

**Safeguarding Adults Review Overview Report  
Mr Andrew Strazdins**

Safeguarding Adult Review for Mr Strazdins, commissioned by  
Dudley Safeguarding Adults Board

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## **1. Background**

**1.1** In April 2015 Dudley Safeguarding Adults Board (SAB) commissioned two Safeguarding Adults Reviews in respect of 2 people who had died as a result of choking. Although neither person had any contact with each other, and received services from different agencies and specialist services, they both had identified difficulties with swallowing, known as dysphagia.

**1.2** Both of these gentleman's deaths were subject to criminal proceedings and the timetables for the SARs have been dictated by the Courts' timetables. The Safeguarding Adults Review (SAR) in respect of the first gentleman was presented to Dudley SAB on 13<sup>th</sup> May 2016. The SAR for Mr Strazdins was presented to Dudley SAB on 12<sup>th</sup> August 2016.

**1.3** "Lung inflammation caused by solids or liquids, and foreign bodies in the windpipe, were involved in 1,048 deaths (14% of those identifiable) of people with learning disabilities or possibly associated conditions. In other people they were involved in just over 2%. Adjusting for ages at death, people dying with this were 9 times more likely than others to have a learning disability-related condition" 'How People with Learning Disabilities Die' Glover and Ayub DOH/IHAL<sup>1</sup> 2010. This significant health inequality has been central to the thinking and analysis in this SAR.

## **2. Terms of reference**

**2.1** The full Terms of Reference are attached at Appendix 1. The specifics in the terms of reference were as follows.

"It is essential that the Investigator have expertise relating to the care and support of people living in community settings with dysphagia and learning disability and the content of the Review is likely to include the following:

Identify whether there are lessons to be learned from the death of the late [PERSON A] and [PERSON B] in which local professionals and agencies work together to safeguard adults at risk.

Identify what those lessons are, how they will be acted upon and what is expected to change as a result within a given timescale; and as a result to improve practice, with a view to promoting the positive practice highlighted amongst other relevant factors.

Inform and improve local inter-agency working including with commissioned services.

Review the effectiveness of procedures (both multi agency and those of individual organisations) of those supporting the late [PERSON A] and [PERSON B] and make recommendations for improvement.

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<sup>1</sup> Improving Health And Lives Learning Disabilities Observatory, Public Health England  
<https://www.improvinghealthandlives.org.uk>

To commission whatever information is required of agencies involved in the care of the late [PERSON A] and [PERSON B]. To prepare an overview report which brings together and analyses the findings of the various reports from agencies in order to identify the learning points and make recommendations for future action.”

### **3. Process and methodology**

**3.1** Dudley SAB requested that the approach to the SAR to be informed by the West Midlands Region – Safeguarding Adults Review Framework (agreed December 2013) and learning from the West Midlands Regional Network SAR/SCR Event 2014, in line with the requirements of the Care Act 2014.

**3.2** Dudley SAB Sub group met with the Investigator for an initial meeting to discuss the commissioning of Individual Agency Management Reports (IMR). The IMR’s were commissioned and, following their receipt, a series of interviews were held with key personnel in agencies and a further examination of some records. The IMR’s provided individual agency findings and recommendations, some of which were put into effect by those agencies immediately. The findings and recommendations from the IMR’s are attached in Appendix 2.

**3.3** Families are very important to the SAR process. Andrew’s immediate family are his sister and brother-in-law, Mrs Elaine and Mr Keith Scott. I met with Elaine and the then Chair of the SAB on 14<sup>th</sup> August 2015. During the meeting Elaine spoke about her experiences both of the services that Andrew received from various agencies over the years, but also how she felt about the way the different agencies communicated with her and her family following Andrew’s death. The Chair of the SAB asked that I incorporate Elaine’s issues into the SAR and also look at how to improve support to families following a death which results in a SAR, as part of the learning from this review. Elaine provided a written statement which can be found at the end of the review, in which gives her account of the impact of action or inaction by the various agencies involved with her brother following his death. This statement was written before criminal proceedings concluded.

The investigator met with Elaine and Keith at their home on 2 occasions and spoke with Elaine on the telephone over the course of the review.

**3.4** The investigator produced an interim report for the SAR Sub-group which was discussed in November 2015. The draft report identified areas for exploration arising from key themes identified in the Safeguarding Adults Review and these were discussed by the sub-group.

**3.5** Criminal proceedings against 2 members of staff concluded in April 2016. The 2 support workers pleaded guilty to charges brought under the Health and Safety at Work Act.

**3.6** The draft report was shared with Elaine after the criminal proceedings were completed. The Learning Event could not be held until after the conclusion of the criminal proceedings. A full SAR learning event was held on 7<sup>th</sup> June 2016 and

attended by 26 professionals representing all the agencies involved with Andrew. Further changes to the draft report were made following a meeting on 11<sup>th</sup> July with 2 managers from the provider service, Lifeways, and the Interim Safeguarding Manager for Dudley and further checks with Elaine, Lifeways and the Learning Disabilities Team.

**3.7** This final report arises from the interviews, written documentation and the Learning Event and was presented to Dudley SAB on 12<sup>th</sup> August 2016. The recommendations arise from the analysis, findings and the discussions of learning points covered at meetings and the learning events. All those involved in the SAR have been open and reflective in their approach throughout the process and have contributed to the analysis, findings and recommendations.

## **4. Summary of findings**

**4.1** This safeguarding adult review found that Andrew's death could have been prevented.

**4.2** The process of the review has identified areas of learning where services and systems could be improved. Findings and recommendations are identified in the body of the report and summarised at the end. These include initiatives that are already in place from individuals and individual agencies, as identified in IMR's and the learning events and multi-agency activities.

## **5. Background information relating to Andrew Events Leading up to Andrew's death – Factual Summary**

**5.1** Andrew was born on 19<sup>th</sup> April 1962 and died on 19<sup>th</sup> May 2014. He was 52 years old. Andrew was a much-loved brother, brother-in-law and uncle and the much loved son of his late parents. His parents died in 2008. Andrew was considered to lack mental capacity as defined under the Mental Capacity Act (MCA) 2005 and there is evidence of some best interest decision-making in respect of dental treatment, finances and medication.

**5.2** Andrew had severe learning disabilities and sometimes presented with behaviour that challenges. He was admitted to Lea Castle hospital as a child and in 1978, when he was 16 years old, he moved into Ridge Hill Hospital, a specialist hospital for people with learning disabilities.

**5.3** Responsibility for arranging his care was transferred to the Local Authority in 2004. Ridge Hill Hospital was being closed down and Andrew's needs were assessed with a view to him receiving community rather than hospital based services, in line with Government policy and recommendations.

He moved into a supported living arrangement in 2007, with his own home and staff support. His care provider was Lifeways and tenancy was with Bromford Housing Association. He had close links with his family and they were central to his daily life and emotional well-being. Over the years he went on holiday with his family and with support staff.

**5.4** Andrew had dysphagia, which is a difficulty in swallowing. He had eating and drinking guidelines in place to minimise the risk of his choking and/or aspirating.

**5.5** On 19<sup>th</sup> May 2014, Andrew was on his way to a holiday in Devon (Haven holidays) with two of his support staff. Andrew was seated alone in the back of his car. One member of staff was driving and the other was seated in the passenger seat. The member of staff in the passenger seat passed food to Andrew – chicken bites and jellies. These were foods that he should not eat. The staff members had decided to drive the long journey without breaks and, to reduce the need for him to go to the toilet, his fluid intake was restricted. He was given a drink of water whilst travelling. This drink was not thickened as required in his drinking guidelines, and again, was passed back to him. The staff member noticed that he had become very quiet and when she turned around she found that he was not breathing. Andrew had choked on the food. He was attended by paramedics, the police and the Air Ambulance Service. At 13:19 hours he was pronounced dead by the Helicopter Doctor and his body was taken to Plymouth Hospital. As these events were dealt with through the courts it is not appropriate to elaborate further.

**5.6** Cause of death as recorded by the Forensic Pathologist:

- 1a. Choking on food
2. Likely progressive supranuclear palsy.

**5.7** Andrew's post-mortem report also stated that he had gall stones. These were undiagnosed at the time of his death.

## **6. AS's circumstances and needs**

**6.1** Andrew's diagnosis in 1978, when he lived in Ridge Hill Hospital, is recorded as "learning disability with no specific aetiology, behavioural challenges and limited communication and comprehension. He had an unsteady gait, mobility difficulties and periods of fluctuating behaviour including aggression and self-injury." No swallowing difficulties were noted at that time. Andrew was under the care of the multi-disciplinary team in the hospital and received input from the Psychiatrists, Physiotherapy (PT), Occupational Therapist (OT), Speech and Language Therapists (SALT), Behaviour Support and Clinical Psychology. He was assessed for swallowing difficulties in 2004.

**6.2** Andrew is described as having some speech, he could be quite noisy and he liked using repetitive speech patterns. He could follow directions and his expressive/receptive communication was considered to be good. He had a good memory. Andrew had difficulty with fine motor movements and this impacted on his daily living and personal skills. He also liked repetitive movements, for example when he was eating, and this could lead to his overfilling his mouth with food. Following his diagnosis of dysphagia, his eating and drinking guidelines covered not only what he should eat and drink but also how he should eat and drink as both had associated risks.

**6.3** Responsibility for the provision of Andrew's care was transferred to the Local Authority in 2007. The service offered and then provided to him was supported living and accommodation in a bungalow built in the grounds of the hospital. Andrew had 24-hour support to meet his needs and he continued to receive input from the specialist health services including Psychiatry, Speech and Language Therapy and Occupational Therapy over the years. The health professionals were located approximately 100 yards from his new home. His accommodation was provided through a tenancy with Bromford Housing Association (BHA).

**6.4** Organisational changes to the structure of health and social care, along with a mix of paper and electronic recording systems makes it difficult for those involved in service delivery to gain a clear view of the integration of assessments, changes to Andrew's needs over the years, and his personal history. Much of his original assessments are not easily accessible and local authority records are difficult to locate on the system. His MAF (My Assessment Form), dated 19<sup>th</sup> July 2011 when the Local Authority moved to personal budgets, is quite basic and contains little information about Andrew. Significant information that was available on his file was not referenced including for example, his psychiatrist's view that 'Andrew struggled with young female staff and this has to be managed.' Much of his history would have been lost had he not had a family to advocate for him.

## **7. Environment**

**7.1** Andrew lived in a group of houses on the former hospital site, formed into a 'cul-de-sac' or courtyard arrangements. His neighbours were other people with learning disabilities living either alone or in 2 person dwellings, all with support staff from Lifeways, a private supported living provider. It had been hoped that there would be further house building on the site as it was sold off, creating a wider community, but this has not materialised. However, Andrew's family report that he loved living in his own home and receiving visitors. He had a positive relationship with his neighbour and they would visit each other at home and go on outings together.

**7.2** There is evidence in records that his home, managed by BHA, needed a lot of work to bring it up to standard and his sister worked with the Lifeways, the supported living provider, to improve decoration and fixtures and fittings. His brother-in-law tended the garden. The housing association provided limited gardening by way of grass-cutting.

## **8. Activities**

Andrew enjoyed a range of activities including puzzles, going to the garden centre and the pub, holidays, swimming, visiting his family, talking about his family and things they had done together whilst looking at his photographs, people-watching and Eastenders. He did not like long car drives and could become noisy and distressed during long journeys. He is reported to have enjoyed short car journeys where he could people-watch. He is described as having a good memory and would

recognize people he had met in the past. He made choices about whom he liked and whom he didn't. He is said to have really liked slap-stick humour.

## 9. Health

**9.1** Andrew had a range of health needs which were treated by primary and secondary health services.

His active medical problems are listed as:

1964 – Mental handicap

1970 – Behavioural problems *Aggressive behaviour, head banging, unpredictable*

1978 – Learning Disability

1978 – Gastro oesophageal reflux

1993 – Cerebral Atrophy

1999 – CAT Scan brain *Moderate dilation of ventricles neurodegenerative disorder*

2007 – Recurrent falls

2008 – Mole

2007 – Standard chest X-ray

2007 – Physiotherapy – *has physio every Friday*

2008 – CAT scan abnormal – *showed old right sided pons infarct*

2008 – Shortness of breath

2009 – Transient Ischaemic Attack

2009 – Seborrhoeic keratosis

2009 – Asthma – chest infection

2010 – Chest Infection x2

2011 – Chest infection x2

2011 – Dribbling from mouth

2013 – Chest infection

2014 – Excessive saliva

2011 – Dribbling from mouth

2013 – Chest infection

2014 – Excessive saliva

**9.2** In 1978 he had gastro-oesophageal reflux, and in 1989 he had a blood transfusion after suffering an oesophageal tear. He was diagnosed with asthma in 2008 and used a spacer and inhaler. Andrew also had cerebral atrophy, and a history of strokes. He had a Transient Ischaemic Attack (TIA), sometimes known as a mini-stroke, in 2009. He was treated for Seborrhoeic Keratosis (warts) in 2009. In 2011 he presented with excessive saliva/dribbling which was treated by Hysocine<sup>2</sup> patches. The excessive dribbling/saliva production also presented a risk as Andrew had an impaired swallow function. Andrew had an unsteady gait which could result in falls, and for which he had received physiotherapy. He would self-injure by head banging and was prescribed a safety helmet to protect his head. His GP records indicate that he had recurrent chest infections from 2010. Support staff took Andrew to the GP when he showed symptoms of hay fever. He was prescribed medication to reduce his behavioural challenges and the Community Consultant Psychiatrist Learning Disabilities reviewed this quarterly.

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<sup>2</sup> A drug similar to Atropine which reduces secretion of saliva and other bodily fluids



**9.3** Although Andrew was diagnosed with dysphagia, this is not listed in his active medical problems on his GP records. His Post Mortem identified previous aspiration, which the pathologist thinks could have been silent, and gall stones. It should be noted that that gall stones can be present and not cause pain or discomfort. However, gall stones can also cause significant discomfort and pain.

**9.4** In March 2014, Andrew's physical health was declining and he sustained falls and had a difficulty/reluctance to mobilise. He had two falls during transfers. He received physiotherapy and during a session on 9<sup>th</sup> April 2014 he presented with left sided weakness, breathing difficulties and increased saliva production. His oxygen saturation level was checked and was normal. Support staff were advised to report these concerns to his GP. Support staff had reported his shortness of breath to the GP the day before and he had his annual review with his GP on 10<sup>th</sup> April. His changes in behaviour were noted as well as physical health. His behaviour was described as being more quiet than normal, less interested in things and generally more sleepy, including sleeping during the day. He had full blood tests and renal function tests, all with normal results. The GP noted that he had not seen the SALT for over a year and that he should be referred for a SALT assessment given that Andrew was dribbling more over the past year. He was seen again by the GP on 15<sup>th</sup> May, four days before his death, with shortness of breath. The GP noted that he had not heard from the SALT and, although it may be that no further intervention was possible with respect to dribbling, Andrew did need a swallow assessment. Unfortunately, it appears that the original referral to the SALT service was not sent.

## **10. Equipment**

**10.1** Andrew used a range of equipment. This included a helmet to protect his head (falls and head banging); a walking frame for indoors (4 wheeled); an electric wheelchair for use outdoors; a weighted spoon, lipped plate and a dysphagia mug to support his safe eating and drinking, a walk-in shower and shower chair. He was continent of urine and faeces but occasionally had difficulty getting to the toilet as a result of impaired mobility, and he used Kylies<sup>3</sup> sheets on his bed. He had his own car via the motability scheme.

**10.2** Although Andrew was provided with a protective helmet he did not wear it and it is reported that it did not fit him.

**10.3** Elaine also reports that staff lost Andrew's dysphagia mug and said that he did not need it and just gave him an ordinary plastic mug.

## **11. Daily living skills**

Andrew needed support with showering and using the toilet. He was able to dress himself. He could feed himself but needed someone to sit alongside him to ensure that he ate and drank slowly and did not overload his spoon or overfill his mouth. He was at high risk of choking. He also ate sitting upright in his chair. He had

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<sup>3</sup> Absorbent bed protection incontinence sheet

thickened drinks (one third of a cup only at any time) and his food had to be a mashed consistency. He could not eat high-risk foods (e.g. salads with lettuce, fibrous or stringy fruits and vegetables, mince with thin gravy, crumbly biscuits). Andrew could not prepare his own food. He was described as not being interested in housework but he would wipe his dining table after meals if he was given a cloth.

## **12. Finances**

**12.1** Andrew's money was managed by his sister, Elaine, under the Court of Protection. She took over responsibility over from her parents following their deaths. He was financially secure and therefore money for holidays, for which both accommodation and staff costs would be met by him, was not an issue.

**12.3** Elaine has reported that on occasions the staff would contact her as they did not have cash for his needs, such as food shopping, as it had not been handed over to them from their Head Office. Although this had not happened in the last two years of his life, the provider thinks it is likely to have happened when their administration office was some distance from where Andrew lived and some staff may not have been able to drive to get to the office to pick up money. It is important to note that staff raised the issue with Andrew's family rather than their managers.

**12.4** Elaine also raised the concern that some staff were very young and had little life experience to draw upon to support them in the discharging of their responsibilities. This included budgeting, shopping and healthy eating. This could result in situations where a staff member saw that he had cash and would take him clothes shopping, without checking if he had food for the week. Lack of training in menu planning, budgeting and healthy eating led to occasions where staff are reported to have bought unsafe food for him, such as packets of pork chops. Elaine would deal with these issues but this does indicate a lack of oversight from both the provider and commissioners. Lifeways managers also state that that some staff who had been in post for a long time had a "we know best" attitude and were reluctant to accept supervision or guidance from team leaders.

## **13. Primary care services**

**13.1** Andrew was listed under the same GP practice for many years. He received annual health checks from the GP and his health needs including asthma and epilepsy reviews were completed. The practice has a dedicated GP for people with learning disabilities and a dedicated member of administrative staff who follows up reviews and any missed appointments.

**13.2** Although dysphagia is not listed as one of Andrew's medical problems, it was noted at his last Annual Health check (10<sup>th</sup> April 2014) that he had not seen a SALT for over a year and may benefit from a SALT review, especially in relation to dribbling. On his next visit to the GP on 15<sup>th</sup> May 2014, the GP records that that they have not heard from the SALT. On reflection the GP cannot find any correspondence with the specialist services and thinks that they had not followed up on making the referral.

**13.3** The GP records indicate that Andrew's chest was checked when he presented with shortness of breath and chest infections. However, it is not recorded if the GP asked support staff what Andrew had had to eat and drink. This is not to say that this question was not asked during the consultation. As Andrew had dysphagia, it would be reasonable to check whether his symptoms could have been a result of aspiration. Staff did not take the food diaries with them to GP visits and would not be able to give a full history of his recent intake or any coughs, as staff worked a shift system and there are no built in handovers between shifts to ensure full communication of issues. Lifeways managers have also acknowledged that quality of written daily records was poor. This is coupled with evidence that his eating and drinking guidelines were not followed on a regular basis. Given the Post Mortem findings of previous aspiration it likely that some of his chest infections were a result of aspiration.

## **Key themes for consideration in this SAR**

### **14. Transport risk Assessments**

**14.1** Andrew had his own car, a 4-door Vauxhall that could take his wheelchair in the boot. His pen profile dated 20<sup>th</sup> February 2007 from the community nurse (Health and Social Care for adults with learning disabilities was integrated service at that time) and in Lifeways records states the following:

'Andrew is able to transfer onto a standard car seat.'

'Andrew should be placed behind the passenger seat and an escort sit in the rear of the car to ensure Andrew does not attempt to head-butt the driver'.

**14.2** The transport risk assessments produced by Lifeways' staff make no mention of this. When he died both members of staff were seated in the front seats. The two transport risk assessments in place related to travelling, and the car having mechanical problems and Andrew becoming agitated. It is known that Andrew disliked long journeys. The strategies identified to reduce risks of harm are too generic e.g. 'Talk to him, tell him what is happening, make sure he is seated appropriately.' They did not say where staff should sit in relation to Andrew. There is no mention at all of Andrew not eating or drinking whilst he is in the car. This could be because no one would consider it likely to take place. Similarly, there is no mention of the need for comfort breaks on long journeys, although this was discussed in his pre-holiday planning meeting prior to his last holiday. Andrew's health and mobility had been deteriorating but his risk assessments were not updated to reflect these changes. Risk assessments and care plans were treated as separate documents and not routinely cross-referenced.

### **15 Learning point/finding**

**15.1** Risk assessments and care plans should be integrated and dynamic documents that are reviewed and updated regularly, and especially if a person's needs or health changes. In essence, risk assessments and care plans are key to person centred planning and should maximise the opportunities for an individual to do things that

make them happy and fulfilled. For example, the transfer of a person into their transport will be different for each individual.

**15.2** Risk assessments and care plans are also key documents for the staff who are supporting an individual. Andrew's transport risk assessments were neither person centred nor relevant to his needs. The Learning Event considered that managers need to have an understanding of a person's needs and have oversight of care plans and risk assessments. Participants recommended 6 monthly, rather than annual, reviews of a person's needs and resultant updating of plans and risk assessments, with a coordinated approach that involves Primary Health Professionals, specialist teams, family and care providers. Risk assessments for people who have complex health and care needs should be guided by professionals with particular expertise such as occupational therapists (OT), speech and language therapist (SALT), stroke nurses. The appointment of a lead health professional would provide an integrated, partnership approach to risk assessment and care planning.

**15.3** There is a concern that some staff do not understand care plans and risk assessments. Supervision and team meetings are key mechanisms for discussing and monitoring the adherence to plans as well as opportunity to establish if changes are needed to reflect new circumstances.

#### **15.4 Recommendation:**

- **Care plans and risk assessments should be integrated. Risk assessments for people who have learning disabilities and complex health and care needs should be guided by the relevant health professional.**
- **Consideration should be given to appointing a named lead health professional for each person with a learning disability and complex health and care needs.**

## **16. Dysphagia**

**16.1** Andrew had very specific eating and drinking guidelines in place which were supported by clear photographs to show how they should be implemented. The key issues were:

- What he could and could not eat.
- What and how much he should drink.
- The use of equipment, including lipped plate, weighted spoon and dysphagia mug.
- How he should be seated.
- Where staff should be seated in relation to Andrew to support his safe eating and drinking.
- How staff should support Andrew to eat and drink safely.

**16.2** Lifeways have already acknowledged that there was some difference between his risk assessments and care plan in respect of eating and drinking. They have now introduced integrated plans.

**16.3** Andrew could engage in repetitive behaviour, and this translated into his actions when eating. He would fill his spoon and bring his spoon up to his mouth repetitively. As a result, he would cram food into his mouth as he may not have finished eating the previous mouthful. He would also overfill his spoon. Staff had to sit alongside Andrew whilst he was eating and gently hold his hand until he had completed eating, before he took the next spoonful. They were also advised to ensure that he did not overfill the spoon. He had thickened drinks and his dysphagia mug was only to be filled to one third as he would drink the contents of the mug in one go.

**16.4** It does appear from interviews and reports that the eating and drinking guidelines were not routinely followed. Food diaries are maintained by Lifeways and Andrew's were signed off by the previous Service Manager. A random check of food diaries covering 4 weeks over April 2013 to May 2014 found that some diary entries were undated and Andrew was given foods that he should not eat on a regular basis. Description of how the food was presented includes sausage – 'cut up small'; 'pizzas slices – cut up small'; 'slices of cake – cut up'; 'chicken bites and potato croquettes – cut up into bite size pieces'; 'mini-fish and chips and curry sauce- cut it up small'. A specific example is Andrew's lunch on 17<sup>th</sup> Feb 2014 which was a cheese and tomato slice, cut into bite size pieces. It is recorded that he coughed once. Andrew did not have a menu plan and it is difficult to see how he would have received a balanced, healthy diet which met his eating and drinking guidelines without one.

**16.5** Elaine reports that when she raised with staff and managers that he was given unsafe food such as salad, the response she received from support staff was that he had been okay eating salad before. She also challenged staff when she found pork chops in his freezer. These are examples of a culture of staff not understanding the risks associated with not following the guidelines, and also of the cultural impact of 'usual practice' in the organisation. Elaine says that there had been an improvement over the last year of Andrew's life, but she feels that this was a result of her intervention and persistence, rather than attitudinal change. Unfortunately, the food diaries record that Andrew's guidelines were not being followed during this period.

**16.6** Lifeways managers acknowledge that staff did not routinely follow the eating and drinking guidelines when they took Andrew out. Dysphagia guidelines were ignored when he ate out e.g. having fish and chips, a pint of Guinness. These were included in his care plans as things he enjoyed, with no cross-reference to the dysphagia guidelines. From interviews it is apparent that when he had a pint of Guinness it was not thickened.

**16.7** Andrew's support staff bought and prepared his food. Competency in food preparation and understanding of dietary needs, healthy eating, menu planning and budgeting are not assessed in either the recruitment or training of support staff, despite this being central to their role. Team leaders were described as being young and, again, not recruited or trained in these areas.

**16.8** The local specialist Learning Disabilities Team (Speech and Language Therapy Service) provided training to Lifeways staff in 2008. They continue to offer dysphagia awareness training to local providers and assessors on 6-8 week rolling programme. Some Lifeways staff attended this over the years but it not mandatory training under the Care Standards Act. One of the support workers who was with Andrew when he

died had undertaken safer swallowing/dysphagia awareness training in June 2010, but the other had not. The Learning Disabilities Team has also provided nutrition awareness training to local providers since 2011. This training covers the preparation of food to different textures as may be required and identified in an individual's eating and drinking guidelines, such as a mashed food, thickened drinks. The take up of this training, again as it is not mandatory, has been variable.

**16.9** There is an ongoing difference of opinion between the local NHS Foundation Trust, who are responsible for the specialist SALT service, and Lifeways over which dysphagia guidelines should be used, as both bodies want to implement resources from best practice in the field. My observation would be that it is important that people with learning disabilities who have dysphagia and family carers are involved in this discussion and any recommendations. This would have the added benefit of raising awareness of the risks associated with dysphagia more widely. This approach was used successfully in Hampshire in the development of their strategy "Reducing the risk of choking for people with a learning disability: A Multi-Agency Review" September 2012.

**16.10** Andrew was discharged from the SALT service on 30<sup>th</sup> August 2011. He was re-referred by the Consultant Psychiatrist Learning Disabilities on 8<sup>th</sup> February 2012 for input regarding communication and behaviour. Between February 2011 and 11<sup>th</sup> June 2012 Andrew and Lifeways staff were supported by the SALT, working with the Clinical Psychologist, with a review assessment; communication guidelines; guidance on communication passport revision; and liaison with staff and Andrew's family. The Psychiatrist recorded on 15<sup>th</sup> June 2012 that Andrew was making good progress with his behaviour input and that dysphagia recommendations were reported to be being followed. More latterly she checked this again at Andrew's outpatient appointment on 10<sup>th</sup> March 2014, where support staff reported that dysphagia guidelines were being followed (however we know from food diaries that this was not the case). The Psychiatrist also observed Andrew drinking a thickened drink when she undertook a home visit to him on 11<sup>th</sup> April 2014.

**16.11** The SALT service does not keep cases open, that is, does not retain clinical responsibility for a patient once their input is no longer required. The service is accessed via a re-referral as needed and there is facility to emergency referrals. As previously stated, the SALT team provides a rolling programme of dysphagia awareness/safer swallowing and nutrition awareness sessions for professionals and carers.

**16.12** There is also an issue regarding food found at Andrew's home. Whilst Elaine reported that she would check the contents of the cupboards and fridge-freezer, community professionals did not believe that they should. Support staff also put their food unlabelled into Andrew's cupboards and fridge freezer.

## **17 Learning points and recommendations**

**17.1** It is apparent that dysphagia is not sufficiently understood by many professionals in health and social care, and nor is it in the public consciousness. Dysphagia or swallowing difficulties are associated with many conditions. The risks

of choking or aspirating are very serious and can result in death. However, dysphagia can be managed very successfully and deaths are preventable. It would be helpful if dysphagia was clearly identified on Social Care Assessments, separate from support needs in relation to food preparation and eating.

**17.2** Although there is a difference of opinion between the local learning disabilities team and the provider over the format of eating and drinking guidelines, the key issue is that staff and managers routinely ignored Andrew's eating and drinking guidelines and he was given unsafe food and liquids. Managers did not support staff to understand that the guidelines were in place to keep Andrew safe from choking. A culture appears to have developed around the view that restrictions on the type of food and drink that Andrew was given was unkind to him, or that he had not suffered harm the last time he ate or drank something that was high risk, therefore he would be okay. It is very worrying that staff did not follow eating and drinking guidelines when Andrew was out and about in the community. In discussions with professionals from the various agencies in interviews and at the Learning Event, this issue was acknowledged as widespread. Food is culturally very important in all societies and restrictions on food cause can cause distress to paid carers and families. The Learning Disabilities team separates its speech and language service into a distinct communication service and distinct dysphagia service in recognition of the emotional issues associated with eating and drinking.

**17.3** The re-enforcement of the need to adhere to eating and drinking guidelines for those at risk of choking needs a strategic approach to bring about a cultural shift. The fact that dysphagia is not mandatory training in the Care Act means that it is not prioritised. The CQC have said that they will check during inspections on staff training and competence to support people who have dysphagia, which will provide some oversight. However, dysphagia awareness is required at all levels within commissioning and provider agencies to improve knowledge and skills across the board and reduce premature mortality.

**17.4** The Learning Event heard that some providers in Dudley have linked up with local pubs and cafes to create dysphagia friendly visits, where staff can prepare food for individual in line their eating and drinking guidelines e.g. mash or liquidize food, thicken drinks. These positive initiatives show really creative ways of supporting people with dysphagia to enjoy community life and be safe.

**17.5** Although buying food, planning menus and preparing meals are core tasks for support workers, the skills and knowledge to deliver them are not tested in recruitment. Some support providers, including Lifeways, are now providing training in these areas and healthy eating. If it were included in recruitment and selection it would emphasise the importance of food and diet in the support of individuals, and provide a firmer foundation for staff supporting the provision of adapted diets.

**17.6 Recommendation:**

- **Job descriptions and person specifications for support worker should include demonstrating competence in menu planning, healthy eating and food preparation.**
- **People with dysphagia must have support from staff who have had training in dysphagia/safer swallowing and nutrition awareness.**

**17.7** Taking food diaries to Doctor's appointments could be a positive development but they must be recorded fully and accurately to be of benefit, and should be an additional support to good quality written records and handovers meetings. Written records and food diaries should be monitored through supervision to ensure understanding and compliance with care plans and guidance. Supervision should also provide a time for discussion over issues such as following guidelines when away from home, or checking out any anxieties and fears of staff.

**17.8 Recommendation:**

- **Quality checks and supervision records should examine food diaries to ensure that they are compliant with individual's eating and drinking guidelines.**
- **Support staff should complete these accurately and honestly.**
- **Support staff working with people with learning disabilities and dysphagia should take food diaries to appointments with health professionals including GP and specialist services.**

**17.9** Thought needs to be given to how and where staff store their food in someone else's home and agreed policies put in place which respect the home of the person with learning disabilities as well as provide facilities for staff.

**17.10 Recommendation:**

- **Dudley SAB should consider developing a local strategy to reduce the risk of choking for people with learning disabilities using the approach developed in Hampshire.**  
<http://documents.hants.gov.uk/adultservices/safeguarding/Reducingtheriskofchokingforpeoplewithlearningdisability.pdf>

## **18 Multi-agency Reviews**

**18.1** Andrew did not receive any multi-agency reviews from the Local Authority after his MAF assessment in 2011. Although this resulted in a change in his service through changes to the contract, the impact was not considered in a review. Andrew's community professionals were noting significant changes in his behaviours, health and relationships to others during the subsequent three years, as were his family and support staff, however there was no forum for looking at these holistically and developing a pro-active response. Elaine was left to respond to many of these changes. She received copies of letters from his health staff and attended internal meetings and reviews with his provider. However, these did not fulfil the functions of a multi-agency review, which would have supported her to express concerns about changes to Andrew's needs, raise any concerns about the quality of care and support, and make plans for his future with key agencies. Without her input on a regular basis many of Andrew's needs would have been unidentified and consequently unmet.

**18.2** Andrew's health deteriorated in the last few months of his life but, although he received medical input, there was no multi-agency review to look at the impact on his daily life and activities and to update his care plans and risk assessments



accordingly. Had there been a mechanism for convening a multi-agency review a number of issues could have been explored, including the appropriateness of the holiday planned for him.

## **19. Learning point**

**19.1** Multi-agency reviews for individuals are central for maintaining a focus on the individual and ensuring that those services are working together to deliver person-centred services. They also provide a forum for addressing concerns and forward planning. As Andrew did not have a named worker in the Local Authority with whom he, his family, partner agencies or his provider could liaise and convene meetings, changes to his needs were addressed in a piecemeal manner. Elaine posed the question 'should a best interest's meeting under the MCA 2005 have been called to consider the proposed holiday?' In hindsight this would have been a positive way of looking at the appropriateness of the holiday and any necessary preparations prior to the holiday being agreed. Had Andrew had multi-agency reviews issues such as holidays could have been discussed and planned in that process.

### **19.2 Recommendation:**

- **Regular multi-agency reviews should be arranged by the Commissioning authority to support the delivery of person centred services. The frequency of these reviews should be agreed around the needs of the individual, and families and advocates should have access to clear information about how to request a multi-agency review. A change in an individual's needs or health should trigger a multi-agency review.**

## **20. Changes from Block contract to personal budget**

**20.1** Andrew received an individual service of 6257 support hours per annum and 365 nights of care.

**20.2** The change of contract from a block contract with Lifeways to individual budget plans resulted in a net loss of support hours for Andrew. There is no evidence that the impact of this reduction in hours was reviewed subsequently. Some of the reduction in hours was achieved though the loss of handover time between shifts. This reduces effective communication time between staff who then rely on written records. The managers at Lifeways said that the quality of written daily records was poor.

## **21. Supervision of Support Staff**

**21.1** Staff supervision at Lifeways was contracted as six sessions a year. Lifeways' Managers say that this was delivered through 1-1 meetings, staff meetings and conversations. It should be noted that the contractual requirement is six supervision sessions plus staff meetings. There is no agreed definition or quality framework in place for supervision between the Commissioners and Providers.

Regulation 18 of the Health and Social Care Act 2008 (Regulated activities) covers staffing and Skills For Care have developed a definition of supervision for social care staff.<sup>4</sup> The frequency of supervision is not specified in the regulation.

It is doubtful that Lifeways' team leaders had the competence and confidence to provide effective challenge and leadership through the supervision. Some of the team leaders were described by their manager as quite young and although they had NVQ Level 3, would not have had the experience to challenge more confident long-standing support workers. This does appear to have had an impact on the safe delivery of Andrew's care plans, as well as some of his choices such as visits to his family and swimming. Similarly, rota-ing issues such as Andrew's need for a driver to be working with him was not prioritised and his family are of the view that staff choice rather than his choices influenced the rota and support worker allocation. Lifeways managers have also raised the issue of the low pay of support workers. They advise that there are real challenges in recruiting drivers as the costs of driving lessons and insurance are prohibitive for many of the core pool of potential staff.

**22.2** Support staff also made arrangements to take Andrew on holiday without getting approval from their manager in advance. Lifeways' managers were only told about the holiday 6 weeks before he went, by which time the choice of holiday destination was already determined, as was the staffing.

**22.3** It also appears from interviews with Elaine that support staff would talk with her about their disgruntles with management.

## **23. Learning point and finding**

**23.1** Although a lot of work has been undertaken by Commissioners and Providers on contracts, there are gaps in common understanding and language. Contracts do not define supervision, nor do they reference some key features of support and shift work, such as handover time so that these can be protected in any changes to contract hours. There does not appear to have been any discussion about handover and supervision. The Commissioners have assumed that the monthly model of social work supervision was used in supported living services, however this is not the case. Work is needed around what is being contracted and the most appropriate supervision model for support staff. Handover time and supervision are key communication tools in delivering quality services to people with learning disabilities and complex health needs. Commissioners need to be very clear in contracts about how they want these to be delivered by providers and monitored. Handover times are excellent opportunities for team leaders to give support and direction to support staff.

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<sup>4</sup> "Supervision involves making the time and developing the practical structure to give support to co-workers. This is done using various approaches during formal and informal supervision and appraisal.

A supervisory relationship is one in which a person with some knowledge and skill, takes responsibility and accountability for the wellbeing and work performance of the person being supervised—the supervisee. It is 'one-to-one' (with exceptions), and is supportive rather than judgmental" <http://www.skillsforcare.org.uk/Learning-development/Effective-supervision/Effective-supervision.aspx>

### **23.2 Recommendation:**

- **Commissioners and Providers should undertake further work to ensure that contracts are explicit and specific in setting out what is expected from services that are supporting people with learning disabilities and complex health needs.**

## **24. Provider records and paperwork**

**24.1** Andrew's care plan, support plan and communication plan were clear and related to each other and were of a general good quality. Plans and assessments from the SALT were incorporated, as were photographs of how best to support him.

**24.2** However, the content of some of his files was weak e.g. his health action plan, which stated that he took Procyclidine<sup>5</sup> for Schizophrenia. Andrew did not have a diagnosis of Schizophrenia, but he was prescribed anti-psychotic medication to support the management of his behaviours.

**24.3** As stated before, the transport risk assessments were poor. However, Andrew's risk assessment for choking (dysphagia), dated 29.04.2013 states clearly that there is a risk of death. It also states that staff are to be trained in first aid, to provide support to Andrew in case of choking and how to administer safely.' The first aid training of one of the staff who was with Andrew when he died had lapsed as it had been taken more than 3 years previously. There is evidence of poor oversight of the relationship of risk assessments to care plans. Elaine says that she spoke to staff frequently about taking him swimming, which is an activity he enjoyed, whereas staff detailed in his care plan that he would never want to go swimming. There is a concern that some of the staff did not want to take him swimming, or did not have the confidence and skills to support him swimming and this was translated into Andrew not enjoying swimming.

## **25. Learning point**

**25.1** Risks assessments and care plans should be integrated and Lifeways are now following this process. The weaknesses in the records and paperwork demonstrate how the activity of producing care plans can be separated from the provision of support to an individual, and limited supervision for staff can result in there being a disconnect between the two. Good communication is the key to delivering quality services and the quality framework should have this at the centre, reducing the opportunities for significant errors.

### **25.2 Recommendation:**

- **Support and care providers should ensure that integrated care plans and risk assessments are discussed and reviewed in supervision sessions and staff meetings, and that these discussions are recorded.**

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<sup>5</sup> An Anti-cholinergic drug, similar to Atropine, sometimes used to counter the side-effects of some drugs used in the treatment of psychoses such as Schizophrenia.

- **Health action plans should be overseen by a health professional and agreed with the GP linking to the individual's annual health check.**

## **26 Andrew's visits to his family**

**26.1** In the Individual Agency Management Report (IMR) from Lifeways it states that Andrew was supported by staff to go to visit his family. Sadly, further investigation by Lifeways has found that this was not the case. He was only supported to visit his family at Christmas and one birthday celebration. This reduced his access and participation in normal family life. Elaine and Keith asked staff and managers to ensure that he had drivers allocated to support him, and for them to bring him to their house at weekends to see his family. A lack of drivers meant that this was not always available to him, and when he did have staff who could drive they didn't offer him the option of a visit to his family. It is evident that he went out for short drives, visited the pub and garden centres so it is hard to see why he was not supported on visits to his family, other than staff not wanting to take him, or not having the confidence to undertake family visits.

## **27. Learning point**

**27.1** The right to respect for a private and family life is enshrined in Article 8 of the Human Rights Act 2000. Central to this is a person's choice about their private and family life but there appears to have been little attention paid to supporting Andrew to visit his family. Staff are sometimes unclear about their roles and boundaries when supporting a person to visit their families and this can result in avoidance. The presumption that Andrew was being supported to visit his family indicates that managers have given this little thought, and the lack of multi-agency meetings meant that there was no forum where this could be discussed and any barriers, expectations and anxieties explored.

### **27.2 Recommendation:**

- **Support for the right to family life should be explored when people move home or if there are changes in their circumstances and plans developed to make it happen, including discussions with staff, agreement about how staff should support the person when they are with their family and friends, equipment and any other issues pertinent to that individual's choices and wishes.**

## **28. Agencies' response to Andrew's family following his death**

**28.1** Andrew's family report that the support they have received from Devon and Cornwall Police has been excellent and is ongoing. However, the agencies involved in the care of Andrew did not provide a compassionate or thought through response to Elaine and Keith and their family following his death. No one senior manager from health, social care, the provider or the housing association took responsibility for ensuring that someone liaised with them or coordinated the communication between

the agencies. The agencies responded to Andrew's death through safeguarding processes but that is not the same thing as supporting families.

**28.2** Elaine received a letter of condolence from the Chief Executive of Lifeways which was written just a few days after Andrew died. However, there was no later acknowledgement of the circumstances of his death and the on-going criminal investigation and proceedings, as these became apparent. Elaine contacted Lifeways Headquarters 6 weeks after her brother's death. This was after she was asked by another department in Lifeways to produce Andrew's death certificate in order that his money could be released to her. This left Elaine distraught and she felt that she could no longer go to the local Lifeways' office. Elaine did receive personal support from the new local Lifeways Service Manager and some of the support staff, but she feels very let down by the senior management, and local staff did not deal with issues such as Andrew's tenancy.

**28.3** These are Elaine's words:

The day after Andrew died. "We left [Deriford Hospital] the following day and on the journey back I received a phone call from the coroner's office and informed them that I felt that we were looking at a negligence case. In the days that followed I received no calls or support from Lifeways or social services. I was told that Andrew's property needed to be cleared within 10 days or I would be charged. Lifeways held approx. £800 of Andrew's money and I had to meet members of staff in Tesco coffee shop to obtain this money. I had to clear his property, sort all his affairs myself with no support from anyone. It was such an awful time and would have been made easier with just a little support.

Three weeks after Andrew's death our son got married in Ibiza. This had been booked for 12 months; there was a party of 30 guests. We had to attend, it was our son, but the event for me was completely ruined when it should have been such a joyous time. I had 5 weeks off work covered with a sick note and have since lost another 10 weeks in April of this year and am now on anti-depressants, as is my husband."

## **29. Learning point**

**29.1** The code of practice for Victims of Crime (Victim's Code)<sup>6</sup> was introduced in 2006 and sets out the minimum levels of service which victims can expect from agencies that are signatories to it (cps.gov.uk 2015). It recognises a victim as a close relative of a person whose death was directly caused by a criminal offence and the relatives of a deceased person are entitled to receive services as 'victims of the most serious crime'.

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<sup>6</sup> The Code of Practice for Victims of Crime is issued by the Secretary of State for Justice under section 32 of the Domestic Violence, Crime and Victims Act 2004. It implements relevant provisions of the EU Directive 2012/29/EU establishing minimum standards on the rights, support and protection of victims of crime

**29.2** The Victim's Code does not apply to agencies who provide or commission health and social care. However, it has a lot to offer these agencies in providing a framework for improving the support to families of those who have died, or experienced a serious event, in health or care services where the death or event is subject to investigation through safeguarding procedures, SAR or criminal proceedings. Elaine and Keith feel supported by the Police and Prosecution Services and the Learning Event heard from the Police about the values and approach that underpins their work. Most importantly, the Victims Code gives victims a status and rights.

**29.3** The lack of any clear strategy around supporting victims in this case meant that the various agencies, with the exception of the Police, and through default rather than design, failed to consider the impact of Andrew's death on his family. As a consequence, Elaine and Keith were left to deal with things such as emptying his flat, closing his accounts and other practicalities on their own. A simple decision such as a senior officer of Lifeways, the Housing Association or the Local Authority taking responsibility for extending the tenancy period until Andrew's family could cope with clearing his flat would have saved a great deal of pain.

#### **29.4 Recommendation:**

- **That the Dudley SAB gives consideration to commissioning a strategy to develop a victim's code for Health and Social Care, to be informed by the Police and local signatories of the Code of Practice for Victims of Crime, families of those who have deaths have been subject to a SAR, and linking with the findings of the recent Making Families Count Conference April 2016 which was hosted by Cygnet Care in collaboration with the Making Families Count team and NHS England South. <https://www.cygnethealth.co.uk/news/making-families-count/>**

**And Making Families Count video. <https://vimeo.com/133131650>**

### 30. Summary of Recommendations

1. Care plans and risk assessments should be integrated. Risk assessments for people who have learning disabilities and complex health and care needs should be guided by the relevant health professional.
2. Consideration should be given to appointing a named lead health professional for each person with a learning disability and complex health and care needs.
3. Job descriptions and person specifications for support worker should include demonstrating competence in menu planning, healthy eating and food preparation.
4. People with dysphagia must have support from staff who have had training in dysphagia/safer swallowing and nutrition awareness.
5. Quality checks and supervision records should examine food diaries to ensure that they are compliant with individual's eating and drinking guidelines. Support staff should complete these accurately and honestly. Support staff working with people with learning disabilities and dysphagia should take food diaries to appointments with health professionals including GP and specialist services.
6. Dudley SAB should consider developing a local strategy to reduce the risk of choking for people with learning disabilities using the approach developed in Hampshire.  
<http://documents.hants.gov.uk/adultservices/safeguarding/Reducingtheriskofchokingforpeoplewithalearningdisability.pdf>
7. Regular multi-agency reviews should be arranged by the Commissioning authority to support the delivery of person centred services. The frequency of these reviews should be agreed around the needs of the individual, and families and advocates should have access to clear information about how to request a multi-agency review. A change in an individual's needs or health should trigger a multi-agency review.
8. Commissioners and Providers should undertake further work to ensure that contracts are explicit and specific in the setting out what is expected from services that are supporting people with learning disabilities and complex health needs.
9. Support and care providers should ensure that integrated care plans and risk assessments are discussed and reviewed in supervision sessions and staff meetings and that these discussions are recorded.
10. Health action plans should be overseen by a health professional and agreed with the GP linking to the individual's annual health check.
11. Support for the right to family life should be explored when people move home or if there are changes in their circumstances and plans developed to make it

happen, including discussions with staff, agreement about how staff should support the person when they are with their family and friends, equipment and any other issues pertinent to that individual's choices and wishes.

12. That Dudley SAB gives consideration to commissioning a strategy to develop a victim's code for Health and Social Care, to be informed by the Police and local signatories of the Code of Practice for Victims of Crime, families of those who have deaths have been subject to a SAR, and linking with the findings of the recent Making Families Count Conference April 2016.

### 31. Index of Acronyms

Acronym	Full title or phrase
SAR	Safeguarding Adults Review
SAB	Safeguarding Adults Board
IMR	Individual Agency Management Report
MCA	Mental Capacity Act
BHA	Bromford Housing Association
MAF	My Assessment Framework
GP	General Practitioner
PT	Physiotherapist
OT	Occupational Therapist
SALT	Speech and Language Therapist
TIA	Transient Ischaemic Attack
IHAL	Improving Health and Lives
CQC	Care Quality Commission

#### Appendix 1.



SAR Overview  
Report For Mr St

#### Appendix 2.



SAR Overview  
Report for Mr St