Housing & Safeguarding Adults Alliance

Lessons for support and supported housing providers from the SCRs concerning Amy and James, published October 2015. Extracts from the SCRs.

		Page numbers of SCRs	
		James	Amy
1	**Introduction** Two SCRs concerning people with disabilities were published in October 2015. This paper is primarily concerned with the implications for support/housing support providers and is intended to build on my earlier MA research dissertation 'Adult Serious Case Review: lessons for housing providers'.		
2	**James** James 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. It is likely that his death was from aspiration pneumonia.	3	
3	**Amy** Amy was a woman with learning disabilities, epilepsy, cerebral palsy and known bowel problems, aged 52. She lived in a Supported Living scheme – Crane Court – run by Leading Lives, where concerns about the staff's understanding of Amy's health care needs led to a safeguarding referral in January 2013. (The facility had originally been run by Papworth Trust, until November 2011, then Suffolk County Council until July 2012). On 6 April 2013 she was re-admitted to Ipswich Hospital with breathing problems, having been discharged back to Crane Court, earlier that day. A further safeguarding referral was made by the Community Learning Disability Nursing service which was concerned about the discharge taking place without apparent full investigation or consideration of her health problems. Amy's condition deteriorated and she died in hospital on 7 May 2013. The death certificate states: aspiration pneumonia, faecal impaction, cerebral palsy, epilepsy .		3

4	**Overarching themes** The SCR on James is 53 pages long and that for Amy is 55. The purpose of this paper is not to summarise the SCRs published by Suffolk SAB nor to focus on the general findings (which are well summarised in Community Care, 27 October 15). My intention is to highlight lessons for support providers, particularly those providing support to people with learning disabilities. But a few extracts will be helpful first regarding the general thrust and themes of these SCRs.		
4.1	**Diagnostic overshadowing** A key theme of both reports, particularly explicit in James, is the phenomenon of 'diagnostic overshadowing, where symptoms of physical ill-health are seen to be a result of an individual's learning disability or mental health rather than requiring investigation in their own right'. The report on James comments on the individual's issues being attributed to mental health, not physical health. Medical staff were criticised for their lack of professional curiosity and for concentrating on mental health. James' 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.	27, 38, 41	49
	There are references to the influence poor bowel management may have on the long term health of an individual illustrated by the 'significant omission from his hospital passport of reference to James' history of life-long chronic constipation'.	37	
	The report remarks on the 'keen anguish of James' parents when a nurse said, after his death, that it was 'his time to go'. The report says that 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'.	30	
	In March 2013 (shortly before her death) Amy's CLDN was advised that Amy is no more of a priority than anyone else, when chasing up an urgent, overdue appointment with the gastroenterologist.		31
	There are several examples of poor oversight in Amy's acute care.		36
	Valuing People stated that people with learning disabilities fare poorly in health services that are reliant on patients disclosing why they need medical attention. Amy could not communicate her needs and depended on her family and support staff to do so on her behalf. Amy's misdiagnosis and premature hospital discharge in 2013 suggest... that the hospital was unwilling to listen to the concerns of family, support staff or community based professionals.		52

4.2	**Poor clinical practice regarding bowel management** There is particularly strong criticism of the psychiatrist involved in James' care who saw James 19 times between January 2010 and his death in November 2012. The report states that records suggest that psychiatry worked in isolation, did not seek advice from the CDLT, did not communicate with the GP directly, declined an invitation to a case review, did not relate James' problems in 2012 to his previous history in 1998 and 2000 (when a link was clearly made between his behaviour and constipation'), refused to communicate with support staff. The report is also critical of the implementation of the CPA/ GP/ QAF and other quality monitory systems in place. These are alongside criticism of failures of joined up working within NHS structures and between them. There is also criticism of clinical practices at Ipswich hospital immediately prior to both deaths.	46 48 25-8 28	 29-34
4.3	**Poor multi-disciplinary working and absent care coordination** There were no multi-disciplinary meetings 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 LD service, general practice and social work service. The other professionals – GPs, DNs, 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. Failure to bring professionals and family together and plan jointly to address James' needs were not a result of DPA/confidentiality fears but were the result of a lack of attention to whether James had capacity to make decisions and an assumption that because his problems were attributable to his LD and mental ill health, he was in safe hands because psychiatry was the lead discipline and James saw a psychiatrist regularly. There are several examples of failures of communication between, for example, Ipswich Hospital and the GP eg 'there is no record in the GP notes of a link being made between this advice (to stop laxatives) and faecal loading identified by the hospital'. On 25 November 2012 Amy was discharged from a 4 day admission to hospital, the hospital discharge summary identified 'gross faecal loading' as the main cause of Amy's difficulties but no written discharge information was given to Leading Lives care (?) staff. Although many agencies were involved, there is little evidence of joined up working or multi-disciplinary planning (eg no involvement of GP in Health Action Plan or evidence of their content, who holds them or how they are used). Amy's various admissions to Ipswich hospital should have been triggers for multi-disciplinary review and action planning. A multi-disciplinary meeting would have made everyone aware of the seriousness of Amy's bowel problems, agreed appropriate actions and allocated responsibilities.	47 48	 17 21 35 36

	Why did the CLDN service, DN service and primary care not meet to compare notes and share information, particularly as the DNs did not attend the safeguarding strategy meeting in January 2013 and may not have fully understood the multi-agency concerns? The GP relied on the DNs and the support staff; the Community LD Nursing service was attentive but did not bring people together to formulate a clear bowel management plan; the DNs did not consult the GP's electronic record or provide feedback to the GP and relied mainly on telephone contact with the support staff. Finally, social services did not convene a review meeting to assure themselves that Amy's needs were being met and that there was no risk of a further death. If Ipswich Hospital had taken a more consistent approach to information sharing, Leading Lives might have received vital information about Amy's bowel condition and treatment which would have alerted them to her health support needs. The dietician was working in isolation, illustrating again, the lack of multi-disciplinary joined up working on Amy's behalf. Health Action Plans and social work led Person Centre Reviews failed to involve a range of professionals in the meetings or follow up. The lack of multi-disciplinary attention to Amy's needs is stark... and an over-reliance on unqualified (and largely untrained) support staff.		37 38 40 47 48, 53 53
4.4	**Poor understanding and practice regarding the MCA** There was a lack of understanding by all agencies about the use of the Mental Capacity Act and Best Interests Decision's processes and no evidence that such measures were used when decisions were made about medical treatment, diet or behaviour.	32, 34	52
5	**Issues relevant to supported housing providers/support providers**		
5.1	**Change of registration from care home to supported living** Change from registration as a care home to supported housing was not explained or understood properly by staff or families. The GP for Amy stated on 15 January 2013, at a safeguarding strategy meeting, that they had never been advised (which was incorrect)of the transfer from NHS to non-health care staff and may have made different decisions if they had been aware that information provided was gathered from non-medical staff – raising concerns about the ability of care (?) staff to cope with complex health needs, advising a move to a nursing home. The records suggest that there was confusion amongst some agencies about the status of accommodation at Crane Court illustrated by references by many health care agencies to care home and care staff.	15, 32, 35, 36, 38, 50	26, 39, 42 39

	In 2008, Crane Court transferred from the NHS to Papworth Trust, managed under contract to Suffolk CC. This was primarily a social care service and staff were not qualified nurse or trained in how to manage people with complex needs. Leading Lives was not a provider of health care; it was registered with CQC to provide dom care, not health care. The significance of this and the implications for the monitoring of the health of tenants with complex needs such as Amy seems not to have been fully understood by people's immediate families, by social care commissioners, by specialist LD services or by primary care. As those responsible for Amy's care appeared to be unaware of her bowel problems, the question of whether these needs were being met, or could be met, appropriately in a supported living setting did not arise until the GP raised the need for nursing care at the strategy meeting in January 2013.		41 43 48
5.2	**Poor understanding by support staff of the MCA** Poor practice re reading tenants' letters and failure to understand the significance of repeated failure to attend appointments; misapplication of MCA by staff regarding the importance of eating certain food etc	16, 18, 19, 32, 33, 40	40 41
5.3	**Poor contract specification and contract monitoring** There were detailed contracts between Suffolk CC and United Response for residential care and supported living after July 2010 but neither was actively monitored. The main focus of the contract between Suffolk CC and Papworth Trust is on cost and volume.... The county council had no way of knowing whether Amy's health needs were being met appropriately. The lack of specific requirements and the weakness of the care management review process meant that Amy's health care needs were not monitored or reviewed beyond the input of the generic primary care team.	7, 45, 46	 38 39 53
5.4	**Support staff with insufficient training on the needs of people with LD** Staff have no specific training to work with James. James was described as having poor verbal communication skills and people had to try and deduce his mood, preferences and need from body language. James will answer 'yes 'in appropriately especially in response to bowel functions. No specific arrangements were made for the scheme to have access to or get support from specialist LD service. Failures to ensure or enable verbal or other communication about pain or discomfort.	44 34 50 34,36	 47
5.5	**Support staff with insufficient advice or training on recognising and managing bowel problems** Staff had no information about the association between behaviour change and constipation or between medication and constipation.		

	Changes in his behaviour (eating, staying in bed, withdrawing from activities) 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. The lack of advice and guidance for the Goshawk Close staff meant that James' chronic constipation and associated risks weren't effectively managed. Staff misinterpreted James's soiled underwear etc not recognising these were possible indicators of overflow diarrhoea. Domination of medical opinion (staff accepted advice of psychiatrist not to put pressure on James when he declined.... healthy food, or insisted in staying in bed).	19, 40, 48 43	
	In 2012 (support) staff recording of bowel movements was inconsistent and their monitoring did not necessarily lead to any further action.		45
	Despite Amy's known history of constipation, dating back to 1988, Leading Lives were not asked to monitory Amy's bowel movements until 12 December 2012. .... However it is not possible to infer from the daily records whether the staff had a good understanding of the difference between loose bowel movements and overflow diarrhoea because of impaction.		46
	'The Community LD nursing service wrote to the GP on 14 December 2012 to raise significant concerns about the care of Amy by care (?) staff at Crane Court and their understanding of her illness and health care need. Staff were reported as not understanding the significance of Amy's constipation, their belief that the hospital admission was for pneumonia, not following the medication regime... the GP believed that a principal difficulty is in the lack of training for carers in dealing with Amy's problems. Yet the following month the GP was asked by a member of the support staff could be overflow from constipation... the advice from the GP was (incorrectly) that if she had bowel movements, it couldn't be overflow and the swollen abdomen was the result of her breathing difficulties and possibly an infection. (The GP the next day arranged for Amy to be sent to A and E who discharged her that day asking the GP to refer to the surgical team. Combination of errors and misdiagnosis were tackled by the Community LD Nurse and the LD liaison nursing service who were both concerned the care(?) home continue not to be managing bowels'. But the manager of Leading Lives told the CLDN that when she visited Amy in hospital she wasn't advised by hospital staff that constipation was the main problem. The Home (?) Manager had apparently stated that the admission had been due to pneumonia and did not realise that the problem was in fact constipation. An enquiry from CLDN about fluid intake elicited the reponse that they don't do health and therefore recording wasn't in place. Staff do not appear to have the understanding and knowledge to care for Amy. On 10 January 2013,while Amy was in A and E following an acute asthma attack, the CLDN stressed to A and E staff the possible links between breathing and bowels. A and E staff responded that if Amy came in with breathing difficulties, that is what would be treated. No information from previous admissions was considered. Meanwhile it came to light that the wrong dose of laxatives was being administered		21, 22 23 23 24 25

	to Amy at the Court and training needs were identified – asthma care and recording, bowel care and recording, accurate recording of GP visits and outcomes, admin and recording of medication. Further questions about Crane Court's staff abilities were raised on 14 January 2013 by the police while investigating possible wilful neglect under the MCA.		26
	But at a further Adult Safeguarding Review meeting it was noted that Leading Lives staff previous failure to monitor Amy's bowel movements was not wilful and there was no evidence that they had been advised by health professionals to do so. As a provider they have a duty to monitor health needs... they have implemented guidelines and training to remedy this deficit. But by March Amy was showing signs of bowel problems again and overflow being misinterpreted, exacerbated by a doctor's instructions (not to reduce bowel medication and to give additional medication) not recorded or implemented by Crane Court.		29 30 36
	The CLD Nurse continued to raise concerns with the GP practice about the understanding of Crane Court staff of Amy's bowel problems and their ability to monitor and manage them. Amy was admitted to hospital on 4 April, discharged on 6 April, readmitted two hours later.		33
	Reference by Suffolk CC to Amy being on regular laxatives but not administered correctly as care (?) staff misinterpreted leakage of bowel as loose stool. Agreed at multi-disciplinary meeting on 25 April that Amy not to be discharged again until constipation is cleared. Died 7 May.		33
	Support planning by Leading Lives was based on current records and care plans which did not indicate that Amy was prone to constipation and needs specific bowel monitoring (November 2011 when responsibility for the service at Crane Court was transferred from Papworth Trust to SCC/Leading Lives). Little additional support was given to Crane Court staff to enable them to understand Amy's bowel problems and monitor her health effectively.		43 50
	The significance of managing Amy's bowel problems and the importance of close monitoring of her bowel movements were lost once responsibility for the service transferred from the NHS to a social care provider. The Papworth Trust did not accurately record bowel movements (and it is not clear that they were required to do so) and there was no formal transfer of information between providers. The knowledge about her specific health care needs was therefore diluted until reference to her bowel health disappeared altogether from care reviews. The first reference to bowel problems in the GP records was in May 2012 and it was not until December 2012 that Crane Court staff received any training in bowel care.		51
	Staff did not understand the fine detail of bowel care; they appear to have assumed that a bowel movement in itself indicated that all was well, without understanding the difference between a loose bowel movement and overflow diarrhoea arising from impaction. There is		52

	no evidence that staff had any specific training about bowel care until December 2012 when the LD Liaison Nurse provided some training following the concerns they had raised through the safeguarding alert.		
5.6	**Lack of effective communication between medical and support staff regarding bowel management** Support staff always accompanied James to psychiatry appointments but were not subsequently included in correspondence about his health needs or treatment, just given advice verbally.... psychiatrist refused to communicate with them. Support staff were not treated as professionals who were knowledgeable about Amy and were regarded as 'chauffeurs'. In January 2011, Amy attended Ipswich Hospital for an abdominal ultrasound but support staff received no advice by the hospital about corrective action. Information concerning Amy contained in hospital outpatient and discharge letters was not routinely shared with Crane Court support staff.	47 48	 35 42 52
5.7	**Lack of advice to support staff about their monitoring role regarding bowel management** The safeguarding investigation of January 2013, concerning Amy, would suggest that concerned vigilance by all agencies should have followed with specific, detailed and continuous attention to Amy's health need and to the ability of staff to monitor and record her bowel movement appropriately. The expectation of support staff 'monitoring' Amy's bowels and general health as arguably deficient as they were not included in clinical decision-making and received no instruction concerning how, what or with what they were to monitor.	18, 19, 22, 43	 38

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See also the short accompanying document 'Amy and James summary v2'

The purpose of these two documents is to help support and supported housing providers learn the lessons from these Serious Case Reviews. Lessons for housing providers from other housing related Serious Case Reviews were the subject of my dissertation for the Keele University MA in Safeguarding: Law, Policy and Practice and were published in the Journal of Social Welfare and Family Law in 2014. Note that the Care Act 2014 has made the commissioning and publication of Safeguarding Adults Reviews (formerly called Serious Case Reviews) statutory (Section 44).