Suffolk Safeguarding Adults Board

Suffolk County Council

A Serious Case Review

James

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Section one: Background

The circumstances that led to the Review

1. James[1] died when he was 33. He had Down's syndrome which resulted in a moderate learning disability. As an adult he was diagnosed with a mental illness and hypothyroidism. He had lifelong problems with constipation. He lived in a Supported Living scheme – Goshawk Close – run by United Response. On 14 November 2012 he was admitted to Ipswich Hospital with a distended abdomen, having been admitted to the learning disability Assessment and Treatment Unit earlier that evening following concern about auditory hallucinations and confusion. Following a surgical procedure under anaesthetic to remove impacted faeces, James' condition deteriorated and he died in hospital on 17 November 2012.

About this Serious Case Review

2. The SCR was commissioned by Suffolk County Council and is based on information from:
    - James' family who own records and documentation that they had secured from the coroner for example
    - Suffolk County Council, Adult and Community Services
    - Ipswich Hospital NHS Trust
    - Norfolk and Suffolk Foundation NHS Trust
    - NHS England East Anglia
    - United Response
    - Suffolk Police
    - Great Yarmouth and Waveney Clinical Commissioning Group (this currently covers the involvement of three organisations: IC24 [Its predecessor was Harmoni which provided an out of hours service for *much of the time covered by the SCR*], James Paget University Hospital and East Coast Community Health Care)

3. The following abbreviations are used in the report:

A&E	Accident and Emergency Department
Suffolk CC	Suffolk County Council
NSFT	Norfolk and Suffolk NHS Foundation Trust
CLDT	Community Learning Disability Team
Community LD Nurse	Community Learning Disability Nurse
CPN	Community Psychiatric Nurse

4. All agencies were asked to produce an Individual Management Review (IMR). The timeframe for the IMR chronologies was 1 January 2010 to 17 November 2012, with time samplings of 1 to 28 February for four consecutive years 2006 to 2009; 1 to 31 July 1999 (whilst in a hospital based mental health unit); 1 August to 1 November 1999 (covering the transition period to Goshawk Close on 20 September); and 1 May to 31 October 1998 (health intervention in relation to digestive investigations).

[1] This is a fictitious name to ensure the anonymity required by Suffolk's SAB.

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. This process was brought to a halt during July 2015.

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 James:
    i. Was James 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 James appropriately ascertained and taken into account and to what extent were family/carers consulted with over decision making?
    iii. Were James' needs for health services correctly identified and were the right services provided in response?
    iv. Were the care placement needs of James fully identified by way of appropriate assessment? Were services delivered in accordance to the identified need?
    v. Was James' 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 James' assessed needs?
    vii. Identification and analysis of good and best practice which had a positive impact to James and also identification of failings of service delivery which had a detrimental effect on James' health and wellbeing.

James

7. James suffered from constipation soon after he was born. When he began to have solid food his constipation became an *ongoing problem*. From the age of one James was prescribed daily laxatives, the dose dependent on bowel movements. He lived with his parents until he was 18 and visited them every weekend; his parents managed his constipation through a combination of encouragement, laxatives and physiotherapy – gentle exercise on the toilet to facilitate a bowel movement.[2] In 1998 his behaviour deteriorated and he moved into a respite placement. He then spent some time in the assessment and treatment unit at a hospital based mental health unit, before moving into Goshawk Close, a residential care home.

8. His family describe James as *a cheeky chappy.* He had a fun-loving and very happy childhood and was involved to a very high degree in everything that happened. He enjoyed all activities that little boys enjoyed. At secondary school he did a lot of horticulture and was good at it. On a good day, he was cheerful and *enjoyed toilet humour.* He had a good vocabulary

[2] Family report

although he did not often initiate conversation. *He was able to build relationships with other people and participate in group activities* although he favoured interaction with staff over his peers and co-tenants. *He liked his own space and might choose to sit separately* to watch or *withdraw to his room. James was stubborn but could be persuaded if encouraged…by being offered a small reward…when he was well he would help with housework like getting his clothes out for washing, loading the washing machine and helping with meal preparation* for example.[3]

9. He would watch TV and DVDs, go swimming and enjoyed being in amateur dramatics and gardening groups. However, he suddenly stopped taking part in these activities. He did not ever disclose that he was in pain or discomfort.[4]

10. James' family produced a video of James as a child and as a young person so that staff supporting and caring for him might glimpse something of his life prior to being diagnosed with a schizoaffective disorder. A term that recurred in the notes of staff supporting James on a daily basis was 'unfocussed.' This encapsulated their experience of James' estrangement from his favoured activities, his want of motivation and apparent lethargy.

Section two: Key events and service interventions

11. The full chronology for James is 64 pages long. What follows are the pivotal events.

Significant history

12. James' school education report stated that his learning disability was *moderate/severe.* He had *a moderate learning disability, schizoaffective disorder,*[5] *depression and hypothyroidism*.[6] The latter was diagnosed during 2001.

13. James was known to the James Paget Hospital as a child and then the Norfolk and Norwich Hospitals from 1980s to 1999, during which time the association of Hirschsprung's disease with his chronic constipation was considered.[7] However, there was *a reluctance to undertake the procedure* [for a rectal biopsy] *in 1987, 1998 and 1999 mainly due to the level of associated distress for James and there being no strong indication of the disease.* He had *other diagnostic*

[3] United Response IMR

[4] Information from family at meeting with the authors

[5] This is a disorder of the mind that affects thoughts and emotions and may affect actions. Episodes that are combinations of 'psychotic' and 'bipolar disorder' symptoms may be experienced. These symptoms are clearly present for most of the time over a period of at least two weeks.
See http://www.rcpsych.ac.uk/healthadvice/problemsdisorders/schizoaffectivedisorder.aspx (accessed on 31 August 2014)

[6] *Hypothyroidism (underactive thyroid gland) is the term used to describe a condition in which there is a reduced level of thyroid hormone (thyroxine) in the body. This can cause various symptoms, the most common being: tiredness, weight gain, constipation, aches, dry skin, lifeless hair and feeling cold. Treatment is usually easy by taking a tablet each day to replace the missing thyroxine. Treatment usually works well and symptoms usually go.*
See http://www.patient.co.uk/health/hypothyroidism-underactive-thyroid-leaflet (accessed on 30 August 2014)

[7] James' family shared an X-ray report of 26 June 1998. It stated *Instant Barium Enema: There is a marked difference in the degree of dilatation of the sigmoid colon just above the recto sigmoid junction highly suggestive of Hirschsprungs disease rather than functional constipation. Rectal biopsy is advised. There is an opacity at the right upper quadrant, possibly due to a gall stone*

tests that are used in supporting the diagnosis for Hirschsprung's,[8] *for example a barium enema (26/06/98).*[9] The histopathology department at James Paget Hospital did not have the necessary staining facilities to test a biopsy sample[10] and *the potential risks* of the invasive procedure *would have been a factor also for not considering the procedure even during a general anaesthetic.*[11] That is, although the evidence was *highly suggestive* that James may have had Hirschsprung's disease, this was not confirmed.

James' contact with services

14. James lived at Goshawk Close at which **United Response** provided support services from August 1999 until his death in November 2012. *A team of support workers employed by United Response work in shifts over 24 hours, seven days a week to enable the people living there to live their lives…The support is provided to people in their own homes and to help individuals access their community.* Goshawk Close staff maintained diary records for all residents. From 2007 – 2008 James *was eating an increasingly low fibre diet and* in 2012, *he was regularly refusing meals.* Some of the foods which James favoured were likely to result in constipation. Although staff did not meticulously record James' fluid intake, there are records of him being encouraged to drink. The staff were *advised by the psychiatrist not to put pressure on* him…*and as he vehemently declined healthy food or any food at all they accepted that any food was better than none.*[12]

15. James was known to Suffolk Mental Health Partnership during 1998. This merged with Norfolk and Waveney Mental Health Partnership during January 2012 and became the **Norfolk and Suffolk NHS Foundation Trust**. James was seen by the Community Learning Disabilities Team from 1999 to 2003 following the Care Programme Approach (CPA). His care coordinator was a Community LD Nurse. Between 2003 and 2008 James was seen by a consultant psychiatrist. From 2008, the CPA *was re-launched as Non CPA* and James remained on this *pathway* until his death. The *Non CPA* meant that James *did not have a formal community care coordinator.* Also, it meant that he *was not deemed to have complex or high risk needs and could therefore be managed by the Consultant Psychiatrist as he was thought to need medical/ medication review. His social care and primary health care needs were provided and monitored outside of the mental health trust.*[13]

16. James' physical health was monitored by the GP practice, which had been an early adopter of the Learning Disability Direct Enhanced Services (DES) scheme which it joined in 2009/10. James had been included in the DES register at its inception in 2009 and had been included in the learning disability QOF (Quality Outcomes Framework) register in 2006 when this was first established. *He was, therefore, a long identified member of this cohort of people who would need specific attention to ensure their health needs are met.*[14]

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[8] A bowel disorder in which a section of the bowel is permanently squeezed, narrowed and unable to relax resulting in stools becoming stuck and forming a blockage.
See http://www.nhs.uk/conditions/hirschsprungs-disease/Pages/Introduction.aspx (accessed 25 August 2014)
[9] Further information, CCG
[10] NHS England further information
[11] Further information, CCG
[12] James' family insist that when with them he ate a healthy diet
[13] Suffolk CC IMR
[14] NHS England East Anglia IMR

17. James had regular outpatient appointments with psychiatry following which letters were written to general practice. Concerns were not raised about James' constipation in psychiatry's letters until the month of James' death - November 2012. The general practice was not notified about the transfer of Goshawk Close from residential care to supported living in July 2010. Between January 2010 and November 2012, James was seen five times by members of the practice and there was a single contact with the practice with his father. Support staff from Goshawk Close always accompanied James to the general practice. The latter *saw Goshawk Close as needing to have a general overview of James' health and concerns about his physical health and to bring these to the GP's attention.* Two GPs were *clear that they were responsible for James' physical health, adjusting his medication…and arranging tests, screening services etc.*

18. James received a social work service from **Suffolk CC's Adult and Community Services** from January 1998 until November 2012. The purpose was *to enable his considerable and complex care and support needs to be met in a homely and small scale environment and to provide him with day activities. James* received respite care from June 1998 - March 1999 at a council run care home and subsequently residential care at Goshawk Close. The care home was de-registered during July 2010 becoming part of a registered home care service. Suffolk CC had a supported living contract with Goshawk Close from this date. James' family associate the introduction of supported living at Goshawk Close during 2010 with less intensive support.

19. James attended a council run day centre from 1998 to 2012. The management of this centre was taken over by Leading Lives during July 2012. James had the same key worker at the centre from May 2006 – November 2012. He had regular annual reviews between December 1999 and October 2007 *undertaken by a range of Community Care Practitioners and Review Co-ordinators (unqualified social workers) as James no longer had an allocated social worker.*[15] There was a single care plan for James. Until August 2006, reviewers were attuned to James' bowel problems. After this date, his bowel condition and management are no longer cited in social care records. There were detailed contracts between Suffolk CC and United Response for residential care and supported living after July 2010. However, neither was actively monitored.

20. **1998**

James had medical reviews on 12 and 19 January, 9 February, 2 and 23 March 1998. The NSFT note that *the care team were acutely aware that James'* mother *was struggling on her own and were making a real effort to be available and support her. Carer's stress was not as well understood or provided for in 1998, or formally assessed. There is good evidence of responsive support leading to respite care which was not something the family were initially asking for but became unavoidable.*[16]

[15] Suffolk CC IMR
[16] Email from NSFT 2 June 2015

During early **May 1998**, a home visit by a Community LD Nurse triggered James' referrals for (a) a psychiatry review since he was *refusing to get out of bed,* he was *incontinent* and he appeared *scared*; and (b) a safeguarding referral. James was attending college where he encountered other young men who *had previously sexually abused James// had been hitting/ nasty to James at college.*[17] (This was *related to a historic incident when* he *was assaulted as a child by other children and the assailants began to attend the same college…as young adults. This was dealt with through the police.*[18] However, neither the police nor Suffolk CC has any record of this). James' father described James' state as *up and down…trance-like… refuses food* and *appears frightened.* Psychiatry determined that James had a *depressive illness with psychotic features…may need to admit.* It was noted of James' physical health that he was subject to constipation and that he had had a hernia operation. James' parents met with psychiatry and discussed sectioning James.[19]

Towards the end of May, Community LD Nursing established that James no longer had *behavioural issues.* However, a visit to General Practice was *advised* since his abdomen was *noted to be distended despite* a *bowel movement earlier that day* which was *frothy…foul smelling* and *not formed.* Subsequently James' father informed the Community LD Nurse that James *had been referred to James Paget Hospital for an x-ray due to constipation.* Also, James, his parents and a Community LD Nurse attended a police unit concerning James' experience at college.

During early **June 1998**, James was *extremely constipated* and an x-ray revealed *distension* of his *lower bowel.* Patient records noted that James' parents were *struggling* with his psychotic episodes, physical aggression[20] and *bowel problems* which were impacting *on jobs* and their health.[21] A social worker and CPN visited James' family which resulted in James' admission to a *care home run by Suffolk CC…for emergency respite.* Correspondence between general practice and psychiatry noted that James had had two enemas at James Paget Hospital, that *his behaviour is observed to be worse when he is constipated* and further that *medication*[22] *could worsen his constipation.* Psychiatry noted that James needed *to be admitted for a period of assessment and treatment* and that S.2 (admission for assessment under Section 2 of the Mental Health Act 1983) was required since James *has no capacity.* However this was not used because he *was not objecting and his parents were acting as advocates at that time.*[23]

During mid-June psychiatry visited James at the care home and adjusted his medication because his abdomen was *very distended*. Rather than being admitted to an Assessment and Treatment Unit, James remained at the care home because *he was settled*. A multi-disciplinary team meeting noted (i) that James was *withdrawn but settled* albeit with a

[17] Patient record of the Suffolk Mental Health Partnership
[18] Norfolk and Suffolk NHS Foundation Trust IMR
[19] S.2 Mental Health Act 1983, Norfolk and Suffolk NHS Foundation Trust IMR
[20] James' family assert that professionals *never saw him in a psychotic episode*
[21] A limitation of time-sampling is that particular and unique contexts may be sacrificed. James' family recall that he attacked his mother (recorded as during Christmas 1997 by NSFT) and that she required hospital treatment – and medication was the only treatment provided to James
[22] The medication cited was Venlafaxine and Thioridazine
[23] NSFT further information

distended abdomen and (ii) that James' parents' views about an *out of area placement* were to be sought. Patient records noted that for eight days during June, James did not have a bowel movement and that his abdomen was *very distended.* Further medication adjustments were planned.
At the end of June, James was admitted to James Paget Hospital initially for a barium enema and subsequently for an *anal stretch under general anaesthetic.* While the care home staff reported that James was *settled, eating and sleeping well, getting on with other residents, getting up and going to college,* his mother reported that *strange behaviours had returned* i.e. *grimacing, withdrawn, smiling inappropriately* – [which were] *mainly aimed at* her.

At the beginning of **July 1998**, James was discharged from hospital to the care home where his *mood swings* became *evident* and within days he was *refusing to get up* and once up, *taking himself back to bed.* When a Community LD Nurse visited James it was noted that he had a *distended abdomen* and although his room *smelt of faeces* he claimed that his *bowels were working better.* It was noted that there was *no evidence of mental health concerns.* A visit to James' parents by a social worker and Community LD Nurse confirmed that they were *finding caring for James difficult* and that they did *not feel able to have James home.*
By mid-July, patient records noted that James' placement was *going well* and his behaviour was *improving…enjoying college and day centre, looking at course for more able service users.* Since James was occupying a respite place in a care home, a multi-disciplinary team undertook to *look to move James* to a *community placement.* The family noted that *within days* concerns were raised about changes in James' behaviour which led to James attacking his father twice within three days *and Community LD Nurse was contacted*.[24]James *shouted at no one "leave me alone," which* fuelled concerns that he was possibly experiencing *auditory hallucinations.* Also, he was observed to be *tearful…withdrawn* and *isolating. James did not want to see* his parents at the end of the month. A *dual diagnosis*[25] was considered since James' mother reported *deterioration* in his comprehension, *anxiety around mirrors, TV and radio.*
There were four references to James' *distended abdomen* in patient notes during July and one reference to his abdomen being *very distended.* Support staff recorded limited and irregular bowel movements. *There was a further home visit to James'* parents at the end of July *to continue planning* for his *ongoing care.*[26]

During early **August 1998**, general practice was informed of James' distended abdomen and an appointment at James Paget Hospital resulted in scheduling a further anal dilation procedure (for October 1998) irrespective of *some improvement* and James' continued abdominal distension. During mid and late August, James attacked his father. Other events which featured in his patient record included *faecal incontinence…*unexplained *changes in behaviour…*James walking *to college in his pyjamas in the evening…*and a multi-disciplinary

[24] Information from mother's diary
[25] A term used to describe people with a learning disability and a mental illness – which is more commonly used to describe people with a mental illness and a substance misuse problem
[26] Suffolk CC's Adult and Community Services

team meeting *with parents* to discuss James' behaviour and the reduction of anti-depressant medication.

At the beginning of **September 1998**, as social work hinged on a *look at future residential placements with James,* psychiatry *diagnosed…*an *acute psychotic mental health problem that will respond to treatment.* It was proposed that James would have four weeks of *intensive* psychological *therapy.*[27] Following a visit to James, social work recorded that he *was very withdrawn and uncommunicative. James'* anti-depressant medication was increased since he was *not eating…not getting out of bed* and was described as being in a *low mood.* By mid-September however, James was described as *improving but needs encouragement…smiling, talking…improved in mood…happy.* There were two occasions within three days when James declined to have enemas. His abdomen was distended and yet *he stated* that *he had been to the toilet.* A district nurse undertook *to discuss James'* refusal with general practice, and a Community LD Nurse undertook to *discuss* the procedure with James. There was a further meeting between his parents and a social worker concerning his care and support.
Towards the end of September, a psychiatry review acknowledged that James' *behaviour had deteriorated following a reduction in Venlafaxine however he was again constipated with a distended abdomen.* It was noted that James *was denying any pain.* Psychiatry *increased the Venlafaxine dose* with the result that James' *mood and behaviour are reported as having improved. No mention of constipation…This episode demonstrates the dilemma posed by the effectiveness of Venlafaxine in improving James' mental health against its side effects in relation to his constipation.*[28] Subsequently, general practice stopped lactulose and *prescribed Co-danthramer.*[29]*James'* mother expressed concern that he was gaining weight and that his personal hygiene was poor. Regular weighing and recording was advised and the home was asked to provide fewer snacks and to encourage James to bathe.[30]

During early **October 1998**, it was observed that James favoured attending his day centre rather than college since he was *reluctant to get up on college days.* Also, his *abdomen* was *distended,* and the *new medication* had *nil effect.* A professionals' meeting during mid-October undertook to *discuss with parents and James the fact that he will not be returning home* as well as *Christmas arrangements.* (The subject of *how James will be told* was still being considered at the end of the month.) This coincided with residential care staff describing James as *difficult to engage…a bit odd…staring a lot* – descriptions with which his father concurred. James' father and a Community LD Nurse accompanied James for an anal stretch

[27] This was *primarily to assess James' resilience to the decision around his change in residence, namely that he would not be returning home to his mother's or father's address* - Norfolk and Suffolk NHS Foundation Trust
[28] NHS England East Anglia IMR
[29] A stimulant laxative which is usually prescribed to people who are terminally ill.
See http://www.netdoctor.co.uk/digestive-health/medicines/co-danthramer.html (accessed 24 August 2014)
[30] In terms ofJames'weight, concern about this was raised by his family on several occasions. It is known thatJameswas intermittently *following a weight watchers' plan* between 2004 and 2008 and that *weight checks* were undertaken intermittently during this period. There was further concern *that* his weight continued to increase during 2010 when it was recorded that he was *overweight*. During the last year of his life, United Responses' records cite the importance of a *balanced diet due to James putting on weight easily/ being overweight.*

procedure. He was discharged to the care home three days later. Towards the end of October James was observed to be *happy, no concerns* and two days later – *not focused, staring, difficult to engage...vacant, difficult to motivate…abdomen distended. James* had gained a stone in weight.

In **December 1998**, James' family wrote to the psychiatrist expressing concerns about the care home's ability to meet his mental health needs. They requested his admission to a health care facility in order for *proper assessment to take place in a safer environment.*[31]

21. **1999**

During **March 1999**, James was admitted to a hospital based mental health unit because he *had been displaying some aggressive and uncharacteristic behaviour*.[32] His parents and social worker were concerned about his placement at the respite home and did not want him to return there. *This appears to have been associated with James 'wandering' out of the unit overnight…being found in his pyjamas and concerns about his health needs* and also, *the care workers were not trained in health care.* James' parents were noted to be, *hopeful that he would be placed in an NHS establishment long term, rather than a social care environment* and *the social worker supported this.*[33] (NB: James' parents deny this. Their concern had been to ensure James' admission to an NHS unit for assessment. Their preference was for his long term placement was for him to be near to his family.)

During **April 1999**, James' *suitability to living in supported housing* was assessed by Resettlement Team social work and Goshawk Close support work. This drew from a January 1999 assessment of James which stated that he was *continent and uses the toilet independently.*

During **July 1999**, general practice noted that a surgeon had confirmed *the difficulty in reaching a diagnosis of Hirschsprung's disease.* General practice received a copy of the mental health unit's *Statement of Special Health Needs.*[34]

During **August 1999**, James' discharge from the mental health unit to Goshawk Close[35] was negotiated. A statement of James' *Health Needs* was prepared during his placement at the mental health unit. This stated that his *Primary health care needs* included *ongoing monitoring of bowel function* and his *Secondary health care needs* included *referral to…Norfolk and Norwich Hospital for chronic constipation…Specific reference must…be made to James' needs for diligent monitoring of bowel function and management. James' non-negotiable, quality of life needs* included *maintenance of bowel management programme…Has taken laxatives regularly since one year old. Abdomen becomes extremely*

[31] Information from James' family
[32] Norfolk and Suffolk NHS Foundation Trust
[33] Norfolk and Suffolk NHS Foundation Trust
[34] NHS England East Anglia
[35] A registered care home provided by United Response

distended with faecal overflow and discomfort. The comprehensive care plan aimed to promote regular bowel movements *by maintenance of medicine regime…exercise, veg and fresh fruit daily…fruit juices, linseed…encouragement but not pressure to use the toilet. James will answer yes inappropriately especially in response about bowel function…characteristics of poor but not severe mental health are evident for 2/3 days every 2/3 weeks. May be related to constipation as well as his mental illness.*
Following this assessment *it was felt by the health team there, and the CLDT, that he would benefit from returning to a supported social care unit which he was familiar with rather than cause further disruption by being moved to another facility at that time…*the assessment *did not recommend a health setting from either a physical or mental health provider.*[36]

During **September 1999**, James moved to Goshawk Close. Colorectal surgery noted that James *will probably require* invasive *rectal biopsies to exclude Hirschsprung's disease…initially wanted to see if he had anorectal inhibitory reflex*[37] only proceeding *to a full thickness biopsy if his inhibitory reflex* was *absent.* Psychiatry expressed uncertainty about James' tolerance of these procedures and noted that since *his bowel function is reasonable at present, the benefits outweigh the risk of deterioration in his mental state.*

During **October 1999**, there was a review of James' placement at Goshawk Close. It was noted that James' *bowels are functioning really well and his diet and the support from staff at Goshawk Close is proving very successful.*

James was discharged from the mental health unit at the beginning of **November**. The documentation stated that he had a *schizo-affective disorder.* He was prescribed Risperidone *to control what were judged to be negative behaviours.*[38] A review of James' placement during **December**, recorded his father as saying that Goshawk Close was *a superb placement.* A detailed review six weeks after his placement at Goshawk Close *fully explored…his physical and mental health needs.* There was however, *no care plan identifying James' care needs…against which his care can be monitored and reviewed.* [39]
A psychiatrist supported the view of consultant surgeons that James should not be subject to a rectal biopsy to determine whether or not he had Hirschsprung's disease.

*After **2003**, there is no evidence in* Goshawk Close *records…of any requests to district nurses to undertake an enema when James had not had a bowel movement for several days…staff at Goshawk Close suggested that as James' bowels were being managed this type of intervention was not needed…*and *were reassured by the regular contact with…a psychiatrist and the fact that James took laxatives to treat constipation.*[40]

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[36] Norfolk and Suffolk NHS Foundation Trust
[37] Relaxation of the internal anal sphincter in response to increased pressure in the rectum
See http://www.encyclo.co.uk/define/rectoanal%20inhibitory%20reflex (accessed on 25 August 1014)
[38] United Response IMR
[39] Suffolk CC IMR
[40] United Response IMR

During **July 2004**, James *was discharged from the care of his CPN to the care of the Consultant Psychiatrist and multi-agency Care Programme Approach Planning Meetings ended.*[41]

During **January 2005**, Goshawk Close management wrote to James' general practice to confirm that the service *was not able to evidence that it was meeting* the regulatory *national minimum standards for James in relation to annual medication reviews and annual health checks.* The general practice confirmed that it was *happy to provide longer medical check appointments which would be longer than routine GP appointments.*[42]

22. **2006**

During **January 2006**, James was placed on the practice's *learning disability Quality and Outcomes Framework register.*

During **March 2006**, James had a psychiatry appointment at which he was described as communicating *economically.*

During **September 2006**, James had a further psychiatry appointment at which a support worker from the care home asked on behalf of James parents whether or not *any meds could be reduced.* This resulted in *a small reduction in anti-depressants* because James' *mood had been so good.*

23. **2007**

During **May 2007**, James had a psychiatry appointment with accompanied by a support worker. This considered *one incident of violence* and it was noted that James *received light therapy…due to* his *low mood in winter.* A subsequent appointment for **September** had to be rearranged.

From 2007, and *based on daily diaries James' diet…gradually changed with him eating more high fat foods, less fibre and some foods…liable to constipate him…when he started to refuse food and miss meals…that staff were pleased to get him to eat something…*his fluid intake was *less meticulously recorded…His continued interest in having a daily drink of diet coke will have provided fluid but may also have contributed to the accumulation of gas in his stomach.*[43]

24. **2008**

During **January 2008**, James was seen by general practice for gastric reflux and an *examination* showed *that James had a soft abdomen and palpable colon.*

During **February 2008**, James had a psychiatry appointment which he attended with a support worker. The records note that James *had been depressed over winter* and that the GP was addressing his *sickness.*

Six months later, during **August 2008**, James had a psychiatry appointment which he attended with a support worker. He was noted to be *stable in terms of mood and behaviour…biological*

[41] Suffolk CC IMR
[42] United Response IMR
[43] United Response IMR

functions intact…continue on meds, review in October/ November to address winter depression.

During **October 2008**, James had a psychiatry appointment which he attended with a support worker and his father. It was noted that his *mood* was *stable,* that he had *suffered a gastric upset* and that he was *more alert since* the *reduction in anti-depressants.*

From **2008**, James *was eating an increasingly low fibre diet.* United Response highlighted changes in James' behaviour and a deterioration from this time. The changes included, *declining to go to the day centre; declining meals; staying in bed or returning to bed in the daytime; refusing to allow staff into his room; showing signs of distress, rocking, hitting his head, repeatedly saying 'no' and 'I don't know'; defecating in his room, putting soiled underwear into his drawers; wetting himself…when he had rarely been incontinent of urine in the past.* [44]

25. **2009**

During **January 2009**, James attended A&E with *a minor foot injury.* Also, he had a psychiatry appointment which he attended with a support worker. It was noted that he was *stable in mood; history of fracture to foot…biological functions intact, blood test results requested from* general practice. Also, there was a social work review which recorded a discussion with James' mother *about the nature of supported living as opposed to residential care…the review concluded that James could be considered for a 24 hour supported living project.*

During **February 2009**, there was *a review of James' day service. The review records that James and his mother both said that they were happy and satisfied with the service.*

James' family provided a written account of their experience. This reads as a diary. It states that during ***April/ May 2009****, Suffolk CC carried out an…unscheduled review…leading up to the change of designation of Goshawk Close from a Registered Care Home to a Supported Living provider. The report contains no mention of James' chronic bowel condition nor the measures referred to in the mental health unit's report as being necessary to ensure his health and safety. This is despite the fact that no more recent assessment had superseded the one from 1999.* The family state that *Social Services assessed him in April 2009 as needing 24/7 care.* [45]

During **December 2009**, James had a psychiatry review since his mental health was *deteriorating* and he was *not attending activities…no incidents of aggression or self harm but* he was *less communicative. James'* mother expressed *concern about the length of time James had been on medication* and she requested psychotherapy. It was determined that James' anti-depressants should be increased with further blood tests. Also, an invitation letter for James to attend a health check was sent by the surgery to Goshawk Close, to which there was

[44] United Response IMR

[45] Information from James 'family

no response. A second invitation letter was sent on 24.11.09 and contact was then made with the surgery to arrange the appointment for **8 December**. The health check was undertaken by a nurse practitioner during which his *physical and mental health needs were examined including* his *digestive system…this was his first health check following the introduction of the Learning Disability Directed Enhanced Service*[46] i.e. primary medical services other than essential services.

26. **2010**

During **January 2010**, James had a psychiatry review which he attended with his mother and a support worker. His medication was adjusted and it was noted that his *physical management* was *to continue as per general practice plan* – all correspondence from psychiatry to general practice reiterates this note…*changes in medication* were *reported as being Beneficial…physical health was reported to be stable. James'* mother *expressed concern about the long term effects of James' medication.* Due to *possible hallucinations* the dosage of Risperidone was *increased.*

The former *Resettlement Team* became the *Accommodation Review Team* and was *responsible for carrying out Suffolk CC's "Accelerated Moving On Strategy" which was a programme, where possible and appropriate, of moving people in expensive out of county placements back into supported living arrangements in Suffolk. The team also oversaw the process of deregistration of residential Care Homes including the review of individual residents to assess whether this was appropriate for people living in the home.*[47]

The minutes of the *Accelerated Moving On Strategy Group* for January 2010 noted that: *All parents are happy with the change of registration, finance and tenancy.*[48] However, during the consultation with families about the change to supported living, *there was no suggestion that this would in any way diminish or change the support to people living at Goshawk Close. The emphasis of the consultation was on increased income and control over finances, tenancy rights and choice of activities.*[49]*James'* family wrote that the *log of this process clearly shows that he had no understanding* of the implications of the transition and that he *was erroneously deemed to have capacity to make this decision and his family were denied the opportunity to contribute to a best interests' decision.*

During **February 2010**, James had a psychiatry review – which he declined to attend. His mother and a support worker attended and *gave a history.* It was noted that James was *refusing blood tests for Risperidone…physical health unchanged, nil side effects of medication, residual psychotic symptoms, Risperidone increased…his biological functions were better.*

Also in February, James attended the GP's practice and his weight was recorded as 73.5 kgs; his family were concerned that he had put on weight.

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[46] http://bma.org.uk/working-for-change/negotiating-for-the-profession/bma-general-practitioners-committee/general-practice-contract/enhanced-services (accessed on 26 August 2014)

[47] Suffolk CC further information

[48] Suffolk CC IMR

[49] United Response IMR

During **March 2010**, James had a Support Plan which was produced by the day centre and Goshawk Close. This outlined his *care needs and* was *applicable to his care at* the centre *and Goshawk Close.* It described his *need to maintain a healthy diet to avoid constipation and in a separate personal care summary, his need for supervision when having a bowel movement.*[50] The Centre recalled that James *was self-caring as regards using the toilet but might require prompting.* However, *he could be stubborn in respect of taking advice on his use of the toilet.*[51]

During **April 2010**, James had a psychiatry review – which he declined to attend because he favoured going to an event at the local theatre. His mother and a support worker attended. James' mental health *was reported as being much better, he was brighter and more responsive, and his biological functions have improved as well.* The GP was requested to carry out blood tests. Also, Suffolk CC's social work service (i) produced a support plan with Goshawk Close staff which recorded James' *need for supervision of bowel functions* and (ii) made an application on James' behalf to the Independent Living Fund.

During **June 2010**, Goshawk Close's registration as a residential home was cancelled, it became a supported living service[52] and it was determined that James would not be charged for the service.

During **July 2010**, James had a psychiatry review which he attended with his mother and a support worker. James' mental health was reported to have improved and *his mental health, emotional well-being and his biological functions were reported as stable. Salivation* was described as a *mild side effect from medication* for which *Procyclidine*[53] *prn* was prescribed. Correspondence with general practice noted that although James was *generally not keen on having his weight taken or having blood test,* the latter was required. The provision of supported living at Goshawk Close began on **12 July.** James' family provided a written account of their experience. This reads as a diary. It states that James *signed his paperwork, we commented that in a Court of Law the agreement would carry no weight as* he *didn't have the capacity to understand what he was signing. The Manager told us they had done lots of work with James and that he understood it all. Despite our feeling that this was ludicrous we felt obliged to allow him to sign the document otherwise he wouldn't have been allowed to stay there.*

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[50] Suffolk CC IMR

[51] Suffolk CC IMR

[52] *Involving a person living in their own home and receiving care and/or support in order to promote their independence. The care they receive is regulated by the Care Quality Commission, but the accommodation is not.* (p29) Care Quality Commission (2010) *Essential standards of quality and safety - Guidance about compliance. What providers should do to comply with the section 20 regulations of the Health and Social Care Act 2008.* It may also be referred to as a *supported housing and care* arrangement

[53] This blocks the effects of certain chemicals in the brain. It is used to treat Parkinson's disease or extrapyramidal side-effects which have been caused by other medicines.
See http://www.nhs.uk/medicine-guides/pages/MedicineOverview.aspx?condition=Extrapyramidal%20side-effects&medicine=procyclidine%20hydrochloride (accessed on 28 August 2014)

During **September 2010**, there was a *Person-Centred Review* at James' day service attended by James' mother and his key worker. It was recorded that James *needed more support in maintaining a healthy diet and help to cope with changes in routine.*[54] While James' mother described Goshawk Close and the day centre as *brilliant,* concerns were noted *about how James made decisions…He needs far more direction with the choice to opt out if he really wants to.*[55]

During **October 2010**, James had a psychiatric review which he attended with a support worker. Changes in the staff team at Goshawk Close were *noted* and James was *reported as coping very well…His mental health, emotional well-being and physical health are reported very positively.* Psychiatry gave a *blood requisition form for various blood tests to be accessed through Goshawk Close,* which was also required *to monitor James' mental health and side effects of medication…*general practice was *asked to continue with James' physical management.* At the end of the month a letter was sent to Goshawk Close to invite James for a health check with the practice nurse. He did not respond and a further letter was sent, following which an appointment was made for **14 December.** It is not known who accompanied him. His *physical and mental health needs were examined including* his *digestive system. Nothing abnormal detected in abdomen…recent diarrhoea and vomiting…*Although the record noted that a s*ample of faeces should be checked…*there is no record of which professional/ agency was responsible for ensuring that this was undertaken. His weight was recorded as 73 kg.

At an unknown date during 2010 United Response notes concerning James' appointments state: *Stop seeing the Chiropodist!* The family confirmed that this means that he was refusing to see the chiropodist.

27. **2011**

During **January 2011**, James had a *large hernia* diagnosed by general practice. The visit resulted from support workers noticing the hernia. It was noted that it *had not been noticed previously as James is independent in self caring.* There were no *symptoms of obstruction and the hernia completely reduces on lying down flat. Bowel sounds are present and opening regularly.*

During **February 2011**, Goshawk Close informed psychiatry that James *was refusing to attend* his out patients' appointment. Psychiatry sent *United Response another blood requisition form.* At the end of the month James went to general practice with a *lump in* [his] *abdomen.* The accompanying support worker was *unable to say when the lump was noticed.*

During **March 2011**, James had a psychiatry review which he attended with his mother and a support worker. *His mental health and emotional well-being* were *reported as stable…physical health…normal.* The psychiatrist made *reference to James' lack of mental*

[54] Suffolk CC IMR
[55] Suffolk CC IMR

*capacity to consent to treatment and that this is given in his best interests***.** It was noted that *staff at Goshawk Close* were *to monitor behaviour, mental problems and side effects of medication*.
Also during March, the day centre staff were *in contact with Goshawk Close…to raise concerns about James' distended stomach…*staff were advised that James *was scheduled for a scan of his stomach later in the month.*[56] The ultrasound examination was *limited due to severe shadowing. No obvious right hypochondrial mass.*

The family's written account states that between January and March 2011, they *became increasingly concerned about the changes in regime at Goshawk Close. James had put on weight. We kept hearing that it was Supported Living and the residents had the right to make their own decisions and choices, regardless of whether they were sensible decisions or not.* They wrote that during a meeting with managers at Goshawk Close during March to discuss concerns, they *suggested ways in which James could be allowed to make healthy decisions…because of his chronic bowel problem it was essential that he eat plenty of fruit and veg…rather than the unhealthy stodge which he seemed to exist on. We were told that* he *had exactly the same right to make unwise choices as anybody else. We didn't manage to convince them that this was a wrong interpretation of the Mental Capacity Act 2005.*

During **April** and **June 2011**, James had a psychiatry review which he attended with his mother and a support worker. He was described as *stable in terms of physical and mental health, compliant with medication and treatment…blood test taken by* general practice. His weight was recorded at psychiatry outpatients as 70kg. Subsequently psychiatry wrote to general practice to *reduce Risperidone in view of raised Prolactin* level. This was explained during a telephone call from general practice to Goshawk Close. The following month, Goshawk Close made contact with general practice to enquire why the medication had been reduced, suggesting that communication within Goshawk Close about the medication change was *not effective.*

During **September 2011**, there was a Person-Centred Review of the care James received at Goshawk Close and his day centre. His mother and staff from Goshawk Close attended. It was recorded that James needed *more support to ensure healthy eating and taking exercise.*[57]

During **October** and **November 2011**, *when James had stopped attending the day centre,* his key worker *made three visits to Goshawk Close to try to encourage him to resume attendance…these efforts were unsuccessful.*[58] Goshawk Close noted *deterioration in James' mental health, changes in his behaviour and communication* and *advice* was sought from psychiatry. The latter proposed that staff should *not…overload James with choices and work with him at his own pace.* Notes from the meeting include the statement *staff have no specialist training to work with James.* At the end of the month James was invited by letter

[56] Suffolk CC IMR
[57] Suffolk CC IMR
[58] Suffolk CC IMR

to Goshawk Close to contact general practice to make an appointment for a health check. *No contact was made to arrange an appointment.* A practice note was made that *a home visit will be needed.*[59]

At a review during November 2011, *the responsibility for identifying James' health needs then becomes the concern of Goshawk Close, the Lowestoft Centre and relevant community health services.*[60] It was made clear that there was *no allocated Social Worker, and the referral pathway* was *explained to the relevant support staff.*[61]

The staff supporting James accepted the advice of the psychiatrist *not to put pressure on James when he declined things and as he more vehemently declined healthy food or any food at all they accepted that any food was better than none. When he chose to stay in bed for several hours during the day time as he increasingly did over the last two years of his life, the staff felt they could only go so far in cajoling and incentivising him to get up; when he got angry they would desist.*[62]

During **December 2011**, the psychiatrist visited James at Goshawk Close *following growing concerns about his behaviours although not his mental health…no physical health concerns were raised and bowel movements were reported as unchanged.* It was noted that James' *motivation* was *down, not engaging with staff, withdrawn, isolating, challenging at times but not aggressive, sleeping more…agreed with care home* and father to switch medication…Procyclidine was discontinued. At a review with Community Care Practitioners, *both James and his father confirmed that James liked living at Goshawk Close. Staff were going to encourage James to resume some activities that he had stopped.* Goshawk Close sought *clarification* from general practice concerning changes to James' prescription. *Advice was given by the practice.* At the end of the month James was invited to attend general practice for a health check by the practice nurse. A second letter was sent when he did not respond, *asking James to come to the surgery for his health check* and advising that *he could request a home visit*. *It is not known why no contact with the surgery was made.*[63]

The family's written account states that *through 2011/12James began to refuse to have his nails cut, particularly his toe nails. We were not made aware of this and only discovered it ourselves when his toe nails had become like claws. This was despite our always having made it clear that we wanted to be informed of difficulties and of our intention to help with them whenever possible. At some stage James declined to attend his day service…refused personal care, declining baths, teeth cleaning and hair washes on a regular basis – all apparently part of his right to choose to make unwise decisions…By the time we became aware…his behaviours had become entrenched and so were far more difficult to change.*

28. **2012**

[59] NHS England East Anglia IMR
[60] Suffolk CC IMR
[61] Suffolk CC further information
[62] United Response IMR
[63] NHS England East Anglia further information

During **2012**, James was recorded as *regularly refusing meals.*[64] *Regularly* is not defined.

During **January 2012**, James had a psychiatry review which he attended with a support worker. It was noted that *generally James' mental health and emotional well-being were improved. His physical health is reported as normal.* He was described as having an improved *mood, biological functions improved*, *more alert and engaging, attending activities in the community*. James' medication was adjusted, general practice was *asked to continue with physical management* and Goshawk Close staff were *to monitor* his *behaviour, mental problems and side effects of medication.* His weight was recorded as 70 kg. At the end of the month *a third health check letter was sent from general practice to Goshawk Close inviting James to contact the surgery to make an appointment for a health check.*[65]

During **February 2012**, the Care Quality Commission's inspection of United Response at their Ipswich office determined that the company was compliant with domiciliary care standards.

During **March 2012**, following the third, *failed invitation* to James to contact the surgery to arrange a health check appointment, *the GP practice policy removed James from the invitation list for 2011/12. The policy would have resulted in James receiving a further invitation during March 2013, resulting in a gap of at least 16 months between health checks.*[66]

During **April 2012**, a support worker *called 111 for medication support…about giving medication late due to social activity.* Towards the end of the month James had a psychiatry review which he attended with his parents and a support worker. It was noted that he was *refusing to get out of bed…less focused and resisting help with personal care…physical health and biological functions* were *reported as normal.* James' medication was adjusted, staff were *to monitor behaviour, mental problems and* the *side effects of medication.* Correspondence to the GP raised the possibility of James developing dementia. The general practice requested that district nursing undertake a blood test: *the entry is ticked and initialled.*
It was in April, James' *family had noticed that he looked skinny in his arms and legs but had a large stomach.*[67]

During early **May 2012**, general practice requested that district nursing undertake a blood test: *the entry is ticked and initialled.* The results *appear to be within the normal range for all parameters.* Goshawk Close *requested confirmation by letter* of the changes to James' medication from the GP.

During **July 2012**, James had a psychiatry review which he attended with his mother and a support worker. Correspondence with general practice noted that James' *bad days* were *increasing…poor motivation, less focussed, needs prompting or may resist personal care. On good days, happy, cheeky and will engage in activities. Compliant with medications, no*

[64] United Response IMR
[65] NHS England East Anglia further information
[66] NHS England East Anglia further information
[67] United Response IMR

physical health concerns including biological functions…increase in anti-depressant…GP to continue with physical management. Staff at Goshawk Close were *to monitor mental health and side effects of medication.* At the end of the month psychiatry was invited by United Response to attend James' Person-Centred Review since Goshawk Close staff had some unspecified *concerns.* Psychiatry sent apologies.

United Response noted that: *for some time before James' death, staff would file his nails (he did not like them cut). His acceptance of this became more difficult and his father took on this role as he responded well to his father. As his mental health deteriorated he refused to let his father undertake this as well. In a staff member's statement to the police,* it was *stated "His nails had to be filed as he had tiny flaps of skin covering them, I believe he may have had a bad experience in the past, so he wouldn't let anyone cut them. His Dad was the only person he would let cut his toe nails." There is a reference in the communication book dated 28 July 2012 as follows: 28/07/2012 – Message to staff to ask Dad to cut his finger nails when he visits on Sunday.*

During **August 2012**, James' father attended the Person-Centred Review at James' day service. James' father and Goshawk Close staff attended. It recorded *concerns about James' mental health…declining attendance at the day centre and deterioration in attention to personal care. James no longer had a structured routine, was declining opportunities to take part in activities and staying in his bedroom.* An Action Plan sought to address these by *providing outreach support at the Centre and Goshawk Close…maintaining communication between keyworkers* and by *staff being more assertive in making choices on James' behalf.*[68] Towards the end of August there was (i) a *retrospective request for a health and social care assessment* and (ii) *a request from care home to carry out a dementia assessment.* Psychiatry *wished to see the* [Goshawk Close] *carers before agreeing to this to hear their concerns.*

During early **September 2012**, general practice requested that district nursing undertake a fasting blood test: *the entry is ticked and initialled* –James had a blood test at Goshawk Close. Days later and at the request of psychiatry *a baseline dementia assessment*[69] was undertaken by a Community LD Nurse in the presence of James' parents. They reported *changes in his behaviour, drinking, eating and taking medication…does not engage with banter with staff/ residents anymore, becomes frustrated, sad face, missing meals, does not play Buckeroo anymore, not interested in TV…speech reduced, needs prompting to use toilet, restless at night – awake/ agitated. James had stopped attending the day centre and had little structure to his day. No activities involving exercise* were noted *other than walking to the shops for Coca Cola.* It was noted that he had *not had the increased dose of antidepressants prescribed* during July. It is suggested that James' repeat prescription had been issued before the request for the change was made. The medication was corrected for the prescription collected by the Goshawk Close staff on 7 September, following James' psychiatry review which he attended with his father and two support workers. Psychiatry noted *a worsening of James' mental*

[68] Suffolk CC IMR
[69] *The results did not indicate dementia* - Norfolk and Suffolk NHS Foundation Trust

*health…*also that *his food intake* had *reduced without any loss of weight.* Based on reports from Goshawk Close, *His physical health* was *reported to be normal. James* was discharged from the learning disability Community Mental Health Nursing Team but remained under the care of the psychiatrist. Correspondence with the GP was not copied to Goshawk Close, even though the staff were *to monitor James' mental health and give psychiatry feedback on his response to the increased antidepressant medication.*

At the end of September, the psychiatrist visited James at Goshawk Close. James' parents and a member of staff were also present. James was *increasingly lacking in motivation to be involved in activities or to care for himself…has declined to visit either his mum or his dad…sleep and appetite erratic, less focused, confused…poor hygiene, anxious…not showing any increased symptoms of mental illness…medication adjusted.* In correspondence, the GP was *asked to continue with physical management and arrange for ECG, (in view of possible cardiac side effects of venlafaxine and Risperidone.*) The ECG was not arranged. *Staff at Goshawk Close to monitor James' mental health and side effects of medication;* they were asked verbally during the consultation and this was confirmed in the letter to the GP.[70]

During early **October 2012**, general practice requested that district nursing undertake a blood test. Since the entry was neither ticked nor initialled it is not known whether James' blood was taken. Days later, James declined to have his blood taken and a support worker suggested that James' father should be *contacted…to offer reassurance and reduce anxiety during the procedure.* Later in the month a GP took James' blood. Towards the end of October, James' father took James' urine sample to the general practice and met a GP to discuss James' blood test results.

At the end of October the Care Quality Commission's inspection of United Response at their Ipswich office determined that the company was compliant with domiciliary care standards.

29. **November 2012**

On **11 November 2012**, a support worker noticed that James' stomach was *noticeably large and James' father, who was at Goshawk Close… agreed* and *an appointment was* made for 15 November. James had a psychiatry review on **12 November** which he attended with his parents and a support worker. James' confusion was *reported as slightly reduced…lack of motivation and self-care continues…reported to be smearing faeces…hallucinatory behaviour, losing weight but tummy distended, mood flat…discussed admission for Assessment and Treatment due to lack of improvement.* The family recall that the psychiatrist was very concerned about the hardness of James' abdomen. An *urgent GP appointment* was recommended and the psychiatrist *tasked Goshawk Close staff with contacting the surgery*. They did so on **13 November** and the duty GP visited James on the same day. However, this was before the psychiatrist's letter was faxed the following day so the GP *was reliant on the summary information from the practice notes rather than up to date information from the psychiatrist.*[71] This stated that James *had a learning disability, was chronically constipated*

[70] NSFT further information
[71] NHS England East Anglia further information

and had behavioural/mental health difficulties. The GP noted that he had *faecal impaction and protuberant abdomen loaded with stool, not tender…no signs of acute intestinal obstruction…James is denying any pain…no vomiting or fever…carers report that James goes to the toilet but…are unsure whether he is constipated.* The staff were advised to call general practice *if symptoms of abdominal pain or vomiting or constipation do not resolve* and laxative medication was prescribed. General practice also advised that James *should go to A&E if* there was *no noticeable improvement in three days.*[72] Although James was given Laxido and Fybogel he remained constipated. His family note that this was *despite that fact that* James *had been taking Laxido/Movicol and Ispaghula husk on a daily basis as a matter of course for years.*

On **14 November**, James' family *received notification that a place at an Assessment and Treatment unit was available…and he could go that afternoon. We went to Goshawk Close at about 2.00pm…to prepare* him *for this move…he was quite amenable to the transfer.* During the afternoon however, *he seemed quite unwell. He was very pale and tired, resting his head on his hand. The Manager updated James' hospital passport to send with him. It described him as 'a mostly independent man.'*

During the evening of 14 November, James was transferred from Goshawk Close to the Assessment and Treatment unit *due to deteriorating mental state*. James' family had been *delighted* at the prospect of this transfer *as it seemed to offer hope that with close observation and assessment by specialist mental health workers it might be possible to improve* his *quality of life by getting his treatment updated/modified.* Nurses at the unit subsequently rang Goshawk Close to ask about James' *stomach and hernia.*

James was *brought to Ipswich Hospital* at **19.47 hours** *with massive abdominal distention. His rectum was impacted with faeces. He was accompanied by a nurse from the Assessment and Treatment Unit – who knew little about him. It was noted that his hospital passport states that 'I do not like injections/needles. When having a blood test I usually like my Dad to be there to support me. It helps if the person performing the procedure talks to me in a calm and friendly way'.*[73]

At **22.20 hours** James was seen by a medical student *not confident to handle the case* who informed the Registrar.

At **23.00 hours** James was seen by the Registrar. James' x-ray showed massive colonic distension with faeces affecting the whole colon. *Disimpaction in theatre the next morning was planned.* An A&E doctor rang Goshawk Close to ask about James' stomach. Staff at Goshawk Close were *unaware of James' admission and advised that James' father could be contacted at any time.*

At **01.24 hours** on **15 November**, James *was reviewed by a senior house officer following transfer to the Emergency Assessment Unit. On examination: very painful anal fissure*[74] *and*

[72] NHS England East Anglia IMR

[73] Ipswich Hospital NHS Trust IMR

[74] An anal fissure is a tear or ulcer (open sore) that develops in the lining of the anal canal. One symptom is a sharp pain when stools (faeces) are passed, often followed by a deep burning pain that may last several hours

faecal impaction. The plan was to review IV fluids, VTE (Venous thromboembolism) *prophylaxis, analgesia and anti-emetics, routine observations, maintain James Nil by Mouth and monitor urine output.*

Since attempts to contact James' father on his mobile phone were unsuccessful, his mother was contacted at **03.30 hours**. She provided the landline number for James' father who undertook to go to the hospital.

At **05.00 hours**, the surgical registrar reviewed James' history with James' father. A Best Interests' decision was indicated on the consent form which James' father signed (indicating that the *procedure had been discussed with him*). The form stated that James was unable to comprehend and retain information material to the decision. Subsequently James *underwent an examination under anaesthetic and a large quantity of faeces* was removed *from his rectum.* James' family state that he was subject to *physical restraint…without documenting this or considering the least restrictive options…they administered anaesthetic* via a cannula *by having several adults forcibly hold him down while he screamed.* This was witnessed by James' father.[75]

James' family state that after surgery, the *recovery nurse advised that we should prompt James to drink as much fluid as we could. We were surprised by this as removal of material from the rectum wouldn't have cleared the obstruction in the colon which had been shown to be impacted too…we complied with this instruction and supported James to take regular drinks.* Ipswich Hospital NHS Trust stated that James' diagnosis was *faecal impaction, not obstruction. The post-operative advice to the nurse from the surgeon was to eat and drink.*[76]

At **17.00 hours** James was violently sick, producing copious amounts of a very dark brown liquid. His bedding had to be changed as it was soiled to the foot of the bed. According to the family, *the nurse did not register any alarm at this.*[77] The Assessment and Treatment unit informed the Learning Disability Liaison Nurse that James had been admitted to Ipswich Hospital and that he had his *hospital passport with him. The liaison nurse contacted the ward to advise of passport…and recommended a safeguarding adults referral…due to the degree of impaction.*

At **19.20 hours**, James *vomited* and at **23.30 hours**, his bowels opened, producing *massive amounts of faeces.* Although he continued to have bowel movements during the following morning….*his abdomen remained massively distended.*[78]

Also on 15 November, the letter arising from James' psychiatric outpatient appointment of 12 November was faxed to James' general practice.

On **16 November**, at **00.40 hours**, James was reviewed by a foundation year doctor…James had *not passed urine since theatre…catheterisation attempts failed* since James *refused.*

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http://www.nhs.uk/Conditions/Anal-fissure/Pages/Introduction.aspx (accessed 12 July 2015)

[75] Meeting with James' family and Ipswich Hospital personnel, *Final agreed version of minutes as sent to coroner,* 22 April 2013

[76] Further information Ipswich Hospital NHS Trust 16 July 2015

[77] Information from family

[78] Information from family

At **03.15 hours**, he was *settled and sleeping.*
At **07.00 hours**, James' father was *contacted and asked to come to hospital to support James with urinary catheter insertion.* He remained *all morning supporting care delivery.*
At **10.45 hours**, James was reviewed by the specialist registrar *who felt James' abdomen was less distended and advised that he could eat and go home later with laxative treatment.* His family recall that *a doctor…asked if his abdomen was normally that shape* and advised that *the plan would be to discharge James on laxatives and suppositories.*[79]
At **11.35 hours** James' Modified Early Warning [MEWS] score was 4 which should, according to the Hospital's protocol, have led to *minimum hourly* observations. These did not occur.[80] According to Ipswich Hospital NHS Trust, James' *saturations were 91% at **11.35** which led to the MEWS score being 4. This can be related to positional issues, removal of nasal* oxygen *etc and therefore these aspects of care are reviewed prior to escalating to CCORT* [Critical Care Outreach Team] *or medical staff.* It has not been confirmed that these actions were taken. *The saturation measurements were repeated after this and had returned to 94% which was within the target parameters set by the medical staff.*[81]
At **14.00 hours**, *the ward nurse noted that James' oxygen saturations were…deteriorating and he was receiving oxygen…an assumption that James would not be going home* was not recorded. [Ipswich Hospital NHS Trust acknowledges that *senior medical input at this point should have been sought.*] *Encouraging the patient to drink during the day when he remained obstructed contributed to the risk of aspiration.*[82] *During the afternoon James' oxygen levels dropped and he was put on oxygen…*[83] *the manager from Goshawk Close…raised concern at James' breathing as it didn't seem to be his normal rate and depth.* A *nurse reassured that this was quite normal following general anaesthetic.* A *consultant has since agreed that this is only true for about 4 to 6 hours after anaesthesia, but this was more than 24 hours later.*[84]
At **18.20 hours**, *the ward nurse noted that James' MEWS was 3, (the score is an indicator of acute deterioration - a MEWS score of more than 3 should be escalated to the medical team) saturations were 94% and pulse rate 116/min.*[85] A score of 3 *necessitates 4 hrly obs. The observations were repeated at 20.30, 22.20 and 23.00.*[86] *The ward nurse did an ECG* [the results were normal] and *asked a foundation year doctor to review him. James* was reviewed at **18.30 hours** by a senior house doctor and *noted to be tachypnoeic, tachycardic and distended…The plan was for laxatives and enemas. No senior input was requested…In retrospect it is likely that he started to aspirate at this point. An abdominal x-ray at this point*

[79] Information from family
[80] Information from James' *Adult Vital Signs*
[81] Further information from Ipswich Hospital NHS Trust 16 July 2015
[82] Significant Incident Requiring Investigation (SIRI) final report 2
[83] Ipswich Hospital NHS Trust state that James *was already on oxygen, it was increased from 21 to 31.* Further information 16 July 2015
[84] Meeting with James' family and Ipswich Hospital personnel, *Final agreed version of minutes as sent to coroner,* 22 April 2013
[85] This is contradicted by James' family who state that: *There was then a MEWS 6 at 18.15 which again should have sparked hourly obs and it didn't. Should also have meant an emergency call to registrar and consultant but no record of this happening. No further obs recorded until 22.20.*
[86] Further information, Ipswich Hospital NHS Trust 16 July 2015

may have been useful in confirming that the patient was still constipated but this appears obvious clinically and a digital rectal examination might have been more useful.[87]

By **22.20 hours**, James' *MEWS score was 8 with oxygen saturation of 91%.* The nurse contacted *the foundation doctor who advised* increasing the oxygen to 28%. Since this did not change the saturation levels, the nurse contacted the doctor back and *was advised to increase the oxygen to 60% with humidified oxygen.* Ipswich Hospital's protocol states that a MEWS score of 6 or more should trigger *an emergency call registrar to review* and with *increased MEWS minimum hourly.*[88]

At **22.40 hours**, the foundation year doctor reviewed James. His oxygen saturation levels *were 91%, his chest appeared to be full of crepitation and wheezes and his abdomen was very distended. The plan was for nebulizers and x-rays and bloods but the latter was impossible due to lack of cooperation from James…*the Registrar was called *who advised an abdominal x-ray. The requirement of the MEWS escalation pathway requires that the patient has senior medical review (Registrar or Consultant).*

On **17 November**, at **00.30 hours**, James' father was contacted and updated. James' abdominal x-ray *showed a dilated small bowel and colon consistent with a large bowel obstruction and the likelihood that James would vomit.*

At **1.00 hours**, the nurse called the foundation year doctor again and James' mother was also contacted. At **1.20 hours**, James was reviewed by the surgical registrar. His *heart rate was 130/min, respiratory rate over 40/min, saturation 91-94%...abdomen very distended. A diagnosis was made of respiratory compromise secondary to distended bowel and advised that he needed decompression…consultant on-call…suggested ITU* (Intensive Therapy Unit) *opinion and flexible sigmoidoscopy in theatre. A nasogastric tube would not have been tolerated by the patient without intubation. Consent form completed in James' best interests for flexible sigmoidoscopy.* His parents were contacted and *advised that James may need to go to theatre.*

At **1.40 hours**, James was reviewed by *Intensive Care Registrar and whilst* being examined *before he could be intubated, James had a cardiac arrest at* **1.55 hours.** A cardiac arrest call was made. A surgical registrar, clinical care registrar and an anaesthetist were present*…two cycles of resuscitation commenced and James was intubated.* The ward *tried to contact James' father but he had left home…James' mother was advised that James was very ill.*

At **2.14 hours**, *resuscitation was unsuccessful and discontinued*. James' father arrived at **3.15** hours.

30. **Investigations**

On **20 November 2012**, there was a post mortem. This *showed that the bronchi and nasal passages contained gastric contents and that it was likely that death was from aspiration pneumonia.*

[87] SIRI

[88] The Ipswich Hospital NHS Trust *Adult Vital Signs*

On **21 November**, a single safeguarding referral made by the Assessment and Treatment unit was sent to the police Central Referral and Tasking Unit (CRTU) for a strategy discussion. The referral was categorised as *deprivation/neglect* by adult safeguarding and it was determined that there should be a *joint investigation – police and adult safeguarding.* Subsequent information from Adult Safeguarding states: *The area safeguarding team and the police jointly sought further information from health colleagues regarding bowel management and the influence poor bowel management may have on the long term health of an individual, following which the police concluded there was no evidence of a crime being committed with regards to criminal neglect under Section 44 Mental Capacity Act 2005. Whilst this marked the end of police involvement, the investigation continued as a single agency approach by the safeguarding senior practitioner. The single agency investigation was concluded some months later as being 'partially substantiated' as although there was no single identified perpetrator, it was recognised that harm had been caused on the basis of evidence of intensive, though at times un-coordinated, support for James' condition. At this point there was an expectation the health service would instigate a SUI* [Serious Untoward Incident report]*. These reasons meant that in isolation, and without hindsight, James' case did not trigger a SCR on its own.*

Up until 2013, the safeguarding service in the county was divided into four geographical areas, with each area consisting of one Safeguarding Manager and one Safeguarding Senior Practitioner. Whilst the safeguarding teams met on a monthly basis, James' details, which were considered to be unique, were not formerly shared with the other safeguarding teams. As a social work profession, the safeguarding team had little medical knowledge on the extent of which a person may suffer as a result of poor bowel management, and the impact this may have on morbidity. In cases such as James, the expectation was for health to undertake a Serious Untoward Incident (SUI)/a root cause analysis. The critical event was when this happened a second time and it became possible to view this as a system failure and not a one off tragedy.[89]

On **26 November**, police and social work attended Goshawk Close *to seize and copy relevant care records*…The police recorded *until James' capacity is known we cannot make a judgement on whether…the Mental Capacity Act would be suitable if it were found that there was some form of wilful neglect…appears unlikely at this stage.*[90]

On **27 November**, a statement from a nurse at the Assessment and Treatment unit noted shock at *the size, shape and hardness of James' abdomen. James gave no indication of being in pain, including during a physical examination.*

On **28 November**, a statement from the psychiatrist noted that James *could not consent to treatment for his mental health condition as he lacked the capacity to do so…did not believe James would understand the consequences of not opening his bowels and due to limited communication would not express an opinion on this…shocked by James' abdomen.*

On **6 December 2012**, police reviewed the investigation.

[89] Further information from Suffolk CC

[90] Police IMR

On **10 December**, police made contact with general practice.
On **20 December**, police transferred the case and ultimately the *record was closed on **28 December**…*There was *no record of a crime record having been created* resulting in *a gap in recording.*

On **23 January 2013**, the police took a statement from James' father.
On **12 February 2013**, the police took statements from Goshawk Close and United Response management.
On **1 June 2013**, James' family requested access to his health records. Correspondence stated that there were *no health records held.*[91] *The records held by East Coast Community Healthcare were focussed around the district nurse's work diary and the provider had no other electronic or paper records within their internal record keeping systems.*[92]
On **18 July 2013**, James' *family* discussed James with the district nurse. There is no *diary evidence of such a meeting.*
On **19 August 2013**, areas for improvement for United Response were identified by Suffolk CC's Accommodation and Review Team.
On **21 October 2013**, Adult and Community Services record that the police *had found no evidence of crime.*
On **18 December 2013**, police record that there is *sufficient information to conclude that James lacked capacity.* The police did *not believe there was sufficient evidence to support…wilful neglect.*

Although the chronology concerning James does not detail the events following his death,[93] Ipswich Hospital NHS Trust commissioned a Serious Incident Requiring Investigation (SIRI). *Following the SIRI, three external reviewers were commissioned to review 1) the SIRI process and RCA* [Root Cause Analysis], *2) review the care given to James specifically in relation to his learning disability, 3) an external surgeon to review the surgical care provided.*[94]

The *external reviewer's* account is cited as confirming that although *the correct health services were provided with regards to surgical treatment…IHT does however acknowledge that there was a lack of recognition of severity of James' condition when he first developed respiratory problems.* Also, although it asserts that there *was no evidence of discrimination or diagnostic overshadowing* the basis for this is not clear. The SIRI concluded that: *There was a lack of awareness of the possibility of aspiration pneumonia by all clinical staff and particularly patients with learning difficulties. Respiratory distress was attributed to abdominal distension.* The SIRI acknowledged that: *earlier senior review is likely to have supported earlier recognition of James' deteriorating condition;* he *remained distended and was continuing to vomit. If there was doubt re: obstruction then further abdominal x-rays should have been*

[91] NHS CCG IMR
[92] NHS CCG further information
[93] On 10 June 2015 Ipswich Hospital noted: We have no further records relating to James' care immediately pre and post death except the resuscitation notes which contain a high level of clinical interventional information i.e. drugs used
[94] Clarification received from Ipswich Hospitals NHS Trust on 16 July 2015

requested; escalation processes were not consistently followed relating to Moderated Early Warning Scores. In addition, the external reviewer noted that the *SIRI report demonstrates limitation with regards to embedding a person-centred approach…the investigators…needed to demonstrate more appreciation of James' learning disability and expertise from learning disability, safeguarding and mental capacity/DoLS hospital leads; there was an over reliance and unrealistic expectation of the learning disability liaison nurse role, which are office hours based Monday to Friday;…reasonable adjustments policies must be followed and discussions/ outcomes identified.*

The *Independent Review 2* noted that *the lead investigator of the SIRI had not attended training on Root Cause Analysis or any Serious Incident related training and this was the first SIRI* they *had undertaken; the family members were not interviewed as part of the SIRI; the terms of reference…are not explicit within the SIRI report…the inclusion of aims and objectives…would have been helpful; the final report was submitted on 01/02/2013 – this exceeded the 45 day reporting requirement; at the initial…meeting recognition and escalation of the deteriorating patient was thought to be the core of the investigation – this may have provided a narrow view to this SIRI; there were times when clinical decision needed to be made where a mental capacity assessment should have been carried out; although there was evidence in the notes that reasonable adjustment had been applied, this was not always documented clearly; junior doctors who had made clinical judgements were not interviewed as part of the SIRI.*

The Ipswich Hospital NHS Trust states that there had been *considerable development…internally* arising from James' death citing: *the liaison, safeguarding and mental capacity assessment processes…in place with identified leads…there are plans and the need for mandatory training for Mental Capacity Act/Deprivation of Liberty Safeguards; LD Liaison Nursing audited admissions of patients with a learning disability that week and acted on the high incidence of patients with severe constipation and faecal impaction…trends were identified and fed into the training plan* and [during October 2013] *delivered training to GPs on the specific health needs of people with learning disabilities with particular reference to constipation, faecal impaction and aspiration;* [in May 2013] *a specific Learning Disabilities Policy was implemented; a patient pathway for 'deteriorating patient' has been implemented in response to James' death addressing the issues regards assessment, decision-making, policy, assessment of competency of all clinical staff, outreach support and access to senior medical advice; best practice review of MCA documentation…; audit programme of a randomised sample of patients' notes of patients with a learning disability is ongoing…; family/carers policy, carers passport and carers kitchen have all been implemented;…purple dot on patients' notes…to alert hospital staff of patients with a learning disability; service level agreement with general practice to alert hospital of potential admissions of people with learning disabilities.* In addition, *Review 1* states: *The hospital staff interviewed expressed their concerns as to how the family had been responded to with clear lessons learnt regarding engagement with family members at a time of loss and bereavement.*

A source of keen anguish for James' parents was the observation of a nurse after his death that it was *his time to go*. The inference taken by the family was that there is nothing untoward concerning the death of a 33 year old man from complications arising from faecal impaction.

Section three: Analysis

Mental Capacity, Best Interests and Decision making

31. James had been known to NHS learning disability services since 1998 when his parents experienced difficulties managing his behaviour. Until he was 18 (in 1997), decisions would generally have been made by his parents, unless there were areas of disagreement with health or social services. When he became an adult, and prior to the implementation of the Mental Capacity Act 2005,, decisions for James *would have been made under 'best interests' and with the agreement of his next of kin and/or social worker.*[95] There are two key areas during this period where decision-making on behalf of James was significant.

32. From March to November 1999, James underwent assessment at a hospital based mental health unit. He had been admitted there from a social care respite unit because of his *aggressive and uncharacteristic behaviour.*[96] It was agreed that a return to live with his mother was not possible because of his unpredictable behaviour and an alternative placement was sought. James was introduced to Goshawk Close, a care home run by United Response, and after introductory visits and overnight stays he was finally discharged there during November 1999. Although the records include discussions amongst professionals about how to tell James that he would not be returning home, there is no evidence that this discussion actually took place or that a process was followed or even for determining that such a move was in James' best interests.

33. The second area for decision making concerned health interventions to investigate James' distended abdomen and his ongoing problems with constipation. There was discussion concerning the possibility of Hirschsprung's Disease, the diagnosis of which would have involved invasive procedures that James' psychiatrist did not believe he would be able to tolerate; *as his bowel function is reasonable at present the benefits outweigh the risk of deterioration in his mental state.*[97]*James* did, however, undergo two anal stretches under anaesthetic and there is no evidence of whether his capacity to agree to these procedures, or a Best Interests Decision process, was documented. It is not known when he developed an anal fissure.

34. Following the implementation of the Mental Capacity Act, there were many aspects of James' day to day life that should have been considered in relation to decisions such as his refusal to go to the day centre or participate in activities that he had previously enjoyed (such as swimming and the theatre); his choices about diet (such as eating cereal bars instead of a proper breakfast and drinking coca-cola); his tendency to stay in bed or return to bed during the day time; his take up of health checks; his consent to blood tests and other investigations; and his refusal to have an enema (which may have been associated with his anal fissure) and his reluctance to be weighed. The only reference in the GP records to James' lack of capacity

[95] NSFT IMR
[96] NSFT IMR
[97] NHS England East Anglia IMR

is in a letter from psychiatry in April 2011 which states that the treatment (investigations and on-going medication) was given in his best interests. The GP practice found James to be *reluctant rather than resistive* to investigations such as blood tests and that with the support of Goshawk Close staff he could usually be persuaded to co-operate. They therefore did not believe *it was necessary to invoke the MCA and document Best Interest decisions.*[98]

35. In November 2011, a local authority-led review of James' care and support needs was held but the standard question about mental capacity assessment was left blank. James' family and Goshawk Close support staff were of the view that he did not have the capacity to *understand why eating certain food, having regular drinks or being active* were important for his health or the risks associated *with a low fibre, low fluid diet and sedentary lifestyle*[99]*.* Such factors proved crucial in his deterioration. Yet there is no evidence in the records that these matters were considered or plans agreed on how to address them within a Best Interests Decision framework. It is therefore possible that staff supporting James presumed that he did have capacity. This is extremely problematic and arguably constitutes an example of the misapplication of the legislation by front-line staff. Where a person with a learning disability is refusing beneficial interventions such as medication and health checks for example, an assessment of capacity should be undertaken. This may require more imaginative engagement by service providers such as arranging a home visit rather than issuing an invitation to attend for a health check; although this was suggested at one time at the GP practice, it was not followed up and James was removed from the list for that year because of his *non-attendance*.

36. A significant period of transition for James was when Goshawk Close changed its status from a registered care home to tenanted supported living accommodation[100] in July 2010. Although the social worker noted in the local authority care record in April 2009 that James might require further assistance to understand the proposed changes and that *a mental capacity assessment may be required and a deputy may need to be appointed in the future,*[101] there is no further reference to James' mental capacity. The minutes of the Accelerated Moving On Strategy steering group indicate that responsibility for capacity assessments was passed to the housing provider, which was the Landlord, but the domiciliary care provider, United Response, was responsible for the capacity assessments with regards to the tenancy agreement.[102] The outcome for James was not recorded in his care record. This is a significant omission and the practice was contrary to Suffolk CC's guidance on recording mental capacity at the relevant time.[103] His family report that James did sign the tenancy agreement despite

[98] NHS England East Anglia IMR
[99] United Response IMR
[100] Registered as domiciliary/home care
[101] Suffolk CC IMR
[102] Suffolk CC further information
[103] *Mental Capacity Assessment Recording Guide* Suffolk Adult and Community Services, March 2009

their expressed concern that he did not have capacity to understand what this involved.[104] It should also be noted that James could not read.

37. Following James' final admission to Ipswich hospital, the consent form completed by the surgical registrar noted that James was *unable to comprehend and retain information material to the decision or use and weigh the information in the decision making process, therefore best interests decision made on consent form.*[105] The form was signed by James' father. Apart from this form, there were *limited documented mental capacity assessments or best interest assessments* in the patient records.[106]

38. The only other record of consideration of whether James had mental capacity was during the police investigation after his death. Following consultation with the psychiatrist, the investigating officer came to the conclusion that James lacked capacity, but that there was insufficient evidence to support a view of *wilful neglect*.

39. James' family expressed misgivings about the inattention of support staff to cutting James' nails. They are distressed that his toe nails had not been cut for *some time* before his death, and recalled that they were curling under his toes.

40. James' family were not persuaded, by the readiness of staff supporting him, that they should accept his unfettered 'choices' as irrevocable and non-negotiable. James was allowed to assume responsibility for situations for which he could not be entirely responsible. It is not reasonable to expect that a man who depended on staff for his day to day support could extricate himself from the consequences of adopting an increasingly sedentary lifestyle, long term inattention to hygiene and eating food which compromised his bowel function, for example. The fact that knowledge about ends and means is accumulated gradually may have been overshadowed by a misplaced respect for James' choices. It is unlikely that James understood the interlocking cause and effect sequences over time of his choices, most particularly since they were not promising of his future well-being. There is a compelling case for shifting the burden of proof from adults with learning disabilities to professionals, support personnel and service providers, that is:
    i. *is the evidence compelling that the short and long term effects of the choice have been presented in different and engaging ways to the decision-maker?*
    ii. *can the decision maker explain what the different consequences of their 'choice' would be in the short and long term?*
    iii. *[In the light of identified 'choices,'] how can the service demonstrate that they are actively seeking to promote healthy lifestyles?*
    iv. *what preparation has the decision maker had in making supported decisions?*

[104] Family report
[105] Ipswich Hospital NHS Trust IMR
[106] Ipswich Hospital NHS Trust IMR

v. *has the documentation behind the choice to resist treatment been shared with people's relatives, senior managers and the Primary Care Team?*[107]

41. The House of Lords Select Committee on the Mental Capacity Act 2005 Report of Session 2013-14 *Mental Capacity Act 2005: post-legislative scrutiny* (HL Paper 139) stated that *The Act has suffered from a lack of awareness and a lack of understanding. For many who are expected to comply with the Act it appears to be an optional add on, far from being a central to their working lives…the prevailing cultures of paternalism (in health) and risk-aversion (in social care) have prevented the Act from becoming widely known or embedded. The empowering ethos has not been delivered. The rights conferred by the Act have not been widely realised. The duties imposed by the Act are not widely followed.* This is a critical backdrop to James' circumstances.

42. In summary, all agencies failed to address the issue of whether James had capacity to make a range of decisions, not least in relation to his physical health. His assumed choices about drinks, diet and exercise impacted on his bowel health, and yet the provisions of the Mental Capacity Act were not invoked.

Ascertaining James' needs and wishes and involvement of family in decision making

43. James was described as having poor verbal communication skills and *people had to try and deduce his mood, preferences and need from body language.*[108] The Statement of Special Health Needs produced by the hospital based mental health unit in 1999 states that James *will answer 'yes' inappropriately especially in response about bowel function.*[109] From the Goshawk Close care records it is clear that staff were familiar with the things James enjoyed doing and supported him appropriately in the areas where he had difficulty. However, James' behaviour and mood changed significantly from mid-2009 and he became increasingly difficult to motivate. He became agitated and upset when pressed to do certain things, such as eat a proper meal or get out of bed in the morning, and the staff withdrew rather than provoke a confrontation, particularly as the advice from the psychiatrist was to avoid putting too many demands on him. These changes were ascribed to his deteriorating mental health, rather than to any physical health problems, so typically resulted in changes in anti-psychotic or anti-depressant medication.

44. James' family questioned whether or not staff supporting him had accessed the composite video they compiled, not least so that they might appreciate the impact of mental illness in his life. United Response noted: *we have no evidence that staff accessed this and we were unable to find such a film in the files or archives.* It also noted: *though that this was a film of James as a child,* it *would not necessarily have been relevant to him as an adult; indeed staff may have thought of this more as being background to his history rather than a guide to the*

[107] Keywood, K., Fovargue, S. and Flynn, M. (1999) *Best Practice? Health-care decision-making by, with and for adults with learning disabilities* Manchester Institute of Medicine, Law and Bioethics and the National Development Team
[108] United Response IMR
[109] United response IMR

adult.[110] Given that the nature of service delivery impacts on the wellbeing of family carers it is disappointing that the significance of James' life history before his opportunities were foreshortened by mental illness was not acknowledged. Arguably the video was an important means of demystifying the family's experience and engaging with their agenda at a time when their strengths were being overshadowed by James' difficulties. The act of sharing significant events and images using a family album or, in this case, a video is not undertaken lightly. This is particularly poignant since, from a family perspective, they were dealing with the loss of the man they knew and the end of the full-time active caring role they shared. A significant consequence of a chronic illness is that it separates the past from the present and the present from the future – rendering a person's biography 'discontinuous' (e.g. Corbin and Strauss 1988).

45. James lived at home with his parents (latterly his mother) until he was 18 and they remained actively involved in his care throughout his adult life. The decision to arrange an emergency admission to respite care in 1998 was made following discussion between James, his parents, social work and community psychiatric nursing. There is evidence that his parents were consulted regularly about care arrangements for their son. However, the placement was not ideal from the perspective of James' parents because they did not believe that his mental health needs were being adequately addressed; although their view that it was no longer possible for James to live at home was taken seriously and alternative plans for his care were made. This led to his placement in Goshawk Close. One or both of his parents usually attended reviews and accompanied him to hospital out-patient appointments. However, there is little recorded consultation specifically with his parents about the proposed changes to supported living at Goshawk Close, although the minutes of the Accelerated Moving On Strategy steering group note that *all parents are happy with the change of registration, finance and tenancy.*[111]

46. During 2009, prior to the change in status of the accommodation in 2010 but during the planning period for the change, staff at Goshawk Close stopped using bowel charts. It is not clear why this change occurred, but his family were not aware of it. Had they known about it, they would certainly have raised concerns because they knew the importance of bowel care for James' health, having managed this successfully when their son lived with them. They had also been assured that the change to supported living would not result in any dilution of the level of support provided to tenants, so this change in care practice was of particular significance for James and his family. However, *the charts themselves had an inherent weakness due to the difficulty of observing directly what James did in the toilet*. That is, although bowel charts were maintained until January 2009, they were unreliable as a method of determining his bowel health since there were *occasions when James did not have a bowel movement for 5 or 6 days or longer; sometimes there is a question mark in the column about size/consistency;* and *using marks on the toilet pan or evidence of soiling in clothes* was

[110] Email 25 May 2015
[111] Suffolk CC IMR

described as *counter-productive for staff who were unfamiliar with the complications of severe constipation and faecal impaction.*

47. United Response acknowledges that the model of supported living was not explained to support staff *in a way that made sense to them*. Consultation with families also happened in advance of discussions with staff about the changes. They therefore felt at a disadvantage when families asked questions about the proposed model. Initially the new model resulted in Goshawk Close becoming *dirty and untidy because the tenants were not able to help with domestic chores as envisaged* and cleaning without the assistance of tenants was no longer part of the role of staff.[112]

48. James' family did raise concerns from time to time. For example, in early 2011James'mother talked to the staff about his diet and weight gain and suggested that he could be offered healthier options. The staff responded by purchasing Weight Watchers' meals for him and he was later supported to join a Weight Watchers programme, losing weight successfully. However, support for his dietary choices came to be related to James' weight rather than to maintaining good bowel health.[113] His family reported that too often problems were allowed to develop without their being informed, to the point where behaviours became entrenched and so much more difficult to deal with. They sought to ensure *that best interest decisions could be made for him and to discuss proactive strategies for encouraging and prompting self-care.*[114]

49. In summary, James' weight ranged from 73.5Kg [11st. 8lbs] to 70Kg [11st]:
    September 1998, *gaining weight*
    October 1998, *gained a stone in weight*
    February 2010, 73.5Kg [11st. 8lbs]
    October 2010, 73Kg
    April-June 2011, 70Kg
    January 2012, 70Kg [11st]
    September 2012, *his food intake* had *reduced without any loss of weight*
    November 2012, *losing weight but tummy distended*

50. James had occasional contact with the GP practice, attending for health checks and for particular concerns; e.g. early in 2011 he had a lump and a hernia was diagnosed. He was always accompanied by support staff from Goshawk Close who provided information and mediated James' wishes. However, neither general practice nor United Response had explored with the family how they had discerned when James was in pain or discomfort. In addition they had no materials to aid communication.[115]

[112] United Response IMR
[113] United Response IMR
[114] Family report
[115] NHS England East Anglia IMR

51. During James' final hospital admission, attempts were made to contact his parents promptly and his father arrived at the hospital in the early hours of 15 November. James had a hospital passport which noted that he was *a mostly independent man…I do not like injections/needles. When having a blood test I usually like my Dad to be there to support me. It helps if the person performing the procedure talks to me in a calm and friendly way.*[116] Although the hospital state that passport was used as a tool to help ascertain his wishes, it is significant that it omitted to reference James' *history of life-long chronic constipation*[117] and gave a misleading impression of his self-care skills.

Identification of James' needs for health services and provision of services in response

52. James had known bowel problems from an early age. He was prescribed laxatives from infancy. He had two conditions which are known to carry increased risks of constipation: Down's syndrome and hypothyroidism. In addition, James was prescribed medication for his mental health problems that had known side effects of constipation: Venlafaxine (for the treatment of depression) which was prescribed for about fifteen years right up to his death; and Risperidone (for the treatment of schizophrenia and psychoses), which had been prescribed again for James in September 2012.

53. The link between James' bowel health and changes in his behaviour had been identified by the psychiatrist in a letter to general practice in 1998 and included in the Statement of Special Health Needs document from the hospital based mental health unit in 1999. Such documentation clarified the link between James' mental health, bowel management programme and quality of life and this information was valid beyond 1999 and his move to Goshawk Close.

54. There is evidence that, for the first five or six years at Goshawk Close, James' diet was designed to promote spontaneous bowel openings; the daily diaries up until 2007 included All-bran, prunes, fruit juice and fresh fruit for example. Documents such as a Medical Profile and Dietary Needs sheets referred to high fibre foods and fluids. The use of bowel and stool charts for many years – up until January 2009 – is consonant with the original assessment.[118] However, it is acknowledged by United Response that in a residential environment where an individual is fully mobile and able to use the toilet on their own, accurate monitoring is very difficult without invading a person's privacy and restricting unaccompanied access to the toilet. It is possible that in the more clinically focused setting of a hospital based mental health unit, more accurate monitoring was possible and that staff understood that James had a serious condition, even without a formal diagnosis of Hirschsprung's Disease.[119]

55. The information in the Statement of Special Needs should have featured at the front of James' care notes, GP notes and psychiatric notes since this was lost.

[116] Ipswich Hospital NHS Trust IMR
[117] Family report
[118] United Response further information
[119] United Response further information

56. Following James' move to Goshawk Close he was subject to the Care Programme Approach (CPA), with four multi-agency meetings taking place during 2002 to 2004. At a CPA meeting in July 2004, James was discharged by the CPN and he became the responsibility of the Consultant Psychiatrist; multi-agency CPA meetings ceased and he was monitored under the standard CPA. When national guidance changed in 2008,[120]James was categorised as Non CPA, which meant that he was not considered to have complex or high risk needs and could therefore be managed by the consultant psychiatrist. His CPA status was not subject to further review. Although he was assessed by a Community LD Nurse at the request of the psychiatrist in September 2012 for possible dementia, this *concentrated on memory and cognitive function*[121] and there is no evidence that it included wider consideration of possible physical causes of his change in mood and behaviour or a review of his CPA status. Missing meals and his symptoms of agitation and restlessness at night were consistently attributed to mental health problems.

57. A more thorough review, in the light of his deterioration in functioning, may have concluded that he met the criteria for CPA, given that these include
    - *Self-neglect/non concordance with treatment plan*
    - *Current or significant history of severe distress/instability/ or disengagement*
    - *Presence of non-physical co-morbidity e.g. learning disability*
    - *Significant reliance on carers*

    This was a missed opportunity for the wider CLDT to have considered the link between his behaviour and his bowel health and the level of understanding of the Goshawk Close staff of how to monitor his bowel function and support him appropriately.

58. In June 2010, Goshawk Close was de-registered as a residential care home and became a supported living scheme. This had implications for how James' health needs were going to be met. The other tenants in the scheme had *varying levels of complexity of need, including mild learning disabilities, cerebral palsy, mild epilepsy, anxiety, challenging behaviour, mobility issues and complex mental health needs.*[122] There is no evidence that the GP practice (or other health services) was involved in reviewing the delivery of services following the contract change for any of the tenants. Any specific implications for the GP role were not identified and, conversely, information and guidance from the GP to Goshawk Close about James' health needs and the responsibilities of the practice were not provided.[123]

59. In January 2006, James was placed on the GP practice learning disability QOF (Quality Outcomes Framework) register. This initiative was an early attempt to ensure that the additional health needs of people with a learning disability and inequalities in accessing health services were recognised and addressed. James' inclusion on the register should have enabled

[120] *Refocusing the Care Programme Approach: Policy and Positive Practice Guidance* (2008) Department of Health
[121] NSFT further information
[122] United Response further information
[123] NHS England East Anglia further information

the practice to ensure that there were plans to have his health needs assessed and met. However the QOF register and payment did not require any evidence of health services delivered and there was no guarantee that entry on the QOF register would lead to any specific attention being paid to their needs. In 2000, *Valuing People* sought to address the fact that (i) people with learning disabilities experience a greater variety, number and frequency of health problems than the rest of the population and yet they use the NHS much less than they need to; and (ii) the wider NHS relies unduly on specialist learning disability services, rendering it unskilled in making services responsive, accessible and acceptable. In response, the Learning Disability Directed Enhanced Service was introduced in 2008/9 with full payment made only after the patient has had a health check.[124] Although James' GP practice was an early adopter of the scheme, there is little evidence that this incentive had any significant impact for James- despite the fact that he had long been identified as a man who would require persistent health advocacy since he relied on others to be attentive to observing changes to his body and his behaviour.

60. The Royal College of General Practitioners guidance (2010)[125] explains what annual health checks under the Learning Disability Directed Enhanced Service should comprise. It identifies people with a moderate learning disability as a priority group for health checks and these should include *assessment of feeding, bowel and bladder function***.** The guidance states that If the person with a learning disability does not have capacity to consent then the GP should consider the risks of not doing health checks and whether 'best interests' should apply.

61. The annual health checks should have provided a vehicle for the GP practice to monitor James' health generally and to give particular attention to his bowel health and known constipation. Psychiatry had alerted the practice in 1998 to the fact that two of James' medications could worsen his constipation. James had health checks in December 2009 and in 2010; in both instances two letters of invitation were required. He missed his health check in 2011 despite three letters of invitation; the practice had no policy of follow up to ascertain the reasons for non-attendance, so James was transferred to the list for the following year. In his case, the invitation letter for his 2013 health check would have been sent 26 months after his 2010 health check.[126] This is a remarkable lack of attention to the particular needs of a cohort of people who are on a register because of their learning disabilities, that is, with some degree of cognitive difficulties, requiring additional support to access health care. Although the nurse noted that James would *need a home visit for learning disabilities, defer for current time,*[127] this was not followed up and two further standard invitation letters were sent, with no response. The removal of James from the annual check list after a series of non-attendance is at odds with the RCGP guidance: *If you assess that the person does not have capacity to consent to the procedure, consider if the principles of 'best interests' need to be used. If they*

[124] NHS England East Anglia further information
[125] *A Step by Step Guide for GP Practices: annual health checks for people with a learning disability* (2010) Royal College of General Practitioners www.rcgp.org.uk/learningdisabilities accessed 13.01.15
[126] NHS England East Anglia IMR
[127] NHS England East Anglia further information

do, involve the carer, doctor and document your combined findings in the notes. In most patients with a learning disability it will be in their best interests to have an annual health check.[128]

62. United Response described their *standard practice:* it *has always been that our staff read and respond to important correspondence such as primary care appointments on behalf of people we support where they are unable to read or write such information themselves. We have recently supplemented this with our new people we support files (which have been revised and updated) and now, In the case of a primary care appointment, our staff are required to fill out a new "appointment form" which documents that an appointment has been received and action taken following this. If a person refuses to attend an appointment, this form then prompts staff completing it by asking whether the person has capacity and whether a best interests meeting needs to be convened. This was always our practice but we are now requiring that this be documented. Our people we support files include a whole section on mental capacity and decision making around health and our policy states that our staff must make sure that a local GP knows our assessment of someone's capacity and that this must be reviewed at least annually. If there any concerns about someone's health these are first raised with the person themselves and escalated to the area manager and divisional director if not resolved.*

63. United Response's *standard practice* did not work for James since he did not attend appointments which would have ensured an *enhanced service* for him. The service's self-scrutiny confirms that his *most frequent and regular contact with health professionals was related to mental health* and his physical *health and wellbeing was seen primarily through the lens of mental illness.* Goshawk Close staff had (a) no information about the association between behaviour change and constipation or between medication and constipation from either the lead clinician in James' care, the psychiatrist, or the GP with whom he had very limited contact and (b) no training in relation to bowel management or constipation. *It seems that over time concerns about his weight became predominant with dietary choices considered in that light more than being related to bowel management.*

64. *In James' case, health concerns focused primarily on his MH problems – especially during the last two years of his life. These were reported to his consultant psychiatrist by our staff. A family member, often his father, would attend all health appointments. Had James routinely missed such appointments, it is likely this would have been discussed with the family and reported to the psychiatrist as evidence of his deteriorating mental health.*[129]

65. This correspondence concerning the health check occurred during a period when James' behaviour and mood deteriorated and he was seen at home by the psychiatrist, in addition to reviews in the out-patients clinic. Subsequent letters to the GP practice in January, April

[128] *A Step by Step Guide for GP Practices: annual health checks for people with a learning disability* (2010) Royal College of General Practitioners www.rcgp.org.uk/learningdisabilities (accessed 13 January 2015)
[129] Email from United Response 25 May 2015

and September 2012 asked general practice to *continue with physical management.* The September letter also reported James' worsening mental health, his lack of motivation to take part in activities or to care for himself and that his food intake had *reduced without any loss of weight*.[130] However, there was no direct patient contact by general practice between February 2011 and October 2012 although there were regular referrals to district nursing for blood tests; indeed, district nurses visited James in September and October to undertake blood tests and on neither occasion did the Goshawk Close staff request *an assessment or advice or required advice to remove impacted faeces*[131]*.* Neither did the district nurses demonstrate professional curiosity by asking questions about his general health. General practice visited to take blood on 19 October 2012; given the length of time since James had last been seen, the reports of his changed behaviour and his known problems with constipation, this was a missed opportunity for a physical examination.

66. The events of 11-14 November 2012 are worth examining in some detail. On 11 November, a support worker at Goshawk Close noticed that James' stomach was *noticeably large.*[132] This was pointed out to his father, who agreed, and the worker undertook to arrange a GP appointment; this was made for 15 November. On 12 November James was reviewed in the psychiatric out-patients clinic accompanied by his parents and a support worker from Goshawk Close, who pointed out James' distended stomach. The letter to general practice noted: *not so confused, but poor self-care, faecal smearing… losing weight but tummy distended, poor self-care,*[133] yet a physical examination was not prioritised. Instead the psychiatrist requested that general practice *continue with physical management*, asked Goshawk Close to liaise with general practice, set a review for five weeks hence and considered *an admission for assessment and treatment*[134] to assess *treatment and mood.*[135] The GP visited the following day at the request of Goshawk Close staff and found *faecal impaction and protuberant abdomen loaded with stool.*[136] However, the GP did not identify the acute nature and risk of James' condition and prescribed laxatives, although they advised that James should go to A&E if there was no noticeable improvement in his condition. Following the decision of the psychiatrist at the out-patient appointment, James was admitted on 14 November 2012 to the Assessment and Treatment Unit where he was physically examined according to the admission protocol. It was immediately apparent that James' condition was serious and he was taken to A&E.

67. In summary, the references to James' abdomen are as follows:

    May 1998, his abdomen was *noted to be distended*
    June 1998, his abdomen was *very distended*
    July 1998, he had a *distended abdomen*

[130] NHS England East Anglia IMR
[131] CCG IMR
[132] United Response IMR
[133] NSFT IMR
[134] NSFT IMR
[135] NSFT further information
[136] NHS England East Anglia IMR

September 1998, his abdomen was distended
October 1998, his *abdomen* was *distended*
March 2011, *distended stomach*
April 2012, *family had noticed that he looked skinny in his arms and legs but had a large stomach*
November 2012, stomach was *noticeably large…distended…protuberant abdomen*

68. Ipswich Hospital NHS Trust acknowledges the findings of the SIRI which noted: *Earlier senior review is likely to have supported earlier recognition of the patient's deteriorating condition. Before James' respiratory system was irreversibly compromised it should have been clear that* he *remained distended and was continuing to vomit. If there was doubt then further abdominal x-rays should have been requested…There is a requirement to escalate for appropriate senior review as per MEWS protocol. If the registrar or consultant is not immediately available, assistance may be sort via the CCORT* (Critical Care Outreach Team) *or by consultant advice to refer to ITU* (Intensive Therapy Unit)*.*

69. James was known to the mainstream community nursing service since it carried out the GP's requests for blood tests. Although it had been involved prior to 2003 by administering enemas to James, there is no evidence that it was involved in this aspect of James' health care after this date; Goshawk Close staff did not seek their advice about his bowel problems and the GP did not ask them to check his bowel functions or give him enemas.

70. James' health needs were not effectively monitored or managed. There was an over-reliance on the out-patient oversight of a psychiatrist. James' presenting problems of withdrawal from activities, lack of appetite without accompanying weight loss and poor personal self-care were viewed consistently through the lens of mental health rather than as symptoms of discomfort or pain arising from severe impaction. The lack of attention by general practice to the importance of regular health checks – specifically aimed at ensuring that the health needs of a known, vulnerable population are addressed – meant that it relied entirely on the psychiatrist and on the Goshawk Close staff to alert it to any concerns about James' physical health. General practice did not involve district nurses in monitoring James' bowel health, using them solely as phlebotomists. The psychiatrist paid insufficient attention to James' bowel problems despite his diagnosis of hypothyroidism, the known side effects of two of his medications and his lifelong history of constipation. Although psychiatry had lead clinical responsibility for James, there is no evidence of assumed responsibility to review James' physical health needs or to co-ordinate his health care. All these factors are suggestive of *diagnostic overshadowing*, that is, where symptoms of physical ill-health are seen to be as a result of an individual's learning disability or mental health rather than requiring investigation in their own right.[137]

[137] See, for example, Disability Rights Commission (2006) *Equal treatment: closing the gap – a formal investigation into physical health inequalities experienced by people with learning disabilities and/ or mental health problems* Part 1 of the DRC's formal investigation report, London; see also the General Medical Council Guidance concerning inadvertent discrimination http://www.gmc-uk.org/learningdisabilities/200.aspx#207 (accessed 1 August 2015)

Assessment of James' care placement needs and appropriate service delivery to meet them

71. The first care placement for James was in 1998 when he was admitted to emergency respite because his behaviour had become difficult to manage at home. There was good liaison between the social worker and the various health professionals during this crisis. James received appropriate mental health care following his admission to a hospital based mental health unit and plans were initiated for his future care and support.

72. The second care placement was James' move from the mental health unit to Goshawk Close in 1999. He was assessed as requiring *24 hour care as part of a small group in a residential setting.*[138] The hospital produced a Special Health Needs Assessment but there was no care plan identifying James' care needs or how they would be met. However, a detailed review was held six weeks after his admission at which his physical and mental health needs and the care he was receiving were explored: James' *bowels are functioning really well and his diet and the support from staff is proving very successful.*[139] It would appear that James' prescription of daily laxatives masked the necessity to monitor his bowel health.

73. The final care placement was the transition from residential care to supported living at Goshawk Close in July 2010. The most recent assessment of James' needs had taken place in January 2009, some eighteen months previously, and had concluded that he *could be considered for a 24 hour supported living project.*[140] No new care plan was produced by the local authority, so his needs in relation to his bowel care were not identified or specified, and there was no *Health Action Plan*.

Management, monitoring and review of final care placement and responsibilities of each organisation

74. The lack of advice and guidance for the Goshawk Close staff meant that James' chronic constipation and associated risks were not managed effectively. Monitoring James' bowel functions was problematic. His assumed independence in using the toilet – at least until signs of his deterioration were evidenced in the last three years of his life – and the lack of recognition by the Goshawk Close staff of evidence that he was chronically constipated meant that his bowel problems increased. James did not understand that he was constipated and he was unable to tell the staff that he felt unwell, bloated, and uncomfortable or had a hard and swollen tummy; his bowel health was dependent on others identifying and interpreting the signs. His behaviour changed, that is, he ceased to tell staff that he had used the toilet and did not ask for help in cleaning himself. He sought *to keep staff out of the toilet by pushing them away.*[141] The staff thought that his soiled underwear and the marks on the toilet bowl were evidence that his bowels were being opened normally; they did not recognise these as possible indicators of overflow diarrhoea. When James became lethargic and was reluctant to get out of bed, the advice from the psychiatrist was that staff should reduce the demands they were making on him. Significantly, the lack of involvement from either the CLDT or district nursing meant that the Goshawk Close staff did not benefit from expert advice about

[138] Suffolk CC IMR
[139] Suffolk CC IMR
[140] Suffolk CC IMR
[141] United Response IMR

the significance of good bowel health and the risks of constipation for someone with James' known history and medication regime.

75. Formal reviews of James' final care placement by social services should have been undertaken in accordance with Suffolk CC's good practice guidance on *Assessments, Care Plans and Reviews*, which required that these should be annual.

76. A social work review was held in November 2011. There was no input from health professionals or from the day service staff and the quality of the review was poor: despite the fact that there was no current local authority care plan, it was concluded that the aims of the current care plan were *being met*; there was no discussion about James' bowel condition or how it was monitored or managed; and there was noted to be *no change since last review* in his psychological well-being, despite his having become *suddenly … unmotivated and stopping swimming and attending church.*[142] It was also noted that *staff have undertaken no specialist training to work with James.* According to Suffolk CC's guidance, the review should have included a completed Needs Assessment Questionnaire and revision of the care plan's aims and objectives. The reviewer was unaware of this guidance.[143] External, local authority-led reviews at Goshawk Close seem to have been *sporadic rather than regular.*[144]

77. James had attended a community resource centre since 1998 and from July 2010 (when Goshawk Close became a supported living service) to November 2012 he attended on four days a week. From 2006 he had the same key worker who produced a Support Plan with a senior support worker from Goshawk Close in 2010 and co-ordinated Person Centred Reviews in 2010, 2011 and 2012. These were always attended by Goshawk Close staff and either James' mother or father. The review in 2010 identified that James needed more support in maintaining a healthy diet and that he had recently started to withdraw from activities he previously enjoyed. The Action Plan identified the need for a *Health Action Plan* and this was produced in December 2010; there is no evidence that general practice or the specialist learning disability service was involved in this process or knew that it existed, so it had no impact. His parents were recorded as viewing the care at the day service and at Goshawk Close as *brilliant, good care and range of activities* but they also said that their son needed *far more direction with the choice to opt out if he really wants to. He isn't always capable of making the best choices so he misses out if his 'no' is always accepted.*[145]

78. The review the following year noted again that James *needed more support to ensure healthy eating and the taking of exercise*.

79. The review during August 2012 coincided with increasing concerns about James' mental health, his declining attendance at the day service and his deteriorating self-care. The

[142] Suffolk CC IMR
[143] Suffolk CC IMR
[144] United Response IMR
[145] Suffolk CC IMR

psychiatrist was invited to attend by the Goshawk Close staff, but apologies were sent; it might have been expected that psychiatry would ask CPNs or other CLDT professionals to attend on their behalf. The Action Plan agreed at the review included increased 1:1 support in both settings, including outreach support from the day service. James' key worker made three visits to Goshawk Close to persuade him to resume attendance, without success. Despite the good rapport and joint work between the day service and the supported living unit, there was no liaison with Suffolk CC's social work teams; James did not have an allocated social worker and day service staff were unsure about who to contact, despite this being only eight months after the last social work review *when the referral pathway was explained to the relevant support staff.*[146] Also, there was no liaison with the learning disability service despite the effort of the Goshawk Close staff to engage psychiatry.

80. Suffolk CC had a contract with United Response for the provision of a residential care service up to July 2010, followed by a supported living service, which commenced on 12 July 2010. Both should have been subject to contract compliance monitoring. Following the change in James' accommodation status, Joint Advisory Group meetings should have been arranged by the provider, with attendance from the Suffolk CC learning disability manager.[147] However, the Terms of Reference for such meetings make it clear that their purpose is to consider *issues from a housing-related perspective and should not concern matters relating to individual customers or complaints,*[148] so it is by no means certain that such a meeting would have picked up any concerns about James' physical and mental health or the changes in his mood and behaviour. No evidence that either service was monitored has been provided.

81. According to Suffolk CC's detailed requirements, monitoring meetings should have taken place at three, six and 12 months from the start of the supported living contract – that is, in October and December 2010 and in July 2011 – followed by annual strategic contract review meetings, the first of which should have been in July 2012 for Goshawk Close. There is no evidence that any of these review meetings took place.[149] Furthermore, there was no Individual Service Agreement for James so there was no oversight of whether the contractual obligations towards him as an individual – as distinct from reviewing his care and support needs through the care management process – were being fulfilled.

82. When Goshawk Close was de-registered from residential care to supported living, CQC stopped their annual inspection visits to the site. Instead, they inspected United Response as an organisation, through visits to their office in Ipswich in February and November 2012; on each occasion all five inspected standards were met. There is no evidence that Suffolk CC considered these reports or took into account the changes in the inspection regime by the regulator in determining how to monitor the quality of supported living services they had commissioned.

[146] Suffolk CC further information
[147] Suffolk CC further information
[148] United Response further information
[149] Suffolk CC IMR

83. In summary, there was no effective external review or monitoring of James' final care placement from July 2010 when Goshawk Close became a supported living service. CQC inspected United Response as a registered domiciliary care provider, rather than their individual service settings; Suffolk CC failed to carry out any contract monitoring or quality assurance process checks; and the social work review of November 2011 did not meet the requirements of the county council's own guidelines. This is remarkable given that the change from residential care reflected a major shift in policy and service delivery; Suffolk CC should have assured itself, residents' families and the public that this change was effective.

84. Goshawk Close implemented United Response's Person Centred Planning system with internal reviews of James' support being carried out on an annual basis. In addition, the day service made concerted efforts to review James' needs; they held regular, well documented reviews involving Goshawk Close staff and James' family and included action plans to address his changing needs. However these took place in isolation from the learning disability service, GP practice and the social work service.

Inter-agency communication and planning

85. There is evidence of good communication between social work and mental health professionals in 1998 and 1999 when James moved out of his mother's home into, firstly, emergency respite care, then a hospital based mental health unit and finally to Goshawk Close. There are documented multi-disciplinary meetings in addition to discussions between the specialist learning disability staff, general practice and the college James was attending. James' discharge from hospital was planned with the Goshawk Close staff and with the psychiatrist who agreed to a return overnight stay at the hospital so that James could *say goodbye properly*.

86. Once James moved to Goshawk Close, the agencies involved with his care were:
    - United Response Goshawk Close staff
    - Suffolk CC day service staff
    - Suffolk CC social work service (case was open to the area team, but no allocated social worker once the service moved to supported living)
    - GP practice
    - East Coast Community Healthcare, district nursing service
    - Suffolk Mental Health Partnership learning disability service (up to merger in 2012), Community Psychiatric Nurse (up to July 2004) and Consultant Psychiatrist
    - Norfolk and Suffolk NHS Trust (from 2012), Consultant Psychiatrist

87. The lead discipline for monitoring James' health was psychiatry through the non-CPA (Care Programme Approach) process; the same Consultant sawJames19 times between January 2010 and November 2012. The records suggest that psychiatry worked in isolation; did not seek advice from the CLDT; did not communicate with general practice directly, relying on faxed typed letters and information from the Goshawk Close staff; declined an invitation to a

case review without further enquiry or sending a substitute; and did not relate James' problems in 2012 to his previous history in 1998 to 2000, when a link was clearly made between his behaviour and constipation. The psychiatrist provided regular reports to the GP practice following James' out-patient appointments. However, these focused on his mental health and included only brief details about James' physical health. James was always accompanied by support staff from Goshawk Close, but they were not included in any correspondence about James' health needs or treatment. Instead, the staff member present was given advice and instructions verbally to take back to Goshawk Close, and there is evidence that these were written down in James' record,[150] although the consistency with which such information was recorded it is not clear. The psychiatrist expected that Goshawk Close would liaise with the GP practice; hence there were often phone calls to the GP practice to confirm changes in medication recommended by the psychiatrist. However, no specific concerns about James' bowel health were raised.

88. The GP practice had regular communication from psychiatry following James' out-patient appointments but reference to his physical health was usually reassuring: *stable in mental and physical health* (October 2010 and April 2011); *no physical health issues, bowel movements unchanged* (December 2011); *biological functions improved … weight stable* (January 2012); *no physical health problems noted* (April 2012); *no physical health concerns including biological functions* (July 2012); *concerns as above re mental health, physical health no concerns* (September 2012); concerns about his *faecal smearing … losing weight but tummy distended* were put down to mental health problems (November 2012). There were no ongoing links, advice and support for the GP practice from the specialist learning disability service beyond this correspondence. Consistent links with community learning disability nursing can enhance the effectiveness of health checks, but James did not qualify for their input because of his non-CPA status; the CLDT assessment in September 2012 was concerned with possible dementia, made no links between his behaviour and his physical health and did not review his CPA status. This was a critical weakness in the multi-disciplinary approach to James' care.

89. At no point did any professional take the initiative and convene a multi-disciplinary meeting to review James' physical health and changes in mood and behaviour. The only real example of collaborative working was between the day service and Goshawk Close, yet this was done in isolation from the specialist learning disability service, general practice and the social work service. The other professionals – general practitioners, district nurses and psychiatrists – did not recognise that there were any problems that merited such multi-disciplinary attention, even though James' physical and mental health deteriorated over a long period of time. The social work service was unaware of problems because no-one alerted it to these and its own arrangements for reviews were flawed. A formal review including health and social care professionals and James' family would have enabled a full exchange of James' social and

[150] United Response IMR

medical history and a consideration of all the factors potentially at play. It would have offered support to all professionals – who were working in isolation – and a clear plan as to the most effective course of action. It might have elevated James to the CPA programme again, thereby drawing in additional resource and expertise in learning disability.

90. The failure to bring professionals and family together and plan jointly to address James' needs does not appear to have been as a result of concerns about confidentiality or breaches of the Data Protection Act for example. Rather this seems to have been the result of a lack of attention to whether James had capacity to make decisions and an assumption that, because his problems were all attributable to his learning disability and mental ill health, he was in safe hands because psychiatry was the lead discipline and James saw a psychiatrist regularly.

91. Serial and parallel investigatory processes are confusing for professionals and for families. James' family did not know that there had been a safeguarding investigation and were not informed of its outcome. Pan-disciplinary Safeguarding Adult Boards should be informed of the outcome of all relevant investigations and inquiries and the associated actions and learning (Department of Health 2010). Since there is little merit in duplicating investigations the onus is on safeguarding personnel across sectors to coordinate these and share information and learning.

Identification of good and best practice and failings of service delivery

92. James' move from home, via firstly emergency respite and later a hospital based mental health unit, to Goshawk Close appears to have been handled well. There was good communication between professionals and his family were involved in decision making; their views that he should not return home and needed alternative care were respected, documented and acted on.

93. There is little doubt that the staff at Goshawk Close cared about James and did their best to support him to do the things he enjoyed. Their records indicate that they were attentive to any minor health problems, and tried to understand what was happening to him; they pointed out James' distended stomach and his weight loss to the psychiatrist who, according to the Goshawk Close staff, apparently *refused to communicate with the Goshawk Close staff team, despite a number of requests being made by them.*[151] However, the psychiatrist did make two home visits in December 2011 and September 2012. The support staff relied on others to interpret signs and symptoms from a medical point of view. Their want of training in the management of bowel health and the increased risks of constipation for people with learning disabilities meant that they did not recognise that James was becoming increasingly impacted – faecal smearing, soiled underwear, overflow diarrhoea, distended tummy, and loss of appetite without weight loss – and did not realise that his condition was becoming acute.

[151] United Response further information

United Response acknowledges that *there is evidence in the communication book that we intermittently monitored James' weight; however this was not done consistently.*[152]

94. The staff at James' day service organised regular reviews of his care and worked well with the Goshawk Close staff to respond to the changes in his mood and behaviour. They invited the psychiatrist to attend the review in August 2012, one of the few examples of an attempt to seek expert advice and, following this review, visited James at home to motivate him to resume his attendance.

95. There were several failings in service delivery. Despite James' known history, there was no co-ordination of his care following the decision to transfer him to non-CPA in 2008. Psychiatry worked in isolation and did not engage with the wider CLDT or community health services when James' needs changed. General practice relied too much on psychiatry to monitor James' physical health and did not use the annual health checks as an additional opportunity to check his bowel health. The Suffolk CC did not fulfil its obligations either to review James' care and support or to monitor the contract with United Response. The CLDT did not offer support needs to either Goshawk Close or the GP practice to aid their understanding of the physical health needs of people with learning disabilities. United Response did not train their support staff in what constituted good bowel care for identified residents with known problems.

Section four: Conclusions

96. James had a known, life-long bowel problem, exacerbated by Down's syndrome, hypothyroidism and the side effects of long term medication. Yet the only health discipline which reviewed him on a regular basis was psychiatry. James was a non-CPA patient so did not have the benefit of input from the wider specialist CLDT. Communication by psychiatry with the GP was primarily in relation to James' mental health, with only passing – and reassuring – reference to his physical health needs. It is concerning that professionals cannot explain the repeated reference of psychiatry to the barely changing status of James' *biological functions.*

97. The nature of the task of providing intimate care to individuals who cannot attend to their own bodily functions is 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 for as well as good support and supervision. Goshawk Close staff received no training in how to support and monitor the bowel health of people with learning disabilities. Although they were attentive to James' general health and accompanied him to GP and out-patient appointments, they had no direct communication from psychiatry and were reliant on others interpreting James' moods and changes in behaviour. These were overwhelmingly seen as

[152] Email of 25 May 2015

related to his learning disability and mental health needs and not symptomatic of deteriorating physical health.

98. The change of status of Goshawk Close from residential care to supported living was significant at several levels. Government targets and local finances had a part to play, not least since performance indicators were designed to reward local authorities with a high ratio of service users living independently and the social security system of the time placed a greater burden on local finances for people living in residential care than for those living independently or in supported living. Thus a local authority could improve both local finances and their performance rating by changing the status of people's accommodation and encouraging homes to de-register (Clements and Thompson 2007). Suffolk CC's intention was to enhance people's financial benefits to *afford greater choice and opportunities to access ordinary everyday experiences, often denied to them in residential/nursing settings*. However, it should not entail *any loss of access to the right support to meet health needs.*[153] It is evident that Goshawk Close staff fulfilled the general responsibility on the provider within the service specification to promote access to health care, but no specific arrangements were made for the scheme to have access to or get support from specialist learning disability services. This is surprising given that all Goshawk Close tenants had complex needs and the services of psychology, neurology, physiotherapy and community nursing were called upon for individual tenants in subsequent years.[154] The lack of such specific requirements, the weakness of the care management review process and the inappropriate approach to annual health checks meant that James' health care needs were neither monitored nor reviewed beyond the limited and questionable input of psychiatry.

99. Although the GP practice was an early adopter of the LD Directed Enhanced Service and James was placed on the QOF (Quality Outcomes Framework) Learning Disability register, this had few tangible benefits for him. The practice made no reasonable adjustments to encourage him to attend the annual health checks and there was no face to face contact with James between February 2011 and October 2012 – a period when his behaviour changed significantly and his motivation to participate in activities diminished. The practice continued to write to James even though he could not read. More recent guidance[155] offers little reassurance, referring only to *providing information in a format that* the patient *can understand* – that is, when they are physically present.

100. There was no multi-disciplinary approach to supporting James' physical and mental health and opportunities for reviewing his needs were missed, for example through the annual health check, at the social work led review or the dementia assessment by the CLDT.

[153] Suffolk CC further information
[154] United Response further information
[155] Direct Enhanced Service Schedule 5: Learning Disabilities Health Check Scheme 1 April 2014-31 March 2015

101. There was a lack of understanding by all agencies about the use of the Mental Capacity Act and Best Interests Decision processes and no evidence that such measures were used when critical decisions were made about James' medical treatment, diet or behaviour.

102. The rationale for Ipswich Hospital NHS Trust's assertion that there was no diagnostic overshadowing in James' case is not known. As their independent review states that *there is a need for it to be everyone's responsibility to meet needs of patients with a learning disability and support for family members/carers with need* [sic] *for all hospital staff to be aware of the complexities and needs of people with learning disabilities and other vulnerable adult's patients.*[156]

103. Finally, at a time when most people with learning disabilities may expect to live longer lives than previous generations, the death of a 33 year old man is shocking. James' family has sought to make sense of the traumatic circumstances of their loss by asking questions of all agencies which have had roles in supporting him. The contingent and variable responses of agencies to the urgency of their search for answers have left them far from consoled.

Section five: Recommendations

104. **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

[156] Ipswich Hospital NHS Trust IMR

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 such as diet, as well as in relation to invasive treatments such as anal stretching, 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 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

viii. 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

ix. 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

x. 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

xi. 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

xii. 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

xiii. seeks confirmation from all partner agencies of the specific actions they have taken to address the issues raised by James' (and Amy's) circumstances and how these will be embedded in future practice

xiv. promotes the learning from James and Amy's circumstances by ensuring that the reviews are used as a resource for the professional development of health and social care practitioners in Suffolk

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