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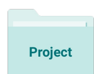

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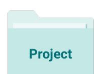

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BABICM
British Association of Brain Injury & Complex Case Management

Supported Decision Making:
Brain injury case managers' experience of mental capacity and the mental capacity act

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ENGAGE WITH PLYMOUTH UNIVERSITY

February 2018 Report

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Introduction

Acquired Brain injury (ABI) can be categorised as any injury to the brain occurring since birth (Headway, 2017). ABIs have many causes, including strokes, tumours or external traumas to the head (traumatic brain injuries; TBI) from a fall, road accident or assault (Headway, 2017). TBI is the biggest cause of brain injury and a major public health problem estimated to affect 8-20% of the general population in a lifetime (Williams & Atkinson, 2012). ABI can affect many aspects of an individual's cognition (e.g. memory, information processing), emotion (e.g. personality changes, sense of loss) and behaviour (e.g. lowered inhibition) as well as physical and sensory impairments (Headway, 2017). These alterations can dramatically impact a person's sense of self, including their role in their social world.

Individuals with ABI often experience executive impairments post-injury associated with damage to the frontal lobes. These impairments include difficulties with flexible thinking, multi-tasking, social behaviour and motivation. Further complications can include problems with planning and organisation, problem-solving, self-awareness and decision making (Headway, 2017). It is often these "hidden disabilities" that cause the greatest long-term problems for individuals with ABI (Clark-Wilson & Holloway, 2015).

The Mental Capacity Act (2005) provides criteria that must be used to support any individual with reduced capacity, including those with ABI, to make their own decisions. Assessments of Mental Capacity must consider four functional elements that have to be addressed; whether the person can understand the information that is given, whether they can retain it, whether they can use or weigh it up to come to a decision, and whether they can then communicate that decision. The Mental Capacity Act (MCA) also states that capacity is decision and time specific, and that an individual may have capacity to make a decision at one time but lack the capacity to make the same decision at another time, thus emphasising that Capacity should be reassessed as appropriate.

The Act emphasises the importance of assuming capacity unless there is reason to suppose otherwise and was designed to protect and empower individuals to be supported in independent decision making. Despite this premise underpinning the MCA, family members, researchers and clinicians have long argued that the MCA does not meet the needs of individuals with a range of different conditions, including ABI (House of Lords Select Committee, 2014). The House of Lords Select Committee report on the MCA highlighted significant shortcomings in the way assessments were being undertaken in relation to individuals with ABI who may lack capacity and in the assumptions that were being made by professionals regarding their capacity (House of Lords Select Committee, 2014).

The ABI and MCA interest group (ABIAMCAIG, 2014) published their recommendations following the Select Committee report. They asserted that supporting people with ABI during capacity assessments in a very structured way can in fact create a false sense of 'capacity', supporting individuals to appear, act and feel more capable than is entirely accurate. The process of assessment may be the compensatory strategy required by individuals to support decision making in the abstract. Owen et al (2015) argued that executive dysfunction associated with ABI is more likely to become apparent outside such structured assessments, and that during clinical interviews people with ABI may appear "unimpaired and lucid" (Manchester et al, 2004).

The MCA guidance makes reference to making 'static' information available during assessment, when actually it is the dynamic, real-life situations that should be tested (Brown & Marchant, 2013). This can cause problems when the individual is required to make complex decisions. Furthermore, standardised capacity assessments do not account well for the impact of emotional state, psychological functioning on people's ability to make decisions (Beadle-Brown, 2015). This creates difficulties when people are faced with real-world complex decisions which have emotional content leading to poor decision-making that may put an individual's safety and wellbeing at risk, or that of others around them (Brown & Marchant, 2013).

Further problems present when assessments of capacity take place without the presence of family members or other professionals who may better understand the needs of the client. For example, the concept of "lack of insight" is not included in the code of practice for MCA (Williams et al., 2012). A common cognitive impairment following ABI is a lack of ability to understanding the degree of one's own impairment; a loss of self-awareness (Prigitano, 2005). Individuals with ABI often struggle to develop an understanding of their difficulties post-injury due to the damage to the brain that reduces the ability to process information, learn from experience and perform higher-level functions such as abstract reasoning (Mantell, 2010). This makes it difficult for some individuals with ABI to make decisions about their long-term care needs without the support of others, including family members and experienced professionals.

The third principle of the MCA seeks to avoid undue paternalism through ensuring people are not deemed to lack capacity simply because they make an unwise decision. Nevertheless in ABI it is often the fact of repeated unwise decision making that is the prominent factor and significant cause for concern (Lennard, 2016; Flynn, 2016). For example, rates of substance use and alcohol dependency post-injury have been reported to be as high as up to 26% (Bombardier et al., 2003; Simpson & Tate, 2002), with rates increasing with the time post-injury. Brain injury is also associated with a greater likelihood to engage in criminal activity, in part due to an inability to make wise decisions post-injury (Shiroma et al, 2012).

There are other common areas where individuals with ABI have been identified as experiencing difficulties in making decisions. These include finances, medical care and living arrangements. Following brain injury, people with moderate to severe injuries have been found to experience global impairment of financial capacity (Dreer et al, 2015). Whilst this improved over a 6-month period post-injury for simple financial decisions, more complex financial management skills remained problematic. Cognitive impairment has been found to impair individuals' abilities to live independently (Harding & Tascioglu, 2017). This, along with poor assessment processes for supported living accommodation is associated with a higher rate of homelessness among individuals with brain injuries than the general population (Topolovec-Vranic et al., 2012).

Following the House of Lords Select Committee request for information regarding the use of the MCA with clients with ABI, the British Association of Brain Injury Case Managers (BABICM) undertook a very successful response, members' evidence playing a significant part in the report that their Lordships produced. We are aware from our practice and our colleagues that issues relating to the assessment of mental capacity, to supported decision-making and supporting people in the community remain a key area of concern. Brain Injury Case Managers (BICMs) have significant experience that will be invaluable in this regard. This research aimed to gain a greater understanding of the experiences and knowledge of BICMs of the issues presented by mental capacity and the application of the MCA. The intention of undertaking this research was to utilise the knowledge and experience of BICMs to inform policy makers, support improvements in the services provided to brain injured people and their relatives and to support BABICM members by the sharing of knowledge and experience.

Method

Participants: A total of 93 participants took part in the survey. Of those, 62 (66.7%) fully completed the survey, with 31 (33.3%) partial completions. The average number of brain injured clients' case-managed in the last five years was 13.2 (*SD* = 6.8), with the minimum being 2, and the maximum being 30. The most common response was 20 clients (Figure 1).

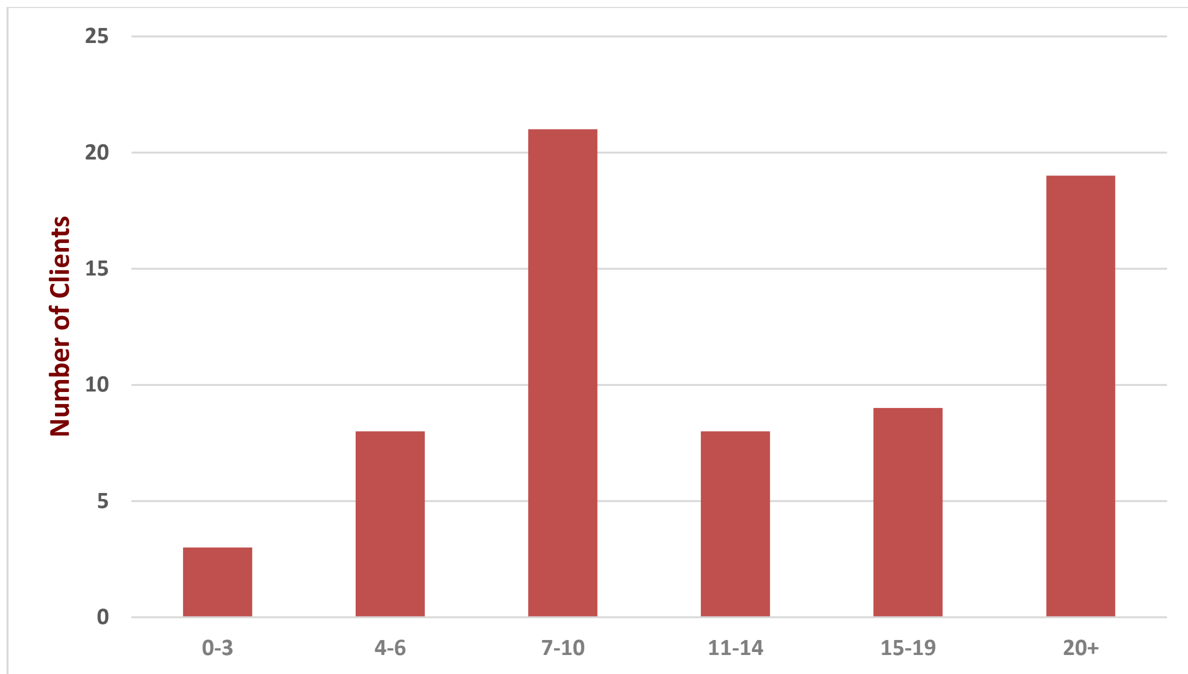

Figure 1: Ranges of Clients case managed in the past 5 years

Design: Respondents completed a questionnaire via 'SurveyGizmo', this included methods such as multiple choices, 4 and 5-point Likert Scales and free text comment boxes. This allowed for the collection of both qualitative and quantitative data detailing BICM's experience with brain-injured clients in the last five years. At the end of the survey respondents were invited to provide detailed feedback about the kinds of issues they had experienced regarding capacity and assessment following ABI. Respondents were also invited to take part in a future telephone interview which will be conducted in Spring 2018.

Results

BICMs were asked to report how many of their clients in the last 5 years had to have capacity decisions addressed of any kind, with 21 clients being the highest reported. Of the 69 responses, the answer ranged from one to over 20 clients (Figure 2). The average number of clients was seven (*SD* = 5.7). Respondents were then asked how many of their clients have multiple capacity issues. Of the 67 participants, the average response was 5.1 (*SD* = 4.9) clients with the minimum being 0 and the maximum being 20 clients (Figure 3).

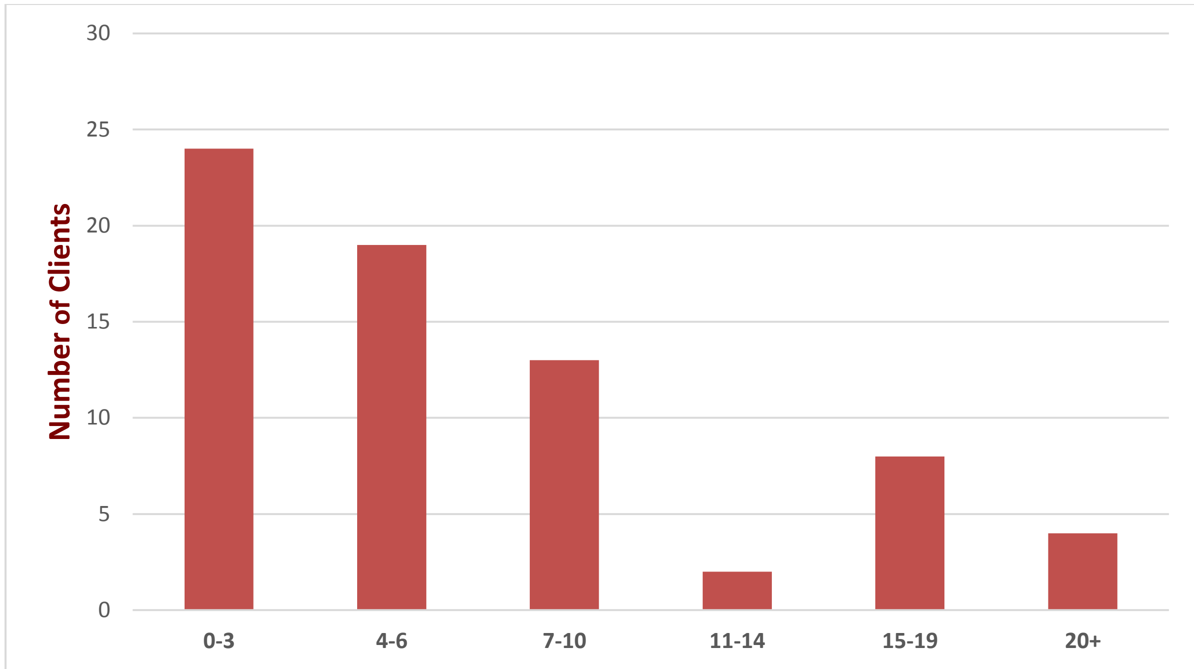

Figure 2: Number of clients in the last 5 years with capacity issues.

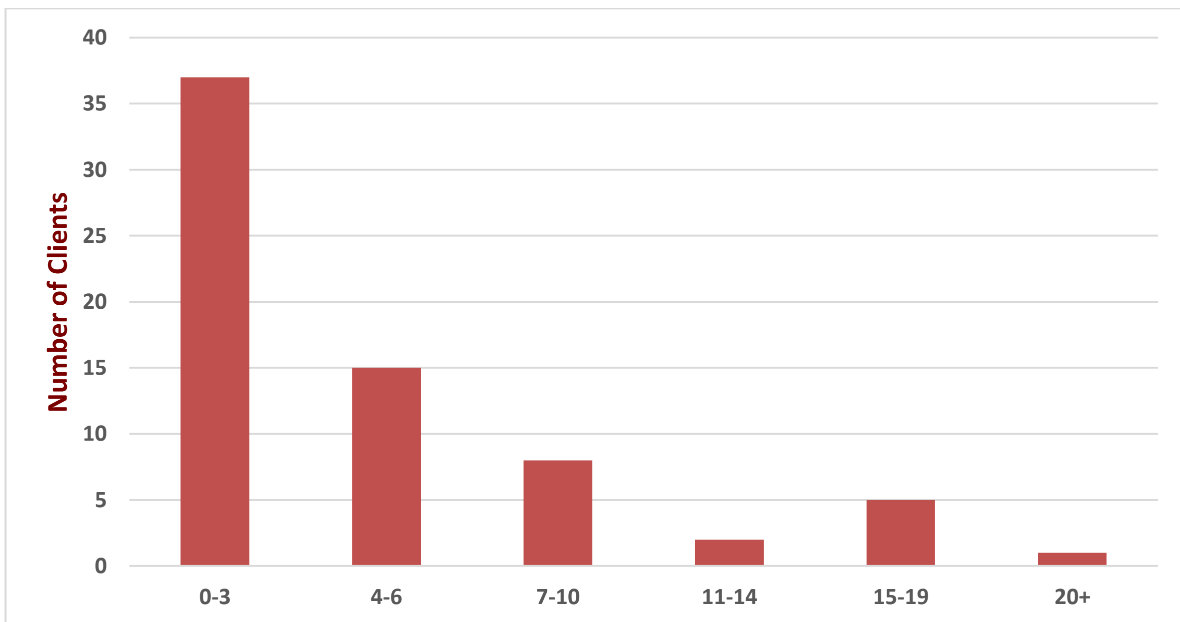

Figure 3: Number of clients with multiple capacity issues in last 5 years

Over half of participants (61.8%) reported that they had experiences where clients had made unwise decisions but were considered to have capacity following an assessment by another professional. Additionally, the majority of participants responded that they had dealt with clients who had fluctuating capacity in the past

five years (Figure 4). This indicates that the majority of participants that completed the survey had experience of dealing with clients with mental capacity issues.

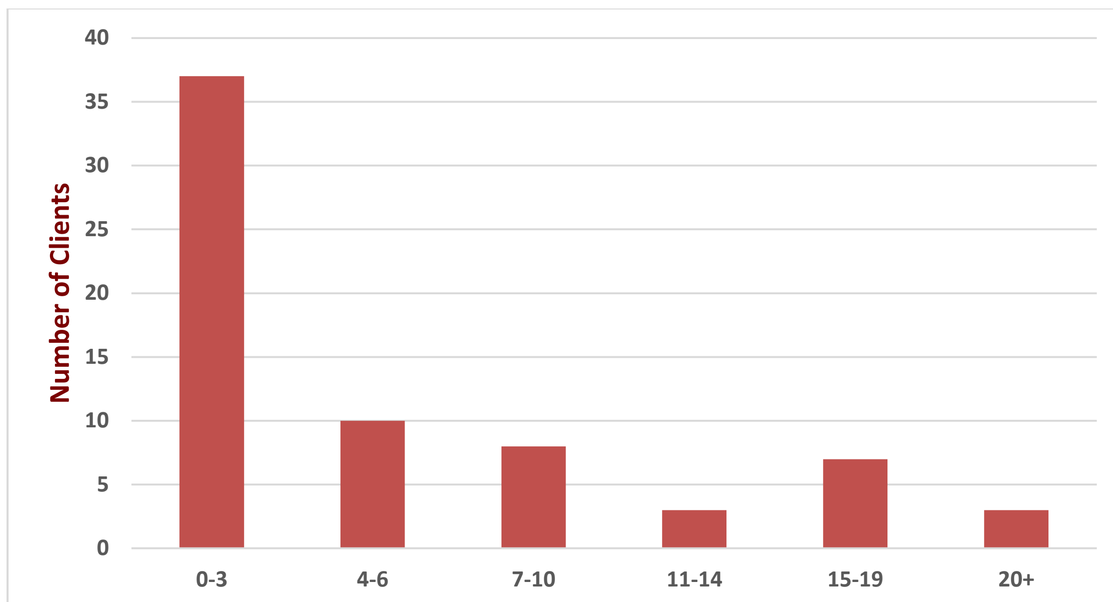

Figure 4: Number of clients reported with fluctuating capacity

There was a significant correlation between the number of clients case managed and the number of clients with fluctuating capacity ($r(66) = .411$, $p = .001$). This shows that as BICMs manage more brain-injured clients, the number of clients reported to have multiple capacity issues increases. Additionally, the number of clients case managed with capacity issues was significantly correlated with the number of clients with fluctuating capacity ($r(66) = .500$, $p = .001$). As expected, this suggests that the more BICMs have clients with capacity issues, the more likely they are to have clients with fluctuations in capacity. Finally, the number of clients case managed with multiple capacity issues was also significantly correlated with the number of clients with fluctuating capacity ($r(64) = .423$, $p < .001$). This shows that as BICMs encounter more clients with capacity issues, they also encounter a greater number of those with fluctuating capacity, as one might expect. The summary of the above results can be seen in Figure 5 below.

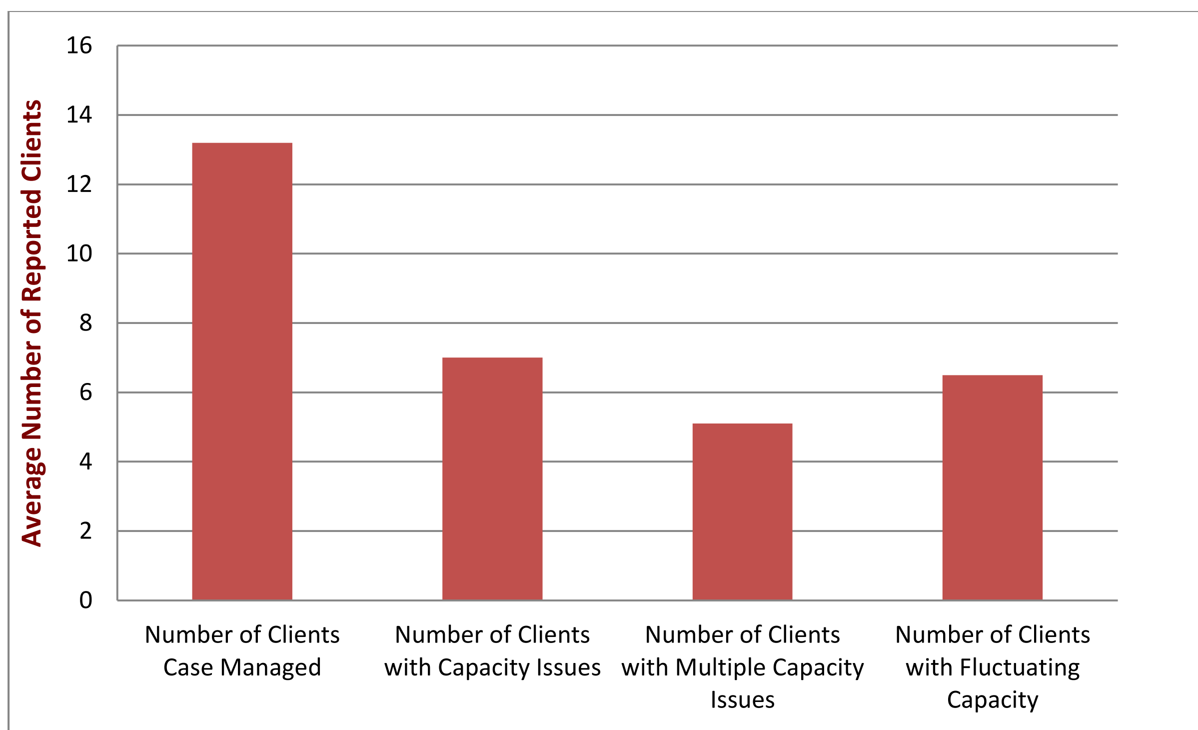

Figure 5: Breakdown of clients with capacity issues

Results from the survey found that in the past 5 years more than half the participants (63.2%) reported having disagreement with other people/agencies regarding a client's capacity. The most commonly sighted issues for disagreement were around a lack of capacity for welfare issues (financial abuse, physical and medical care, and vulnerability), risk-taking behaviour (unwise sexual relationships, substance use and social interactions) and living arrangements (independent living, financial management and need for greater physical care). Although participants were not specifically asked to state which people/agencies that they had experience of disagreements with, 36 respondents provided this information. The results suggest that disagreements most commonly occurred with social services (14 respondents). Others cited disagreements with health professionals (5) or non-professionals (5), and in four cases independent mental capacity assessors (4). Other responses included psychologists (3), insurance assessors (2), solicitor (1) and family members (1).

When asked to rank the domains in which participants felt their clients would be most likely to demonstrate a lack of capacity, "weighing up and using the information' was ranked the highest. The second highest ranked response was "understanding the information", the third highest was "retaining the information for long enough" and the lowest rank response was "is the client able to communicate in any way" (Figure 6). No correlations were found between the answers to these questions and the number of clients managed in the last 5 years, the numbers with capacity issues, or the numbers with multiple capacity issues and the ranking of the answers to the above questions.

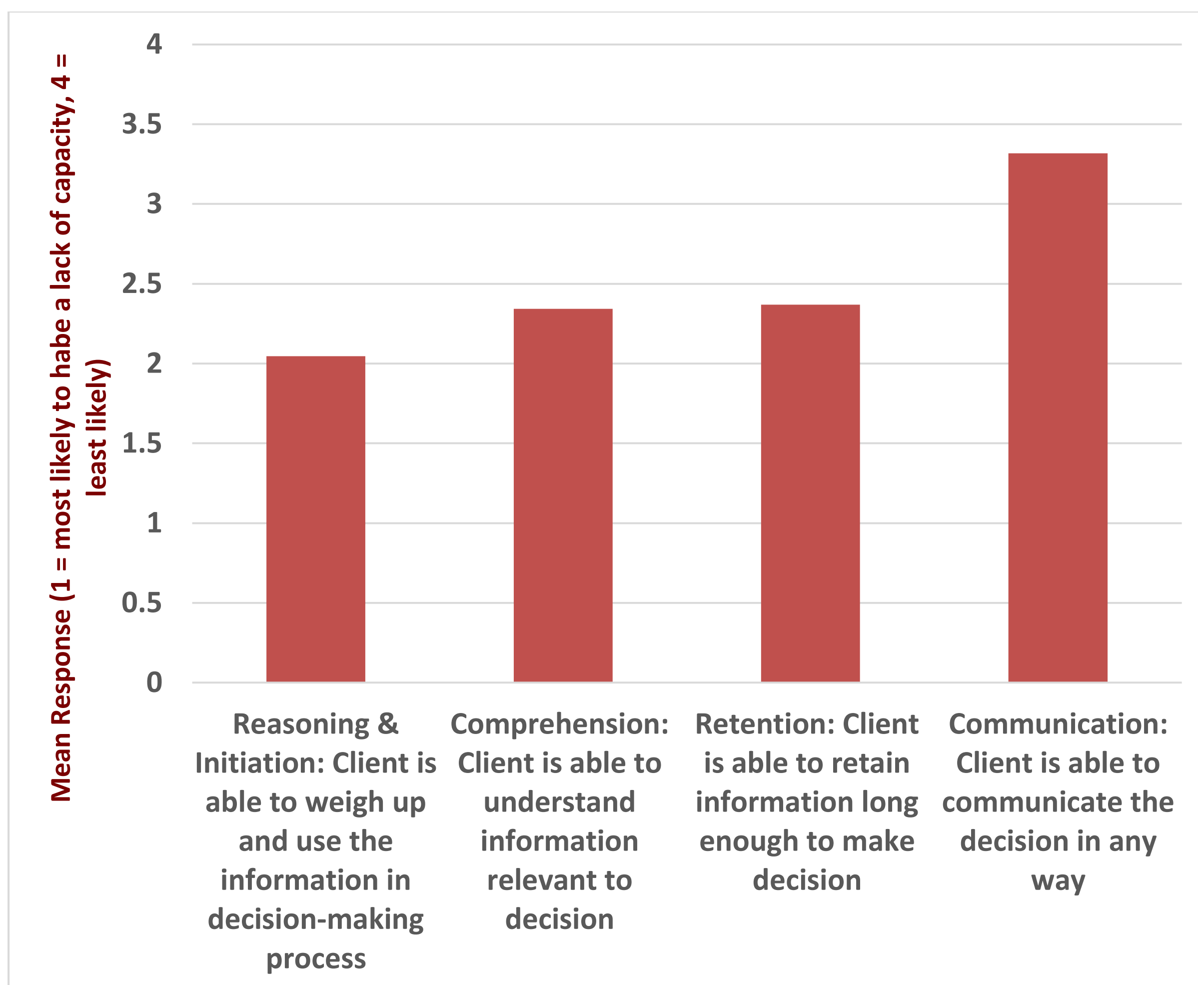

Figure 6: Decision-making abilities in clients

All of the respondents in this survey reported having helped to support individuals with brain injuries to make decisions. When asked to report their agreement with a number of statements, 48.8% strongly agreed that they help clients generate ideas of how to help them manage decision making in specific situations. Additionally, 58.1% strongly agreed that they help clients create pros and cons of outcomes and 56.5% strongly agreed that they support clients to see the potential implications of outcomes. 58.1% of respondents agreed that they provide written feedback to support clients.

Respondents were asked about the involvement of clients and others in the decision-making process. 40.3% agreed that the clients' wishes and feelings are the most important factor in decisions; however, 8.1% of participants disagreed with this statement. Just over half the participants (53.2%) reported that they agreed with the statement 'I support the clients by engaging trusted family members or others into conversations regarding decisions". Furthermore, 64.5% reported that knowing the client and family well helped them support decision making. In contrast, 61.3% neither agreed nor disagree with the statement that 'family members are best placed to

support decisions making, with 30.1% disagreeing, and 1.6% strongly disagreeing. Knowing the client was viewed as an important part of support decision-making. The role of BICMs is long term which enables them to build a relationship with the client and get to know them better than professionals who may only see them for assessments.

The survey went on to ask participants about factors involved in supporting successful decision-making. 33.9% of respondents agreed that their relationship is the main factor in supporting decision making, whilst 37.1% neither agreed nor disagreed. Written agreements with the client in the role BICMs will play with decision making was viewed as being useful in some instances but not in others, resulting in a neutral response, with 46.8% neither agreeing nor disagreeing that they could create these with clients.

No significant correlations were found between the number of clients managed in the last 5 years or the numbers with capacity issues and the responses outlined above. A significant correlation was found between the numbers with multiple capacity issues and responses to question 10.5 in the survey "I provide feedback in writing to support clients to make or sustain decisions" ($r(59) = .301$, $p < .005$). This suggests that the more experience BICMs have in dealing with clients with multiple capacity issues, the more likely they are to provide written feedback to support decision making. Greater experience of working with clients with capacity issues, leads practitioners to improve their working practices in such complex settings by adjusting the way in which they feedback to clients.

The majority of participants (72.6%) responded that they were not aware of any resources to support decision making, with only 27.4% saying they were. This raises an important point about the knowledge of resources out there for supporting decision making. Materials regarding support decision-making do exist on the Local Government Association and Association for the Directors of Adult Social Services websites, yet these were not mentioned by BICMs. This suggests these materials are either not well publicised, or may not be suitable for people with ABI.

No significant correlations were found between the number of clients case managed, the number of clients case managed with capacity issues, or the number of clients with multiple capacity issues and whether participants knew of any resources to support decision making. This suggests that level of experience as a BICM was not associated with awareness of supportive resources to aid decision making.

Throughout the questionnaire, respondents were asked to provide qualitative feedback about their experiences of working with brain-injured clients who lacked capacity. BICMs were asked to provide feedback about the capacity issues they have had to address, the cases they had found most problematic and examples of repeated unwise decisions by clients who were deemed to have capacity. They also provided feedback

on the difficulties brain-injured clients have with decision-making and any examples of good practice involving supported decision; capacity surrounding welfare, risk-taking behaviour, living arrangements, and issues with the Mental Capacity Act (see Figure 7).

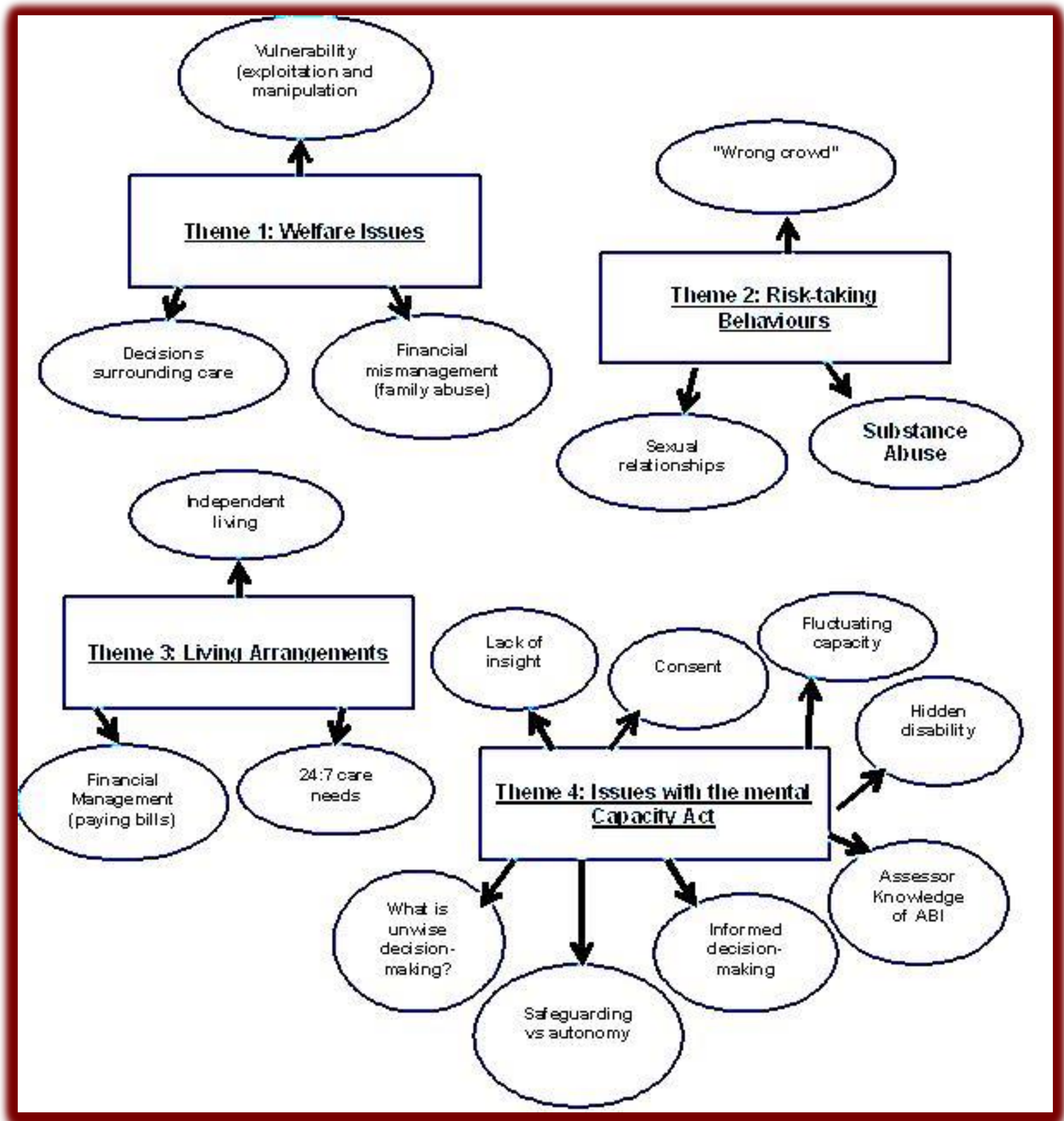

Figure 7: Thematic map of decision-making issues

Theme 1: Welfare Issues: This theme highlighted regular issues surrounding poor decision making about welfare needs and requirements. The theme was related to three sub-themes of vulnerability, decisions surrounding care and financial mismanagement. Vulnerability within the community was identified throughout. Whilst the Court of Protection processes separate out the concepts of finances and welfare, the issue of financial mismanagement is intrinsically linked to welfare issues, as highlighted in this theme. Particularly, it was commented on clients giving away their personal belongings or money to others, being victims of abuse, and breaking the law. This then left participants in vulnerable positions without the resources needed on a daily basis. Additionally, participants commented that clients often do not see anything wrong with giving away their finances/behaving in this way as they do not consider that they are not future orientated.

> *"Client is engaged. Fiancé is thought to be taking advantage financially but she feels this is ok" (P53).*
> *"… leading to exploitation of handing over bank card, however client still viewed these associates as friends" (P63).*
> *"Vulnerable adult – domestic abuse, sexual abuse, financial abuse" (P9).*
>
> *"A young male adult, was deemed to have capacity to live independently and manage a small budget. Client was particularly vulnerable and repeatedly sold/lost / gave away his possessions" (P22).*
> *"Given money to a boyfriend continued to break the law by fare-dodging on trains" (P77).*

These examples of vulnerability included BICMs reporting working with clients who were being manipulated or exploited by family members or partners, or being taken advantage of either financially, often by perceived friends or family members.

> *"Vulnerability and the possibility of other people taking advantage of their situation. This could be family members/ friends or even professionals who do not always act in a client's best interests" (P22).*
> *"Welfare issue relating to whether a client had the capacity to refuse to consent to allow a social worker to approach his girlfriend to discuss with her the fact that she had made threats against him and had threatened suicide if he left" (P6).*
> *"Consider that vulnerable adults with money who may be exploited 'consent' to remain in the relationships, despite the risks identified for harm, exploitation and manipulation" (P7).*
>
> *"Pressures on client from family members or friends" (P55).*
> *"Money, decisions relating to whether to give considerable sums of money away to family members" (P6).*

Participants also spoke about how clients do not necessarily have the capacity to make decisions surrounding their care and the services/support that they need. However participants stated that clients were often deemed to have capacity surrounding decisions regarding their care/support. It was reported that clients often failed to weigh up the effects and the potential outcome of harm regarding their decisions. This is likely to be associated with the cognitive and executive impairments experienced by many brain-injured clients. Capacitous adults may choose to make unwise decisions when armed with all the relevant information and having "weighed up" the pros and cons of that decision. However, for adults with ABI, they often cannot use that rational decision-making process to weigh up necessary information. Instead such clients tend to remain in the present time, being unable to plan for the future or make accurate predictions about how their decisions might influence their future. In these areas, the BICMs may be better placed than non-ABI specialist professionals or clients to predict likely outcomes associated with particular decisions.

> *"Client lacks capacity to make decisions re care treatment … and continues to disengage with each less restricted option that they are supported to engage with". (P33).*
> *"Client decided to not have medical treatment which will affect his mobility longer term" (P39).*
> *"Where client was deemed able to make decisions about medication but repeatedly forgot the reasoning and then failed to take" (P89).*
>
> *"Related to health care decisions - … making unwise and potentially harmful decisions about health care". (P8).*
> *"Hospital staff deciding client has capacity to make decisions regarding hospital discharge plans - two different clients, two different authorities" (P28).*
> *"…decision relating to whether a severely impaired client who was very troubled by a health condition had the capacity to consent to medical treatment (surgery) to fix this bearing in mind his post-operative behaviour was likely to place himself at some risk and his pre-accident anxiety meant that he was unable to retain information relating to the benefits and risks of the procedure" (P6).*
>
> *"Decisions about care provided by the family" (P11).*
> *"Capacity to make decisions around level of care hours/ care planning. Capacity to make decision about therapy engagement Capacity to make decisions around medications" (P12).*
> *"Consent to covert medication. Make decisions about a support package-hours/reduction/risk. Capacity to consent to support in context of DOL testamentary capacity" (P12).*
>
> *"capacity to be involved in a decision at all regarding which support provider to use (in the face of a provider seeking to 'ask the client' what he would like to do*

and give him the choice- when his main reason for liking the provider is that he finds the manager attractive, and lacks insight into his needs and the shortfalls of the provider). Capacity assessment had to be very clear and had to be clear that discussing with him at all would be detrimental to his wellbeing and increase self-harm risk." (P13)

Theme 2: Risk taking behaviour: Another theme that was highlighted by participants was risk taking behaviour. In particular, engagement in sexual relationships was a recurrent issue with BICM's questioning their clients' capacity to make informed decisions regarding sexual consent. It was commented that clients often felt negative after engaging in sexual relationships but still continued to repeatedly carry out the same behaviour. It was acknowledged that some clients were unable to see the potential risks associated with having sexual relationships. Additionally, participants spoke of clients putting themselves in vulnerable positions in attempt to find relationships. This was also the concern in relation to sex work with some BICMs reporting their clients' desire to pay for sex, their concern over their decision to pay for sex, and the sexual exploitation of some clients. One of the key issues here is whether the individuals with the brain injury are making similar decisions to those they might have made prior to injury. Decisions that would not have been made prior to injury may be indicative of capacity issues.

"Client was assessed as being able to have sexual relationships. She subsequently slept with numerous partners who she believed loved her… She was subsequently raped" (P53).
"Client describing low self-esteem and worth subsequent to sexual encounter, however appears unable to choose not to repeat. Capacity assessment indicates otherwise" (P10).
"Using social media inappropriately, to attempt to find a relationship".
"client being used as an unpaid sex-worker, extremely vulnerable in the community" (P25).

"drug using client who was sex working to fund her habit and other people's" (P6).
"Capacity to have sex with boyfriend, with his so-called friends and on line (sometimes at the same time)" (P16).
"Sexual relations. The bar is very low, and psychologists coming in just for assessment may not see the full picture.. psychologist said client had capacity to have sexual relations… Client decided what he wanted… but when I would then go and talk to him about seeing a sex worker (which psychologist said he wanted) he would always tell me there was no need as he was going to get a girlfriend soon. It seemed to me client was fantasying during sessions, and what he actually wanted was a relationship (like others in his extended family) which his cognitive and behavioural difficulties meant he would not be able to" (P19)

"…have queried my client's capacity to have sex… In the last 2 years has begun a relationship with someone who exploits her sexually. He has solicited her for sex with strangers (all men) via a website…The client has said she doesn't really want to have sex with these men, but tells us that she agrees because she wants to keep her boyfriend happy. She does sometimes say "no" to his suggestions that she have sex with someone, but typically always says "yes". She has been found to have capacity to have sex with this man, as capacity to have sex cannot be person-specific" (P21).

"Re consensual sex, psychologist considered client had capacity to consent. Client communications with CM [BICM] suggested otherwise and due to vulnerability, context, expectation this varied incredibly" (P10).

Another area that was highlighted within the theme of risk taking behaviour was that of substance use. A large proportion of participants commented on their clients' decision to engage in substance use, sometimes at the expense of purchasing items required for daily living. Participants spoke of how clients engaging in substance use resulted in participants being taken advantage of and being placed in a dangerous position. Additionally, it was noted that although this behaviour resulted in significant risks, clients were still deemed to have capacity.

"Clients will decide to purchase illegal drugs above their own personal and basic needs such as food" (P26).

"Client drinks and loses all inhibitions, has previously been involved in serious incidents when travelling alone, assessed and has capacity to travel without support outside of Europe" (P59).

"Repeat use of illicit substance leading to exploitation of handing over bank card, abduction … Client not of view support required" (P63).

"Purchasing drugs when they do not have any food, heating in the house. As client has been deemed to have capacity…" (P64).

"when potential behaviours are placing client at high risk and this is considered by statutory services to be a lifestyle choice. For instance, when brain-injured clients are vulnerable and turn to drugs and are then targeted by drug barons, and it is considered this to be 'the client's choice'" (P16).

Overall, there was a sense amongst respondents that brain-injured clients were often unable to make sensible decision regarding the company they kept. Participants spoke of clients engaging with others, despite being taken advantage of on numerous occasions. Engaging with people who may not have the individual's best interests at heart led clients to be involved in situations that put themselves and others in danger. It is important to note here that a key role of the BICM is to promote positive risk (e.g. living independently) in order to foster greater overall independence and progress rehabilitation. This must be managed alongside protecting clients from engaging in

excessive or negative risk when they are unable to weigh up the consequences of their actions.

> *"Regular removal of children due to domestic violence/ drugs/ gangs etc…Client is 'able' to continue with risk taking behaviour, despite the obvious and significant risks' (P7).*
> *"Repeat use of illicit substances leading to exploitation of handing over bank card, abduction, however client still views these associates as friends" (P63).*

Theme 3: Living Arrangements: Many participants commented on their clients decisions regarding their living arrangements. The issues came down to difficulties with assessing a client's ability to live independently due to a lack of insight into their own care needs. In particular, clients are often reported as having the capacity to decide to live independently, despite struggling to sustain a stable living environment. Additionally, participants commented on the clients' choice of accommodation, in particular that they were unsafe, did not meet the requirements to enable support, or were in unfamiliar environments.

> *"We explored various different supported living accommodations and semi-independent living accommodations. We experienced issues with implementing appropriate levels of support and with obtaining regular feedback. We gave the client multiple opportunities to prove himself capable of living independently and remaining in his choice of accommodation, particularly concerning the hygiene of himself and his flat" (P22).*
> *"Accommodation-own home or care home" (P4).*
> *"Decision about where to live in the future (requires 24/7 support but wanted to live in own home independently" (P3).*
>
> *"Capacity to…. what degree / level capacity to make a decision about where (location) and type of accommodation to live in"(P12)*
> *"When a client is homeless and Financial Deputy providing client funds to purchase items that are unrealistic to their circumstances" (P26)*
> *"Client wants to move to Camden, where he knows no-one, and to live alone" (P93).*
>
> *"The choice to purchase unsuitable accommodation, against fire safety and advice and limiting the amount of care that are able to receive due to the size of the accommodation lack of space for live in care staff"(P65).*
> *"Psychologist stated client has capacity, but client kept on making vulnerable unwise decisions about future, such as accommodation" (P50).*
> *"Placing themselves at risk of harm by their impulsive behaviour, unable to sustain stable or consistent place to live, behaviour that places themselves or others at harm" (P20).*

Additionally, with regards to living arrangements, participants commented on the client's capacity to manage finances with regards to living alone. Particularly, it was reported that clients often spent finances on items that were not needed, meaning they had no money left to afford things that support daily living, such as food. Clients often lacked the ability to plan how they would spend their finances and this resulted in them ending up with multiple issues such as debt. The three themes of welfare issues, risk-taking and living arrangements are intrinsically linked in this respect. Decisions are often linked to multiple aspects, requiring the integration of a range of information and variable to make coherent decisions. The BICM can support clients in this way by aiding that integration process.

> *"Repeatedly getting into debt, but said to be able to manage own finances" (P4).*
> *"Client assessed as having capacity to manage financial and property affairs but amassed escalating debts spending money he did not have resulting in (Mortgage arrears – negative equity) unpaid loans. Signing a price tenancy agreement despite acknowledgement this would jeopardise his place on LA housing waiting list" (P36).*
> *"Purchasing drugs when they do not have any food or heating in the house…" (P64).*

Theme 4: Issues with the Mental Capacity Act: Another theme that was commonly highlighted by participants was the need to resolve discrepancies within the MCA itself, and between professional groups. The most commonly reported issue surrounding the MCA was that of intellectual awareness, or a lack of insight. Multiple participants spoke of times that clients reported understanding their actions and the consequences and still continuing to partake in the behaviour. Clients are often unable to learn from past experiences and failures, or integrate their previous experiences to make decisions about, or plan for, the future. Furthermore, it was documented that during assessments, clients appeared to present well overall and have a good level of communication. These clients were often assessed as having capacity, evidencing a 'false sense of capacity'. The capacity to make informed decisions with executive dysfunction was often not considered.

> *"It is the weighing up and using, it is the ability, in real time, online and in the moment, in complex environments to take decisions and act upon them. This is a function of difficulties with idea generation, rigidity, ability to judge what is happening in the environment, deal with feedback and adjust behaviour, inhibit responses, not be overwhelmed by emotional drives, not get caught with concrete and rigid thinking etc" (P6).*
> *"circumstances, context, suggestion and influence of others, episodic dyscontrol, fatigue, memory, attention, mood, impulsivity"(P10)*
> *"client's lack of, or fluctuating, insight" (P54).*

"Memory difficulties which result in client having difficulty retaining information to make informed decisions, and without additional confusion on their part" (P15).

"*Issues associated with lack of insight and dysexecutive functioning" (P16).*

"I have found that my clients can sometimes understand information given to them about a significant decision, and can take part in a discussion of pros and cons about the decision, but are not able to take those discussions into account when they are alone and in the heat of the moment" (P21).

"Clients who have repeatedly made the same unwise decisions, often state they have learnt from previous occasions – but do not…"(P16).

"Placing themselves at risk of harm by their impulsive behaviour… However due to their general presentation and level of communication and their ability to discuss any issues and state what they want and plan to do to manage they have been assessed as having capacity…"(P20).

A common issue that was reported was the lack of understanding of ABI on the part of the professionals who carry out capacity assessments. This was either due to lack of knowledge of brain injury in general, or a lack of awareness due to not consulting with other professionals (for example, case managers) or with family members. It was reported that services/professions can interpret different responses/behaviours as a demonstration that the client has capacity, despite disagreements with other services.

"In each instance, team members of generic/not TBI-specific statutory services have demonstrated woeful misunderstanding of the needs and issues related to this client group as well as, often, mistrust of professional teams involved simply by virtue of the fact that we operate within the independent sector" (P17).

"Assessment completed by social worker who did not know my client, did not take into account any information that was shared regarding the clients history or difficulties" (P20).

"A lack of understanding by non-specialists is devastating in this arena, it kills, quite literally" (P6).

"service management disagreements (lack of understanding of subtle high level difficulties which impact decision making" (P14).

"The lack of knowledge of executive impairment and the role of reduced insight post ABI by professionals who come into contact with people with an ABI and yet fail to notice this. Such non-specialists apply a "common-sense" approach which completely ignores the functional reality of the condition" (P6).

"Assessments being carried out by people who don't understand brain injury, and incorrectly presume capacity, based on a cloak of competence due to injuries being hidden and face to face interactions being misleading. This can be

so strong that as a CM I have felt that the other party truly believes I am 'making up' the difficulties my client experiences" (P13).

"The variety of injuries, subtleties and lack of awareness regarding these from professionals who are identified as proficient. Lack of time to establish relationship to ensure positive decision making. Assumptions regarding family suitability and encourage dependence on the views of others rather than the client" (P7).

"NHS psychiatrist disagreeing with independent psychiatrist re capacity to make support decisions in relation to a DOL assessment" (P13).

"Client was probably borderline with regards to having capacity to decide the next steps in her rehab placement and was being heavily guided by family members. The outcome of the decision was potentially detrimental to her recovery. Clinicians refused to test capacity which would have confirmed or denied the case."(P25).

"poor understanding of BI and the impacts this has, especially with subtle injuries Clients who do not need physical care and live independently, however display more risks and issues"(P7).

"MCA assessor not understanding TBI - dysexecutive syndrome, social worker lacking TBI experience" (P9).

There were also perceived disagreements as to what constitutes appropriate assessment of capacity and how well capacity can be assessed without real world observation. In part this is an issue of a lack of understanding of ABI by non-specialist professionals. BICMs have experience of the executive impairments experienced by clients and the difference between "offline" and "online" decision-making. This respectively refers to the difference between discussing decisions cogently and being able to adjust behaviour accordingly in practice respectively,

It was reported that participants have been advised by other services that capacity of clients can only be assessed if the client engages with the services in the first place. The issue of basing capacity-related judgements from a consultation with the client in isolation was a theme throughout. A lack of time to get to know the client was partly at fault, paired with the effects of ABI being "hidden". When capacity was judged without context, the client's good presentation and "cloak of competence" decided the result of capacity assessments without consideration, or knowledge, of their conflicting actions and behaviours. There was also the issue of fluctuating capacity influencing MCA assessments inappropriately when the client is not known in the context of their daily living and without an in-depth knowledge of the history or previous decision-making.

"Client not of view support required and supported by social worked despite numerous assessments from other professionals' opinion not to have capacity" (P63).
"Psychologist stated client has capacity, but client kept on making vulnerable unwise decisions about future, such as accommodation" (P50).
"Decisions are not discrete, this is a mistake within the act and its application. Decisions are complex, interrelated, developed over time, are environmentally mediated and have emotional contexts". (P6).

"who need capacity to be assessed cannot have their capacity assessed if they do not engage with services!" (P7).
"capacity issues where social services become involved- and I have assessed capacity as being lacking, bit SS have made a presumption of capacity , based on a good presentation (but hidden injuries) and then taken action regarding assessments, support decisions on the basis of capacity, when In fact, I think capacity has been" (P13).

Finally, BICMs highlighted problems with identifying what was classified as unwise decisions and when these could be construed as being a safeguarding issue. It was generally felt that professionals assessing capacity tended to focus on the need for autonomy in decision-making, but this was often at the expense of safeguarding vulnerable adults.

"Changing capacity and how to ensuring they have the support to make decisions when ever needed without over protecting them - just in case a decision needs to be made"(P12).
"current issue with client and power tools - therapists all say unsafe with tools and requires supervision - he agrees but then uses them unsupervised - do we remove tools? lock tool shed?" (P18).
"Decisions where a client has been assessed as having capacity and done something their parents (say) have not liked- tattoos, piercings, having sex- conflict about their right to make capacitous choices and take risks V parents wanting CM to be more controlling" (P13).

"Right to refuse treatment. Client had no capacity and had voiced prior to his injury in the event they became injured that they were no longer to care for themselves they would like no intervention or treatment, no advance decision in place, hospital continued to treat against client" (P23).
"General difficulty in defining "unwise decisions!"" (P8).
"Frustration at not being able to make decisions independently" (P1).

Discussion

The results suggest that the majority of BICMs who took part have worked with clients with brain injury who have issues around their mental capacity, including multiple capacity issues and fluctuations in capacity. Additionally, it demonstrates that those working with clients with mental capacity issues have often had disagreements with other services/professionals regarding the outcome of mental capacity assessments of their clients.

The survey identified three key areas of difficulty regarding mental capacity following ABI. These were those surrounding the client's welfare, risk taking behaviour, and living arrangements. Respondents clearly identified that there was a need to support their clients with decision making with 100% of the respondents stating that they had helped their clients with decision making. This is important as it is reported that helping clients make informed decisions is a key activity undertaken by case managers (Clark-Wilson, 2006). BICMs are well placed to perform this supportive role, because unlike other professionals who may have limited time with clients, or may only interact with them during an assessment, BICMs work long term with clients and their families. They are therefore uniquely experienced in supporting clients to make decisions that are in their best interest long term. A recent report on everyday decisions highlighted that BICMs were particularly good at supporting complex decisions and communicating in a nuanced way (Harding & Tasciolu, 2017).

Whilst BICMs highlighted the need to support decision making in their brain-injured clients, and generally felt that a client's wishes and feelings should be considered, a small number of case managers disagreed with this statement. This is interesting from the view of the MCA which states that if decisions are to be made for a client, they should be made as close to the client's wishes as possible. It also relates to the current personalisation agenda, in which the individual service user or those closest to them, are considered to be the best at understanding the individual's needs. This model suggests services should be fitted to meet the needs of the individual, and that service users should, for example, be able to control their own budgets. However, this may not always be the best course of action for individuals with brain injury, where their ability to have sufficient insight into their difficulties, coupled with an inability to manage their own finances could make this option unrealistic or to some extent, dangerous (Holloway & Fyson, 2015). The impact of the client's environment must also be taken into account, as this has been found to impact decision-making, risk and capacity (Harding & Tasciolu, 2017).

There was disagreement amongst respondents regarding the importance of including family members in decision making processes. Whilst research has identified a need to include family members who often know the client better than others (Norman et al, 2018), the cases of financial abuse reported by case managers here denotes the need

for caution when involving family members who may not necessarily be working in the client's best interests. Additionally, clients can often be involved in litigation claims, so involving the family might not be the best option as there may be a potential conflict of interest.

Participants reported several issues with regards to the MCA and mental capacity assessments. In particular, the MCA does not take account of the interrelated, complex, and emotional aspects of decision making. Additionally, different statutory services can have different 'thresholds' for capacity. This therefore suggests discrepancies within the MCA that can be interpreted differently by different assessors and services. On this note, many of the examples of issues around capacity documented by participants involved the client making 'unwise decisions'. However, one of the principles of the MCA is that "a person is not to be treated as unable to make a decision merely because he makes an unwise decision". It is argued that in fact, ABI often results in repeated unwise decision making, and it is this that is a prominent factor and significant concern (Lennard, 2016). The executive impairment associated with ABI makes it difficult for individuals to learn and generalise from previous experiences. Whereas, adults more generally may choose to make unwise decisions in possession of all required information, individuals with ABI often make consistently unwise decisions that are not based of the weighing up of all information, or their past experiences and failures, as stated by the British Psychological Society in their response to the House of Lords Selective Committee on the Mental Capacity Act 2005 (2014). Furthermore, these decisions may be in conflict with the decisions that might have made prior to their injury.

Most participants highlighted "weighing up and using the information' as the key domain where a client is likely to demonstrate a lack of capacity. This is associated with the idea of intellectual awareness (Crosson et al., 1989), in that in a structured and formal environment, with the right support, clients with ABI can appear to demonstrate a 'false sense of capacity'. Some clients are able to comment on their difficulties, and even highlight strategies to compensate for them, but they do not evidence this behaviour outside of the formal setting of capacity assessments (Holloway, 2014). Furthermore, a number of clients were even reported to be able to identify the consequences of their actions but this did not have an effect on their subsequent behaviour. When exposed to decision making away from this environment, the client is unable to weigh up and retain the information in order to make decisions, especially if the decision is complex and contains emotional content, which can put them at risk (Brown & Marchant, 2013). These multiple facets of real-world decision-making are not discrete decisions that are time-limited or easily separable as the MCA assumes.

In conclusion, this survey has identified many key areas where clients with brain injuries are struggling to make capacitous decisions. In many of these instances, the MCA and

the capacity assessments are not suitably protecting these vulnerable individuals, leading to unwise, unrealistic and often dangerous decision making. Changes need to be made to the application of the MCA in order to take account of the complex needs of individuals with ABI, particularly regarding lack of insight, and the often hidden effects of their executive impairments.

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