Serious Case Review
Executive Summary[1]

Adult E
Died July 2010

Nottinghamshire Safeguarding Adults Board

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[1] This is the summary of a serious case Overview Report commissioned by the Nottinghamshire Safeguarding Adults Board (NSAB). The report is based on information provided by Adult E's mother and relevant agencies, and analysed by the independent author. The findings and recommendations have then been drawn from that analysis. An improvement action plan has been developed by the NSAB from the recommendations.

Acknowledgements

Nottinghamshire’s Safeguarding Adults Board (NSAB) would like to thank all those who contributed to this Serious Case Review (SCR).

We would particularly like to express our condolences to Adult E’s family and to thank her mother for giving time to share her knowledge and observations about how agencies worked with her daughter. She did this in the spirit that people would learn from her daughter’s very sad death, and in the hope that similar deaths may be prevented.

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1. Introduction

Adult E died in a Nottinghamshire hospital in July 2010. She had been admitted as an emergency and tragically died the next day.

The cause of her death "was massive sepsis leading to multi-organ failure as a result of necrotising fasciitis (NF) in pressure ulcers to her perineum". The death certificate listed the cause of death as:

1a. necrotising fasciitis of perineum[2]
1b. pressure ulcers
1c. spina bifida

The decision to hold a serious case review (SCR) was made by the Nottinghamshire Safeguarding Adults Board (NSAB) following the investigation of a complaint that had been made by Adult E's mother about the care provided by a number of agencies to her daughter before her admission to hospital. The Board commissioned an independent person, not employed by any Nottinghamshire agency, to be involved in the review and to write the Overview Report.

The Review was recommended on the grounds that:

- a vulnerable adult had died and abuse or neglect was known or suspected to be a factor in her death; and
- the case gave rise to concerns about the way in which professionals and services worked together to safeguard her.

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[2] Necrotising fasciitis (referred to as the flesh eating disorder) is a rare but serious soft-tissue infection caused by a number of bacteria; one of these is *Streptococcus pyogenes* (also known as *S. pyogenes* or Group A streptococcus). Unless the infection is rapidly diagnosed and treated, the bacteria may cause gangrene, tissue death, systemic disease and toxic shock and can result in death. The National Reporting and Learning System (NRLS) from September 2008 to September 2011 found 75 reports concerning this condition.
See www.nrls.npsa.nhs.uk/resources/?EntryId45=132976 and www.hpa.org.uk

2. Why and how the Review was carried out

2.1 The purpose of holding a serious case review (SCR) is neither to reinvestigate nor to apportion blame. The purpose is:

- to establish whether there are lessons to be learnt from the circumstances of the case about the way in which local professionals and agencies work together to safeguard vulnerable adults;
- to improve practice by acting on learning; and
- to prepare or commission an overview report which brings together and analyses the findings of the various reports from agencies, in order to make recommendations for future action.

2.2 A Panel (the SCR Panel) of senior staff from agencies represented on the NSAB was convened to consider Adult E's case. They decided, on the evidence that was initially available, to limit the time frame of the enquiry from 2004 until Adult E's death, though relevant events prior to 2004 were also considered.

2.3 The Panel drew up 7 questions that formed the Terms of Reference for the review. These can be found in section 4 of this report.

2.4 Contributors to the Review

Some agencies which had more substantial contact with Adult E produced detailed individual management reports (IMRs), whilst other less involved agencies were asked to respond to particular questions.

The agencies contributing to the Review were:

- Sheffield Teaching Hospitals NHS Foundation Trust
- Sheffield City Council Adult Social Care
- Nottinghamshire County Council
- Nottinghamshire Adult Social Care, Health and Public Protection
- Nottingham University Hospitals NHS Trust
- NHS Nottingham City and Nottinghamshire County
- Nottinghamshire Healthcare NHS Trust
- East Midlands Ambulance Service
- Spirita Housing Association

A senior officer from Nottinghamshire Police chaired the serious case review panel, as the police had no involvement with Adult E.

Adult E's mother provided verbal and written information and opinion to the independent author of the SCR report.

3. Key information and the circumstances that led to this Review

Adult E was of white British origin and aged 40 at the time of her death. She had been born with spina bifida, which her mother described as giving her 80% physical disability, though she had no learning disabilities. She was paralysed from the waist down and used a wheelchair.

It is clear from the information that has been brought together by this Review that Adult E was a remarkable person in many respects. She had drive and resilience and managed her life with very little support from public agencies in spite of the severity of her impairment.

She lived on her own in an adapted rented property and received some disability benefits as well as her earnings from her part-time supported employment. She had been in this skilled post since leaving college.

She was a car driver, liked going to concerts, was interested in photography, enjoyed socialising with her work colleagues, loved going on holidays abroad, and had a strong work ethic. She is variously described as a private, though friendly, person, and as someone who was fiercely independent. It was evident that she didn't want her disability to define her and limit her opportunities in life.

Between 2001 and 2006 Adult E had several hospital admissions for treatment, including surgery, to repair damage from serious pressure ulcers. Her paralysis meant that she was not always aware of the development of pressure ulcers as she felt no pain. She was absent from work for a considerable period and when she did return she had to reduce her working hours. However, she did recover and managed, somewhat to the surprise of some professionals, without any community care services, other than from community nurses. She had infrequent contact with her GP but attended regular outpatient appointments at Sheffield Hospital Spinal Injury Unit (SIU). She had a brief contact with Sheffield Adult Care services in 2004/5 during a hospital admission.

During 2007 and 2008 she had no further pressure ulcers or hospital admissions, and continued to work. However, she did begin to experience some financial difficulties as her wages from work reduced in line with her shorter working hours and some mistakes were made in her benefit entitlement.

In 2009, following referrals from her mother, who was concerned that her daughter was struggling to cope, she had brief contact with Nottinghamshire's adult care services. Later that year she also had one face-to-face contact with a mental health nurse practitioner following a referral from her GP about her low mood. In addition she had some contact with an occupational therapist (OT) about adaptations to enable her to put her new Motability car into her garage.

In 2010 there was again contact with the OT about adaptations and the replacement of a torn shower chair seat. At the instigation of her mother a social worker also had a brief contact with Adult E. However, it was not until the day before her death in July 2010 that professionals became aware, again alerted by her mother, of her seriously deteriorating health. She had been in work in the week before her death, though professional opinion is that she is likely to have been developing pressure ulcers as well as leg ulcers in the weeks before she died.

Adult E was regularly receiving services from the Community Nursing Service[3] (CNS) from 2002. Initially the main focus was on treatment of her pressure and leg ulcers but from 2007 onwards visits were almost exclusively to change her suprapubic catheter.

The organisations mentioned above all held some information about Adult E, as did her Housing Association (HA) landlord who communicated with her intermittently about rent and housing benefit issues.

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[3] The Community Nursing Service is sometimes described as the District Nursing Service. The term community nurses will be used in this report as nearly all the nurses who had contact with Adult E were registered general nurses rather than registered district nurses.

4. Key Findings, Analysis and Learning

The following 7 questions were asked of all agencies, some of which provided individual chronologies of their involvement and management reports that detailed their own findings and what they had learned from their analysis. Where relevant, each made recommendations about what their service was doing / would do following Adult E's death. The independent author collated this information and provided further independent analysis as can be seen below.

1. **What evidence, if any, did your agency possess which suggested that Adult E had a tendency to underplay the seriousness of her physical health problems? How was this understood by practitioners and what interventions did they put in place to minimise the risk this posed?**

Adult E did not ring any safeguarding alarm bells with agencies. She had very little contact with agencies other than with the community nursing service, where she was attended by a changing rota of staff. Her mother raised concerns about her daughter's deteriorating emotional health and ability to cope in 2009 but Adult E made few direct contacts with services. When she did make contact it was for specific reasons and her message was consistent: she did not want personal care support.

In May 2010 Adult E attended an outpatient appointment at Sheffield Hospital and the notes record that she had not had a urinary tract infection over the past year, which suggested that she was maintaining good standards of hygiene.

Adult E displayed some coping strategies that were beneficial to her most of the time: "pride in self-sufficiency" combined with behaviour that attempted to preserve continuity of her identity as an independent person, who was not seen as defined by her disability. Unfortunately this "fierce independence" and history of overcoming some serious health episodes and returning (to the surprise of some professionals) to a self-caring lifestyle, helped mask her vulnerability from busy and, on occasion, narrowly task-focused professional staff.

On one occasion in 2009 with the MHP, she took a significant step in sharing her fears about losing her independence and that she was trying to do too much. Given that avoidance was her main coping strategy it is not surprising that she did not take up the offer of further meetings to explore different coping strategies. It appears that the service was designed to offer little encouragement to do this, so an opportunity was missed.

The receipt of intimate care is difficult for most people, made more difficult if it is received from an ever-changing band of even the most kindly and skilled people. There was a need for recognition and open discussion with Adult E about how she was putting her independence at risk by insisting on doing all her personal care and avoiding intimate examinations. If this had been done, it might have been possible to reach a solution that managed her health risks whilst maintaining her control over other aspects of her life that were important to her.

The key learning from this analysis is that it is very difficult to detect if someone is underplaying their risks or avoiding service contact unless this is frequent and results in harm. Her GP was aware that she tended to use “avoidance as a coping strategy”, and referred her to a mental health practitioner in 2009, but as she again “recovered” and returned to work, her avoidance in some aspect of her life was not seen as posing a significant risk to her health by anyone other than her mother.

2. Were there formal assessments of Adult E’s mental capacity? What choice was Adult E perceived to have made and how did this influence decision making?

There are no recorded occasions when any agency questioned Adult E’s mental capacity to make decisions, even up to the night before her death when her consent was being sought (and was given) for surgery. There is evidence that she made some unwise decisions, usually about not taking or delaying certain actions, but nothing that suggests that she did not have the capacity to make those decisions.

Professional workers were well aware that Adult E did not want to be dependent on services that involved physical interventions or support. Her reluctance was respected by staff and the risks her choices posed seem to have been unexplored.

Her behaviour as an adult with capacity to make decisions had a significant impact on how agencies responded to her. They arranged their contacts at her convenience, and didn’t identify that some of this might have indicated avoidance activity on her part.

The key learning from this analysis is that when staff receive information that a patient / service user may underplay their difficulties and may be making decisions that put them at risk, staff need to try to ensure that they do not miss opportunities to discuss the behaviour and encourage the person to receive support.

3. What knowledge did agencies have of the full extent of Adult E’s vulnerabilities in terms of pressure ulcers?

Whilst all professionals had some understanding of Adult E’s history of pressure ulcers, they also had experience and records that indicated she had not had an ulcer for 4 years, and most were not aware of the severity and serious impact of her previous ulcers, particularly reducing her capacity to work.

What seems clear is that Adult E remained at high risk of developing pressure ulcers, as her underlying condition remained the same; lower body paralysis, which meant she didn't feel pain and did not always recognise when pressure ulcers were developing, and occasional incontinence leaks. A standard risk assessment carried out by community nurses in 2007 identified her risk of developing pressure ulcers to be as high as it was in 2002.

The suprapubic catheter inserted at the beginning of 2004 after a hospital admission was seen as very positive as it has a number of advantages over a urethral catheter[4]. However, for Adult E the unintended consequences were serious as she no longer had to expose her perineal area for the community nurses to change her catheter. They relied on Adult E's reporting that she was self-checking and accepted her reluctance to be examined as part of respecting her dignity.

It also emerged during the course of the Review that on occasion her perineal area was not always examined when she attended hospital outpatient appointments at Sheffield Spinal Injuries Unit (SIU). Again her self-reporting as an adult with capacity was accepted.

As Adult E had a long period without pressure ulcers a "climate of optimism" developed amongst professionals and Adult E herself. Professionals stopped directly examining her skin; accepted her self-assessment of skin "intact"; and did not consider how her previously successful coping strategies could be affected by her loss of protective factors. These included less social interaction and status as a valued employee and a reduced income including complex and unreliable benefit support as she worked fewer hours.

Letters following her outpatient appointments were sent to the GP describing her skin as "intact" and it is worrying that this might have been based on Adult E's word alone. The possibility of the GP, the community nurses and SIU thinking that someone was observing her skin, when no one was, is very concerning.

Professional terms can be unintentionally ambiguous to those who are not part of that professional group. The use of the term "intact" referring to skin is a case in point. There was trust in Adult E's self-reporting even

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[4] The suprapubic catheter has advantages compared to the urethral catheter: The risk of urethral damage is eliminated, a suprapubic tube is more patient-friendly, bladder spasms occur less often because the suprapubic catheter does not irritate the outflow area of the bladder, and suprapubic tubes are more sanitary because the tube is away from the urethra/anal area (perineum). Suprapubic tubes may cause fewer urinary tract infections than standard urethral catheters. Information for Patients on www.emedicinehealth.com. Website viewed by SCR author in August 2012.

though there was evidence that she did not feel pain in her trunk area and had not identified a perineal pressure ulcer on at least one occasion.

The key learning is that professionals need to be more aware that the likelihood of a risk resulting in harm is increased if the person at risk experiences life changes that remove some of their support / protections; for instance loss of employment, reduced income, loss of social supports, bereavement etc.

Professionals need to make themselves aware of past significant harmful events and be vigilant that they challenge their optimism with evidence from regular assessment of risks *and* protective factors.

Professionals need to be more specific in the language they use in their records and in their communications with the patient / service user and other professionals.

4. What was the extent of agencies' engagement with significant informal carers e.g. mother and how effective was this?

Adult E's mother is a capable person and knew how to get things done. She provided support and prompted action so that Adult E had her needs met. When she became seriously concerned about her daughter and sought help from a number of agencies in 2009 and again in 2010, this did not elicit action from any agency to discuss formally her needs as a carer.

In spite of being aware that Adult E had given permission, and on occasion specifically requested, that her mother be involved in discussions about her needs, not all staff did this consistently. Quite properly new staff would have needed to check out exactly what those permissions covered, and all staff would have needed to check whether this extended to all discussions on all occasions and whether it changed over time.

The key learning from this is that professionals should encourage even the most capable involved relative / carer to take the opportunity to discuss their needs. This should focus on how they are supported to take care of their own wellbeing, particularly as they age or their circumstances change. Staff should also be mindful of the need to maintain a relationship between the relative and the service user which does not revolve solely around providing care for them. A carer's assessment of Adult E's mother would have identified how dependent Adult E had been on her at certain times, and possibly the fact that she needed more support herself as she approached 70.

5. **What was the quality of assessments, care planning, treatment or interventions and reviews? Include in this a consideration of decisions made about Adult E's eligibility for services. Was this information shared effectively within and between agencies?**

There is no evidence that any agency carried out and documented a comprehensive assessment of Adult E's physical, emotional and social needs for support in the last 4 years of her life. Consequently there were no care plans or interventions, other than to give information.

Assessments that were carried out by the community nurses identified a continuing high risk to Adult E's skin integrity, but the tool used to do this did not adequately consider protective factors including the effectiveness of her coping strategies, or assess her ability to manage that risk.

Brief assessments by adult care workers identified Adult E's strong need for independence and to remain free from personal care support. The OT assessment in 2010 identified the need for a new shower chair and also the risks posed by the torn chair to Adult E's skin but there appeared to be little consideration about how she would manage whilst a new chair was being sourced.

The key learning is that without adequate assessments it is difficult to put appropriate treatment, care, and support plans in place and to review them effectively. A multi-disciplinary assessment in 2009 might have been triggered if Adult E had signs of pressure ulcers or continuing bladder infections but her emotional difficulties were not seen as severe enough to prompt such action. In fact, her emotional difficulties were not known to community nurses, who were the only people to have regular contact with her.

People with long term conditions are likely to benefit from consistent support to develop and maintain effective coping behaviours. Investing in such support can produce good health and wellbeing outcomes for them and savings to high cost health and care services.

Research[5] also informs us that service users repeatedly relate good outcomes from receiving services to the quality of the relationship they build with a health of social work / care worker. Given the number of community nurses who had contact with Adult E and her determination that she was self-reliant, there was little chance of her developing such a relationship.

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[5] The College of Social Work, in its submission to the Department of Health consultation on the White Paper, called for social workers to be "liberated from the care management strait-jacket" so as to take a more creative, problem-solving approach to supporting users and carers. "Caring for our future: reforming care and support" White Paper July 2012 www.dh.gov.uk (website viewed August 2012)

When assessments do take place and equipment is assessed as risky, as happened with the shower chair, workers need to take responsibility to act more quickly to seek a remedy. Where they have identified a risk, agencies and individuals have a responsibility towards all adults to exercise a duty of care even if the adult has capacity.

Adult E is described as being preoccupied by her financial / benefit situation in 2009. Money may not make us happy but anxiety over the lack of it, and the threat of action over debts, can have a debilitating effect on any individual's ability to cope[6].

6. What was the extent of communication between agencies and was this effective?

It is commonplace in SCRs for there to be a recommendation to improve communication between agencies. The 20/20 vision developed by looking back on events frequently elicits the response of "if only we had known that / you had told us that". Communication deficits, between agencies and within agencies, have also been identified in this SCR.

In order to communicate concerns effectively across agencies and act on them they first have to be identified. The only person who was seeing Adult E's circumstances and behaviour as a major concern was her mother, and although some action was taken, there was no communication between key agencies.

GPs play a pivotal role in the lives of many people with long term conditions living in the community. They are also seen as the "normal / least stigmatising" professional in that nearly all people have a GP. The new Clinical Commissioning arrangements provide an opportunity to see how they can be linked more effectively with other professional staff.

The key learning is that whilst shared electronic records (often cited as the way to improve communication between agencies) can assist information sharing within defined protocols, in practice there is a need for all involved staff to be more aware of each other. This usually means one professional being identified to take the lead and co-ordinate information sharing. There has been some recognition of this in community health services where adults living in the community with certain complex long term conditions have been allocated a case manager (community matron).

The holding of a multi-disciplinary community-based meeting in 2009, when most agencies were made aware of Adult E's problems, would have potentially benefited her and her mother, particularly if the co-ordinating role her mother was trying to play had been recognised.

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[6] Money and mental health booklet 2011 www.mind.org.uk (Viewed on line August 2012)/assets/0001/5894/

7. What was the level of supervisory oversight of this case and was it in line with agency guidance?

Capacitated adults, who are potentially vulnerable due to illness or disability, and who make risky decisions (including the “decision” not to engage with services and / or who underplay their own needs and avoid services), are often those who create the greatest levels of anxiety in front line workers. As there are often no “right answers” to the dilemmas posed by such adults, individual staff and agencies can be at risk as they try to identify the right balance between a general duty of care to protect vulnerable adults from harm and obligation under the Human Rights Act to respect privacy and autonomy.

The key learning points are: all staff working with adults at risk of harm have the right to expect regular, supportive, and challenging supervision from their agency and the responsibility to insist on it.

Managers should have processes for checking staff practice including the use of regular assessments of risk and frequency of visiting.

5. Recommendations

5.1 Assessment of need for support and identification of and management of risk

Recommendation 1

Professionals need to make themselves aware of past significant harmful events and be vigilant that they identify and challenge any “climate of optimism” with evidence from regular assessment of risks and protective factors.

Recommendation 2

The current decision making guidance and tools to aid risk assessment in health and social care agencies need to be reviewed to see if they are designed to:

a) capture historical information on the person including past harm / illness and encourage reflection on current risks, protective factor and patient / user coping strategy information;

b) enable professional staff to use their experience to inform decisions and to challenge their optimism with the use of evidenced incidences of harm;

c) facilitate front line workers in developing and monitoring a risk management plan that supports positive risk taking and shares and records concerns, including escalation to managers, when there is a high risk of harm even if the adult has mental capacity; and

d) identifies multi-disciplinary discussion and assessments as a way of managing risks that cannot be removed or effectively mitigated

An action plan should be developed to amend the guidance / tools if they do not meet these criteria and to develop a training programme.

Recommendation 3

Social care as well as health agencies should issue guidance to staff to consider and report repeat presentations of the same / similar health problems such as pressure ulcers, as an indicator of potential neglect, including self-neglect.

5.2 Meeting the needs of service users through risk enabling person centred assessment and relationship based practice

Recommendation 4

Agencies need to consider, with the establishment of a small interdisciplinary team of professionals, how they can improve consistency of named staff and develop relationship based work, which is increasingly seen as good practice with adults with long term conditions, particularly those who have capacity but are at high risk due to self-neglect and service avoidance / refusal.[7]

Recommendation 5

Workers and managers in “case holding services” need to be reminded that closing the file of someone identified as at high risk of potentially life threatening pressure ulcers or similar, and described as ”fiercely independent”, should be subject to a risk focused reflective practice supervision discussion, and the reasons for the decision to close their ”case” to be fully recorded.

Recommendation 6

a) The Primary Mental Health Service should review its policy of total self-reliance in making contact and re-booking contact for adults referred to the service, particularly when reluctance / avoidance in receiving support are identified in the referral information.

b) The Primary Mental Health Service should also review its written information to ensure that it assumes enthusiasm to engage on the part of the potential service user, and uses language that encourages the person to engage.

5.3 Family involvement and carer assessments

Recommendation 7

Current policy and practice of all agencies in relation to Carers should be reviewed.

Good practice places expectations on all agencies to provide information and encouragement to all family or friends who are providing care, emotional and practical, as well as hands on care, to have a carer’s assessment. This is particularly important where the user of services has potentially high risks and is receiving few services. The proposals

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[7] Relationship-based practice is founded on the idea that human relationships are of paramount importance and should be at the heart of all good social work practice. Relationship-Based Social Work - Getting to the Heart of Practice (Ruch, Turney and Ward 2010).

within the new Care and Support Bill should act as an incentive to improve practice in this area, including how to engage with carers of service users who decline support and could be said to self-neglect.

5.4 Communication, service co-ordination and information sharing

Recommendation 8

All staff should be reminded to check regularly with the patient / service user which other professionals are involved with them and permission sought to share information as appropriate.

Recommendation 9

All staff need to be reminded that records need to be precise about who did what in any contacts and to use language that is unambiguous. If an assessment is a self-assessment it needs to say so and if a patient / service user contacts a service the record needs to be specific about who initiated the contact. Records that indicate that the patient / service user is well, for example skin ”intact”, need to show if and how that was verified.

Recommendation 10

GPs should be reminded of their pivotal role in information sharing within their own service and the multi-professional team and design systems for them / their practice staff to ensure adults at risk are identified and safeguarded by protocol protected and systematic communication with other professionals.

5.5 Supervision[8] and management oversight

Recommendation 11

Health and social care agencies need to review their supervision policies and management oversight arrangements of practice. They should assure themselves that workers are supported and demonstrating through practice and the recording of practice that their decision making is focused on enabling patients / service users to have maximum control of their own treatment and support; records evidence that capacity is always considered; challenges optimism that is not supported by evidence; and is defensible in terms of good practice. The fact that discussion has taken place in supervision and ***key decisions*** agreed should be evident on case records.

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[8] In health individual supervision in relation to individual cases is termed clinical supervision

5.6 Effective and timely service provision of aids and adaptations

Recommendation 12

The planning and implementation programme for greater integration of occupational therapy staff with social / care workers needs to include a plan to ensure the rapid provision of equipment or alternative ways in which needs can be safely met to people at high risk of harm. These arrangements need to be widely communicated.

5.7 The responsibilities of housing and benefit agencies in relation to adults at increased risk due to ill health or disability

Recommendation 13

Agencies, including national benefit agencies, and employers of disabled people should assess their staff's awareness of the increased impact of poverty and debt on disabled people, including those with mental health problems. Agencies need to ensure that they provide guidance to staff about how to actively and sensitively support people to seek help. They should review their induction and training programmes for staff to ensure that training programmes include this information.

5.8 Staff development and training and wider learning from this SCR

Recommendation 14

The Safeguarding Adults Board should consider holding a training / workshop event for professionals and users and carers to share concerns and information about responsibilities and good defensible practice in work with capacitated adults using learning from this SCR as well as examples of intervention that demonstrates effective practice.

5.9 Policy and Procedures

Recommendation 15

When an individual who is subject to a SCR has received services from staff in a number of Safeguarding Board areas, information should be shared formally with Chairs of Boards, as well as agency safeguarding staff. Nottinghamshire Safeguarding Adults Board (NSAB) should include this guidance in their next review of their Procedures.

Recommendation 16

Agencies should review their File Destruction policies, particularly timescales, and consider bringing timescales for younger adult service users in line with those for services for children and families.

Recommendation 17

When considering a case for a SCR the Safeguarding Adults Board needs to have evidence that all other investigations, for example complaints, are either completed or a plan is in place to complete and that there is appropriate communication about progress during the SCR.