Just a Little Bit of History Repeating: The recurring and fatal consequences of lacking professional knowledge of acquired brain injury

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Just A Little Bit of History Repeating: The recurring and fatal consequences of a lack of professional knowledge of acquired brain injury

Abstract

Purpose: The purpose of this paper is to review Safeguarding Adult Reviews (SARs) pertaining to individuals with Acquired Brain Injury (ABI) since 2014. This extended literature review also explores the lessons and recommendations from these reviews in relation to social work practice within the UK.

Design/methodology/approach: The literature review reported and discussed findings across reviews and then used a thematic analysis to synthesise the findings and recommendations from the SARs reviews.

Findings: The authors identified four main themes; 1) a lack of awareness of the needs of those with ABI and their families, and around the symptoms and nuances of brain injury, particularly executive impairment and mental capacity, among social workers, 2) poor interdisciplinarity led to a lack of shared communication and decision-making with professionals with such knowledge, 3) a poor understanding of aspects of the mental capacity legislation, particularly surrounding unwise decisions, led to inappropriate or absent mental capacity assessments and 4) a lack of professional curiosity led to a lack of action where intervention or assessment was required.

Originality: While there have been extensive reviews conducted on SARs, this is the only review that has focused solely on ABI.
**Research Implications:** The review identifies significant shortcomings in social work practice, education and training within the UK with regards to ABI.

**Practice Implications:** The paper provides recommendations to current social work practice and highlighted the need for significant improvements in pre-qualification and post-qualification training and supervision of social workers.

**Key words:** Acquired Brain Injury, Social work, Safeguarding Adults, Mental Capacity.
**Introduction**

Individuals with acquired brain injury (ABI) are often poorly served by adult social care services. While advances have been made to protect and save the lives of those with injuries to their brains, the long-term neuro-psycho-social support available to both service users and families is woefully inadequate. Inadequate assessments of need by social workers who know too little about ABI are part of the problem.

Acquired brain injury (ABI) from illness or injury (e.g. tumours, illness, accidents), sustained during or after birth results in alteration to brain function (Headway, 2018) with the most common cause being traumatic brain injuries (TBIs; falls, road accidents, assaults). ABIs cause damage to the brain and adversely impact a range of functional domains including cognitive (impairments in language, attention, concentration and memory, and executive impairments), behavioural (irritability, and aggression), emotional (anxiety, depression and wider personality changes) and physical (mobility, speech, sensory impairment, and fatigue) (King & Tyerman, 2003).

The executive impairments associated with ABI are particularly important when considering social work practice, as they are hidden invisible disabilities that impact planning, problem solving, decision-making, inhibiting and initiating appropriate behaviour, and level of insight into disability (George & Gilbert, 2018; Owen et al, 2017).
Since 2014, plentiful research has commented on the difficulties of providing appropriate long-term support to those with ABI within the confines of current social work practice. Specifically, the research has identified that a lack of knowledge of the impact of cognitive and executive impairments and the impact of reduced insight upon functioning and behaviour can negatively impact on assessments and on identifying needs (George & Gilbert, 2018, Flynn, 2016, Norman, 2016, Adshead et al, 2019; Norman et al, 2020; Norman, 2020; Moore et al., 2019, Odumuyiwa et al, 2019; Holloway, 2014, Holloway, 2017, Holloway et al., 2019, Holloway & Tasker, 2019). The failure of social workers to take account the potential impact of ABI upon individuals and the decisions they make has been identified as creating significant harm to people with a brain injury and their families (Moore et al, 2019; Flynn 2016; Norman, 2016).

The purpose of this paper is to review Safeguarding Adults Reviews (SARs) pertaining to individuals with Acquired Brain Injury that have taken place since 2014. This extended literature review also explores the lessons and recommendations from these reviews in relation to social work practice within the UK. The aim of this paper is not to provide an extensive scoping review of safeguarding adults reviews in relation to individuals with brain injury, but to review some of the cases the authors have been made aware of to identify common themes.

**The Role of Social Work with Adults in the UK**

Whilst individuals and families affected by ABI may encounter many health and social care staff from different professional backgrounds, social work has a particularly pertinent role. Social workers working with adults, particularly in the
community, are often gatekeepers to service provision and implement legislation such as the Care Act (and associated Safeguarding investigations), the Mental Capacity Act and Mental Health Act. “Social worker” is a protected title and Social Work England (SWE) is the specialist regulatory body that sets professional standards for practice and education of social workers, and investigates complaints and undertakes disciplinary processes. By way of example, Standard 4 of the qualifying education and training standards 2021 produced by SWE notes:

“Social work courses are shaped by the needs and insights of academia, employers, practitioners and people with lived experience of social work. This is to ensure a continually evolving curriculum which is evidence-informed, matches the contemporary demands of the whole sector, is delivered by appropriately qualified and experienced professionals, and produces informed, capable, prepared and motivated graduates who deliver safe and effective services.”

Whilst social work and social workers are able to play a pivotal role in the lives of individuals and families following brain injury, they do not do so in a vacuum. A myriad of services and agencies including those concerned with health, housing, policing and welfare benefits may be required. The social work role is however perhaps unique, being able to undertake a more holistic and longer-term role on occasion.

Within the field of social work the word “vulnerable” is a definitionally contested term and one that, in particular, fails to recognise power imbalances on a societal level that may
impact upon an individual’s ability to act with autonomy (Virokannas et al, 2018). However the word is constructed and used, it would be our argument that present social work education, training and practice is an intrinsic cause of “vulnerability” for people with an ABI, most usually relating to a failure to act.

The impact of ABI and the needs of service users and their families

Typically, individuals with ABI fall between gaps in services. The cognitive impairments following ABI make long-term reintegration problematic for individuals wishing to return to education or employment or wanting to re-engage with social networks (De Netto & McKinlay, 2019; McKinlay & Buck, 2019; Odumuyiwa et al, 2019; Abrahamson et al, 2017; Hicks et al, 2017; Piccenna et al, 2016; Mealings et al, 2012; Van Velzen et al 2009). An inability to return to work has a devastating impact on people’s quality of life, with increased social isolation and high levels of social deprivation (Knight et al, 2020; Williams et al, 2020; Odumuyiwa et al, 2019; Oddy et al, 2018; Sariaslan et al, 2016; Whiteneck et al, 2016a; Whiteneck et al, 2016b).

The cognitive impairments associated with ABI have additional difficulties associated with poor planning and decision-making (George & Gilbert, 2018; Lennard, 2016). They can lead to poor financial decision-making, inability to plan and maintain adequate housing or difficulties accessing welfare (Norman 2020; Harding & Tasciolu, 2017; Norman 2016). For a number of people with an ABI their impairments are such as to create life-long needs for services users who often require complex ongoing support packages (Clark-Wilson & Holloway, 2015) that are often not forthcoming due to the lack of understanding of their needs and decision-making impairments among health and social care professionals, and a lack of availability and commissioning (Norman et al 2020; Odumuyiwa et al, 2019; Barnes...
et al, 2018; House of Lords, 2014). This is particularly problematic in reference to mental capacity (Moore et al, 2019; Ruck Keene et al, 2019). While the new NICE guidelines on the Mental Capacity Act highlighted the importance of considering executive impairments when considering or undertaking capacity assessments (Moore et al 2019; NICE, 2018), it is unclear how widely this guidance is being considered by professionals in practice.

These impairments, alongside a lack of social care provision, leads individuals with ABI at an increased risk of homeless (Mason et al, 2017; McMillan et al, 2015; Oddy et al, 2012), anxiety and depression (Konrad et al, 2011), and long-term substance misuse (Ponsford et al, 2007) and leaves individuals more at risk of financial, physical and sexual abuse (Moore et al, 2019), as well as being over-represented among prison and probation services (Eriksson et al, 2019; O’Rourke et al, 2018; Woolhouse et al, 2018). Ultimately, these factors culminate in a three-fold risk of suicide in comparison to the general population (Madsen et al, 2018).

These issues demonstrate a high level of need among service users, individuals who are often already at increased risk due to high levels of adverse experiences in both childhood and adulthood (Ma et al, 2019; St Ivany & Schminkey, 2019; Brain Injury Australia, 2018). These issues also have a determinantal impact on family members who often experience anxiety, depression, stress and often have to reduce or give up paid employment in order to support their family member (Clark-Wilson & Holloway, 2019), often with little to no practical information and advice about brain injury (Clark-Wilson & Holloway, 2019; Holloway et al, 2019; Holloway & Tasker, 2019; Holloway & Tyrell, 2018; Townshend & Norman, 2018; Holloway & Tyrell, 2016;).
Evidence generated from practice describes specific difficulties with the role of social work in relation to ABI. Evidence from a review of the Mental Capacity Act and the National Institute of Health and Care Excellence guidance that followed, similarly identified difficulties with social work involvement with people affected by brain injury (Acquired Brain Injury and Mental Capacity Act Interest Group, 2014; House of Lords, 2014; NICE, 2018). One such difficulty is that many ABI survivors present well, even to the extent of being able to describe their difficulties and the steps they need to take to account for these but are unable to put these steps into practice (Mantell, 2010). This confuses assessment and confirms the need to ensure the assessment process is in accordance with the true nature of ABI and its functional impact (Moore et al, 2019; George & Gilbert, 2018; Acquired Brain Injury and Mental Capacity Interest Group, 2014; Mantell, 2010; Manchester et al, 2004).

The current review focused on SARs published after 2014. This year is auspicious as it was the year that the second author’s brain injured brother committed suicide following years of neglect by social workers who failed to appreciate the impact of his cognitive and executive impairments and his lack of insight (Norman, 2016). The author’s brother himself became the subject of a SAR (Flynn, 2016). The first author is a practitioner-academic with 30 years’ experience of working with adults with ABI who has sought to counteract the lack of knowledge about this condition within the social work profession (Holloway 2014; Holloway & Fyson, 2016). The second author is a research psychologist and psychotherapist with ongoing experience working with families and service users following brain injury in both a therapeutic and research
capacity. The case of “Tom” outlined below has been outlined elsewhere (Flynn, 2016; Norman, 2016, Norman, 2020) but the key points are outlined in the results section.

While Tom’s case serves as an example of the kinds of errors that occur when working with people with ABI, his case is by no means unique. It is one of many case reviews, and other cases that did not make it to full SARs that demonstrate the problems associated with a poor understanding of ABI among social workers and other professionals in health and social care settings.

Publications since 2014

Since Tom’s death in 2014, and even since the publication and release of his SAR in 2017, there have been many publications pertinent to the issue discussed here; the needs of individuals and families affected by ABI that are in the purview or duty of a UK social worker. Academic social work however has proved to have very limited interest in the condition with few articles (albeit an increasing number) published across the English speaking world (Mantell et al., 2012, Mantell et al, 2017; Mantell et al., 2018). A search in the British Journal of Social Work for “brain injury” identifies 83 articles published since 1971, of which only 5 relate solely to social work practice with people ABI. For comparison purposes, a search for “mental illness” identifies 1,842 articles, “learning disability” 1,430 articles and “mental health” 3,224 articles.

Social work practice is informed by guidance which identifies clearly the need for practitioners to hold the requisite knowledge and skills, and to refer to other professionals to assist and support assessment or interventions as is needed for the
specific situation. For example, the Care Act Statutory Guidance section 6.3 regarding assessment states the need for:

“A face-to-face assessment between the person and an assessor, whose professional role and qualifications may vary depending on the circumstances, but who must always be appropriately trained and have the right skills and knowledge.”

And the Mental Capacity Act Code of Practice notes the need to utilise specific expertise to undertake assessments in s 4.51:

“Anyone assessing someone’s capacity may need to get a professional opinion when assessing a person’s capacity to make complex or major decisions..... If the person has a particular condition or disorder, it may be appropriate to contact a specialist (for example, consultant psychiatrist, psychologist or other professional with experience of caring for patients with that condition)..... In some cases, a multi-disciplinary approach is best. This means combining the skills and expertise of different professionals.”

And, very pertinently when considering the matter under discussion here, section 4.53 of the Mental Capacity Act Code of Practice notes that specialist involvement might be needed if:

- The decision that needs to be made is complicated or has serious consequences,
• **Or, a person repeatedly makes decisions that put them at risk or could result in suffering or damage.**

Work published in recent years, often from outside of the profession, has identified difficulties with an absence of social worker knowledge of ABI and the impact that this has upon other sectors of health and social care, upon family and upon affected individuals (Fins 2015; Holloway, 2014, Golightley & Holloway, 2016; Holloway and Fyson, 2016, Simpson & Yuen, 2018; Holloway and Tasker, 2019, Moore et al., 2019, Norman et al., 2020). A review by the House of Lords into how the Mental Capacity Act was working in practice identified significant and specific difficulties relating to ABI (House of Lords, 2014). This review and call for evidence was responded to by many professionals of varying backgrounds working in the field, noting that a lack of social work knowledge of the condition was implicated in difficulties (Acquired Brain Injury and Mental Capacity Act Interest Group, 2014). As a direct consequence of the House of Lords review, NICE developed and published guidance relating to supported decision making, and identified ABI as a particular issue that may require specialist support to assess, and that assessment of mental capacity needed to be based upon decision making “in action” rather than simply in words (NICE, 2018); what is sometimes referred to as the difference between decisional capacity and executive capacity.

Perhaps the most significant recent UK contribution regarding the assessment of people with an ABI was undertaken by a practicing Consultant Neuropsychologist and a Cognitive Neuroscience researcher (George and Gilbert, 2018). This paper
examined the conflict that could exist within neurorehabilitation settings when differing professional groups disagreed regarding an individual with an ABI’s decision making abilities; in particular the disagreements that developed between social workers and professional rehabilitation staff, most usually focussed upon the former assessing an individual’s abilities by what they stated they could do and the later by how they actually functioned. It was noted that these disputes could lead to unsafe discharge from rehabilitation when the brain injury specialist’s knowledge and views were countermanded by the social worker without such knowledge. This led to the under-supporting of individuals with an ABI who, in particular, lacked insight into their executive impairments. Very unusually the authors of this paper received 100+ unsolicited responses from professionals around England and Wales, all in agreement with the authors’ findings. An analysis of these unsolicited responses identified three key themes:

1. The issues raised in the article are very well-known by clinicians, researchers, and family members.

2. However, these issues are not well known by those carrying out capacity assessments, local authorities, or policymakers. This leads to continual conflict between individuals who understand the care needs of individuals with an ABI and those carrying out capacity assessments.

3. There is evidence that this has directly harmed individuals with an ABI.

Methods
Search Strategy: This literature review was not conducted as a comprehensive scoping review, rather as a more general review of the literature. As such, the authors did not undertake a systematic scoping review, the searches consisted of approaches to relevant authors working within the field of brain injury and safeguarding, reviewing the existing literature on safeguarding reviews to identify those that included individuals with ABI and identifying reviews mentioned within other safeguarding adults and serious case reviews.

Inclusion criteria: All SARs published within the UK since the ‘Tom’ case of 2016 that included individuals who had been either formally identified as having a brain injury within the review or had reference to medical history that would indicate the existence of a brain injury. All details from the included reviews are within the public domain but the authors have personal or professional interest in the cases of ‘Tom’ and ‘James’, hence they are reported in greater detail here than the others that were based purely on documented information within the SARs.

As noted above, Tom’s case is not unique but as there was much in the way of academic and local authority interest in the case at the time, the authors were specifically interested to identify any changes that had taken place during this time. Although the review was not published until 2016, the authors decided to look from 2014 to gain an understanding of any changes over time.

Review of SARs (Preston-Shoot et al, 2020)

A comprehensive review of safeguarding reviews was conducted by Preston-Shoot et al. (2020). While this review is extensive, it must be noted that the authors limited
the dates of the reviews to April 2017 to March 2019. Therefore, some of the cases reported in our paper were not included in this synthesis. We contacted the authors who informed us that of the 231 SARs in the review, only two named ABI specifically (SU and Graham). It must also be noted here that there may have been other cases within the sample that related to brain injury, but this was not noted or identified during the review process.

**Data Extraction:** Information from each SAR was extracted by one of the two authors and consisted of information pertaining to the subject of the review, the basic facts of the case, the role brain injury may have played in the case, the role of organisations surrounding the individual, with a particularly focus on social workers and any key point and recommendations made by the authors of the reviews.

**Data synthesis:** It was anticipated that the included reviews would vary greatly in terms of the issues arising and the types of injury identified. Therefore, a narrative synthesis approach was implemented (Arksey & O’Malley, 2005). The focus of the narrative synthesis was on understanding the experiences of the subjects of the review and their interactions with organisations around them with regard to assessment, service provision and safeguarding. This was performed with a view to producing a list of implications for practice for future services.

The process of synthesis followed the guidelines developed by Popay et al (2008) for narrative synthesis. Stage one involved extracting the data from each individual paper as outlined above. The reviewers highlighted sections of relevant text and any recommendations or guidelines for future practice. In stage two, the extractions
were summarised in a data extraction table. The data extraction table was adapted from the table of themes generated by Preston-Shoot et al. (2020) in their comprehensive review of safeguarding reviews using a framework approach to analysis (Smith & Firth. 2011) that specifically looked for examples of poor practice.

Stage three involved exploring the relationships between those reported elements to identify similarities in safeguarding oversights and errors in practice. This clustering of the data allowed the development of a narrative structure for the findings. The final stage of the narrative synthesis was to study the clusters of data to identify key themes across the studies using a process of thematic analysis (Braun & Clarke, 2006).

**Results**

Six SARs (including Tom’s) were identified for inclusion within this literature review. A basic overview of each case is given below.

**The case of ‘TOM’ (Flynn, 2016)**

In June 2014, a 43-year-old man from Somerset took his own life following a brain injury 20 years previously. Following his death ‘Tom’ became the subject of a Safeguarding Adults Review (SAR), a process that began in April 2015 and was published in June 2016. Tom had a range of physical, behavioural, emotional, and cognitive impairments, including executive impairments that manifested in a range of disabilities and difficulties in functioning independently. Tom also had issues with
substance misuse and reported ongoing mental health difficulties, particularly around depression. Despite Tom being known to adult social care and the mental health team at the local NHS trust, he was not offered substantial support for living with his brain injury or with the subsequent mental health problems he reported. In fact, he was deemed by mental health services to not be experiencing an organic mental health issue but was merely ‘responding to life events’ for which they were not responsible for providing support because he was ‘not suicidal’.

The report catalogued a range of failings and shortcomings of the care providers and professionals who were responsible for, and interacted with, Tom during his life. Overall, failings were categorised within three major sub-heading; communication and information sharing, assessment of mental capacity and safeguarding and risk management.

The case of ‘SU’

In 2018, the case of SU was published in London. SU was 61 when he died. SU was bedbound and immobile due to a series of strokes and epileptic seizures. SU had originally experienced a traumatic brain injury because of an assault in 1997. SU was a known smoker. SU was identified to have mild cognitive impairment, depression, a drug and alcohol dependency, severe pain for which he was self-medicating and taking prescription pain medication. Despite the evident fire risk this may pose, no detailed risk assessment was conducted. SU died in a house fire caused by a cigarette dropped on to his bedclothes.
The SAR identified that a mental capacity assessment and staff awareness of mental
capacity issues were lacking in this case. Wider safeguarding and risk assessment
protocols should also have been undertaken by those coordinating SU’s care.
Communication between teams was identified as a failing, with information not
being passed between and across teams within adult social care. The review
explicitly required the safeguarding board to review and redistribute the information
sharing protocol.

The case of ‘Graham’

In 2018, the case of Graham was published in Solihull. Graham was 54 years of age
when he died, having experience a stroke in 2016 that affected his speech and
mobility. Graham was given a personal budget and access to care staff three times a
day to support personal care. Graham died of a respiratory infection in February
2018. While the case of Graham is somewhat different to the other SARs presented
here, the recommendations for the report suggest some similarities that are worth
noting. For example, it was identified that service failed to take a ‘Whole Family’
approach to Graham’s case and that this way of working may have mitigated the
impact on Graham’s partner and her young children. Multi-agency working was also
identified as failing to provide a holistic picture of the care Graham needed. Finally,
the review identified that brain injury had not been appropriately considered when
mental wellbeing and capacity assessments had been undertaken.

The case of ‘Christopher’
In 2020, the case of Christopher was published in Brighton & Hove. Christopher was 39 years of age, had a brain injury, learning disability, a history of anxiety and substance misuse issue. He died because of heroin toxicity while living in temporary accommodation March 2017. Christopher was known and being supported by seven different local services. He was exploited by others around him, and this abuse was not fully appreciated by professionals working with him.

The review concluded that the professionals involved in Christopher’s care failed to appropriately assess mental capacity and did not question the underlying assumption that Christopher had capacity. It was also concluded that services failed to work together to provide holistic care for Christopher. It was specifically documented that there needed to be a lead practitioner who took primary responsibility for Christopher’s care and liaising between organisations. Finally, the review highlighted that the organisations involved in Christopher’s care seemed unwilling to consider services or options for care that would restrict Christopher’s liberty even though this would have potentially led to rehabilitation and changes for the better. The lack of these factors meant that Christopher was at risk of and suffered physical and sexual abuse at the hands of others and was himself a perpetrator of sexual abuse. This risk of abuse was not documented in safeguarding alerts and the review concluded that no safeguarding protocols were followed across agencies.

The case of ‘Jonathan’
In 2021, the case of Jonathan was published by Northamptonshire Safeguarding Adults Board. Jonathan was a 46-year-old man who died in December 2019 while living in a hotel. The cause of death was found to be coronary artery thrombosis and coronary atherosclerosis. Prior to his death, Jonathan had been admitted to hospital with meningitis and encephalitis and spent time in intensive care. He was in hospital from October 2019 to December 2019 where CT scans identified a series of historic strokes and traumatic brain injuries. There was no evidence that Jonathan had ever undergone a formal cognitive assessment. Jonathan’s housing status was not highlighted as a risk factor despite his experiences of street homelessness which had led to frequent visits to the emergency department. His homeless status and potential increased risks from his previous injuries were not acknowledged during discharge planning.

The review identified that Mental Capacity Act assessments were not undertaken due to assumptions that Jonathan was able to make informed decisions for himself, despite considerable evidence to the contrary. This meant that unsafe discharge from hospital repeatedly happened after each admission and housing did not view Jonathan as a priority for housing despite his very clear and poor functioning and the belief that Jonathan could make his own application for housing. The review noted a series of issues with a lack of planning, communication and coordination across the organisations supporting Jonathan with no multi-agency working. No safeguarding referrals were made by the hospitals he was admitted to, despite the 40 or more occasions he presented in 2019 alone. The review concluded that there was a lack of ‘professional curiosity’ demonstrated towards the clear functional difficulties
Jonathan had. Jonathan’s risk of assault and self-neglect were not considered to be safeguarding issues. Each part of Jonathan’s case was viewed in isolation rather than as part of a wider picture leading to Jonathan being wrongly assessed as not presenting with an acute mental illness despite his regular referrals and complaints of suicidal thoughts.

The case of ‘James’

James suffered a very significant brain haemorrhage in his early 30’s. Prior to his brain injury James had worked in the building industry, had purchased his own accommodation, ran his own company, had a partner, and travelled regularly, DJ’ing on the Balearic Islands. James had a lengthy history of recreational drug use, but this had seemingly not impacted upon his ability to succeed personally and professionally. James had limited contact with his family.

Evidence of poor practice

As noted previously, a more extensive national review of SARs was undertaken by Preston-Shoot et al (2020) and this review used the areas of poor practice to synthesise the SARs in this current review. The findings of the national synthesis identified many commonalities with the cases noted in the current review. Table 1 highlights the areas of poor practice across the four domains listed in the National review: direct work with individuals, interagency working, organisational behaviour, and safeguarding adults board governance. The SARs reported here show broadly similar themes to those in the original review.
While the information is table 1 presented with the brief outline of the cases above demonstrate the areas of poor practice in these cases, the authors have used the final case, the case of James in more detail to provide a more detailed illustration of how these areas of poor practice played out. The details of this case are taken from the Coroner’s court and have been included with the express permission of James’ immediate family.

INSERT TABLE 1 HERE

The case of ‘James’ (continued)

James’ brain injury was significant, he had:

- A relatively mild hemiplegia that affected his gait and reduced the use in one of his upper limbs.

- Assessment in neurorehabilitation identified a very significant language impairment, he was left functionally nearly illiterate, and he had great difficulties with expressive and receptive understanding of the spoken word.

- Memory for new information was very impaired, it is speculated here that this included prospective memory, remembering things that were in the future, such as upcoming appointments.

- He appeared to be very “dysexecutive”, his functioning showed poor idea generation, reasoning, planning, initiation of activity and the ability to learn and apply learning across time and settings.
• Whilst he was aware of his physical impairments and (sometimes) aware that
he was experiencing difficulties functioning with concrete tasks such as
shopping, cleaning, managing his money and protecting himself from violent
people, this awareness was most usually in the context of a discussion with
another party. James did not have insight into his condition and how it
affected him or led to the difficulties he was able to be supported to
recognise.

James reportedly did not understand why he was in a specialist neurorehabilitation
unit and concerns were expressed by clinical staff at the time of his discharge home
that he lacked capacity with a range of decisions including those relating to his
finances and his welfare and support needs.

In his own home the extent of his difficulties and the impact this had upon his
functioning and wellbeing was quickly apparent. James was unable to shop, to
launder his bed sheets soiled by his incontinence, could not manage his finances,
and he was observed to be hungry. His hot water and heating system broke, and he
was unable to arrange for this to be repaired for over a year. This was eventually
undertaken on his behalf. His property, which he initially did not recognise as his
own, was reported to fall into significant disrepair and to be unhygienic with piles of
vomit left on the floor. James did not respond to letters from health services
regarding the management of the ventriculoperitoneal shunt that was inserted
during neurosurgery at the time of his brain haemorrhage.
A very minor support work package (6 hours per week) was commissioned to support James however he was frequently rejecting of the support even though the aim of the intervention was identified by James and others as what he required help with. James was brought food by staff, but this was observed to be left to rot in bags, even though he was observably hungry when provided with meals.

Over time James fell in with a street community who used and abused his property and resources. A range of community safety and other services were involved in James’ life, all concerned that he was being stolen from, physically abused, and threatened by others who used his premises to cultivate and deal drugs from. James was regularly assaulted, and the property he owned was, after a significant number of events of anti-social and criminal behaviour, closed to him. James was forcibly moved into temporary hostel accommodation. James was able to note in conversation that he was frightened of others, but he had no ability to self-safeguard. Individuals that “cuckooed” James were imprisoned but others followed. Threats were written on his walls by the visitors he could not keep out.

Safeguarding investigations were launched but recommendations were not commensurate with his needs and abilities. Even though substance use was a very significant element of his presentation, there was little involvement from such services, his brain injury would have precluded him from using standard substance use services. There was no lead practitioner, no member of staff with any brain injury experience and no referrals were made for specialist services or intervention. Underpinning these failures was a belief that James “had capacity” to make unwise
decisions. This belief was never tested by a formal assessment of his mental capacity as this was assumed by staff who acknowledged that they had no training or experience of ABI but stated that this was not an issue as they had training in the Mental Capacity Act.

Records are peppered with phrases that give James greater agency and ability than was demonstrably the case in practice. He was adjudged to have “allowed” himself to be abused and cuckooed and to have made choices relating to his lifestyle, including the “choice” to let people into his property who regularly assaulted him. Some of the (very many) records state that James’ needs related to “mental health problems” rather than to his brain injury, some simply identify his physical impairment. Other records do note that he had an ABI but the impact of this on an impairment level (severe language, memory, and executive impairments in the context of not having insight into them) is not mentioned, nor mentioned is how these impairments are connected to his very poor functioning or decision making. The very stark difference between his pre- and post-ABI functioning is not considered, the reasons for the change in his life and habits lay unexamined.

One submission to the Coroner’s process (prior to the publication of the SAR) from an involved professional stated that James “held the keys to his future and had to take advantage of what was being offered to him.” There is no recognition in this statement that James was significantly impaired. He could not “take advantage” of what was offered. To do so he would need to be able to understand what he was being offered, retain this information, be able to weigh up and take a decision to use
what was offered, be able to initiate actions relating to the support offered, maintain focus upon completing such actions relating to the support offered and understand why such actions would be able to help him. James’ impairments to language, memory, and executive abilities, in the context of his lack of insight, absolutely precluded this. His drug use further clouded this picture but appears to be the only aspect visible to services. Evidence from a social worker acknowledged that she had no knowledge or training in ABI but felt this was irrelevant as she had significant training in the Mental Capacity Act. No assessments of Mental Capacity in relation to welfare or support decisions were ever undertaken.

**Themes**

From the literature that has been produced since 2014, as well as the content of the multiple SARs that have been published on individuals with brain injury, the authors drew out some key themes present among many such cases (Figure 1). These included; 1) Brain injury awareness and understanding, 2) Interdisciplinary/Multidisciplinary Team Working, 3) Mental Capacity, 4) Professional Curiosity.

**INSERT FIGURE 1 HERE**

**Theme 1: Brain Injury awareness and understanding**

The largest single factor in these cases was a lack of basic understanding of the impact of brain injury among professionals, particularly social workers, when undertaking assessments and care planning. It is vital that professionals are working within the limits of their professional knowledge. Where they do not possess appropriate knowledge, they should be provided with further training, or they
should seek expert advice. It is important to note here that brain injury knowledge is not currently a staple of social work training. This particular theme is important as it demonstrates that brain injury is not yet being considered appropriately in practice and is a finding that was not identified in the National review of SARs due to the lack of cases that were identified as pertaining to brain injuries.

**Sub-theme: Documentation**

In some of the cases, there seemed to be either a lack of documentation of historic brain injuries from medical records or inconsistent reporting. This meant not all assessments were undertaken with this important condition being factored in. This is a vital part of any assessment or care planning.

**Theme 2: Interdisciplinary/Multidisciplinary team working**

There was a distinct lack of interdisciplinary (IDT) working across organisations in health and social care, particularly hospital admissions, social workers, and housing departments. There was limited or no IDT/MDT working in the cases outlined here. There was also an inherent failure to nominate a named lead professional to coordinate management of the cases.

**Sub-theme: Information sharing**

Specifically, organisations repeatedly failed to share key information about service users and their potential risk. This meant that any assessment of risk, formal or informal, was not based on the whole picture, but rather on information available only through that one agency.
Sub-theme: Discharge planning

When discharge from hospital was planned, there was no joint assessment or information sharing to ensure the process was safe. While this only took place in two of the reviews, it is worth noting as it is a vital part of IDT/MDT working when dealing with service users with complex needs.

Sub-theme: Whole family working

Information sharing and risk assessments would have been vastly improved if agencies had included family members within an IDT/MDT structure. This would have provided greater insights into the service users and identified wider risks of which each individual agency may not have been aware.

Theme 3: Mental Capacity

Professionals showed a distinct lack of ‘legal literacy’ regarding the use of the Mental Capacity Act and mental capacity assessments. There was confusion over unwise decisions versus incapacitous decisions in many of the reviews. This theme links closely with brain injury knowledge and understanding (lack of), as professionals often failed to appreciate the functional impact of cognitive and executive impairments and the significance of issues pertaining to insight and the “frontal-lobe paradox”, the difference between ‘saying’ and ‘doing’. This is often associated with the brain injury related impairments that may significantly impact upon decision making and therefore influence mental capacity. While mental capacity was highlighted in the original review, how it pertains to brain injury was noted as a key
recommendation for practice in the SARs presented and is an important point to outline here.

**Sub-theme: Safeguarding**

Due to the lack of knowledge of ABI and lack of relevant training by social workers, safeguarding issues were not appropriately identified or acted upon. Within this sub-theme, the lack of IDT/MDT working played a role as there was no interagency safeguarding and a lack of reviewing of historic risk assessment that may have helped to mitigate the lack of understanding of how ABI impacts upon decision making and mental capacity. Additionally, the role of mental capacity was not considered in individual’s susceptibility to abuse, either by others or through self-neglect, a finding identified in a review of multiple SARs (Preston-Shoot, 2018). This is exacerbated by the existence of brain injury that was often not considered as a factor when deciding whether to make safeguarding referrals.

**Theme 4: Professional Curiosity**

Throughout the reviews, there are multiple times where professionals failed to ask the right questions to garner appropriate information about their clients, failed to identify possible risks, failed to get to know the person they were working with and failed to engage in any obvious form of reflective practice. This was specifically identified in two of the reviews, and was noted in a commentary to the second author’s 2016 paper on her brother’s own SAR (Morgan, 2017). This lack of professional curiosity meant that professionals did not take the time to question the impact of the service users’ brain injuries, or their own personal level of knowledge.
of such a condition. They also failed to consider the need for risk assessments and safeguarding. In the case of James, a lack of knowledge of ABI was specifically acknowledged by the social worker who deemed this irrelevant to the safety or quality of her practice. It is difficult to perceive any circumstance where it is acceptable for a professional to acknowledge an absolute absence of knowledge which is key and vital to their task but to fail to accept that this had any relevance.

**Sub-theme: Trauma-informed approach**

The reviews paint a picture of a series of interactions between the service users and professionals that consistently failed to consider their traumatic history, both in terms of brain injury but also other factors such as abuse, coercion, exploitation or adverse life events more generally. This led to a failure to recognise their complex needs. Failing to take a trauma informed approach meant that professionals often viewed the service users in terms of what was ‘wrong’ with them rather than what had happened to them (Johnstone & Boyle, 2018).

**Sub-theme: Deprivation of Liberties**

There is a sense within the reviews, although only occasionally explicitly noted, that professionals, particularly social workers, seemed reluctant to undertake an intervention which would be restrictive. This may be due to their training and a professional culture that highlights the importance of the autonomy of the service user’s choice as being paramount. However, in the instances reported within these reviews, this reluctance was misguided and led to wider risk and greater safeguarding issues that may have been prevented had restrictive measures been
put in place in the individuals’ best interests. Similarly, a lack of knowledge of ABI
and of how neurorehabilitation works and may improve a person’s functioning and
potentially increase their autonomy, means that social workers are unaware of how
an intervention perceived as more restrictive *initially* may lead to a far less
restrictive future option becoming possible at a later stage. At the time of writing the
implementation of the Liberty Protection Safeguards (which are due to replace the
Deprivation of Liberty Safeguards) has been delayed again. However, unless the
Approved Mental Capacity Professional who will be responsible for implementing
the new safeguards has specific knowledge and training regarding ABI, it is difficult
to see how the new system will be an improvement for people with an ABI.

**Sub-theme: Unconscious Bias**

On reading the case reviews, and through our personal involvement with two of the
cases, there are some striking similarities that are worth noting. All individuals had a
range of complex needs, including substance misuse as well as their brain injury,
physical impairments, and mental health issues. Within the review, several note the
presence of abuse or exploitation from others and/or evidence of self-neglect. Yet
these issues were not identified as being significant enough to require safeguarding
interventions. It is possible that these individuals were ‘problematised’ by the
organisations that were working with them, whereby their issues were seen as being
because of ‘lifestyle choices’ rather than of their inherent risk, related directly to
their functioning, consequent to their brain injury related impairments. This is not
an uncommon view of service users who have substance misuse issues, and these
reviews highlight the need for a culture shift within organisations that addresses these assumptions and biases.

**Discussion**

The findings from the SARs published since 2014 paint a dismal picture of the care currently provided to individuals living with brain injury within the community. The themes identified in this paper highlight that there is limited understanding from social work professionals about brain injury and its possible difficulties. This point has been recognised by a breadth of previous literature (Holloway, 2014; Holloway & Fyson, 2016; Holloway, Orr & Clark-Wilson, 2019; Holloway & Tasker, 2019; Holloway & Tyrell, 2018; Holloway & Tyrrell, 2016; Moore et al, 2019; Norman et al, 2020; Odumuyiwa et al, 2019). This lack of knowledge is further exacerbated by poor reporting of brain injuries in case notes that prevents social work teams from identifying brain injury as a key factor in assessments and care planning. A further difficulty has come from a lack of interdisciplinary or multi-agency working. Social workers do not work in silos but often form part of a comprehensive team of health and social care professionals that are working with and around an individual. To ensure appropriate care needs are met it is vital that such team-working and information sharing takes place. This is a factor that can potentially mitigate the difficulties associated with lack of knowledge by single professionals by working together to knowledge share (Moore et al, 2019; Norman et al, 2020).

This can be enhanced further by inclusion of family members where appropriate to provide information about pre-morbid functioning but also to address the difficulties
associated with cognitive impairments, particularly the executive impairments that may compromise development of insight (Holloway and Tasker, 2019; Moore et al, 2019; Norman 2016). ABI has long been recognised as a family condition by both social worker authors (Romano, 1974) and others (Lezak, 1978). The injury may occur to only one party, but the impact is felt across the family and across time and criticisms have been made of non-systemic work practices which fail to capture and respond to the reality of the lived experience of families (Yeates, 2007, Holloway et al 2019).

While Safeguarding and Mental Capacity Act training is a core part of social worker education and training, there is limited to no training for social workers in knowledge around brain injury or how to consider issues of executive impairment within a Mental Capacity Act assessment (House of Lords, 2014). It is only relatively recently that NICE guidelines on supported decision making, and the MCA have been produced and contain within some mention of executive impairment. The information provided within the guidelines regarding the impact of executive impairment is not extensive and certainly insufficient to provide comprehensive guidance to professionals without experience of the impact of the condition (NICE, 2018). While the guidelines highlight that some individuals with brain injury may lack insight into their own difficulties, there is limited information about how social workers should successfully address this within assessments. Assessments need to involve functional observations of behaviour and third-party evidence from family or others, rather than relying solely on self-report and/or office-based assessments (Moore et al, 2019; Cameron and Codling, 2020). Training tools do exist for social
workers within the UK (BISWG & BASW 2016, Copstick et al 2021), but access to these require social workers identifying that there is knowledge they do not have (Norman et al, 2020).

Finally, a lack of professional curiosity highlights that social workers seem reluctant to intervene in cases where they may be evidence of safeguarding concerns in those with brain injuries. The social work literature focuses very heavily on the rights of the individual to choose their own path in life. While this is an admirable goal for any professional, it can fail to take into consideration the nuances of working with individuals who may not have the inherent ability to adequately assess what is in their own best interests (Jenkinson and Chamberlain, 2019; Norman, 2016). Social workers may naturally shy away from restrictive interventions that can take autonomy away from an individual. However, this reticence may be underpinned by a lack of understanding of how such approaches to rehabilitation can, long-term, foster high levels of independence. Successful brain injury rehabilitation requires a structured, consistent, and person-centred approach (Lukersmith et al, 2016). In the early stages, rehabilitation teams must provide intensive and careful ‘scaffolding’ around an individual to ensure that they are able to function to the best of their ability while controlling for cognitive and executive impairments. The success of such a structured model, is dependent on rigorous consistency in the way the rehabilitation and care plan is administered day-to-day (Clark-Wilson et al, 2014). Over time, once this scaffolding has been put in place, clients can often be supported to develop and exercise greater autonomy and independence. Improvements in interdisciplinary team working would enable social workers to gain a better
understanding of these processes and the person-centred and autonomy promoting approach that underpins them. It would mean that they would be better able to assess the needs of service users and identify where structured community neurorehabilitation may be a positive option rather than viewing residential care as the only option, which may appear too restrictive.

**Implications for practice**

After evaluation of the existing literature and the various SARs since 2014, the authors propose a series of recommendations to improve SW practice when supporting service users with ABI in the future:

1. Specialist training is required for social workers to better understand the impact of brain injuries on service users and their families. This training must specifically address Mental Capacity Act assessments and the difficulties of lack of insight in service users with executive impairments.

2. All long-term health conditions that impact upon functioning and decision-making ability should be reported in service user case notes. This must be standard procedure. It is important that brain injury is viewed by all health and social care professionals as a long-term health condition and not a condition that is likely to change significantly over time without adequate, integrated and skilled support. While improvements in functioning after brain injury are common and usual, brain injuries are life-long conditions.

3. It is vital that information is shared across organisations and between professionals with different disciplinary backgrounds. Through the multi-
agency, interdisciplinary working, professionals can ensure that assessments
and care plans meet the needs of service users and their families. The
implications for practice identified here have the potential to apply to other
disciplines and agencies.

4. Communication across organisations and between professionals is also
important to ensure that all professionals working with an individual are in
possession of relevant information that pertains to care needs and risk.

5. Where appropriate, family members need to be included in the process of
assessments and care planning to ensure pre-morbidity is considered
alongside executive impairments that may influence insight.

6. Alongside specific training in the difficulties associated with brain injury,
social workers also require training in how to understand how to undertake
Mental Capacity Act assessments with those who have brain injuries. This
includes moving to functional assessment rather than self-report or office-
based approaches. It also includes a wider acceptance and understanding
that ‘unwise decisions’ (especially repeated ones) can be a sign of a person’s
lack of insight and inability to consider what is in their own best interests.
This may include choice of friends and acquaintances, choices of living
accommodation, substance misuse or evidence of self-neglect. This may also
involve greater consideration of approaches that may lead, initially at least,
to deprivation of liberties in the best interests of the incapacitous client.

7. Social work professionals need to take a more trauma-informed approach to
the care of individuals by asking questions about what has happened to them
in terms of abuse, coercion, exploitation, adverse life events and the nature
of their brain injury/injuries. It is important for social workers to reflect regularly on their client load, be prepared to ask difficult questions about the situations their clients have found themselves in and also what may lie beneath their behaviours. These reflections must also come along with consideration of the biases with which individuals may see the world. Better on the ground supervision to facilitate such reflective practice is a necessity.

**Conclusions**

Whilst Safeguarding Adults Reviews and deaths will undoubtedly garner more headlines and be more immediately impactful, the issues reported upon here in relation to lack of social worker knowledge of ABI will also impact upon less dramatic circumstances. The themes identified within these SARs are likely to play out in poor care provision for individuals with brain injury up and down the UK every day. This review has identified that:

- The knowledge of social workers surrounding ABI is poor due to a lack of pre-qualifying education and post qualifying training in the area.

- A lack of knowledge surrounding ABI leads to poor assessment and application of statutory duties within the social work role for these service users.

- Social work practice exacerbates the lack of information about and knowledge of brain injury, through poor lead professional and interdisciplinarity as outlined by the reviews in this paper, and the consistent failure to link with other professions who may have an improved knowledge
base. Lack of knowledge of ABI is not limited solely to SW as a profession, however.

- While social workers have training on the Mental Capacity Act, this is not sufficient to stand in place of having knowledge/training of the impact of ABI. Social work is ultimately concerned with functional outcomes relating to wellbeing (however defined or self-defined) and uses law and guidance to do so. Training and knowledge relating to the law cannot be conflated with (or stand in place of) knowledge about the underlying reasons why an individual may or may not be a client of social work.
- People with an ABI are therefore NOT safeguarded and cannot be so until these gaps in basic knowledge and inappropriate work practices are addressed.

The recommendations in this paper are vital to ensure that people with ABI are supported to participate in daily life and enabled to maximise their wellbeing, as enshrined in the principles of the Care Act and Mental Capacity Act. It is also important to note that by providing better care for service users, social workers can also reduce the foreseeable impact on family members who inevitably take on the lion share of care responsibilities. Currently, social work practice with regards to ABI is acting in contradiction with its own self view, code of practice and ethos. Rather than promoting human rights and wellbeing, it precisely performs the reverse function. The fault lines that cause this commence at the stage of pre-qualifying education where no training is provided to prepare social workers to work with a large population of service users. The national failure in the discourse means that
ABI remains the elephant in the room and is left unaddressed, despite the huge costs associated with it. Sadly, the SARs reported within this paper will not be the last. There are many service users in the UK who may ultimately become the next ‘Tom’; history will have to repeat, and lessons are unlikely to be learned without reform of pre and post-qualifying education and a commitment from the profession and its regulator to face and address gaps in knowledge and practice.
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<th>Themes of poor practice (Preston-Shoot et al, 2020)</th>
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<td><strong>Domain A: Direct work with individuals</strong></td>
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<td>Tom (2016)</td>
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No assessment of how Tom had changed since his injury was undertaken and no attempt made to engage with family.

There was no sense of planning for the future to support Tom with his mental health, substance use or housing-related difficulties.

**SU (2018)**

No detailed risk assessment was undertaken to highlight this fire risk smoking, drug use, depression and cognitive impairment was create.

No attempt was made to understand SU and his unique set of circumstances

An insufficient understanding of brain injury was identified within the social care team

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<tr>
<th><strong>No assessment of how Tom</strong></th>
<th><strong>Issues with poor organisational structures, policies, procedures and guidance were identified within the review across adult social care and the NHS trust</strong></th>
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<tr>
<td><strong>Tom had changed since</strong></td>
<td><strong>There was no sense of planning for the future to support Tom with his mental health, substance use or housing-related difficulties.</strong></td>
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<td><strong>his injury was</strong></td>
<td><strong>undertaken and no attempt made to engage with family.</strong></td>
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<th><strong>Poor case co-ordination and no safeguarding or risk assessments</strong></th>
<th><strong>Poor supervision was identified as a factor in this case</strong></th>
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<td><strong>A lack of leadership in this case</strong></td>
<td><strong>Supervisors did not provide appropriate oversight</strong></td>
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<td><strong>No MDT working</strong></td>
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<td><strong>Poor communication across teams</strong></td>
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<td><strong>Poor communication across adult social care</strong></td>
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<td><strong>Safeguarding protocols were not</strong></td>
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<th><strong>Review of the process of transferring cases between teams within Adult Social Care</strong></th>
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<td><strong>Improve and update guidance on information sharing protocols</strong></td>
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<td><strong>Safeguarding adults board to consider ‘team around the adult’ meetings to mitigate risk</strong></td>
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<td><strong>Need for a multi-agency fire risk strategy</strong></td>
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<td>Graham (2018)</td>
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<td><strong>Christopher (2020)</strong></td>
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<td>Christopher was the victim of financial and physical abuse that was not fully appreciated by social work teams, nor was his own risk as a perpetrator of sexual abuse. No assessment of mental capacity. No attempt was made to understand Christopher and his personal circumstances. An insufficient understanding of brain injury was identified within the social care team. There was no evidence of forward planning or consideration of how Christopher’s circumstances had changed over time.</td>
</tr>
<tr>
<td>The review specifically highlighted a lack of coordinated care. No one person took a leadership role in liaising between organisations. Limited evidence of MDT working. Information was not shared across or within organisations. There was a lack of detailed referrals within adult social care. Safeguarding protocols were not adhered to appropriately.</td>
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| James (2021) | James was the victim of very significant abuse, regularly and over a very sustained period of time. Some of his abusers were imprisoned, but his mental capacity was never assessed, and he was deemed to not meet the criteria for a safeguarding investigation. Assessments of need failed to acknowledge his very significant brain injury or link his brain injury to his functioning.
No attempt was made by organisations, particularly adult social care to understand the specific needs of James nor to seek specialist support and expertise to assist them.
Staff within organisations, particularly adult social care had insufficient | Poor case co-ordination and a delegation of responsibility to unqualified community support. Safeguarding referrals were not adequately followed up and were not informed by the reality of James’ functional abilities, ascribing him “choice” to be abused.
There was no named of leadership in the team that worked with him, no referrals to brain injury specialist services and poor communication across teams | Improvement of services for people with acquired brain injury
**Health and Social Care commissioners to consider how to develop and improve services for people with ABI to provide better direct long-term service delivery. This work to include how to develop substance misuse services to enable them to be more accessible and effective when working with people with ABI.**
Health and Social Care to provide a pathway to guidance for practitioners on mental capacity |
No assessment of how James had changed since his injury was undertaken. There was no sense of planning for the future to support James, despite his very clear and enduring difficulties.

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<th>Assessment with those with ABI.</th>
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<tr>
<td>Training for all staff on ABI and the impact on capacity</td>
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<td>Greater awareness training of ABI among staff</td>
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<td>Develop a briefing document based on the learning from this review regarding ABI and all agencies use this to develop a greater awareness of ABI and its relevance when making judgements about a person’s capacity.</td>
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<tr>
<td>Review the effectiveness of the lead professional role in engaging with other agencies to deliver care plans.</td>
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<td>Increase the knowledge and understanding of the SAR process across all agencies.</td>
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Figure 1: Thematic map of Themes from brain-injury-related SARs

338x190mm (96 x 96 DPI)