

Camden Safeguarding Adults Partnership Board

“Safeguarding is everybody’s business”

A Safeguarding Adults Review Overview Report concerning “Hannah”

Independent Reviewer: Eliot Smith

15 December 2020



Camden Safeguarding Adults Partnership Board

SAFEGUARDING ADULTS REVIEW

Hannah

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Date: 15 December 2020

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PREFACE

Safeguarding Adults Reviews are statutory reviews that take place when an adult dies as a result of abuse or neglect, whether known or suspected, and there are concerns that partner agencies could have worked more effectively to protect them. The case of Hannah has been as challenging to professionals and services in Camden as any. Hannah's life ended too soon but has offered organisations working in the London Borough of Camden an opportunity to learn about how they can work with, and support individuals, and protect them from harm. The Safeguarding Adults Review has benefitted from the full engagement of the Safeguarding Adults Board and contributions from individual agencies themselves. This review was in progress during the onset of the Covid-19 pandemic and the approach taken needed to be flexible as public health measures were taken by the UK Government. I would like to express my thanks to practitioners and services who gave their time and commitment to the review and shared their experiences.

I would also like to thank Hannah's daughter who spent time reading the report, and who was happy to contribute her views. In offering her views, Hannah's daughter demonstrated compassion and understanding, and a genuine wish for organisations in the London Borough of Camden to heed the lessons of Hannah's case and make changes to practice to ensure that lessons are learned from her mother's death. I have agreed to present Hannah's daughter's views in the preface of the report.

Eliot Smith, Independent Reviewer
11 December 2020

Hannah had a long history of contact with services, and Hannah's daughter recalls contact with social services, and emergency services throughout her life, going back years to the 1990's. A pivotal point for Hannah's daughter is that with all this history and information available, services should have been able to respond more effectively, and avoid making generalisations and assumptions about Hannah based on her use of alcohol and risky behaviours. Hannah's daughter felt that Hannah experienced a lack of long-term services and support, with most interventions happening in crisis and through emergency services.

When safeguarding systems were alerted to Hannah's need and risks her case was passed between agencies who failed to share responsibility to address long-term needs and short-term risk. Hannah's daughter believed that the Huntington's Disease Association and her support worker were left with too much responsibility for protecting Hannah from harm and supporting her through her experience with Huntington's. There was a need for services to focus more on engagement – taking extra care to meet people on their level and engage with compassion rather than being offered a procedural response which can feel impersonal. Hannah's daughter felt that there had been too much emphasis placed on Hannah's use of alcohol, at the expense of mental health needs, and Huntington's Disease. Hannah's daughter ended by saying:

"I had better plans for Mum – we had discussed them together. For Mum to move closer to me. But the door kept closing"

INTRODUCTION

“Local Safeguarding Adults Boards must arrange a Safeguarding Adults Review when an adult in its area dies as a result of abuse or neglect, whether known or suspected, and there is a concern that partner agencies could have worked more effectively to protect the adult” (Department of Health, 2017).

In 2019, the Safeguarding Adults Board considered the case of Hannah who died in February 2018. Hannah had been known to a number of agencies and following her death it was felt that agencies could have worked together more effectively to support her.

The purpose of a Safeguarding Adult Review (SAR) is to determine what, if anything, agencies, and individuals involved in this case could have done differently to prevent Hannah’s death. This is so that lessons can be learned from the case and those lessons applied in practice to prevent similar harm occurring again.

Camden Safeguarding Adults Partnership Board determined that Hannah’s case meets the criteria for a Safeguarding Adults Review. This review is being conducted as a statutory review under section 44 Care Act 2014. Such reviews must take place when –

An adult in the area dies as a result of abuse or neglect, *whether known or suspected*, and there is concern that partner agencies could have worked more effectively to protect the adult

The Safeguarding Adults Review will be carried out in line with SAR Quality Markers developed by SCIE and RiPFA (2018).

Background to the case

Hannah, aged 55-years-old, was found dead in her flat by builders working on the buildings cladding. Lucy, aged 44-years-old, was convicted of her murder. The case was referred to the Camden Safeguarding Adults Partnership Board as there were concerns about accountability and responsibility for leading on safeguarding. At the time of referral, it was not known whether Hannah and Lucy shared previous acquaintance, or whether her death was a result of abuse over a period of time, or a one-off event.

Hannah was known to health and social care services in Camden and was a frequent caller to emergency services. Hannah had a diagnosis of Huntington’s Disease, recurrent depressive disorder, and was known to use alcohol. Hannah had been brought up in the Irish care system before moving to the UK. She had a history of traumatic experiences and low mood from a young age. Hannah had been known to become verbally aggressive in the context of alcohol which on one occasion resulted in a 6-month Community Order for threats and verbal aggression.

On the night in question Hannah had been out drinking at a local pub in the area where she encountered Lucy. At the end of the evening Hannah left the pub with Lucy and another male; they returned to her flat where she was stabbed to death.

Methodology

The review methodology draws on systems learning theory to evaluate and analyse information and evidence gathered from available data and documentary records, practitioners and decision-makers in agencies and teams, national research, and the offer of involvement to Hannah's family.

A Review Panel of senior representatives from involved agencies and members of the Safeguarding Adults Board was convened to provide expertise on the design of local safeguarding systems, clinical pathways, and processes, and to support an iterative process of sense-checking the draft overview report for relevance and accuracy. The Review Panel played a key role in the review, offering consultation, comment, and feedback on review evidence, and providing information about local systems and processes.

In line with statutory guidance, professionals within local agencies will be given the opportunity to be "involved in the review and invited to contribute their perspectives without fear of being blamed for actions they took in good faith."

The Review took place at a time when public health measures were introduced by HM Government to contain the spread of the COVID-19 virus. This meant that the approach to practitioner involvement needed to change – from a workshop-based approach to individual interviews conducted by telephone.

Agency involvement

The following agencies were invited to contribute to the Review:

- London Borough of Camden
- Community Safety Partnership
- Housing authority
- Swiss Cottage GP Practice
- Camden and Islington NHS Foundation Trust
- University College London Hospitals NHS Foundation Trust
- Huntingdon's Association
- Metropolitan Police
- London Ambulance Service

All agencies engaged in the Review process and contributed fully. Agencies were open in their approach and demonstrated a commitment to learning from Hannah's case.

Family involvement

The Review has benefitted from the input of Hannah's daughter, who not only offered her views in the preface to this report, but who was able to confirm that the findings of the report resonated with her experience of contact with services and of supporting her mum throughout her life. In addition to the preface above, Hannah's daughter's views have been woven into the report.

Principles

Safeguarding Adults Reviews must adhere to the six safeguarding principles outlined in Care and Support Guidance (Department of Health, 2020); these are Empowerment, Prevention, Proportionality, Protection, Partnership and Accountability.

In addition to these, this Safeguarding Adults Review will be conducted in line with the following principles:

- Culture of continuous learning – incidents can provide the opportunity to learn and improve
- Proportionality
- Independence and independent challenge
- Meaningful involvement of practitioners without fear of blame for actions taken in good faith
- Involvement of family members and individuals affected by circumstances of the case
- Awareness of risks of hindsight bias and outcome bias
- Focus on system and teams functioning
- Not a re-investigation of incidents or performance

Terms of reference

Terms of reference for Safeguarding Adults Reviews are agreed by the Safeguarding Adults Partnership Board and should be published and openly available (Department of Health, 2020). In order to maintain proportionality and structure Hannah's Review was undertaken against clear and focused terms of reference. The findings in this report are structured around the agreed terms of reference, which were adapted during the early stages of the review to reflect emerging evidence during the collation of the case chronology.

The agreed terms of reference are as follows; that the Review should explore:

1. The circumstances and events leading to Hannah's death
2. Hannah's use of emergency services and unplanned care
3. The response of multi-agency safeguarding mechanisms; including the Multi-Agency Safeguarding Hub and roles and responsibilities in safeguarding referral and enquiry
4. The operation of the section 75 (NHS Act 2006) agreement between the London Borough of Camden and 'Camden and Islington NHS Foundation Trust'
5. Management of complex needs: Huntington's Disease, Mental Health, and harmful use of alcohol and their impact on vulnerability and risk

6. The application of the Mental Capacity Act in relation to Hannah's decisions and risk-taking behaviours
7. The impact on Hannah of the Grenfell Tower tragedy and subsequent move from her accommodation

NARRATIVE SUMMARY

Hannah first came to the attention of health services following a presentation to the Psychiatric Liaison Team at Royal Free Hospital in 2010. At this time, a pattern of alcohol intoxication, verbal aggression to others, and experience of assault herself was noted. April 2011 Hannah was diagnosed with generalised anxiety disorder; harmful use of alcohol (with a pattern of binge drinking) and with borderline personality traits linked to trauma. In May 2013, she had an allocated Care Co-ordinator and Doctor who saw her regularly at least once a month. They supported her to get funds to refurbish her studio flat, maintain contact with her daughter and grandson, and provided emotional support when she was diagnosed with Huntington's disease in August 2013.

Adult Social Care's first contact regarding Hannah was a London Ambulance Service (LAS) report received in February 2014. Between 01 January 2015 and 30 November 2016, Adult Social Care's Multi-Agency Safeguarding Hub (MASH) team received 25 police and ambulance reports regarding Hannah. These reports described intoxication, depression, experience of suicidal thoughts and threats to self-harm. Reports outlined a pattern of repetitive calls to emergency services and were forwarded to mental health services for follow up.

In April 2015, Hannah was referred to Adult Social Care for an assessment of her physical needs with respect to her diagnosis of Huntington's Disease. The assessment was completed a month later, concluding that Hannah did not have eligible needs for care and support. A low-level service was later offered to support with shopping but declined by Hannah. The case was closed to Adult Social Care in July 2015. The Local Authority Multi-Agency Safeguarding Hub continued to receive reports from emergency services which they passed on to the Mental Health team for triage and response. In Camden, integrated mental health services are provided under a section 75 (NHS 2006) agreement. This means that social care services for Hannah, including safeguarding, were provided by the Complex Depression, Anxiety and Trauma Team (CDAT).

In November 2016, her mental health team advised the Multi-Agency Safeguarding Hub that Hannah had been discharged from their services in July 2016. As a result, Emergency Services reports passed to the team by the Multi-Agency Safeguarding Hub were not managed by the Mental Health Team. This meant that no service scrutinised or responded to the reports between July and November 2016. This was discussed by the services and there was a feeling that the outcome would not have been different if reports had been responded to – it was recorded that Hannah had a historic pattern of alcohol related incidents, for which she had declined support.

Hannah's GP maintained regular contact with her, and she was well-known to the GP Practice. Hannah took pride in her appearance and would regularly have her hair and nails done at a local salon. Hannah's GP commented that it was possible to gauge if things were not going well if she had allowed these things to deteriorate. Hannah regularly attended for treatment of a finger wart – it is implied that as the finger wart interfered with her nail care regime her GP was able to use this as a pretext to check-in with her regularly – without labelling the appointment mental health monitoring.

Hannah's pattern of alcohol use continued, at times resulting in verbal aggression, or Hannah becoming the victim of a physical assault. Hannah was again receiving support from her mental health team, and her pattern of alcohol use was the subject of discussion. The team formed the view that Hannah was reluctant to stop drinking. Hannah had stated that she wished to still go out while she could – concerned that her Huntington's Disease would prevent this at some point. Referral to local alcohol services was discussed and on one occasion, Hannah initially agreed although withdrawing her consent less than a week later. A request from Hannah for a female Care Coordinator was made, but not followed up.

During February 2016, Hannah was reported to be functioning well, in between approximately fortnightly binges on alcohol. Hannah was recorded as presenting with mental health issues such as cognitive problems and some speech difficulties, likely to have been caused by progression of her Huntington's Disease. Hannah had begun to find word retrieval difficult and could become confused by complex information. Hannah could also become stuck on certain subjects and experienced some memory issues. Hannah also found herself getting easily emotional about small things and becoming angry quickly. A joint visit took place on 24 February by workers from her mental health team and Huntington's Association to discuss discharge from the Complex Depression, Anxiety and Trauma Team.

In March 2016, incidents were reported of Hannah threatening to jump from her window. On one occasion this resulted in a night-long deployment of emergency services and an out of hours GP. The outcome of this episode was a short admission (of under 5 days) to a local psychiatric ward under section 2 MHA 1983. In July 2016, Hannah was discharged from mental health services. Her discharge CPA meeting recorded discussion of recognised patterns of behaviours including the use of alcohol and contacts to emergency services followed by refusal of admission or follow up by alcohol services.

During this period, health and social care services fell into an established pattern of response, correlated to Hannah's use of alcohol, and frequent contact with emergency services – often with Hannah reporting that she had been the victim of an assault. These incidences of alcohol intoxication and assistance-seeking of emergency services appear to have been episodic in nature, from fortnightly to monthly. In between episodes Hannah appeared to be functioning well – she continued to be proud of her appearance and her flat was described as clean and tidy.

At the same time, Hannah was engaging well with Huntington's services: Hannah reports issue with response from staff in Co-op; Hannah and her HD support worker visited store and spoke to Manager. They made an agreement for leaflets and educational material to be given to staff about Huntington's Disease which improved relations significantly. Hannah also wanted to know more about the disease and about how it would affect her in the future.

Hannah was concerned about her speech and about losing the ability to communicate, more so than losing her mobility and other aspects of Huntington's Disease. A report from Neuropsychology stated that Hannah's symptoms reflected "a significant degree of intellectual decline from premorbid estimates. Focal cognitive testing revealed evidence of executive dysfunction, reduced speed of information processing and attentional difficulties with weak naming. Her recognition memory, perception, and spatial skills [were] relatively preserved. Overall, the profile was one of significant anterior/subcortical dysfunction."

In October 2016, Hannah attended Age Concern and obtained information about day centres. Hannah attended a local street resource centre; she offered the Manager leaflets on Huntington's Disease and helped in kitchen. Shortly afterwards, during the early hours Hannah made a call alleging an assault outside the flats and a male friend in her flat who was aggressive and asking for sex. Police attended and resolved the situation.

This pattern continued with contact with services fall into four categories:

- Calls to paramedics complaining of chest pain, leg pain, or deterioration in Huntington's Disease. Hannah regularly makes the call but on paramedic's arrival, refuses treatment
- Calls to Police to report an assault or to assist in the removal of a person in her flat. Hannah appears to invite strangers in and then seek support to have them removed. On arrival, Hannah frequently denies that she has in fact been assaulted
- Hannah sees her GP regularly in relation to her finger wart (cryotherapy) at her GP surgery
- Hannah reports concerns about the progression of her Huntington's Disease – she states her brain is not working properly, her legs and coordination have deteriorated. Hannah was referred to Neuropsychiatry. The result was the initiation of anti-psychotic medication to help with increased anger and aggression. This was communicated to the GP through a letter and a telephone call

From April 2017 Hannah's calls to services begin to centre on falls and associated injury. A total of four or five falls are recorded. On attendance, Hannah is described as being drunk or intoxicated, difficult to understand (slurring), and often as uncooperative or verbally aggressive. Falls were often attributed to alcohol intoxication – in the likely context of progression in her Huntington's Disease. When seen by her Huntington's Disease worker some involuntary leg movements were noted; it is recorded that she had reduced her alcohol intake significantly (although Hannah stated that when she had taken a drink she felt more relaxed and noticed issues with her legs less).

On 22 June 2017, Hannah's tower block was identified as one with the same cladding as Grenfell Tower block. This resulted in residents being evacuated and re-homed in alternative accommodation. Hannah's daughter arranged for a hotel for her on Euston Road, before she relocated to a hotel in Horsham in West Sussex. Hannah stayed out of the area for a time before returning to her flat (even though works had not been completed).

Hannah's calls to emergency services in relation to falls and associated injury were frequent towards the end of 2017 into 2018. However, this information was not available to her GP surgery – in a follow-up appointment; her GP noted that her last fall had been March. The

GP records did not contain any information about the frequent calls to the ambulance service for falls.

This pattern of numerous contacts made with services continued. In six calls on 31 January 2018, Hannah reported she had fallen, and reporting that she had been the victim of a sexual assault. Hannah had also contacted her HD support worker and was reportedly also seeking contact with her sister. On this occasion, she had been conveyed to Hospital.

There were no further direct contacts with Hannah prior to her death.

FINDINGS

At different points in her life, Hannah had been well-known to services, and her case is able to shed light on a number of aspects of the safeguarding system in the Borough of Camden. The findings of this review are based upon analysis of documentary evidence and data, learning from national and local reviews, and further evidence provided by agencies and practitioners involved in Hannah's life. The findings of this report are presented thematically, demonstrating learning from Hannah's experience that has general applicability for the wider system. Findings have been set out according to the terms of reference for the review.

TOR 1: The circumstances and events leading to Hannah's death

Hannah, aged 55-years-old, was found dead in her flat by builders working on the buildings cladding. Lucy, aged 44-years-old, was convicted of her murder. On the evening of 05/02/2018, Hannah and Lucy were seen drinking at a Public House. Later in the evening Police had been called to a group being disorderly outside, and Hannah returned to her flat with Lucy and another male. Hannah was found dead with 40-55 wounds inflicted by a knife and scissors, and with the imprint of Lucy's shoe on her face.

Lucy was not known to health or social care services and was not known to have any additional needs.

Hannah had a diagnosis of Huntington's Disease and during her life had been treated for depression and anxiety. Huntington's Disease is known to cause disorders of movement, it can impair cognition and can have a significant impact on a person's emotional regulation and behaviour. Individuals who have Huntington's Disease can also be more susceptible to the influence of alcohol and may become more easily intoxicated.

Hannah was known to drink alcohol on a regular, but not daily basis; choosing to binge drink periodically. In the context of her Huntington's Disease, this may have had a significant impact on her ability to make decisions and on her judgement. The combination of these factors may have led to risk-taking behaviour and impaired judgement of the intentions of others – she often sought company when intoxicated leading to situations of risk. Hannah was known to frequently make calls to the emergency services.

A context of vulnerability and risk factors exists; however, there is no information to suggest any previous acquaintance between Hannah and Lucy, nor of any systematic exploitation or abuse of Hannah's vulnerability prior to the night of Hannah's death. It is therefore not possible to say that this incident was predictable or preventable.

TOR 2: Hannah's use of emergency services and unplanned care

Context

Hannah's chronology of events between 01/12/2016 to 09/02/2018 tells of two identifiable patterns of engagement with services in Camden and by association different formulations of decision-making ability, level of independent functioning and levels of risk. The first could be categorised as her engagement with planned care, her GP, Huntington's Support Worker, and at times her Mental Health Team. The second pattern includes her contact to emergency services, Police, London Fire Brigade, and London Ambulance Service, and by extension and onward referral, the Multi-Agency Safeguarding Hub and Mental Health Team screening.

In the three years leading up to her death, the Computer-Aided Despatch¹ system had recorded over 166 hits. Hannah had been categorised as a "repeat caller and/or victim". This category is used when an individual makes persistent calls to the Police, London Ambulance Service, or London Fire Brigade. Many of Hannah's calls reported allegations of assault, and sexual assault, and latterly of injuries and falls.

To borrow terminology associated with crisis intervention theory, her engagement with planned care may represent her 'steady state' and her contact with unplanned care, her 'crises'². The personal experience of crisis is highly subjective – one person's crisis may not be another's emergency. Hannah had an experience of trauma from a young age and into her adulthood. It is not known what impact this had on her resilience to further life events, including her diagnosis of Huntington's, progression of the disease, or knowledge of her father's own deteriorating health. Understanding the causes for an individual's presentation in frequent crises, or emergencies, requires a holistic assessment of a person's underlying needs, patterns of behaviours, motivations, and risk factors.

During an emergency deployment, attending officers and paramedics have access to limited alert information. Responding agencies rely on individual's self-report, personal memory of having attended previously, on reading the presenting situation, injury, and in situ risk assessment. Ambulance crews attended with a basic warning about Hannah's history of intoxication and a previous occasion of aggression to attending paramedics.

The analysis of agency chronologies over the two years preceding her death reveals that Hannah's use of emergency services strongly correlates to her binge use of alcohol and reflects her perception of a need for protection. At times services attended after she had invited another back to her flat, and on others when her need for protection or feeling of vulnerability may have passed and she denied previously made allegations of assault or sexual assault. There are other occasions when Hannah retracted allegations or referred to historical allegations of assault.

¹ Computer Aided Despatch (CAD) – System that phone calls to the Metropolitan Police Service are recorded on.

² A well-used definition of crisis is "an upset in a steady state" (Rapoport, 1970)

Findings

Information sharing

At the point of risk or perceived emergency, information about a person's experience and behaviours must be reliably recorded by responders and shared with agencies or practitioners concerned with recovery. In the context of Hannah's allegations of assault and sexual assault. The National Crime Recording Standards (NCRS) states that in relation to drunkenness or impairment:

"The fact that a person is drunk or otherwise impaired might have a bearing on the balance of probability issue within the Crime Recording Decision Making Process (CRDMP). As a minimum, an incident must be recorded and followed up by the police when the person is in a fit state. However, if at the time of reporting supporting evidence shows that on the balance of probability the crime happened then it must be recorded, regardless of the victim's condition – the presumption is that victim reports should be believed". (Home Office, 2020).

When a crime report is made, an individual *may* have access to specialist-trained Advance Achieving Best Evidence officers, for individuals with additional vulnerabilities or communication needs, intermediaries are also available to investigating police officers who can interview individuals at a more appropriate time. Alcohol intoxication was also a complicating factor in the health response. Paramedics were able to respond to the immediate concern and Hannah's presentation but were often met with the same challenge as Police – a denial of injury or a refusal of treatment or support.

Individuals responding to Hannah generally worked hard to establish rapport and offer support. On occasions Hannah, self-reported information about her Huntington's Disease and with the Police advice was sought from a specialist Huntington's advisor which is good practice. Taken in isolation each response to Hannah's calls for assistance demonstrated expected or good practice. However, the system failed to piece together the jigsaw in a multi-agency forum – systems exist (safeguarding, frequent caller groups, community Multi-Agency Risk Assessment Conference) yet were not considered and were not used. The response of the wider system to individual incidences of risk is considered later in this report.

For emergency services, a picture was building of an individual who placed themselves at risk through alcohol intoxication, made allegations of assault, sexual assault, and sustained injuries or falls but who could retract allegations or refuse treatment and support. With limited information about underlying health conditions (most paramedics attending would not be aware of Hannah's diagnosis of Huntington's Disease or history of depression or anxiety), attending crews were not always able to identify underlying care and support needs.

For individuals with care and support needs, health conditions and multi-factorial vulnerabilities, it is known that alcohol is a complicating risk factor in safeguarding. In a recent review of Safeguarding Adult Reviews where alcohol was a factor, Alcohol Change

UK found that *“alcohol misuse can lead to a person becoming more vulnerable to exploitation by others”*.

It is important that the system is able to identify and respond to individuals who are at greater risk of exploitation and abuse through the complicating factor of alcohol over underlying vulnerabilities. Services who respond in emergencies need support to recognise risk-factored service users and should be alerted to service users who are at risk in addition to those who present a risk.

There are systems in place within the Police and across the health system which can identify individuals on end of life care or addresses where risk factors are present such as domestic abuse, child protection, or risks to attending officers/crews. However, these such systems are not currently used for safeguarding adult concerns or multi-factored adults at risk. This meant that attending crews and officers from responding agencies failed to refer all safeguarding concerns and risks – many of which were then hidden from view in the wider system.

In addition, as Hannah’s physical health and Huntington’s Disease progressed, and in the latter stages of the chronology, she began to experience falls which in some cases were attributed to her use of alcohol rather than as an aspect of her worsening movement disorder. This meant that clinically-relevant information was not shared with Hannah’s GP who was not aware of the extent of Hannah’s movement disorder or frequency of falling – even in the context of Huntington’s and alcohol use.

Finding 1: Information sharing

Underlying issue

There is no system to provide agencies and practitioners who respond to emergencies with information about adults with care and support needs who may be at an enhanced risk of exploitation or abuse. Attending professionals may therefore miss an opportunity to share safeguarding intelligence with the wider system – safeguarding concerns and clinically-relevant information may remain hidden from view.

Impact on system

Attending staff will be more attuned to vulnerability and risk, which may be given greater emphasis in response and report.

Recommendation

The Board and relevant responding agencies should consider how attending staff may be briefed with appropriate information about a person’s risk factors and vulnerability

TOR 3: The response of multi-agency safeguarding mechanisms; including the Multi-Agency Safeguarding Hub and roles and responsibilities in safeguarding referral and enquiry

Context

“An adult safeguarding concern is any worry about an adult who has or appears to have care and support needs, that they may be subject to, or may be at risk of, abuse and neglect and may be unable to protect themselves against this” (London Safeguarding Adults Board, 2018)

Safeguarding concerns can originate from a variety of sources – the adult may self-disclose to a member of staff, concerns may be ‘passively noticed’ by a practitioner or result from observations of risk. Concerns may also be raised through notification processes – in Hannah’s case the majority of referrals were made through police Merlin Adult Came to Notice (ACN) reports. Upon receipt of a concern the Local Authority must make a decision about whether statutory criteria is met for a safeguarding enquiry under section 42 Care Act 2014.

Within the London Borough of Camden, Merlin reports are submitted to the Multi-Agency Safeguarding Hub (MASH). At the time of Hannah’s death, the MASH consisted of the Adult Social Care Team with virtual input from Police, Community Safety, GP’s, and housing. The MASH Team also benefited from a Mental Health Social Worker on 2 days per week. The Safeguarding Hub operated two systems of screening for concerns, notifications, and Merlin reports.

If the person was known to an adult social care team or mental health services within the last 12 months, then the concern would not be screened but would be passed directly to the involved team. The MASH Adult Social Care Team would have no role in the screening of the concern nor make any recommendations about next steps. The practice of ‘blind onward referral’ would also mean that information would not be sought from any of the virtual agencies that make up the Multi-Agency Safeguarding Hub.

In the case of Hannah’s, concerns received by the MASH were passed on to the Mental Health Team. From July 2016, Hannah’s case had been closed to the mental health team which meant that a number of Merlin Reports were lost in this system – they were not screened by the mental health team as the case was closed, and they had not been screened by the MASH Teams due to the policy of onward referral.

Findings

Stage 1: Concern

Between July and November 2016, none of the concerns passed on by the Multi-Agency Safeguarding Hub to Mental Health Services were screened or considered against criteria for safeguarding enquiry. None of the concerns submitted by responding agencies at this time were considered individually or in the context of a pattern of behaviour. Information was not sought, or shared, with partner agencies, Hannah's GP and no risk plans were made. For the remainder of her contact with services, no safeguarding actions were taken, although Hannah continued to make calls to the emergency services, reporting assault, sexual assault, and injuries sustained from falls.

Mental Health Services and the Multi-Agency Safeguarding Hub both agree that this was unusual. None of the agencies involved in the review have indicated that the 'lost' concerns represents an underlying issue. In most cases agencies in Camden feel that processes are robust, however Hannah's case does highlight a vulnerability in the system – the more passing on of referrals, the greater the risk that concerns and patterns of risk may be missed.

Finding 2: Concern screening

Underlying issue

The Multi-Agency Safeguarding Hub (MASH) are the gatekeepers of safeguarding concerns but have "no role in Mental Health Merlin reports". Reports are blindly passed on to mental health services, creating a vulnerability in the system and risk of lost concerns, or inconsistencies in the application of safeguarding criteria and thresholds.

Impact on system

The blanket policy of onward referral of all mental health concerns without screening for risk factors or patterns or risk leaves the system vulnerable to miscommunication, administrative errors and may allow a case to fall through the gaps.

Recommendation

There should be a single point of referral for safeguarding concerns, and a single team tasked with the initial safeguarding response. At the time of writing, there are proposals for a change in MASH process, and these are supported: that the MASH Teams undertake the initial risk response, screening of information, and make recommendations for further action by identified local social care teams – including mental health.

Escalation

When the Multi-Agency Safeguarding Hub were informed that the case was closed a discussion took place about holding a professionals meeting, however this did not ever occur. In safeguarding practice errors may occur or teams have disagreements about who should work on a particular case. The Multi-Agency Escalation and Resolution Procedure (Camden SAPB, 2018) was published in 2018 and contains a clear four-stage process to ensure that issues within the system are resolved appropriately. Agencies and practitioners who gave evidence to the review knew of the policy and were able to describe its use. The Multi-Agency Escalation Policy was not used in Hannah's case, but this aspect of the system is sound.

Stage 2: Enquiry – the Safeguarding response to concerns about Hannah

The Multi-Agency Escalation Policy was not triggered in Hannah's case, and this may reflect the organisational view that her case did not meet the threshold for safeguarding enquiry. Submissions to the Safeguarding Adult Review have stated that even had the concerns been screened, the response would not have been significantly different – Hannah's case would have been unlikely to have proceeded to the next stage of the safeguarding process – the Enquiry.

Hannah was an adult with care and support needs, she was known to suffer from Huntington's Disease, a condition that may have had a multifaceted impact on her ability to make decisions and to protect herself from harm. However, the organisational view seemed to have settled – that Hannah was making decisions to drink alcohol, was making decisions about risk, and that she could therefore protect herself from the adverse effects of both.

Alcohol Change UK, in their thematic review into Safeguarding Adult Reviews featuring alcohol use, found that

“the level of its significance varies, and its role is always relational. It is rarely the case that alcohol is the sole, or even the defining, factor in these incidents; rather, it usually emerges as part of a complicated set of causal factors, but a factor that exacerbates every other factor.” (Alcohol Change UK, 2019)

Hannah's condition could have made her more susceptible to alcohol, and cognitive impacts of the disease may have also left her less able to understand or discern the intentions or motivations of others. Hannah's condition, exacerbated by her use of alcohol *may* have left her vulnerable to exploitation and abuse from which she could not protect herself, as a result of her need for care and support.

We have seen above that had her allegations, made in the context of alcohol, been recorded as a crime, she *may* have benefited from contact from a specialist trained officer, or from an intermediary, and an interview at a more suitable time. In a similar vein, had Hannah's case been considered to meet the threshold for safeguarding further actions may have been taken

to gain her views and an account of her experiences when she was in a different state of mind. Each year the Safeguarding Adults Partnership Board publish an Annual Report. In the Annual Report for 2018-19, the year Hannah died, the Board included a case study demonstrating the response to a safeguarding concern (Appendix 1). Case Study A (Caroline) demonstrates a flexible, person-centred approach, and a safeguarding response that was able to triangulate health information from the GP. In the case study a person with care and support needs faced an experience of domestic abuse – in this case exploitation and abuse occurred in the context of a relationship that the person was reluctant to give up.

Finding 3: The impact of alcohol a risk factor for individuals with care and support needs

Underlying issue

This case provides evidence that the impact of alcohol use, as a risk factor rather than a causal factor for individuals with underlying health conditions and care and support needs, was not widely understood. This means that an individual's ability to protect themselves from harm may be over-estimated.

Impact on system

Individuals who have underlying health conditions, vulnerabilities, and care and support needs, who use alcohol, may be denied the safeguarding response they are entitled to under the Care Act 2014.

Recommendation

Professionals working in core safeguarding services and who make safeguarding decisions should be trained to recognise the role alcohol (and drug) use may play in a person's risk of exploitation and abuse and their ability to protect themselves from harm.

Alternative safeguarding systems

It is generally accepted that the best approach to management of risk is person-centred and multi-agency. In the management of risk, and in particular in relation to risk of serious harm, the General Data Protection Regulation, and Data Protection Act 2018 are not barriers to sharing of information between health and social care agencies.

Had it been felt that Hannah's case had met the threshold for section 42 (Care Act 2014) Enquiry, safeguarding responses could have included the allocation of a practitioner engagement with Hannah to establish her views (at a more suitable time) and may have included a multi-agency strategy meeting where information could have been shared and a risk management or safeguarding protection plan formulated.

Had Hannah's case not met the threshold for safeguarding enquiry, then a number of alternative processes and forums exist that may have achieved a similar result – engagement of Hannah in risk discussions and processes, and a multi-agency approach to formulation of a risk management plan.

Alternative mechanisms that support multi-agency risk management in Camden include, but may not be limited to, the following:

System	Lead	Description
High Risk Panel	Camden SAPB	The HRP is a 6-weekly multi-agency panel designed to prevent escalation of safeguarding risks includes regular attendance from the Police and Safeguarding Leads from Central North West London NHS Foundation Trust, and a GP.
Professionals meeting	Any agency can call	Brings together professionals working with a person to share information and devise risk management strategies.
Care Programme Approach (CPA)	Mental Health Services	The Care Programme Approach (CPA) is a framework for how services are assessed, planned, delivered, coordinated, and reviewed, for someone with mental health problems or a learning disability, with a range of complex needs and risks.
Network Meeting	Community Safety / neighbourhoods	Agencies invited to attend case-specific meeting. May include network check – information sought from Local Authority and other partners to inform management plan.
Community Multi-Agency Risk Assessment Conference (MARAC) ³	Community Safety	Any agency can refer to the Community MARAC, which is a monthly, risk-focused panel. The Community MARAC is chaired using a similar approach to domestic abuse MARAC. Can be triggered by emergency services, including where concerns exist about frequent callers.

³ At the time of Hannah's death, the Community MARAC was an emerging process which has since been consolidated into business as usual practice.

Finding 4: Responding to concerns about risk

Underlying issue

A number of options are available to safeguarding decision-makers beyond simply the application of the statutory criteria for a safeguarding enquiry under section 42 Care Act 2014. On receipt of a concern about a person who is at risk of harm, a risk-based approach is recommended where the goal is to achieve a person-centred, multi-agency approach. This could be achieved through a number of mechanisms. The key components of alternative processes are that they are person-centred, multi-agency, and generate a risk management plan, or strategy which can be coordinated across different services.

Impact on system

Individuals about whom concerns have been raised, but where the threshold for statutory Enquiry under the Care Act 2014 has not been met, will benefit from a person-centred multi-agency approach to risk management.

Recommendation

Key decision-makers across the safeguarding system should have a good knowledge of the different options available for managing risk, and the referral pathways to ensure that the appropriate mechanism is selected and implemented in a timely fashion. Evidence-based approaches should be employed by each process and research and training should be available to each organisation leading a multi-agency mechanism.

TOR 4: Section 75 (NHS Act 2006) agreement between the London Borough of Camden and 'Camden and Islington NHS Foundation Trust'

Context

Section 75 NHS Act 2006 makes provision for NHS bodies and Local Authorities to contribute to a pooled budget to enable partnership arrangements in relation to the exercise of NHS functions and certain health-related functions⁴ of Local Authorities. This allows an NHS body to exercise, on behalf of the Local Authority, prescribed health-related functions.

In many areas, section 75 arrangements have been used to combine NHS and Local Authority mental health care to create integrated Adult Mental Health Teams made up of medical, nursing, allied healthcare professionals, and psychologists employed by the NHS trust, and Social Workers and other Social Care staff employed by the Local Authority. Teams were often operationally led by the NHS Trust exercising on behalf of the Local Authority key functions of care management, Mental Health Act duties (Approved Mental Health Professionals), and safeguarding duties. Integration and cooperation have been encouraged where possible and remain a focus of government policy. Statutory guidance to the Care Act 2014 states that:

“For people to receive high quality health and care and support, local organisations need to work in a more joined-up way, to eliminate the disjointed care that is a source of frustration to people and staff, and which often results in poor care, with a negative impact on health and wellbeing. The vision is for integrated care and support that is person-centred, tailored to the needs and preferences of those needing care and support, carers and families.”
(Department of Health, 2020)

It is through this lens that the Review has considered the arrangements in the London Borough of Camden and the impact these had on the care and support received by Hannah. In Camden, a section 75 agreement exists between Camden Council and Camden and Islington NHS Foundation Trust.

Health and Social Care

For NHS care, mental health services in Camden are diagnosis-driven with a range of specialist teams working with individuals according to their primary mental health need. When initially referred to secondary mental health services, Hannah had received treatment from the Complex Depression, Anxiety and Trauma Service (CDAT). Huntington's Disease in Camden, as in many areas of the country, is not considered a core psychiatric condition. An individual's needs arising from such a diagnosis would only be addressed by the mental health team when Huntington's Disease was a co-existing condition. In Hannah's case, she was treated by the team for depression and low mood and she was discharged from the service when her depression had resolved.

⁴ “Health-related functions” of Local Authorities include any function that has an impact on a person's health, have an effect on NHS functions, or are connected with NHS functions (s.75(8) NHS Act 2006)

In relation to social care needs, while being supported by the CDAT service Hannah could have expected that any needs identified through a well-being assessment (s.1 Care Act 2014), or needs assessment under section 9 (Care Act 2014) would have been provided by the CDAT service under the section 75 agreement. For individuals to meet eligibility for health and social care interventions, the coordination of social care needs takes place within the Care Programme Approach (CPA), and Hannah had an allocated Care Coordinator who she knew well and whom she worked with for over three years. During this time, the CPA offered Hannah a person-centred and holistic approach to her health and social care needs. All the while Hannah was supported by the team the partnership working between her Care Coordinator and other professionals across the health and social care system (for example Hannah's Huntington's Disease worker) has emerged as a real strength.

Once Hannah was discharged from NHS treatment, the assessment of, and provision for her social care needs was less apparent and in the example of safeguarding her referrals appeared to fall between the social services 'front door' and the mental health team.

Safeguarding

Safeguarding concerns were referred by the Multi-Agency Safeguarding Hub to the CDAT service for a decision by the Social Care element of the team. The policy in Camden is that the appropriate team to screen and make decisions about safeguarding is the team to whom the person is open or had been open to, up to twelve months following case closure / discharge. After twelve months, any further Merlin Reports and concerns were returned to the Multi-Agency Safeguarding Hub for a decision.

Throughout the time period covered by this review, Hannah's case was not felt to meet criteria for safeguarding procedures, so it is not possible to fully explore how the safeguarding procedures are delivered under the section 75 agreement. Based upon submissions to the review had the case 'gone to safeguarding', whether Hannah had at the time been open to the team or not, she would have been allocated a worker who would have made contact with her to discuss her views and experience of abuse, and if a number of agencies were involved then a case conference could have been called, led by Social Care staff in the CDAT service. The description of safeguarding practice within the team is consistent with the model proposed in the current London Multi-Agency Safeguarding Policy and Procedures (London Safeguarding Adults Board, 2019).

Findings

In July 2016, the CDAT service believed that in treatment for depression, Hannah had reached her recovery potential – her depression was not significant and it was felt that she no longer needed support from a specialist service, that her mental health needs could be managed in primary healthcare. Based upon evidence submitted to this review it would appear that the same criteria may have been applied to Hannah's social care needs, and in particular to safeguarding concerns. As she did not meet diagnostic criteria for support under the CPA, she did not meet eligibility criteria for a social care response.

There is a risk with any section 75 agreement that eligibility for NHS care and Social Care may be conflated, and that decisions about social care needs may become entwined with decisions about diagnostic eligibility. In many cases an individual's eligibility for specialist mental health care and their needs for care and support will be consistent. In those circumstances a conflation of the two has little effect on the decision about safeguarding eligibility. However, in cases such as Hannah's a conflict may arise – Hannah may not have had care and support needs arising from a mild to moderate depression, however she was likely to have met criteria for care and support arising from her Huntington's Disease.

Evidence submitted by agencies in this review indicate that with the benefit of hindsight, Hannah may well have been eligible for a safeguarding response under Multi-Agency Procedures. If not, then the expectation would have remained that the risks facing Hannah would have been managed by the team using an alternative multi-agency framework. There is evidence that in the case of Hannah, there *may* be inequities in the application of eligibility criteria and thresholds in safeguarding decision-making.

Camden Council and Camden and Islington NHS Foundation Trust have both recognised that in Hannah's case silo-working was evident and that there could have been stronger links between the Mental Health Team and Multi-Agency Safeguarding Hub. Both organisations have expressed a wish for closer working and a desire to forge close working relationships that will result in more consistent safeguarding practice

It has been recognised that in some cases there remains disagreement about which service should respond. While both organisations are committed to improvement and resolution it will be important that a systems solution is found to the issue of referrals falling between agencies and appropriate fail-safes developed to prevent incidents of abuse going un-responded to.

Finding 5: the differentiation of health and social care decision-making in safeguarding eligibility

Underlying issue

There is a risk with any section 75 agreement that eligibility for NHS care and Social Care may be conflated, and that decisions about social care needs may become entwined with decisions about diagnostic eligibility. Social care thresholds should be applied consistently across all care groups, including physical health, mental health, and learning disability. Where services are provided under section 75 NHS Act 2006 agreements the criteria for treatment, and care and support should be explicit and systems in place to ensure each is provided in an equitable way.

Impact on system

In many cases, an individual's eligibility for specialist mental health care and their needs for care and support will be consistent. In those circumstances, a conflation of the two has little effect on the decision about safeguarding eligibility. In some cases, a conflict between the two may arise – a person may be eligible for social care provision who may not meet criteria for specialist health care. If health and social care eligibility criteria are combined, there is a risk that some individuals may not receive their statutory entitlements to care and support.

Recommendation

The London Borough of Camden Council and Camden and Islington NHS Foundation Trust should work together to forge closer working relationships. Training together, supervision, and regular strategic and operational meetings may help to ensure consistent application of social care duties.

TOR 5: Management of complex needs: Huntington's Disease, Mental Health, and harmful use of alcohol, and their impact on vulnerability and risk

Context

Hannah had a diagnosis of Huntington's Disease, she had been treated for depression, and she was known to use alcohol to harmful levels, becoming intoxicated on a regular basis. Within the NHS, many services are led by diagnosis, allowing an individual with a particular health condition to be treated by an expert in that condition. Huntington's Disease is a rare genetic disorder. In the UK approximately 1 in 10,000 people have Huntington's Disease⁵ (a rate of 0.01% of the population). Individuals are often supported through their GP, specialist clinical and research centres, and voluntary sector organisations such as the Huntington's Disease Association.

Huntington's Disease is a genetic disorder characterised by movement disorder, cognitive disorder, and behavioural disorder. The average onset of symptoms is between 30 and 50 years old and can be categorised in three stages – early, middle, and late. Hannah was believed to be in the early stages of the disease, a stage characterised by:

- Some involuntary movements, and voluntary movement harder to control
- Depression
- Deterioration in organisational skills and planning ability
- Impact on speech, word-finding, and word-formation
- Behavioural disturbances – becoming more angry, irritable, and frustrated
- Activities take longer to complete
- Change and new situations more difficult to manage
- Increase in forgetfulness

The treatment for Huntington's Disease is largely symptomatic with medication and therapies beneficial for movement and psychiatric impacts, including mood disorder, anxiety, irritability, and jerky or involuntary movements. Hannah, for a period of time had been prescribed an anti-psychotic medication which had been felt to have helped her. It is generally accepted that there is little treatment for cognitive impacts beyond establishing a routine and adaptive behaviours that mitigate against lost cognitive functioning. Hannah received support from her GP, from a Huntington's Disease Association support worker and from the National Huntington's Disease Centre (a consultative service). The national service and Hannah's support worker would be able to provide expertise to the mental health team, where Huntington's Disease was a co-existing condition to a recognised psychiatric disorder (such as complex depression) through the CPA process. Having been discharged from the mental health team as her depression had resolved, there was limited input of specialist expertise into the safeguarding system or formulation of social care needs. Hannah had begun to experience increasing worry about the progression of her condition, she had questions and anxieties from her knowledge of family experiences (the progression of her own father's Huntington's Disease).

⁵ SOURCE: Huntington's Disease Association: Huntington's disease: Outside looking in on a rare condition; infographic published on: <https://www.hda.org.uk/blog/outside-looking-in-on-rare-condition>

Individuals suffering from Huntington's Disease may also be more susceptible to the influence of alcohol, becoming more intoxicated, more quickly with the usual impairments to judgement, emotional regulation, and social inhibitions. There are also some similarities in some of the symptoms of Huntington's Disease and alcohol intoxication: poor gait, stumbles and staggering walk, slurring and speech difficulties and many individuals experience stigma from this. Hannah was known to use alcohol to excess and it is likely that her presentation was exacerbated by her use of alcohol, making her actual level of intoxication more difficult to assess. It is good practice that the Police sought the advice of a Huntington's Disease specialist when considering how to respond to Hannah's frequent calls reporting that she had been the victim of a crime.

Depression and alcohol misuse are more commonly diagnosed conditions, and individuals have access to local NHS services for treatment and support. During 2017-2018 in the London Borough of Camden, the rate of people accessing support from their GP for depression was 7.64% compared to the London average of 7.11%⁶, and in the same year the rate of alcohol dependence was 1.6% compared to the London average of 1.3%⁷.

The overall assessment of Hannah's complex needs would need to take her health conditions into account, alongside other biological and social factors, in order to form a holistic understanding of risk.

In her younger life, Hannah had grown up in the Irish care system, she had suffered from mental health difficulties in her younger life and as an adult had been victim to sexual assault. The impact of childhood trauma and abuse on adults' long-term health and wellbeing has led to a body of evidence of the risk factors and consequences for many adults of Adverse Childhood Experiences (ACEs).

Adverse Childhood Experiences have been found to have lifelong impacts on health and behaviour; individuals who have faced one or more ACE have been found to be at a higher risk of impaired cognitive and social development, future violence victimisation, substance misuse, depression and PTSD (Felitti, et al., 1998) (Centres for Disease Control and Prevention (CDC), 2020). Some children are less susceptible to the negative effects of ACE risk factors, but it is believed that the greater the number of experiences, and experience of trauma, the higher the risk of a negative health impact over an individual's adult life.

As with any risk factor it is important that their impact on each individual is carefully assessed; in health, social care, and safeguarding practice, a holistic assessment of an individual must include not only risk factors, but protective factors and personal resilience. When faced with a complexity of needs and risks, there may be a tendency for services to concentrate on areas of expertise and fail to see the wider picture. Hannah's risk factors and experiences were complicated by her underlying diagnosis of Huntington's Disease.

⁶ SOURCE: NHS Digital: Quality and Outcomes Framework, Achievement, prevalence and exceptions data - 2017-18

⁷ SOURCE: University of Sheffield (2019) *Estimates of the number of Adults in England with and alcohol dependence potentially in need of specialist treatment*. Published on gov.uk by Public Health England

Findings

In the management of Hannah's health conditions, many services in Camden performed as expected and as designed, with areas of good practice, flexibility and good partnership working. Hannah engaged well with her GP and was seen regularly. Hannah took pride in her appearance and enjoyed getting her nails done. With this as motivation, Hannah attended the GP to have treatment for a finger wart, and the GP also used this as a pre-text for monitoring of her mental health and other concerns. Hannah talked to her support worker about her concerns and anxieties and also received from her, education, and advice. To assist Hannah with some of her neuro-psychiatric difficulties Hannah was prescribed treatment – an anti-psychotic medication which appeared to help calm her behavioural and emotional disturbances.

There is no known cure for Huntington's Disease, and no treatments that have been shown to reverse symptoms or impacts. Interventions and treatments for Huntington's Disease focus on symptom-management and onward referral to relevant specialisms for treatment, strategies, and techniques.

The National Institute for Health and Care Excellence (NICE) do not produce any specific guidance on Huntington's Disease and there has been some criticism that Huntington's Disease is not viewed as a psychiatric, or neuro-psychiatric condition, but an organic disease that does not meet criteria for psychiatric support, except as a co-existing condition. This is felt to be an issue nationally, and in Hannah's case could have been mitigated through better communication, networking, and education, rather than through an individual agency case-holding or management. Huntington's Disease services are available to support mainstream health and social care services and are able to offer advice on management of an individual's care.

During the time period covered by the review there is no evidence that Hannah received an assessment of her social care needs under the Care Act and it is not known if she would have been eligible for additional support to maintain independence. Hannah was also reluctant to address her pattern of use of alcohol, declining a referral to alcohol services. Agencies across the system, from responding emergency services, her GP, and specialist mental health services, each worked in silo, concentrating on their areas of expertise and capacity. Where there is learning from Hannah's case, it is in the management and response to risk and the lack of cross-organisational management. It could be argued that this approach did not have an adverse impact on the management of her health conditions, there was an impact on management of risk factors and on safeguarding. Working to a diagnostic or role focus may have prevented the wider system from attempts to support Hannah with her risk behaviours, and decisions.

The system also demonstrated a limited understanding of her Adverse Childhood Experiences and their impact on her longer-term health outcomes. In particular agencies often demonstrate a limited understanding of Huntington's Disease and the impact it may have on a person's movement, cognition, and behavioural abilities. There is expertise in the system, through the National clinical-research centre and Huntington's Disease Association, however few agencies sought help, advice, or education, from a specialist and many did not

know that this was available. The impact of Huntington's Disease includes movement disorder, cognitive disorder, and behavioural disorder. The course of the disease is known medically to professionals but can also be known to the individual through their own experience of relatives with the condition. Hannah had witnessed her father's deterioration from Huntington's Disease which had a profound impact on her. These aspects, including the psychiatric impact of Huntington's Disease itself, should be taken into account in decision-making about mental health support by Local Authorities and Mental Health Trusts.

The challenge for diagnosis-driven services is to see the patient as a whole person. Hannah was unique, not only in the combination of her health conditions and their particular impacts upon her, but also in her life experiences, risk factors, and resilience. In the management of Hannah's complex needs, health, social care, and emergency services needed to work together, sharing their own experiences of Hannah and their specialist knowledge and expertise in order to offer Hannah a holistic service that was as unique as she was.

Finding 6: Access to specialist expertise

Underlying issue

Huntington's Disease is a rare condition and there is limited expertise in mainstream services. When individuals have rare conditions, and multiple needs, practitioners offering support and decision-making in safeguarding should have access to and seek relevant specialist expertise in order to evaluate the impact of multiple risk factors on a person's health and social care outcomes and safety.

Impact on system

Practitioners are often called to make decisions about a person's needs, risk, and eligibility for services based upon a complex presentation of multiple risk factors. Practitioners that have access to the relevant specialist expertise will be able to make informed decisions based on the impact of interconnected risk factors. This is especially relevant to safeguarding and mental capacity practice.

Recommendation

When individuals with rare or unusual conditions present to services mainstream practitioners and safeguarding decision-makers should identify and access relevant specialist expertise so that eligibility decisions are based on all appropriate information and context.

Finding 7: The person as a whole

Underlying issue

Eligibility for many health and social care services depends on specific diagnoses or conditions, rather than the cumulative impact of their difficulties and risk. There is a risk that people with Huntington's Disease fall outside the criteria for most mainstream secondary services. There is a need for the system to consider the whole person – and the interconnected impact of their diagnoses, experiences, and risk factors. Multi-agency processes are vital to address risk factors for exploitation and abuse that may not arise from a single condition or factor, but the combination of many.

Impact on system

Communication and information sharing are important features of an effective multi-agency response to multiple and complex needs. Agencies are able to access multi-agency processes, including safeguarding and professionals meetings, in order to share clinically-relevant information and formulate an assessment of risk factors that is based upon the whole person rather than just one aspects of the health and social care functioning.

Recommendation

When people with complex needs, co-existing conditions, and adverse childhood experiences present to services there should be consideration of a professionals meeting or other communication model, to consider the management of multi-agency interventions.

TOR 6: The application of the Mental Capacity Act in relation to Hannah's decisions and risk-taking behaviours

Context

The Mental Capacity Act provides a statutory framework for the assessment of capacity and the ability to make particular decisions at a particular time.

A person may be found to lack capacity to make a particular decision at the time it needs to be made if, because of, impairment in the function of mind or brain they are unable to make a decision by failing to be able to do any of the following:

- Understand the information relevant to the decision
- Retain the information for long enough to be able to
- Use and weigh-up the information as part of the decision-making process; or
- Communicate their decision, by any means.

It has been confirmed through case law⁸ that a person's inability to make a decision must be *because of* an impairment in the function of mind or brain. It is neither enough that a person has a mental impairment, nor that they are unable to make the particular decision in question. The link between mental impairment and lack of ability to make a decision must be established.

Both of these cases contribute to the discussion that is relevant in Hannah's case – should the existence of her mental impairment have called into question her mental capacity to use alcohol, which appeared to inevitably result in her placing herself at risk of harm and abuse.

Huntington's Disease can result in a significant cognitive impairment with difficulties in executive functioning, social cognition (including facial and emotional perceptions), and deficits in attention and concentration. Under the Mental Capacity Act 2005, the symptoms of alcohol use can also be treated as a mental impairment (Department of Health, 2007). For an individual suffering Huntington's Disease, the impact of using alcohol on the ability to make decisions could be significant. It is known that for a person with Huntington's Disease less alcohol is required to produce the symptoms of intoxication leading to:

- Deterioration in movement disorder
- Impaired social judgement
- Intoxication is more rapid
- Increase in impulsivity
- Lack of insight and self-awareness
- Rigid thinking and a degree of argumentativeness

⁸ *PC v City of York Council* (2013) EWCA Civ 478; *Heart of England NHS Foundation Trust v JB* (2014) EWHC 342 (COP)

Findings

In Hannah's case, mental capacity was often mentioned but "*not gone into*". At certain points (for example in decisions about admission) there are statements about mental capacity, or a yes/no box ticked, however no evidence of the assessment (if any) that took place, or an explanation of the findings. In the case of Hannah there was a general view across agencies that she had mental capacity to make decisions about her risky behaviours which was one factor that contributed to the decision not to take her case into safeguarding.

A person must be assumed to have capacity unless it is established that he [sic] lacks capacity (s.1 (2) MCA 2005). In a joint report by the Local Government and Parliamentary Health Ombudsman's, agencies are warned against relying on the assumption of capacity where concerns exist about a person's ability to make decisions that could place them at risk (LGO & PHSO, 2014). The report found that a person experienced self-neglect in their home and criticised the NHS Trust and Local Authority for failing to have assessed his mental capacity sufficiently.

Hannah may well have had mental capacity in relation to patterns of alcohol use and social risk-taking, however it would appear that there was sufficient concern about the impact of her mental impairments for this to have been more fully assessed.

Finding 8: Statements of mental capacity and evidence of assessment

Underlying issue

Hannah suffered from a mental impairment which, when exacerbated by her use of alcohol, could have called into question her mental capacity – her ability to make decisions about interventions for alcohol use, and decisions about her social risk. At key points, decisions about the use of safeguarding were made on the basis of mental capacity, without this having been assessed.

Impact on system

Assumptions of mental capacity may be justified, even when a person has a mental impairment within the meaning of the Mental Capacity Act 2005; however, if individuals are assumed to have capacity without assessment, or regard to their ability to make decisions, then individuals may be left without the mental capacity and safeguarding protections to which they are entitled.

Recommendation

When safeguarding decisions are being made about a person who has a mental impairment within the meaning of the Mental Capacity Act 2005 due regard should be given to their ability to make the decisions in question. When a threshold decision is being made on the basis of mental capacity, this should be evidenced through an assessment of capacity.

TOR 7: The impact on Hannah of the Grenfell Tower tragedy and subsequent move from her accommodation

Context

On 14 June 2017, a fire broke out in the 24-storey Grenfell Tower Block of flats in North Kensington, London. The fire claimed 72 deaths and left more than 70 others injured. On 23rd June 2017, following advice from the London Fire Brigade (LFB), the Council evacuated four of the five blocks on the Chalcots Estate. The process and experience of evacuation was a period of tremendous disruption for residents involved, as well as for the wider community. It was also a major undertaking by the Council, involving the mobilisation of the entire organisation to deliver what was one of the largest peacetime residential evacuations in London's history (London Borough of Camden Council, 2018).

Hannah was one of the individuals who needed to be evacuated from her home and was a traumatic period for her. Hannah's home was important to her in many ways. She maintained her home to a high standard and may have relied on a structured environment to assist her in her management of day to day independent living skills. Many individuals who suffer from Huntington's Disease develop functional behaviours that can appear obsessive or rigid to others. As individuals begin to struggle with their cognitive function and memory a structured home environment can offer a sense of safety and stability. Many people find their routines protective and adaptive behaviours can be contextual to a familiar environment.

During the works programme, Hannah initially accepted accommodation in a hotel, before moving out of the area to stay with her family. While she benefitted from the opportunity to spend time with her family, her time away from her home was traumatic for her. At this time, Hannah was on a trial of anti-psychotic medication. Due to the unprecedented scale of the evacuation Hannah's GP surgery was unable to support her while she resided temporarily in another area – it is not known if she registered with a GP in West Sussex, nor if she was able to continue with her trial of medication.

The evacuation of the Chalcots estate has been subject to independent review and this report is not able to add to the findings of the Review; however it should be noted that this was a traumatic time for Hannah and may have contributed to her use of alcohol as a fall-back, maladaptive, coping mechanism.

CONCLUSION

At different points in her life Hannah had been well-known to services, and her case is able to shed light on a number of aspects of the safeguarding system in the Borough of Camden. It is not possible to show a direct link between the actions of the safeguarding system and the cause of Hannah's death, and it may not have been possible (or desirable) to have moderated Hannah's behaviours that could be described as risky but an expression of individual choice and self-determination.

SUMMARY OF RECOMMENDATIONS

No.	Finding	Summary	Impact	Recommendation
TOR 2: Hannah's use of emergency services and unplanned care				
1.	Information sharing	There is no system to provide agencies and practitioners who respond to emergencies with information about adults with care and support needs who may be at an enhanced risk of exploitation or abuse.	Attending staff will be more attuned to vulnerability and risk, which may be given greater emphasis in response and report.	The Board and relevant responding agencies should consider how attending staff may be briefed with appropriate information about a person's risk factors and vulnerability.
TOR 3: The response of multi-agency safeguarding mechanisms; including the Multi-Agency Safeguarding Hub and roles and responsibilities in safeguarding referral and enquiry				
2.	Safeguarding stage 1: Concern	The Multi-Agency Safeguarding Hub (MASH) are the gatekeepers of safeguarding concerns but have "no role in Mental Health Merlin reports".	The blanket policy of onward referral of all mental health concerns without screening for risk factors or patterns or risk leaves the system vulnerable to miscommunication, administrative errors and may allow a case to fall through the gaps.	There should be a single point of referral for safeguarding concerns, and a single team tasked with the initial safeguarding response.
3.	Safeguarding stage 2: Enquiry	This case provides evidence that the impact of alcohol use, as a risk factor rather than a causal factor for individuals with underlying health conditions and care and support needs, was not widely understood.	Individuals who have underlying health conditions, vulnerabilities, and care and support needs, who use alcohol, may be denied the safeguarding response they are entitled to under the Care Act 2014.	Professionals working in core safeguarding services and who make safeguarding decisions should be trained to recognise the role alcohol (and drug) use may play in a person's risk of exploitation and abuse.

No.	Finding	Summary	Impact	Recommendation
4.	Alternative safeguarding systems	A number of options are available to safeguarding decision-makers beyond simply the application of the statutory criteria for a safeguarding enquiry under section 42 Care Act 2014. On receipt of a concern about a person who is at risk of harm, a risk-based approach is recommended where the goal is to achieve a person-centred, multi-agency approach.	Individuals about whom concerns have been raised, but where the threshold for statutory Enquiry under the Care Act 2014 has not been met, will benefit from a person-centred multi-agency approach to risk management.	Key decision-makers across the safeguarding system should have a good knowledge of the different options available for managing risk, and the referral pathways to ensure that the appropriate mechanism is selected and implemented in a timely fashion.
TOR 4: Section 75 (NHS Act 2006) agreement between the London Borough of Camden and 'Camden and Islington NHS Foundation Trust'				
5.	Health and Social Care eligibility decisions	There is a risk with any section 75 agreement that eligibility for NHS care and Social Care may be conflated, and that decisions about social care needs may become entwined with decisions about diagnostic eligibility. Social care thresholds should be applied consistently across all care groups, including physical health, mental health, and learning disability.	In many cases an individual's eligibility for specialist mental health care and their needs for care and support will be consistent. For some individuals, a conflict between the two may arise – if health and social care eligibility criteria are combined there is a risk that some individuals may not receive their statutory entitlements to care and support.	The London Borough of Camden Council and Camden and Islington NHS Foundation Trust should work together to forge closer working relationships. Training together, supervision, and regular strategic and operational meetings may help to ensure consistent application of social care duties.

No.	Finding	Summary	Impact	Recommendation
TOR 5: Management of complex needs: Huntington’s Disease, Mental Health, and harmful use of alcohol, and their impact on vulnerability and risk				
6.	Access to specialist expertise	Huntington’s Disease is a rare condition and there is limited expertise in mainstream services. When individuals have rare conditions, and multiple needs, practitioners offering support and decision-making in safeguarding should have access to and seek relevant specialist expertise in order to evaluate the impact of multiple risk factors on a person’s health and social care outcomes and safety.	Practitioners are often called to make decisions about a person’s needs, risk, and eligibility for services based upon a complex presentation of multiple risk factors. Practitioners that have access to the relevant specialist expertise will be able to make informed decisions based on the impact of interconnected risk factors. This is especially relevant to safeguarding and mental capacity practice.	When individuals with rare or unusual conditions present to services mainstream practitioners and safeguarding decision-makers should identify and access relevant specialist expertise so that eligibility decisions are based on all appropriate information and context.
7.	The person as a whole	Eligibility for many health and social care services depends on specific diagnoses or conditions, rather than the cumulative impact of their difficulties and risk. There is a risk that people with Huntington’s Disease fall outside the criteria for most mainstream secondary services and a need for the system to consider the whole person – and the interconnected impact of their diagnoses, experiences, and risk factors.	There is a need for the system to consider the whole person – and the interconnected impact of their diagnoses, experiences, and risk factors. Multi-agency processes are vital to address risk factors for exploitation and abuse that may not arise from a single condition or factor, but the combination of many.	When people with complex needs, co-existing conditions, and adverse childhood experiences present to services there should be consideration of a professionals meeting or other communication model, to consider the management of multi-agency interventions.

No.	Finding	Summary	Impact	Recommendation
TOR 6: The application of the Mental Capacity Act in relation to Hannah’s decisions and risk-taking behaviours				
8.	Mental capacity statements, and the record of assessment	Hannah suffered from a mental impairment which, when exacerbated by her use of alcohol, could have called into question her mental capacity – her ability to make decisions about interventions for alcohol use, and decisions about her social risk. At key points, decisions about the use of safeguarding were made on the basis of mental capacity, without this having been assessed.	Assumptions of mental capacity may be justified, even when a person has a mental impairment within the meaning of the Mental Capacity Act 2005; however, if individuals are assumed to have capacity without assessment, or regard to their ability to make decisions, then individuals may be left without the mental capacity and safeguarding protections to which they are entitled.	When safeguarding decisions are being made about a person who has a mental impairment within the meaning of the Mental Capacity Act 2005 due regard should be given to their ability to make the decisions in question. When a threshold decision is being made on the basis of mental capacity, this should be evidenced through an assessment of capacity.

REFERENCES

- Alcohol Change UK, 2019. *Learning from tragedies: an analysis of alcohol-related Safeguarding Adult Reviews in 2017*, London: Alcohol Change UK.
- Brabbs, C., 2017. *Safeguarding Adults Review in respect of YY*, London: Camden Safeguarding Adults Partnership Board.
- Camden SAPB, 2018. *Annual Report 2017/18*, London: Camden Safeguarding Adultst Partnership Board.
- Camden SAPB, 2018. *Multi-Agency Escalation and Resolution Procedure*, London: Camden Safeguarding Adults Partnership Board.
- Camden SAPB, 2018. *Safeguarding Adults Strategy 2018-2021*, London: Camden Safeguarding Adults Partnership Board.
- Camden SAPB, 2019. *Annual Report 2018/19*, London: Camden Safeguarding Adults Partnership Board.
- Camden SAPB, 2019. *Delivery Plan 2019/20*, London: Camden Safeguarding Adults Partnership Boards.
- Centres for Disease Control and Prevention (CDC), 2020. *Adverse Childhood Experiences (ACEs)*. [Online]
Available at:
<https://www.cdc.gov/violenceprevention/childabuseandneglect/acestudy/index.html>
[Accessed May 2020].
- Department of Health, 2006. *NHS Act*. London: TSO.
- Department of Health, 2007. *Mental Capacity Act 2005: Code of Practice*. London: TSO.
- Department of Health, 2008. *Refocusing the Care Programme Approach: Policy and Positive Practice Guidance*, London: Department of Health.
- Department of Health, 2020. *Care and Support Statutory Guidance (online version, updated 2 March 2020)*. London: TSO.
- Felitti, V. J. et al., 1998. Relationship of Childhood Abuse and Household Dysfunction to Many of the Leading Causes of Death in Adults. *American Journal of Preventative Medicine*, 14(4), pp. 245-258.
- Heart of England NHS Foundation Trust v JB* (2014) EWHC 342 (COP).
- Home Office, 2020. *Home Office Counting Rules for Recorded Crime*, London: HM Government: Home Office.
- LGO & PHSO, 2014. *Investigation into a complaint against South Essex Partnership University Trust and Bedford Borough Council*, Coventry & London: Local Government Ombudsman & Parliamentary and Health Service Ombudsman.

London Borough of Camden Council, 2018. *Response to Independent Review of the Evacuation of the Chalcots Estate*, London: London Borough of Camden Council.

London Safeguarding Adults Board, 2018. *London Multi-Agency Adult Safeguarding Policy & Procedures*, London: London Adult Directors of Social Services.

London Safeguarding Adults Board, 2019. *London Multi-Agency Adult Safeguarding Policy & Procedures*, London: London Adult Directors of Social Services.

Murphy, S., 2019. *A Safeguarding Adults Review: Significant Event Analysis Report in respect of the case of Ms UU*, London: Camden Safeguarding Adults Partnership Board.

Murphy, S. M., Irving, C. B., Adams, C. E. & Waqar, M., 2015. Crisis Intervention for people with severe mental illness. *Cochrane Database of Systematic Reviews*, Issue 12.

PC v City of York Council (2013) EWCA Civ 478.

Pierson, J. & Thomas, M., 2002. *Dictionary of Social Work*. Glasgow: Harper Collins.

Rapoport, L., 1970. Crisis Intervention as a mode of brief treatment. In: R. W. Roberts & R. H. Nee, eds. *Theories of Social Casework*. Chicago: University of Chicago Press.

Rethink Mental Illness, 2017. *Factsheet: Care Programme Approach (CPA)*, Birmingham: Rethink Mental Illness.

Sharples, J., 2019. *A Safeguarding Adults Review Overview Report concerning "Adult W"*, London: Camden Safeguarding Adults Partnership Board.

Social Care Institute for Excellence and NSPCC, 2016. *Serious Case Review Quality Markers; supporting dialogue about the principles of good practice and how to achieve them*. London: SCIE and NSPCC.

Social Care Institute for Excellence and Research in Practice for Adults, 2018. *Safeguarding Adult Review Quality Markers checklist*. London: SCIE & RiPfA.

Wye Valley NHS Trust v Mr B (2015) EWCOP 60.

Case study A

Domestic Abuse



Caroline is a 67 year old lady who suffers from arthritis and depression. She is the main carer for her husband who has a mental health condition. Caroline has had a hip replacement, is undergoing surgery for another one and wears a stoma bag (a pouch bag which allows faeces or urine to be collected on the outside of your body).

She is self-caring and prefers to remain as independent as possible for as long as she can manage.

Her case concerns domestic abuse dating back many years. The district Stoma nurse raised a concern about Caroline when she confided in her that her husband is very controlling, manages her money for her and practically controls almost everything she does. He is verbally abusive and physically threatening towards her and has physically assaulted her on more than one occasion. He has been recently discharged from hospital for a mental health concern and had to give up his job possibly due to mental health concerns.

The concern was raised to MASH (Multi Agency Safeguarding Hub) who took immediate steps to ensure Caroline's safety. Caroline had also been known to a domestic violence support network for some years back. MASH established that there were no immediate concerns for Caroline's safety but there were ongoing issues with her husband's behaviour towards her.

The MASH social worker contacted Caroline to establish her views, provide information to her and to gather her opinions about how she would like to proceed with the concern. As it was difficult to arrange to see Caroline at home, the social worker met with her at her GP's surgery. The GP provided information about the ongoing issues in the family and Caroline agreed for the social worker to have triangulated information from her and the GP as well.

The case was transferred from MASH to the Access and Response team and allocated to a social worker. The social worker involved worked at Caroline's pace while ensuring that she had adequate information to keep herself safe. Caroline delayed most of the actions agreed with the social worker because she was reluctant to have her husband separated from her.

With her consent, the social worker explored options for initiating a family group conference and access psychological support from her

husband. She also supported her to open her own bank account and provided her with information about contacting Careline services so she could contact Careline at weekends and evenings, if she experienced any incidents that made her feel unsafe.