



PEARL

A preventable death? A family's perspective on an adult safeguarding review regarding an adult with traumatic brain injury

Norman, Alyson

Published in:

The Journal of Adult Protection

DOI:

[10.1108/JAP-08-2016-0017](https://doi.org/10.1108/JAP-08-2016-0017)

Publication date:

2016

Link:

[Link to publication in PEARL](#)

Citation for published version (APA):

Norman, A. (2016). A preventable death? A family's perspective on an adult safeguarding review regarding an adult with traumatic brain injury. *The Journal of Adult Protection*, 18(6), 341-352. <https://doi.org/10.1108/JAP-08-2016-0017>

All content in PEARL is protected by copyright law. Author manuscripts are made available in accordance with publisher policies. Wherever possible please cite the published version using the details provided on the item record or document. In the absence of an open licence (e.g. Creative Commons), permissions for further reuse of content should be sought from the publisher or author.



A Preventable Death? A family's perspective on an adult safeguarding review regarding an adult with Traumatic Brain Injury

Journal:	<i>The Journal of Adult Protection</i>
Manuscript ID	JAP-08-2016-0017.R2
Manuscript Type:	Case Study
Keywords:	Safeguarding, brain injury, mental capacity, social work, advocacy, Mental health

SCHOLARONE™
Manuscripts

1
2
3 **A Preventable Death? A family's perspective on an adult safeguarding review regarding an**
4
5 **adult with Traumatic Brain Injury**
6
7

8 **Abstract**
9

10
11 **Purpose of this paper:** To review the care management of a man with a Traumatic Brain
12
13 Injury (TBI) from a family member's perspective.
14

15
16 **Approach:** The paper provides a case history of "Tom" both prior to his TBI and after.
17

18
19 **Findings:** Tom was the subject of an adult safeguarding review in Somerset following his
20
21 death in 2014. Ultimately the paper highlights the shortcomings and failures in the care Tom
22
23 received by various organisations which ultimately contributed to his suicide.
24

25
26 **Practical implications:** The paper highlights the need for more effective communication
27
28 between professionals managing the care of those with TBI. Furthermore, professionals
29
30 need training in the need for mental capacity assessments and improved safeguarding and
31
32 risk assessments with adults with TBI.
33
34

35
36 **What is new in this paper:** This paper provides insight into the needs of an adult with TBI
37
38 from the perspective of a family member who is also a trained psychologist.
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60

Introduction

In December 1993 my older brother “Tom” had a serious road traffic accident. This accident led him to suffer a significant traumatic brain injury (TBI) which changed his and our lives forever. Tom took his own life in June 2014. This paper will discuss Tom’s life, the impact of his head injury and provide insight into the shortcomings and failures in the care he received post-injury.

Tom prior to TBI

Tom was 10 years older than me so I didn’t really know him as a child. He moved out when I was six and had his accident when I was 12. My main memories of him are from when he was about 16 onwards. I idealised him as most little sisters idealise their big brothers. Even then he was a troubled young man with mental health difficulties, namely depression, but all I saw was a boy who loved his little sister who always wanted to spend time with her.

Tom had a different father, and the separation between our mother and his father was acrimonious. His Dad rejected him and to a certain extent, so did our Mother, leaving him feeling isolated and unloved. At secondary school Tom made lots of new friends who took away some of that sense of rejection, but they were not real friends. He was a poor working class boy in a public school environment and they used him. Before long he was getting into trouble and was ultimately expelled from school. He went on to be expelled again and then once at his third school, gave up attending.

Tom loved motorbikes and was always getting into trouble for riding too fast, or too dangerously. He was often in trouble with the police for traffic offences or other crimes involving drugs or petty theft. He was eventually assigned a social worker as result of these

1
2
3 activities. What he needed was love and affection and someone to listen to him, but that
4
5 didn't happen and as a result he was set on a path of self-destruction.
6
7

8
9 Tom's upbringing meant that he often seemed depressed, although he had no formal
10
11 diagnosis. He also struggled to manage his emotions and would often become frustrated
12
13 and agitated. Tom also experienced a series of small, yet potentially significant, head
14
15 injuries throughout his childhood that may have contributed to his risk taking behaviour,
16
17 depression and difficulties with emotional regulation. At the age of four, Tom was hit by a
18
19 car, and although it was at low speed and the injuries were mild, Tom did hit his head and
20
21 experienced a concussion injury. Then again at the age of eight, Tom fell off his bike after
22
23 riding it too fast down a hill. This resulted in him being hospitalised overnight for concussion
24
25 injuries. He then went on to have a further accident with a cricket ball early on in secondary
26
27 school. The significance of these multiple head injuries was missed by the clinical teams at
28
29 the time, and nobody made the potential connection between these injuries, his emotional
30
31 dysregulation, depression, and his increasingly risky behaviour (Sariaslan et al, 2016). Tom
32
33 needed intervention at this point, and this really should have been in the form of a child
34
35 psychologist who may have been able to identify the underlying issues for Tom and provide
36
37 him with greater support. It may also have proven useful to us as a family by providing us
38
39 with a greater understanding of Tom's behaviour.
40
41
42
43
44
45

46 47 **Tom's Accident**

48
49 On the afternoon of the 22nd December 1993, Mum and I were in town doing some last
50
51 minute Christmas shopping and we bumped into Tom. We had not seen him for a while and
52
53 he seemed different; positive and full of life. He had a girlfriend; they were happy and in
54
55 love. He told us about a new job he had and how much he enjoyed it; he was very much
56
57
58
59
60

1
2
3 looking forward to finally turning over a new leaf. I was excited and felt I might finally get
4
5 my brother back, be able to spend more time with him and get to know him properly. Little
6
7 did I know at the time that I was right but in a way I couldn't possibly imagine.
8
9

10
11 Later that afternoon Tom got in a car. I never saw that man again. That evening the police
12
13 informed my Mother that Tom had been involved in a serious accident and was in hospital.
14
15 They did not know what the prognosis was, but it did not look good. At that time our family
16
17 were all distraught. We just wanted Tom to wake from his coma and be with us again. In
18
19 many ways our grieving process for Tom started that day over 20 years ago.
20
21

22
23 Looking back I don't remember much about those early weeks and months. I don't know if
24
25 that's because of time or if I have deliberately forgotten much of it. I know it was painful
26
27 and I felt way too young to be able to cope with what was happening to us. I remember the
28
29 main focus though. Firstly we were thinking in terms of whether he would live or die. Soon it
30
31 became clear he would live, so the focus shifted to whether he would wake from his coma.
32
33 Once he was awake, the focus shifted again to whether he would ever walk or talk again,
34
35 and what kind of life he might have. Overall we were just so pleased to have him back with
36
37 us. Unfortunately as the years progressed it became increasingly apparent that it would
38
39 have been kinder to everyone concerned, including Tom, if he had died in that accident.
40
41
42
43
44

45
46 Each stage of Tom's recovery was exhausting and terrifying but filled with such sense of
47
48 hope. I can honestly say that once he started to show small signs of recovery, we really
49
50 started to believe everything was going to be alright. None of us had any idea of what was
51
52 ahead of us. This is a story that you will hear time and time again from family members of
53
54 those with brain injuries because there is simply not enough information and support in
55
56 those early months.
57
58
59
60

1
2
3 I do remember a couple of visits to the hospital. One was early on when Tom was still in a
4
5 coma. The other was going to visit him once he had regained consciousness. He was fairly
6
7 alert but couldn't walk or talk. At that stage he couldn't feed himself because his jaw was
8
9 wired and he had hemiplegia on his dominant right side. I remember I was asked if I wanted
10
11 to feed him. I cannot describe what a difficult experience that was; a 13 year old girl feeding
12
13 her 23 year old brother. He sat there in silence just staring at me and I wasn't sure he knew
14
15 who I was. Overall I was very impressed with the care Tom received from the hospital in
16
17 those early days. Sadly, leaving hospital and intensive rehabilitation behind marked a drastic
18
19 decline in the care and support Tom received.
20
21
22
23

24 25 **Tom post TBI**

26
27
28 Tom left hospital in the spring of 1994 and shortly after got married to his girlfriend. This
29
30 was when the reality of our situation really started to hit. Within a few months, Tom's wife
31
32 had walked out on him and we were left to pick up the pieces. This was obviously a
33
34 devastating emotional blow for him but was compounded by a complete lack of support
35
36 from any organisation. Tom could just about cook for himself but was not really able to
37
38 function properly. However, he never received any support and it was up to us to try and
39
40 guide him to keep the place clean and to look after himself. This was a difficult task as he
41
42 had no sense of smell or appetite due to neurological damage, so often did not eat properly.
43
44 He also had obsessive tendencies, mainly around collecting items. This meant that he would
45
46 pick objects up from his walks and keep them, or refuse to throw useless items away. He
47
48 was also prone to emotional outbursts, and was fiercely independent. This meant trying to
49
50 tidy his house, or remove any of his newly acquired possessions (e.g. unpaired shoes or lost
51
52 cuddly toys) had to be handled very carefully. For example on one occasion he returned
53
54
55
56
57
58
59
60

1
2
3 from town with a single black stiletto. When I suggested it should be thrown away as it
4 served no useful purpose, he became agitated and said to me "I have no purpose but you
5 aren't throwing me away". The shoe eventually became glued to his wall above the door in
6 his lounge.
7
8
9
10

11
12
13 Tom obviously had a history of drug abuse prior to the accident but in that first year post
14 injury he had remained clean and was proud of that for a short time. But it didn't last and he
15 soon sought out support from a small number of his old friends, the few who were still
16 prepared to see him, and this inevitably led to a gradual creep back into drug use. Initially
17 only cannabis and alcohol but this slowly led to opium and ultimately heroin.
18
19
20
21
22
23
24

25
26 I had wanted desperately before the accident to know my brother better and instead he
27 was taken away and I was presented with a complete stranger who I was now partially
28 responsible for at the age of 13. As Tom's friends had mostly abandoned him, he started to
29 go out with me and my friends as a way of getting some social contact. This was hard for me
30 as I loved him so much but he was often very embarrassing as he would be inappropriate
31 with my female friends as he hadn't relearnt his social filters yet. For example one evening
32 when we were out, Tom grabbed the bottom of one of my close friends. She turned around
33 and politely asked him to let go, but was clearly agitated. Tom's response was "well you
34 smiled at me, you clearly want sex". My friend was only 15 and Tom was 25. He would also
35 get angry and aggressive if people didn't understand him when he spoke, or if they
36 inadvertently made him feel weak and inferior. For example, on occasion a male friend of
37 mine held a door open for him into a pub. Tom responded by shouting "I'm not a f***ing
38 invalid". This would lead to disagreements with my friends and a feeling in me of torn
39 loyalty. Nobody understood these behaviours and it was really only intuition on my part that
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60

1
2
3 I understood this was a result of the injury to his brain and not him. Nobody ever discussed
4
5 the problems we may have along these lines and certainly offered us no support in
6
7 managing it. He hated being in a wheelchair and would really get angry about it. So he
8
9 started training himself to walk further and further each day. For months I would leave
10
11 school, walk to his flat and walk with him back and forth until he was able to navigate the
12
13 journey to the local newsagents.
14
15

16
17
18 Tom's accident changed him in several profound ways. Although he had always been quite
19
20 headstrong, he had never been unusually angry or aggressive. But after the accident this
21
22 was a central part of his character. He was volatile; one minute he would be happy and
23
24 joking and the next angry or deeply depressed. He had severe memory problems but this
25
26 was often hidden behind an ability to remember very specific detailed accounts from
27
28 aspects of his life pre-injury. This often gave others the perception that his injuries were not
29
30 that severe. For example one of his crowning achievements was being able to regularly
31
32 complete the mathematical challenges on the TV show countdown. He even boasted of the
33
34 numerous times he had managed to get the answer within the time even when Carol
35
36 Vorderman could not. Yet he would regularly forget important tasks, like attending
37
38 appointments and conversations he had had with people. He also struggled with attention
39
40 and was easily fatigued. His speed of comprehension was particularly affected, especially if
41
42 he was in a group of people. He would struggle to follow a conversation and it would take
43
44 him some time to catch up afterwards. This led him to become very quiet in group
45
46 situations and only later would he announce that he had not understood what was said, or
47
48 more often, he would seize on a fairly innocuous comment and view this as evidence that
49
50 people were "out to get him" and fail to process any other parts of a conversation. For
51
52
53
54
55
56
57
58
59
60

1
2
3 example, on one occasion a meeting was held between the family and Headway Somerset
4
5 to try and see what could be done to support Tom further. At the meeting the then
6
7 Manager of Headway made several suggestions for supporting Tom and was obviously
8
9 genuinely concerned. However, Tom's take home message from the meeting was that "she
10
11 wants to lock me up". This was in reference to a comment she had made about how he may
12
13 end up in prison if his drug taking did not get under control. Again this was often missed
14
15 because he had maintained his intellect and seemed quite capable of expressing himself.
16
17 These symptoms of TBI are often described by those who are familiar with them as hidden
18
19 disabilities, and Tom did have many. But he also had very obvious physical disabilities too.
20
21 Sadly at times I feel his movement problems and his shaking were put down to his drug
22
23 taking rather than symptoms of his neurological damage.
24
25
26
27
28
29

30 During the time between 1997 and 2004 Tom found something to give his life some
31
32 meaning. Tom started to attend a day centre and soon became very keen on woodwork. He
33
34 spent a long time learning this new found skill, making lots of interesting and bizarre gifts
35
36 for his friends and family. The day centre was also the place where he first met his long-
37
38 term girlfriend.
39
40
41

42 For the next few years, things ticked over fairly normally in Tom's life and ours. Tom's new
43
44 girlfriend was great for him. She gave his life purpose and meaning and for once something
45
46 to live for. They had their many ups and downs but their companionship was unyielding.
47
48 Further to that, Tom's relationship with her also led him to come in contact with the newly
49
50 formed Headway Somerset. Headway too gave Tom's life some purpose, and was
51
52 particularly important given the financial cuts at the day centre he had been attending. The
53
54 team at Headway did everything they could to help Tom improve his life and were an
55
56
57
58
59
60

1
2
3 important source of support for me too. By this time I had formally taken on the role of
4
5 Tom's advocate, so it was my job to speak for him where necessary and to generally support
6
7 him. This was not for a specific purpose, but as a general advocate to assist him in
8
9 appointments and general interactions with professionals.
10
11

12
13 Although I say this was a fairly stable point, the years were still punctuated by many regular
14
15 "crises". There were drugs overdoses (deliberate or otherwise) and passing out or falling
16
17 over as a result of his substance abuse, which often landed him in hospital. He would fall out
18
19 with his girlfriend or his girlfriend's family, or be threatened with eviction because he
20
21 couldn't keep his flat clean and tidy. Towards the end of 2004 it became evident to me that
22
23 Tom was not doing well. I remember turning up at his flat one evening and he was sitting in
24
25 his chair smoking a cigarette and I recall thinking he looked like an AIDS patient - thin, drawn
26
27 and grey and I knew he needed help. His neurological recovery was going reasonably well
28
29 but he had become very depressed and introverted.
30
31
32
33
34

35 **Service responses to Tom's care**

36
37
38 In the early years following Tom's accident, he presented on numerous occasions to the
39
40 emergency department with falls as a result of his drinking. His TBI had left him with severe
41
42 epilepsy and alcohol did not agree with him or his medication. We never received any
43
44 contact from the hospital during this time informing us of these injuries, so he was always
45
46 considered by the medical staff to not require any additional support. Even once I became
47
48 Tom's advocate I received no contact from them. He was also meant to have a social worker
49
50 but we didn't really know much about this after his initial post-hospital accommodation had
51
52 been sorted. We felt utterly alone as a family. We had no support from anyone.
53
54
55
56
57
58
59
60

1
2
3 Tom's declining mental health led to an assessment and appointment with the local hospital
4
5 mental health services in 2005. In the initial session the psychologist discussed with Tom the
6
7 principles of cognitive behavioural therapy and trying to map emotions, thoughts and
8
9 behaviours. We spent some time over the next two weeks trying to piece together Tom's
10
11 triggers. When we went back for the next session it became apparent that it had all been a
12
13 waste of time. She told us that unless Tom was prepared to give up drinking and drugs she
14
15 would be unable to provide any clinical intervention. She referred him to Turning Point and
16
17 said that she would see him again once he was drug free. Whilst he was willing to try to stop
18
19 his drink and drug taking, he was unable to engage with Turning Point. Tom had memory
20
21 difficulties so often failed to turn up for appointments and struggled to comply with
22
23 treatment due to the nature of his cognitive impairments and mental health issues. He self-
24
25 medicated because of the intense thoughts and emotions he experienced and without
26
27 someone helping him to manage those he was never going to be able to stop the drugs. In
28
29 my view this was a major failing in Tom's care. We were let down by the NHS and we
30
31 received no support from social services in fighting his corner. It is my opinion that Turning
32
33 Point was simply not capable of supporting a man with dual diagnoses and TBI. A specialist
34
35 treatment service was required that took all of these factors into account (Walker et al,
36
37 2007).
38
39
40
41
42
43
44

45
46 By 2012, Tom's periods of abstinence were becoming few and far between. He was in agony.
47
48 Tom spent most of his life living in torment psychologically. And in these later years, due to
49
50 his increasing physical frailty and intense pain in his hip due to osteoarthritis, he was also
51
52 physically tormented. Tom had always experienced pain as a result of his TBI, something
53
54 that although highlighted in literature (Nampiaparampil, 2008) was never addressed by
55
56
57
58
59
60

1
2
3 health professionals. Additionally, his increasingly low mood seemed to heighten his
4
5 perception of pain (Hoffman et al, 2007). The combination of this chronic pain with the
6
7 increasing pain from his hip was unbearable for him. His GP was prescribing pain medication
8
9 but between the very real pain he was experiencing and his high tolerance due to his heroin
10
11 use, he was eating them like smarties and they were offering very little in the way of pain
12
13 relief. It was clear he needed an operation.
14
15

16
17
18 Until this point social services had done very little to support Tom. Since 2011, Headway
19
20 Somerset had become increasingly concerned about the situation. They informed me that
21
22 on numerous occasions they had requested the appointment of a social worker for Tom and
23
24 to arrange a case review to look at how he and his girlfriend were living. It took them nearly
25
26 a year to even assign someone to his case and even then no direct contact was made.
27
28

29
30 In early July 2013, Tom was admitted to hospital for his hip replacement surgery but
31
32 presented drunk. The operation was cancelled and he was sent away being told he would
33
34 need to be clean before he would be allowed back on the waiting list. No time frame was
35
36 given to him about how long his abstinence would need to last, or what benchmark he
37
38 needed to reach in order to meet the definition of "clean", and none of this was ever
39
40 articulated to me, his advocate. I wasn't even informed he had been discharged without the
41
42 surgery. I spoke at length to Tom's GP to try and come up with a course of action, but
43
44 ultimately we were stuck. He couldn't stop as he was in so much pain and without the
45
46 operation that wasn't going to change. But without stopping he wasn't going to get the
47
48 operation. And in the middle of all of this it was decided that Tom was a fully functioning
49
50 adult who made his own choices so it was his choice all this was happening and the NHS
51
52 weren't prepared to do anything to help. I made it clear to Tom's GP that the only way he
53
54
55
56
57
58
59
60

1
2
3 would get clean was to go into rehabilitation and then straight from there to hospital for the
4
5 operation. But he apparently wasn't entitled to that support. Social services refused to
6
7 provide support for a referral and eventually Tom was referred back to Turning Point for
8
9 monitoring.
10

11
12
13 In October 2013, Tom was serviced notice of eviction from his girlfriend's house for bringing
14
15 drug dealers to her home and allowing them to extort money from her. Social services again
16
17 offered little support. They did not raise any safeguarding alerts regarding the relationship
18
19 between Tom and his girlfriend and they did not provide any support in helping Tom to find
20
21 alternative accommodation.
22
23
24

25
26 Just before his eviction, Tom told me he wanted to hang himself but was fearful he didn't
27
28 have the physical strength to do it, and might leave himself alive but more severely disabled.
29
30 It was at the end of that week that he had a breakdown whilst drunk and presented at the
31
32 hospital asking to be sectioned. That Sunday the crisis team came to his home to do an
33
34 assessment and he was told he wasn't eligible for treatment because he was simply
35
36 "responding to life events not mentally ill". Given the vast literature surrounding the link
37
38 between TBI and mental health conditions (Bessell et al, 2008; Bombardier et al, 2010;
39
40 Koponen et al, 2002), the poorer prognosis when associated with substance abuse (Graham
41
42 & Cardon, 2008) and the increased rate of suicidal ideation and suicide risk (Bahraini, et al.
43
44 2013; Felde et al, 2006; Mackelprang et al, 2014), it seemed quite unbelievable to me that
45
46 this was the response.
47
48
49
50

51
52 Tom was eventually evicted from his girlfriend's home in early December 2013. He had to
53
54 present himself to the housing office as homeless and as there was no intervention from
55
56 social services, he was treated as though he was not a vulnerable adult. During this initial
57
58
59
60

1
2
3 period, Tom stayed in a few hotels and B&Bs and ultimately with our mother because he
4
5 kept getting evicted either due to his physical health problems (his seizures meant he was a
6
7 high risk case) or his drug taking behaviour. He was forced to stay with our mother because
8
9 no more support was available for him because he had made himself “intentionally
10
11 homeless” through his actions. There seemed to be little appreciation of Tom’s TBI or his
12
13 mental health problems. It seemed to me that most of the time the professionals he
14
15 interacted with simply saw an addict and that coloured their view of him to the extent that
16
17 they were unwilling to provide him with the support he so desperately needed. Tom
18
19 eventually ended up at a homeless shelter, adding to the already high rates of homeless
20
21 people who have experienced TBIs prior to homelessness (Bousman et al, 2010; Hwang et al,
22
23 2008; Oddy et al, 2012). At this stage I was still fighting for support for Tom and most
24
25 importantly some form of Mental Capacity Assessment as it was my firm belief that he was
26
27 no longer able to make informed decisions for himself. There was also a real issue around
28
29 safeguarding as he was a vulnerable adult who had now been placed in a dangerous
30
31 environment surrounded by people who could manipulate and abuse him.
32
33
34
35
36
37
38

39 **Tom’s final months**

40
41
42 During the final 6 months of his life, Tom was constantly reporting to us incidents of people
43
44 stealing his money or phones. There had been a time when we didn’t go more than 48 hours
45
46 without exchanging texts but during these final months I got used to not hearing from him
47
48 for days, sometimes weeks at a time. This was usually because his phone had been stolen
49
50 and he would then have to get a replacement number. It would be ages until I would find
51
52 out what had happened and make sure he had my number again. During this time his drug
53
54 and alcohol addictions spiralled even further out of control. After months at the homeless
55
56
57
58
59
60

1
2
3 shelter Tom was found local authority housing in a bedsit in the middle of the worst estate
4
5 in the town. He was yet again surrounded by drug dealers and people who would take
6
7 advantage of him.
8
9

10 On the 18th June 2014 I saw my brother for the last time. He was in his wheelchair in our
11
12 local town. He told me that money had gone missing from his flat and that his card had also
13
14 gone. He had given the person responsible his pin number sometime previously to withdraw
15
16 some cash for him and now that person had cleared out his account. So he had gone into
17
18 town to ask the bank for an overdraft as it was 10 more days until he received another
19
20 benefit payment and he had nothing to live on. I don't know what happened to him in those
21
22 last 12 days before he died. I heard nothing from him despite my many attempts.
23
24
25
26
27

28 On the afternoon of the 30th June, my mother, as frantic as I about the situation, emailed
29
30 adult social care yet again pleading for help. She impressed upon them yet again how
31
32 unstable he was and how she feared he would end up dead in a ditch somewhere. Little did
33
34 either of us know that at that point in time that he was in fact already dead. At around 5pm
35
36 that afternoon, a policeman arrived to tell us my brother was dead. Tom tied ropes to his
37
38 wheelchair and used them to hang himself; a modification to the way he had told me nine
39
40 months previously he wanted to end his life. So it shouldn't have been a shock. But it was.
41
42 Not least that he had chosen such a brutal way to end things.
43
44
45
46
47

48 At the end of that week we had to go and pick up what few meagre possessions Tom had
49
50 left. Going to his flat was so painful. The place was a tip, with stuff piled up on the bed so
51
52 nobody could possibly have been sleeping in it. Yet more stuff was piled up in the shower
53
54 cubicle, so it was evident he hadn't washed for at least as long as he had been in that flat,
55
56 which was about two months. And there were used needles everywhere. The worst thing
57
58
59
60

1
2
3 though was that his wheelchair was still inside the front door, presumably where it had
4
5 been left when he died. It was such a surreal feeling seeing this object that I was so used to
6
7 being part of him and now viewing it as the device that ended his life.
8
9

10
11 A few weeks after Tom's death my mother and I went to a meeting at social services. This
12
13 had originally been a safeguarding meeting, but in light of the events it was to review what
14
15 had happened. Nobody expected us to turn up. I was horrified during this meeting that
16
17 social services turned to us as a family and stated that they had been shocked by the turn of
18
19 events as they had no idea this would happen. I think this was the final insult after years of
20
21 indifference to Tom's situation. It was beyond me how anyone could suggest they didn't see
22
23 it coming given the number of phone calls, emails and meetings where we had clearly stated
24
25 that this was exactly what would happen.
26
27
28

29
30 After Tom's death, an adult safeguarding review was opened. The report catalogued the
31
32 various failings and shortcomings of the care providers and professionals who were
33
34 responsible for, and interacted with, Tom during his life. Whilst the report findings are
35
36 important, I have taken the opportunity here to outline some of the worst failings from my
37
38 perspective as a family member rather than directly reporting the outcomes of the review.
39
40 However, following this I have then outlined the recommendations of the adult
41
42 safeguarding review along with my own personal recommendations for future practice.
43
44
45
46
47

48 **Communication and Information sharing**

49

50
51 Since Tom's TBI, I have been endlessly horrified by the lack of information that is shared
52
53 between organisations responsible for his care. Whilst social services often did not have
54
55 direct involvement with him, as a vulnerable adult he did fall under their service. Yet
56
57
58
59
60

1
2
3 information from organisations such as the NHS regarding Tom's health, drug use and
4
5 mental health difficulties rarely seemed to be flagged to them.
6
7

8
9 Furthermore, we as a family were never informed of any incidents where he presented at
10
11 hospital. Even after I became his advocate, I was never given this information and was never
12
13 included in conversations surrounding his care. When I first got to see the findings of the
14
15 safeguarding review, at points it felt like I was reading about a person I did not know.
16

17
18 Behind the scenes there had been multiple appointments with various people within the
19
20 NHS and I had not been present and was in fact completely unaware of what had taken
21
22 place.
23
24

25
26 Some may wonder why the family of a fully grown man should have such involvement in his
27
28 day to day care. But the reality of brain injury is that individuals rarely have good insight into
29
30 their own condition and limitations (Prigitano, 1996). This makes them vulnerable as they
31
32 will often refuse treatments that they need, neglect their own personal care, and it leaves
33
34 them open to abuse. As such it is important that family members are kept involved in
35
36 ongoing conversations about daily care. For example, in 2012, Tom broke his shoulder after
37
38 falling off his bicycle. I was unaware of this until I found reference to it in the safeguarding
39
40 review. He should have had his arm in a sling for several weeks whilst it healed, but I didn't
41
42 once see him wearing it and neither did my mother. Hence we were unaware of the injury,
43
44 unable to support his recovery from it, and unable to prevent further injury by helping him
45
46 to understand why he had been advised to stop riding his bike.
47
48
49
50

51
52 As well as difficulties with insight, Tom also had problems with his memory. This meant that
53
54 he would regularly miss appointments with his doctor or other health professionals.
55

56
57 Without knowing that these appointments were taking place, there was no way for us to
58
59
60

1
2
3 ensure he attended. Instead, he wouldn't present at the right time and then be viewed as
4
5 having dropped out of treatment and be discharged.
6
7

8
9 Another failing in Tom's care was a lack of multidisciplinary team working. Tom had a
10
11 moderate TBI and was a substance user. He was also displaying signs of mental illness.
12
13 Although, he was assessed by the community mental health team as not having a mental
14
15 health condition, anyone who knew him will tell you this was a falsehood. During this period
16
17 each organisation and discrete service wanted to address one issue at a time. Therefore, he
18
19 was being asked to attend Turning point for his substance abuse, but he couldn't fully
20
21 engage in this because he needed psychological support as his addictions were so closely
22
23 tied up with his mental health problems; he was self-medicating to numb the physical and
24
25 psychological pain he was experiencing. But he couldn't get psychological support either
26
27 because he couldn't engage in those services until he was "clean", or because he was
28
29 viewed as not being mentally ill or suicidal. This was despite having told anyone who would
30
31 listen that he wanted to end his life. In my opinion, the reason his mental health problems
32
33 were missed was because his difficulties and behaviour were wrongly attributed to his
34
35 substance abuse, and that he was never assessed in the presence of an advocate who could
36
37 speak for him where necessary. His lack of insight into his own condition meant that he
38
39 would not necessarily have answered honestly during assessment. As highlighted in the
40
41 literature, individuals like Tom need multidisciplinary team working, a tailored treatment
42
43 approach and this needs to be guided by an experienced neuropsychologist who can allow
44
45 and plan for the unique difficulties associated with TBI with regard to lack of insight and
46
47 poor compliance with treatment (Holloway, 2014; Holloway & Fyson, 2015).
48
49
50
51
52
53
54
55
56
57
58
59
60

1
2
3 The difficulties in managing the interactions with these various services supporting Tom can
4
5 be summed up as being a categorical failure to appreciate the biopsychosocial model of
6
7 health (Engel, 1980). This model highlights how biological and psychological factors can
8
9 combine with environmental factors to influence individual's health. In Tom's case, the
10
11 neurological damage caused by his TBI, alongside his mental health issues, substance abuse
12
13 and social deprivation both prior to, and after, his injury led to a distinct vulnerability. At no
14
15 point was this identified by the organisations working with him. Instead each "difficulty"
16
17 Tom was experiencing was viewed in isolation, meaning that the organisations involved
18
19 often missed the bigger picture.
20
21
22
23

24
25 Finally, when providing any kind of long-term care for those with brain injuries, it is
26
27 imperative that organisations involve the family in trying to understand how much of the
28
29 exhibited behaviour is related to neurological damage. At no point following Tom's initial
30
31 discharge from hospital were we asked to provide any information about what Tom had
32
33 been like prior to the accident or highlight anything important that might guide his care.
34
35 Therefore, social services in particular had no benchmark by which to understand his needs
36
37 and behaviour and often dismissed his unusual appearance and behaviour as being
38
39 "eccentric" or "anti-establishment"¹ rather than being a symptom of his TBI. Furthermore,
40
41 as was highlighted in the safeguarding review, Tom had previously experienced three minor
42
43 head injuries as a child. The literature highlights that even mild TBI can be associated
44
45 substance abuse, mental health issues and criminality (Sariaslan et al, 2016; Williams et al,
46
47 2010), all of which Tom was experiencing pre-injury. This is significant as it suggests he may
48
49 already have experienced TBI-related complications and then received a significant head
50
51 injury which may have affected his post-injury prognosis.
52
53
54
55
56

57
58 ¹ These were terms used by professionals about Tom and recorded in the safeguarding review.
59
60

The importance of Mental Capacity Assessments

The Mental Capacity Act (2005) provides guidelines to help support individuals with reduced mental capacity to make their own decisions. The Act is designed to protect and empower individuals with various conditions, including brain injury. The premise of the Act states that individuals should be assumed to be capable of making their own decisions unless it is proved otherwise through a Mental Capacity Assessment (MCA). The Act also highlights that just because a decision may be viewed as unwise, that is not necessarily grounds for diminished capacity. Whilst this is an important point, in the case of Tom, he was endlessly making “unwise” decisions both in terms of lifestyle choices and with regards to his care. In the earlier years following his TBI, we were of the opinion that he was still an adult and could still think for himself, so he was able to make most of his own decisions. However, by 2010 he had become so mentally unwell alongside his TBI that it was my firm belief this was no longer the case. Yet at no point was a MCA done. How can one identify whether someone has capacity if organisations responsible for their care will not carry out assessments? I believe that because Tom was making unwise day to day decisions and these weren’t necessarily about life or death matters, he was not viewed as requiring a MCA. Yet when his substance abuse prevented him having a major operation to save his ability to walk, this was still not viewed as an issue of capacity.

Furthermore, the Mental Capacity Act states that individuals should have an independent advocate who can support them to make decisions. Tom had an advocate, one that he had chosen himself. Yet I was never privy to any of the conversations regarding his care. It is my belief that had I have been actively included in those conversations he probably would have complied with treatment where he otherwise did not.

1
2
3 The nature of Tom's dual diagnosis seemed to prevent the appropriate organisations from
4
5 identifying his need for a MCA. In reality he was a man with a moderate TBI who had a
6
7 history of undiagnosed mental health problems dating back to pre-injury, and he was a
8
9 substance abuser. However, it seemed organisations often identified the substance abuse
10
11 and wrongly attributed his behaviours and physiological condition to that rather than to
12
13 wider neurological damage and mental health issues.
14
15

16 17 18 **Safeguarding and Risk Management** 19

20
21 During Tom's post-injury years, there were many occasions when safeguarding alerts or risk
22
23 management assessments should have taken place. Even in the earlier years post-injury
24
25 where Tom's behaviour was more stable, Tom should have been treated as a "vulnerable
26
27 adult", yet often was not. The Care Act 2014 replaced the term "vulnerable adult" with the
28
29 definition of "adults at risk". This change identified that any adult with an illness or
30
31 condition that may lead to physical or mental impairment should be viewed as "at risk" and
32
33 that this does not require a formal diagnosis. It is possible that had this change come sooner,
34
35 Tom would have received greater support from adult social care. However, I admit that I am
36
37 sceptical. After all, it must be argued that Tom did have a diagnosis – he had a moderate TBI
38
39 with reasonable cognitive impairment and yet he still was not viewed as "vulnerable" under
40
41 the old terminology.
42
43
44
45
46
47

48 Tom's girlfriend also had a brain injury and was in a wheelchair. For many years he was her
49
50 main carer. This meant that he was putting constant stress on his already weakened body by
51
52 performing manual lifting. This should have warranted a risk management assessment but
53
54 one was not forthcoming. Headway Somerset even alerted social services and requested a
55
56
57
58
59
60

1
2
3 review of their living arrangements once Tom's physical condition started to deteriorate,
4
5 but still nothing happened.
6
7

8
9 There were also numerous times when his substance abuse led him to pass out whilst his
10
11 girlfriend was in his care. At times she was left on the toilet unattended, or left to sleep in
12
13 her wheelchair because he couldn't be woken to help her to bed. Again none of this was
14
15 flagged as a safeguarding issue for her or him in terms of an indication of his deteriorating
16
17 mental health.
18
19

20
21 Subsequently, Tom's substance abuse reached a point where he was allowing drug users
22
23 and dealers to frequent the property. His girlfriend was being threatened for money; she
24
25 had her home alarm system disabled, and her house sprayed with graffiti. There were even
26
27 claims that Tom himself was extorting money from her for drugs. When adult social care
28
29 were informed of this, a meeting was held but as Tom and his girlfriend said they didn't
30
31 want any help, their social workers left without action. This should certainly have been
32
33 grounds to initiate a safeguarding alert. A complaint letter I wrote to social services
34
35 regarding this was left in his file and was never responded to or dealt with.
36
37
38

39
40 Tom was later evicted from his girlfriend's home. During this time adult social care did not
41
42 provide any support to him with regards rehoming. Tom's social worker seemed unwilling to
43
44 provide support and did not respond to our calls for his need for rehabilitation services even
45
46 after Tom's own presentation to hospital asking to be admitted for inpatient care. They did
47
48 not seem to take Tom's erratic behaviour, or his constant and increasing declarations of
49
50 suicide, seriously. On one occasion whilst at a Headway Somerset day centre Tom stated his
51
52 intention to kill himself. Headway spoke to a GP at Tom's practice who told them it was not
53
54 their responsibility and to contact his social worker. Social services told them to go back to
55
56
57
58
59
60

1
2
3 the GP as it was not their responsibility either. The GP then told Headway to contact me as
4
5 Tom's advocate. This was the only time my role as an advocate had been acknowledged and
6
7 in this instance it was wholly inappropriate. One or both of those organisations should have
8
9 raised a safeguarding alert, but neither did.
10

11
12 During the last months of Tom's life, he was living in a homeless shelter and then a local
13
14 authority bedsit. In both cases he was living in close proximity to individuals who were
15
16 taking advantage of him. Yet, it still took five months before any kind of safeguarding alert
17
18 was made. Sadly this was far too late. Meetings took place between all relevant agencies
19
20 and Tom underwent a risk assessment about a week before his death. Again I was not
21
22 present at this assessment and was unaware it had happened until after his death. The
23
24 paperwork from it shows that Tom did not fully highlight all the difficulties he had been
25
26 experiencing, or the personal and financial abuse he had been experiencing. He also refused
27
28 rehabilitation services. In my opinion this was partly because there was nobody there to
29
30 support him through that decision making process, and because by that point he had given
31
32 up hope. He needed someone in that meeting to explain things to him and be there for him.
33
34 Perhaps then things would have been different.
35
36
37
38
39
40
41

42 **Recommendations for future Practice**

43
44
45 To conclude, I have outlined below a brief summary of the main recommendations made by
46
47 the safeguarding review conducted in to Tom's care and subsequent death. Below these
48
49 recommendations, I have provided my own insight and comments on why they are
50
51 fundamentally important for shaping current practice:
52
53
54
55
56
57
58
59
60

- Tom's case study features in sector-led and multi-agency training...and that multi-agency work with individuals with complex needs is shaped by shared goals and clear leadership.
- A learning event should be hosted concerning Tom and others currently known to Headway Somerset.
- The fact of a person's TBI and mental capacity is foregrounded in all professional assessments and referrals and that family involvement is prioritised with a view to understanding the continuities and discontinuities and the unpredictable and complex process of reconstructing the self which arise from such critical injury.
- Public Health, Somerset County Council, and NHS commissioners should set out how local practice and priorities match good practice concerning the support of people with brain injury, dual diagnoses and the expectations of the National Suicide Prevention Strategy for England.
- Homefinder Somerset and Housing partners identify how tenants with extensive support needs, including those with acquired brain injuries, may access supported housing.
- The review is shared with Headway UK for dissemination beyond Somerset to stimulate debate.

These recommendations provide concrete actions following the safeguarding review. Below

I have tried to elaborate on some of these by thinking about the issues that would have directly improved care for Tom.

1
2
3 Echoing the recommendations above, it is my belief that the NHS and social services need
4
5 to work together to ensure information about vulnerable adults is routinely shared for the
6
7 better management of their care. They often have complex needs and must be looked after
8
9 by specialist multidisciplinary teams (Headway, 2014). Organisations need to take a more
10
11 active role in case management for individuals with TBI. There needs to be one individual
12
13 accountable for information sharing and to act as a conduit for support and care for
14
15 individuals and their families and to provide better access, and signposting, to services.
16
17 Adult social care need to undertake regular specialist assessments to monitor the health
18
19 and wellbeing of individuals with TBI (Holloway & Fyson, 2015). It is also imperative that
20
21 Health and Social work professionals receive better training in understanding the difficulties
22
23 associated with TBI, particularly with regards to mental capacity and dual diagnosis.
24
25 Specifically, more awareness is needed of the co-occurrence of TBI alongside mental health
26
27 problems, suicidality and substance use.
28
29
30
31
32

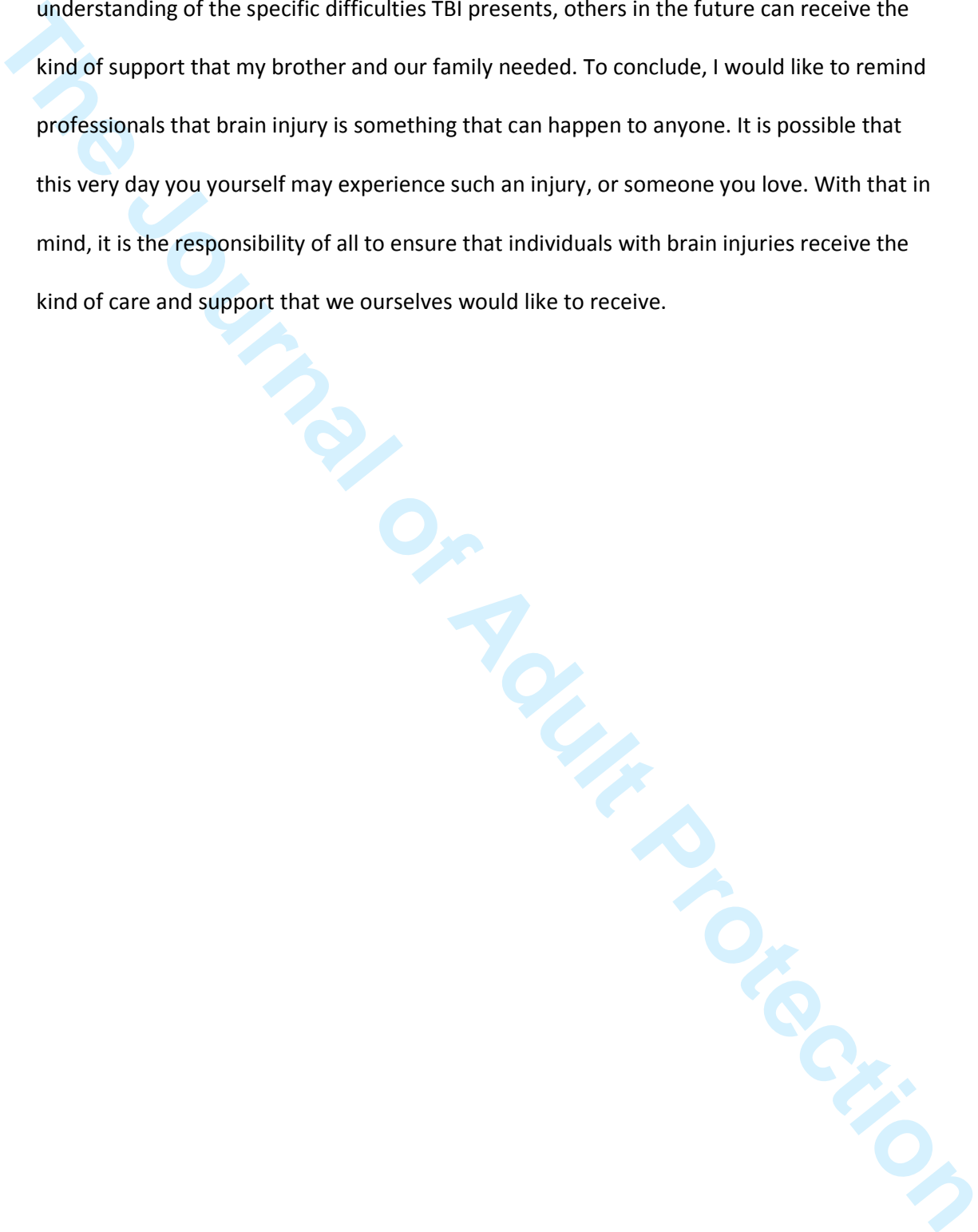
33
34 Routine involvement of families is crucial in the care of those with TBI to circumvent the
35
36 difficulties caused by lack of insight. Lack of insight is associated with diminished capacity.
37
38 Furthermore, because individuals following TBI have residual intellectual capacity, there is a
39
40 very real danger that they can present as being capable of making complex decisions
41
42 (Holloway & Fyson, 2015). The advocacy role must be taken more seriously and routine
43
44 contact made by all organisations. Family and advocate involvement is crucial to ensure
45
46 cases of diminished capacity are not overlooked.
47
48
49
50

51 **Conclusions**

52
53
54
55 Although none of what is highlighted above will bring back my brother Tom, it is my hope
56
57 that this case study can provide information that will help to save the lives of other
58
59
60

1
2
3
4
5
6
7
8
9
10
11
12
13
14
15
16
17
18
19
20
21
22
23
24
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60

individuals with TBI in the future. By providing more consistent sensitive care with a better understanding of the specific difficulties TBI presents, others in the future can receive the kind of support that my brother and our family needed. To conclude, I would like to remind professionals that brain injury is something that can happen to anyone. It is possible that this very day you yourself may experience such an injury, or someone you love. With that in mind, it is the responsibility of all to ensure that individuals with brain injuries receive the kind of care and support that we ourselves would like to receive.



References

Bahraini, N.H., Simpson, G.K., Brenner, L.A., Hoffberg, A.S., & Schneider, A.L. (2013). Suicidal ideation and behaviours after traumatic brain injury: A systematic review. *Brain Impairment, 14*, 92-112.

Bessell, A.L., Watkins, E.R., & Williams, H.W. (2008). Depressive rumination reduces specificity of autobiographical memory recall in Acquired Brain Injury. *Journal of the Neuropsychological Society, 14*, 63-70.

Bombardier, C.H., Fann, J.R., Temkin, N.R., Essleman, P.C., Barber, J., Dikmen, S.S. (2010). Rates of major depressive disorder and clinical outcomes following traumatic brain injury. *Journal of American Medical Association, 303(19)*, 1938-1945.

Bousman, C.A., Twanley, E.W., Vella, L., Gale, M., Everall, I.P., & Heaton, R.K. (2010). Homelessness and neuropsychological impairment: Preliminary analysis of adults entering outpatient psychiatric treatment. *The Journal of Nervous and mental Disease, 198(11)*, 790-794.

Engel, G.L. (1980). The clinical application of the biopsychosocial model. *The American Journal of psychiatry, 137*, 535-544.

Felde, A.B., Westermeyer, J., & Thuras, P. (2006). Co-morbid traumatic brain injury and substance disorder: Childhood predictors and adult correlates. *Brain Injury, 20(1)*, 41-49.

Graham, D.P., & Cardon, A.L. (2008). An update on substance use and treatment following traumatic brain injury. *Annals of the New York Academy of Science, 1141*, 148-162.

1
2
3 Headway. (2014). *A ticking time bomb: The false economy of cuts to brain injury*
4
5 *support services*. Nottingham: Headway: [www.headway.org.uk/research/a-ticking-time-](http://www.headway.org.uk/research/a-ticking-time-bomb-the-false-economy-of-cuts-to-brain-injury-services.aspx)
6
7 [bomb-the-false-economy-of-cuts-to-brain-injury-services.aspx](http://www.headway.org.uk/research/a-ticking-time-bomb-the-false-economy-of-cuts-to-brain-injury-services.aspx).
8
9

10 Hoffman, J.M., Pagulayan, K.F., Zawaideh, N., Dikmen, S., Temkin, N., & Bell, K.R.
11
12 (2007). Understanding pain after traumatic brain injury. *American Journal of Physical*
13
14 *Medicine Rehabilitation, 86*(12), 962-969.
15
16

17
18 Holloway, M. (2014). How is ABI assessed and responded to in non-specialist
19
20 settings? Is specialist education required for all social care professionals? *Social Care and*
21
22 *Neurodisability, 5*(4), 201-2013.
23
24

25
26 Holloway, M., & Fyson, R. (2015). Acquired brain injury, social work and the
27
28 challenges of personalisation. *British Journal of Social work, 2015*, 1-17.
29
30

31
32 Hwang, S.W., Colantonio, A., Chiu, S., Tolomiczenko, G., Kiss, A., Cowan, L., et al.
33
34 (2008). The effect of traumatic brain injury on the health of homeless people. *Canadian*
35
36 *Medical Association Journal, 179*(8), 779-784.
37
38

39
40 Koponen, S., Taiminen, T., Portin, R., Himanen, L., Isoniemi, H., Heinonen, H., et al.
41
42 (2002). Axis I and II psychiatric disorders after traumatic Brain Injury: A 30 year follow-up
43
44 study. *American Journal of Psychiatry, 159*(8), 1315-1321.
45
46

47
48 Mackelprang, J.L., Harpin, S.B., Grubenhoff, J.A., & Rivara, F.P. (2014). Adverse
49
50 outcomes among homeless adolescents and young adults who report a history of traumatic
51
52 brain injury. *American Journal of Public Health, 104*(10), 1986-1992.
53
54
55
56
57
58
59
60

1
2
3 Nampiaparampil, D.E. (2008). Prevalence of chronic pain after traumatic brain injury:
4
5 A systematic review. *Journal of American Medical Association*, 300(6), 711-719.
6

7
8 Oddy, M., Moir, J.F., Fortesque, D., & Chadwick, S. (2012). The prevalence of
9
10 traumatic brain injury in the homeless community in a UK city. *Brain injury*, 26(9), 1058-
11
12 1064.
13

14
15 Prigitano, G.P. (1996). Behavioural Limitations TBI patients tend to underestimate: A
16
17 replication and extension to patients with lateralized cerebral dysfunction. *The Clinical*
18
19 *Neuropsychologist*, 10(2), 191-201.
20
21

22
23 Sariaslan, A., Sharp, D.J., D'Onofrio, B.M., Larsson, H., Fazel, S. (2016). Long term
24
25 outcomes associated with traumatic brain injury in childhood and adolescence: A
26
27 nationwide Swedish cohort study of a wide range of medical and social outcomes. *PLoS Med*,
28
29 13(8), e1002103.
30
31

32
33 Walker, R., Cole, J.E., Logan, T.K., & Corrigan, J.D. (2007). Screening substance abuse
34
35 treatment clients for traumatic brain injury: prevalence and characteristics. *Journal of Head*
36
37 *Trauma Rehabilitation*, 22(6), 360-367.
38

39
40 Williams, W.H., Mewse, A.J., Tonks, J., Mills, S., Burgess, C.N.W., & Cordan, G.
41
42 (2010). Traumatic brain injury in a prison population: prevalence and risk for re-offending.
43
44 *Brain Injury*, 24(10), 1184-1188.
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60