

Factors leading to James’ and Amy’s compromised health status

The Safeguarding Adults Board in Suffolk (SAB) commissioned two Serious Case Reviews now known as Safeguarding Adults Reviews (SARs) in early 2014 in to the deaths of two people with learning disabilities. The Board would first of all like to offer its deepest sympathies to the families of both of these people, and would hope that the recommendations offers some reassurance and comfort to both families. The Safeguard Adult Review reports looks to identify the learning from these reviews and taken with the Action Plan identify the work that the SAB and our partners have undertaken to date and ongoing work to address some of the highlighted concerns. While it is clear that no amount of future change can ever alleviate the loss of a loved one, we hope and intend that the progress we have made in working with the independent authors of both review reports will serve to prevent similar circumstances from occurring in Suffolk in the future.

All of the organisations involved, and additional organisations who can benefit from the learning have made a commitment to review and where required improve processes and systems in the coming weeks, months and years which will see significant changes for the better, for those who have a right to access timely and effective care. Many changes have already been implemented within organisations and across the partnership. The SAB will hold the partnership organisations to account for delivering the required change through regular reviews.

In the following table the disadvantage experienced by adults with learning disabilities is explored in terms of

1. individual factors concerning James and Amy and
2. service and policy based factors.

The SARs are an incentive to build expertise in devising improved health care practices and health-conscious support services in Suffolk. Read in conjunction with the recommendations from the reviews it begins to answer the question: why has the poor health status of people with learning disabilities not yet been reversed?

James	Amy	Service and policy based factors
Health challenges associated with Downs syndrome, including hypothyroidism; psychiatric co-morbidity; communication difficulties; life-long, documented challenges concerning constipation; he was prescribed medication with side effects which included constipation. James could not	Health challenges associated with learning disability; cerebral palsy; epilepsy; asthma; communication difficulties; using a wheelchair; and life-long, documented challenges concerning constipation. Amy could not self-report symptoms of physical pain and emotional distress. She could not read. She	Primary and secondary health care reliant on self-reporting; irrespective of the cornerstone status of community learning disability teams, neither James nor Amy were eligible for their multi-disciplinary overview; James’ healthcare was aligned to the discipline of learning disability psychiatry;

self-report symptoms of physical pain and emotional distress. He could not read. He died from complications arising from untreated yet treatable medical condition - constipation	died from complications arising from an untreated yet treatable medical condition – constipation. Her respiratory distress was treated as asthma rather than it being associated with her bowels	irrespective of both of their GP practices including them on the Quality Outcomes Framework Register (the effectiveness of which is not known), both missed appointments for LD health checks to which they had been invited by letter
Parents actively involved in health and social care meetings and reviews when James left the family home	Parents actively involved in health and social care meetings and reviews when Amy left the family home	Assumptions about the knowledge, skills and experience of clinical and support staff about (i) the health support needs of individuals with learning disabilities and (ii) the necessity of persistent health advocacy
James developed poor nutritional habits; his parents were concerned about his diet and weight gain. Between 2010 and 2012, James’ weight ranged from 73 to 70 kgs – however, the distribution of his weight conspicuously altered the shape and hardness of his abdomen	Amy relied on others to assist and encourage her to eat and drink. Between 2009 and 2011, Amy’s weight ranged from 64 to 51 kgs - and her parents described her abdomen as “like concrete”	A psychiatrist advised support staff not to put pressure on James when he resisted eating particular foods; a dietician advised <i>full fat foods</i> to address Amy’s weight loss; the food and fluid intake of James and Amy was inconsistently recorded. In spite of concern about James’ weight gain and Amy’s weight loss they were weighed intermittently and since no service had the means to weigh a person using a wheelchair, Amy was not weighed for almost 18 months
James’ parents had developed a method of encouraging and supporting him to use the toilet. His parents believed that such methods were being adopted by support staff. They were disbelieving that James was described as “mostly independent”	Amy’s parents had developed a method of encouraging and supporting her to use the toilet. Until she began to use incontinence pads, her parents were accustomed to sharing information about the quantity and consistency of her faeces with staff since they believed that her general health and bowel health were being monitored	An expectation of monitoring was deficient insofar as James’ and Amy’s support staff were peripheral to clinical decision-making. Detailed information from clinicians about (i) <i>what</i> behaviour to monitor; (ii) <i>how</i> evidence of mental health issues might be readily distinguishable from non-mental health issues; and (iii) <i>how</i> medication side-effects might become manifest in the context of very low levels of physical activity, and established and troubling behaviours, was not available

		to support staff
James' increasing withdrawal, refusal to cooperate and engage in previously favoured activities were not associated with physical discomfort or pain	When Amy became agitated this was managed by removing her to her room; "putting herself on the floor," biting her hand and shouting were not associated with physical discomfort or pain	Health professionals and support staff interpreted distressed behaviour in terms of LD or mental health, despite the phenomenon of <i>diagnostic overshadowing</i> ¹ characterising many families' experience of supporting relatives with learning disabilities in the NHS
James was subject to invasive treatments and procedures	Amy was subject to invasive treatments and procedures	Neither James' nor Amy's support services invoked the Mental Capacity Act 2005 – irrespective of the invasive treatments for constipation and the techniques and advice for managing stressed behaviour – until the end of their lives
James was assessed as being capable of signing and understanding a tenancy agreement when his residential care home changed to a supported living service	Amy was determined not to have the capacity to understand the implications of her residential care home changing to a supported living service	The assessment processes for determining James' and Amy's capacity were unclear.
James' residential care home was subject to announced and unannounced inspections by the regulator. These ceased when the accommodation changed to supported living	Amy's residential care home was subject to announced and unannounced inspections by the regulator. These ceased when the accommodation changed to supported living	The Care Quality Commission inspects the registered domiciliary care provider as an organisation – not individual locations where domiciliary care is provided
The transition to supported living resulted in an overarching assumption about James' capacity to make choices concerning health-risk behaviour and the capacity of support staff to promote the independence of tenants	The transition to supported living resulted in lost information about Amy's health support needs and the loss of her customised wheelchair	The transition to supported living exposed weaknesses in (i) negotiating arrangements to support people's physical health needs (ii) the training and support for social care staff in understanding bowel health for example, and recognising when things were going wrong and (iii) engaging key health professionals, including GPs, in the implications of the transition
James' last case review was in November 2011. It was in breach of Suffolk CC's guidance. Neither	Amy did not benefit from annual reviews, that is, no reviews held within this required timescale.	There was a lack of attention to the life-long concern about bowel care in reviews and a

¹ **Diagnostic overshadowing** is the term used to describe the tendency for clinicians to overlook symptoms of mental and physical health problems in patients with learning disabilities and attribute them to being part of the "having a learning disability." Such inadvertent discrimination is considered at <http://www.gmc-uk.org/learningdisabilities/200.aspx> (accessed 15 August 2015)

the GP nor the psychiatrist was invited. They were not asked to submit information. No health professionals were involved in James' person centred reviews	Her last review was in May 2011. Amy's GP was not informed or invited to submit information. No health professionals were involved in in-house, person centred reviews	failure to involve health professionals for James and Amy. Suffolk CC's policy for care reviews was breached for both. Their person-centred reviews were disconnected from concern about their health and wellbeing
There was no monitoring of the contract with supported living/ United Response and there was no Individual Service Agreement for James	Suffolk CC did not monitor the Papworth Trust contract. The Leading Lives contract was monitored but the specification did not include any detail about how Amy's health needs would be addressed	Suffolk CC's policy for contract compliance was not followed for James and was inadequate in relation to the health support needs of James and Amy
James had a Health Action Plan. This made no reference to his constipation and had no impact on his health outcomes	Amy had a Health Action Plan. This made no reference to her constipation and had no impact on her health outcomes	No health professionals were involved in drawing up the Health Action Plans and primary care staff were unaware of their existence
District nurses took blood samples from James. They did not advise on the wider aspects of his health care and were not asked to do so by support staff	District nurses were asked by the GP to administer daily enemas. These did not occur since the nurses relied primarily on telephone reports from Amy's support staff	The potential significance of district nursing intervention was not realised

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