specifically on some key questions. Please address these, build them into the narrative referring if necessary to information given in the section above.

a) How was Jo-Jo’s voice or views heard. What attempts were there to engage with her to obtain her views

b) What multi-disciplinary discussions or analysis were asked for. What discussions took place

Please also consider the following issues relating to your service(s):

Safeguarding

- What response was there to the concern raised on 23rd January 2017 by GPL.
- What follow up was there by GPL having raised this concern.

Assessment, Planning and Decision Making

- Did any worker form any view about the relationship between the Mother and Jo-Jo.
- What was the original care plan and was this followed through.
- 14 October 2015 - the Overview Assessment and Care and Support Plan and the GLP Needs and Support Plan notes mother is main carer and supports Jo-Jo in expressing her needs and providing personal care in the home. If workers felt that Jo-Jo's needs were not being expressed how did the agency to address this.
- Were other options for maintaining support to Jo-Jo discussed in December 2016 when Jo-Jo was unwell and services were cancelled (on a running basis by the mother and then formally by ASC in February 2017).
- How did you respond to any actual or perceived risk(s) following visits or contacts.

Multi-Disciplinary Working

- Were there any multi-disciplinary discussions or analysis

Risk Analysis

- Please give details of any risk analysis the care agency made over the period October 2015 to 23rd January 2017

Cancellation of Service

- Chronology states that service was cancelled on 25th December 2016 (Christmas Day) – is that correct
- 3rd February 2017 [query date of this entry – the chronology says 2016] – Mother cancelled services from the beginning of January via email:
  - What was the response from Hackney.
  - What consideration was there that the cancellation was not being made by the client.
  - What reason for the cancellation was recorded.
  - What were the views of Jo-Jo.
  - What follow up was there by GPL in light of Hackney's response

LeDeR

Page 13 of the LeDeR makes reference to a statement by the GPL care worker saying that there were a few occasions Jo-Jo could hardly walk due to sores on her feet, legs and back – was this recorded. What action was taken

Health Services

Analysis of and reflection on your agency's involvement

- What significant actions were taken or not taken during your agency's involvement, and the reasons you have been able to identify for the actions taken or not taken.
- How do the actions taken or not taken measure up against legal requirements, policy and procedures, contractual requirements, codes of practice and good practice standards (nationally and locally).

- What approach was taken to the individual's capacity, dignity, wishes and feelings, issues of diversity and equality.
- Inter-agency collaboration: what good practice or difficulties were experienced, how did these affected your agency's involvement and how did your agency attempt to address difficulties.
- Has your agency already identified practice/improvement issues and changes it may have made as a result.
- What management oversight and scrutiny was given to the case within your agency; were any issues of concern escalated by staff.

In the narrative of your involvement and engagement please consider:

1. Were there any significant events/changes and how did your agency respond
2. Give evidence of this in terms of any reports, reviews etc
3. Support any practice and decision making with your own existing policy or guidance documents

All agencies are asked to comment specifically on some key questions. Please address these, build them into the narrative referring if necessary to information given in the section above.

a) How was Jo-Jo's voice or views heard. What attempts were there to engage with her to obtain her views

b) What multi-disciplinary discussions or analysis were asked for. What discussions took place

Please also consider the following issues relating to your service(s):

A) GP Practice

Safeguarding

- Where any safeguarding concerns raised and was there any consideration of referral to the local authority for this.

Assessment, Planning and Decision Making

- What records are there of decision-making, diagnosis, treatment options or risk analysis
- Was a safeguarding alert considered when the practice received notification that the house had been fumigated in March 2016.
- What pain management approaches were discussed or implemented
- Were any LD Annual Health Checks conducted (provide details if carried out)
- Were there any other health monitoring systems in place for Jo-Jo based on her LD condition (Downs)
- Was Continuing Healthcare ever considered as an option for supporting care
- Any comments on the relationship between mother and daughter

Risk Analysis

- Please give details of any risk analysis at any time over the period January 2014 to 9th March 2017

LeDeR - Follow up points and clarification

- How many GPs were involved in the care of Jo-Jo
- How was the referral to the podiatrist on 4th September 2015 and 5th January 2016 followed up.
- Were missed appointments noted and was there any response or follow up.
- How was the non-collection of repeat prescriptions picked up and dealt with.
- On 21st January 2016 record states “Terrible hyperkeratosis, scaly rash on hands, glove size changed. Only using Epaderm on face not hands, encouraged to continue. ‘Not sure what else to do as mum only has a very limited understanding of her condition’”. Can you expand on this with further information or examples. Was consideration given to any other action eg treatment plans or safeguarding action
- What action was taken after the mother contacted the practice asking for help in managing Jo-Jo’s skin condition as she was refusing to have the cream applied to her head and back. Was there any follow up as a result of that action.
- On the last visit to the house (9th March 2017) what was the basis of the decision that was taken in relation to the patient Jo-Jo.
- What treatment or other medical options were discussed.

B) District Nurse Service

Safeguarding

- Were any safeguarding concerns raised and was there any consideration of referral to the local authority for this.

Assessment, Planning and Decision Making

- What records are there of decision-making, treatment options or risk analysis
- Following the visit in January 2017:

    i) How was the ability or capacity of Jo-Jo (supported by her mother) to apply the creams to herself assessed.
    ii) Was this considered to be a viable and sustainable plan
    iii) Was this considered to be a delegated health task (to the Mother)
    iv) What pain management approaches were discussed or implemented
    v) Was a safeguarding referral or risk assessment considered.
    vi) Were multi-disciplinary discussions considered.

- Did the home have the capacity and resources to provide practical responses to Jo-Jo's condition (eg laundry, cleaning, separate facilities)
- Any comments on the relationship between Mother and daughter

C) Hospital Care including A&E

<u>Safeguarding</u>

- Where safeguarding concerns raised and was there any consideration of referral to the local authority for this.

<u>Assessment, Planning and Decision Making</u>

- What was the outcome of Jo-Jo's attendance at Homerton A&E on 14th July 2016 when she was brought in by paramedics because she could not walk and was in pain. -Which agencies were notified of this event. What was the outcome.
- Any further detail of Jo-Jo's attendance at the dermatology clinic on 10th March 2017, including:
    - How did she get there
    - Any comment about signs of neglect
    - What was the state of her physical condition
    - What was the state of her scabies infection
    - Any comments on the relationship between Mother and daughter
    - Any relevant details and timescales of the events and her subsequent 1st cardiac arrest
    - Why Jo-Jo had not been transported to ITU

Appendix G: Norwegian (Crusted) Scabies

Scabies is an infestation of the skin by the human itch mite. The mite burrows into the upper layer of the skin where it lives and lays its eggs.

Norwegian or Crusted scabies is a severe form of scabies that can affects people with a weakened immune system (the body's natural defence against infection and illness). This includes:

- The very young and the elderly
- People with Down’s Syndrome
- People with brain disorders
- Pregnant women
- People with conditions that affect their immune system
- People taking steroids
- People having chemotherapy

People with crusted scabies have thick crusts of skin that contain large numbers (thousands or millions) of scabies mites and eggs. Crusted scabies is very contagious to other people and can spread easily both by direct skin-to-skin contact and by contamination of items such as their clothing, bedding, and furniture.

People with crusted scabies may not show the usual signs and symptoms of scabies such as the characteristic rash or itching.

Crusted scabies should receive quick and aggressive medical treatment to prevent outbreaks of scabies. Persons with crusted scabies can be infested with thousands of mites and should be considered highly contagious.

Scabies mites cannot survive more than 2-3 days away from human skin. Items such as bedding, clothing, and towels used by a person with scabies can be decontaminated by machine-washing in hot water and drying using the hot cycle or by dry-cleaning. Items that cannot be washed or dry-cleaned can be decontaminated by removing from any contact with the human body for at least 72 hours.

Because people with crusted scabies are considered very infectious, careful vacuuming of furniture and carpets in rooms used by these persons is recommended.

Treatment:

The 2 most widely used treatments for scabies are permethrin cream and malathion lotion. Both medications contain insecticides that kill the scabies mite.

Permethrin 5% cream is usually recommended as the first treatment. Malathion 0.5% lotion is used if permethrin is ineffective.

Both treatments require application to the whole body and because it must stay on the body for 8 hours it is usually applied overnight.

There is also a medicine called ivermectin, which is taken by swallowing a tablet. Ivermectin kills the mites by stopping their nervous system working.

Appendix H: Death by Indifference

Extract from Mencap Report **Death by *indifference*: 74 deaths and counting A progress report 5 years on (published 2012)**

In March 2007, Mencap published Death by *indifference*, which reported the appalling deaths of six people with a learning disability – deaths that the six families involved and Mencap believe were the result of failings in the NHS. The report put the spotlight on the tragic consequences of the healthcare inequalities experienced by people with a learning disability.

The publication of the Death by *indifference* report also prompted a number of families to contact Mencap, and they continued to do so in the weeks, months and years that followed. It is these cases – a total of 74 to date – that form the basis of the article published in *the Guardian* on 3 January 2012. Mencap believes they are only a tiny proportion of the actual number of such cases. They do, however, highlight an NHS that continues to fail people with a learning disability, doctors whose practices appear to show no regard to the Equality Act or Mental Capacity Act, and nurses who fail to provide even basic care to people with a learning disability.

These shocking cases, each as serious as the six in our Death by *indifference* report, must also be seen in the wider context of the strong criticisms made about the performance of the NHS in regard to other vulnerable patients, such as older people. These accounts echo our own concerns that the NHS is too often failing to provide the most basic nursing care such as nutrition, hydration and pain relief, and is denying people dignity and respect. This lack of dignity and respect, together with the poor nursing care that is too often experienced by people with a learning disability, is illustrated by Alan’s story.

Delays in diagnosis and treatment

26 families reported that there had been delays in making a diagnosis and starting treatment.
Diagnosis may be difficult in people with learning disabilities if they cannot describe signs and symptoms clearly. ‘Watch and wait’ will only work if the watching is close and skilful, with a full history taken from those who know the person well and appropriate additional investigations used if the diagnosis is unclear.

Some of the Mencap cases also show that health professionals mistakenly believe that there are some procedures and treatments that someone with a learning disability would not be able to tolerate. There is no evidence that people with a learning disability cannot tolerate particular treatments. As with any patient, treatment and interventions for someone with a learning disability should be considered on a case-by-case basis and, where reasonable adjustments are given proper consideration and planning, most treatments can be administered.

If someone lacks capacity to decide for themselves, a best interest decision must be made. An apparent lack of cooperation should never be automatically associated with lack of consent.

Failure to recognise pain

“They said they didn’t think she was in pain, that her screams were just the noises people like that make.”

11 families reported a failure to recognise pain.
As highlighted in Death by *indifference*, there is an entirely false but widespread belief among health professionals that people with a learning disability have a higher pain threshold than the rest of the population.

...a range of factors contribute to patients with a learning disability being left without appropriate pain relief. Tools do exist to assist staff in assessing the pain of disabled patients who cannot communicate verbally. Such tools, used in conjunction with family carers’ knowledge and appropriate training, can be used to prevent unnecessary pain. Every member of staff whose role involves pain treatment needs to be aware of the potential difficulties in diagnosing pain in patients with a learning disability. This is especially important in cases that involve people with limited verbal communication. Staff must be trained to overcome issues around communication in order to bring about the best outcome for the patient.

Appendix I: Extract from LB Barking and Dagenham “Quick Cards: An introduction to the Care Act 2014”

1.P.

Individual advocacy for those with substantial difficulty

Advocacy means supporting a person to understand information, express their needs and wishes, secure their rights, represent their interests and obtain the care and support they need. The requirement to provide independent advocacy applies equally to individuals requiring care or support and to carers with support needs.

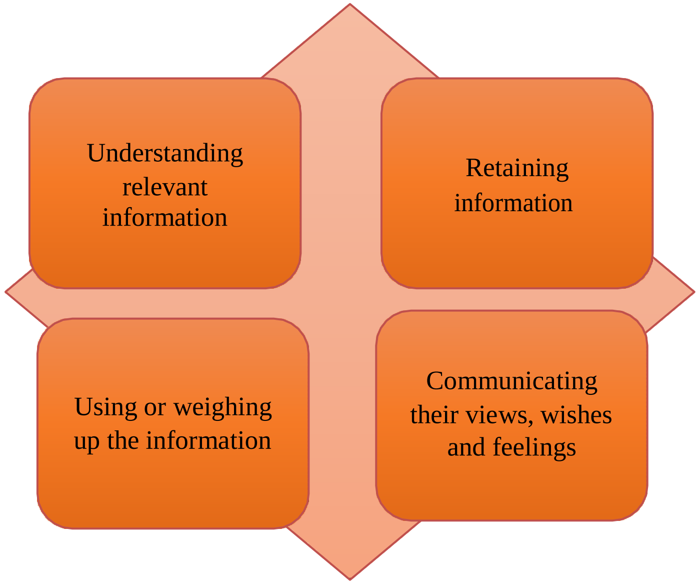
Policy
Statutory advocacy duty is based on the principle of enabling everyone to be fully involved in the key decisions that shape their lives by providing extra help to those who need it most. It is different and distinct from general advocacy or campaign activity as it is totally focussed on the individual within the stated criteria.

- Consider independent advocacy if the individual would have substantial difficulty understanding the process
- Consider the need for independent advocacy at first point of contact and throughout the process

When is advocacy needed?
Advocates may be needed during:

- initial information gathering
- assessment of needs
- safeguarding enquiries and reviews
- care planning, and care and support reviews

Stated criteria: To be able to access individual advocacy, a person must have substantial difficulty as set out below:



Understanding relevant information

Retaining information

Using or weighing up the information

Communicating their views, wishes and feelings

Note: This is not a substitute for the Care Act 2014 or Care and Support Statutory Guidance

4.P.

Assessment - individuals

An assessment must seek to establish the total extent of needs before the local authority considers the person's eligibility for care and support and what types of care and support can help to meet those needs.

The assessment should take a 'whole family approach', recognising personal, family and community resources or 'assets' that individuals can make use of:

- Taking an holistic view of a person's needs and relevant history
- Seeing the family, wider networks and activities as a source of support and prevention, where they are willing and able
- Considering the impact of needs on family and wider networks
- Considering the impact of the cared for person's needs on the young carer's wellbeing, welfare, education and development
- Considering whether a young carer's caring responsibilities are appropriate

Working with others

Many other people may have information, insight or assessments that could be used to give a more complete understanding of need:

- Health derived information, analysis or assessment
- Specialist assessment or advice (if required it must be sought)
- Housing/accommodation or community organisations
- Family and relevant 'others'
- Historical patterns of need or health/social care involvement
- Assessed or diagnosed medical conditions

Risk or safeguarding concerns should be explored and, where necessary, underpin the assessment and, in the case of safeguarding, be acted upon.

Note: This is not a substitute for the Care Act 2014 or Care and Support Statutory Guidance

4.P

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Assessment - carers

Carers have the same rights to an assessment as individual adults. Local authorities have a duty to undertake an assessment of any carer who appears to have any level of need for support. This is regardless of whether or not the local authority thinks the carer has eligible needs

A carer is

•Anyone who cares, unpaid, for a friend or family member who due to illness, disability, a mental health problem or an addiction cannot cope without their support.

There may be circumstances where the adult providing care, either under contract or through voluntary work, is also providing care for the adult outside of that. The local authority may then consider whether to carry out a carer's assessment for that part of the care they are not providing on a contractual or voluntary basis.

A carer's assessment must:

- Explore the carer's need for support
- Consider whether the carer is currently able to care for the adult needing care, and whether they will be able to continue caring
- Consider whether the carer is willing, and likely to continue to be willing, to provide care

This will allow local authorities to make a realistic evaluation of the carer's present and future needs for support and whether the caring relationship is sustainable. Where appropriate these views may be sought in a separate conversation independent from the adult's needs assessment.

A carer's assessment must consider the impact on the carer's activities beyond their caring responsibilities, including the carer's:

- Desire and ability to work
- Opportunities to partake in education, training or recreational activities
- Opportunities to have time to themselves

Risk or safeguarding concerns should be explored and, where necessary, underpin the assessment and, in the case of safeguarding, be acted upon

Note: This is not a substitute for the Care Act 2014 or Care and Support Statutory Guidance

5.P
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Establishing eligibility – individuals

For an adult's needs to be considered eligible for support by the local authority they **must meet all three** of the criteria.

1. Does the person have needs due to physical or mental impairment or illness?
2. As a result are they unable to achieve two or more of the specified outcomes?
3. As a result is there likely to be a significant impact on their wellbeing?

The adult is unable to achieve two or more of the specified outcomes:

- Manage and maintain nutrition
- Maintain personal hygiene
- Manage toilet needs
- Be appropriately clothed
- Be able to make use of the home safely
- Maintain a habitable home environment
- Develop and maintain family or other personal relationships
- Access and engage in work, training, education or volunteering
- Make use of necessary facilities or services in the local community, including public transport and recreational facilities or services
- Carry out any caring responsibilities the adult has for a child

We will also ask individuals about how they manage medication and the impact this may have on their condition.

Guide to 'unable to achieve outcomes'

- Cannot do it without assistance
- May be able to do it without assistance but doing so causes the adult significant pain, distress or anxiety
- Can do it without assistance but doing so endangers or is likely to endanger the health of the adult, or of others
- Consideration should be given to fluctuating ability to achieve, or not achieve, the outcomes based one valuation of the specific physical or mental impairment or illness

Any major risks to the individual should be considered, noted and taken into account in arriving at a determination of eligibility

Note: This is not a substitute for the Care Act 2014 or Care and Support Statutory Guidance

5.P

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Eligibility criteria – carers including young carers

For a carer’s needs to be considered eligible for support by the local authority they **must meet all three** of the criteria.

1

Does the person have needs due to physical or mental impairment or illness?

2

As a result are they unable to achieve two or more of the specified outcomes?

3

As a result is there likely to be a significant impact on their wellbeing?

The carer is unable to achieve one or more of the specified outcomes: •Carry out any caring responsibilities the carer has for a child •Provide care to other persons for whom the carer provides care •Maintain a habitable home environment in the carer’s home, whether or not this is also the home for whom the carer provides care •Manage and maintain nutrition •Develop and maintain family or other personal relationships •Engage in work, training, education or volunteering •Make use of necessary facilities or services in the local community, including recreational facilities or services •Engage in recreational activities	Guide to ‘unable to achieve outcomes’ •Cannot do it without assistance •Can do it without assistance but doing so causes the adult significant pain, distress or anxiety •Can do it without assistance but doing so endangers or is likely to endanger the health of the adult, or of others •Consideration should be given to fluctuating ability to achieve, or not achieve the outcomes based on evaluation of the specific physical or mental impairment or illness
Link to NHS choices website www.nhs.uk	**Further information:** Sections 9 to 13, Care Act 2014; Chapter 6, Care and Support Statutory Guidance; Care and Support (Assessment) Regs 2014; Care and Support (Eligibility Criteria) Regs 2014

Note: This is not a substitute for the Care Act 2014 or Care and Support Statutory Guidance

Appendix J: Biographical details of SAR author

Ian Winter CBE

Ian has over 40 years' experience at local, regional, national and international level in health and social care. He was the Director of Adult and Children's Services in a large shire county, pioneering work on reablement, care management and integrating learning disability and mental health services.

Ian led an in-country assignment for the Royal Government of Cambodia, securing substantial World Bank funding for Healthcare.

He served for 6 years as senior civil servant in the Department of Health as regional director for London and worked on other national projects.

Following this he worked on an integrated response to the Winterbourne View abuse scandal and researched and produced the national stocktake of progress which was used as the bench mark for further action.

Ian has advised Safeguarding Adult Boards on their development and has authored other Safeguarding Adult Reviews.

He has provided consultancy support to local authorities and led Peer Challenges on behalf of the Local Government Association.

He was the independent Chair of Transforming Care Partnership Board for Learning Disability Services for services in Oxfordshire and is the independent Chair of the Children's Safeguarding Board in Barking and Dagenham

Ian was awarded a CBE for services to social care in 2012.

Appendix K: Resources

Department of Health (2001). *Valuing People: A New Strategy for Learning Disability for the 21st Century*. London: Department of Health. **http://bit.ly/17DUyVN**

Department of Health (2009). *Valuing People Now. A new three year strategy for people with learning disabilities – making it happen for everyone*. London: Department of Health. **http://bit.ly/1fywmHd**