

A Serious Case Review

Amy

Margaret Flynn and Ruth Eley

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Contents	Page
Section one: Background	3
The circumstances that lead to the Review	3
About this Serious Case Review	3
Amy	4
Section two: Key events and service interventions	5
2006	5
2007	5
2008	6
2009	7
2010	8
2011	12
2012	16
2013	22
Section three: Analysis	35
Multi-disciplinary working	35
Commissioning and contract monitoring	38
Decision making with Amy and her family	40
Amy's known health problems and how they were monitored	41
Care coordination and case review	47
Safeguarding responses	49
Section four: Conclusions	51
Section five: Recommendations	54

Section one: Background

The circumstances that led to the Review

1. Amy¹ was a woman with learning disabilities, epilepsy, cerebral palsy and known bowel problems, aged 52. She lived in a Supported Living scheme – Crane Court – run by Leading Lives, where concerns about the staff’s understanding of Amy’s health care needs led to a safeguarding referral in January 2013. On 6 April 2013 she was re-admitted to Ipswich Hospital with breathing problems, having been discharged back to Crane Court, earlier that day. A further safeguarding referral was made by the Community Learning Disability Nursing service which was concerned about the discharge taking place without apparent full investigation or consideration of her health problems. Amy’s condition deteriorated and she died in hospital on 7 May 2013.

About this Serious Case Review

2. The SCR was commissioned by Suffolk’s Safeguarding Adults Board and is based on information from:

- Amy’s family
- Suffolk County Council, Adult and Community Services
- Ipswich Hospital NHS Trust
- Norfolk and Suffolk Foundation Trust
- NHS England, East Anglia
- Leading Lives
- Suffolk Police
- East of England Ambulance Service NHS Trust
- Ipswich and East Suffolk Clinical Commissioning Group

3. The following abbreviations are used in the report:

A&E	Accident and Emergency Department
CLDT	Community Learning Disability Team
Community LD Nurse	Community Learning Disability Nurse
DN	District Nurse
IMCA	Independent Mental Capacity Advocate
OT	Occupational Therapist
SALT	Speech and Language Therapist
Suffolk CC	Suffolk County Council
SMHPT	Suffolk Mental Health Partnership Trust

4. All agencies were asked to produce an Individual Management Review (IMR). The timeframe for the IMR chronologies was 1 January 2010 to May 2013, with a time sampling of 1 to 18 February for four consecutive years 2006 to 2009. In addition, a full chronology was required for 1 March 2008 to 31 August 2008, to cover the period of contractual service change in May 2008 when the Papworth Trust became the provider of care at Crane Court.

¹ This is a fictitious name to ensure the anonymity required by Suffolk’s SAB and was also requested by this woman’s family

5. On the basis of the information provided, agencies were asked to answer additional and specific questions to clarify their interventions and add further detail.
6. The IMRs were written according to the Standard Terms of Reference agreed by Suffolk Safeguarding Adults Board, with the addition of specific Terms of Reference in relation to Amy:
 - i. Was Amy's mental capacity assessed in relation to specific decisions and documented in line with the Mental Capacity Act 2005? What was the quality of these recorded assessments?
 - ii. Were the needs, wishes and feelings of Amy appropriately ascertained and taken into account and to what extent were family/carers consulted with over decision making?
 - iii. Were Amy's needs for health services correctly identified and were the right services provided in response?
 - iv. Were the care placement needs of Amy fully identified by way of appropriate assessment? Were services delivered in accordance to the identified need?
 - v. Was Amy's final care placement managed, monitored and reviewed appropriately and were the responsibilities of each organisation appropriately fulfilled?
 - vi. What evidence is there of inter-agency communication and planning in accordance with Amy's assessed needs?
 - vii. Identification and analysis of good and best practice which had a positive impact to Amy and also identification of failings of service delivery which had a detrimental effect on Amy's health and wellbeing.

Amy

7. Amy was described by her parents as "a gorgeous baby". She grew up normally and was walking at ten months, but did not progress beyond speaking a few words. When she was five years old she fell and banged her head. She had concussion and the following morning *she threw her leg* – a muscle spasm which persisted throughout her life. Amy's fall heralded the beginning of her life-long contact with medical services and specialists. She was subsequently diagnosed as "mentally handicapped" by Great Ormond Street Hospital and developed epilepsy at the age of eight, after which she started to deteriorate slowly. When she was sixteen, she went into care; her parents described this as "the worst thing we did". Amy came home every weekend and visited each Wednesday. She had a good memory, could remember the names of people from her childhood and always asked for her brother. She had a great sense of humour and would use slightly offensive words to get a reaction. Amy's parents remained involved and attentive throughout her life. Her father would drive her adapted van, funded through her mobility allowance, as staff at Crane Court were not always available to do it; otherwise she would have been unable to go out or to come home on occasions. Amy lived at Crane Court for about ten years. Her parents believe her health difficulties developed because of a lack of knowledge rather than a lack of care.

Section two: Key events and service interventions

8. The full chronology for Amy is 123 pages long; what follows is an abridged version which nonetheless covers a significant period of time and is sufficiently detailed to convey the accumulating changes in Amy's circumstances. However, at the request of her family, some details have been removed.

9. 2006

In **April, June and September 2006**, Amy was reviewed in the psychiatric outpatient clinic when it was noted that *physical health, seizures and mood all reported to be stable and very well, no concerns.*²

In preparation for the transfer of care and support from the NHS to social care, an extensive list of requirements for the new provider was documented in Suffolk CC's observation record dated **4 September**. This noted that *Amy can become constipated and there is a comprehensive care plan to help address this for her ... there will be a regular assessment as part of her bi-annual review to monitor any changes in Amy's physical abilities and general health and a regular continence assessment and aids used.*³

10. 2007

On **7 February 2007** a psychiatric review was held, when *an adjustment of medication was requested*; this review was significantly overdue.

On **19 February**, the care home expressed concern to the CLDT that *Amy shows disturbed behaviour during the day and sometimes at night*. As a result, the psychiatrist wrote to the GP informing them of the *changes in medication agreed with the staff.*⁴

In **April 2007**, the nursing staff completed a care plan detailing Amy's holistic support needs. The Care Plan specified that *Amy needs to be toileted at regular intervals throughout the day. She can suffer from constipation. Her bowel movements need to be recorded ... Amy wears continence pads ... She is prescribed a laxative daily. An enema should be given every third day if there is no natural bowel movement. The night before the enema an additional laxative is given.* [This would presumably be administered on the evening of the second day in anticipation of no further bowel movement⁵]. *Amy has a high fibre/low fat diet to help with constipation... may suffer from wheeziness at times usually upon exertion for which she is prescribed inhalers, one for prevention and one for acute episodes.*⁶

Amy was reviewed in the psychiatric out-patients clinic in **July and August 2007**; she was noted as *physically and mentally well, disturbed sleep, waking early ... does not keep hydrated – reluctant to drink?*

On **22 October 2007**, Suffolk CC's review noted *Amy has six monthly consultations with psychiatrist but no consistent current evidence of depressive illness ... Declining mobility ... no longer any structured day time activities as 2 sessions at CLDT premises have ceased.* A mental

² NSFT Patient record

³ Suffolk CC IMR

⁴ NHS England East Anglia IMR

⁵ Leading Lives further information

⁶ Leading Lives IMR

capacity assessment was undertaken *due to the re-provisioning of services from SMHPT [Suffolk Mental Health Partnership Trust] to an alternative provider ... to decide if Amy has the capacity to understand the impending changes in service provider and status.* It concluded that *Amy is unable to understand information relevant to the re-provision process ... does not require IMCA [Independent Mental Capacity Advocate] support with her decision ... as she is supported by an active family.*⁷ A Statement of Needs and how they would be met was sent to Amy on **1 November 2007**.

In **November**, the Essential Lifestyle Plan completed by Crane Court staff stated that *Amy is prone to constipation and needs adequate fibre in her diet and supplements as appropriate to manage this ... she should use the toilet in the mornings, and before lunch and dinner and before going to bed.* There are no written notes to show that this regime was adhered to.⁸

11. **2008**

On **30 January 2008**, a Learning Disability Re-provision Contract Implementation Meeting noted that *Community Care Assessments ... Essential Life Plans and IMCA assessments* were completed for all residents.⁹

On **12 February 2008**, Amy was reviewed in the psychiatric out-patient clinic. *No problems reported although fluid intake still an issue. Review in 3 months.* The review was *6 months overdue and is the last psychiatric review until 10.11.11 which is requested by the GP... This gap may be linked with the change of care provider which occurred shortly after this review.*¹⁰

On **30 March 2008**, staff at Crane Court informed the GP that *the service would be provided by a social care provider from 1.5.08. The provider is Papworth Trust with a request that the letter be placed in all the relevant patient notes, including Amy's.* The Learning Disability Re-provision Contract Implementation Meeting **the following day** noted that *Papworth have held meetings with relatives and that Papworth staff are able to carry out invasive procedures if trained by DN and risk assessments completed.*¹¹

On **18 April 2008**, a further LD Re-provision Contract Implementation Meeting noted *an offer of individual meetings to go out to relatives and an information day held for relatives.*¹²

The care and support in Crane Court transferred from the SMHPT to Papworth Trust on **1 May 2008**. The records *evidence daily observations re fluid and food intake and regular comments about bowel movements. However the observations about bowel movements are not meticulously maintained ... between 26.05.08 and 17.06.08 there are no observations about bowel movements at all.*¹³

On **25 May 2008**, Amy was *discharged* from SMHPT's service.¹⁴

⁷ Suffolk CC IMR

⁸ Leading Lives IMR

⁹ Suffolk CC IMR

¹⁰ NHS England East Anglia IMR

¹¹ Suffolk CC IMR

¹² Suffolk CC IMR

¹³ Leading Lives IMR

¹⁴ NSFT IMR

On **18 June 2008**, the LD Re-provision Contract Implementation meeting noted that *appointments made to resettlement team posts.*

On **25 July 2008**, *Amy was discovered on the floor in her bedroom by waking night staff... no apparent injury.* On **30 July** she was found to have *a bruised and possibly infected finger.* Four days later she was found to have *a carpet burn down the middle of her back ... a dressing was applied because it was weeping.* On **4 September 2008** she was again found on the floor in her bedroom by the waking night staff ... *no apparent injury.* The same member of staff from an agency reported both night time incidents. There is no incident report form or record of follow up available concerning any of these incidents.¹⁵

On **8 September**, Amy attended the GP for a medication review which resulted in *some adjustment.*

On **15 September**, *Amy got a bit upset during the evening after another client had a seizure ... was rocking violently, shouting, biting her hand and hitting her mouth... taken to her room where it was quiet to calm down.* On **18 September** and again on **6 October 2008**, *Amy was found on the floor in her bedroom by waking night staff ... no apparent injury,* reported by the same agency worker. There were no incident reports on file and no follow up instructions.¹⁶

On **3 November 2008**, a review was held at which Amy's parents, key worker and the home manager were present. It was noted that *Amy has suffered constipation but the use of lactulose and fruit and fibre has had a significant effect and the use of enemas has stopped.*¹⁷

On **15 November**, Amy was noted to have *marks on her face.* There is no incident report and no follow up instruction.

On **18 November**, Amy was again found on the floor in her bedroom by the waking night staff, this time by a different member of staff. Amy's parents recalled that cushions were placed on the floor beside Amy's bed to reduce the risk of her being hurt.

12. 2009

During **February 2009**, there is *evidence that the Papworth Trust were experiencing severe staffing difficulties. For the period 09/02/09 – 25/02/09 there were agency staff on 2 and sometimes 3 shifts per day. There are few if any comments about Amy's bowel movements.*¹⁸

On **5 February**, Amy was described as *so difficult that she slipped from the chair to the floor. She was hoisted to get to the chair.* On **17 February**, she became *agitated at dinner time and was taken to her room to calm down.* **Three days later** she *scratched her right upper arm.* On **23 February** she *did not eat all her dinner, was agitated and was taken to her room.*¹⁹

On **25 February**, *IMCAs and families witnessed and signed tenancies* at Crane Court.²⁰

On **26 February**, it was noted that *Amy's left shoulder is wounded by herself and the senior is informed.*

¹⁵ Leading Lives IMR

¹⁶ Leading Lives IMR

¹⁷ Suffolk CC IMR

¹⁸ Leading Lives IMR

¹⁹ Leading Lives IMR

²⁰ Suffolk CC IMR

On **4 March 2009**, it was noted that: *When Papworth took over each customer had fully updated care plans which included Health Action Plans.*²¹

On **6 May 2009**, the LD Re-provision Contract Monitoring Meeting noted that *all tenants have Health Action Plans using the SCC [Suffolk CC] format. Long standing health issues being resolved e.g. 'for all people at Goshawk House [another supported living scheme] ... invasive bowel care has been ceased and this is being managed through improved diet. IMCAs are happy with the way in which the service is responding to people's health needs. All tenants have had a twelve month review by the resettlement team.*²²

On **6 November 2009**, the Combined Risk Assessment listed Amy's known medical conditions as *cerebral palsy, epilepsy and learning disability*. There is no mention of constipation. *Amy needs help to get onto the toilet and change her incontinence pads. She may soil and wet herself*. There is no mention of bowel management.²³

13. 2010

The Leading Lives IMR indicates that there are incomplete Crane Court records available for 2010, with a significant gap for the period 30/07/10 to 01/11/10. The records refer to *medical notes*, the *black folder* and the *Communications book*, none of which were available to the IMR author.

On **4 January 2010**, *towards dinner time Amy started shouting and rocking so was removed to her room to calm down.*

On **12 January**, Amy attended a gynaecology outpatient appointment at Ipswich Hospital *prior to surgery* (D and C²⁴). Her mother *was contacted and informed that Amy had MRSA.*^{25 26}

On **28 January**, Amy was prescribed glasses by the optician. On the same day she *became agitated and hit the table so hard drinks were spilt ... she was taken to her room to calm down.*²⁷

On **4 February 2010**, general practice carried out a medication review resulting in *some adjustment to medication.*

On **8 February**, Amy was noted to be *scratching herself ... staff member applied sudocrem as she was very red and sore*. Amy's parents recall that in a specific time period, their daughter was scratching her leg and sometimes she would lash out at others. They believe that it was related to Amy's medication.

On **9 and 11 February**, Amy was *agitated after tea*. On the latter date a *staff member noticed a scratch on her face which was bleeding*. On **13 February**, Amy *came on the floor* [possibly recorded by a member of staff whose first language was not English; unclear whether Amy

²¹ Suffolk CC IMR

²² Suffolk CC IMR

²³ Leading Lives IMR

²⁴ D and C = Dilatation and Curettage, a minor surgical procedure to remove tissue from the endometrium (lining of the womb): NHS Choices [www.nhs.uk/conditions/dilatation-and-curettage\(DC\)](http://www.nhs.uk/conditions/dilatation-and-curettage(DC)) accessed 13.04.15

²⁵ Ipswich Hospital NHS Trust IMR

²⁶ MRSA = methicillin-resistant staphylococcus aureus, a type of bacterial infection that is resistant to a number of widely used antibiotics: NHS Choices www.nhs.uk/conditions/mrsa accessed 13.04.2015

²⁷ Leading Lives IMR

fell or put herself on the floor²⁸]... *was encouraged back to bed but 30 minutes later was discovered on the floor again. She was then put in her recliner chair where she remained.*²⁹

On **16 February** staff noted that *Amy had a large bowel movement*. This is the first recording of a bowel movement during 2010 – reason for the recording unknown.

On **1 March 2010**, Amy was *prescribed cream for her face*; there is no record of GP contact.

On **3 March**, it was noted that *Amy came on the floor [sic] and was settled into her recliner chair*.

On **5 March** Amy was admitted to Ipswich Hospital for a *vaginoscopy examination under anaesthetic*, accompanied by her mother.³⁰ *Everything is OK and no further treatment is needed... prescribed medication for pain and to stop bleeding.*³¹ On **9 and 11 March** she was noted as having *diarrhoea and loose bowels*, most likely a reaction to the medication prescribed on 05/03/10.

On **12 March**, a review was held at the home, attended by Amy's parents. It noted that *Amy has a learning disability, cerebral palsy, epilepsy, depression, anxiety, hypertension and constipation... will not ask for a drink ... does not point or gesture... although she is able to push things away if she dislikes what is put in front of her. Amy is able to indicate when she wants to go to the toilet... may need a hysterectomy ... ultrasound has identified fibroids... Staff describe her as generally healthy otherwise although her asthma can flare up... has a health action plan in place... Staff have a good awareness of her needs and meet them appropriately.*³² On the **same day** Amy was noted as being *agitated at tea-time* and during the night *came on the floor [sic] and was settled into her recliner chair.*³³

The **following day**, Amy was *very difficult and couldn't stand to assist with personal care... put herself on the floor refusing to get up ... she got up with lots of prompting after 10 minutes*. A similar incident occurred on **15 March** when the staff member noticed *some blood coming from Amy's bottom... Cream applied ...also has redness on her face from scratching*. She was similarly reluctant to stand the **following evening** and on **18 March**. On **19 March** she was *very hot and sweaty*. 2 *prn*³⁴ *paracetamol* given. The **following day** a large (old) bruise was noted *on her left hip*. On **23 March** Amy was again described as *reluctant to stand and get into her wheelchair and so she walked on her knees to the bathroom... GP has changed her medicines and notes to staff are in the 'black folder'*. There is nothing to indicate when Amy saw the GP or why.³⁵

On **1 April 2010**, Amy had *peeling skin on her hands ... note left in the Communications book about seeing the GP*. There is no further comment in the daily record. On **13 April** Amy became *agitated after supper* and was *put in her room*. The **following day** she had an *unsettled*

²⁸ Leading Lives further information

²⁹ Leading Lives IMR

³⁰ Ipswich Hospital NHS Trust IMR

³¹ Leading Lives IMR

³² Suffolk CC IMR

³³ Leading Lives IMR

³⁴ *prn* – an abbreviation meaning 'when necessary'(from the Latin *pro re nata*: for an occasion that has arisen, as circumstances require, as needed) Medicine Net www.medicinenet.com/medterms-medical-dictionary/article.htm accessed 13.04.2015

³⁵ Leading Lives IMR

morning and so was unable to go to her parents. On **15 April** Amy saw a GP as she was continuing to have night sweats, also tremors which were making it difficult for her to eat, particularly in the morning. Staff told the GP that her weight had fallen from 64.3 kg in September 2009 to 55 kg, a 9.3 kg reduction in six months. On **29 April** Amy attended the GP practice for a fasting blood glucose test.³⁶

On **30 April** the physiotherapist visited Amy to do a full assessment.

On **7 May 2010** Amy was in a bad mood, refusing to go to bed 3 times. On **11 May**, she decided to get down from her wheelchair whilst still strapped in. She later came [sic] from the wheelchair to the floor twice and the same with the bed ... very unsettled and very loud throughout the night. The next morning she was so agitated. On **15 May** she was very co-operative but poor on standing.

On **22 May**, Amy was noted to be, in a bad mood this evening ... shouting non-stop and she is sweating. At 21.30 she was stuck in her wheelchair ... the chest part was left in the wheelchair while part of the body was sliding on the floor. She was assisted and the seat belt was discontinued all night though she was in and out of the bed and chair... She didn't stop shouting until 03.00 when she fell asleep and was then assisted into bed. She has a bruise on top of her right arm.

On **27 May** Amy failed to transfer into her wheelchair from the toilet so was encouraged to crawl to her bedroom where there is more space and then into her chair. On **30 May** her parents reported that she had her bowels open when with them and they were concerned that Amy is very hot and sweaty. She was again hot and sweaty on **6 June** and her feet are swollen.

On **13 June 2010** she was agitated and was transferred from the dining room to her bedroom where she ate her tea... later reported as being vocal and hot before going to bed but slept well after taking 2 prn paracetamol. On **15 June** she was given prn paracetamol again as she was very hot and reluctant to transfer from chair to WC and back again. On **22 June** she required a cool washdown and was given 2 prn paracetamol. She also scratched her face.³⁷

On **9 July 2010** the daily record stated that Amy has not looked right. She has been very sleepy and tired. While giving personal care staff member noticed she had 2 bruises on her left hip.

On **16 July** Amy was really agitated this morning, screaming, shouting and thrashing about in her wheelchair... mood fluctuated all afternoon... very vocal throughout the night.

On **23 August 2010** the senior support worker at Crane Court referred Amy to the OT as she has problems putting her feet flat on the floor and ... transferring from chair to stand, to bed, to wheelchair.³⁸

On **9 September 2010**, Adult Safeguarding received a referral from Papworth Trust following an incident two days previously. Staff had noted bruises on Amy's legs. The home staff had completed a body map and reported the findings. Initial discussion indicates may be a moving and handling issue. The following day a GP visited Amy because there was concern about weight loss; no obvious cause identified.

³⁶ NHS England East Anglia IMR

³⁷ Leading Lives IMR

³⁸ Suffolk CC IMR

On **14 September** a telephone safeguarding strategy discussion agreed that a joint investigation would be carried out by a social worker and a Victim Care Officer; a visit was arranged for 24 September. On **22 September** Amy had a health check at the GP surgery. It was not possible to weigh her there so it was agreed to weigh her in the home using *'sitting scales' and phone the weight in*. No concerns about constipation were noted but there was mention of *bowel screening polyp surveillance*.³⁹

A joint safeguarding investigation visit took place on **24 September**. It was established that *bruises could have been caused through several means – Amy wore orthopaedic boots and was known to kick her own legs. Amy also used a wheelchair which may have tied in with the location of the bruises if she caught her leg accidentally and she also had bed sides*. The case conference review meeting on **4 October 2010** determined that no further action was required. *Papworth will continue to monitor the situation and inform Customer First of any further concerns. Papworth Trust have introduced more thorough daily log recording sheet to include comments on customer's moods and behaviours that may lead to bruising. Recording issues within staff team to be addressed and further safeguarding training to be arranged. Management team will work more closely with staff team to ensure a better quality of care*.⁴⁰ The police investigation was closed on **6 October**.⁴¹

On **30 October** Amy attended the gastroenterology out-patients clinic following referral by the GP practice. *Examination did not reveal any physical symptoms... Further test to be undertaken. Mum concerned that could be cancer and asking for invasive investigation. Consultant reluctant and advising conservative approach... noted that the home did not have a set of scales so difficult to weigh Amy*.⁴²

During the early morning of **6 November 2010**, Amy was found to have been incontinent and required washing. **The following day** the bed was stripped at 6 a.m. *as Amy was saturated and incontinent*. On **20 November** Amy was recorded as *off colour, grey colour and sweating*. On **22 November** when checked at 5.30am she appeared to be troubled *and had been incontinent*.

On **30 November** she attended a gastroenterology out-patients appointment and was referred for *an abdominal ultra-sound*.

The Papworth Trust Consistency Plan dated **2 December 2010** stated that *Amy can get very agitated with herself when she is feeling ill or lethargic as her mobility and transferring deteriorate ... she becomes sweaty and red-faced and also occasionally lashes out at staff if they get close to her face mainly when assisting with personal care*. The Leading Lives IMR notes that the *instances of agitated behaviour detailed above and below should be looked at in the light of this Consistency Plan – was Amy feeling ill at these times? ... ABC (Antecedent, Behaviour and Consequence charts) are on file but they are few and poorly completed*. The

³⁹ NHS England East Anglia IMR

⁴⁰ Suffolk CC IMR

⁴¹ Suffolk Police IMR

⁴² NHS England IMR

IMR author suggests this was: *Possibly reflecting a lack of training. Goal charts and learning logs are all blank.*⁴³

On **3 December** Amy was incontinent during the night and on **7 December** she was *agitated, hot and sweaty*. On **18 December** Amy *helped to pack her belongings* in preparation for the move to respite while Crane Court was refurbished.

14. **2011**

Amy was noted in the daily record as *agitated, sweating and shouting* on **2, 4, 16, 19 and 26 January 2011**. On **8, 11 and 17 January** she was incontinent of faeces and required assistance with washing. On **12 January** the driver *had to stop nine times* on the return journey from visiting her parents as Amy *kept sliding down in her wheelchair*. On **9 January** she *kept biting her hand* and on **16, 17 and 23 January** she had *scratched her face*.

On **18 January** she attended Ipswich Hospital for an *abdominal ultrasound scan which noted extensive gas in small and large bowel*.⁴⁴ The daily record states that the *hospital report no obvious symptoms except that she is a bit bunged up, they will see her again next week*.⁴⁵ The patient record indicates a 4cm fibroid and the consultant's letter to the GP advises *not to undertake invasive investigations due to Amy's frail condition*.⁴⁶ On **20 January** Amy was visited by a continence adviser who recommended different pads.

On **25 January** Amy returned to Ipswich Hospital to the gastroenterology department, accompanied by her mother and one of the care staff. The daily record states that *Amy is to have a fasting blood glucose test for diabetes*. [There is no further reference to this.] *Ultra sound results normal... Amy is to be weighed once a week for three months and if considerable weight loss is noted to book a further appointment... Hospital is referring Amy to a dietician*. The Consultant's letter to the GP included *concern about her weight loss but with no data because the home was not weighing her*.⁴⁷ On **26 January** Suffolk CC noted that *Amy is having hospital investigations due to loss of weight and is due to have a CT scan [a specialised x-ray test]. Home staff has been asked to weigh her but do not have scales to use with a hoist... Staff advised to make regular GP visits to enable Amy to be weighed*.

On **31 January** there was a series of e-mails between the Care Management Team and the Resettlement Team about who should complete an application for funding. *Eventually after some uncertainty it is clarified that the Resettlement Team is responsible for payment of invoices for care and support*. This exchange *illustrates potential for lack of clarity about which ACS [Adult Care Services] team is responsible for Amy's care and support*.⁴⁸

On **1 and 2 February 2011** Amy was incontinent of faeces. On **4 February** she had a blood and urine test at the medical centre. On **17 February** she had a sore toe. A medication review by the GP on **22 February** resulted in *some adjustment*. Although the tenants' move back to

⁴³ Leading Lives IMR

⁴⁴ Ipswich Hospital further information

⁴⁵ Leading Lives IMR

⁴⁶ NHS England East Anglia IMR

⁴⁷ NHS England East Anglia IMR

⁴⁸ Suffolk CC IMR

Crane Court is not specifically recorded, there is a reference to *Amy taking a shower in her new wet room on the same day.*

There is then a gap in the Daily Record until 1 **March 2011** when Amy was reported as being *agitated early in the evening.* On **4 March** she *had an OT assessment and is now being hoisted.* The undated Health Action Plan for this period makes no reference to a bowel problem or constipation; it stated that *I have asthma, epilepsy, cerebral palsy and oedema... I need to put on some more weight... If I become angry take me away from the situation and place me on my own.* The Support Plan dated **18 March** stated that *I have lost a lot of weight in the last year and so I need help to put a healthy weight on. I see a dietician and my daily food and drink is being recorded.* The only reference to regular toileting is in the *Evening Routine* which states *I like to sit on the commode in my en-suite for 15 minutes before washing – this gives me a chance to have a bowel movement.* It also stated: *If I start to get anxious my support workers should try to distract me (otherwise) I scream and shout and sweat a considerable amount. I have an ABC chart.* The Leading Lives IMR notes that *there is no ABC chart on file and the ABC reports are poorly completed and possibly reflect inadequate staff training [by Papworth Trust].*⁴⁹

On **19 March** it was noted that *Amy has a circular bruise on her right leg along with 3 little ones going up her shin.* On **24 March** Amy was weighed at CLDT premises and her weight was recorded as 60kg,⁵⁰ the second occasion that her weight was recorded. On **29 March** the Daily Log states that *skin is breaking down on Amy's bottom. Cream applied and she now has a pressure cushion ... please observe and put double base cream on bottom x2 daily.* There is no further comment in the Daily Log.

On **8 April 2011** Amy was visited by the physiotherapist who recommended that *Amy should rest on her bed after lunch with a pillow between her legs and also through the night ... to bring a 'T-roll' at the next appointment to help straighten out Amy's pelvis.* The physiotherapist returned on **14 April.**

On **19 April** Amy's skin was noted to be *breaking down with bed sores.* *Staff are advised to apply sudocrem 3 x daily. Advice within the record to check that diabetes tests come back normal and to weigh Amy properly and give full milk, milk shakes etc. every hour. Amy needs to eat more during the day.* There are no details of where this advice came from,⁵¹ although Amy did attend a dietician's appointment at Ipswich Hospital that morning.⁵²

On **3 May 2011** Amy attended the gastroenterology department at Ipswich Hospital, accompanied by her mother and a care staff member. The Consultant's letter noted *continuing difficulties of weighing Amy in the community* and confirmed advice that *management should be through diet. No need to see Amy again.*⁵³

On **4 May**, a review was held by Adult Social Care at which Amy's parents were present. They requested *review of epilepsy medication as Amy has not experienced fits for many years (since*

⁴⁹ Leading Lives IMR

⁵⁰ Further information from Health Action Plan, Leading Lives

⁵¹ Leading Lives IMR

⁵² Ipswich Hospital further information

⁵³ NHS England East Anglia IMR

age 15 or 16). She was reported to have a *health care plan and to be attending well woman clinics*. There is no reference to bowel management but the medication summary gives *dose of Lactulose as 30ml 2 x day* which is twice the normal dose.⁵⁴

On **11 May** Amy visited a GP for a medication review. *Staff to ensure Amy has salbutamol (blue) inhaler as prn (when she is wheezy). All other medication is fine. No change.*⁵⁵ There was no specific reference to Amy's epilepsy medication.

On **12 May** Amy was assessed for a hoist sling.

On **14 May** her bottom and groin *are a bit red* and sudocrem was applied. IMR author notes that Amy is spending *all day either sitting or lying down and she has bed rest for physio purposes for around 2 hours most afternoons. She has little fresh air in the form of outings and physical activity.*⁵⁶

On **17 May** a GP visited Amy following concern by staff about her *breathing and wheezing*. A *blue inhaler* (salbutamol) was prescribed prn and the GP returned on **31 May** to review this. *All other medication is fine.*

On **24 May** Leading Lives records indicate that Amy was weighed at Ipswich Hospital gastroenterology clinic and her weight was recorded as 49kgs (7st 5 lbs).⁵⁷

On **1 June 2011** Amy had a scratch under her right eye. On **8 June** she was incontinent of *faeces during the night* and required washing. On **12 June** a *small reddish mark* was noticed on her left buttock and three days later the record stated that *bottom breaking down, sudocrem applied*. On **17 June** her groin was red.

On **22 June** Amy returned from visiting her parents *hot, sweaty and shaking* and visited the GP on **27 June** concerning *having hot sweats*. The GP gave advice and organised a blood test to check hormone levels. On **29 June** a staff member rang the GP concerning *broken areas on Amy's bottom... small but there was risk of infection. GP suggested turning every hour but was advised this was not a solution. GP subsequently prescribed Clotrimazole 2 x daily and would ask DN to visit and assess*. The following day it was noted that *Amy's bottom is very sore again. GP was called and has prescribed some cream*. The GP advised they would *involve the DN for dressing and to call back if worsens*.⁵⁸ The DN visited on **1 July** and *after a thorough look couldn't see anything big enough to put a dressing on but is going to order a barrier cream Cavalon*.

Also on **29 June** Amy's Personal Support File was *read and understood by 26 staff, of which at least 16 were Agency*; the Manual Handling Plan was *read and understood by only ten staff of whom only two were agency [staff] at a time when the service was employing a high number of agency staff*.⁵⁹

⁵⁴ Suffolk CC IMR

⁵⁵ Further information from Health Action Plan, Leading Lives

⁵⁶ Leading Lives IMR

⁵⁷ Further information from Health Action Plan, Leading Lives

⁵⁸ NHS England East Anglia IMR

⁵⁹ Leading Lives IMR

On **1 July 2011** the GP practice received a letter from the Professional Deputy Service advising that *Suffolk CC are seeking orders from the Court of Protection for Neil Cawthorne and Associates (Solicitors) to be appointed as Deputy for Property and Financial Affairs for Amy.*⁶⁰

On **7 July** Cavalon cream was withdrawn in favour of Cavalon spray.

On **13 July** the blood test results were *slightly low* and the GP had asked for further tests to be completed in December.

On **18 July** Amy had an annual asthma review at the GP surgery. *Advice given to the staff member about use of inhaler and cleaning it.*

On **20 July** Amy was incontinent of faeces. She needed to be washed and was *wheezy*.

On **22 July** Amy was weighed at Ipswich Hospital and her weight recorded as 51.4kgs. This is the last occasion until 12 February 2013 on which her weight was recorded.

On **1 August 2011** the NHS was contacted for advice following the omission of Amy's evening medication. Staff were told *it should not be a problem.*

On **3 August** Amy attended the hospital for breast screening but *it was ineffective because Amy could not stand. Staff advised to be vigilant to any changes in breasts.*

On **8 August** Amy was very *verbal towards another tenant and was taken to her room to calm down.* On **10 August** she was incontinent of faeces *on awakening* and required washing. Two days later staff contacted the GP to *seek agreement to reduce the dose of Lactulose from 30mls to 15mls due to a lot of bowel movements. GP agreed.*

On **14 August** Amy had a *bruise on her left lower leg of significant size. An incident report was completed.* On **18 August** the physiotherapist felt that *the T-roll is not effective* and advised *alternative arrangements using a pillow....also keeping Amy's feet on the footplates in a wheelchair to avoid bumping and bruising her ankles.*⁶¹

On **25 August** Amy was sent an appointment for a Disability Health Check on **6 October**. However she did not attend (possibly because she had two visits to the surgery prior to that date) and the matter was not followed up by the GP practice.

The daily record reports that Amy had her bowels opened twice on **6 September 2011** – *only three occasions since 20/08/11 although there are seven occasions when the record is blank.* There is then no further recorded bowel movement until **12 September**. On this day Amy visited the surgery for a hypertension review – *no concerns noted.* The following day she saw the GP for a medication review; *the staff member explained about Amy's sweating and GP suggested that bloods be taken to check hormone levels and referred to Learning Disability psychiatrist.*⁶² The blood results were recorded as *normal* on **26 September**. On **14 October 2011** the GP suggested the cause for the excessive sweating might be the Paroxetine and *undertook to write to the CLDT about this.* An out-patients appointment was made for **10 November 2011.**⁶³

On **1 November** Suffolk CC took over the management of the service from Papworth Trust. They reverted to the *old style Daily Record* so from **8 November** there is *no tick box to record*

⁶⁰ NHS England East Anglia IMR

⁶¹ Leading Lives IMR

⁶² NHS England East Anglia IMR

⁶³ NSFT IMR

bowel movements. [The transfer of care provision from Papworth Trust to Suffolk CC was noted in the minutes of the Safeguarding Strategy meeting on **15 January 2013**; the GP practice was not informed and the transfer is not noted in Suffolk CC's CF6 case recording system.]

On **10 November** Amy kept her psychiatric out-patient appointment, resulting in a decreased dose of Paroxetine, with a follow up appointment for six weeks' time. This was the first psychiatric review since 2008. Amy was actually reviewed by the psychiatrist two weeks later on **23 November** when it was noted that *sweating reduced, sleeping excessively. Reduce Lorazepam, review two months.*

On **6 December 2011** Amy attended the GP surgery for an asthma review, when it was noted that she was on the learning disability register. *No concerns about asthma, advice given about inhaler technique and asthma management plan given.*

On **12 December** Amy was incontinent of faeces and required washing on the early shift and **three days later** she *required lots of support with B/O [bowel opening] issue.* On **23 December** she had a follow up review with the psychiatrist who noted *night sweats reduced. Some further adjustment in medication and for review in two months.*

15. 2012

On **6 January 2012**, Amy's stomach was *hard and distended* and she was *offered prune juice.* Later that day she was described as *very bloated but had a bowel movement on the commode... maintain observations.*⁶⁴ There are four bowel movements recorded over the **next seven days** – two of these on **12 January** – and five over the following **6 days to 19 January**. There were no further recordings until **10 February**. Over the years of Amy's residence, her parents reported the hardness of Amy's stomach "on several occasions." There were times when "it was like a lump of concrete."

On **23 January** an Adult Safeguarding referral was made following small amounts of money found to be missing, including £10 belonging to Amy. The matter was *resolved through change to procedure and staff training with the investigation closed* on **27 February**.

On **25 January** an in-house, Person-Centred Review was held. Though wide ranging, it made no specific reference to ongoing health needs other than *it is important that I have a healthy diet and that I need to have regular medical checks.*⁶⁵ A medication review on **27 January** led to *some adjustments.*

Amy was noted to have a *rash on face* on **16 February 2012** and on **20 February** her *right leg and ankle* were *very swollen.*

On **20 February 2012** Amy had a follow up review with the psychiatrist. She was *wheezing, difficulty in breathing and uncomfortable.* The Consultant's letter to the GP included a *request to review URTI [upper respiratory tract infection]*⁶⁶ and was dated **22 February**, the day after Amy visited the surgery because staff were concerned about her asthma. On **22 February** Amy

⁶⁴ Leading Lives IMR

⁶⁵ Leading Lives IMR

⁶⁶ NSFT IMR

returned from her parents *hot, sweaty and breathless*. Having tried to contact the GP, staff rang 999 and Amy was taken to Ipswich Hospital, where *a chest infection was diagnosed* and she was admitted. She had a suspected deep vein thrombosis which was later discounted. Following concern raised by a Crane Court staff member that there were *faeces on bed sheet* and her tummy was *very hard*, Amy had a stomach x-ray which *revealed she was very constipated... given a rectal enema and oral laxatives... was followed by four large bowel movements*.⁶⁷ A chest x-ray appeared *cloudy on the right side*. Home staff were told there was *fluid on the right side which could have been when she chokes when she drinks*.⁶⁸ Whilst in hospital she was reviewed by gastroenterology and by the SALT. The latter recommended *normal fluid and diet as able...pace one sip at a time and sit at 90 degree angle*⁶⁹ [NB: despite this, the Independent Review stated: *there is no indication that a referral was made to SALT...A continued to choke with fluids. The care staff also reported that Amy's abdomen was very swollen and hard*⁷⁰]. A care staff member visited her on **28 February** and found her *lying in bed half naked and very wet ... still chesty and had not had a bowel movement for 2 days, but was discharged home*.⁷¹ The care concerns were raised with the LD liaison nursing service which *directed them to the ward manager*.⁷² Until this point, the LD liaison nursing service was unaware of the admission. The ward manager *made attempts to contact the carers to discuss concerns...but they were unsuccessful*.⁷³ The discharge letter to the GP noted that there was *marked faecal loading seen in the rectosigmoid*.⁷⁴ Amy was discharged on the same day.

The first recorded bowel movement after returning home was on **9 March 2012**, with a further one recorded on **13 March** *very loose* and accompanied by a request from a staff member to *please omit lactulose tonight as Amy going home tomorrow*. On **18 and 19 March** laxatives were omitted due to Amy's excessive *faecal incontinence*. Consultation with the GP confirmed that it *would be okay to stop both Macrogel and Lactulose for 48 hours*.⁷⁵ The NHS England East Anglia IMR notes that there is no record in the GP notes of a link being made between this advice and the *faecal loading* identified by Ipswich Hospital one month previously. A number of night-time bowel movements followed and on **23 March** Amy was found *in the early morning to have been incontinent of faeces* and needed washing.

On **25 March** Amy returned from a visit to her parents *very bloated*. By **1 April 2012** records show *six instances of loose bowel movements*.

On **5 April** she had a mark on her left shoulder and on **12 April** she saw the GP about one of her ribs. On **1 May 2012** she had *a graze on her stomach from the chair restraint*.

⁶⁷ Leading Lives IMR

⁶⁸ Independent review commissioned by Ipswich and East Suffolk CCG 27 September 2013

⁶⁹ Ipswich Hospitals NHS Trust further information July 2015

⁷⁰ Independent review commissioned by Ipswich and East Suffolk CCG 27 September 2013

⁷¹ Leading Lives IMR

⁷² Ipswich Hospital further information

⁷³ Ipswich Hospitals NHS Trust further information July 2015

⁷⁴ NHS England East Anglia IMR

⁷⁵ Leading Lives IMR

The first bowel movement since **18 April** was recorded on **8 May**. On this day also the OT visited Amy about a new wheelchair. Amy was *very wheezy. Stomach very hard and may be constipated. Given Laxide and ... had a large bowel movement but ... stomach still hard...May need to be given Laxide for a couple of days and if no better to contact GP.* On **9 and 11 May** she was *wheezy* and had *a bit of a temperature* and by **13 May** was *still wheezy*. On **14 May** the GP prescribed anti-biotics.

On **15 May** an Adult Safeguarding review considered an anonymous complaint about mishandling of medication following Amy's discharge from Ipswich Hospital. This was found to be a hospital dispensary error, *admitted to issuing the tablets twice and apologised.*⁷⁶

On **17 May** Amy was *quiet and subdued*. Staff called the GP on **21 May** as they *felt she needed to be seen*. GP performed a rectal examination because her stomach was *slightly distended and determined that she was constipated... suppositories to be administered over next three days*. Records confirmed regular bowel movements for this period.⁷⁷ NHS England East Anglia notes that the GP records identify these concerns about Amy's bowels for the first time.⁷⁸

On **24 May** Amy was taken to the surgery as *her right leg is swollen*. The practice nurse identified oedema and *advised staff to monitor and return if necessary*. From this date until **10 June 2012** records indicate *regular although not daily bowel movements.*⁷⁹ On this date she *picked her left ear and made it bleed*. On **18 June** she went on holiday to Wales and while away this ear *became infected and she was prescribed an ear spray by a local GP*.

The OT returned on **25 June** concerning the wheelchair. The GP was asked *to review Amy's medication to see if anything she was taking might be the cause of her spasms*. This reference by NSFT to *spasms* is the first by any agency.

On **1 July 2012**, care provision transferred from Suffolk CC to Leading Lives.

On **7 July** a *broken area of skin on Amy's left buttock* was noted.

From **9 to 12 July** Amy was unwell, *being sick in the morning, off her food and asleep* a lot of the time. On **13 July** she was reported to be better. From **18 to 31 July** there was one reported bowel movement.

On **26 July** Amy had *red marks on her bottom* and on **2 August 2012** she had *a broken area on her left buttock requiring her to lie on her left hip at night*. On **7 August** she had *a large bruise above her right ankle*.

On **14 August** Amy was seen by the SALT from the Norfolk and Suffolk Foundation Trust because of *her difficulties with swallowing drinks*. They recommended to the GP that her drinks *be thickened with Thick and Easy.*⁸⁰

On **18 and 20 August** Amy had night-time bowel movements and needed washing.

⁷⁶ Suffolk CC IMR

⁷⁷ Leading Lives IMR

⁷⁸ NHS England East Anglia IMR

⁷⁹ Leading Lives IMR

⁸⁰ NHS England East Anglia IMR

On **22 August** Amy was seen by the physiotherapist at the GP's request. *The severity of Amy's tone⁸¹ has increased and the GP is asked to prescribe Baclofen.⁸² Two days later the DN visited and prescribed a pressure mattress and a cushion for the comfy chair. There was discussion whether bath hoist slings might be responsible for the marks on Amy's hips and bottom. It was also noted that in view of Amy's weight loss she requires a full fat diet and snacks should be offered regularly, e.g. chocolate, cake and biscuits.*

On **30 August** Amy saw the physiotherapist again. They stressed the importance of her relaxing on her bed in the afternoon for an hour or so – having 1:1 time will help her relax and she will get more benefit from the T-Roll.⁸³

On **1 September 2012**, it was noted that *Amy is slipping more in her chair since she has the ripple cushion.* She was described as *very agitated* on the morning of **5 September** and it was noted the following day that *the physio has re-introduced the T-Roll for two hours daily.* On **10 September** Amy visited the GP surgery. *Concern is weight loss. Examination identified no problems in abdomen. Cause unclear.* Following blood tests on **17 September**, a referral was made to the dietician on **25 September**. There is no record of Amy's weight being noted or requested.

On **12 September** Amy had a small red mark which looks like a blister on her right inner thigh.

On **15 September** she was hot and sweaty and continuously slipped down in her armchair despite having a one-way sheet. Amy visited the physiotherapist on **20 September** – recommendation that the Baclofen be increased. *Amy's leg has improved and she should have her own T-cushion (rather than the one on loan from the physiotherapy service).*

On **22 September** on the return journey from a day trip to Great Yarmouth, Amy became wheezy... agitated and started biting herself and swearing. She also lashed out at staff. There were no reported bowel movements since **16 September**. She was hot and sweaty on **24 September** and given two paracetamol prn. On **25 September** she saw the GP who increased the Baclofen as advised by the physiotherapist.

On **29 and 30 September** it was explicitly recorded that there were no bowel movements. On **7 and 9 October 2012** Amy was very wheezy in the morning and on **12 October** in the afternoon. On **16 October** a lump on her left leg was noted. The following day she was seen by the GP who prescribed antibiotics for the chest infection. A further appointment was made for the following week to review *whether a chest x-ray was required.* The GP stopped the Baclofen because *Amy is not receiving any benefit and it has made her worse... the lump on her left leg has been caused by a knock and will take a while to go down. Please be extra vigilant with manual handling.*⁸⁴

On **18 and 20 October** Amy's face was covered in blood from a scratch and a cut lip. Two days later she knocked her face which bled quite a lot and also bit her hand... she became agitated again at tea time. On **23 October** she was described as very lack lustre and the bite on her

⁸¹ There is a normal amount of contraction in a resting muscle; in cerebral palsy, the muscle tone is increased so that muscles contract, becoming stiff and painful

⁸² NHS England East Anglia IMR, the drug is a muscle relaxant - it reduces muscle tone and unwanted muscle contractions

⁸³ Leading Lives IMR

⁸⁴ Leading Lives IMR

*hand appears to be inflamed. On 24 October she saw the GP again – chest much better.*⁸⁵ Although the staff asked about the agitation and scratching, for which Sulfadiazine⁸⁶ was prescribed for all infected areas, *there is no evidence they reported any concerns about Amy's bowels.*⁸⁷

On **6 November 2012** she had a *red rash on her lips* and on **7 November** a *red mark on the top of her right front thigh*. On the night of **8 November** staff changed Amy's pad and washed her. She had a *coughing bout of about 30 minutes after tea when she coughed up phlegm and scratched her face making it bleed. She also coughed a lot during the night*. The following morning she was chesty and the GP was called, but *her breathing became worse* at 12.30 and she *became distressed*. Staff rang 999 and the ambulance crew decided she had a chest infection, confirmed by the GP who had arrived and then prescribed antibiotics. Her condition improved during the day. Although her parents reported *no problems* when she visited on **11 November**, the next day *Amy went downhill as the morning progressed; she had a temperature and looked worn out*. She went home for a visit on **14 November** and her mother requested a GP visit for the next day because *Amy had a temperature and was very wheezy*. The GP visited on **15 November** as requested and advised to *carry on with the course of antibiotics and use her inhalers as necessary*. For the next **four days** Amy was described as *wheezy, chesty, sleepy and not her usual self*. On **19 November** the records indicate no bowel movement and *prn Movicol should be given*.

On **20 November** Amy was seen in out-patients by the dietician who noted that she was reported as *losing weight over 18 months but had not been weighed* (the last recorded weight was on 22 July 2011). They also noted *tends to be constipated and is managed through medication*. She was to be weighed at the Chantry Clinic *where there is a hoist as soon as possible and before next appointment*.⁸⁸ The dietician also recommended *milkshakes x1 per day, cream in coffee and cereal and high calorie deserts ... to review in 3 months*.⁸⁹

On **21 November**, *Amy was very wheezy and sweaty* and an ambulance was called. At A&E she was diagnosed with *faecal loading and impaction* and was admitted. *She was also noted on admission to have completed two courses of antibiotics for chest infection described as SOB [shortness of breath] and distended abdomen*. In the short stay medical ward the diagnosis was *severe faecal impaction, shortness of breath secondary to splinting of diaphragm*. X-ray confirmed that there was *no pseudo obstruction* and the patient was constipated. The LD Liaison Nursing service saw Amy and discussed the constipation issues with the care staff member and Amy's mother. She was also reviewed by the SALT who recommended *continuing stage 1 fluids*.

⁸⁵ NHS England East Anglia IMR

⁸⁶ This eliminates bacteria that cause infections

⁸⁷ Leading Lives IMR

⁸⁸ NHS England East Anglia IMR

⁸⁹ Ipswich Hospital further information

On **23 November**, Amy's bowels opened following enemas. Tummy reported as softer...taking fluids. B/P down but temperature remains up.⁹⁰ On **24 November**, Amy's temperature down, B/P good, tummy much smaller and softer.

Amy was discharged home on **25 November**. The Hospital Discharge Summary clearly identifies *gross faecal loading* as the main cause of Amy's difficulties.⁹¹ *No written discharge information given to Leading Lives care staff.*⁹² The hospital advised the GP to keep Amy on *lifelong laxatives* and to seek a referral to the DNs *to administer enemas as care providers unable to undertake this task. LD Liaison Nurse referred to CLDT for community follow up with regard to constipation management.*⁹³ The GP prescribed daily enemas up to **14 December**.

On **26 November**, a DN visited. Having examined Amy and using the Bristol Stool Chart to obtain information from staff about her bowel movements, they reported *no enema required, carers advised about medication to administer to maintain bowel movements.*⁹⁴ The Independent Review notes *GP's visit – Amy not to have daily enemas at the moment, to have movicol x2 sachets at night. To be reviewed on 30 November.*⁹⁵ A similar visit was made on **29 November** when Amy was reported to be *eating and drinking without difficulty*. Staff informed the DN on **3 December** in a telephone review that *bowel movements were regular and there were no problems*. The running record shows that with one exception, *Amy had daily bowel movements until 30 November*. On **10 December** Amy was incontinent of faeces and needed to be washed. On the same day she attended the wheelchair clinic; it was noted that *Clinic want full review of Amy's needs before deciding upon a new chair and also queried where the original chair had gone as it was more suited to her needs.*⁹⁶ Also on that day she was noted to have *two small red marks on her bottom – small blisters are appearing and she does not appear very well*. The following day her *bottom is very sore at present and ... she needs to be changed regularly*. The DN noted that day that *Amy's bowel movements were sluggish at times, medication was being given*.

On **12 December 2012** a community nurse and a Community LD Nurse visited Amy and discussed her bowel management; her mother was also present. The running record notes that *it is important to record all bowel movements and to have a high fibre diet*. There was a query about *when Movicol should be administered* and also *why the Lactulose had been changed to every other day*. Staff were *advised to ring the surgery to clarify*. Two days later the GP *confirmed that Movicol should be administered 1 sachet x 2 daily and Lactulose 5ml 2 x daily*. He also said he would re-prescribe Baclofen. Also, *cream applied to buttocks. Please make sure the bowel chart is completed*. The Community LD Nursing service wrote to the GP on **14 December** *to raise significant concerns about the care of Amy by care staff at Crane Court and their understanding of her illness and health care needs, after a visit to the home following concerns raised by the Ipswich Hospital LD Liaison Nurse*. Staff were reported as *not*

⁹⁰ Independent review commissioned by Ipswich and East Suffolk CCG 27 September 2013

⁹¹ NHS England East Anglia IMR

⁹² Independent review commissioned by Ipswich and East Suffolk CCG 27 September 2013

⁹³ Ipswich Hospitals NHS Trust IMR

⁹⁴ CCG IMR

⁹⁵ Independent review commissioned by Ipswich and East Suffolk CCG 27 September 2013

⁹⁶ Leading Lives IMR

understanding the significance of Amy's constipation; their belief that the admission was for pneumonia; not following the medication regime. The letter also noted that *Amy's agitation may be due to her severe constipation.* The service also faxed *medication charts* and a copy of *a Safeguarding Referral letter regarding Amy's care at Crane Court.* The GP reply is dated **20 December** and noted their telephone conversation and that he had asked the Crane Court staff to keep a regular bowel chart. It also noted that *both believe a principal difficulty is the lack of training for the carers in dealing with Amy's problems.*⁹⁷ On **15, 16 and 17 December** *Amy's bottom was sore with some broken areas ... she hasn't had a B/O in 2 days. DN visiting tomorrow [18 December] and to be informed if she doesn't have a B/O tonight.* A DN visited as expected and *assessed condition of Amy's bottom... advised on appropriate management of areas that are breaking down.*⁹⁸ There was no mention of Amy's bowels in either the running record or the DN's record.

On **20 December**, *Amy was agitated pm and scratched her face.* On **22 December** it was noted that *large B/O, sweaty and wheezy pm.* On **23 December** her mother expressed concern about Amy's wheeziness following a visit home. She was *also off her food.* On return to the home, the staff recorded that *Amy's tummy was hard and bloated.* The staff member records that they *rubbed Amy's stomach which appeared to alleviate the problem and wondered whether it was "trapped wind."*⁹⁹ On **25 December** she had *nasal congestion* and was sneezing. On **30 December** the records showed evidence of *regular large, loose bowel movements to date.* Following a visit to her parents, Amy was described as *sweaty, blotchy and her breathing is shallow.* The Out of Hours GP was called at 20.15... *advised to increase the Salbutamol.* The GP also said *he was worried about her stomach as it was very hard ... would ask a colleague to visit.*¹⁰⁰ He asked Amy's own GP to *review her abdomen the following day.*¹⁰¹ The GP visit noted *possible chest infection or urinary tract infection.* Antibiotics were prescribed and there is no indication of whether the medication regime and enemas were checked.¹⁰² A DN visited the same day *as carers concerned about constipation and possible chest infection*¹⁰³ and did a rectal examination. They *confirmed that everything was OK and that Amy was not constipated at that time.*¹⁰⁴

16. 2013

From **25 December 2012** to **2 January 2013** the bowel records showed daily and more frequent bowel movements described as loose and medium size. A visit by a DN on **31**

⁹⁷ NHS England East Anglia IMR

⁹⁸ Leading Lives IMR

⁹⁹ Leading Lives further information

¹⁰⁰ Leading Lives IMR

¹⁰¹ Independent review commissioned by Ipswich and East Suffolk CCG 27 September 2013 states: *OOH GPs do not have access to a patient's medical records and are reliant on the home staff to inform them of any current treatment and medication*

¹⁰² NHS England East Anglia IMR

¹⁰³ CCG IMR

¹⁰⁴ Leading Lives IMR

December involved a rectal examination and it was concluded that Amy was *not constipated*.¹⁰⁵

On **2 January** the GP visited in the morning and *performed a thorough examination of Amy... prescribed Prednisolone*¹⁰⁶... *Amy was breathless in the morning and hot and sweaty pm. Her stomach was swollen and distended and very hard. Staff rang the GP for advice ... to continue with meds and wait for improvement. During the night was wheezing and unsettled.*¹⁰⁷ The GP was asked by a member of the support staff if Amy's diarrhoea *could be overflow from constipation*. The GP responded that since Amy had *had bowel movements it was not overflow and the swollen abdomen was the result of her breathing issues and perhaps an indication of infection.*¹⁰⁸ The following day Amy's chest was still *bad* and *she didn't sleep at all at night*. On **4 January**, the GP visited again and noted *Amy becoming more ill. Chest infection and bowel impaction identified*. Ipswich Hospital was unwilling to accept a surgical admission and asked the GP to send Amy to A&E. The A&E attendance summary stated *bowel obstruction, query paralytic ileus.*¹⁰⁹ She was given *a chest and stomach x-ray and discharged home.*¹¹⁰ The Emergency Department discharge summary¹¹¹ stated that the GP was advised to *refer to the surgical team for review*, although this summary does not appear on the GP Patient record. On **4 January** also, the Community LD Nursing service wrote to the GP *requesting clarification of medication and ... clear direction to staff on this*. There was concern that *laxatives stopped as staff misinterpreted faecal overflow for diarrhoea, although discharge summary had recommended increased dose. Also that DN had stopped attending to give enemas (although discharge summary [from 25 November 2012] recommended daily enemas for long term treatment).*¹¹² The LD Liaison Nursing service and a Community LD Nurse spoke on the telephone and *were both concerned that care home continue to be not managing bowels.*¹¹³ The Leading Lives manager e-mailed the Community LD Nursing service to say that when she visited Amy in hospital *she was not advised by hospital staff that constipation was the main problem. At team meeting on 22 November she spoke to team about need to support people in all aspects of their life (i.e. including medical as well as social needs).*¹¹⁴ Still on **4 January**, Adult Safeguarding recorded a phone call from the Mental Health Team about the fax sent on **14 December** by the Community LD Nursing service; no record of the fax was found and a new referral was e-mailed and actioned as a safeguarding referral. The detailed letter was written by the Community LD Nursing service, following the visit to Amy on **12 December**. Details included: *Amy was admitted in an emergency, experiencing shortness of breath, the cause of which was ... splinting of the diaphragm due to severe constipation... We spent time*

¹⁰⁵ Independent review commissioned by Ipswich and East Suffolk CCG 27 September 2013

¹⁰⁶ Helps to control inflammatory and allergic conditions such as asthma

¹⁰⁷ Leading Lives IMR

¹⁰⁸ Independent review commissioned by Ipswich and East Suffolk CCG 27 September 2013

¹⁰⁹ Ipswich Hospital further information

¹¹⁰ Leading Lives IMR

¹¹¹ Ipswich Hospital NHS Trust IMR

¹¹² Suffolk CC IMR

¹¹³ Ipswich Hospital NHS Trust IMR

¹¹⁴ Suffolk CC IMR

during the visit with the home manager who informed us the admission had been due to pneumonia. She did not appear to realise that the problem was in fact constipation... We enquired about recording fluid intake and were told that this is seen as a health matter and they didn't do health and therefore recording was not in place ... Amy had not had her bowels open for two days up to our visit ... staff do not appear to have the understanding and knowledge to provide basic care for Amy ... Two members of staff have been asked on separate occasions if Amy has epilepsy, both people said no. She does have a diagnosis of epilepsy and has two different anti-epileptic medications. This brings to question whether staff are trained around administering medication... a £3500.00 specially moulded wheelchair was issued in 2008, this has been discarded and is in a privately bought inappropriate wheelchair ... no "safe seating" for Amy in the home ... we feel this home needs urgent investigation.¹¹⁵ The police noted in their record system that Adult Social Care have strongly requested a joint investigation in light of a recent death due to constipation.

On **5 January** the running record states that Amy's condition is improved. On **8 January** the DN rang the home and noted *no problems reported by carers. They agreed to ring ... if there were any problems.*¹¹⁶

Also on **8 January** a telephone strategy meeting considered the referral letter and the case was allocated for joint investigation by CCP [Community Care Practitioner], a Learning Disability Nurse and Victim Care Officer. Care notes and care plans for whole service (other residents) to be looked at.¹¹⁷

On **9 January**, the LD Liaison Nurse advised the Community LD nursing service that the GP should be contacted to explore further reasons for constipation following on from discharge summary recommendation of 4 January.¹¹⁸ The latter wrote to the GP suggesting that a referral should be made for further investigation in relation to Amy's constipation and informing the GP of the Adult Safeguarding meeting on **15 January**. In reply on **10 January** the GP identified that Amy's symptoms indicate that *paralytic ileus seems less likely and constipation more likely.*¹¹⁹

On **10 January** Amy attended A&E following an *acute asthma attack during physiotherapy session.*¹²⁰ Her condition settled and she was discharged home. However, a Community LD Nurse had visited her in A&E following information from the LD Liaison nursing service and stressed to A&E staff the possible links between breathing difficulties and bowels ... A&E staff explained that if Amy came in with breathing difficulties that is what would be treated. The Leading Lives Team Leader and staff member were present when she was discharged.¹²¹ The Independent Review also noted that *the care staff were told in A&E that the presenting condition only would be addressed, no indication that information from previous admissions*

¹¹⁵ Suffolk Police IMR

¹¹⁶ CCG IMR

¹¹⁷ Suffolk CC IMR

¹¹⁸ Ipswich Hospital NHS Trust IMR

¹¹⁹ NHS England East Anglia IMR

¹²⁰ Ipswich Hospital NHS Trust IMR

¹²¹ Suffolk CC IMR

or A&E attendances was considered.¹²² On the same day, a fact finding meeting was held at Crane Court involving the social worker, a manager and colleague from Leading Lives and a Community LD Nurse. They established that *Lactulose being given every other day but MARRS [sic] sheet said should be twice daily. Not clear why change made or on whose advice... GP confirms medication should be given twice daily. No chart in place to record asthma attacks. Training needs identified – asthma care and recording, bowel care and recording, accurate recording of GP visits and outcomes, administration and recording of medication.*¹²³ **Later that day**, the allocated police officer noted that they had contacted the social worker *today to find that she has already completed a visit with Health ... she had not read the referral properly and if she had ... would have seen it was a joint Police/SCS matter [probably a typing error for SCC] ... She confirms at this time that the home have given medication as directed by the GP ... will check this with GP and report back... we will consider any further action tomorrow.*¹²⁴ On **11 January** a DN visited: *request made by carers to examine patient following a Safeguarding meeting. Request was made to have patient's abdomen examined x2 weekly. Carers reported medication for bowels was being given twice daily, bowels were being open regularly and skin on buttocks intact. Abdomen examined, no rectal examination required.*¹²⁵ Also on that day the GP record notes that a Community Care Practitioner was *concerned re standard of care.* The GP decided to *try and arrange for the Admission Avoidance Team to become involved – 2 messages left with Single Point of Access.*¹²⁶ Also on **11 January** Suffolk CC recorded receipt of a *Diagnostic Imaging letter* from Ipswich Hospital (following Amy's visit to A&E on 4 January) which detailed *dilated loops of large bowel, faecal loading of rectum, damage to diaphragm and lung.*¹²⁷ ¹²⁸ This letter was not received by the GP practice. On **13 January** an *Asthma Support Plan* and an *Elimination Support Summary* were recorded at Crane Court, both *drafted in response to the Adult Protection Investigation.*¹²⁹ The former stated that *severe constipation may make it very difficult to breathe and this has happened before so make sure that the medical professionals check Amy's stomach as well as her chest.* The latter detailed the signs of constipation and what to look out for and concluded that *the GP should be consulted if Amy has not opened her bowels for more than 1 day.* On **14 January** staff rang the GP surgery as she was *not eating well ... short of breath and distressed. Coughing, very red and sweating. Then was sick. Became very agitated.*¹³⁰ The duty GP gave advice about medication for asthma and *home visit arranged for following day.*¹³¹ Also on **14 January** social care e-mailed the Police to inform them of the strategy meeting the following day concerning two residents at Crane Court – including Amy – *to discuss both cases*

¹²² Independent review commissioned by Ipswich and East Suffolk CCG 27 September 2013

¹²³ Suffolk CC IMR

¹²⁴ Suffolk Police IMR

¹²⁵ CCG IMR

¹²⁶ NHS England East Anglia IMR

¹²⁷ Suffolk CC IMR

¹²⁸ On 22 May 2015 Ipswich Hospital NHS Trust stated that *there was faecal loading in the rectum, elevated right hemidiaphragm. NOT damage to diaphragm and lung*

¹²⁹ Leading Lives IMR

¹³⁰ Leading Lives IMR

¹³¹ NHS England East Anglia IMR

which look like lack of awareness rather than intentional neglect.¹³² On **15 January** the police spoke to Adult Social Care at length this morning. They noted a dispute over the suitability of medication between the ladies [sic] GP and her physio ... GP is stating Leading Lives were not advised to reduce her Movicol the home is insisting they were ... misunderstanding over the reason for hospitalisation and over discharge ... are there any lasting effects from the constipation ... what systems are in place to monitor specific needs ... can they meet this person's needs, did they accept this persons needs when taking on their care ... have they accessed the right professionals for support to meet these needs? Once established I will review the case to consider neglect.¹³³

That morning, the GP visited and noted Amy's chest reported as being a lot better and had had 2 good bowel movements the previous day but none on the day of the visit. No mention of constipation. Plan is to refer to Consultant respiratory physician for investigation.¹³⁴

Later that day (**15 January**) the Safeguarding Strategy meeting was held at the GP surgery. The police and the District Nursing service did not attend. The GP informed the meeting that they had never been advised of the transfer from NHS to non-health staff and may have made different decisions if they had been aware that information provided was gathered from non-medical staff. The GP raised concerns about care staff's ability to cope with complex health needs and advises move to a nursing home. The move was felt to be detrimental to Amy's well-being so not to be implemented. Until a formal diagnosis of her condition is made, staff feel they can meet Amy's needs. There was concern that the GP was looking at Amy's current health needs in isolation to her holistic needs i.e. would a generic nursing home have sufficient knowledge and experience in working with a young lady with a learning disability and communication difficulties?¹³⁵ Actions agreed included Leading Lives to be more proactive in monitoring health needs and ... to introduce Bowel Charts to all tenants that have bowel management issues... Further investigation of Amy's health needs by GP.¹³⁶ Further, it was agreed that a Continuing Health Care Assessment check list should be completed to look at the possibility of additional funding which could be utilised to support Amy's current placement.¹³⁷ The GP placed an alert on the practice patient information system saying history of chronic constipation and acute respiratory distress secondary to diaphragmatic splinting. Advise have a low threshold to visit if requested by home.¹³⁸ The GP also noted to lead ongoing health investigations and to contact Consultant respiratory physician.

The police and social care had a further discussion following the strategy meeting and the police noted having considered all this information I do not consider this amounts to Wilful Neglect under the MCA.¹³⁹

¹³² Suffolk Police IMR

¹³³ Suffolk Police IMR

¹³⁴ NHS England East Anglia IMR

¹³⁵ Suffolk CC further information

¹³⁶ Suffolk CC IMR

¹³⁷ Suffolk CC further information

¹³⁸ NHS England East Anglia IMR

¹³⁹ Suffolk Police IMR

On **16 January** the DN visited Amy *no examination required, carers reported patient was having bowels open.*¹⁴⁰ **Two days later** the DN telephoned to check on Amy. The staff went through the bowel chart activity with her and she indicated that she was satisfied.¹⁴¹ A telephone call to the home notified the appointment on **24 January** with the respiratory consultant.

The DN rang again on **21 January** and the carers *reported bowels being open.*¹⁴² On the same day Amy was noted to have *two bruises on the side of her knee*¹⁴³ and she was referred to Customer First for completion of Continuing Health Care checklist and to ACS area team for a review of placement.¹⁴⁴ On **22 January**, the Adult Safeguarding Senior Practitioner and the Community LD Nurse visited Crane Court to discuss with staff the monitoring of the bowel charts. On the same day Amy *refused to take the Movicol the last two days and ... she spat out one of her tablets today. GP informed.*¹⁴⁵ On **23 January** the DN had another telephone consultation with the staff in which they *went through the bowel chart verbally ... was satisfied all ok.*¹⁴⁶ Amy had a *choking fit* that afternoon.

On **24 January**, Amy attended the respiratory clinic at Ipswich Hospital. The Consultant rang the GP and advised that *the most likely cause of shortness of breath was raised hemi diaphragm due to abdomen being full with air and faeces. They advised trial of magnesium hydroxide as a laxative in conjunction with other prescribed laxatives ... home to keep food and bowel charts. Referred to gastroenterology team.* The staff were given a nebuliser on loan for which they will need to be trained.¹⁴⁷ The Health Action Plan notes that the Consultant showed staff x-rays of constipation as follows: 04.01.13 – constipation, 11/12 – right side bowel was compressing Amy's lung,¹⁴⁸ 02/12 – right lung was smaller than the left lung.¹⁴⁹

On **25 January** the GP noted that Amy had seven bowel movements, breathing good and no blood or mucus.¹⁵⁰ They reduced dose of Movicol to 1 x sachet, 2 x daily.¹⁵¹ On **29 January** a DN visited and observed Amy with the carers who *reported bowels being open daily. No signs of breathing difficulties.*¹⁵² On the same day Amy attended the asthma clinic. Notes record *currently asthma is under control and no immediate concerns ... carer knows when to initiate salbutamol or raise medical assistance... carer demonstrates good inhaler technique.*¹⁵³

From **29 January to 5 February 2013** the running records indicate that Amy was *looking and feeling better, is having settled nights, regular bowel motions and eating and drinking well.*

¹⁴⁰ CCG IMR

¹⁴¹ Leading Lives IMR

¹⁴² CCG IMR

¹⁴³ Leading Lives IMR

¹⁴⁴ Suffolk CC IMR

¹⁴⁵ Leading Lives IMR

¹⁴⁶ Leading Lives IMR

¹⁴⁷ Ipswich Hospital NHS Trust IMR

¹⁴⁸ E-mail from Ipswich Hospital NHS Trust states this should read *the bowel was compressing the right lung*

¹⁴⁹ Leading Lives IMR

¹⁵⁰ NHS England East Anglia IMR

¹⁵¹ Leading Lives IMR

¹⁵² CCG IMR

¹⁵³ Leading Lives IMR

On **5 February** a DN visited and noted *still awaiting nebulizer medications*,¹⁵⁴ nearly two weeks after the nebuliser was provided. On **8 February** a Community LD Nurse rang the home, was informed *magnesium still not prescribed* and intended to contact GP.¹⁵⁵ On **10 February** the home noted that *settled mood and state of health has continued*. On **11 February**, the GP prescribed the magnesium hydroxide as prn medication. On **12 February** the Leading Lives Contact Sheet states that *Amy was weighed at Felgains [wheelchair supplier] and found to be 47kg*.¹⁵⁶

Also on **12 February** the District Nursing service was informed that the nebuliser medication had arrived and arranged a visit for the following day, when they *provided training to carers in the use of a nebuliser*.¹⁵⁷ On the same day *following a home visit mother reported concerns that Amy appeared bloated*.¹⁵⁸ Also on **13 February** an Adult Safeguarding Review was held. This noted *nutritionist appointments... bowel chart from 15.01.13 and fluid chart from 24.01.13; DN monitoring bowel movements. Bruising to inside of knees mapped and recorded ... physiotherapy sessions reduced from fortnightly to monthly. Amy now using a nebuliser. Continuing Healthcare checklist completed and faxed to PCT*.¹⁵⁹ It was also noted that the care provider was *making extensive use of agency staff because short of permanent staff... may be adversely affecting communication with other disciplines*. However Leading Lives records suggest that since they became service provider the use of agency staff had significantly improved insofar as they had endeavoured to ensure continuity by using the same agency staff regularly.¹⁶⁰

On **15 and 16 February**, although previous good evidence of bowel movements, *Amy had a bowel motion in the afternoon while having her bed physio*, although the *settled period of mood and health* continued. On **19 February** a DN visited and noted *carers reported bowels being opened daily and it is being recorded. No obvious breathing problems. Inhalers rather than nebuliser being given*.¹⁶¹ On the same day Amy attended an out-patient dietician appointment and was advised to continue with full fat foods. In the letter to the GP, the dietician noted that *Amy's current weight is recorded as 47kg* but it was *still uncertain whether Amy is losing or gaining weight... foods are not being consistently fortified as per the dietary plan*.¹⁶²

On **20 February** the LD Liaison Nursing *delivered digestive health training to the care providers*.¹⁶³ On **the same day**, a Community LD Nurse contacted the *care home* and was informed that *magnesium still not prescribed*,¹⁶⁴ [now four weeks since this was recommended by the Consultant].

¹⁵⁴ CCG IMR

¹⁵⁵ NSFT IMR

¹⁵⁶ Leading Lives further information

¹⁵⁷ CCG IMR

¹⁵⁸ Leading Lives IMR

¹⁵⁹ Suffolk CC IMR

¹⁶⁰ Leading Lives further information IMR

¹⁶¹ CCG IMR

¹⁶² Ipswich Hospital NHS Trust IMR

¹⁶³ Ipswich Hospital NHS Trust IMR

¹⁶⁴ NSFT IMR

On **21 February** Amy was *assessed for a special moulded wheelchair* but to await a further appointment with the OT and Consultant at the wheelchair service on **15 March**.

On **24 February** Amy had an *asthma attack when she arrived home from visiting her parents... appeared to recover after a short while*.¹⁶⁵ She was *wheezy and very hot* the following day. Also on **26 February**, a DN rang the home and was told that Amy's bowels were *being open 3-4 times a day, patient at risk of getting very sore*. DN advised *reduction in medication for bowel care*.¹⁶⁶ The home wrote to the GP asking him to confirm the DN's recommendation; he *agreed to this but asked the staff to be aware of overflow signs*.¹⁶⁷ On the same day a Community LD Nurse rang the GP to ask if he was *going to prescribe the magnesium hydroxide as recommended by the consultant*. It had been prescribed as prn on **11 February**; *as the bowels appeared to have improved clinically at that stage there did not appear to be an indication to prescribe the medicine*.¹⁶⁸

On **27 February** a further Adult Safeguarding Review was held. It was noted that *police and ACS investigation now completed. Leading Lives staff previously omitted to monitor Amy's bowel movements but this was not wilful and there is no evidence that they had been advised by health professionals to do so. As provider they have a duty to monitor health needs... they have implemented guidelines and training to remedy this deficit*.¹⁶⁹ Discussion with the police in relation to wilful neglect was that *there was no evidence of a care plan explicitly advising to monitor or evidence the provider had either wilfully ignored or displayed a don't care less attitude*.¹⁷⁰

On **28 February** a DN rang the home and was told *patient continues to have loose stools, staff encouraged to contact DN if they had concerns. Patient eating and drinking well*.¹⁷¹ A Community LD Nurse also rang that day and was advised of Amy's *very loose stools*. Also on **28 February** the GP received a letter from the gastroenterology consultant reporting *the outcome of a colonic transit study that shows a significantly prolonged transit time estimated at 100 hours*.¹⁷²

On **2 March 2013** Amy was *all hot and bothered* on return from her parents. *Bad bout of faecal incontinence during the night*.¹⁷³ On **5 March** a DN rang the home and noted *patient distressed in mornings having loose and frequent bowel movements... requested GP assessment. Nebulizer only being used at night or PRN. Fungal infection of mouth and face being treated with cream*.¹⁷⁴ On receipt of the DN's letter, the GP discussed Amy with a Community LD Nurse and agreed *medication not changed*. The GP *referred Amy for an x-ray to clarify whether the DN is observing Amy having loose stools or overflow because of*

¹⁶⁵ Leading Lives IMR

¹⁶⁶ CCG IMR

¹⁶⁷ NHS England East Anglia IMR

¹⁶⁸ GP further information

¹⁶⁹ Suffolk CC IMR

¹⁷⁰ Suffolk CC further information

¹⁷¹ CCG IMR

¹⁷² NHS England East Anglia IMR

¹⁷³ Leading Lives IMR

¹⁷⁴ CCG IMR

constipation. On **6 March**, the gastric transit study time shows that the rate was very slow. Amy to have an abdominal x-ray.¹⁷⁵

On **10 March**, Amy was chatty, cheerful, taking lots of food and fluids, but continues to have very large loose bowel movements and sometimes diarrhoea. On **12 March** she had three bouts of diarrhoea in the afternoon.¹⁷⁶ On **13 March** the DN rang again and agreed not to visit due to the weather as Amy was still having regular bowel movements (although loose).¹⁷⁷ On the same day the GP received the report from the x-ray two days previously; *marked dilation of large colon; suspected sigmoid colon with prominent faeces at rectal level; no free air can be seen*. The GP then contacted the care staff and instructed that *bowel medication must not be reduced. Staff should trial additional medication (magnesium hydroxide) as per consultant's letter. Staff asked to report effect in one week.*¹⁷⁸ There is no reference to this phone call or request in the Crane Court care record. A Community LD Nurse spoke to the DN on **14 March** to discuss ongoing bowel issues – *x-ray shows faecal loading. Review visit to be made 19.03.14.*¹⁷⁹ On the same day the Community LD Nurse e-mailed the home to confirm that the problem was *constipation, overflow not diarrhoea.*¹⁸⁰ Also on **14 March**, Amy saw the Consultant in Rehabilitation Medicine in Norfolk Community Health Trust, accompanied by two support staff. In the letter to the GP, the Consultant *requested a Bowel Care Plan and medication to establish regular bowel pattern*. It was noted that there were *no medical records available for consultation*, so the Consultant relied on information relayed by the support staff and the physiotherapist. There were also *suggestions re wheelchair and medical intervention to aid positioning.*¹⁸¹ Amy attended the wheelchair clinic on **15 March**.

On **18 March** Amy was noted to have been *quieter than usual and a bit wheezy and sweaty* for the last two days. On **19 March** the DN visited Amy and noted *patient continues to have loose stools and bowels open 3-4 times per day. Pressure areas intact.*¹⁸² On the same day a Community LD Nurse contacted the home and *confirmed x-ray findings again, enquired re magnesium – only given prn, advised to contact GP today re dose interval.*¹⁸³ On **21 March** a DN performed a rectal examination, *virtually empty, patient eating and drinking well, pressure areas intact.*¹⁸⁴ On **21 March** a Community LD Nurse *requested an earlier appointment with the gastroenterologist in view of the x-ray.*¹⁸⁵ On the same day this nurse visited Amy with her parents – *no concerns*. On **25 March** the nurse met with the *care home staff* and reviewed *fluid and nutrition charts, medication charts – all satisfactory.*¹⁸⁶ On **26 March**, Amy was *very incontinent in the early a.m.*¹⁸⁷ The DN rang the home that day and notes *no bowel problems*

¹⁷⁵ Independent review commissioned by Ipswich and East Suffolk CCG 27 September 2013

¹⁷⁶ Leading Lives IMR

¹⁷⁷ Leading Lives IMR

¹⁷⁸ NHS England East Anglia IMR

¹⁷⁹ CCG IMR

¹⁸⁰ NSFT IMR

¹⁸¹ NSFT IMR

¹⁸² CCG IMR

¹⁸³ NSFT IMR

¹⁸⁴ CCG IMR

¹⁸⁵ NSFT IMR

¹⁸⁶ NSFT IMR

¹⁸⁷ Leading Lives IMR

reported by carers, no breathing problems reported.¹⁸⁸ A Community LD nurse expressed concern about the delay in securing an appointment with the gastroenterologist *in view of the abdominal x-ray and gastric transit study results.*¹⁸⁹ A Community LD nurse was advised that Amy was no more a priority than anyone else.¹⁹⁰ The running records up to **31 March** report Amy to be *quieter than usual, sweaty and sleepy/tired.* On **2 April 2013** the DN reviewed again by telephone *bowels open well but loose... advised to continue with medication regime unless informed otherwise.*¹⁹¹ On **3 April** Amy was *not well today so didn't go home to see her parents... a bit chesty, off her food, sweaty and rigid... is she coming down with a cold.*¹⁹² The GP visited the following day and examined Amy, *was extremely wheezy.*¹⁹³ The GP rang 999 and Amy was admitted from the A&E department; noted concern that Crane Court staff did not know how to use the nebulizer;¹⁹⁴ the Leading Lives manager reports that the GP set the nebuliser up without asking the staff to do so.¹⁹⁵ In the Emergency Assessment Unit it was noted */overflow diarrhoea... chest x-ray raised hemi diaphragm (old). Very distended loops of bowel, left lung clear. Admitted to respiratory ward.*¹⁹⁶ The following day she was described as *looking better... Diagnosis: lower respiratory tract infection, chronic bowel dilation and constipation secondary to long gut... Home over weekend if improving.* Amy was reviewed by the dietician who noted *requires increased calories and increased fat diet to maintain weight.* On **6 April** Amy was seen by the junior doctor who noted she was *off oxygen, on antibiotics and improved.* The registrar was consulted and was *happy to discharge, family OK with plan.*¹⁹⁷ Amy returned to Crane Court *arriving at 7.00pm...no explanation why discharged late in the day.*¹⁹⁸ The staff found her *breathing was shallow* and were so concerned that they *received authorisation for someone to sit with her throughout the night.* However during the evening staff rang 111 for advice and an ambulance was called. The paramedics felt that *an infection was still evident* and Amy was re-admitted to hospital at 21.00.¹⁹⁹ The record states that Amy's mother when contacted said *Amy was not seen by a doctor prior to discharge.*²⁰⁰ The Community LD Nurse noted *grave situation; pneumothorax, impaction, splinting of diaphragm – Amy may not survive* and made a *safeguarding referral re Ipswich Hospital for discharging Amy too early/without full investigation.*²⁰¹ [E-mail of 23 May 2015 from Ipswich Hospital NHS Trust states that there was no pneumothorax]. The admission record states *Discuss resuscitation with family* and on **7 April** *not for escalation/not*

¹⁸⁸ CCG IMR

¹⁸⁹ Independent review commissioned by Ipswich and East Suffolk CCG 27 September 2013

¹⁹⁰ Further information NSFT 16 July 2015

¹⁹¹ CCG IMR

¹⁹² Leading Lives IMR

¹⁹³ Leading Lives IMR

¹⁹⁴ NHS England East Anglia IMR

¹⁹⁵ Leading Lives further information

¹⁹⁶ Ipswich Hospital NHS Trust IMR

¹⁹⁷ Ipswich Hospital NHS Trust further information

¹⁹⁸ Independent review commissioned by Ipswich and East Suffolk CCG 27 September 2013

¹⁹⁹ Leading Lives IMR

²⁰⁰ Leading Lives IMR

²⁰¹ NSFT IMR

for Critical Care Unit admission.²⁰² Amy had an abdominal x-ray which revealed faecal loading, dilated bowel loops...bowels opened following phosphate enema. On **8 April**, Amy was reviewed by the respiratory team and it was determined that she should be weaned off oxygen and referred to the gastroenterologist...DNAR in place...Discussion with the parents, who praised the care Amy had in her last 5 weeks, they did not mention and were not aware that end of life care had been discussed with them.²⁰³ On **9 April** the safeguarding referral (concerning the discharge of 6 April) from the Community LD Nursing service was received. The strategy discussion the following day resolved that as the referral related specifically to Amy's previous discharge from hospital, *Adult Safeguarding would take up the referral with the hospital.*²⁰⁴ On **10 and 11 April**, the respiratory review's note for *urgent gastro review* and *still waiting gastro review* respectively. On 10 April, *the gastroenterologist SHO was contacted and SHO to speak to Consultant.*²⁰⁵ Amy was finally seen by the Gastro team on **12 April** when a repeat x-ray shows gross faecal loading, to continue with current laxatives with prn phosphate enemas. A LD Liaison Nurse delayed discharge as this was being considered for 12/04/2013. Over the next four days the plan was *continue with current laxatives ... await gastro review ... plan discharge.*²⁰⁶ On **15 April** the Consultant Gastroenterologist and team undertook the *first full review of Amy 10 days post admission*²⁰⁷ and spoke to her mother - *long discussion...despite multiple laxatives nothing has really changed ?consider surgery.*²⁰⁸ On **17 April** Amy had a CT scan *Results: dilated rectum and sigmoid, significant faecal loading noted.* On **18 April**, the Independent Review notes: *CT shows chronic sigmoid volvulus. Review by surgeon, to have further Arachus enemas at night by catheter and phosphate enemas in the morning. To consider surgery to create a loop ileostomy. Plan for chest x-ray, nebuliser and chest physiotherapy.* However, the Adult Safeguarding record noted that *condition described as fragile. Consultant feels she should not have been discharged. Concerns about GP's earlier diagnosis of asthma. Shortness of breath caused by faecal impaction pushing lungs into chest cavity, not asthma. Bowel is 18cm across – should be 5cm... A cannot have a general anaesthetic due to condition of her lungs.*²⁰⁹ Amy's mother and staff from the care home spent the majority of the day with Amy and addressed her personal care needs as well as diet and fluids. *Very intensive treatments no indication of reactions from Amy, mention of a contracture to her right hand, no mention of physiotherapy to her contracted lower limbs.* Later on 18 April, she was reviewed by the colorectal surgeon who advised *once rectum is cleared, high colonic washouts. If this fails it would be possible to create a loop ileostomy which would then allow antegrade washouts.* However, later that day Amy became tachypnoeic and she was started on IV antibiotics on **19 April**. A Critical Care outreach review

²⁰² Ipswich Hospital NHS Trust IMR

²⁰³ Independent review commissioned by Ipswich and East Suffolk CCG 27 September 2013; Ipswich Hospital states that *Amy was not end of life. DNAR does not signify end of life*

²⁰⁴ Suffolk Police IMR

²⁰⁵ Ipswich Hospitals NHS Trust further information

²⁰⁶ Ipswich Hospital NHS Trust IMR

²⁰⁷ Independent review commissioned by Ipswich and East Suffolk CCG 27 September 2013

²⁰⁸ Ipswich Hospitals NHS Trust IMR

²⁰⁹ Suffolk CC IMR

– pyrexial, no significant changes from last night’s x-ray, urine dip-stick positive, encourage oral fluids.²¹⁰ On **20 April**, Amy was improving. On **22 April**, she was reviewed by Gastro Consultant – “looks unwell, plan for oxygen nebulisers, iv antibiotics, iv fluids, bloods and chase result of msu”. On **23** and **24 April**, the hospital notes recorded a discussion with surgical team – “as bowels opening not much further input, surgical review to be arranged” and awaiting surgical review respectively. Also on 24 April, Suffolk CC noted: Historically on regular laxatives but not administered correctly as care staff misinterpreted leakage of bowel overflow as loose stools. CT scan shows constipation high up placing pressure on diaphragm, compressing lungs and causing respiratory function loss... Decision of MDT [multi-disciplinary team] meetings is that Amy is not to leave hospital until condition is stabilised and she is no longer constipated.²¹¹ On **25 April**, it was agreed with a LD Liaison Nurse, Adult Safeguarding Officer, Hospital Social Worker, Ward staff Nurse, Leading Lives Director, Crane Court support worker that Amy will not be discharged until constipation is cleared. Continuing Healthcare checklist to be completed once Amy is further recovered. Discussion with Amy’s family on her on-going care. Concerns over Amy’s contracted limbs.²¹² On **26 April**, abdominal x-rays and bloods were repeated and Amy was awaiting surgical review. On **30 April** it was noted that Amy was developing chest infection. To chase surgical review ... Concerns that Amy would not survive surgery, decision still to be made by surgical team. On **1 May 2013** she was reviewed by the surgeons, nine days after a surgical review was first requested:²¹³ try more enemas, x-ray after bowel motions... not for surgical intervention... opening bowels every day. It was noted that Amy was not a surgical emergency not for surgical intervention. A further surgical review on **2 May** noted bowels working well with enemas... x-ray shows much less faecal loading ...think stoma would be appropriate. Second opinion required. It was also noted that Amy was becoming sore on perineum...massively enlarged colon...markedly reduced lung volume due to splinting. Amy was observed to have a fixed stare, she was sweating and constantly shook and her abdomen was noticeably distended. She was on regular oramorph for pain relief. On **3 May** the SALT assessed and noted at high risk of aspiration. For nasogastric tube. Later that day, the medical review noted nil by mouth today due to unsafe swallow. Not had normal anticonvulsant medication therefore seizure activity evident. Urgent review... epilepsy medication to be given rectally. Following seizures Amy lost her swallow reflex, and was not alert. Unclear from discussion with the family how much they were really aware of Amy’s poor prognosis family agreed not to escalate to ITU, family did not want invasive treatment, commenced on the Liverpool Care Pathway. On **4 May**, Amy was sleeping heavily did not respond to touch or voice. Urine dark, no bowel movements. On **5 May**, Amy was treated for aspiration pneumonia, continue antibiotics, oxygen and bloods. Not for escalation as per plan. Remains unwell, MEWS at 7²¹⁴ deteriorating. Patient appears septic, peripherally shut down, cold, clammy. Amy’s Mother left in the evening having been with her

²¹⁰ Independent review commissioned by Ipswich and East Suffolk CCG 27 September 2013

²¹¹ Suffolk CC IMR

²¹² Independent review commissioned by Ipswich and East Suffolk CCG 27 September 2013

²¹³ Independent review commissioned by Ipswich and East Suffolk CCG 27 September 2013

²¹⁴ A score of five or more is statistically linked to increased likelihood of death or admission to an [intensive care unit](#)

*all day. She was called back and she then remained all night. Amy was sleeping heavily, seizure occurred. On **6 May** the Crane Court staff record that Amy is unresponsive to voice and touch. The hospital record notes that currently being treated for aspiration pneumonia. All meds by NGT [nasogastric tube]. Patient not for escalation to critical care. Later that day the doctor discussed with Amy's mother that she was likely to die today. Amy died on **7 May** with her mother by her side. Amy's death certificate states: Aspiration Pneumonia; Faecal Impaction; Cerebral Palsy; and Epilepsy.*

Section three: Analysis

Multi-disciplinary working

17. Agencies and professionals involved with Amy were:

- Papworth Trust (to November 2011) and Suffolk CC (from November 2011) which became Leading Lives (from July 2012) as a divested social enterprise, care providers
- Suffolk CC, commissioner of care;
- GP practice, including primary care nurse practitioner to monitor asthma;
- District Nurses;
- Acute hospital services – gastro-enterologist, A&E, respiratory team, dietician, LD liaison nurse;
- Community LD Nurses, SALT and physiotherapist in Norfolk and Suffolk Foundation Trust, the mental health and learning disability NHS provider;

18. Although many agencies were involved, there is little evidence of joined up working or multi-disciplinary planning. The GP was the main co-ordinator of care but had no involvement in drawing up or reviewing the Health Action Plan - which did not feature in Suffolk CC records either. Suffolk CC's electronic Care First 6 system notes that *health action plans and person centred plans ... are created for Amy but there is no indication in the record of the content of these plans, who holds them or how they are used.*²¹⁵ This is despite the fact that Health Action Plans were introduced in response to the *Valuing People* White Paper. Health professionals did not attend reviews. DNs had no access to GP held records and continued to use their own records; although GPs had access to these via SCH System One notes, this was at an early stage of development and there is no evidence that these were accessed for information purposes. There was no transfer of the DNs' information to the GP practice. DNs were not invited to review meetings but did have telephone contact with the Community LD nursing service.

19. Amy's various admissions to Ipswich Hospital could have been triggers for multi-disciplinary review and action planning. The first evidence of this was in November 2012 when the Learning Disability Liaison Nurse visited Amy in Ipswich Hospital and referred her to the CLDT. A Community LD Nurse visited Amy at Crane Court and advised the staff of the need for regular bowel monitoring, following this up with a safeguarding alert as she was concerned at the staff's lack of understanding of the significance of Amy's constipation – they thought the hospital admission was because of pneumonia. This was a reasonable assumption given that Amy had been treated for a chest infection earlier that month; they had called an ambulance because of Amy's breathing difficulties; and they had not been advised of the link with constipation made explicit in the discharge letter from the hospital. Amy's parents believe that the support staff were not treated as professionals who were knowledgeable about Amy and were regarded merely as "chauffeurs." The Community LD Nurse made reference to concerns about *basic care* which in this context must have referred to meeting Amy's specific health care needs relating to her constipation problems; there is no suggestion that the Leading Lives staff were not meeting other basic care needs related to hygiene, diet

²¹⁵ Suffolk CC IMR

and social relationships for example. Although a Community LD Nurse arranged a professionals meeting at Crane Court on 25 March 2013, no other health professionals (GP or DN) attended.²¹⁶ On that day a Community LD Nurse recorded that fluid, nutrition and medication charts were *all satisfactory*. Nonetheless, a multi-disciplinary meeting would have made everyone aware of the seriousness of Amy's bowel problems, agreed appropriate actions and allocated responsibilities. Such a meeting might also have prompted the District Nursing service to be pro-active in monitoring Amy's bowels; they tended to rely on Crane Court staff's reports in telephone discussions rather than visits and physical examinations.

20. Following Amy's hospital stay during November 2012, her parents believed that she would be followed up by the hospital and seen again. However, irrespective of the LD Liaison Nurse's referral to the Community LD Nursing service, which took on the case at that point,²¹⁷ this did not happen.
21. A further example of poor oversight in acute care occurred on 10 January 2013 when Amy went to A&E by ambulance, following difficulty in breathing whilst in the physiotherapy department at CLDT premises. A Community LD Nurse accompanied her and stressed to staff the possible links between breathing difficulties and constipation. Despite this, Amy was treated with a nebuliser and discharged home the same day, with the explanation that if she *came in with breathing difficulties that is what would be treated*.²¹⁸ This may be understandable had Amy not required in-patient treatment some six weeks earlier (see 20 November 2012) for *severe faecal impaction, shortness of breath secondary to splinting of diaphragm*. Also, this was shortly after a man with learning disabilities, James, had died in the same hospital from complications arising from severe constipation. A diagnostic imaging letter received from Ipswich Hospital on 11 January by Suffolk CC described *faecal loading of rectum, damage to diaphragm and lung*²¹⁹ yet this information does not appear to have informed Amy's treatment when she was later admitted to Ipswich hospital in April 2013. Further, this letter was not received by the GP practice,²²⁰ although IT would have received the discharge letter via the electronic system.
22. The intervention of a Community LD Nurse in December 2012 was the first contact between the LD/MH Trust and the GP since Amy was reviewed by a psychiatrist in February of that year at the GP's request. Amy was seen in psychiatric out-patients in February 2008 and was discharged in May 2008; this withdrawal of the wider specialist learning disability service following the transfer from the SMHPT to the Papworth Trust took place *without any notification to the GP*.²²¹ There was then no contact until November 2011 when Amy was referred at the GP's request; she was seen again in February 2012, then no contact until December 2012, following admission to Ipswich Hospital. The Community LD Nursing service continued to raise concerns with the GP practice about the understanding of Crane Court staff of Amy's bowel problems and their ability to monitor and manage them. A Community LD

²¹⁶ NSFT further information

²¹⁷ Further information NSFT 16 July 2015

²¹⁸ Suffolk CC IMR

²¹⁹ Suffolk CC IMR

²²⁰ NHS England East Anglia further information

²²¹ NHS England East Anglia IMR

Nurse had two telephone conversations with the DNs who described the engagement and support offered from their service *as an assurance of continued monitoring and advice*.²²² Why did the Community LD Nursing service, District Nursing and primary care not meet to compare notes and share information, particularly as the DNs did not attend the safeguarding strategy meeting in January 2013 and may not have fully understood the multi-agency concerns? Information from NSFT suggests that the CLDT was commissioned to provide a specialist service to people with learning disabilities and mental health problems and was not a universal learning disability service; it does not appear to have a role for people with learning disabilities who may have additional complex health needs. The Community LD Nurse was not a Care Co-ordinator for Amy – the primary responsibility for her health care lay with the GP – but the Community LD Nurse clearly believed that she had a role in following Amy up after her discharge from hospital and endeavouring to make sure that her health needs were better met, even though the Trust management state that this was beyond her remit.²²³ According to NSFT, the difficulties lay in bringing the parties together, their reliance on the hospital's LD Liaison nursing service and the lack of information provided directly to the support staff by Ipswich Hospital.²²⁴ However, there remains a question over how the service was commissioned from NSFT.

23. Amy had two visits to A&E following her admission in November 2012 and prior to the safeguarding meeting – yet the strategy meeting did not trigger a multi-disciplinary review of her care plan to determine whether or not her health needs were being met. This is despite the fact that the GP stated at the strategy meeting that, in his view, Amy *required nursing care*. Amy's mother says she always accompanied her daughter to see the GP, although this is disputed by the GP practice. She told the GP that she believed Amy didn't receive the same kind of service as others. She recalled that the GP disagreed stating "No, no, no" to which Amy's mother asserted, "Yes, yes, yes" – which is also disputed by the practice.²²⁵
24. In November 2012, Amy saw the dietician who recommended continuation of the full fat diet. It was noted that Amy tended to be constipated but that this was managed by medication. At the further appointment on 19 February 2013, this dietary advice was repeated. It was not queried by the GP practice, despite the safeguarding strategy meeting one month previously and the known concerns about Amy's constipation and the hardness of her abdomen. The recommended diet, along with a sedentary lifestyle and considerable periods spent lying down on the recommendation of the physiotherapist, are likely to have exacerbated her constipation.
25. The safeguarding investigation of January 2013 was allocated jointly to the police and to adult social care at the request of the latter *in light of a recent death due to constipation*.²²⁶ This would suggest that concerned vigilance by all agencies should have followed with specific, detailed and continuous attention to Amy's health needs and to the abilities of the support

²²² CCG IMR

²²³ NSFT further information

²²⁴ NSFT further information March 2015

²²⁵ Further information NHS England 16 July 2015

²²⁶ Suffolk Police IMR

staff to monitor and record her bowel movements appropriately. Yet there is little evidence that any single professional or agency took the lead in ensuring that Amy was safe. Furthermore, the expectation of support staff “monitoring” Amy’s bowels and general health was arguably deficient insofar as they were not included in the clinical decision-making and they received no instruction concerning how, what or with what frequency they were to monitor. The GP relied on the DNs and the support staff; the Community LD Nursing service was attentive but did not bring people together to formulate a clear bowel management plan; the DNs did not consult the GP’s electronic record or provide feedback to the GP and relied mainly on telephone contact with the support staff. Finally, social services did not convene a review meeting to assure themselves that Amy’s needs were being met and that there was no risk of a further death.

Commissioning and contract monitoring

26. Prior to 2008, when Suffolk CC took over responsibility for commissioning the care service at Crane Court, the service was provided by the SMHPT and Amy was technically an in-patient. The change took place as part of Phase 1 of the NHS Campus Re-provisioning and the initial service provider under contract to the county council was the Papworth Trust. Amy was not the only individual affected by the change of provider and it would be expected that the county council would have a contractual arrangement with the Papworth Trust for the service as a whole. The contract for the provision of care and support at Crane Court set out a baseline service level, including *support in the administration and management of medications and support with health needs*.²²⁷ Amy’s parents believe that their involvement in regular reviews, explicitly addressing her health, would have enabled them to provide vital information. The main focus of the contract is on cost and volume. The county council’s assessment of needs before the transfer of care set out the requirements for the new provider regarding Amy’s individual support, including health, mobility, social, financial and spiritual needs. There were full service reviews at three, six and 12 month intervals in line with usual practice, held on 15 July 2008; 4 November 2008; and 6 May 2009. Thereafter the contract stipulated that the provider should establish a Joint Advisory Group (JAG) as the main mechanism for reviewing the service with key stakeholders; these were housing reviews as opposed to individual tenant reviews. The first of these did not take place until 19 December 2011, a gap of two and a half years; further JAGs were held on 26 April 2012, 8 August 2012 and 27 March 2013.²²⁸
27. In 2011 the Papworth Trust served notice on the contract with Suffolk CC because of *financial difficulties*²²⁹ and between 1 November 2011 and 1 July 2012 the service was managed directly by the local authority in preparation for the transfer to Leading Lives, a social enterprise set up specifically for the purpose. A contract was in place with Leading Lives and this was monitored through quarterly monitoring reports and six weekly contract monitoring meetings to ensure that the provider was fulfilling its contractual obligations. In addition, a

²²⁷ Suffolk CC IMR

²²⁸ Suffolk CC further information (2)

²²⁹ Suffolk CC further information (3) 22 May 2015

*senior Governance Board meeting on 13 December 2012 was attended at Director/ Assistant director level.*²³⁰

28. However, it does not appear that the specification for the service or the ensuing contract set out in detail how the health care needs of tenants were to be met, beyond support to *enable them to improve and maintain health and wellbeing e.g. support to access and sustain engagement with primary medical care and treatment services.*²³¹ Leading Lives clearly fulfilled these requirements, taking Amy regularly to see the GP or other primary care practitioners, but Amy (and presumably other tenants too) had complex health needs for which Leading Lives were not registered to provide health interventions. There was no explicit requirement that Amy's Health Action Plan be developed and shared with health professionals, despite being a county-wide inter-agency initiative. This is particularly significant given that reviews of Amy's care and support through the care management process were inadequate. As noted above, neither the Resettlement Team nor the area team undertook further reviews after May 2011, irrespective of the discontinuity arising from the increasing use of agency staff in 2013. The county council had no way of knowing whether Amy's health care needs were being met appropriately.
29. Both social care providers will have been registered with the regulator (CSCI and latterly CQC) and dialogue between them and the local authority commissioner is an important mechanism for sharing any concerns about service provision. Further information about the history of inspection of Crane Court would be helpful; was there anything of note when services were re-registered by CQC in 2010 and was the supported living scheme inspected individually or did inspectors visit the provider's offices? It is unclear whether the county council took note of inspection reports for the care providers routinely, but records confirm that *at the quarterly Information Sharing meeting with CQC in January 2013 while the inappropriate hospital discharge of Amy was discussed, no concerns were raised by any of the multi-agency personnel around the table about the quality of care provided by Leading Lives at [Crane Court].*²³²
30. The records suggest that there was confusion amongst some agencies about the status of the accommodation at Crane Court. The district nursing service, the learning disability nursing service and the acute hospital all referred to *care home* and *care staff* in their records; it was in fact a supported housing scheme with firstly, the Papworth Trust, and then later Leading Lives, as the registered domiciliary care providers. Although the GP practice was informed of the change from the NHS to a social care provider in 2008, the significance of this change was not understood nor the implications fully explored with them. The GP told the safeguarding strategy meeting in 2013 that he may have *made different decisions if he had been aware that the information provided was gathered from non-medical staff.*²³³ However it is clearly

²³⁰ Suffolk CC further information (2)

²³¹ Suffolk CC IMR

²³² Suffolk CC further information (2)

²³³ Suffolk CC IMR

documented that *GPs in Suffolk and the GP for all [Crane Court] residents were written to in 2008 and asked to note on all individual medical records that care and support had now transferred to a social care provider.*²³⁴

31. In January 2013, Ipswich Hospital sent a copy of the diagnostic imaging report to Suffolk CC, the explanation being that this was sent *to the care provider responsible for Amy's care and this was not considered an IG [information governance] breach but [an example of] partnership working.*²³⁵ Suffolk CC was not the care provider; if Ipswich Hospital had taken this approach to information sharing more consistently, and forwarded information to the actual care provider, then Leading Lives might have received vital information about Amy's bowel condition and treatment which would have alerted them to her health support needs.

Decision making with Amy and her family

32. Amy's family were in regular and frequent contact with her throughout her residence at Crane Court. Amy's parents recalled that after their daughter's weekly visits home they always reported (i) Amy's bowel movements to the staff supporting her in terms of the frequency and consistency of bowel movements and (ii) her appetite and food intake. They expected that this would be noted and acted upon as necessary. When her parents went away, Crane Court always asked for, and were given, the contact details of Amy's brother. As Amy's mobility decreased and she was unable to transfer onto a toilet, staff began to put her in incontinence pads. As a consequence, feedback was no longer possible since Amy's parents were no longer as familiar with their daughter's bowel movements. In preparation for the change of provider, a social worker carried out a Mental Capacity Assessment in October 2007 which determined that *Amy is unable to understand information relevant to the re-provision process ... does not require IMCA involvement to support her with the decision ... as she is supported by active family.*²³⁶ However, there is no documented evidence of how this view was reached and there is no supporting Best Interests Decision process. This is the only documented Mental Capacity Assessment, although reference is made on several occasions to Amy's lack of capacity. Her family were communicated with in writing about the transfer and all relatives were offered face to face meetings. This is not to suggest that Amy's family could not advocate on Amy's behalf as they did so on many occasions. Rather it illustrates the lack of regard for whether or not Amy was able to make her own decisions and if not, how such decisions would be made in her best interests.
33. Amy spent a day with her family most weeks, sometimes twice a week. There is evidence that her family were regularly involved in her care, accompanying her on occasions to the GP surgery and to hospital appointments, and were present at those reviews that took place. During Amy's last hospital admission, her family were involved in the decisions about her care and treatment and whether or not resuscitation would be appropriate.

²³⁴ Suffolk CC further information (2)

²³⁵ Ipswich Hospitals NHS Trust further information

²³⁶ Suffolk CC IMR

34. Given the many documented occasions when Amy was subject to invasive procedures such as rectal examinations and enemas, as well as needing to be taken to a quiet area when she was agitated, it is concerning that there were no assessments of her mental capacity or use of a Best Interests Decision process or Deprivation of Liberty Safeguards by the Crane Court staff or by the various clinical professionals responsible for her care, including specialist learning disability nurses, DNs, acute hospital staff and primary care.

Amy's known health problems and how they were monitored

35. Amy had a long history of constipation which was well documented in the SMHPT patient record that began in 1988. She was treated with laxatives and enemas as required, along with monitoring of her fluid intake and vigilance to the frequency of her bowel movements. This was reiterated in 1998 when she became less mobile. In November 2007, Amy's care plan held in the SMHPT stated that she was prone to put on weight and needed low fat diets when possible. She was to be weighed monthly and referred to the dietician if her weight was not maintained. Her Essential Lifestyle Plan stated that she was *obese* and needed to be encouraged to lose weight.²³⁷ This is in stark contrast to the concerns about her weight loss during the last three years of her life and the apparent inability of the Crane Court staff to have Amy weighed regularly to monitor this, despite their efforts to do so, that is, she was taken to an equipment provider to be weighed on a single occasion.

36. During 2008 Crane Court transferred from the NHS (SMHPT) to Papworth Trust, managed under contract to Suffolk CC. This was primarily a social care service and staff were not qualified nurses or trained in how to manage people with complex health needs. Prior to 2008, Amy had technically been an in-patient of the SMHPT, cared for by qualified nurses. Amy's comprehensive care plan identified cerebral palsy, learning disability, epilepsy, asthma and constipation, with the need for regular continence monitoring; this information was confirmed at the case review held in March 2010. Despite this, it is unclear whether or not the Papworth staff paid attention to Amy's bowel difficulties. There is no evidence within the Papworth Trust Combined Risk Assessment and subsequent care and support plans that staff within the organisation recognised the need to routinely monitor Amy's bowel movements or take remedial action if she did not open her bowels for more than three consecutive days. *This omission is perpetuated throughout subsequent care plans and supporting documents. Consequently there was no current information about Amy's bowel management passed to SCC/Leading Lives in November 2011 and the SMHPT documentation was filed in Amy's 2008 care records. It appears such records were only formally requested from 12th December 2012 after Amy's hospital discharge 25th November 2012.*²³⁸ It is unclear whether Papworth Trust staff were given explicit instructions to monitor and record Amy's bowel movements, so it is not possible to infer anything about her bowel health from the spasmodic recording of bowel movements in September 2011 and April 2012, for example. It should be noted that about a third of the Papworth Trust staff transferred employment to Suffolk CC with the service, only two of whom had also previously worked for the NHS, so there was limited continuity of knowledge about Amy and her bowel health needs.

²³⁷ Leading Lives IMR

²³⁸ Leading Lives further information

37. The GP practice was informed of the transfer of responsibility, but the change to social care from the NHS [i.e. the transfer of nursing oversight of the home to the GP and Community Health Services] was not made explicit and possibly reflected an assumption about the knowledge of primary care colleagues, so the GP practice did not appreciate that Amy was receiving a different level of care. In addition, the GP noted *there was no one person who I could turn to help with the specific difficulties we were having ... no-one in the home, which didn't have a clear leadership structure ... and no regular point of contact. I rarely saw the same member of staff twice when called to see Amy and the information I was given was sporadic and incomplete.*²³⁹
38. On 22 September 2010, Amy had a health check – then none for two years. Her non-attendances on 1 November 2011 and 22 November 2011 were not followed up, a matter of concern given her complex health needs. The practice policy at the time in relation to people with learning disabilities was to issue an invitation letter, send a reminder if there was no response within three weeks, then move the person to the following year's list if there was still no response; there was no attempt to find out why they did not attend or to query whether the person had mental capacity to make the decision not to attend. This invitation went out as Suffolk CC was taking over from Papworth – unbeknown to the GP practice – with no handover notes from Papworth, so staff were probably unaware of these appointments. However, Amy had an asthma check up with the nurse practitioner on 6 December. There is no evidence that her other health needs were explored; presumably her non-attendance for her health check the previous month would have been on the patient record?
39. On 18 January 2011, Amy attended Ipswich Hospital for an abdominal ultrasound. Although the Crane Court staff noted that she was *a bit bunged up* there is *no record of advice having been offered to staff by the hospital or Papworth Managers about corrective action.*²⁴⁰ While sonographers would not advise treatment, she was reviewed a week later by the gastroenterologist who had a discussion with Amy's mother and a carer.²⁴¹
40. On 3 May 2011 the Consultant gastroenterologist noted continuing difficulties of weighing Amy. Accessing facilities to weigh her was an unresolved long term issue during the time both Papworth Trust and Leading Lives were the care providers at Crane Court. After April 2010, when her GP was informed of a weight loss of 9.3kg from 64.3kg to 55kg during the previous six months, it is remarkable that there no sustainable or appropriate means of weighing Amy was found over the following three years. In September 2010 it was noted at her health check that she would be weighed in Crane Court using *sitting scales* and her weight would *be phoned in*, yet there were no such scales in the home. Similarly, Suffolk CC noted in January 2011 that staff were *advised to make regular GP visits to enable Amy to be weighed*, even though the GP surgery did not have sitting scales either. Her weight is recorded four times since April 2010, three within a four month period in 2011: on 24 March (60kg) at CLDT premises; on 24 May (49kg) at the gastroenterology clinic; and on 22 July (51.4kg) at Ipswich Hospital. None

²³⁹ Further information NHS England 16 July 2015

²⁴⁰ Leading Lives further information

²⁴¹ Ipswich Hospital further information

of this information is recorded in the GP record. It is unclear why this pattern was not sustained. At the instigation of the Crane Court staff, Amy was weighed at Felgains, a supplier of disability equipment in Ipswich (which was not an appropriate long-term solution), on 12 February 2013 when she weighed 47kg, a reduction of 4.4kg since the last recorded weight two years previously.

41. In summary, Amy's weight ranged between 64.3kg – 47kg
- September 2009, 64.3kg [10st. 1lb]
 - April 2010, 55kg
 - September 2010, *weight loss; no obvious cause identified*
 - January 2011, *Amy is having hospital investigations due to loss of weight*
 - March 2011, 60kg
 - May 2011, 49kg [7st.10lb]
 - July 2011, 51.4kg
 - September 2012, *concern is weight loss*
 - November 2012, *losing weight over 18 months*
 - February 2013, *49kg uncertain whether Amy is losing or gaining weight*
 - April 2013, *dietician...noted requires increased calories and increased fat diet to maintain weight.*
42. In November 2011 responsibility for the service at Crane Court transferred from the Papworth Trust to SCC/Leading Lives but with no formal written or verbal handover of information; about a third of the staff were transferred under the TUPE arrangements²⁴² so there would have been some continuity of care. However, support planning by Leading Lives was based on current records and care plans which did not indicate that Amy was prone to constipation and needed specific bowel monitoring;²⁴³ information concerning her bowel management seems to have got lost. The GP practice was not informed of the change of provider. Further, Leading Lives, like the Papworth Trust, was not a provider of health care; it was registered with CQC to provide domiciliary care, not health care. The significance of this and the implications for monitoring the health of tenants with complex needs such as Amy seems not to have been fully understood by people's immediate families, by social care commissioners, by specialist learning disability services or by primary care. There was apparently no planned growth in specialist Community Health Services to provide expert advice and support to people outside hospital settings such as Amy, as they grew older or as their health needs became more complex.
43. It is apparent from the records that the GP practice was attentive to Amy, visiting when requested to do so; seeing her regularly in the surgery at the behest of Leading Lives staff; carrying out regular asthma reviews; referring for tests and specialist advice when needed; and giving instructions to Leading Lives staff about medication and bowel monitoring once Amy's serious problems with constipation were made explicit following her hospital admission in November 2012. The GP attended the safeguarding strategy meeting in January 2013 – commendable given the usual difficulties of GPs in doing so – and his response was

²⁴² Transfer of Undertakings (Protection of Employment) Regulations 2006, designed to protect employees' rights when the organisation or service they work for transfers to a new employer

²⁴³ Leading Lives IMR

prompt and appropriate, although he remained unconvinced about constipation being the main problem and pursued further investigations by the respiratory physicians. However, the practice did not always follow up instructions to other staff pro-actively. There is no evidence that the GP sought feedback from District Nursing about the effectiveness of the daily enemas prescribed for two weeks in November 2012 – none of which Amy received. This was despite having access to Suffolk Community Health System One notes where nursing decisions were recorded. Neither did the GP seek information about the effects of the new medication prescribed in March 2013, about which he had asked staff to report back within a week; given that there is no record of this request in Amy’s care record in Crane Court, this was particularly significant. There was still no feedback three weeks later.

44. Amy had a Health Action Plan, first referenced in 2009, and in March 2011 this noted that she had *asthma, epilepsy, cerebral palsy and oedema*. The GP was not involved in drawing up this plan and had no record that one existed;²⁴⁴ there was *no health or social care agreement for the HAP to be used as part of undertaking a health check*,²⁴⁵ even though Health Action Plans had been introduced by the Suffolk Disability Partnership Board, with specific investment,²⁴⁶ as recommended by the *Valuing People* White Paper.²⁴⁷ However, implementation was patchy, with variable practice across organisations, reflecting a lack of strong multi-disciplinary working and different agency perspectives of what was required.²⁴⁸ The Health Action Plan could have provided the focus for multi-disciplinary planning for Amy and made explicit both for the Crane Court staff and for all the professionals involved in her health care, their role, who to consult for advice and how to raise concerns.
45. On 25 January 2012, a Person-Centred Review was held; although this included a social worker there is no reference to this review in Suffolk CC’s IMR, even although this was held two days after the safeguarding referral concerning missing money. Nothing specific was stated about Amy’s ongoing health needs other than the need for a healthy diet and regular medical checks.
46. On 23 February 2012, Amy was admitted to Ipswich Hospital via the A&E department and the discharge letter sent to the GP practice noted *marked faecal loading seen in the rectosigmoid*.²⁴⁹ This was the first clinical indication of serious constipation. The GP was of the view that faecal loading was not an uncommon finding in many abdominal x-rays. The practice notes record that Amy was *‘admitted with possible aspiration pneumonia’*. So although the hospital discharge letter is the first indication in the GP record of the possibility of risk through marked faecal loading, *there is no note in the patient record of marked faecal loading*.²⁵⁰

²⁴⁴ See Grant, G. and Ramcharan, P. (2007) *Valuing People and Research: The Learning Disability Research Initiative* London: Department of Health

²⁴⁵ Further info NHS England

²⁴⁶ SCC further information

²⁴⁷ *Valuing People: A new strategy for Learning Disability for the 21st Century* Department of Health, 2001

²⁴⁸ SCC further information

²⁴⁹ NHS England GP practice notes

²⁵⁰ Further info NHS England

47. During 2012 there were four occasions on which Crane Court staff recorded that Amy had *not* had a bowel movement;²⁵¹ on 27/28 February, while Amy was in hospital *not had a bowel movement for two days*; on 21 April; on 8 August; and on 29/30 September. This suggests that although staff may have been attentive to whether or not Amy had a bowel movement, their recording was inconsistent and their monitoring did not necessarily lead to any further action.
48. Constipation was identified as a serious health concern for Amy during her admission to Ipswich Hospital during November 2012, although the Crane Court staff were unaware of the content of the discharge letter, which specified *gross faecal loading*, as this only went to the GP. It is worth noting that she was admitted to A&E a week after “James” – a man with a learning disability - died in the same hospital. He had been admitted through A&E on 14 November with a distended abdomen and undergone surgery to remove impacted faeces. A mini-audit following his death alerted the LD liaison nurse about Amy, resulting in the contact with her mother and a carer. Following Amy’s discharge on 25 November, the GP followed the hospital’s advice and prescribed daily enemas up to 14 December. According to the GP practice, the DN was given access *at a medium level* to the GP surgery’s patient record system on 30 November. This would have *enabled them to read the entries; make their own entries; but not alter notes made by other people.*²⁵² However, further information from Suffolk Community Health states that *The Practice did not have a sharing out enabled to SCH to allow the DN team to access and review the patients GP record;*²⁵³ this was further confirmed by Suffolk Community Health on 20 May 2015.²⁵⁴ It also confirmed that communication between General Practice and district nursing occurred either by telephone or via the daily (Monday to Friday) visits to the surgery.
49. The DN’s patient contacts during this two week period are as follows:
- 26 November: decided no enema was necessary following rectal examination
 - 29 November: decided no enema was necessary following rectal examination and information from staff about bowel movement
 - 3 December: telephone review, informed by staff that *bowel movements were regular*
 - 11 December: telephone review, informed that *bowel movements were sluggish at times, medication being given.*
50. So, during the period for which the GP prescribed daily enemas – which should have totalled 19 – a DN visited twice during the first four days, held two telephone reviews and administered no enemas at all. There is no evidence that the DN informed the GP of these facts or consulted the surgery’s patient record system. Suffolk CH stated that *the decision not to administer the enema was based on clinical examination and information provided by the carers.*²⁵⁵ The DN visited again on 18 December at the request of staff to examine Amy’s skin condition; there was no mention of her bowels. There was then no further contact until 31

²⁵¹ Leading Lives further information

²⁵² NHS England East Anglia IMR

²⁵³ Suffolk CH further information

²⁵⁴ E-mail to NHS Ipswich and East Suffolk CCG

²⁵⁵ E-mail 20 May 2015

December, when the DN visited and did a rectal examination because the staff were concerned about constipation. There are no entries from the DNs on the GP patient record system. On 26 February 2013 – after the safeguarding strategy meeting which had considered Amy’s serious constipation problems – the DN suggested that her laxatives be reduced following a telephone review when Amy was described as *having her bowels open 3-4 times per day* and was *at risk of getting very sore*.²⁵⁶ The request was conveyed via Crane Court staff on the telephone to the GP, who agreed but asked the staff to be aware of signs of overflow. There is no evidence that the DN discussed the matter directly with the GP or ascertained the seriousness of Amy’s bowel problems.

51. Despite Amy’s known history of constipation, dating back to 1988, Leading Lives were not asked to monitor Amy’s bowel movements until 12 December 2012; the first mention of a bowel record in Crane Court is during that month. Following the Adult Protection investigation and meeting in January 2013, Leading Lives implemented two protocols specific to Amy’s care and support. These were an Asthma Support Plan and an Elimination Support Plan or Bowel record. The latter required staff to monitor daily bowel elimination and fluid intake and on a good practice basis was subsequently implemented across all Leading Lives supported living services.²⁵⁷ However, it is not possible to infer from the daily records whether the staff had a good understanding of the difference between loose bowel movements and overflow diarrhoea because of impaction. It is worth noting also that the health professionals involved did not always understand or agree on Amy’s symptoms; even at the safeguarding strategy meeting, the GP was still not convinced that her problems were related to constipation rather than respiratory difficulties, despite hospital discharge letters detailing this on two separate occasions, and intended to seek further advice from secondary clinicians.
52. On 4 January 2013 Amy visited A&E at Ipswich hospital at the GP’s request. An x-ray showed *faecal loading and damage to diaphragm and lung*, providing further evidence of severe constipation problems after the safeguarding referral from 12 December.²⁵⁸
53. During January to March 2013 there were delays in prescribing and administering the magnesium hydroxide laxative to Amy. However, the GP was relying on reports from DNs, who in return relied on Crane Court staff, that Amy was having regular bowel movements and there were no concerns; the DN asked for laxatives to be reduced on two occasions, the second of which the GP refused. The DNs did not see Amy for a month between 19 February and 19 March, relying on four telephone contacts with Crane Court in between, and following the visit on the latter date did not visit Amy again before her admission to hospital on 4 April. This was despite a safeguarding referral and strategy meeting that explicitly cited specific concerns about poor bowel care; an undertaking at the strategy meeting that the safeguarding lead for Community Health Services would visit jointly with the County Council’s safeguarding senior to provide support; a phone call from a Community LD Nurse advising that an x-ray had confirmed that Amy was experiencing overflow diarrhoea because of severe impaction; and a change in medication specifically to assist Amy’s bowel problems.

²⁵⁶ CCG IMR

²⁵⁷ Leading Lives further information

²⁵⁸ See Footnote 122

54. On 19 February 2013, Amy was seen by the dietician, a follow up to her appointment in November 2012. This was after growing concerns about Amy's constipation. The GP did not follow up the dietician's advice about diet i.e. double cream and milk powder in porridge and a daily milk shake. The NHS England IMR comments that there is no mention in the dietician's assessment or plan of the impact or relevance of diet to constipation. The Elimination Support Plan introduced on 13/01/13 stated that the document was drafted in response to the Adult Protection Investigation. *It states that Amy has Aggie Flynn²⁵⁹ on her cereal every morning and that she has a menu which includes a good balanced diet with plenty of fibre. She must have fluids and there is a chart to record these.*²⁶⁰ Crane Court staff did follow up the dietician's advice, adding cream to her drinks and cereal, for example.²⁶¹ However, the dietician was working in isolation and this again illustrates the lack of multi-disciplinary joined up working on Amy's behalf.
55. At the safeguarding strategy meeting on 15 January it was agreed that a continuing healthcare checklist should be completed for Amy *to look at the possibility of additional funding which could be utilised to support Amy's current placement.* Although the checklist was initiated by the social worker who attended the strategy meeting and faxed over to the CCG for completion, there is no evidence that this resulted in a full continuing health care assessment or indeed that the social services area team was asked to contribute to such an assessment.²⁶² There may also have been a case for a retrospective assessment, given that Amy's extensive health care needs were not new. Given the GP's concerns about whether Amy's complex health care needs could be met in a social care setting, which are well documented in the notes of the strategy meeting, it is surprising that this assessment was not followed up; this could have provided a further opportunity to review and document Amy's very specific needs in relation to her bowel health and provide additional support if needed.
56. Finally, there were several occasions when Amy's skin broke down: *bedsores* (April 2011); *bottom breaking down* (June 2011); *broken area left buttock* (August 2012); *bottom very sore and some broken areas* (both in December 2012). Such skin damage, especially where the skin is broken, must have been very painful for Amy, who was unable to verbalise that she was in pain or discomfort. Her increased risk of pressure ulcer damage through spending many hours sitting in a chair or lying on the bed does not appear to have added urgency to the replacement of her bespoke wheelchair that had gone missing sometime in 2011.

Care co-ordination and case reviews

57. The requirements for the new provider for Crane Court set out by the County Council in September 2006 included *a regular assessment as part of her bi-annual review to monitor any changes in Amy's physical and general health.*²⁶³ Such regular reviews did not materialise. Suffolk CC's policy regarding assessment and review is set out in a series of documents

²⁵⁹ A blend of apple, orange and sugar name after its inventor

²⁶⁰ Leading Lives further information

²⁶¹ Leading Lives further information

²⁶² Suffolk CC further information

²⁶³ Suffolk CC IMR

entitled 'Access and Partnerships Good Practice Guidance' and states that *all customers should receive a planned review at least annually.*²⁶⁴ Reviews of Amy's care were held on 3.11.08, 12.3.10 and 4.5.11 by the Suffolk CC Resettlement Team, although Amy would also have been on the area team's case list with the Resettlement Team appearing as support workers, not case managers. They had a particular role in overseeing the Section 75 re-provision funds, which caused some confusion in January 2011 when an application for further funding was made. Annual reviews should be carried out by area teams but the Resettlement Team retained responsibility beyond the first year of transfer as the property at Crane Court was refurbished in December 2010 (residents returned there in February 2011). However, neither the Resettlement Team nor the area team undertook further reviews after May 2011 and no request was made for allocation to an area social worker, presumably because all was believed to be well in the placement.

58. A review was held on 25 January 2012 – *My Person Centred Review.*²⁶⁵ This was an in-house review by the provider and not recorded on the social services record, although it was attended by a social worker. There was nothing specific recorded about Amy's health needs other than the importance of a healthy diet and regular medical checks and there was no health professional present. None of the five safeguarding referrals triggered a review of Amy's needs and how they were being met.

59. There was a lack of attention in care plans and reviews to how Amy's health care needs were to be met. The attention to her bowel health evident while the SMHPT was responsible for her care was not sustained once Crane Court became a social care service. Although her comprehensive care plan produced when the service transferred from the NHS included continence monitoring, the significance of this appears to have been lost over time, so that the review in January 2012 made no specific reference to health care needs beyond a healthy diet and regular medical checks and her bowel health was not mentioned. As those responsible for Amy's care appeared to be unaware of her bowel health problems, the question of whether these needs were being met, or could be met, appropriately in a supported living setting did not arise until the GP raised the need for nursing care at the safeguarding strategy meeting in January 2013. Even then, there was no comprehensive review of her needs, despite the discontinuity of care arising from the increasing use of agency staff noted at the safeguarding review meeting of 13 February. This also had implications for how such staff were briefed about the needs of residents they may not have met before and how information was given at shift handovers. Furthermore, Amy's parents believe that their involvement in regular reviews, explicitly addressing her health, would have enabled them to provide vital information; "if someone had bothered to talk to us, they would have got the information they needed about her tummy".

60. In summary, the references to Amy's tummy are as follows:

January 2012, stomach was *hard and distended*

February 2012, tummy was *very hard*

May 2012, stomach was *slightly distended*

²⁶⁴ Suffolk CC IMR

²⁶⁵ Leading Lives IMR

November 2012, *distended abdomen*
December 2012, *tummy was hard and bloated*
January 2013, *stomach was swollen and distended*
May 2013, *noticeably distended*

Safeguarding responses

60. There are five safeguarding alerts relating to Amy:
- 9.9.10: bruising to legs. Identified as a moving and handling issue, OT assessment booked and care staff to monitor
 - 23.1.12: missing money. Procedures for handling residents' money reviewed and improved
 - 11.5.12: duplicate medication issued on discharge from hospital. Double dispensing error by Ipswich Hospital pharmacy
 - 14.12.12: concerns about care and support raised by the CLDT nurse following Amy's hospital discharge in November 2012; they alleged that care staff were unaware of the significance of Amy's constipation and epilepsy and that she was using an unsuitable wheelchair. The referral was lost and Amy was re-referred on 4.1.13. The conclusion was that the omissions by staff were not defined as wilful because there was no evidence that they had been advised to monitor Amy's condition. There were recommendations concerning health monitoring, training and health action planning; Leading Lives were to implement and the GP was to lead ongoing health investigations.
61. District nurses were not invited to attend the strategy meeting. At this stage neither the LD liaison nurse nor the Adult Safeguarding social worker was aware that the DN was involved and this was not drawn to their attention by any of the medical or nursing personnel who would have been aware of her role. The Adult Safeguarding social worker became aware of their involvement after this meeting, *but only in relation to Amy's use of inhalers and giving advice to support staff on how to administer these.*²⁶⁶ This confirms the views often held by professionals that the health concerns of people with learning disabilities are best dealt with by specialist learning disability nurses, despite the evidence that the physical health of people with learning disabilities is often compromised by limited access to mainstream generic health care and an assumption that the learning disability should take precedence – described as *diagnostic over-shadowing* in the literature.²⁶⁷
62. This is not to suggest that the Community LD Nursing service in this case was not alert to Amy's bowel problems; indeed, it was this service which first raised the alarm about the seriousness of her condition and whether the support staff understood her needs. However, the absence of the DNs at the meeting was a serious omission given that the GP practice relied on them as a source of information on Amy's bowel health on a day to day basis, alongside the Crane Court staff. It may also have contributed to a lack of understanding among the DNs about the seriousness of Amy's bowel problems and the effect on her breathing.

²⁶⁶ Suffolk CC further information (3) received 10.02.15

²⁶⁷ See for example *Death by indifference* Mencap, 2011 and *Equal treatment: Closing the gap. A formal investigation into the physical health inequalities experienced by people with learning disabilities and/or mental health problems* Disability Rights Commission, 2006

63. It was agreed at the strategy meeting that Suffolk CC's Adult Safeguarding social worker would meet with the safeguarding lead for Community Health Services to clarify recording procedures, and subsequently monitor them, and that they would visit Crane Court together to provide support. The Community Health safeguarding lead was off sick when the meeting took place on 22 January [NB this meeting does not feature in any agency's chronology – it was included in further information provided by Suffolk CC]. Instead a Community LD Nurse attended with the safeguarding senior. They met with two staff from Leading Lives and it was agreed that a Community LD Nurse would visit weekly to monitor the charts.²⁶⁸ Community Health Services (i.e. the district nursing service) again appear to have been out of the loop in relation to the safeguarding concerns.
64. Despite the decision to allocate the investigation jointly to the police and to social care, the strategy meeting was arranged without consulting the police. However, there were telephone and e-mail exchanges between the social worker and police officer concerned prior to the first safeguarding strategy meeting on 15 January. The police were unable to attend the meeting because of staff capacity problems. They made the decision after the meeting to discontinue their involvement *based on the views of other professionals from medical and safeguarding backgrounds that the care received by Amy was not wilfully neglectful*.²⁶⁹ The County Council's interpretation was that *no perpetrator could be identified as Amy's bowel management appeared to have been neglected for a long period of time by many professionals*.²⁷⁰ This rather narrow view of what constitutes neglect is not uncommon, but highlights the weakness of current Adult Safeguarding responses and the difficulties in meeting the criminal test threshold; it implies that if you can't nail the blame on an individual, then there has been no wrongdoing.
65. The focus of the safeguarding intervention appeared to be the need to identify a perpetrator to match the identified victim, rather than a concerted effort to ensure Amy's safety through a comprehensive review of how her health and social care needs were being met and a clear multi-disciplinary plan to address any deficiencies. It is worth reiterating that Leading Lives was not a nursing care provider and it was not registered with CQC to provide health interventions; it was a registered domiciliary care provider. Any health monitoring plan for Amy (or any of the Crane Court tenants) would have to be initiated and agreed by a health professional, such as the GP, district nurse or community learning disability nurse, none of whom took the initiative to introduce such a plan. Little additional support was given to Crane Court staff to enable them to understand Amy's bowel problems and monitor her health effectively.
66. The safeguarding referral on 4 January 2013 also made reference to Amy's missing wheelchair. This had been specially made for her some years previously but had been put into storage at some stage when Papworth Trust were the responsible provider as they deemed it no longer suitable. No inventory of property was provided at the transfer to Suffolk

²⁶⁸ SCC further information (3)

²⁶⁹ Suffolk Police further information

²⁷⁰ Suffolk CC further information (1)

CC/Leading Lives and the latter confirmed that they had no knowledge of such a wheelchair. *A Person-Centred Review undertaken with Amy by SCC on 2012/01/12 expresses the intention to refer Amy for an assessment at the Wheelchair Clinic and it is this assessment which evidences that Amy had been previously supplied with a bespoke wheelchair.*²⁷¹

67. Finally, on 06.04.13, Amy was referred by the Community LD Nurse who was concerned about Amy's treatment and early discharge from hospital that day. The safeguarding strategy discussion on 10 April focused on how quickly Amy had been discharged from hospital whilst impacted with faeces, rather than on how she came to be so impacted in the first place. This was despite the previous safeguarding concerns and the specific arrangements put in place to monitor Amy's bowel health. An immediate internal hospital investigation confirmed that treatment had been incorrectly focussed on respiratory factors with no documentation to acknowledge the role of constipation, until Amy was re-admitted following the failed discharge and was seen by the respiratory team.

Section four: Conclusions

68. The significance of managing Amy's bowel problems and the importance of close monitoring of her bowel movements were lost once responsibility for the service transferred from the NHS to a social care provider. The Papworth Trust did not accurately record bowel movements (and it is not clear that they were required to do so) and there was no formal transfer of information between providers. The knowledge about her specific health care needs was therefore diluted until reference to her bowel health disappeared altogether from care reviews. The first reference to bowel problems in the GP records was in May 2012 and it was not until December 2012 that Crane Court staff received any training in bowel care.

69. The CLDT was commissioned to support people with learning disabilities and mental health needs, not people such as Amy with complex health needs. This meant that responsibility for managing these needs implausibly rested solely with primary care practitioners, who are not specialists in learning disabilities. As a GP practice that was supporting all tenants at Crane Court, it received no additional expert learning disability advice and support other than on a patient by patient basis. Under the PMS agreement²⁷² there was no agreement for GP services to be delivered to patients with learning disabilities above and beyond normal GP care as per any patient. Historically, prior to the transfer to supported living, patients were under the direct care of trained nursing staff and the CLDT, including consultant psychiatrists who held regular reviews. When care was transferred, the implications of these changes were not explored and the medical services lost were not replaced; nor was the GP practice involved and informed as to how to cover this loss.

70. The nature of the job of providing intimate care to individuals who cannot attend to their own bodily functions is hard, demanding and often unpleasant, regardless of the dignity and respect which committed staff endeavour to demonstrate when carrying out such tasks. Staff require specific training to understand the particular needs of the individuals they are caring

²⁷¹ Leading Lives further information

²⁷² Personal Medical Services – a locally agreed alternative to the General Medical Services contract with GPs

for as well as good support and supervision. Although the records indicate that staff did show clear empathy, compassion and concern for Amy, they did not understand the fine detail of bowel care; they appear to have assumed that a bowel movement in itself indicated that all was well, without understanding the difference between a loose bowel movement and overflow diarrhoea arising from impaction. There is no evidence that staff had any specific training about bowel care until December 2012 when the LD Liaison Nurse provided some training following the concerns they had raised through the safeguarding alert.

71. Information concerning Amy contained in hospital outpatient and discharge letters was not routinely shared with Crane Court support staff, so although they made their own notes in the care records after accompanying her to appointments, for example, there was a high risk that they would not fully understand the significance of particular x-rays or test results or that they might be working with incorrect information. Good communication with other support staff and entries in the daily records were also essential to relay what they had learnt during the consultation. The clearest example of this is the reasonable assumption of Crane Court staff (perhaps confirmed initially by hospital staff when they visited Amy) that she had been admitted in November 2012 because of pneumonia; despite a discussion by the LD Liaison Nurse with Amy's mother and a member of Crane Court's support staff about her constipation problems, this conversation does not appear to have been reported back to other staff. This meant that the fact that the cause was breathing difficulties exacerbated by severe constipation was not made apparent to the staff until after a safeguarding alert had been raised by the Community LD Nurse the following month.
72. Amy's experience of acute hospital care recalls the concerns which led to the attention to health care in *Valuing People* some fifteen years ago: people with learning disabilities fare poorly in health services that are reliant on patients disclosing why they need medical attention. Amy could not communicate her needs and depended on her family and support staff to do so on her behalf. Even after there was clear, documented evidence of severe impaction and associated breathing difficulties (for example *faecal loading* in February 2012 and *severe faecal impaction, shortness of breath secondary to splinting of diaphragm* in November 2013), she was treated for the presenting symptom of breathlessness by A&E staff in January 2013. This was despite the efforts of a community learning disability nurse – who was well aware of diagnostic overshadowing and associated research – to emphasise the links between breathing difficulties and bowel problems. Three months later, on a subsequent admission, she was discharged home, only to be re-admitted as an emergency with severe impaction later that day. There is little evidence that the hospital was willing to listen to the concerns of the family, support staff or community based professionals.
73. There was a lack of understanding by all agencies about the use of the Mental Capacity Act and Best Interests Decision's processes and no evidence that such measures were used when decisions were made about Amy's medical treatment, diet or behaviour.
74. It is remarkable that there is no information concerning Amy's 'lost' wheelchair. This was designed solely for Amy – no one else could possibly use it – and yet its whereabouts are unknown. Although Amy had a specialist reclining postural chair, the absence of a bespoke

wheelchair had implications for the quality of her daily life given that she spent most of her time in Crane Court, sitting in a chair or lying on the bed.

75. The lack of multi-disciplinary attention to Amy's needs is stark. There was no designated care co-ordinator for Amy; no-one took the lead in ensuring the various professionals and agencies shared information with each other or fed back about their input or allocated tasks from the strategy meeting. There was an over-reliance on unqualified (and largely untrained) support staff. Although Amy had a Health Action Plan, this was not shared with the GP practice and played no part in Amy's health checks carried out by the surgery. It had no impact on how her health care was managed.
76. Having identified Amy as a victim, the joint safeguarding investigation focused on whether or not there was a perpetrator. Neglect is not always wilful and can arise because of ignorance, inexperience, under-resourcing or a skills shortfall; these are the responsibility of the registered provider and subject to an inspection regime. The safeguarding process did not trigger a review of Amy's health and care support needs and how they were being met, other than a request for a continuing health care assessment, the outcome of which is unknown. Indeed, such reviews of her care and support should have been happening routinely and at least on an annual basis, from the outset. This failure to implement Suffolk CC's policy on reviews does not appear to have been picked up through either the contract monitoring process or CQC inspections.
77. Suffolk CC had a contract with the two social care agencies to deliver care and support to people with extensive health care needs. So very clear arrangements should have been in place to specify the service, including how the health needs of Amy and other tenants with complex needs were to be met (given that neither the Papworth Trust nor Leading Lives were registered to provide health interventions) and to manage and monitor the contract. Although contract monitoring arrangements were in place and implemented, the lack of such specific requirements and the weakness of the care management review process meant that Amy's health care needs were not monitored or reviewed beyond the input of the generic primary care team.
78. Suffolk CC did not fulfil its obligations to review Amy's needs in accordance with its own policy and in the light of changed circumstances, i.e. a new provider or a safeguarding referral.

Section five: Recommendations

79. **It is recommended that Suffolk's Safeguarding Adults Board...**
 - i. is assured by Suffolk CC and the CCGs that all 18+ adults with learning disabilities and complex support needs have a named care co-ordinator and that their health and social care needs are jointly reviewed on at least an annual basis. Such reviews should always consider whether an assessment for continuing health care is required
 - ii. is assured that named care coordinators work within structures that facilitate professional interdependence, recognises the value of complementary professional skills and encourages collaboration, most particularly with people's families or representatives

- iii. is assured that care coordination is supported by record keeping and information sharing across professionals and services and that people's families or representatives are regularly consulted
- iv. is assured that the CCGs commission a service that includes (i) the support of people with learning disabilities who have additional complex support needs, including health care needs and (ii) the provision of expert advice to generic services such as supported living, district nursing and primary care to address the disadvantaged health status of people with learning disabilities as compared with the general population and their significantly reduced lifespan which is associated with high rates of unmet health needs
- v. is assured that its policies do not supersede the duty of care of health and social care professionals or their responsibility to assess and review the needs of individuals with complex support needs
- vi. is assured by service providers that their training strategies on the Mental Capacity Act 2005 are credible and attentive to day to day decision making, including how such decisions are recorded and collated and when these should be escalated for a clinical and professional assessment for example
- vii. is assured that the means to weigh patients, including those who use wheelchairs, is available in accessible and known primary care facilities around the county
- viii. is assured that Suffolk CC's Adult Social Care's commissioned services which are providing care to people with complex support needs have explicit access arrangements with NHS providers such as Community Learning Disability Teams
- ix. is assured that NHS England, GP practices, Ipswich and Suffolk CCG, Great Yarmouth and Waveney CCG, the Norfolk and Suffolk NHS Foundation Trust and Suffolk CC draft and communicate a multi-agency protocol for identifying and agreeing changes in roles and responsibilities across the health and social care services which arise from changes to a contract or a change in provider
- x. is assured that health and social care commissioners have systems in place that ensure that contracts with providers address individual transfers i.e. if an adult moves between settings, or becomes the responsibility of a new provider, there is a formal transfer of documentation, explicitly describing their health care needs, and a verbal briefing to ensure that their support needs are fully understood
- xi. engages with the Learning Disability Partnership Board and explains why it may wish to reconsider the promotion and use of Health Action Plans and instead explore how primary care might better fulfil their clinical responsibilities for supporting people with complex needs living in community settings
- xii. is assured that health and social care commissioners encourage support staff to (i) measure and record the waist and hip measurements of adults (most particularly those who are known to experience constipation and/or are prescribed phenothiazines) and (ii) to raise any changes or other concerns about weight or weight distribution during health checks and routine consultations
- xiii. engages with NHS England to develop and promote specific guidance for primary care services about annual health checks for people with learning disabilities, including

follow up after non-attendance, reasonable adjustments to procedures and mental capacity in relation to consent to invasive procedures for example

- xiv. seeks confirmation from all partner agencies of the specific actions they have taken to address the issues raised by Amy (and James') circumstances and how these will be embedded in future practice
- xv. promotes the learning from Amy and James' circumstances by ensuring that the reviews are used as a resource for the professional development of health and social care practitioners in Suffolk