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**Published in:**

Journal of Long term care

**Publication date:**

2019

**Link:**

[Link to publication in PEARL](#)

**Citation for published version (APA):**

Odumuyiwa, T., Kennedy, M., Norman, A., Holloway, M., Freya, S., Hannah, F., & Hilary, D. (2019). Improving access to social care services following Acquired Brain Injury: A needs analysis. *Journal of Long term care*, 0(0).

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## **Improving access to social care services following Acquired Brain Injury: A needs analysis.**

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**Key Words:** adult social care, acquired brain injury, community rehabilitation, social integration

**Acknowledgements and Declarations:** No funding was received for this research study. Thank you to Headway UK and Headway Somerset for supporting recruitment. It is acknowledged that three of the authors work as ABI specialists so have a potential conflict of interest in this research arena.

## **Abstract**

**Context:** Survivors of acquired brain injury (ABI) experience long-term cognitive, behavioural, psychological and social consequences often overlooked by health and social care providers, as are the implications for family members.

**Objective:** To improve understanding of 1) the long-term community rehabilitation needs of ABI survivors and their families, and 2) their experiences of community health and social care provision within the United Kingdom.

**Method:** A mixed-methods, predominantly qualitative, approach was employed using questionnaires and semi-structured interviews in a two-stage design. Stage one: Seventy-six participants (31 ABI specialist professionals, 26 family members and 19 survivors) completed an online survey analysed using conventional content analysis. Participants were invited to take part in stage two, which recruited 21 participants (12 ABI survivors, 5 family members and 4 professionals) to semi-structured interviews analysed using a mixed thematic approach.

**Findings:** Three main themes were identified with associated sub-themes 1) consequences of ABI (cognitive and behavioural; psychological and social consequences, impact on family) 2) types of services required (tailored, specialist and interdisciplinary care) and 3) poor access to services (associated with; lack of understanding of ABI among professionals, the hidden nature of ABI, organisational structures and a lack of available services).

**Limitations:** The study failed to achieve a sample distributed evenly across the United Kingdom making it difficult to draw conclusions around best practice.

**Implications:** The study concluded that professionals need training to understand the needs of ABI survivors and their families and that services need to be provided in a long-term, integrated manner.

**Key words:** brain injury, social care, health care, rehabilitation

## **Introduction**

An Acquired brain injury (ABI) is any damage to the brain, from any cause, that happens during or after birth. Figures suggest that approximately 350,000 people in the UK experience an ABI every year (Headway, 2018a). ABIs are caused by damage to the brain from a traumatic cause (for example road traffic accidents, falls or other external forces) or non-traumatic cause (such as stroke or infections; Headway, 2018a). Physical symptoms include mobility issues, speech difficulties, sensory impairment and fatigue (Haywood, 2010; Marshall et al., 2007). Cognitive problems include language loss, impairments in attention, concentration and memory (King and Tyerman, 2003; Konrad et al., 2011). Some cognitive difficulties are specifically associated with impairments in executive functioning impacting on planning, organisation, initiating activity, problem solving, and decision-making, and often associated with impaired insight into the level of disability (Maas, Menon and Adelson, 2017). Behavioural problems can include irritability and aggression, obsessive behaviour and impulsivity (Arciniegas and Wortzel, 2014; Kelly et al., 2008). Further emotional difficulties include mood swings, anxiety and depression and wider personality changes (Holloway, 2014).

The difficulties faced by ABI survivors can make community rehabilitation and reintegration challenging. ABI survivors may have multiple contacts with health and social care services, including (but not limited to); adult or children's social care, primary health care, community mental health care, housing services, employment services, benefits agencies, homelessness organisations, substance use services, and criminal justice services (Holloway, 2014). There is only limited research studying the experiences of ABI survivors and their families when interacting with community services post-discharge from hospital (Holloway and Fyson, 2016). The period of

discharge from hospital has been criticised for being “fragmented and unsatisfactory for supporting a successful return home” (Piccenna et al., 2016). Several studies have acknowledged existing barriers to community rehabilitation and reintegration for ABI survivors. For example, Hofgren, Esbjornson and Sunnerhagen (2010) found that there was limited flexibility shown to ABI survivors from employers or colleagues when attempting to return to work, and others found that behavioural problems in schools were often not addressed, with the majority of schools failing to acknowledge ABI as the cause (Hawley et al., 2004; Linden, Braiden and Miller, 2013). This results in the individuals not getting the help and the support they need.

Beyond the challenges of returning to employment and/or academic study, the breakdown of interpersonal relationships and family difficulties following ABI can cause social isolation and feelings of loneliness, increasing the vulnerability of those with ABI (Wood, Lioffi and Wood, 2005). Higher rates of homelessness amongst individuals with an ABI has been identified in UK populations, with significantly increased rates mortality compared to non-brain injured homeless people (McMillan et al., 2015; Oddy et al., 2012). Olson-Madden et al. (2012) found that characteristics such as disinhibition, impulsivity, and impaired executive function that can arise from ABI can contribute to the risk-taking behaviour of substance use. The high likelihood of a proportion of people with ABI experiencing these situations highlights the importance of proactive services that can rehabilitate or prevent those from getting into vulnerable situations (Corrigan and Deutschule, 2008; Hwang et al., 2008).

However, it can prove problematic to engage vulnerable ABI survivors in rehabilitation, particularly in instance where emotional or mental capabilities to actively decision-make concerning care have been compromised (Owen et al., 2017). Invisible symptoms including deficits in executive function, verbal reasoning and working

memory significantly impair the ability to understand, reason and appreciate the details of treatment and engage with it (Dreer et al., 2008), and are often coupled with a lack of insight into disabilities (George and Gilbert, 2018). The research undertaken on the vulnerability of ABI survivors and possible impairments regarding capability to make decisions shows the importance of safeguarding those individuals who may find themselves in vulnerable situations (Douglas et al., 2015).

Much research has addressed the difficulties that ABI survivors have, concerning their cognitive, behavioural, psychological, and emotional outcome, and the subsequent effect on quality of life and wellbeing (Braine, 2011; Hawley et al., 2004; Materne, Lundqvist, and Strandberg, 2017; Olson-Madden et al., 2012). This research emphasises the importance of long-term community rehabilitation and support (Salter et al., 2008). However, there is limited research regarding the interface between individuals and families affected by brain injury and health and social care services.

This current study used a mixed methods approach to needs analysis to further our understanding of the long-term rehabilitation needs of ABI survivors, and their family members, and their experiences of accessing community services. By exploring unmet needs, this study aims to 1) identify the long-term community needs of ABI survivors and their families and 2) the experiences of ABI survivors when accessing community rehabilitation services.

## **Method**

### **Participants**

Participants were recruited through social media via adverts on Twitter by the authors and shared by Headway UK and local headway groups across the UK and brain injury case management organisations in the UK. Recruitment also took place directly

through Headway (a network of brain injury charitable organisations), as well as independent brain injury case management organisations across the UK. The authors approached the organisations who advertised the study through posters and leaflets and their website and sent emails to their staff informing them of the study. Interested people then contacted the researcher to take part. To be eligible to participate people had to have had a brain injury at any point in their lives severe enough to cause some form of disability, or be a family member of someone with such an injury or have worked with people with brain injuries for at least 2 years.

Ethical approval was gained through the University faculty ethics committee. Seventy-six participants (aged 19 to 73, mean age 35 years, 48 females and 26 males, three unreported) took part in an online questionnaire on the platform *Survey Monkey*. Participants consisted of ABI survivors (19; 10 males and nine females aged 29 to 72 years, mean age = 44.6 years), family members (26; five males and 21 females; aged 20 to 73 years, mean age = 48.3 years) and professionals working with ABI survivors (32; 18 females, 11 male, three unreported, aged 19 – 60 years, mean age = 35.3). The types and cause of ABI represented by families and survivors can be seen in table 1. The number of years since injury ranged from less than one year to over 41 years, making the cohort a long-term one allowing for the identification of long term needs (see Figure 1). Twenty-one participants (nine female, aged 35-63 years, mean age =) agreed to take part in a follow-up interview. Participants consisted of 12 ABI survivors (10 males and 2 females aged 36-72, mean age = 45 years), five family members (four females, one male aged 21 – 73 years, mean age = 52 years), and four professionals working with ABI (three female and one male, aged 40 – 43, mean age = 42 years).

***Insert Table 1 here***



***Insert Figure 1 here***

### **Design and Procedure**

Participants were invited to complete an online questionnaire on the platform *Survey Monkey* designed to identify long-term needs after ABI. Questions consisted of free text responses analysed using summative conventional content analysis. At the end of the questionnaire participants were given the option to self-select to take part in follow-up semi-structured interviews about service needs and interactions with health and social community care services. The researchers were keen to collect a range of different opinions through the online survey methodology, but also wanted to collect rich in-depth data about the experiences of individuals. Therefore, it was decided to follow up the survey responses with a small number of interviews to gain depth as well as breadth of data. Interviews with professionals and family members took place over the phone, with interviews with the ABI survivors taking place face-to-face, as non-verbal communication can be difficult for ABI survivors (Douglas, 2010). Interviews lasted between 25 minutes and one hour. Interviews were transcribed verbatim and analysed using a mixed inductive and deductive approach to thematic analysis.

### **Qualitative data analysis**

The questionnaires were analysed using conventional content analysis, which provides summative detail of responses along with interpretation of underlying meaning (Hsieh and Shannon, 2005). The responses were read through thoroughly to identify initial codes which were then grouped together into meaningful groups and assigned themes and sub-themes. Data analysis was then refined to create clear category distinctions and to identify evidence of themes through the use of quotes from the original questionnaires. The data were analysed by the investigator and then

validity checked by another member of the research team. Further member checking took place within the follow-up interviews to ensure the validity of the content analysis (Guest, MacQueen and Namey, 2012).

The data from the interviews were analysed using a mixed inductive and deductive approach to thematic analysis (Braun and Clarke, 2006). Themes identified from the content analysis were used to construct a deductive framework for analysing the interviews in order to triangulate the research findings. Each interview transcript was re-read several times and codes relating to the themes identified in the framework were noted. On completion of this process the transcripts were each re-read to identify any new themes that were not present in the initial deductive coding.

While the principles of reliability and validity as applied to quantitative research are inappropriate in this context, internal coherence of the study, transparency and rigour were used to provide a rigorous and robust analysis (Smith and Osborn, 2008). The study aims and objectives outlined above are coherent and consistent with the methodological approach taken to identifying key elements of unmet need and experiences with services. The results displayed below are also consistent with this approach. Transparency was achieved through the use of an appropriate number of quotes to provide evidence of the analysis and through the description of the process of analysis. Finally, validity checking of the analysis by a second member of the team and member checking of the analysis by participants were utilised to ensure rigour.

## **Results**

The analysis revealed three main themes with associated sub-themes; 1) impact of ABI, 2) types of services required and 3) poor access to services (see Table 2).

**Insert table 2 here**

## **Theme 1: Impact of ABI**

The participants in this study identified multiple ways in which their ABI affected long-term functioning not just for survivors but for family members too. The data also illustrated how ABI can have diverse effects on different people. The consequences were best categorised as being associated with; 1) cognitive and behavioural effects of ABI, 2) psychological and social effects of ABI, and 3) impact on families.

### **Sub-theme: Cognitive and behavioural effects of ABI**

This sub-theme emerged as a number of participants reported the degree to which community health and social care services were unaware, or had a lack of understanding, of the impact that ABI can have on their cognition and behaviour. This leaves services unable to appropriately respond to the needs of survivors and their families.

*“Poor understanding of implications of cognitive and behavioural changes, so poor capacity assessments/care needs assessments.”* Survey participant (S)21

Common cognitive and behavioural symptoms described by participants included memory impairments, behavioural and personality changes, and executive impairments including difficulties with planning and initiation of tasks.

*“This happens to me a lot I’m going to say something and then it just goes it’s absolutely rubbish”* Interview participant (P) 19

*“I can’t remember if it was my long-term or my short-term memory. I think it might be a bit of both because I have noticed if people ask me...”do you remember so and so” and I’ll go no [laughs]”* P19

*“I was laughing, giggling making jokes during the funeral service... I lost my libido and then became like, I became a sex addict...”* P8

The issue of lack of insight was particularly problematic with services often failing to understand the complexities of executive impairments that can leave survivors with

residual intelligence but a poor ability to use their intellectual understanding of their deficits in a functional manner. It was reported that this led to safeguarding issues where survivors were placed in potentially dangerous positions by health or social care professionals, and was closely linked to theme three (poor access to services).

*“for that information to...sink in...that conversation to be understood or been taken literally... so on the face of it...they respond quite normally or, or seem whatever is normal and respond appropriately and what we see afterwards is something completely different...there needs to be an approach where have a multidisciplinary meeting and discuss you know...best interest and things like that but ultimately that person has capacity and they chose they're say they're choosing to live like that, well nobody would actually choose to live like that” P3*

*“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”. S32*

This illustrates the tendency to overlook whether or not someone has the mental or emotional capability to discuss the implications and options they have following ABI. Having a hidden disability is linked with cognitive impairments that are not visible, but have an effect on the types of services survivors and their families need, and on the access they receive to community health and social care services.

*“Police not understanding how vulnerable a person is when they can't see the disability.” S11*

*“The way people in various organisations look and treat you .....just because you look ok.” S42*

*“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.” S69*

*“If you met him now you wouldn't think there was a problem...this is where the so-called professionals have kind of not...kind of seen, what was there, I've seen it urm my friends have seen it, my family have seen it because when he has gone to these professionals he has kind of made a supreme effort...” P4*

## **Sub-theme: psychological and social effects of ABI**

Participants highlighted the psychological symptoms associated with ABI, which include; significantly reduced self-esteem, depression, mood swings and PTSD if the injury was caused by a traumatic event.

*"I suffered with I suppose depression for a brief time... I've suffered with PTSD the last couple of years. I had you know very low mood back then."* P23

*"But since then it's knocked my confidence quite a lot..."* P19

*"I think the first month or two I didn't really get a lot of psychological effects but then I started feeling sorry for myself getting frustrated with life in general ...I did feel I was very grumpy as well it completely changed my character in a lot of ways"* P20

As well as the psychological impact of ABI, participants reported the social consequences of living with a brain injury; returning to work or education, gaining functional and financial independence and social reintegration. For example participants found return to work and/or education difficult due the physical, cognitive, behavioural and psychological changes, which often led to difficulties with social inclusion, with many reporting a loss of their social network.

*"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."* S41

*"It's clear he is desperately unhappy, he talks about taking his own life...he hasn't been able to maintain many close friendships"* P5

These changes in circumstances often led survivors to become isolated and had an additional impact on their mental health, and was compounded by other difficulties such as substance misuse. Furthermore, these factors accompanied by social deprivation and cognitive impairments, leads survivors to become vulnerable to exploitation and homelessness.

*As well as increasing social isolation, the long-term symptoms of ABI also have an impact on social deprivation and vulnerability"* S41

*"They tend to urm, be isolated in the community, urm, and they're more likely to, attract people who may have other motives by befriending them, urm, around sort of...using their*

*house...as somewhere to stay if they may be homeless or... exploiting them financially...urm some form of exploitation” P7*

*”he started smoking weed and it was helping him that stuff sleep” “ and it you know when we tried to talk to him about it he said, it’s the only thing that makes him feel better, and I mean it broke my heart one time he said the weed is the only friend I got, he sees it as his only support.” P5*

### **Sub-theme: Families**

The diagnosis of ABI also had an impact on family members, including transitioning to becoming a carer and feeling the burden of care (even when not in a formal care role). In interview one, the participant described the new responsibilities the family had towards her brother and how they adapted to this.

*”urm my mum was expected to, to case manage like she was supposed to know what she was doing and she’s only just floundering above like trying to suss it out for herself...when it comes to (name) personal care, I do that between me and my mum...and because we’re both mothers, I think it makes it easier. When it comes to going out and doing activities, my younger brother (name) tends to do a lot more of that because they have, they’re close, they have good fun with each other, urm but when it comes to hospital appointments my dad mainly goes.” P1.*

Participant 1’s account shows the variety of responsibilities and adjustments families must make to be able to care for those with ABI. However, the mother’s expectations to take on the role as a “case manager” without the specialised knowledge of ABI became a burden. Family burden is also common in those who do not have other members to help with the different roles.

*”you do don’t you, 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.” P4*

*”until eventually the situation became very intolerable” – “cause my daughter at this point struggled to cope” P5*

The participants revealed the impact caring for someone with an ABI can have on their own psychological well-being. This is evidenced by participant four’s interview who described having “suicidal thoughts” when managing the dynamic effects of her husband’s ABI whilst “being an advocate for him”. Some of the participants also

experienced a sense of loss and grief when reflecting on the changes in the person's identity.

*"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." P1.*

*"his personality was totally changed and urm he adopted this, urm very bizarre inappropriate sense of humour, not to the way he was" P4.*

## **Theme 2: Types of services required**

Within the interviews and questionnaires, participants were given the opportunity to provide information about the types of services they felt ABI survivors and their families needed. Specifically, participants discussed the need for services that were tailored, personal and individualised, as opposed to a "one-size-fits-all" approach. Participants also highlighted the importance of care consisting of interdisciplinary teams working together to support the wide range of difficulties experienced by ABI survivors and their families. This care, however, was only considered effective if it was provided by specialist services with specific training and experience of working with individuals following a brain injury. For example, participants pointed to a need for occupational therapy, speech and language therapy and legal support, but that these should be provided by individuals with a background in working with individuals with ABI.

*"Working with disability learning support advisors at University – they treated me as an individual and responded to my needs on an individual basis." S81*

*"The police seemed to understand my brother as a human being better than any other organisation. They tried to offer him tailored support. So did the housing office when his home was frequented with drug users and dealers". S101*

*"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." S29*

*"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." S13*

All participants mentioned the importance of services that include family members and carers, where appropriate, in conversations and decisions about medical treatments and social care support. It is important that families are actively involved to enable them to develop the skills they need for supporting ABI survivors.

*"Police sent female officer as requested. [...] They fully included me as carer". S51*

Other more specific service provision suggested by participants included increased information provision on brain injury at diagnosis, more routine follow-ups post-discharge, a wider focus of longer-term community rehabilitation and support, and better information sharing between agencies about an individual's ABI. Participants described not receiving any information about the potential long-term impact of ABI even in the case of moderate injuries and that this information was not necessarily flagged to other professionals including their GP.

*You'd be a bit more in the system ... you'd have a follow up appointment...and they would know why you needed help, like they would know they would have you on file" P21*

*"I would have liked to have been warned about by a medical professional [of the symptoms of ABI]" P22*

*"um I think it would have been a good idea for me to well for me not to have had to have actually seek out the neurologist in the first place: It would have been nice if they'd actually thought well hang on a minute we put this woman in HDU overnight thinking that she wouldn't survive because she'd bashed her head so hard Perhaps we should have called her [laughs]" P23*

Finally, participants highlighted the need to provide financial support to ABI survivors and their families. This may be through compensation packages to provide money for long-term care needs, or it may be through improved benefits systems that allow easier access to financial security to reduce social deprivation. This is increasingly important as many participants highlighted the increasing number of benefits



assessments that are going for appeal mainly due to a lack of understanding of cognitive deficits on the part of assessors and disability assessments being too heavily weighted in favour of physical impairments (Headway, 2018b).

*"Providing direct payments and personal health budgets that allow personalised care and support." S11*

*"Social Workers 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". S70*

### **Theme 3: Poor access to support**

While theme two describes the types of support participants felt ABI survivors and their families needed, theme three focuses on the challenges in accessing those services experienced by some participants. The problems of poor access to services were best explained through; 1) limited service provision 2) lack of professional knowledge of ABI, 3) ABI as a hidden disability and 4) organisational factors

#### **Sub-theme: Limited service provision**

Participants identified that some lack of access to services resulted from a general lack of services, both general and ABI-specific, across the UK. Specific mention was made to a lack of mental health provision (both generally and a post ABI specialist service) and limited adult social care resources.

*"Follow up care and support after discharge from acute care is very poor, often non-existent". S102*

*"You do begin to start to feel the services aren't going to help you anyway, you know this sort of imagination that there's all this talk about this you know mental health doing this that and the other but what we can't seem to see is we haven't been able to contact these places for years and access any of it." P5.*

*"We hoped he'd get into CAHMS but at social services meetings one of the workers was saying that she'd been working with the school with a boy who actually attempted suicide the whole time, and they still couldn't get him into CAHMS so what became evident was that you know getting a young person...therapeutic help...feels...impossible." S22*

*"I'm on talking therapies. That took 18 months to come to fruition." P13.*

This general lack of service provision has led to a lack of specific, tailored and interdisciplinary care needed by survivors and their families.

*"They might do a program for a sh short period of time...the specialist services that were available were quite generic services, urm it's limited, it's when I say limited I mean none."*  
P3

*"Challenge in accessing psychological assessment or OT assessment for ABI. (S50)"*

*"There is not a specialist service operating in our area and therefore these clients are missing out on specialist rehab."* S31

*"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".* S29

### **Sub-theme: Lack of professional knowledge**

Participants identified that the lack of access to services for ABI survivors and their families is often caused by a lack of knowledge of ABI among professionals acting as gatekeeper to services. A lack of understanding of cognitive, behavioural and psychological symptoms makes it difficult for professionals to accurately assess need. This is particularly important with executive impairments which may lead to issues relating to the need to assess mental capacity regarding specific decisions.

*"Mental health 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. MHS proceeded to tell the client that they could help the client have capacity to manage their money'".* S14

Most participants commented on the positive experience and efficiency of the physical and medical treatment they were given. However, they reported too much focus on this side of the person's care and not enough on other aspects. This may be due to a lack of understanding of the importance of these services in improving long-term functional outcomes for survivors. Participant one described the amount of energy put into the physical rehabilitation of her brother, whilst participant six highlighted the contrast between the short-term medical care to long-term rehabilitation.

*“Everyone seems to focus on getting the person active again, getting them moving, getting 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” P1*

*“My rehabilitation and that was kind of more about my medical needs rather than, long-term you know change” P6*

### **Sub-theme: Hidden disability**

Some of the difficulties associated with professionals’ lack of understanding of ABI could be contributed to the hidden nature of ABI-related disabilities. Participants described how these hidden disabilities acted as a barrier in providing appropriate support due to difficulties in identifying and knowing the severity of ABI. The lack of adequate care towards supporting functional changes owing to cognitive and executive difficulties in particular led to long-term difficulties in accessing services.

*“...but after that 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...sufficient in in long term rehabilitation.” P6*

*“urrrm they closed my case saying look she’s rehabilitated, she can work. Shortly after that, very shortly after that I lost my job...“not getting any support from services and I was written off by people that I used to manage.”P8*

*“Going to see the neurologist was quite a big deal. But I had to do that myself like nothing was really offered.” P23.*

*“The ophthalmologist didn’t know they were interested in my eyes...The fracture clinic was interested in my shoulder... And the maxillofacial people wanted to know whether the bones were healing around my skull...But no-one really knew or cared about what [laughs] what was going on inside my brain you know” P22.*

### **Sub-theme: Organisational factors**

Participants highlighted a catalogue of organisational issues that led to difficulties in accessing services post-ABI. One of the key factors included structural issues that restrict cross-organisational multi-disciplinary team working and information sharing.

*“Social services refused to step in when my brother was made homeless because of his drug taking. [...] The same way true of mental and drug rehabilitation. Each service wanted*

*to treat each of his problems in isolation, rather than treating all the problems as a whole. As a result, he often fell through the gaps in services.” S101*

*“I have found the police (who I work for) and housing officers may not have the information at first point of contact, but will endeavour to get that information before taking action and using this to inform their decision making. A GP is generally a good source of information, however this is not always readily accessible”. S80*

Another obstacle to support included organisational practices that prevented or discouraged active engagement with the family members of those with ABI. Family members are often best placed to understand the changes that have occurred to their loved one post-injury and the degree to which those changes have impacted their functioning. Yet, carers were often excluded from discussions about service requirements or their involvement was not appropriately utilised, affecting the quality of the assessment of the ABI survivor’s care needs.

*“One of the resources that I found that was really lacking in my care was that, I got a very close family and my family members, knew an awful lot about my personality, and about my interests before the injury, and lots of things like that and um I didn’t feel that...the immediate sort of medical services drew on that support they almost tended to exclude my family members from rehabilitation or meetings and things like that and I think that, they really could have really learnt a lot about the way that my interest have formed, and the way that I was involved in my family to a greater degree.” P6.*

*“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”. S17*

Other organisational issues included a lack of funding, lack of resources for professionals, high staff turnover, and high caseloads leading to professionals being overworked and unable to dedicate sufficient time to understanding the needs of ABI survivors and their families. Finally, participants raised concerns that many organisations involved in assessing care needs often do so without spending sufficient time interacting with ABI survivors within their home environment.

*“They’re set out to manage people through...meetings, where people aren’t actually in the meetings, so it’s like a professionals meeting, which I think is ridiculous, um or 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." P7.*

## **Discussion**

The purpose of this study was to understand the long-term needs of ABI survivors and their families, and their experiences of accessing services. The main findings of the study revealed key areas that the participants believed to be important in understanding service user needs and experiences. The data highlighted that the impact of ABI is often poorly understood or overlooked by professionals, this acts to limit access to the rehabilitation and support services required. This was found to be particularly true when it came to cognitive, executive and psychological difficulties. The hidden nature of these symptoms left ABI survivors unsupported owing to assessment processes that were often focused solely upon physical impairments. This led in many instances to long-term social consequences including poor social reintegration, social isolation and social deprivation. The findings also highlighted the need for specialist, tailored and interdisciplinary care that was provided by trained professionals with experience of working with those with ABI and their families. The experiences of poor access to services were associated with a lack of knowledge and understanding of ABI among professionals and the often hidden nature of ABI, as well as organisational issues and limits to service provision.

Langlois, Rutland-Brown, and Wald, (2006) found that there was a high tendency among professionals to overlook the invisible symptoms of ABI. This was found to lead to poor access to services and at times mistrust from survivors and families towards professionals. The current study identified that the picture across the UK remains unchanged with regards to the understanding health and social care professionals have of the hidden symptoms of ABI. Participants were frustrated with the

professional's reluctance to acknowledge the hidden symptoms of their ABI and provide care. This is particularly true of executive impairments which often lead to difficulties in relation to the assessment of mental and/or emotional capabilities where survivors may have sufficient insight into their difficulties to articulate them to others, but may not be able to integrate their knowledge of their deficits into action or to create functional changes to behaviour (George and Gilbert, 2018; Hart et al., 2005).

This study has also supported the findings of previous research that highlighted the difficulties that family members experience as carers (Degeneffe, 2001; Knox, Douglas and Bigby, 2015) and the burden felt by the wider family network (Townshend and Norman, 2018). Furthermore, Braine (2011) highlighted that family members often experience a long-term grieving process for the old identity of an ABI survivor. The current study validated this, showing the psychological effects, including depression and suicidal thoughts, experienced by family members. These findings indicate the necessity for a variety of long-term support for families and caregivers as well as ABI survivors.

Participants in this study also discussed the long-term psychosocial impact of living with an ABI. The findings from this study are consistent with previous research which has found that there is limited service provision for ABI survivors in supporting social reintegration (Hofgren et al., 2010; Liaset and Loras, 2016). Those who are not able to successfully integrate back into the community through employment and other means have decreased self-esteem and feelings of loss of control (Gilworth, 2008) and are more likely to experience social isolation and deprivation (All Party Parliamentary Group for Acquired Brain Injury, 2018). This study exposes a gap in community health and social care services in failing to provide appropriate support to facilitate successful community integration following ABI. Signposting to support

services such as those provided by Headway organisations provides access to community rehabilitation and an opportunity to socialise with others who have experienced an ABI which can promote positive adjustment (Salas et al., 2016).

The study highlighted that ABI survivors needed improved follow-up post-discharge, increased information sharing about their ABI across organisations, and most importantly, care from specialists in neuro-rehabilitation with an emphasis on tailored support from an interdisciplinary team. This is supported by previous work by Kreutzer et al., (2002) who suggested that a more holistic health care approach of the person with ABI is necessary to avoid the treatment of the person being solely focused on the symptoms and disability and return to work and/or education. Participants also highlight the need for more family/carer inclusion throughout the treatment and rehabilitation process. Family/carer exclusion was reported as a factor associated with poor access to services and is supported by previous research by Laroie (2003) who highlighted the importance of involving family members in the rehabilitation process to provide further support to the relative and increase their knowledge. These points identify a need for greater focus on the social and respite needs of ABI survivors and their families.

Sadly, the study findings identified that this approach to care was often lacking and generally little support was provided in terms of community neurorehabilitation, particularly to support cognitive and psychological symptoms. The participants reported survivors experiencing limited access to community health and social care services. This included criticisms of organisational structures and ways of working that limited the interactions between professionals and with ABI survivors and their families in their own environment. Other barriers to services included funding issues and overworked staff.

A strength of the current study was the inclusion of a wide range of participants including professionals working with those with ABI, ABI survivors and family members. While sample size is not the focus of qualitative research, the study was felt to have achieved a sample large enough to allow data saturation to be achieved (where no new themes are identified in the transcripts; Fusch and Ness, 2015). A further strength is the inclusion of participants, or referring to individuals, who are many years post-injury. Most studies of need focus primarily on short term rehabilitation needs and others have struggled with loss to follow up when trying to include those many years post-injury (Hoofien, 2001; Langley et al., 2010). Despite this, the study tended to recruit more participants from the south west of the UK making it difficult to ensure that the findings generalise across the UK. This also makes it difficult to identify areas of best practice that may be taking place across the UK.

This study has supported the findings of previous research which suggests that ABI survivors and their families need specialist, tailored and interdisciplinary care. The study also indicates a need for greater long-term community neurorehabilitation and support that is focused on the more hidden difficulties associated with ABI. While current research on these hidden difficulties and their psychosocial impact is considerable (see Holloway 2014 for a review), only limited research has focused on understanding the knowledge base of professionals within the fields of community health and social care. To date research has identified poor knowledge and understanding among education providers (Linden et al., 2013), nurses (Linden and Redpath, 2011), and social workers (Holloway and Fyson, 2016; Norman, 2016). Further research is needed to better understand the gaps in professional knowledge surrounding ABI across a wider range of health and social care professionals.



The clinical implications of this study suggest the need for wider professional training in understanding the needs of those with ABI and their families. A report by Flynn (2016) identified a lack of professional curiosity surrounding the effects of brain injury and evidenced poor multidisciplinary team working practices that need to be addressed in clinical practice across a wide range of health and social care organisations. Improvements in knowledge and understanding of the long-term effects of ABI, along with improved organisational working, is likely to improve access to services and the long-term psychosocial functioning of survivors and their families. Research also needs to focus on the ways in which information about ABI is documented and shared among organisations to ensure that brain injury is considered in any long-term health or social care assessments.

In conclusion, the study has highlighted the need for long-term specialist care for ABI survivors that is tailored to their specific needs and involves effective interdisciplinary team working. This should involve effective information sharing and the inclusion of carers and family members where appropriate. Professionals working in community health and social care settings should consider the long-term psychosocial impact of ABI for survivors and families when assessing need for access to services.

### **Acknowledgements**

The authors would like to thank Headway UK and all the local headway branches and groups who supported recruitment. Thank you to the many case management companies that also supported recruitment.

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**Table 1: Types and causes of ABI reported by ABI survivors and family members**

| <b>Type of ABI (number of respondents)</b> | <b>Causes of ABI (number of respondents)</b>   |
|--|--|
| traumatic brain injury (34)                | Road traffic accidents (17)<br>Falls (7)<br>Sports/work-related injuries (4)<br>Assaults (6) |
| Hypoxic injury (4)                         | Cardiac arrest (1)<br>Oxygen deprivation (2)<br>Surgery (1)                                  |
| Restricted/disrupted blood flow (6)        | Stroke (5)<br>Aneurysm (1)   |
| Brain Infection (1)                        |  |

**Table 2: Emergent themes and sub-themes, and the number of times encoded, based on summative conventional content analysis.**

| <b>Themes and Sub-Themes</b>                      | <b>Number of Times Mentioned</b> |
|---|----------------------------------|
| <b><u>Theme 1: Impact of ABI</u></b>              |                                  |
| Cognitive/Behavioural Changes                     | 18                               |
| Psychological and Social impact                   | 25                               |
| Quality of Life                                   | 14                               |
| Family issues                                     | 13                               |
| <b><u>Theme 2: Types of Services Required</u></b> |                                  |
| Tailored Care                                     | 39                               |
| Interdisciplinary Care                            | 26                               |
| Specialist Care                                   | 18                               |
| Carer Inclusion                                   | 7                                |
| <b><u>Theme 3: Poor access to services</u></b>    |                                  |
| Limited service provision                         | 23                               |
| Lack of knowledge and understanding of ABI        | 53                               |
| Hidden disability                                 | 8                                |
| Organisational issues                             | 21                               |

