Wandsworth Safeguarding Adults Board

Safeguarding Adults Review

(Case WWF)

Lead Reviewers:
Mary Burkett and Alison Ridley

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1. Introduction

1.1 Why this case was chosen to be reviewed

This case was chosen to be reviewed because it met the statutory criteria for a Safeguarding Adult Review (SAR) under section 44 of the Care Act 2014. This case involves issues related to supporting adults with restricted mobility who have mental capacity but chose to make decisions that generate high risks. The case also illustrates some of the advantages and challenges of multi-agency working, and makes links to the learning that emerged from a SAR undertaken in neighbouring London Borough of Richmond in 2016, which also involved an adult who died in a fire at their home.

The Wandsworth SAB decided to use the SCIE *Learning Together* systems methodology to undertake this review in order to gain the broader systems learning from the case. (Fish, Munro & Bairstow 2010).

1.2 Pen picture of WWF and succinct summary of case

WWF had been diagnosed with multiple sclerosis (MS) at the age of 55 (in 1983). She was very independent, was full of character and had a great love of animals. She knew her own mind and had a wide circle of friends and family members that she was regularly in touch with. She was widowed in 2010 which was very significant for her and had an impact on her mood and ability to go out. WWF had smoked for fifty years and remained determined to continue smoking, even though it had become progressively more difficult for her to light her cigarettes safely.

She was known to hold definite views and would not always agree with the professionals who supported her, or her family members, however her care workers and the Local Authority OT were able to develop very effective working relationships with her. In the period under review WWF's mobility had deteriorated and she was using a wheelchair. She had particular difficulties with swallowing, transfers and the use of her left hand. In this period, there were a number of small fires that caused WWF burns, and professionals made considerable single agency efforts to reduce the risk of further fires occurring. However, in January 2016 there was a significant fire which resulted in WWF requiring in-patient hospital treatment for several weeks. Upon discharge the professionals and care workers continued supporting WWF at home, and she continued to engage with the comprehensive support package that was in place. WWF had full mental capacity and understood the risks that her choice to smoke generated. WWF's physical strength declined and the two OTs who were involved both agreed that it was no longer safe for her to be transferred using a standing hoist. WWF was very distressed by this decision and her mood was affected. On 19th July 2016 a further very serious fire occurred and WWF was taken to a local hospital, and was then transferred to Stoke Mandeville Hospital, where she sadly died on 21st July 2016.

1.3 Review timeframe

It was decided that the critical time period to review in this case was from July 2015 when WWF's physical symptoms had started to increase quite significantly until July 2016 when she died.

1.4 Organisational learning and improvement

Statutory guidance to support the Care Act 2014 states that:

> "The Safeguarding Adults Board (SAB) should be primarily concerned with weighing up what type of 'review process will promote effective learning and improvement action to prevent future deaths or serious harm occurring again. This may be where a case can provide useful insights into the way organisations are working together to prevent and reduce abuse and neglect of adults. Safeguarding Adults Reviews (SARs) may also be used to explore examples of good practice where this is likely to identify lessons that can be applied to future cases". (DoH[1] 14:135)

The use of research questions in a *Learning Together* systems review is equivalent to Terms of Reference. The research questions identify the key lines of enquiry that the SAB want the review to pursue and are framed in such a way that make them applicable to casework more generally, as is the nature of systems Findings.

Wandsworth Safeguarding Adults Board (SAB) identified that the review of this case held the potential to shed light on particular areas of practice including addressing the following research questions:

- What light can this case shed on the impact of the interventions of individual agencies and how effectively the agencies work together in Wandsworth?
- What kind of impact do the organisational practices, attitudes and procedures of agencies in Wandsworth have in cases of adults who are felt to be self-neglecting?
- In what ways can this case help us to understand the effectiveness of organisational responses following the death of a service user and how effectively these are discharged across the partnership in Wandsworth?

1.5 Methodology

Statutory guidance requires SARs to be conducted in line with the six safeguarding principles of empowerment, prevention, proportionality, protection, partnership and accountability. In addition, advice states that:

[1] Statutory Guidance to support the Care Act 2014, Chapter 14

- “there should be a culture of continuous learning and improvement across the organisations that work together to safeguard and promote the wellbeing and empowerment of adults, identifying opportunities to draw on what works and promote good practice;
- the approach taken to reviews should be proportionate according to the scale and level of complexity of the issues being examined;
- reviews of serious cases should be led by individuals who are independent of the case under review and of the organisations whose actions are being reviewed;
- professionals should be involved fully in reviews and invited to contribute their perspectives without fear of being blamed for actions they took in good faith; and
- families should be invited to contribute to reviews. They should understand how they are going to be involved and their expectations should be managed appropriately and sensitively.” (DoH,14:138)

It also gives SABs discretion to choose a review methodology that suits particular circumstance: “The process for undertaking SARs should be determined locally according to the specific circumstances of individual circumstances. No one model will be applicable for all cases. The focus must be on what needs to happen to achieve understanding, remedial action and, very often, answers for families and friends of adults who have died or been seriously abused or neglected”. (DoH, 14:141)

1.6 Reviewing expertise and independence

The SAR has been led by two people who are both accredited by SCIE and experienced in the use of the SCIE *Learning Together* model. Alison Ridley and Mary Burkett are independent health and social care consultants and have no previous involvement with this case, nor any current relationship with Wandsworth SAB or partner agencies. The lead reviewers have received supervision from SCIE as is standard for *Learning Together* accredited reviewers. This supports the rigour of the analytic process and reliability of the findings as rooted in the evidence.

1.7 Methodological comment and limitations

<u>The ‘shape’ of the review</u>

The SAB asked that the review process should be based around a one-day *Learning Together* Workshop, which was used to engage with the front-line practitioners and line managers, and generate the qualitative data needed to inform the review process. This was followed by a separate meeting with members of the Review Team (managers of local agencies) to support the process of analysis of the practice within the specific case, and to move beyond that to draw out the broader systems learning that has been highlighted by the case, and produce the generic findings. The reliability of the findings is strengthened by the involvement of local managers who considered local service issues, however as this review did not involve any individual interviews (conversations) with front line practitioners or managers it is important to recognise that there is necessarily a slightly reduced level of case specific detail. Further detail of the review methodology and process is contained in the appendix of this report.

Participation of professionals

Almost all key practitioners and managers involved with the case were able to participate in the Learning Together Workshop. The GP practice were not at the one day workshop but have subsequently been able to comment on the on the Appraisal of Practice. Key senior agency managers from across a number of agencies formed the Review Team, which supported the analysis work.

Perspectives of the family members

Two members of the Review Team met with two family members in June 2017, WWF's sister and WWF's nephew. They were complimentary about the quality of working relationships between WWF and her care workers and other key professionals. They were particularly keen for the review to consider the issue of whether professionals are sufficiently aware of the heightened risk generated when emollient creams are used to treat adults who smoke. Family members also asked for more information around the decisions in relation to WWF being moved to Stoke Mandeville hospital shortly before her death. Both these issues are explored in the 'Appraisal of Practice' at section 2.1.

Family members also asked that the initials used in the report for their family member HB should be WWF, the initials of the World Wildlife Foundation. They requested this because it reflects HB's strong appreciation of animals and animal welfare, and they felt that she would be happy to see this signalled in the report.

1.8 Structure of the report

Statutory guidance requires that SAR reports "provide a sound analysis of what happened in the case, and why, and what needs to happen in order to prevent a reoccurrence, if possible (DoH, 14:149)

- The Appraisal of Practice section provides an overview of what happened in this case in terms of the professional practice that took place. It clarifies the view of the Review Team about how timely and effective the interventions were, including where practice was above or below expected standards.

- A short transition section highlights the ways in which features of this particular case are common to work that professionals conduct with other adults and therefore provides useful wider organisational learning to underpin improvement.

- The Findings section forms the main body of the report, and explores and tests out the key areas of generic learning that have emerged from the case. These are the systems issues that are not only specific to this one case but have a broader application.

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2. The Findings

2.1 Appraisal of professional practice in this case: a synopsis

The appraisal sets out the view of the Review Team about how timely and effective the interventions with the service user were in this case, including where practice fell below or above expected standards and why. This synopsis of practice is a link from the specific case to the wider findings about the local safeguarding system.

Appraisal of practice

2.1.1 WWF had regular input from a range of professionals and a comprehensive care package, commissioned by the London Borough of Wandsworth (LBW) and provided by Parkgate, a care agency with particular experience and expertise in supporting adults who were not always easy for services to support. The positive effects achieved by this specialist agency and the sound commissioning decisions that supported the use of an agency with expertise and higher charges than other agencies locally are explore in **Finding 1**.

2.1.2 The Parkgate care workers had developed an excellent working relationship with WWF over the years they had worked with her. Staff in all agencies demonstrated clear efforts to address the sensitive topic of WWF's longstanding smoking behaviour, which was recognised to be a risk. Her nurse talked to her about the risks of lighting matches while she was on her own, as WWF's poor hand mobility which meant she was likely to drop the lit match. The NHS Neurorehabilitation team OT identified that the smoke alarm needed new batteries and alerted WWF to this, although no arrangements were made to actively assist WWF in managing this task as it was felt that she had the mental capacity to make the arrangements.

2.1.3 In November 2015 an accidental fire incident resulted in burns to WWF's groin and stomach. Her GP visited and notified WWF's vulnerability and fire risk to the Social Services department. The GP left a note for the District Nurse (DN) with the receptionist, notifying them of the burns and the need to visit to dress the wounds. Best practice would have been to have referred the case to the SPOC as it would have ensured a quick response. As it happened the DN made a visit to check on WWF the following day at which she also dressed the wounds. The DN service had been using emollient cream to manage WWF's long term eczema for some years. The Medicine and Health Regulatory Authority have issued a number of guidance notes over the years (most recently in 2016) about the need for practitioners to advise patients using emollients not to smoke and to wash bedding and clothes daily to avoid

a build-up of the cream, which having a paraffin base, is a fire risk. Unfortunately for some patients' emollients are the most effective treatment for their skin. It is not known whether there was an explicit consideration by the GP in this case about the use of emollients, which would be best practice. Care workers in this case advised that they had not been fully aware of the risk factors created by the use of emollient creams for adults who smoke, which highlights the need for further awareness raising amongst professionals. The issue of managing fire related risks including the use of emollient cream and working with adults who are reluctant to use fire repressing equipment is explored in **Finding 4**.

2.1.4 A referral was made to the London Fire Brigade (LFB) by the LBW safeguarding lead, which was good practice. The LFB were responsive, they undertook a home fire safety visit and ordered fire retardant bedding and a plastic protective tray table. The LFB made a referral to the LB Wandsworth for OT input in relation to possible adaptions and equipment required in the house.

2.1.5 The local authority Occupational Therapist (LBW OT) who subsequently began working with WWF ensured that he developed a close and effective working relationship with the care agency from the outset of his involvement. Although individual agencies were working actively towards risk reduction, the Review Team noted there was no consideration of whether a multi-agency meeting or approach might have been indicated. In Wandsworth there is a well-established multi-agency panel which advises practitioners on cases where adults are reluctant to engage or work with risk reduction strategies, the Vulnerable Adults Risk Management Meeting (VARMM). It was co-ordinated by the adult social services, however at the time of this case it was not yet widely known about across the other agencies. It is surprising that no referral was made to the VARMM at this point. Practitioners at the workshop also confirmed that it was not typical to work closely with the London Fire Brigade in all cases at that time. The important advantages of effectively utilising available multi-agency forums are explored in more detail in **Finding 2.**

2.1.6 Additional support hours were agreed by the LBW resource panel. The LBW OT and the care workers continued to talk with WWF about the fire risk, but were conscious that WWF was unwilling or unable to change her smoking behaviours. She was determined in her views and professionals were clear that she did have a full understanding of the high risks associated with smoking. Workers showed continued commitment to supporting her to try to reduce risks as far as they could, and progressed practical measures to

improve her wheelchair access to the front door. WWF’s burns were healing and continued to be tended by district nurses (DNs) and care workers.

2.1.7 Towards the end of January 2016 a serious fire occurred when WWF dropped a lit match on a tissue on her lap beneath the plastic tray table over her wheelchair. Her groin area had emollient cream on it, and the plastic tray melted onto her groin and upper legs. WWF was admitted to the Queen Victoria East Grinstead Hospital (via SGH) for treatment to her serious burns, where she remained for several weeks. Good work was undertaken by all key agencies in support of WWF’s discharge home, and she was reviewed by a psychologist on a number of occasions. However, the Review Team noted that the hospital OT risk assessment focussed on risks associated with manual handling rather than fire risks, despite the fact that her admission had been for fire related injuries. The lack of emphasis on a specific risk assessment and risk management plan relating to WWF’s smoking is an important theme in this case, which is explored in **Finding 4**.

2.1.8 LBW agreed a further increase to WWF’s care package to support her discharge from hospital, and full input was planned from the NHS Neuro-rehabilitation Team to support her discharge. Records confirmed that issues of mental capacity had been properly considered, and the fire risks had been discussed with WWF. She was anxious to go home as quickly as possible and her behaviour was determined; in the last two days prior to her discharge she refused to eat in the belief that this would hasten her discharge home. She was discharged home on 19 February 2016 with a medical review planned for the following day. However, when she was reviewed the following day, she required re-admission due to wound infection. She then remained in hospital for a further 4 weeks and was discharged again on 14 March with a full care package.

2.1.9 The LBW OT arranged a meeting at home with WWF, her friend and care workers for the day after her discharge, which was very good practice. The Review Team noted that while the communication between the LBW OT and Parkgate was excellent, as was between the Parkgate and the nursing staff (Parkgate reported that the nurse would proactively follow referrals and queries), there was less frequent communication between health colleagues and the OT. This was reported to be not unusual, as from a health care perspective, WWF’s treatment plan was not a complex one. However, it was reported that sometimes staff were ‘chasing’ the ‘wrong’ OT and were unclear which agency provided which service; communication between the neuro-rehabilitation team and LBW OTs however managed this situation as they cross referred to each other.

2.1.10 At this time WWF's neurological symptoms were getting worse. The LBW OT reluctantly recommended that carers should stop using a standing hoist to transfer her and instead begin to use a full hoist. This was a very significant and difficult decision as by reducing her use of a standing hoist WWF lost a sense of independence and her increasing physical deterioration was more obvious. The OT advised the change on safety grounds due to WWF's decreasing physical strength, however the change was strongly resisted by WWF and it appeared to have had a significant impact on her mood. The decision was in line with usual guidance and the LB Wandsworth OT communicated well with his health OT (Neuro Team) colleague, who was in agreement with the decision. However WWF continued to raise her unhappiness with other staff including her care workers and her GP. The Review Team have wondered whether given the quite extreme emotional reaction of WWF to the decision, it was perhaps a missed opportunity to have considered with WWF and a wider group of agencies whether there were any acceptable ways to extend the time that WWF was supported to use the standing hoist, given her strong views and the fact that she had the mental capacity to understand the risks this would have involved. This difficult dilemma is explored further in **Finding 3**.

2.1.11 Following her return home WWF alleged to a care worker that a family member had removed some of her personal possessions, including money, from her home while she was in hospital. The care worker told a social worker who visited to speak with WWF in order to determine whether a formal safeguarding enquiry was indicated. There are no records of what was said at the meeting however WWF subsequently relayed to a care worker that she had not wanted the matter to be pursued further, and no section 42 enquiry was initiated. Based on the records available this approach appears to have been appropriate in line with the Making Safeguarding Personal ethos required by the Care Act 2014, in that WWF's views were taken into account and a proportionate response to the risks was followed, however it was not good practice that the initial safeguarding concern was not recorded, no record was made of the outcomes of the follow up visit undertaken and the initial alerter was not made aware of the outcome.

2.1.12 During this period WWF was well supported by her care workers, OT, Physios, GP and DNs to address her recovery from the burns and pressure sores. However, in March 2016 her request for a rehabilitation placement at the Wolfson rehabilitation unit (which provides multi-disciplinary input including from speech and language therapists, occupational therapists, physiotherapists, doctors, nurses, clinical neuropsychology, a dietitian and social workers) was refused on the grounds that her advanced MS symptoms would not be likely to respond to intensive rehabilitation. On-going community

rehabilitation was recommended instead. WWF was very upset and angry, and felt that people were turning their backs on her.

2.1.13 In relation to fire risks, at this stage the workers all felt that another fire was highly likely. They continued to talk with WWF about how to minimise the risks of her smoking, as it was clear that she was not willing to give up smoking. She did initially agree to light cigarettes only when carers or other visitors were in the house; however she was only able to keep to this agreement for one week. Additionally, WWF chose not to use the fire proofed clothing that had been provided by the Fire Service and also did not consistently use the other tools that had been made available to her to reduce risks of fire. WWF was generally very resistant to incorporating suggestions into her routine despite the intensive input by all staff. It is not uncommon for fire bedding not to be used; however, the refusal in this case and the reason were not recoded in any risk management or care plan as would be expected. In May, a comprehensive needs assessment and support plan was completed by a LBW social worker and the care package was further increased on an on-going basis. The OT completed a single agency risk assessment and arranged for a fire proof apron to be provided. There was a reference to risk within their plan however this was primarily around moving and handling. The need to develop a more joined up multi-agency risk management plan that specifically responded to WWF's wish to continue smoking is explored in more detail in **Finding 4.**

2.1.14 In June WWF expressed her continued unhappiness that she was no longer able to use a standing hoist and told her care workers that she was feeling suicidal. The LBW OT and physiotherapist liaised with her GP (who knew her well) about WWF's low mood and suicidal ideation, and in response he visited HB weekly for six weeks, which was beyond what would usually be expected and showed commitment to supporting her psychologically, as did the DN, the care workers and the LBW OT.

2.1.15 On 19th July 2016 a care worker arrived at WWF's home to find the smoke alarm sounding and WWF calling for help. The care worker and neighbour entered the house and found WWF alight and the house full of smoke. The Fire Service and Ambulance Service were called and the police also arrived to assist. The fire appears to have made more intense by the emollient cream that had been used to treat WWF's eczema.

2.1.16 WWF was initially conveyed to St Georges Hospital, Tooting, which is not a specialist burns unit. The severity of her injuries was such that quite soon it was recognised that she was unlikely to survive. The treating Consultant judged that transfer to a specialist unit was necessary to give her the best

possible outcome and care, even if it was palliative. The nearest specialist unit with an available bed was Stoke Mandeville.

2.1.17 The treating team arranged for WWF to be transferred the next day (20 July). Ward records indicate that WWF was still able to make informed decisions at this point and was in agreement with the transfer. Records also suggest that family members were informed, and the Consultant at Stoke Mandeville confirmed that she spoke with family members (including WWF's niece and the niece's husband) about the reasons for transfer and subsequently spoke with the niece's husband again to confirm that WWF's condition was now palliative. However, the family members who have been directly involved in the process of this review (WWF's sister and nephew) did not feel that they had been sufficiently involved in the decision, or that it had been communicated effectively to them.

2.1.18 WWF arrived at Stoke Mandeville hospital, but sadly died the following day on 21st July. WWF's sister and nephew have expressed some distress at the considerable distance WWF had been moved and sadness that they had been unable to visit her before she died. They state that they did not know that she was at Stoke Mandeville until after her death. The Review Team recognise the difficult challenge for the treating team in seeking a balanced decision about whether to move WWF out of the local area at that point. It is accepted practice to seek a specialist burn unit in these circumstances, and records suggest that all appropriate steps were taken to keep family members informed, however the move meant that family members were not able spend time with WWF in her final hours, which is regrettable.

2.2 In what ways does this case provide a useful window on our systems?

WWF's case is unique in many ways however there are also commonalities between her case and others where professionals are endeavouring to work with adults living in the community who have mental capacity and chose to take part in high risk activities. For WWF this was smoking, given the restrictions on her physical movement caused by MS. For other people the activity and what makes it high risk may be different, but may throw up similar challenges for professionals in terms of achieving best outcomes for the person concerned. WWF's case therefore has the potential to shed light common ways of working in Wandsworth more broadly. There are also some links with the learning from this SAR and a recent one undertaken in the Borough of Richmond in 2016 (which are noted in Finding 3).

2.3 Summary of Findings

The review team have developed four findings for the SAB to consider. These are:

	Finding	Category
1.	Is there a pattern of willingness in Wandsworth Adult Social Care to commission agencies with particular expertise in supporting adults who have challenged services, in spite of the additional cost involved?	Management systems
2.	Is there a common perception that multi-agency communication is only required in safeguarding cases or those open to CPA, making it less likely that professionals undertake shared risk assessment or shared risk management where it would be helpful?	Communication and collaboration in response to incidents
3.	The approach to working with adults whose choices generate high risk in Wandsworth tends to prioritise the reduction of risk, over the rights of adults with mental capacity to make their own choices, potentially jeopardizing their quality of life.	Professional norms in longer term work
4.	Current efforts to mitigate fire risk due to smoking are not formally part of risk assessment and management, making it less likely that professionals discuss creative options that have a realistic chance of reducing risk.	Tools

Finding 1: Is there a pattern of willingness in Wandsworth Adult Social Care to commission agencies with particular expertise in supporting adults who have challenged services, in spite of the additional cost involved?

(Management systems)

LB Wandsworth have an approved provider list that is used by the Brokerage Team when making placements. Parkgate Agency are not on this list, but their services can

still be purchased through individual ‘spot contact’ arrangements, if requested by individual Care Managers.

Parkgate are registered as both a nursing and domiciliary care agency. They have very specific, acknowledged expertise in working with people who have not been able to be supported effectively by other agencies. Parkgate have come to be regarded as a provider agency which is ‘the last resort’ for adult’s whose previous packages of support have failed with other agencies. Parkgate are more expensive than many other local care agencies, however their skills have been recognised as exceptional, bringing a high level of continuity, expertise and commitment to their work.

How did the issue manifest itself in this case?

WWF was someone who was known to be an adult that her previous service providers had found challenging. She was very forthright, clear about her likes and dislikes, knew her own mind, and would invariably initially refuse staff interventions, but generally acquiescing after some negotiation on their part. Parkgate had been working with WWF for nine years and had established a strong and effective working relationship, often acting as a conduit for other staff who might not have the negotiating skills, authority or level of respect given to them by WWF.

When WWF was admitted to East Grinstead Burns Unit the agency spoke to her daily and also to nursing staff on the ward. The effectiveness of the relationship they had built up with WWF was demonstrated by the tendency of other professionals to try to time their visits to WWF to ensure that a Parkgate carer was present in order for them to be able to work together to engage WWF. The agency were often able to coax WWF to agree to approaches that would maximise her care, even when she was initially resistant to them.

In this case LB Wandsworth demonstrated a willingness to use Parkgate throughout the nine year period because they were able to support her so effectively, even though their fees were higher than many other local providers.

How do we know it is an underlying issue and not something unique to this case.

Parkgate work with a caseload of about fifty adults. Commissioning care packages is undertaken by the LB Wandsworth Brokerage team who have a list of providers they work with. The level of any ‘matching’ between assessment and care provider is unknown and the Team are initially only able to use providers from their ‘approved list’. Due to Parkgate’s higher hourly rate they are not on the approved list. Feedback from the Review Team suggests that there are no other agencies in LBW offering a similar level of skilled resource to manage and work with clients who are challenging.

Data is not available for the number of cases that break down due to the required level of care exceeding that being able to be provided by the care agency and that are subsequently reassigned to a different provider. However, Parkgate have confirmed that anecdotally they estimate that about 95% of their cases are ones that have come to them following a breakdown with an alternative agency.

The need for the skills demonstrated by the agency are likely to be increasingly sought after as the nature of care and service users continues to become more complex. Within the local Wandsworth community, adult social care commissions packages for approximately 3,500 adults, and there are at least 50 patients with high level needs who would benefit from a care agency who can provide the level of care that Parkgate provides.

What is known about how widespread or prevalent the issue is?

Currently, the community nursing teams consider they have about 40-50 clients who have a similar profile to WWF and would benefit from the same continuity of skilled support. The nurses estimate that about 50% of these clients need support from nursing staff/family over and above their care package to avoid admission to residential/nursing care.

Data is currently being collected across London to look at the similarities and differences between boroughs' commissioning of care packages. LB Wandsworth has only recently provided data for this piece of work. Due to the differences in data collection at a borough level it is proving very difficult to draw comparisons and understand the impact of the range of providers commissioned and rates of failed care packages, etc.

What are the implications for the reliability of the system?

Although often not the first commissioning decision made, LBW have demonstrated willingness to commission effective, high quality care and support from providers that charge a higher hourly rate for adults who have a history of non-engagement with past providers. This willingness indicates an ability to provide flexible and creative commissioning that is focussed on achieving person-centred outcomes for service users, despite the pressures of the current economic climate. The impact of a failed care package prior to the higher cost placement being made is unknown.

Questions to the Board

Finding 1: Is there a pattern of willingness in Wandsworth Adult Social Care to commission agencies with particular expertise in supporting adults who have challenged services, in spite of the additional cost involved?
• What good commissioning principles does the Board think should be endorsed and protected, and are broader cost benefit principles part of this consideration?

- How can the Board be reassured that any potential changes to the current commissioning style won't adversely impact on care delivery to vulnerable adults, either in the short or longer term?

- How best can the broader system support the skill base of care workers and care provider agencies to ensure the market place has agencies who can sustain the level of expertise required to meet the needs of people who struggle to engage with services?

2.5 Finding 2: Is there a common perception that multi-agency communication is only required in safeguarding cases or those open to CPA, making it less likely that professionals undertake shared risk assessment or shared risk management where it would be helpful?

(Communication and collaboration)

Multi-agency communication was confined to situations where specific help/referral was needed and to WWF's assessed needs rather than what she wanted. In this case the difference was significant and as such posed a risk. It is often reported elsewhere that staff are not fully aware of each other's roles and responsibilities and potential interventions that can be offered. In this case agencies worked well together, particularly the Nurse and the LBW OT with the Care Agency; however, they did not make use of the potential support and creative thinking that a more joined up multi-agency approach can bring to a complicated picture. All the agencies independently attempted to manage the fire risk that WWF's smoking presented, but there was no shared ownership of the risk assessment or risk management.

How did the issue manifest itself in this case?

Generally, multi-agency communication only seemed to happen when there was something specific about the care being provided to pass, or refer, on. Practitioners were quite narrowly focussed in their interactions with each other, managing the practical issue in front of them; it was considered by some that WWF's needs were being met as she had a large care package; she seemed to be engaging and not self-neglecting. However some staff in the Case Group acknowledged that they became slightly defensive in their practice as WWF would repeatedly not 'comply' with care.

Although considerable attempts were made to encourage WWF to drink and smoke less these were invariably done in isolation.

There were a number of instances where staff could have, but did not, contact each other to bring a wider perspective to bear on WWF's case, thus not realising the potential that joining forces to consider solutions and challenges brings. After the first fire there was an opportunity for staff to discuss together the strategies and risk management that were being used to support WWF, which could have resulted in more creative solutions being found. It might also have prompted inclusion of the LFB, which would undoubtedly have been helpful. Some staff were not fully aware of the roles and responsibilities of others (OTs in the NHS and LA were confused with each other for example, and a member of staff reported they did not refer to a psychologist as their own agency did not employ one, even though if this was needed a referral to the GP would have accessed possible NHS support). In general, there was a lack of knowledge around possible interventions that the LFB can bring to bear in a situation.

Due to the lack of contact and communication there was neither shared information nor a jointly owned or shared risk managing plan. The VARMM was in Wandsworth during the time covered in this review, however it was not well known to agencies and only social services staff were able to initiate the referral process. Additionally WWF would also not have neatly fitted the criteria for a VARMM as she was engaging with services and in receipt of a comprehensive care package.

The advantages of multi-agency approaches such as sharing of information and joint searching for solutions, also offers considerable support to staff and can have the effect of reducing pressure on those who hold a key role in caring and are perhaps feeling isolated.

How do we know it is an underlying issue and not something unique to this case?

Staff in the workshop reported that this was not unusual practice. Unless there was a specific safeguarding concern a multi-agency conversation about broader holistic issues (either face to face or over the phone) were rare and not consistently held. In cases where attempts are made by some for broader understanding, staff do not always consider whether there is a need for contact with others if the adult's care and treatment is well under control; this would suggest that this is usual practice for this group of staff. Feedback from the Review Team suggested that some local teams have more of a culture of arranging multi-agency meetings than others. The Review Team have also indicated that since the death of WWF there has been an increased understanding amongst professionals about the value of arranging multi-agency meetings where they are needed.

There was also an acknowledgement that with the pressure of workloads that staff sometimes focussed on short term resolutions. The community nursing team considered that communication between themselves and LBW social services had been

better in the past and that recent organizational changes have hampered on-going relationships.

Parkgate reported that on a number of occasions when they have reported serious concerns around care packages they have not always been listened to and have had to threaten to withdraw services, sometimes doing so, in order for the statutory agencies to appreciate the severity of the issues they were raising. In this environment of not feeling heard, it is less likely that care agencies will feel empowered to be able to initiate shared risk management despite often being the closest to the service users.

The process of the Review itself initiated agencies agreeing to, outside the meetings; discuss other cases which were highlighted as having similar features.

What is known about how widespread or prevalent the issue is?

All agencies present reported significant numbers of cases that they held that were similar in some if not all features to this case, community nursing estimating there were about 40 across the borough, and Parkgate's case load of approximately 50.

With the ongoing health and social care policy of increasing numbers of people with complex conditions being cared for in their own home, and with people living alone, it is likely that this number will continue to increase, and challenges presented to services. The Nurse Member of the Review Team estimated that within CHS there are 3 patients who present a similar risk to the ones that WWF presented. Health colleagues in the Review Team report that they are now making increased use of the VARMM, but a recent case has indicated that there is still a lack of understanding amongst staff of the VARRM referral process and criteria, and also about roles and responsibilities for generating a fire risk assessment and practical considerations such as whether the LFB have a budget for equipment and what should happen if an adult refused to pay for fire proofing equipment.

The LFB hold considerable data on fire and risks of fire that is continually updated as new events inform the broader narrative. This is used to help them identify higher risk and allocate priority/vulnerability ratings to groups of the population. If shared this could help health and social care agencies have a broader understanding of the issues involved and potential risk management strategies employed. Since the case under review several of the agencies have asked the LFB for 'training' and to work together on specific cases they are managing; however, this is still on a non-formalized basis.

There was a common acknowledgement that escalation between agencies often did not occur which would assist in situations where there was felt to be the need for multiagency communication but where this was not being taken up by other agencies.

What are the implications for the reliability of the system?

A safe system would be one where all agencies respect each other equally, listen to each other's concerns and respond in a joined-up way across agencies at a practitioner and management level. A system where practitioners are working defensively, or are constrained by time or knowledge and support, misses opportunities for risk management to be maximised and support offered to staff involved in day to day care.

The system in place for practitioner level multi-agency working when there was a case of self-neglect or other high risk behaviours is the VARRM (Vulnerable Adult Risk Management meeting). At the time of the case under review, the VARRM could only be initiated by Social Services to discuss the risk assessment and management for a client who was deemed to be vulnerable, primarily who was self-neglecting or other high risk circumstances, and met criteria for safeguarding, it was not exclusive to those who were not engaging with services. If a meeting was called then other agency staff were obliged to attend. If necessary discussion and decision about care resulting from the meeting was escalated to a CMARAP. The numbers and reasons for VARRMs to be called are not collected and therefore the opportunities for learning about risk assessment and management are limited.

During the Review it became apparent that 2 years on from this case, there were still surprisingly few front line staff in other agencies who were aware of the VARRM and in this case where it was appropriate for it to be called, was not. The addition of the category of self-neglect within section 42 safeguarding guidance under the Care Act 2014, brings a new opportunity for discussing the care of vulnerable people who are less willing to engage in risk reduction measures. Going forward the VARRMs will cease and all cases will now be referred to Section 42 safeguarding meetings and as such will be part of a unified safeguarding response; where there are still risks will be escalated, these will go to the CMARAP.

It is understood that the Section 42 safeguarding meetings in Wandsworth are being changed to incorporate cases where there is a fire risk. These meetings however do not necessarily address underlying issues of the need for closer working between staff involved in care delivery and for underlying good communication. There should not however be the need for a specific safeguarding issue or vulnerability issue to trigger staff in different agencies communicating with each other, specifically when their client is a long term as WWF was.

Questions for the Board

Finding 2: Is there a common perception that even in cases involving high risk, multi-agency communication can be limited to task orientated /single issue focussed conversations rather than undertaking shared risk assessment and management.

- How can the Board be confident that practitioners at the interface with service users listen to each other and together are able to take forward concerns around client management generally and specifically as it relates to risk assessment and management?
- How can the Board help create a climate where all agencies and staff feel mutually responsible for raising and escalating concerns to be taken to multi agency meetings?
- In cases where risk management is being considered and known risk mitigations are unlikely to be effective, how can staff best be supported to practise openly and together support a broader set of client outcomes?

2.6 Finding 3 – The approach to working with adults whose choices generate high risk in Wandsworth tends to prioritise the reduction of risk, over the rights of adults with mental capacity to make their own choices, potentially jeopardizing their quality of life.

(Professional norms and culture in longer term work)

Key background information

2.6.1 Multiple Sclerosis (MS) is a progressive illness that affects the central nervous system. Its course is unpredictable and varies from individual to individual. Symptoms typically include difficulties with balance, speech, walking and fatigue. Memory problems can also be a feature of the condition for some people, however in this case WWF's mental capacity to make decisions about her care and support was never doubted. All professionals agreed that her views and wishes were expressed clearly and that she fully understood the nature and consequences of the risks she was taking.

2.6.2 There were two types of hoists that were used to physically support WWF during the period under review. A standing hoist which enables the adult to be wheeled along on a platform while in a standing position, and a sling hoist which involves the adult being transferred in a semi-reclined position in a hammock like piece of equipment. Most people find the sling

uncomfortable and disconcerting as they have very little control over the manoeuvre.

How did the issue manifest in this case?

2.6.3 WWF had enjoyed smoking and drinking for fifty years. There were some rare occasions when she had been found inebriated, however on the whole her drinking was regular but not excessive. The combination of WWF's reducing physical dexterity and her limited mobility coupled with her wish to continue to drink and smoke and her history of previous fires generated a very high risk that she might be harmed again in a fire. However, the professionals agreed that WWF had the mental capacity to make informed decisions about drinking and smoking, and were conscious of the statutory right of an adult with the capacity to make their own decisions[2] even where they may seem unwise[3].

2.6.4 Nevertheless, in this case there were times when professionals' interventions sought to reduce risk by limiting WWF's choices. Following her discharge from hospital in early 2016 the professionals gained her agreement not to smoke unless there were care workers or visitors present. It was an informal agreement which required WWF's sign up to (which she soon broke), however it was a sign that the professionals were understandably struggling to allow her to make her own decisions about smoking, however unwise those decisions might be. WWF had experienced a number of significant losses and her MS symptoms were progressing. Her wish to drink and smoke were two of the few choices she still had a degree of control over. There are strong links between this finding and a key of the SAR undertaken in the London Borough of Richmond (Mr T) in 2016[4].

2.6.5 A further example of this tendency is illustrated by the difficult decision taken by the Occupational Therapists (OTs) who worked with WWF. As her physical strength declined they recognised the need to review the kind of hoist she used. In line with the Trust manual handling procedure (which draws from national health and safety guidance for hoist, they assessed that she could no longer safely use the standing hoist, and recommended

[2] MCA 2005 – principle 1 and section 1(2) of the Act.
[3] MCA 2005 - principle 3 and section 1(4) of the Act
[4] Finding 3 of the Richmond SAR (Mr. T): The tensions that exist when an adult has capacity and continues to choose high risk behaviours can leave practitioners feeling personally and professionally responsible when they have limited legal or practical authority or power to keep the person safe. Full text of the finding is found in Appendix

instead that she was hoisted in a full sling hoist. This decision also took into account safety issues for the care workers. There is no criticism of the clinical recommendation that was made. Both OT's were in agreement with the decision from a physical clinical perspective, and it was in line with national guidance, however WWF was devastated by the further loss of independence the decision caused, and fought for several months to continue using the standing hoist, approaching other professionals and her care workers to try to gain their support.

2.6.6 The nature of this particular decision was a clinical one so while the views of the adult were sought, it was appropriate for the OT to make the final decision, in line with their professional best practice guidance. However, the process of this case review has highlighted the value of clinicians taking opportunities to develop shared risk assessment and management plans in partnership with the adult that can be communicated to other relevant professionals.

2.6.7 WWF was still highly motivated to use the standing hoist. Given her strong wishes the Review Team raised some questions about whether in this case, there was an opportunity for professionals supported by their managers, to develop a shared plan in relation to how the risks could be managed if use of the standing hoist was extended, even though this generated more risk than using a sling hoist. However, it must be noted that in this case the nature of WWF's condition was progressive and her physical deterioration was very advanced at this point, so there would certainly have been a point when use of the standing hoist could no longer be supported, it was a matter of discerning when that was.

How do we know it is an underlying issue and not something unique to this case?

2.6.8 Members of the Case Group and Review Team confirmed that generally they find many good examples of practitioners supporting positive risk taking, however they did also identify a number of cases which demonstrate a tendency for professionals and their organisations to practice defensively when they are working with adults with capacity whose choices generate risks. One recent example from the Review Team was of an older woman with physical mobility problems and incontinence who was assumed to have mental capacity. She expressed a strong preference to use two incontinence pads at the same time as she had once found that one pad was not sufficient and had leaked. However use of two pads tended to irritate her skin and cause pressure sores. Her GP and Social Worker both advised care workers that they should only use one pad with her, and that the medical risk to use two pads was too

great to be supported unless the woman's daughter was willing to put the pads in place.

How prevalent and widespread is this issue?

2.6.9 A recent Safeguarding Adults Review (SAR) in Richmond[5] explored learning about the dilemma for professionals when they work with adults with capacity who wishes to take risks. The Richmond SAR reviewed the death of Mr T in a fire, a man who had retained mental capacity for his care and support decisions and continued to smoke. It found a closely linked practice issue, 'the tensions that exist when an adult has capacity and continues to choose high risk behaviours can leave practitioners feeling personally and professionally responsible when they have limited legal or practical authority or power to keep the person safe'.

2.6.10 At a national level the evidence gathered by the House of Lords Select Committee[6] in 2014 on the implementation of the Mental Capacity Act (MCA) found that the understanding and application of principle one; the presumption of capacity was "patchy, at best". They found a "poor understanding of the principle of presumption of capacity among professionals, and the difficulties experienced in applying the principle in practice". There was recognition from many witnesses that the instincts of social workers tended to emphasise the need to protect vulnerable adults rather than to enable their decision-making, if necessary by supporting what appeared to be an unwise decision (p.40).

2.6.11 The Committee found that "across the evidence, the balance between empowerment and protection emerged as the key challenge to the implementation of the empowering ethos of the Act, and this seems most clear in relation to unwise decision-making. The right to make an unwise decision runs counter to the prevailing cultures in health and social care, which present barriers to implementation" (p.42).

What are the implications for the reliability of the safeguarding system?

2.6.12 The work of safeguarding is rightly aimed at reducing risk, but there are occasions when empowering practice (both within and outside safeguarding) should appropriately be used to support adults with mental capacity to take the risks they wish to, even if those are considered

[5] Richmond SAR – Mr T (published 2017).
[6] The House of Lords Scrutiny Committee Report 2014, p.33
https://www.publications.parliament.uk/pa/ld201314/ldselect/ldmentalcap/139/139.pdf

unwise. The safeguarding framework affords opportunities for agencies to come together to make shared multi-agency risk management plans in partnership with adults who have capacity. In such cases there could be meaningful exploration about how agencies can appropriately support plans which may include increased risk to the service user. This feels uncomfortable but in cases where the adult has capacity, it is important that practitioners and managers reflect on their interventions to ensure that the powerful machinery of statutory organisations is not used in a defensive way, which is counter to the spirit and letter of the MCA and the empowering safeguarding requirements in the Care Act 2014.

2.6.13 The House of Lords Select Committee that examined the implementation of the MCA, noted that in social care "the prevailing culture was towards protection, for which the term 'safeguarding' was often used as a short-hand; others preferred to use the term 'risk-aversion'" (p.43). Individual practitioners and their managers understandably feel uncomfortable at the "prospect of defending a decision to protect rather than being accused of being neglectful" (p.44). A willingness across health and social care agencies to examine their organisational culture and practice is needed in order to understand to what extent we can avoid defensive practice from impacting negatively on the lives of adult service users.

Questions for the Board

Finding 3 – When working with adults whose choices generate high risks, interventions by practitioners and their managers to reduce risk, can result in a tendency to practice defensively even when the adult has the necessary mental capacity to make their own decisions, impacting negatively on the their rights and quality of life.
• What assurance does the Board have that good practice in relation to upholding the rights of adults with capacity are well understood within their agencies? • Does the Board want to see risk management planning with a greater emphasis on multi agency shared positive risk taking with adults who have mental capacity?

2.7 Finding 4: Current efforts to mitigate fire risk due to smoking are not formally part of risk assessment and management, making it less likely that professionals discuss creative options that have a realistic chance of reducing risk.

(Tools)

Key background information

2.7.1 Needs assessment and risk assessment formats generally have a broad focus, with the intention of providing a holistic approach, however this can result in there being a lack of prompts or headings that facilitate practitioners to assess the specific risks of adults who have reduced mobility and choose to smoke.

2.7.2 There are several multi-agency meetings held locally in Wandsworth which provide structured opportunities for professionals from different agencies to come together to consider risk and develop or review multi-agency risk management plans (i.e. the VARMM, the community MARAP and formal safeguarding processes). The CMARAP provides a multi-agency meeting to review risks in relation to cases of domestic violence. The Vulnerable Adults Risk Management Meeting (VARMM) was well established at the time of the case under review however was generally co-ordinated by social services, and was not well known about amongst other agencies. It would review cases including those that might feature adults who did not wish to engage with services or where there was self-neglect or a fire risk. The VARMMs have now developed to use the framework of a safeguarding meeting.

How did the issue manifest in this case?

2.7.3 WWF was a long-term smoker with a history of fire incidents started by the matches she used to light her cigarettes. She enjoyed smoking and understood the risks it generated. The professionals who worked with her recognised that this was the highest area of risk she faced, but they did not actually undertake or record a risk assessment specifically in relation to smoking and her reluctance to use much of the fire repressing equipment that had been provided to her.

2.7.4 WWF was taken into hospital with burns in January 2016 following a serious fire. The work undertaken in the hospital in preparation for her discharge did not include an assessment of risks generated by smoking,

instead the hospital OT risk assessment focussed on issues of manual handling. Hospital staff were aware the WWF had full mental capacity and that she wanted to continue smoking. They recorded their discussions with her about the risks and the advice they gave, but did not undertake a risk assessment to weigh the continuing risks or generate any shared risk management approach acknowledging or addressing (as far as that would have been possible) that on-going risk.

2.7.5 The community professionals worked to reduce the smoking risks by offering advice, attempting to persuade WWF to stop smoking on her own, suggesting alternative lighters and ashtrays, and advising her to use the fire-resistant equipment supplied by the LFB. However, WWF was reluctant to follow advice or use the equipment supplied, and no risk management plan specifically acknowledged or addressed this on-going unmanaged risk.

2.7.6 During the period under review a multi-agency forum (the VARMM) had been set up by adult social services to support professionals manage risk in cases where the usual risk reduction measures were not proving effective, however it was not widely known about amongst other agencies at that time.

How do we know it is an underlying issue and not something unique to this case?

2.7.7 Members of the Review Team identified that they were aware of a number of current cases in Wandsworth which presented high fire risks, but were not being responded to using a multi-agency risk assessment and risk management process or the local VARMM. A woman with chronic obstructive pulmonary disease (COPD) who has been receiving ‘end of life’ care at home, and chooses to take drugs and to smoke. The woman has oxygen cylinders in her home. Her care workers advised the local services that they thought the fire risk was too high to manage, but the woman was discharged home from hospital with no multi-agency risk management plan in place. Another local case identified involved a physically frail man aged 98, who smokes and has cigarettes burns all over his bedspread. He broke his hip recently so had significantly reduced mobility, but he was discharged home from hospital without a multi-agency risk management plan being put in place. A further case that was identified was of a woman with dementia who lived at home and used her gas oven, sometimes leaving it on. The care worker raised concerns but the social worker advised that she was unable to take any actions saying “my hands are tied”. While reduction of risk would not necessarily be easy

(or even possible) to achieve in these cases, what is notable is that they have not been responded to by undertaking a fire-related risk assessment, by developing a multi-agency risk management plan or by referral to the existing multi-agency frameworks for discussion.

How prevalent and widespread is this issue?

2.7.8 We have not been able to gather any data on the issue of how frequently risk assessments include a specific focus on smoking risk, but we have been advised that the current risk assessment formats within local agencies does not prompt practitioners to focus on and draw out the risks when an individual is continuing to smoke.

2.7.9 Members of the Review Team agreed that in recent years there had been an increase in the level of complexity of needs and risks that are being managed in the community, which in previous years would have more often resulted in an adult being cared for and supported in a sheltered or residential setting, where most risks could be more easily. The local NHS Neuro Rehabilitation Team have a complexity scoring in place to monitor the level of complexity and risk held across the team. The scoring is used to inform caseload management and supervision. However, it also provides a useful indication of the proportion of more complex cases that are being worked with. The current scoring (May 2017) indicates that 36 (14%) of the 250 cases held by the team meet the highest level of complexity.

Why does it matter? What are the implications for the reliability of the safeguarding system?

2.7.10 Adults with mental capacity are entitled to make their own choices about smoking, even if these generate a very high risk and are regarded as ‘unwise decisions’. Professionals need to undertake risk assessments that specifically address the risk of smoking, irrespective of whether the adult is choosing to smoke and is reluctant to change. It is vital to assess the actual risk that is presented when an individual is unwilling to follow the advice given to them and/or use the fire retardant equipment that is issued. Only when those risks are properly acknowledged is there a chance for a realistic risk management plan to be developed.

2.7.11 Accessibility to local multi-agency frameworks in Wandsworth such as the Community MARAC and the VARMM is positive and valuable, but what is required to underpin the panels (which cannot logistically address all

cases) is for front line staff to undertake multi-agency assessment and risk management planning, that ensure an explicit focus on fire risks and smoking risks. The process of developing a multi-agency risk management plan will ensure the adult is engaged and understands that the risks remain high, and will allow agency managers to have an oversight and awareness of these most risky of cases.

Questions for the Board

Finding 4: Current efforts to mitigate fire risk due to smoking are not formally part of risk assessment and management, making it less likely that professionals discuss creative options that could have a realistic change of reducing risk.
• Does this finding resonate with Board members? • What assurance does the Board have that front line staff are working across agencies to assess and risk manage in cases which are not being referred to the VARMM? • Do the Board require additional steps to assure that staff in all key agencies including the independent sector are aware of the additional fire risks associated with use of emollient creams? • What kind of change to risk assessment practice and/or tools would the Board want to see to support practitioners with the assessment and management of risks related to smoking, including when adults are reluctant to make use of the fire repressing equipment that has been made available?

3. Appendices

3.1 Excerpt from Borough of Richmond SAR (Mr T) (2016)

FINDING 3: The tensions that exist when an adult has capacity and continues to choose high risk behaviours can leave practitioners feeling personally and professionally responsible when they have limited legal or practical authority or power to keep the person safe.

The Mental Capacity Act 2005 is very clear that adults with mental capacity have the right to make their own decisions. Capacity should be assumed until there is a clear assessment that confirms a lack of capacity. Practitioners must support a person's right to choose where the individual has mental capacity. However there are many cases where an assessment of capacity is extremely difficult to make. Professionals have to be alert to recognizing whether a turning point has been reached when several lifestyle choices which are deemed to be 'unwise' (but still being made with mental capacity) become on the 'balance of probabilities'[7] a pattern of high risk decisions which may indicate that the person is no longer making an informed decision, and mental capacity has been lost in relation to certain decisions.

The dilemmas experienced by practitioner can be demanding. When a service user with capacity continues to make choices that generate risks, public expectations can be a cause of great conflict for front line staff. The public often wish that agencies and staff could eliminate risk entirely to protect people 'from themselves', but at the same time professionals can be criticized for defensive practice, being over protective and ignoring people's wishes. In recent years there has been an increased focus on positive risk taking as an approach that lends itself to working in partnership with the service user. Guidance on risk assessment and management from the DoH highlights the value of service users being supported to take risks, and refers to risks being a 'natural and healthy part of independent living'.

Even in cases where the adult lacks capacity in relation to certain decisions, and the Courts become involved to make a decision in their best interests, the courts support the need for a balanced approach to the management of risk. The Court of Appeal (v Buckinghamshire CC) turned down a claim of negligence against the Local Authority who had 'allowed' a young woman with learning disabilities to have a continuing sexual relationship. The judge pointed to the need to balance the young woman's happiness with managing risk "there is no point in wrapping people in cotton wool if it makes them miserable".

How did this issue manifest itself in this case?
Mr. T had capacity, as defined under the Mental Capacity Act 2005, and was aware of the risks he was taking by smoking in bed, to himself and to a lesser extent others. He had had two burns from smoking, one resulting in a hospital admission. The risks were repeatedly explained to him by staff working with him and were documented. However

[7] MCA Code of Practice (4.10)

Mr. T's quality of life was a key issue and something that he and the workers around him were focused on. He valued having as much dignity and self-determination as possible, particularly because of the way that his illness had restricted him. Practitioners and care workers needed to balance this with a focus on their duty of care towards Mr. T.

They would be appropriately directive with Mr. T at times to try to persuade him to accept further measures to reduce risks; however he would remind practitioners that it was his right to choose and that he should not be treated like a child. On one occasion the OT took a different colleague with her in an attempt to persuade Mr. T, however Mr. T became very angry and a 'shouting match' ensured. Mr. T's fierce independence was central to his identity and this was something that practitioners understood that they needed to respect and work with.

What makes this an underlying issue rather than particular to this case?
We discussed this issue further with practitioners who attended the Learning Workshop and with members of the Review Team, as we wanted to understand if these dilemmas were specific just to this one case. Feedback received confirmed that practitioners often find themselves working on cases where service users have mental capacity to make key decisions but make choices which do not help to reduce risks and in some cases increase risks. The Housing Provider also discussed the challenge to their agency when their tenants' choices create a risk to themselves and their property, and the provider has to reach conclusions about whether and when to seek legal enforcement to ensure the safety of tenants and property.

The Review Team referred to a number of other cases where service users had mental capacity but their choices generated risks that were difficult to manage. One example was a woman with limited mobility with Cerebella Atrophy who regularly drank alcohol through the day. She hoarded items particularly food and smoked. She did not have access to a phone in her bedroom if she needed to call for help. She was deemed to be at multiple risks from possible fires, financial abuse, self-neglect, increase in depression and alcohol use due to stress. She was assessed as having capacity and despite the risks she chose to continue with her lifestyle decisions. Practitioners working with her did their best to reduce risks to her, but were very aware that she remained at high risk of serious harm.

What is known about how widespread or prevalent the issue is?
Working with these kinds of tensions and ethical dilemma is a regular part of working with adults. There have been other cases where similar tensions have been explored. For example the case (West Berkshire[8] Safeguarding Adults Review 2016) where a service user was mis-using alcohol and at risk of self-neglect. He was not willing to engage with practitioners, but had been assessed as having mental capacity, so the team working with him had very limited options in terms of intervention.

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[8] West Berkshire Safeguarding Adults Review Mr I (July 2016)

The Care Act 2014 statutory safeguarding guidance (chapter 14.108) recognises the dilemma posed to staff in these situations. It states that 'that if the adult has the capacity to make decisions in this area of their life and declines assistance, this can limit the intervention that organisations can make'. Research into cases of self-neglect by Preston Shoot and Braye[9] SCIE (Fact sheet 46) acknowledged the particular difficulties for front line staff who are working with adults who are neglecting themselves and are reluctant to engage with staff. Preston Shoot and Braye noted the frustrations and difficulties stating that "professionals express uncertainty about causation and intervention".
What are the implications for the reliability of the system?
These tensions will continue to be part of the pattern of work life for practitioners; therefore practitioners need to be well equipped to engage with these ethical dilemmas and tensions within their professional practice. Despite the risks that are posed, the rights and wishes of the service user with capacity should continue to be at the heart of decision-making along with considerations for the quality of their life.

In order to ensure good practice outcomes and reduce the frequency of staff burnout, consideration is needed about how best to support practitioners who are working with these tensions. Multi-agency working can be a great help as it allows for a mixture of views, healthy challenges and shared risk management planning. Access to good practice advice and to legal advice if court action is being considered are also key. Senior and strategic managers can consider what kind of organisational ownership there is of these kinds of issues in their agencies or by the multi-agency Safeguarding Adults Board to avoid practitioners being left with the sense that they are having to handle these tensions as isolated individuals.

3.2 How the *Learning Together* review process was undertaken in this SAR

The *Learning Together* methodology can be used flexibly to provide bespoke proportionate reviews to gather and analyse the data and then develop the appraisal of practice and the findings. How the key components of the methodological heart were undertaken in this SAR:

- Generating the 'View from the Tunnel' – from the data provided by front line staff to reduce 'hindsight bias' and generate a more complete understanding of what happened and why. In this SAR that phase of the process was undertaken by front line staff who were directly involved in the management of the case (including practitioners and commissioners) and their immediate line managers at the one day *Learning Together* Workshop.

- Analysing the data using 'Key Practice Episodes' to 'chunk' up the timeline, to appraise the practice of the professionals and to understand what the contributory factors were. In this SAR that phase of the process was undertaken

[9] SCIE research paper no.46 - Self Neglect

by front line staff, their managers and members of the Review Team at the one day Learning Together Workshop. The analysis and appraisal work was then developed further by the Lead Reviewers and written up in the Appraisal of Practice, with input from the Review Team.

- The 'Window on the System' – the generic findings which provide a window on the local safeguarding system, is generated through the analysis of learning from the specific case, in order to tease out which pieces of learning have a broader application. This phase of the review was undertaken by the Lead Reviewers and the Review Team. It was begun during the one day workshop and then developed further in a separate meeting of the Lead Reviewers with the Review Team.

Wandsworth SAR Process – Key Meetings		
Date	**Key Activity**	**To achieve**
25.04.17	SAR training session for SAB members, local front line staff and managers	Familiarity with the SCIE Learning Together model
03.05.17	Learning Together SAR Workshop for frontline practitioners and managers directly involved in the case	Gather and analyse case data
16.05.17	SCIE independent supervision session for Lead Reviewers	To quality assure and support development of appraisal of practice and emerging findings
25.05.17	Meeting of Lead Reviewers and Review Team	Verify developing analysis of practice and input to emerging generic findings
25.07.17	Lead Reviewers facilitate SAB Findings Workshop	To share findings with SAB and facilitate development of SAB action plan

3.3 Members of the Review Team

Member of the Review Team	**Role**	**Agency**
Alison Ridley	Lead Reviewer	Independent
Mary Burkett	Lead Reviewer	Independent
Nic Mayatt	Station Commander	London Fire Brigade
Clinton Beale	Safeguarding Manager	London Ambulance Service
James Isaacs	Service Manager	Richmond and Wandsworth Borough Councils
David Flood	Lead Nurse Adult Safeguarding	St Georges Hospital NHS Foundation Trust

Rachel Sibson	Clinical Team Leader	Community Neuro Team, St Georges Hospital
Keith Burnett	Housing Manager	Richmond and Wandsworth Borough Councils
Roli Alatan	Provider Manager and Company owner	Parkgate Care Agency
Olu Atalan	Provider Manager and Company owner	Parkgate Care Agency
Noyola McNicolls-Washington	Head of Nursing, Adult Community Health Services	St George's Hospital NHS Foundation Trust
Nick D Hale	Safeguarding Lead Nurse	Chelsea and Westminster Hospital Trust
Helen Randell	Detective Sergeant	Metropolitan Police
Nicky Pace	SAB Independent Chair	Wandsworth SAB
Barbara Grell	SAB Coordinator	Richmond and Wandsworth SAB
Clive Simmons	Safeguarding Service Manager	Richmond and Wandsworth Borough Councils
Nuala Waide	Associate Director for Adult and Children's Safeguarding	Stoke Mandeville Hospital
Pat Hobson	Joint Safeguarding Adults Professional	Wandsworth CCG
Krys Rennie	Burns Unit Sister	Queen Victoria Hospital
Katy McQueen	Canadian Wing Matron	Queen Victoria Hospital

3.4 Summary chronology of key events

The period under review is July 2015 – September 2016

DATE	KEY EVENT
20.07.15	MDT assessment completed at home
21.07.15	Speech and Therapy home assessment
24.07.15	OT assessment at home
05.08.15	Pendant alarm in situ
12.08.15	OT session
25.08.15	WWF found in an inebriated state
01.09.15	Police gain entry – WWF had slipped and needed re-positioning
3.10.15	Health OT discussed possibility of Randell Close Gym. Discharged from health OT.
12.11.15	WWF found with burns – referred to DN for dressings. Assessing doctor refers to social services re vulnerability, smoking and reduced mobility.
16.11.15	Referral to London Fire Brigade (LFB) by safeguarding lead for home visit
18.11.15	Increase in care package agreed by LBW
18.11.15	DN visits to address burns and gives safe fire safety advice

23.11.15	OT calls WWF to say wishes to discuss risk around smoking
25.11.15	WWF call s to say she wishes to enquire about sheltered housing
Nov 2015	LFB undertake home safety visit – make referral for fire retardant bedding
01.12.15	OT (LDW) to visit with technician to assess risk
06.01.16	OT emails home improvement agency re door access issues
13.01.16	GP receives letter from neighbour re fire risk
25.01.15	Hairdresser finds WWF alight in her wheelchair, treated at A&E and referred to burns unit. WWF has full mental capacity.
29.01.16	Call from Wandsworth Hospital Team duty to Parkgate Home Care, who advised that WWF had been sat in her wheelchair with an attached table. She tried to light her cigarette with a match stick which fell on a tissue and this went up in flames. Her hairdresser was trying to gain access at the time of the incident; she called the neighbour who had got in. WWF sustained severe burns. This is a second recent accidental incident of lighting cigarette.
29.01.16	TC to Queen Vic Hospital burns unit who confirmed that WWF has sustained burns to both her thighs and left breast. She has just come out of the theatre. Two people are managing her care needs. She has mental capacity. Currently there is no discharge date planned.
10.02.16	Case appears to be assigned to social worker in WHT – Case assigned for assessment and discharge planning. Worker calls hospital, speaks to hospital OT and records a summary of situation.
11.02.16	Email between assigned social worker and Wandsworth OT. Social worker asks if an access/home visit will take place before discharge which is set for 15/02/16 – a full sling hoist is requested due to decreased lower body strength. Wandsworth OT responds that he is liaising with hospital OT to ensure correct equipment is in place for discharge
12.02.16	Burns OT hospital assessment uploaded to case docs – key recommendations are an increase in care, additional equipment and further rehab/physio. Burns Unit made referrals to District Nurse, to community OT and community Physio.
12.02.16	Referral from Burns Unit to Wandsworth Community /Neuro Team
16.02.16	Nurse spoke to Occupational Therapist at Wandsworth Social Services, who informed her that all essential/urgent equipment was in place for discharge. WWF was to be discharged on full hoist, but wanted to retry standing hoist. OT agreed to complete a joint session with WCNT OT and PT as required.
18.02.16	Visit to Queen Victoria (E Grinstead) hospital by social worker on 18/02/16. Care services assessed for and agreed with service user. Interim service/support plan organised (signed off 24/02/16) – increase in care provided from 1 carer 4 times daily, to 2 carers 4 times daily. Wheelchair arranged.
19.02.16	WWF discharged to community with care plus to be followed in community by Chelsea and Westminster hospital for further treatment.
19.02.16	Care package commenced. Carers to support WWF to get out of bed using the full sling hoist (x2 carers for transfer). Carers to support WWF to

	get washed (strip wash in bed at present) and dressed and with toileting needs (empty catheter, change pads, intimate hygiene) to access the toilet using standing aid. Carers to make breakfast and hot drink for WWF. Carers to support with feeding. Support with repositioning.
21.02.16	Re-admitted to Chelsea and Westminster for burns treatment – unclear from notes as to whether this is a planned admission. Decision made to keep WWF in for wound care and to nourish her.
25.02.16	Confirmed that WWF is being kept in hospital for wound infection treatment – SW notified
08.03.16	Social worker has telephone discussion with hospital OT to assess current level of need. Confirmation that OT Home Visit will occur before discharge. Social worker updated care agency by telephone.
11.03.16	Referral received from OT on Burns Unit at Chelsea and Westminster Hospital. Referral prioritised again as semi-urgent (to be seen within 2 weeks). WWF due to be discharged on 14/03/2016 with full package of care and double up carers. On waiting list for Wolfson (rehab) bed as neurological symptoms of her MS had exacerbated.
15.03.16	Post discharge meeting at WWF's home arranged by LBW OT - present: WWF, client's friend, OT and care workers. - Client advised that her current sling was ok however would like to trial an in-situ sling. OT advised that he would arrange to re-visit and trial one. - WWF advised that she wanted to be able to do some washing up however could not turn the taps on. OT advised that he would explore further. OT suggested WWF consider applying for a DFG to adapt her bathroom and make level access, enabling her to wash under running water. Client also advised that she wants better access to the taps in the event of a fire (as a result of smoking) so she can put the flames out. - OT advised that in regards to the issues discussed previously above the position of the door entry system push button and the door entry system itself, he would liaise further with the HIA to see if this is actually something they can attend to or if it can be tweaked under the minor works budget. - OT enquired if client is still smoking on her own considering the risks. Client advised that she was and she was not considering fire proof clothing at this time.
17.03.16	Call from care workers to GP - concern raised that WWF in a lot of pain and was unable to let then into her flat. Carers expressed concern generally that she was not coping well at home. Practice note sent to District nurses to follow up. Agreed call tomorrow to follow up.
18.03.16	Call to patient by GP. Patient said pain better. Declined home visit. Said had appointment at the burns unit the next day.
18.03.16	SW calls WWF to check on her and arranges to visit following Monday
18.03.16	Reviewed at home by OT (health). District Nurses present. DN reported

	WWF has small sacral sore and were dressing it and will be reviewed by the tissue viability service in 3 days' time. WWF now receiving 4 times a day Package of care (was previously 3 times a day). Main problem identified by WWF now is pain from burns and that she is unable to use standing hoist, now full hoist. Plan for joint OT and Physiotherapy visit to review this.
18.03.16	First visit post discharge from hospital. Nurses not informed of discharge from hospital on 14.03.2016. Patient discharged home from hospital with Grade 2 pressure ulcer on sacrum. OT present during visit. Patient has follow up appointment at Chelsea and Westminster hospital on Sunday.
21.03.16	WWF makes call to GP - patient managing at present but requested home visit. Home visit by GP.
March 2016	Visits by nurses to dress wounds on 21.03.2016, 22.03.2016, 25.03.2016, 29.03.2016, 01.04.2016.
24.03.16	Patient assessed as no active movements in legs and no independent sitting balance. Patient reported it being a bad day. Concern raised regarding pressure sore, but WWF Refused transferring to bed until her carers came stating it would 'kill her'. WWF continued to smoke and sit in chair all day despite sore. Physio planned to contact SSOT regarding pressure sore, fire risk, and Community nurses regarding pressure sore management.
29.03.16	OT makes call to Community Nurses. Left message regarding concern that WWF was sitting out all day and had said to the therapists that she would rather die than go back to bed during the day. District Nurse stated that on her visit today, WWF had agreed to return to bed. OT requests high pressure relieving cushion and provide update on current function and made call to SW (message left) to update regarding WWF spending less time sat out and requesting increase in length of care visits to cover hoisting time.
31.03.16	Home visit from SW and care agency in relation to management of affairs and finances (at request of SW). SW records that she believes WWF to have mental capacity to manage own affairs/finances.
01.04.16	Physiotherapy Session at home. WWF not happy at being declined by the Wolfson. Reiterated that this was due to the progressive nature of MS and that she was not appropriate for intensive rehabilitation. Physio contacted the Burns outreach therapist regarding a review and emailed OT to discuss trial of standing hoist and concerns re safety of this.
04.04.16	OT visit from Wheelchair service. Pressure relieving cushion changed as patient prefers to remain in the chair during the day.
05.04.16	Nursing visit to redress burns and pressure ulcer. Hospital doctors have advised that redness in lower legs were due to cellulitis and had prescribed antibiotics.
08.04.16	OT supervision. Update on adaptations, quotes now confirmed for work.

	Decision by supervisor is that case now should be closed to OT
08.04.16	Nursing visit to redress burns and pressure ulcer. Pressure ulcer had deteriorated as patient has been sitting out too long. Planned visit for Sunday. Patient attending hospital on Tuesdays and Fridays.
10.04.16	Nursing visit to redress burns and pressure ulcer. Nurse advised patient to remain in bed to stay off bottom which will improve healing. Patient has finished course of antibiotics. Cellulitis appears to have improved.
11.04.16	Physio visit - WWF agreed it was not safe to trial standing hoist. Advised patient to spend some time during the day lying down to relieve the pressure sore, but patient declined. Exercise sheet provided & demonstrated. Discharged from physiotherapy. WWF continuing declining to comply with recommendations. Wheelchair Service had completed assessment on 04/04/2016.
April	Multiple nursing visits to dress burns and pressure ulcer, improvement noted, visits reduced to weekly.
25.04.16	Call from Community nurses stating that the sore was healing with bed rest. Email received confirming provision of viacave pressure cushion. No further therapy needs identified. Discharged from Occupational Therapy.
27.04.16	OT advises he has identified a fire proof apron that could be worn while smoking so that the risk of burns could be managed should she set herself alight again when smoking
20.05.16	Comprehensive SW review document opened/started - level of care increased on a perm/on-going basis
26.05.16	OT risk assessment completed
June 2016	Multiple nursing visits to redress burns and pressure area checks. Care worker reported that patient becoming non-compliant with care as she would like to stand up using the standing hoist. Advice given to patient that the carers are unable to go against the expert advice given by the OT. Patient expressed that she is feeling depressed and is now feeling suicidal and would like to be re-assessed. Nurse advised that she would speak to the OT.
06.07.16	Final visit from Council OT – confirmation that adaptations have now been completed. These include door release button being moved to a place that is easier for WWF to reach. WWF expresses low mood/suicidal ideation – referred to GP
07.07.16	Call from OT to GP - WWF has expressed thoughts of ‘not wanting to go on’. When actively asked whether she had suicidal ideation she said occasionally but has made no plans. GP who knows her to follow up.
19.07.16	Nursing visits to redress burns and pressure ulcers. All dressings renewed. Patient complained of pain in left foot ’shooting pain’. Nurse to discuss this

	with GP. Nurse to also discuss OT referral as patient has still not heard back. Last visit by community nurses.
19.07.16	At approximately 21:10 hours, care worker arrived at house; she was running late and had been due to arrive at 20:30 hours. She approached the property and rang the doorbell so WWF could let her in. She heard the smoke alarm sounding and WWF calling out for help, she knocked next door for a spare key. Care worker and neighbour entered and found the flat was full of smoke. They found WWF in her wheelchair, her clothing was alight in the leg area and she was shouting"help me, help me". At 21:15 hours the London Operations Centre (LOC) received a call – two fire engines H351and H352 were mobilised to attend from Tooting Fire Station. Care worker returned to the front door and propped it open whilst the neighbour poured a bowl of water over WWF to try and extinguish the fire. The neighbour removed the plastic tray from WWF's wheelchair. Two fire engines arrived on scene at 21:20 hours. Crew Manager entered the property with 2 Fire-fighters; they found WWF conscious and breathing. She had burns to her legs and feet, they applied wet towels and administered Oxygen therapy. The ambulance service was called. They arrived at 21:56 hours, and treated WWF for smoke inhalation, full thickness burns to both legs and partial thickness burns to her stomach. At 22:33 hours, WWF was conveyed to St. Georges Hospital, Tooting by LAS.
19.07.16	It is documented that WWF had fallen asleep; a cigarette had dropped onto a plastic tray melting onto her abdomen and legs. Police attended and reported findings through correct channels.
20.07.16	GP visited. Could not get answer from door. District nurse informed GP had been admitted to St Georges Hospital.
20.07.16	An ambulance was requested by a doctor at St Georges Hospital to attend to transfer WWF to Stoke Mandeville Hospital for on-going care for extensive burns
21.07.16	WWF sadly passed away at Stoke Mandeville Hospital.