Safeguarding Adults Executive Board
Safeguarding Adults Review

Learning Lessons Review: Annie

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Contents

1 Context and reason for this Learning Lessons Review

1.1 The subject of this review is referred to using the anonymised name of Annie, who died on 14th February 2019 at the age of 40. She was a woman of Black / Caribbean / British origin. Speaking to professionals who worked with her, she was described as a beautiful person who was a joy to support. Whilst she had no verbal language, she communicated so much with her eyes and facial expressions.

1.2 Annie had profound and multiple disabilities and as a result was dependent on her carers for all her care and support needs. Her last overview assessment completed in January 2019, described her disabilities and health needs as 'Severe Learning Disability, Epilepsy, Spastic Quadriplegia, Nephrotic Syndrome, and Scoliosis'. Dysphagia left sided lordosis and a hip extension were also noted.

1.3 Annie had three sisters and was generally represented in decisions and meetings by her family.

1.4 Annie was a resident at a supported accommodation scheme for adults with complex learning disabilities and some physical needs, where she had lived since 2013 with 24-hour support. She also attended a learning disabilities day service five days a week. Her care and support was fully funded by NHS Continuing Healthcare (CHC)[1].

1.5 Annie was admitted into hospital on 11th February 2019 and diagnosed with inoperable cancer (stage three carcinoma with metastasis) and died three days later. A safeguarding enquiry under Section 42 of the Care Act 2014 was completed because of concerns of neglect.

1.6 This Learning Lessons Review was commissioned by the Safeguarding Adults Executive Board (SAEB) to complete the process as part of the Section 44 Safeguarding Adults Review (SAR) requirements under Care Act 2014.

2 Aim of the review

2.1 As proposed by the Co-Chairs of the Safeguarding Adults Case Review Group (SACRG), this review will:

- Consider, with the benefit of hindsight, whether the priorities for action, following the Section 42 enquiry, were appropriate and/or whether there were other actions that could/should have been identified.
- Consider if the actions so far implemented have been effective and made any significant difference to practice and outcomes and/or are likely to do so over time.
- Build on areas already highlighted for development, engender trust and confidence across partner agencies.

[1] NHS Continuing Healthcare (CHC) is a package of care for adults aged 18 or over which is arranged and funded solely by the NHS. In order to receive NHS CHC funding individuals have to be assessed by Clinical Commissioning Groups (CCGs) under the National Framework for NHS CHC.

3 Work completed as part of this review

3.1 Phillida Miles, independent consultant, was commissioned to complete this learning lessons review and to work alongside an internal group comprising:

- the co-chairs of the SACRG
- the Interim Head of Safeguarding and Workforce Development of Kensington Chelsea and Westminster City Council, and
- the SAEB's Business Manager.

3.2 An early analysis report was produced to summarise the evidence from the previous enquiries and investigations and highlighted the emerging issues. This was used to support a reflective session with relevant staff and managers to explore the major themes, actions taken and their effectiveness. 17 representatives, from the following agencies, attended this event:

- Imperial College Healthcare NHS Trust
- Central London Community Healthcare NHS Trust (CLCH)
- North West London (NWL) Clinical Commissioning Group (CCG)
- The supported accommodation provider
- Chelsea and Westminster Hospital NHS Foundation Trust
- The learning disabilities day service
- Westminster City Council (WCC)
- Royal Borough of Kensington and Chelsea (RBKC).

Participants in this workshop were asked to comment on the accuracy of information collated, to further test the evidence gathered and amendments were made, where appropriate.

3.3 Additional discussions were held, and information exchanged with key managers from Imperial College Healthcare NHS Trust, the supported accommodation provider, RBKC, CLCH and NWL CCG.

3.4 Before contacting Annie's family, checks were completed across all agencies involved as to their last communication. Contact was initially made with Annie's family, principally her sister by one of the Co-Chairs of the SACRG subgroup and a subsequent letter was sent out to explain the plan for this review and introduce the independent reviewer. Annie's family initially engaged but then withdrew their involvement with this review. It was clear from the limited contact, that Annie's family believe their sister was neglected by services.

3.5 This final report concludes the Learning Lessons Review and documents the overall findings which will be then presented to the SAEB and an action plan developed.

4 Reports evaluated in this review

4.1 In order to complete this Learning Lessons Review, the following documents were read:

- Safeguarding enquiry report completed by CLCH
- Safeguarding enquiry report completed by Independent GP - 10th June 2019
- Serious Incident (SI) report completed by Imperial College Healthcare NHS Trust -1st May 2019

- Overview assessment report by Adult Social Care (ASC). The reassessment was started in November 2018 and completed in January 2019.
- Report completed by the supported accommodation provider following Annie's death.

4.2 The LeDeR process[2] has been initiated and the Co-Chairs of the SACRG were informed that there is a draft report that will be finalised after the completion of this review. As such the draft LeDeR report was not considered within the scope of this commission.

5 Outline of this report

5.1 This report is organised so to provide the following information:

- Summary of health events relevant to this review.
- Findings of the investigations and enquiries completed after Annie's death.
- The emerging themes as identified by the independent reviewer including the observed strengths of practice and the gaps in processes and practice including linked recommendations from the Section 42 Enquiry (and, where relevant, the SSI report).
- The subsequent action taken, and progress made since 2019.
- Summary and conclusion.
- Recommendations from this review for consideration by the SAEB.

5.2 For the sake of brevity, this final report makes reference to, but does not include the appendices in the Early Analysis Report (January 2021) which are shown below. This additional information can be provided on request from the SACRG.

Appendix One:	Chronology of events from GP and acute Trust health records
Appendix Two:	Summary of findings from the safeguarding enquiry (Section 42)
Appendix Three:	The key recommendations from the Confidential Inquiry into Premature Deaths of People with Learning Disabilities (CIPOLD) review of deaths[3]
Appendix Four:	Section 42 enquiry and SI recommendations

6 Summary of health events relevant to this review (taken from the information contained in the Independent GP report and SI report)[4]

6.1 Using the timeline from these two reports, it appears that rectal bleeding was first brought to the attention of a GP on 15th February 2018 by staff at the supported accommodation scheme. The first hospital investigations were started on 30th April 2018 following advice to Annie's carers to take her to A & E, where an X-ray was taken which showed no obstruction or perforation to the bowel.

[2] The learning from deaths of people with a learning disability (LeDeR) programme is a service improvement programme that looks at the deaths of people with a learning disability aged four and over.

[3] Heslop, P., Blair, P., Fleming, P., Hoghton, M., Marriott, A., & Russ, L. (2013). Confidential Inquiry into premature deaths of people with learning disabilities (CIPOLD). *Bristol: Norah Fry Research Centre*

[4] See Appendix One in the Early Analysis report for a chronology of the health records from February 2018 to February 2019 made available to the independent consultant.

6.2 A further attendance to A & E on 1st May 2018 led to the first referral for a colonoscopy. Annie attended the clinic on 27th May 2018, but the procedure was not possible as a hoist was not available. This appears to be the first example of where there was a failure to plan and respond to her additional needs as a disabled person and make reasonable adjustments.

6.3 Despite action by the Learning Disability (LD) Nurse to chase up the colonoscopy in June, the next attempt of the procedure was not made until 31st October 2018. This appears to have been prompted by a practitioner from CLCH contacting Imperial College Healthcare NHS Trust and questioning both the delay and responses to Annie's needs. Two further attempts were made at completing a colonoscopy and a proctoscopy but all three of these procedures were hampered by inadequate bowel preparation. On 26th November 2018, a decision was made at the outpatient clinic to recommend that an elective admission would be needed to adequately prepare for any further colonoscopy. This was planned for 17th January 2019 and there is conflicting information from the hospital and the supported accommodation provider concerning why it did not take place. An elective admission was then rebooked for 25th February 2019 but sadly, Annie died on 14th February 2019.

7 Findings of enquiries and investigations

Conclusion of the Independent GP enquiry of the Primary Care Service

7.1 The Independent GP concluded in this report that in his opinion 'there are no significant gaps or clinical concerns and…the primary care actions were entirely appropriate. '

Conclusion of the SI Investigation for Imperial College Healthcare NHS Trust

7.2 'The Trust failed to use the Learning Disabilities and Autism Policy and Procedure, and thus did not make reasonable adjustments for the patient's profound learning and physical disabilities.'

Summary of the safeguarding enquiry (Section 42)

7.3 The Section 42 report documents a comprehensive enquiry into the concerns of neglect for Annie. It incorporates the findings of both the Independent GP review of the Primary Care Service and the SI report. This report also included additional enquiries such as a joint quality assurance visit to the supported accommodation scheme. The findings in relation to the key services Annie received are summarised in Appendix Two. The enquiry references service providers having best intentions to meet Annie's needs, many gaps in service were identified and 38 recommendations made in response.

8 Emerging themes

8.1 When evaluating the findings documented in the three main enquiry and investigation reports and the overview assessment, a number of themes emerged. These have been separated into strengths of practice and professional working and significant gaps in practice and processes. The recommendations from the Section 42 enquiry have then been reviewed with reference to these main areas of practice and processes.

Strengths of practice and professional working

Emergency responses to Annie's health

8.2 From information available to this review, Annie was taken to A & E on

30th April 2018, 1st May 2018 and 22nd January 2019 following concerns from her sister, supported accommodation care staff and / or her GP. On all three occasions, these actions seem appropriate and proportionate.

8.3 On 22nd January 2019, care staff called Annie's GP who saw her and prescribed antibiotics for a suspected chest infection. However, later that day, care staff had called emergency services as they were worried and reported that Annie had appeared to stop breathing. They were about to commence cardiopulmonary resuscitation (CPR) when the ambulance arrived, and she was taken to A & E. Again, on 10th February 2019, staff called an ambulance and Annie was admitted due to respiratory problems and was clearly in distress from pain.

Action by individuals to raise concerns outside of formal processes

8.4 Examples include the LD Nurse in June 2018 calling the GP Practice Nurse to chase the colonoscopy appointment. Also, the Strategic Health Facilitator for CLCH emailing the LD Lead to respond to Annie's additional needs and make reasonable adjustments. This alerted the LD Lead to the delays in the colonoscopy (from May to October) and led to Annie's electronic record being flagged to alert medical staff to her learning disability and to provide the contact details of the Community Learning Disability Team (CLDT). The LD Lead then also contacted the consultant, leading to a flexible sigmoidoscopy being booked for 31st October. The LD Lead met with Annie and her carer prior to the clinic appointment to establish if any further adjustments were needed.

Coordinated reassessment across health and social care

8.5 An overview assessment was completed between November 2018 and January 2019 involving Annie, her sister, the CLDT, supported accommodation manager, a Specialist Epilepsy Nurse from the hospital, and the day service. This reassessment largely concentrated on Annie's care at the supported accommodation scheme, addressing concerns that had been raised by Annie's sister in a safeguarding referral. It also had input from the Specialist Nurse who had already completed an epilepsy review which together addressed key issues about the care received at the supported accommodation scheme in terms of risks to Annie from seizures. Unfortunately, there does not appear to have been a discussion of rectal (PR) bleeding, the bowel screening or delays in a full colonoscopy being completed. Whilst this reassessment did facilitate some joint exploration, questions emerge as how community learning disability services manage reviews of health care needs.

Gaps in processes and practice

Lack of reasonable adjustments made to support Annie as a disabled adult

8.6 One of the clear findings of the Section 42 enquiry and SI investigation concerned the failure to flag and plan for Annie's health needs in terms of her learning and physical disabilities. This resulted in Annie's additional needs not being recognised, and inadequate provision made to support her access to outpatient appointments. Additionally, the reviewer completing this Learning Lessons Review drew attention to Annie's ethnicity, being a woman of Black / Caribbean / British origin although there did not appear to be any evidence to suggest that this had any bearing on the response to her needs or services received.

8.7 In providing guidance concerning reasonable adjustments under the Equality Act 2010, Public Health England guidance[5] states – 'Public sector organisations shouldn't simply wait and respond to difficulties as they emerge: the duty on them is 'anticipatory', meaning they have to think out what's likely to be needed in advance.'

8.8 From information available to this review, it appears that there were numerous points between April and October 2018 when Annie's additional needs were not flagged to the hospital or recorded on hospital records. This required the making of reasonable adjustments such as:

- Booking a hoist for the first endoscopy appointment.
- Anticipating the difficulties in making adequate bowel preparations.
- Considering alternative screening possibilities.

8.9 The Section 42 enquiry and SI investigation outlined several recommendations in regard to the issue of reasonable adjustments.

Section 42 Recommendation 2 – *'When making referrals for people with learning disabilities, it would be of benefit to understand referral routes and how to champion reasonable adjustments. It would be helpful for the practice to understand what services such as The Purple Pathway are available to people with Learning Disabilities'.*

Section 42 Recommendation 3 – *'It would be of benefit to provide some clarity as to how GP practices alert acute services to adults who are vulnerable, who have additional needs such as learning disabilities when making referrals'.*

Additionally, the SI report recommends:
'The Trust must ensure that all clinical staff have a working knowledge of the availability of the Trust policy and processes to support those patients with specific need for reasonable adjustments'.

'The Trust must ensure that that patients with disabilities are identified from the outset to ensure that the appropriate pathway of care is given along with the appropriate reasonable adjustments'.

'The availability of hoist equipment should be re-iterated to staff on the endoscopy unit'.

Subsequent action taken

8.10 The key issue of reasonable adjustments is central to this review and clearly links to referral processes and partnership working as highlighted below. Imperial College Healthcare NHS Trust confirmed that changes have been made to processes and pathways for learning disabled patients, a Purple Pathway has been introduced for outpatients as well as those admitted to hospitals in the Trust and there is a regular programme of training for all staff in its use. There is a flagging system in place for learning disabled adults on the electronic record system, but this is primarily activated by the LD team so if they do not know about the patient (as was the case with Annie) they cannot add the flag. The hospital has also recruited a specialist LD nurse who

[5] Reasonable adjustments: a legal duty - GOV.UK (www.gov.uk) updated September 2020

works alongside the LD Lead. The LD Lead and specialist nurse are informed of all admissions/attendances of learning-disabled adults.

8.11 The supported accommodation provider has introduced the use of sunflower lanyards and red bags when residents need to attend hospitals, and this appears to help to elicit a more disability friendly approach from health staff.

8.12 NWL CCG reported that whilst there is a system for GPs to flag patients with a learning disability, there is no system identifying specific reasonable adjustments that are required for each individual. There is a national reasonable adjustment pilot (Reasonable Adjustment Flag - NHS Digital) and local discussions are needed to coordinate the development work needed across different services. GP's may also need further training to raise their awareness and increase knowledge in this area of practice.

Lack of partnership working and multi-agency response

8.13 At many stages in the last year of Annie's life, there appear to have been missed opportunities to work collaboratively between:

- The GP and CLDT.
- The CLDT and the supported accommodation provider
- Community health services and acute hospital services.

8.14 Examples include:

- A lack of multidisciplinary discussion to understand and plan responses to Annie's needs as a whole. This might have avoided symptoms and health needs being seen in isolation, as suggested in the Section 42 enquiry.
- Support to care staff within the supported accommodation scheme in responding to Annie's health needs. For example, the bowel preparation required prior to attendance at the endoscopy clinic. On three occasions, a full screen was not possible due the presence of stools in Annie's bowel. It appears that it was not until 20th November 2018, that it was recognised that an admission would be necessary before any colonoscopy could be successfully completed. This obviously also links to reasonable adjustments being made and full account taken of Annie's disability.

8.15 Recommendations from the Section 42 report

Recommendation 1 – *'The CLDT and GP services should work in tandem to deliver specialist clinical care to people with learning disabilities. This is essential when there is an enduring clinical issue needing addressing or when there are concerns in relation to care provision. A visit to a practice or network meeting to confirm the LD referral pathway and services would be of benefit'.*

Recommendation 8 – *'Ensure strong links are developed between the LD Health Team and primary and acute services, which allow for interagency working ensuring that reasonable adjustments are provided for those who need them at the point of referral'.*

Recommendation 12 - *'Review all the clinical and support needs of the residents at [the supported accommodation scheme], with due regard to lessons learned from this*

investigation. Ensuring that appropriate governance measures are in place to support care staff'.

Recommendation 13 - *'Continue to work with [the supported accommodation provider] to ensure effective mechanisms are in place to support care staff. When reviewing individuals in receipt of their care, ensure that staff training matrixes are appropriately reviewed. If there are not internal mechanisms available to support the individual, new providers may need to be considered'.*

Recommendation 19 – *'Develop protocols for joint working arrangements between health and social care following novation'.*

Recommendation 21 – *'[The Supported Accommodation Provider] will need to review how they support the individuals in their care with high health needs and alert the CCG and Local Authority if they do not feel they have the internal mechanisms to support them'.*

Recommendation 33 – *'Develop a regular forum for LD Health Team and Imperial College Healthcare NHS Trust to meet and discuss learning disability patients and problem solve issues like discharge planning'.*

Recommendation 34 – *'Ensure that Imperial College Healthcare NHS Trust are included in the various LD forums held by CLCH, WCC and RBKC Local Authorities to ensure cohesion across services'.*

Recommendation 37 – *'For all patients who have a learning disability and require Palliation in an inpatient setting the LD Health Team should be informed via Duty for attendance at Best Interests and clinical planning meetings'.*

Subsequent action taken

8.16 The health and social care team for learning disabled adults hold shared referral meetings which have become weekly during the Covid pandemic.

8.17 Imperial College Healthcare NHS Trust confirmed that a forum has been introduced between hospitals and the CLDT and there has been an improvement in joint working. Referrals are also being made to the CLDT when learning disabled adults become palliative to facilitate practitioner attendance at Best Interest and clinical planning meetings.

8.18 The supported accommodation provider has created a monthly summary log of health activities to share with the LD health team as a communication and information sharing aid for all CHC funded residents. This log outlines appointments attended and also those cancelled for their service users. This is additional to the routine incident logs. Furthermore, the provider would like to consider using a model called the 'Significant 7' as a training and monitoring tool. (See Significant 7 | NELFT NHS Foundation Trust)

8.19 NWL CCG explained that the different IT system between the hospitals and different community teams such as System One, Mosaic and Cerner, clearly create barriers to collaborative, multiagency working but that local arrangements to ensure meaningful dialogue do assist, for example monthly meetings with the LD Lead at Imperial

College Healthcare NHS Trust and the Lead Nurse for Learning Disability and Transition at Chelsea and Westminster Hospital NHS Foundation Trust.

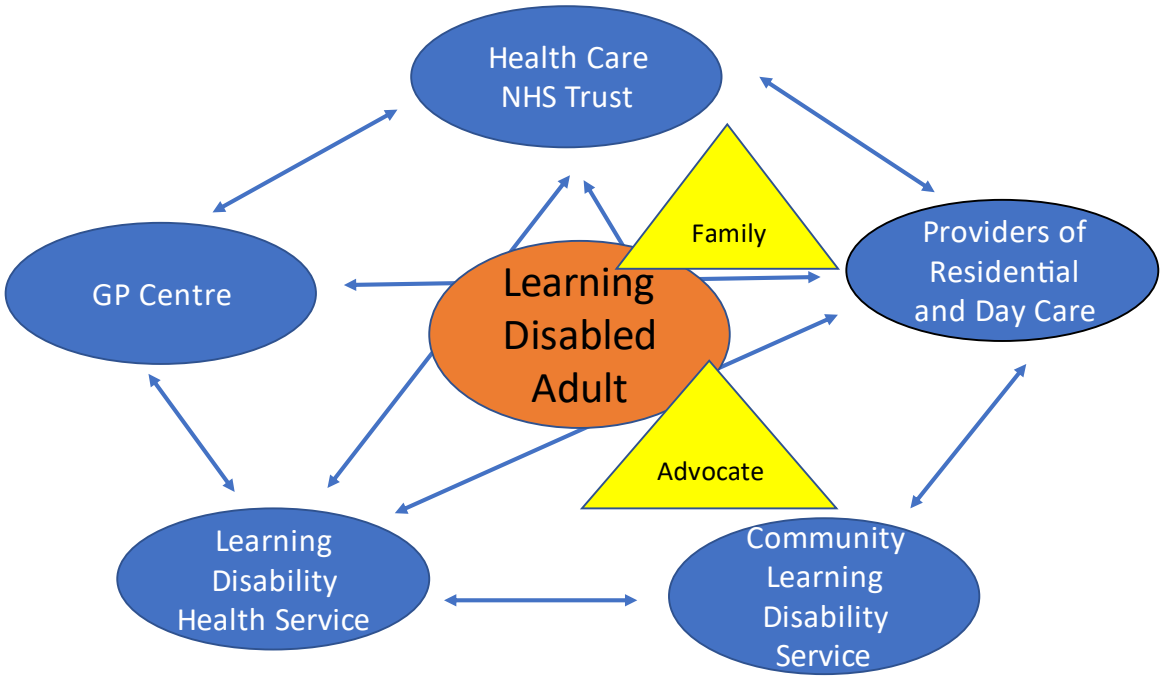
8.20 The protocols that were recommended in the Section 42 Enquiry report have not yet been implemented to drive partnership working across the services for adults with a learning disability and these now need developing.

Roles and responsibilities across the different services

8.21 Annie was a profoundly disabled adult with complex needs who required an array of planned and emergency health and social care services. As noted in the documents reviewed across the last year of Annie's life, she had contact with many different professionals, namely:

1. GP Practice - seven GP's, a physician's assistant and practice nurse
2. CLDT - LD nurse, social worker / care coordinator, LD manager
3. Supported accommodation care staff and management
4. Day service key worker, staff and management
5. A & E staff
6. Endoscopy Clinic staff
7. Specialist epilepsy nurse and consultant.

8.22 Changes have been made to the organisational structures since 2019 for learning disabled adults and is shown, diagrammatically, below. The key change being that community health and social care learning disability services are now in separate team under a different management system. Further changes are planned which has implications for the clarity of roles, responsibilities and the overarching governance.



8.23 The mapping above also includes the crucial role that family members and advocates play in representing disabled adults. This is particularly important for adults with complex needs which affect their ability to self-advocate. Annie's sister was actively involved and had Power of Attorney (referenced in the overview assessment 2019). It was hoped that the family would be able to contribute their perspective to this review but sadly this was not possible.

8.24 One of the key findings of the Section 42 enquiry was a lack of oversight and coordination across these different professionals, teams and services, resulting in roles and responsibilities becoming blurred and accountability unclear.

Section 42 Recommendation 6 – *'Develop appropriate placement review mechanisms to support Case Managers to ensure services are meeting the individual's needs which includes proficient governance within internal information system'.*

Recommendation 9 – *'In house training to be provided regarding healthcare facilitation and its connection to the Mental Capacity Act'.*

Recommendation 11 – *'Review supervision arrangements within the service to ensure that staff are supported, and management are made aware of concerning matter as per above'.*

Recommendation 14 - '*Review Support Planning procedures to support case managers alert providers as to what is expected'.*

Recommendation 15 – '*Ensure that providers are aware of what they can refer to the LD Service for, and for Health to be given a slot at The Provider Forum to enable appropriate feedback'.*

Recommendation 16 – '*Review staffing levels within the LD Service, with specific regard to healthcare facilitation'.*

8.25 With reference to recommendation 9 and the use of the Mental Capacity Act, it appears that there were gaps and at times, a failure to use the Best Interest process as there are no records on System One of any such meetings taking place and the last record on Mosaic is in 2013, regarding a decision taken to change Annie's home.

Subsequent action taken

8.26 The mapping above shows the key agencies across the multiagency network. From observing the discussions during the reflective workshop, it appears that there continues to be some uncertainty concerning roles and responsibilities across the different services. Specifically, the oversight and role of lead on health care issues for learning disabled patients in the community.

8.27 With new arrangements for the CCG and the management of CHC, it will be essential to clarify roles and responsibilities in these new organisational arrangements.

8.28 CLCH verified that there had been some positive developments since 2019, namely:

- Increased understanding of the importance of regular safeguarding supervision and debriefing.
- Improved Datix incident reporting to alert the safeguarding team/Trust of potential safeguarding concerns with patients.
- Increased correspondence with the safeguarding team for advice and support regarding patients with complex learning disabilities.

- Increased recognition of the importance of utilising the Mental Capacity Act and Best Interest decision making.
- Importance of advocacy services being used to advocate for these patients to ensure their voice is heard.

Clear gaps in referral pathways and processes

8.29 At the point of the first referral to the endoscopy clinic, hospital staff should have been alerted to Annie's additional needs so that reasonable adjustments could have been made to facilitate her access to this procedure. The 'purple pathway' would have facilitated this, had it been used, to plan a process that was more conducive to Annie's needs. Additionally, the earlier involvement of the LD Lead would have clearly helped.

8.30 When a referral has been made, are roles and responsibilities clear as to who should chase any delays or interruptions in the process? Are there agreed time parameters for responses to referrals of this kind? The GP notes recorded the LD Nurse from CLDT called the Practice Nurse on 26th June 2018 to check the status of the colonoscopy but then there was no progress until 10th October 2018 when the Manager of CLDT contacted the LD Lead at the hospital. When a GP makes a referral for a learning-disabled patient to an acute trust, are CLDT and the LD Lead notified and how does this link with the Health Action Plan? These would seem pivotal questions to raise.

Recommendation 2 – *'When making referrals for people with learning disabilities, it would be of benefit to understand referral routes and how to champion reasonable adjustments. It would be helpful for the practice to understand what services such as The Purple Pathway are available to people with Learning Disabilities'.*

Recommendation 4 – *'Develop meaningful referral pathways and system. to support individuals with enduring health and clinical needs'.*

Subsequent action taken

8.31 The purple pathways created by Imperial College Healthcare NHS Trust have been expanded to other processes such as outpatients and pre-operative assessment and are reported to be making a difference.

8.32 From information from NWL CCG, it appears that GP's have the facility and routinely flag learning disabled patients when referring to other services but as described above they do not have the same facility to flag what specific reasonable adjustments are needed.

8.33 Work is still needed to develop 'meaningful referral pathways and system' and NWL CCG has committed to coordinating a meeting with the primary care leads, providers, learning disability team and Trusts to take communication and coordination work forward.

Recording and documentation including care plans and health action plans

8.34 There are a number of references in the Section 42 enquiry to poor documentation and recording across different services and the negative impact this had on practice.

8.35 In CLDT, this was described as

- ‘Poor governance in relation to the day-to-day documentation of her needs, resulted in a very staggered care trajectory which was disorganised’.
- ‘No care plans developed highlighting responsibilities across agencies’.

8.36 In relation to the supported accommodation provider the concerns raised included the following:

- ‘The care plans are not really working documents’.
- ‘Written Information was held in different places, so it could not be found easily, e.g., medical forms are in one folder and some of the information does not correlate with the daily reports’.
- ‘One of the biggest problems is that the staff team is trying to manage care and support through several different systems such as medical liaison, the daily communication book, handover logs and health action plans. A cohesive system that works for everyone is needed to ensure support plans are working documents’.

Section 42 Recommendation 5 – *’Develop care plans to ensure responsibility in care is identified, with clear review trajectory and a process for comprehensive closures’.*

Recommendation 7 – *‘Establish clear procedures for feeding back to providers, in easily recognised formats’.*

Recommendation 10 – *‘In house training to be provided in regard to appropriate information governance, providing clarity of what will be expected in regard to record keeping from CLCH moving forward’.*

Recommendation 18 - *'CLCH to review arrangements to use the System 1 platform to help encourage better communication between all parties’.*

Recommendation 20 – *’Review Health Action Planning and Annual Health Check system. within local area, in collaboration with CCG, Primary Care and local providers’.*

Subsequent action taken

8.37 The health and social care team for learning disabled adults hope to move to shared documentation in the future but currently the different services do not have access to the other system.

8.38 Whilst there was some uncertainty in the reflective workshop and subsequent discussions as to whether annual health checks are completed as a routine, numbers are increasing. The Annual Health Checks are completed by GP’s, but further questions arise as to their quality and whether they are widely shared with other professionals and whilst the quantity is increasing, there is some concern to the quality. There was agreement across the participants in this review that Health Action Plans are not working in their current format, and this still needs addressing.

Organisational arrangements for adults with a learning disability

8.39 The Section 42 report described the changes in service delivery for adults with a learning disability that came into force in October 2019. ‘From the first of October CLCH has been commissioned to deliver LD Clinical Services on behalf of Central

and West London CCG. Adult Social Care services continue to be managed by the Local Authority.'

The new arrangements included:

- Appointing a Service Manager.
- Setting up Health Duty system to support those awarded CHC.
- Appointing new Case Managers for those awarded CHC or inpatients requiring clinical therapy surrounding their mental health needs.
- Increasing capacity of service to meet needs.
- Creating joint intelligence mechanisms across health and social care.
- Developing new relationships with the CCG.

8.40 Due to the Covid-19 pandemic, the new organisational arrangements only had five months to settle in before restrictions were in place. Further changes are planned in the near future, such as eight CCG's merging into one and then taking responsibility for and managing all CHC funded patients from July 2021. This is a whole scale organisational change and whilst any change is challenging it does also provide an opportunity to address the learning from this review.

8.41 The Section 42 report also made specific recommendations regarding the working practices of the supported accommodation provider with reference to training and supervision as well as care plans and documentation (as detailed above). It recommended an external audit of practice. The provider has advised that the following measures have been put in place over the last two years:

- There is a key-worker system in place and all residents have someone allocated.
- Supervision is held monthly and there are clear lines of responsibility for management.
- A "short term care plan" was introduced with support from the Section 42 Enquiry Officer and is working.
- Bowel movements, fluid and food intake are all recorded daily and checked by managers. Medication is also checked with one manager who is the 'Meds Champion' which has reduced medication errors.
- The supported accommodation scheme receives specialist input from nursing.
- The Council's Quality Assurance team have contact fortnightly.

8.42 The provider is also in the process of recruiting a health lead as an assistant director. They will lead on all health-related issues including policy and training, day to day support and oversight of safeguarding and quality assurance with a health focus. Additionally, operational managers are in place as leads in specialist areas such as profound and multiple learning disabilities (PMLD), autism, mental health, transitions and personalisation.

8.43 The provider has also presented a case for de-commissioning the supported accommodation scheme for residents with similar levels of need as Annie given their concerns in the challenges of the environment and the model in meeting the requirements for their care.

8.44 The Section 42 report also made recommendations for consideration by the involved acute hospital trusts. These concerned training and awareness raising of the needs of learning-disabled patients and specialist staffing. It also recommended that protocols

should be developed – “For any admission longer than three days or any repeat A & E attendance within a two-month period, the patient must see the LD Lead /Safeguarding team”. Additionally, the SI report, recommended – “The appropriate process for cancelling and rebooking patients should be reiterated to the endoscopy unit staff”.

9 Summary and conclusion

9.1 This Learning Lessons Review has had the full support of the Co-Chairs of the SACRG, the Interim Head of Safeguarding and Workforce Development, RBKC and WCC and the SAEB’s Business Manager and Business Support Officer. The reflective workshop was also well attended by all the key agencies and managers have provided additional information as requested by the independent reviewer. The time and commitment showed by participants to this review has been a positive indicator of the strong motivation to address shortfalls and achieve better outcomes for learning disabled adults.

9.2 Annie was described as a person with a positive energy and personality that staff naturally warmed to, and the reviewer could understand the basis of the comment in the Section 42 report that staff and services “had only the best intentions to support Annie’s health and well-being” (Page 3).

9.3 Sadly, Annie’s family did not proceed with being part of this process and whilst the independent reviewer made several attempts to engage her in the review, her decision was respected. Careful consideration is needed so that sensitive feedback can be provided on the outcome of this review.

9.4 Whilst the Section 42 enquiry and SI Investigation evidence significant gaps in practice and processes, as with all SARs, we must always remember that the emphasis is to review actions or inaction to attempt to establish learning for making improvements for future service responses and it is hoped that this will be possible as a result of this process.

9.5 It is clear that the Section 42 and the SI investigation were very comprehensive, as were the recommendations made and independent reviewer would like to endorse their findings. Some additional recommendations are made in the next section for consideration by the board, in the light of the progress made since 2019, identifying where possible within the scope of this review, any outstanding issues to be addressed.

9.6 With the benefit of hindsight, it appears that Annie would have benefitted from being referred to hospital on a cancer pathway although this is not referenced in the Independent GP enquiry report.

9.7 It appears that significant progress has been made although some of the new organisational arrangements across community health and social care services for learning disabled adults have been affected by the Covid-19 restrictions. Additionally, the restructuring of the CCG’s and the new arrangements being introduced for the management of CHC patients will take some time to settle in and these changes will need to address the emerging governance issues. It has not possible for this review to firmly establish if the current governance across services is working to fully support multiagency working for learning disabled adults, but the independent reviewer noted the concerns expressed in the reflective workshop and subsequent discussions that

gaps still exist and further clarification is needed on roles and responsibility across the different agencies involved.

9.8 From evaluating the documentation and consulting with key staff and managers, this review concurs with the Section 42 enquiry and SI report that there was a failure to plan and implement reasonable adjustments to support Annie's access to bowel screening. This has become a national issue and agenda for the NHS in developing a digital flag for reasonable adjustments and for Public Health England in issuing new guidance: 'Supporting people with learning disabilities to access bowel screening'[6]. The latter was published in January 2020 which was sadly too late for Annie to benefit.

9.9 It appears that the only Best Interests decision on either Mosaic or System One records concerned Annie's change of accommodation in 2013. Given the complexity of her health needs and disability and their impact in completing a satisfactory bowel screening, a Best Interest process could have been used to facilitate the considerations of alternative options to a colonoscopy.

9.10 The Annual Health Check and Health Action Plans that are a primary health care task for GP's were referenced as a focus for development and whilst work has been completed to increase the numbers, there are still inconsistencies in quality which need to be addressed.

9.11 One of the issues that emerged in this review was the impact of tensions and conflict between services and Annie's family. Some participants believe that this inevitably had an adverse impact of the working together to support this profoundly disabled woman. Sadly, this is not an uncommon occurrence in the reviewer's experience which prompts a question as to whether mediation should be used when conflict is acute and /or persistent.

9.12 The tragic death of this disabled woman triggered a number of formal processes including a Section 42 enquiry, SI investigation and a LeDeR review. What has become apparent in this Learning Lessons Review is that some further exploration is needed as to how these processes are aligned with reference to the new LeDeR policy published in March 2021. [7]

10 Recommendations arising from this Learning Lessons Review

10.1 The following are the recommendations arising from this overarching review:

1 A further workshop is coordinated across all the key agencies, to follow the pathway of Annie's referral into hospital and explore how the pathway could have been planned and executed to fully support Annie's needs and make the necessary reasonable adjustments. Good practice examples should be reinforced as well as the identification of changes needed to local processes.

2 An audit is completed as to reasonable adjustments for learning disabled adults across all agencies and relevant organisations as per the Confidential Inquiry into Premature Deaths of People with Learning Disabilities (CIPOLD) report 2013 with best practice examples shared to reinforce best practice.

[6] Supporting people with learning disabilities to access bowel cancer screening - GOV.UK (www.gov.uk)

[7] B0428-LeDeR-policy-2021.pdf (england.nhs.uk)

3 Local protocols are needed to assist partnership working across the different community services for adults with a learning disability as per the recommendation in the Section 42 enquiry. These should underpin work between health services but also between health and social care.

4. Arrangements for access to data system - particularly Mosaic and System One - are reviewed and agreements made for read only access across community learning disability services.

5. The recommendation from the Section 42 enquiry: "*Review Health Action Planning and Annual Health Check system. within local area, in collaboration with CCG, Primary Care and local providers"* is still outstanding and needs to be actioned.

6. Mechanisms for mediation are considered when there is persistent conflict between family members acting on behalf of a learning-disabled adult and professionals.

7. Further discussion is needed across the key statutory agencies concerning communication with Annie's family to explain the process and outcome of the safeguarding enquiry and this review.

8. The processes of SARs and the LeDeR process should be explored between the SAEB and CCG, clearly in the light of the new NHS policy being implemented this year.

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