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## **Long term care needs following Acquired Brain Injury: Final report**

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## Introduction

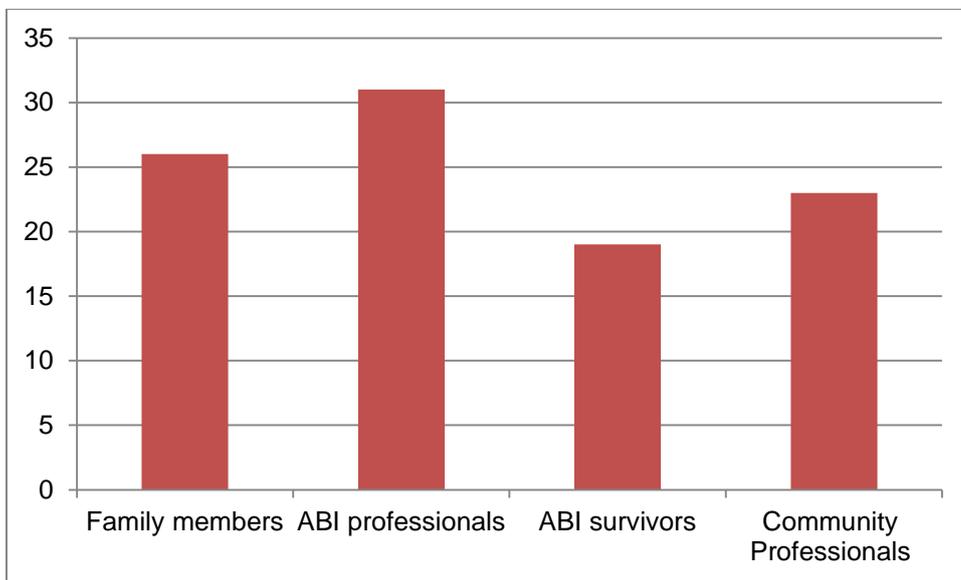
In 2013-2014 in the UK there were 348,934 hospital admissions for Acquired Brain Injury (ABI), equating to approximately 956 admissions per day (Headway, 2015). ABIs are one of the most common reasons for hospital admissions, with the figure having risen by 10% since 2005-2006 (Headway, 2014). An ABI is any damage to the brain that has occurred after birth. Damage can be caused by a range of different conditions, such as strokes, brain tumours and external injuries to the head, known as traumatic cause e.g. a traffic accident – in which case they are referred to as Traumatic Brain Injuries (TBI). People with ABIs often experience cognitive and physical impairments (Dreer et al, 2008) as well as behavioural and emotional changes (Kim, 2002).

The difficulties associated with ABI can affect an individuals' quality of life in terms of relationships, employment and education, and mental health (Townshend & Norman, 2018). Such needs require long term specialised care from a variety of different support services. Behavioural changes can make it difficult for patients to maintain existing relationships and form new ones (Shorland & Douglas, 2010), while a lack of understanding of consequences in the workplace provides challenges to holding down a job (Holloway, 2014). Such issues can heavily hinder the survivor's emotional and psychological recovery due to a decrease in self-esteem, feelings of loss of control and importance, and increased social deprivation. As a result of the subsequent isolation from a loss of social life and increased vulnerability, individuals with ABI may resort to unhealthy coping strategies (Materne et al, 2017) such as the use of substances to relieve the feelings of loneliness. These behaviours, coupled with financial difficulties and problems with managing their homes can lead to an increased risk of homelessness (Norman, 2016). This highlights the need for long-term support following ABI, not just acute care.

In order to improve the quality of life of individuals with ABI long-term, it is important to understand what services they are coming into contact with as part of their community reintegration and rehabilitation, and understand how well those organisations are meeting their needs. This current study focused on identifying what community services people with ABI, and their families, access. Furthermore, the study focused on understanding the needs of people with ABI and how these may or may not be being met by current community services.

## Method

**Participants:** Ninety-nine (aged 18 to 76, 55 females), took part in an online questionnaire (19 ABI survivors, 26 family members, 31 professionals working with individuals with ABI and 23 professionals from various community services). Community services included health care professionals, social workers, police and care workers. Fourteen of the participants (8 female) also took part in an interview. One was an individual with ABI, five were family members, four were professionals working with ABI, and three were community services professionals (nurse, police officer, social worker). Participants were recruited through social media and Headway organisations, as well as case management organisations.

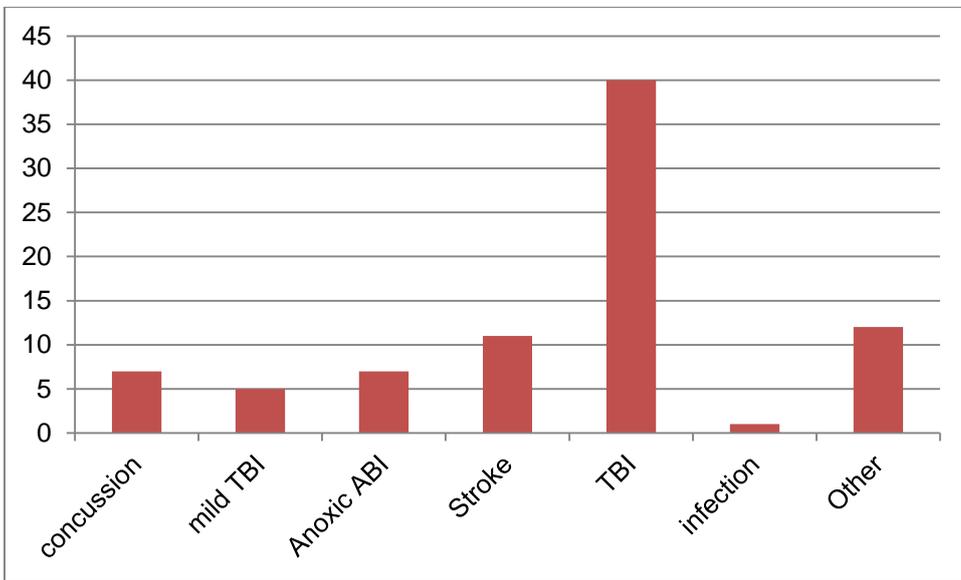


**Figure 1: Participants in survey study**

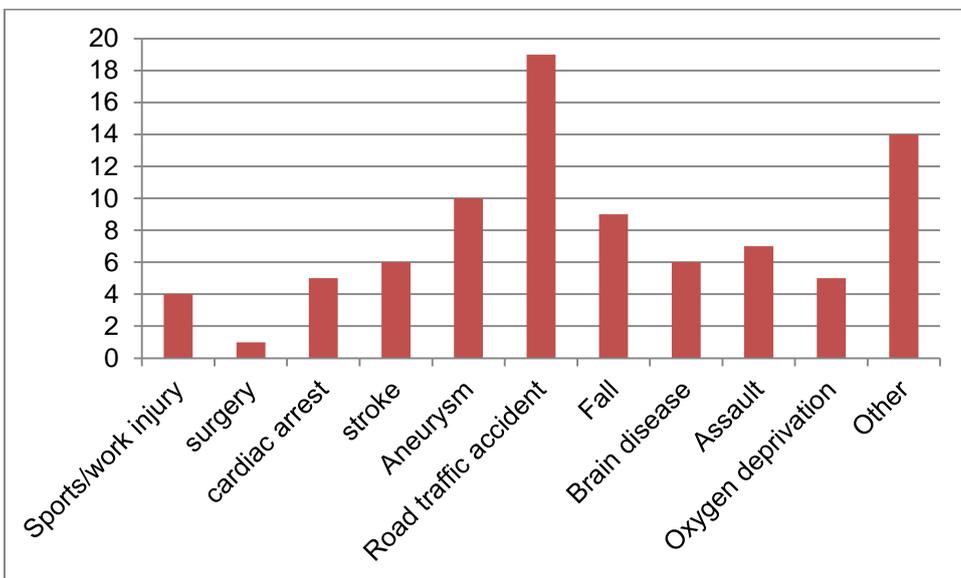
**Design:** Participants completed the questionnaire via ‘SurveyMonkey’, which included methods such as multiple choices, 5-point Likert Scale, comment boxes and rating scales. This allowed for the collection of both qualitative and quantitative data detailing their experience with services they had been involved with. At the end of this survey they had the option to consent to taking part in any future research, including a telephone interview. Those that were chosen for the telephone interview were asked a series of questions in a semi-structured format to gather qualitative data around areas including social services, employment/education, social life and various life changes.

## **Results**

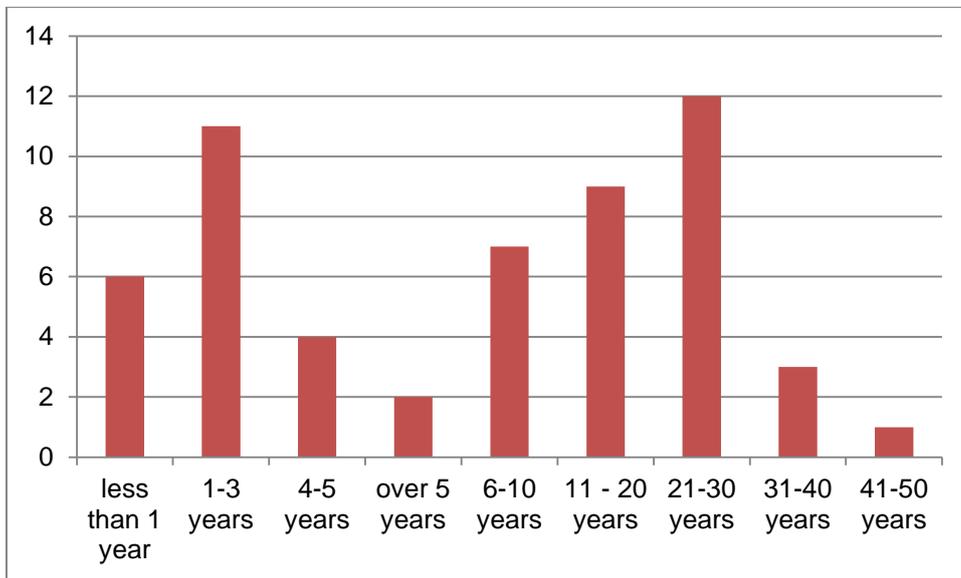
The questionnaire asked respondents to provide information on the types and causes of the injury they or the person/s they had come in contact with had. Responses included traumatic brain injury (TBI), stroke, mild TBI and concussion (Figure 2) from causes such as falls, road traffic accidents (RTCs) or surgery (Figure 3). The time since injury in the study varied from less than one year through to over 40 years (see Figure 4).



**Figure 2: Type of ABI**

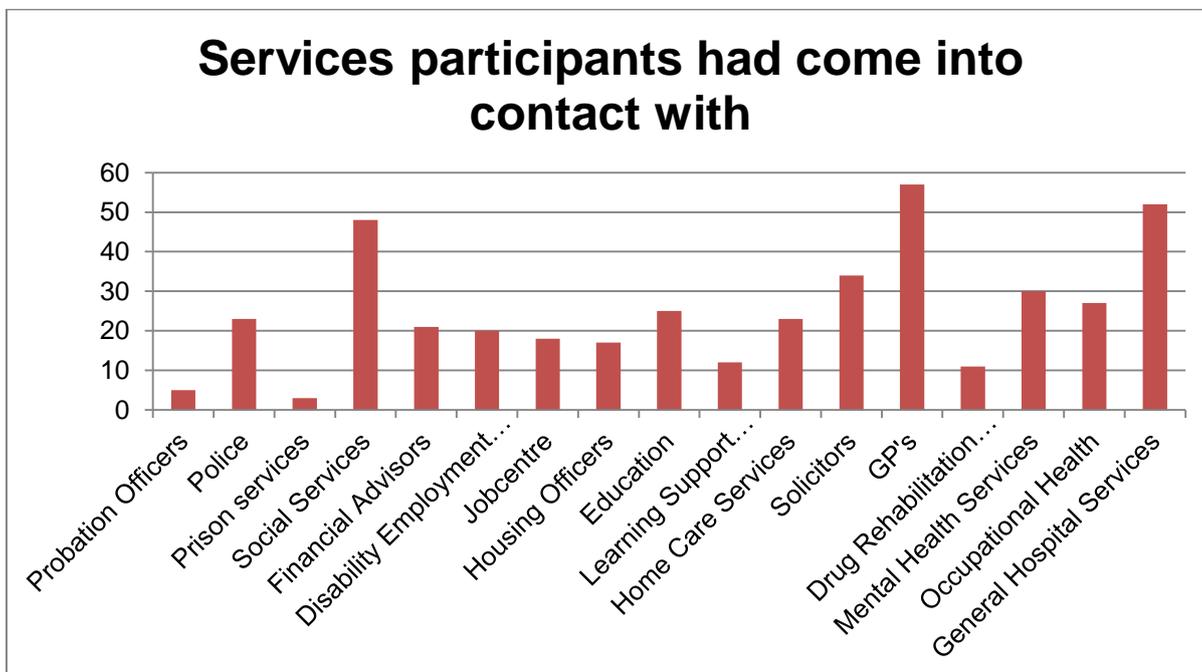


**Figure 3: Cause of ABI**



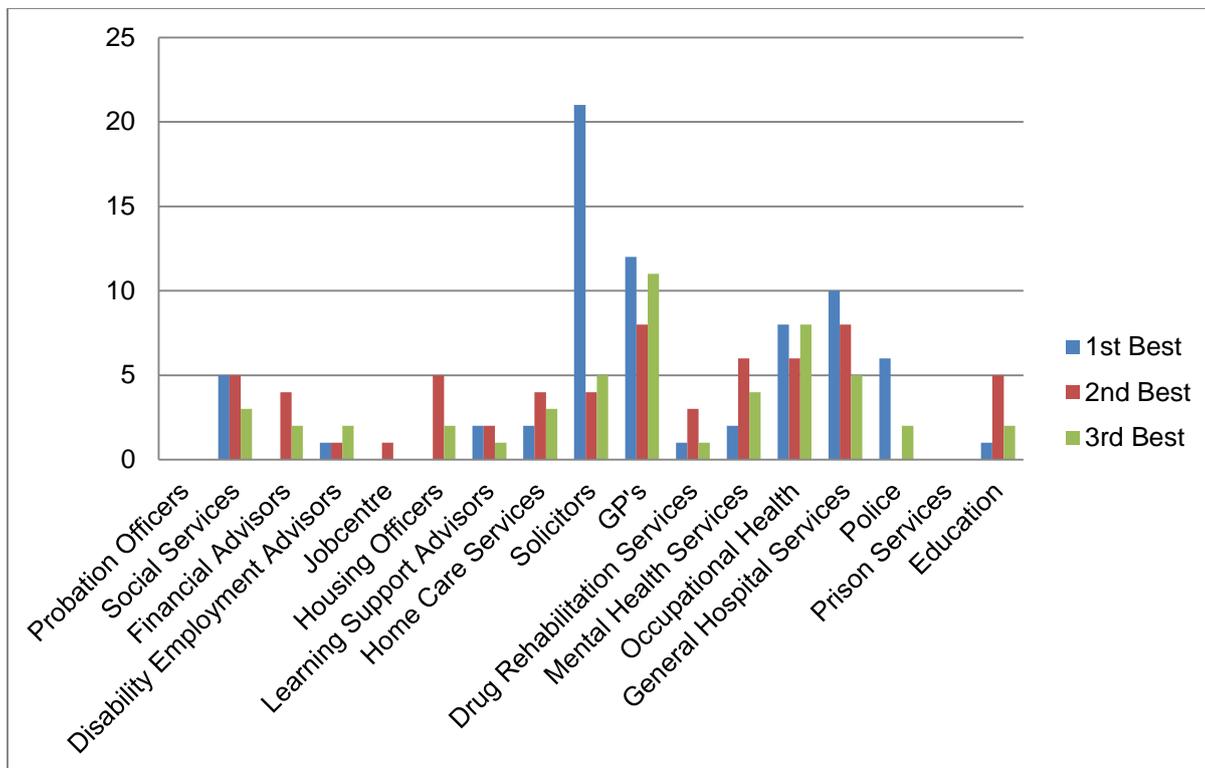
**Figure 4: Time since injury**

Results showed that the majority of ABI survivors had come into contact with GPs (57), more than any other community service, with secondary healthcare (52; general hospital services) and social services (48) also being regularly involved (Figure 5). Participants were asked to rate all the services they had come in contact with on a five-point scale in terms of how well they understood the difficulties associated with an ABI. The mean rating was 2.63, between average and poor.



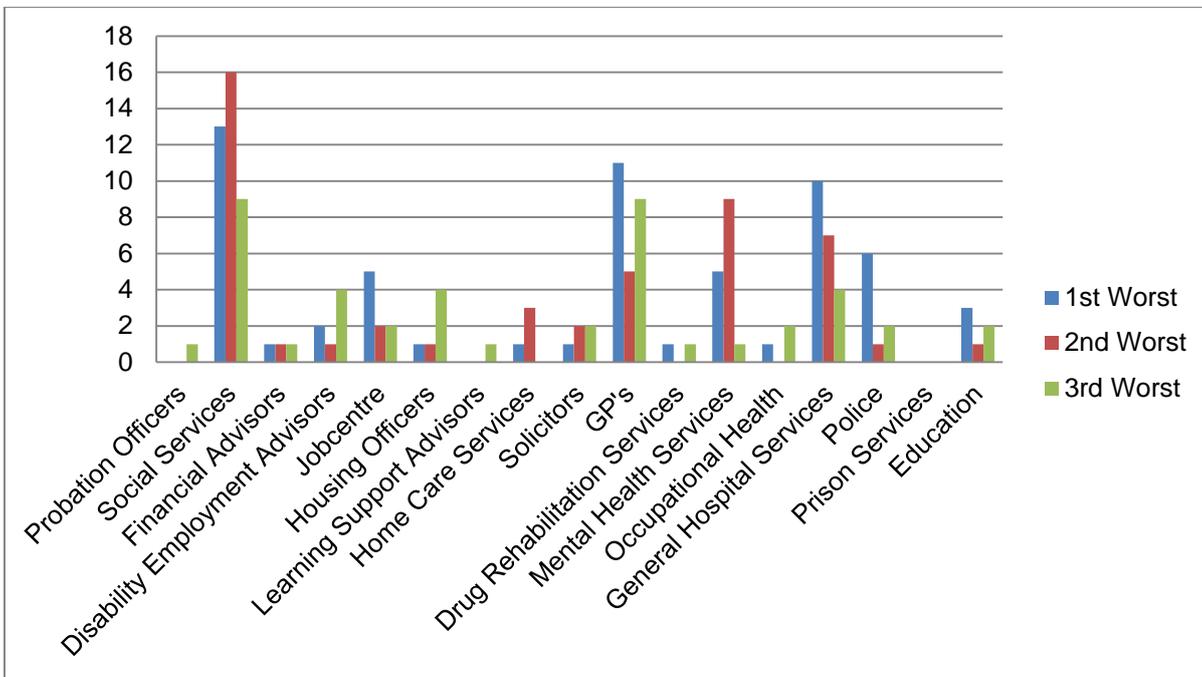
**Figure 5: Community service access by individuals with ABI**

Participants were then asked to rate the three organisations that they had found most supportive in terms of understanding the needs of individuals with ABI. Overall solicitors were ranked most positively, followed by GPs and secondary hospital services.



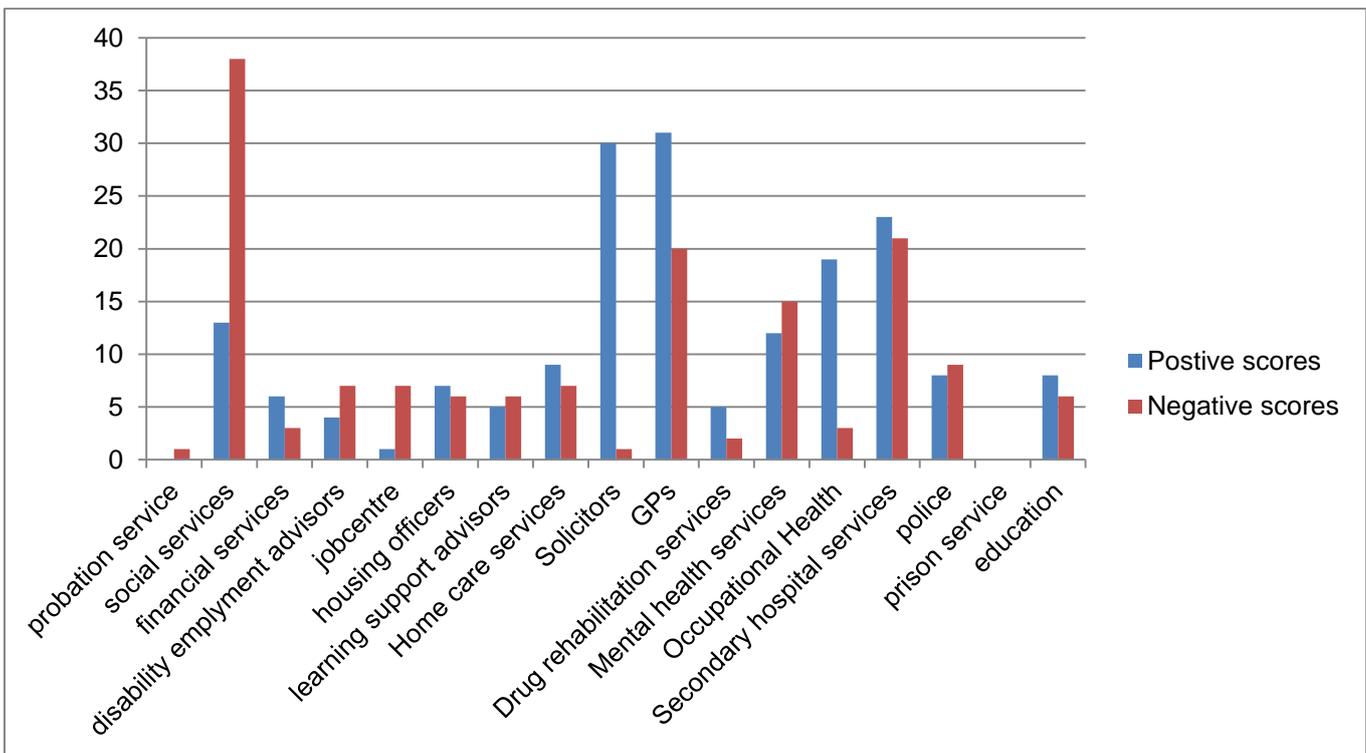
**Figure 6: Most positive services for individuals with ABI**

Participants were then asked to rank their three worst organisations in terms of understanding the needs of individuals with ABI. Social services performed poorly, along with GPs.



**Figure 7: Most negative services for individuals with ABI**

The researchers then combined the results to find the overall positive and negative scores for each organisation. Overall, GPs were rated most often in the top three services, with solicitors coming second and secondary health services coming third (Figure 8). In terms of negatively ranked services, social services performed most poorly, having been nominated 38 times. Secondary health services and GPs also performed poorly, suggesting that in some instances GPs and hospital staff are supporting ABI survivors well, but the picture is mixed.



**Figure 8: Overall scores for each community service**

At the end of the questionnaire, participants were asked to provide free-text feedback about their positive and negative experiences with community organisations. Four themes emerged from the analysis; knowledge and understanding of ABI, access and quality of services, impact of ABI and safeguarding. These themes were also identified in the interviews with a smaller number of participants, except that this identified an additional theme of “hidden disability”. Figure 9 shows a map of the different themes and sub-themes and how they interact.



**Figure 9: Thematic map**

**Theme 1: Knowledge and Understanding of ABI**

Participants identified a poor understanding of the problems and symptoms associated with ABI among professionals working in community services and limited knowledge about needs. Others identified positive instances where they had received good support from professionals.

*“Where do you want to start? There is a terrible lack of underpinning knowledge amongst non-specialist professionals – insight and executive impairments are virtually always missed.” (Survey 69; ABI professional)*

*“A school that has been very keen to work with me and [the] family [were] willing to gain knowledge and understanding regarding brain injury, in order to support and meet the needs of [the] child.” (Survey 53; ABI professional)*

The theme identifies the need for training of staff and information provision to survivors and family members, as well as awareness-raising of the issues associated with ABI more generally. Participants felt empathy was a good skill to employ when dealing with ABI survivors. An absence of this and poor knowledge often led to labelling service users as being “stupid”, “uncooperative” or “lazy”.

*"...the police are...are dealing with each situation without the information or the training..." (Interview 7; Community professional)*

*"...in my case it didn't start until ten days after...my family had no idea, I just started acting very bizarre. If they'd been some kind of explanation of what could happen, like psychologically, what can change in case you did have a brain injury" (Interview 8; ABI survivor).*

*"The education department are probably going to take her to court again for previous lack of attendance...and she probably will have to do a few days in prison...it was presented at court [the ABI] but it wasn't deemed sufficient reason for his...terrible record of school attendance." (Interview 5; family member)*

*"NHS CHC have been a nightmare to work with...total lack of any common sense or compassion". (Survey 35; ABI professional)*

*"GP listened to me rather than thinking he knew all the answers!" (Survey 3; ABI survivor)*

*"Headway supported me when the NHS stopped doing anything...I felt listened to and got a better understanding of what had happened to me". (Survey 55; ABI survivor)*

*"Inexperienced social worker assessed my client as having no needs and no risk. Following complaint and re-assessment, he was identified as high risk and needing a significant support package". (Survey 25; ABI professional)*

## **Theme 2: Access and Quality of Services**

Participants identified that there was often poor availability, or access, to a range of community services. This was related to a lack of tailored care for individuals with ABI, and a lack of quality interdisciplinary specialist services with expert knowledge of ABI.

*"I have worked with solicitors who specialise in working with clients with catastrophic injuries including brain injuries. They have been instrumental in instructing appropriate experts and appropriate brain injury case managers. (Survey 13; ABI professional)"*

*"There is not a specialist service operating in our area and therefore these clients are missing out on specialist rehab". (Survey 31; ABI professional)*

*"They might do a program for a...short period of time but urm the specialist services...available were quite generic services, urm it's limited...when I say limited I mean none." (Interview 3; ABI professional)*

*"A drug rehabilitation service working with one of our clients completely engaged with the multi-disciplinary approach and actively identified the positive role they could play whilst also understanding the roles of others supporting the clients. (Survey 29; ABI professional)"*

*"Outpatient hospital treatment is very long winded and non-personal. (Survey 94; ABI professional)"*

Participants highlighted that they often did not get access to the long-term care from allied health professionals, such as speech and language therapy, occupational therapy or physiotherapy. They also identified issues within the consistency of care, where some services, or specific staff members, may provide good quality care, but others did not. These inconsistencies, in both quality and access, were related back by participants to staffing and organisational issues that prevented inclusion.

*“Challenge in accessing psychological assessment or OT assessment for ABI.” (Survey 50; ABI professional)*

*“Social services actively disengaging from providing services to clients. Ignoring advice regarding the difficulties an individual with an ABI has and using this as evidence of disengagement.” (Survey 29; ABI professional)*

*“...been working with the school with the boy who actually attempted suicide... and they still couldn't get him into CAHMS so what became evident was that you know getting a young person...therapeutic help...feels nigh-on impossible.” (Survey 99; ABI professional)*

*“they [social services] set out to manage people through...through meetings, where people aren't actually in the meetings, so it's like a professionals meeting...they don't actually go to the address, and they don't actually leave their offices – but their organisation just isn't set up for that frontline delivery.” (Interview 7; Community professional)*

*“Working with disability learning support advisors at University – they treated me as an individual and responded to my needs on an individual basis”. (Survey 81; ABI survivor)*

*“The police seemed to understand my brother as a human being better than any other organisation. They tried to offer him tailored support.” (Survey 97; family member)*

*“I found that my GP was overall the best service...understood very well what our concerns were, and how we can improve his quality of life.” (Survey 52; family member)*

*“I'm employed as a police officer. They were sympathetic at the start but soon lost patience when it became clear I would not be returning "as before" the accident. (Survey 41; ABI survivor)”*

*“Not enough staff meaning not enough time for patients (Survey 72; family member)*

*“Physio's didn't have enough time to work with me and get me to where I needed to be” (Survey 95; ABI survivor)*

*“Mental health service refused to see my client with ABI and suicidal thought/depression because they don't take ABI patients...” (Survey 24, ABI professional)*

Finally, access to services was linked with a lack of inclusion of family members and carers in medical and care coordination decision-making. Participants felt that as individuals with ABI often had trouble expressing their needs, or may have impaired executive functioning and insight into their disabilities, it was important that family members were included in assessments where appropriate, but that this needed to be done sensitively to enable family members to provide appropriate input.

*“One of the resources that I found that was really lacking in my care was...I got a very close family and my family members, knew an awful lot about my personality, and about my interests before the injury...I didn't feel that...the immediate sort of medical services drew on that support they almost tended to exclude my family members...” (Interview 6; ABI survivor)*

*“Police sent female officer as requested... they fully included me as carer.” (Survey 51; family member)”*

*“Asking family members to tell it as it really is in front of the client, or asking the client about their relationship with family member in front of [them]. This is incredibly unhelpful, family members have a loyalty to the client and are highly unlikely to share how difficult things are as a result of ABI.” (Survey 17; ABI professional)*

Whilst the study identified difficulties with accessing good quality services with regards to community care and rehabilitation, some participants also identified poor practices taking place in more acute

settings. Additionally, it was noted that too much focus often existed on acute care with limited consideration of more long term needs.

*“...the auxiliary nurses were cleaning...one of them had pulled one of his wires out so he wasn't actually getting any oxygen...alarms going off and they weren't paying any attention and they'd also picked up all the rubbish and put it on [service user] while they were mopping the floor.”* (Interview 1; family member)

*“everyone seems to focus on getting the person active again, getting them moving, getting their, their arms working, their legs walking, no one seems to focus on the cognitive health of the person who's had the accident, or speech and language, as long as he is up and walking and everything you can see is in the right order, mm, that's how it feels”* (Interview 1; family member)

*“...after that [discharge] it was largely up to myself to kind of arrange to go back into society and urm, find my own way, and the services that I found were not...not... sufficient in in long term rehabilitation.”* (Interview 6; ABI survivor)

*“Follow up care and support after discharge from acute care is very poor, often non-existent”* (Survey 98; ABI professional)

### **Theme 3: Impact of ABI**

Participants highlighted that ABI survivors and their families often felt unprepared for the challenges they would face post-injury. It was felt that professionals were often unable to relate to the needs of the family and service users due to their insufficient knowledge of ABI. This theme was related to the sub-themes of cognitive, behavioural, psychological and social impacts of ABI, representing the kinds of difficulties individuals faced post-injury. Furthermore, it was highlighted that survivors face an uncertain time of trying to identify who they are post-injury and establish a new identity.

*“...it's quite literally life changing...emotionally it's very difficult for them...also it has wider ramifications for the family and friends who are suddenly living with somebody who is completely different to how they were before”* (Interview 8; ABI professional)

*“life's changed completely um because I've got now like a...toddler that's never going to grow up”* (Interview 11; family member)

*“Raising awareness of impacts of ABI for housing officers resulting in better assessment experience, support with bidding and opening access to properties that client would not normally meet the criteria for.”* (Survey 17; ABI professional)

*“I was laughing, giggling making jokes during the funeral service... I lost my libido and then became like, I became a sex addict...”* (Interview 8; ABI survivor).

*“Working with alcohol advisory services raising awareness of impacts of ABI [...] increasing knowledge to improve planning and work with client...to reduce alcohol dependence.”* (Survey 17; ABI professional)

*“Poor understanding of implications of cognitive and behavioural changes...”* (Survey 21; ABI professional)

*“School hopeless – no support, they just wanted him out when he returned to education 2 months after the fall/head injury and his behaviour changed.”* (Survey 82; family member)

Specific difficulties were noted, including financial security and poor quality of life. These factors were a problem for families as well as survivors, and family members identified the impact the injury had on them as carers, and the general burden of living with a person who was often “different”

post-injury. Some comments were contradictory, particularly relating to personal budgets, where some respondents wanted to see them used with ABI survivors, and others questioning how useful this would be for people with capacity issues.

*"...should be providing direct payments and personal health budgets that allow personalised care and support. (Survey 11; ABI professional)"*

*"...services [...] told a brain injured client that they have capacity to deal with their own finances despite the client telling them 'I will spend all my money if I was to have a large sum of money'..." (Survey 14; ABI professional)*

*"Social Worker not understanding clients' cognitive difficulties while undertaking assessments, particularly clients with lack of insight/impulsive and risk taking behaviours. Disability benefits do not take into account the above" (Survey 52, ABI professional)*

*"The Job Centre talked to me like I was dirt, it is unfair because it is not my fault I needed their services, I didn't chose to be ill and unable to work" (Survey 91, ABI survivor)*

*"When it comes to [service user's] personal care, I do that between me and my mum...because we're both mothers, I think it makes it easier, when it comes to going out and doing activities, my younger brother...tends to do a lot more of that...but when it comes to hospital appointments my dad mainly goes." (Interview 1; family member)*

*"You go through horrendous times with it. I've actually felt quite suicidal at times. And I don't think people know that I really have." (Interview 4 – family member)*

*"She's still grieving losing the son that she knew and raised and trying to get to know this whole new person who has different memories and a different voice and a different sense of humour." (Interview 1; family member)*

#### **Theme 4: Safeguarding**

Many participants identified the potential executive impairments people with ABIs may have, including difficulties with decision-making and insight. This highlighted safeguarding issues around those with ABI. This included the subtheme of capacity, which is the extent to which someone with ABI can mentally and emotionally make their own decisions about their rehabilitation (Trachsel, Hermann & Biller-Andorno, 2014). Participants described many safeguarding issues that had arisen when ABI survivors did not have the capacity to comprehend topics discussed regarding their treatments and the misconception professionals had about the choices people with ABI have made. The issue surrounding capacity was associated with a lack of ability to effectively weigh up all relevant information when making complex decisions. It was felt that comprehension was sometimes assumed by statutory services but without an appreciation of the difficulties with weighing up complex information experienced by many with ABI. The vulnerability that some people with ABI showed further highlighted the importance of safeguarding, and the need to proceed cautiously with safeguarding issues.

*"No real understanding of what it is like to live with a brain injury. On one occasion I was told that if I got too tired at work I could walk, take a train and bus to get home." (Survey 32; ABI survivor)*

*"for...information...to sink in...we get the after effect of that conversation understood or been taken literally... they respond quite normally...and respond appropriately and what we see afterwards is something completely different" (Interview 3; ABI professional)*

*“He started smoking weed and it was helping him...sleep...when we tried to talk to him about it he said it’s the only thing that makes him feel better...it broke my heart...one time he said ‘the weed is the only friend I got’...(Interview 5; family member)*

*“Client during hospital admission, being subjected to “safeguarding”...without discussion with client nor with family, nor with Capacity assessment. Hospital staff refused to communicate with any involved party for 6 days.” (Survey 56; ABI professional)*

*“...professionals not understanding that a person may appear to understand and have intent to do/not do something during an appointment, but that executive dysfunction will mean that do not follow that through when they leave the aptmt [appointment]...Professionals taking what the person with an ABI says at face value, even when I have explained lack of insight and self awareness... Commissioners arguing that residential carers...are appropriate for a person with significant cognitive difficulty, when in fact they need consistency and support from people who can understand their needs and can direct them when their frontal lobes fail to”. (Survey 24; ABI professional)*

## **Theme 5: Hidden Disability**

The theme of hidden disability illustrated that individuals with ABI have a host of non-physical, invisible difficulties associated with their injury. These included the cognitive, emotional and executive problems experiences by many ABI survivors. Participants explained how these hidden disabilities acted as a barrier in receiving appropriate support due to difficulties in identifying and knowing the severity of ABI. The family members and individuals with ABI revealed the frustration they had towards the professionals and the public who stereotyped their disability.

*“Professionals being unable to understand the nature of ‘hidden’ injury when a person with ABI can present so well during a clinic appointment or assessment and disbelieving my feedback” (Survey 24, ABI professional).*

*“if you met him now you wouldn’t think there was a problem...this is where the so called professionals have kind of not...seen what was there I’ve seen it urm my friends have seen it my family have seen” (Interview 4; family member)*

*“Police not understanding how vulnerable a person is when they can’t see the disability. (Survey 11; ABI professional)”*

*“The way people in various organisations look and treat you .....just because you look ok.” (Survey 42; ABI survivor)*

*“My clients have invisible disabilities and these are not responded to by social workers in particular. The response by social services is embarrassingly bad and is killing people with an ABI. (Survey 69; ABI professional)*

## **Discussion**

The study has identified a need amongst family members and ABI survivors for consistent, specialised long term community support that includes multiple agencies working together as a team. This study has uncovered key areas that participants felt service providers commonly overlooked, from initial diagnosis to long term recovery. Coupled with the fact that many participants rated services as poor to average, it can be suggested that these services do not have a good awareness of the difficulties and complications arising from ABI. A worrying idea given that these services are designed to help with long-term rehabilitation.

It was felt by participants that there was a need to raise awareness of the long term effects of ABI amongst community professionals and the general public. It was also felt that survivors and family members needed better signposting to services to support their needs. During the interviews, participants expressed their concern that family members tended to be excluded when forming a long-term care plan for service users, which also had the negative impact of minimising their support in the wider community. Such an outcome could lead to serious consequences for the individual with ABI, such as feelings of isolation.

Family members also highlighted a wider need for support when they are acting as carers for those with ABI, but also to help them deal with the more general burden of adjusting to life after their loved one has experienced an injury. The impact of ABI on survivors was clearly identified with participants highlighting a range of different difficulties all impacting on people's quality of life and their ability to adjust and re-integrate socially following injury. The hidden nature of many of these disabilities was identified as a major problem for survivors when accessing support and services, and feeling accepted and understood by others.

Finally, there was an important theme raised about the need to protect some individuals with ABI who may have mental capacity issues due to their executive impairments, or may be vulnerable to other long term problems such as mental health difficulties or substance abuse, or to becoming socially deprived due to a lack of social contact and the financial burden of their injury.

Overall, the study provides an insight into the difficulties experienced by individuals with ABI and their families and suggests that their needs are currently not being, or are inconsistently, met by community services. This identifies a requirement for further research into the needs of ABI survivors and their families with a view to restructuring services, or introducing new service provision to better meet those needs.

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