Acquired Brain Injury and Mental Capacity.

Recommendations for action following the House of Lords Select Committee Post-Legislative Scrutiny Report into the Mental Capacity Act:

Making the Abstract Real.

A report by the Acquired Brain Injury and Mental Capacity Act Interest Group

September 2014

1. RATIONALE AND SUMMARY OF CONTENT:

The Acquired Brain Injury (ABI) and Mental Capacity Act (MCA) interest group was established during the House of Lords Select Committee's post-legislative scrutiny of the MCA.

The group is formed of frontline professionals and policy makers who have a specialist interest in brain injury and come from a variety of medical, therapy, legal and other backgrounds. The group members are listed at the end of this document ***(Page 41)***. A majority of the interest group's membership has contributed directly to creating this document.

We fully support the work already carried out in the last twelve months by the Mental Capacity Act steering group, the Department of Health and others to meet the challenges presented by the implementation of the Mental Capacity Act 2005 with what is recognised to be a well-intentioned and drafted piece of legislation.

This document identifies:

- A number of actions that will support the MCA steering group to put forward changes to meet the recommendations made by the House of Lords Select Committee and reduce the difficulties presently encountered by those using or subject to the Act.
- The role of the Brain Injury Rehabilitation Trust's (BIRT) Brain Injury Needs Indicator (BINI) in evidencing brain injury during an adult social care assessment. This tool is presently being piloted by local authorities.
- A number of real-life examples of the use of the MCA and 'on the ground' difficulties experienced by service users, their families and health and social care professionals.
- A referenced outline of where people with an acquired brain injury may encounter services and/or difficulties with decision-making, whether they have or lack capacity.
- The role and difficulties encountered by social workers and others in relation to their role using the MCA with people with an ABI.
- Collates and appends the references to acquired brain injury within the House of Lords report and from the published evidence and matches those with our recommendations.

2. NEURO-PSYCHO-SOCIAL IMPACT OF ACQUIRED BRAIN INJURY:

Most people who suffer a brain injury will not have a physical disability as a result (Higham and Phelps, 1998). Consequences of acquired brain injury are therefore often invisible and can be subtle but devastating for the sufferer and their family and community. People are often left fatigued, with slowed speed of processing, difficulties with attention (divided, sustained, selective etc.), with memory, planning, organising, initiating activity, problem solving, with rigidity of thinking, disinhibited behaviour, predicting and understanding the consequences of one's actions, impulsivity and aggression. The sufferer rarely has complete insight into their condition.

Some brain injury related difficulties are apparent at the time of discharge from hospital but many will not be, becoming more so over time as the injured party endeavours to re-establish pre-injury roles and functions. Impairments to cognition are sometimes measurable via neuro-psychometric testing however tests of executive functioning are noted to have low ecological validity. (Manchester et al., 2004) Observation of changes in functioning pre and post injury and over time, informed by third party evidence supports more accurate assessment.

With this vast array of complex if sometimes subtle problems, it is unsurprising that brain injured people's return to work or education can be severely limited and that friendship networks and psycho-social functioning diminish, sometimes entirely; some of the people we work with are not able to maintain any meaningful friendships.

As the condition itself is not visible, is easily misattributed to wilful behaviour and is not widely understood by health and social care services, it is not surprising that families are left to cope without access to adequate support and information. Frequently IQ is not affected (or not affected greatly) and so the sufferer looks unchanged and may believe themselves so.

Assessment of individuals following an ABI is therefore difficult, sometimes extremely so, and this is a function of the condition itself.

3. OVERALL SUMMARY, CONCLUSION AND RECOMMENDED ACTIONS:

1. The Brain Injury Needs Indicator (BINI) is a very simple-to-use document developed by brain injury specialists to facilitate non-specialist colleagues identify ABI and support the completion of a valid assessment of need. The BINI is currently being piloted in conjunction with the Department of Health. It can be adapted to support non-specialist staff, particularly social workers, to alert them to ABI-related needs and the potential to seek specialist support to aid their decision-making regarding matters of mental capacity.

   A more detailed description of the development and use of the BINI is contained within this document. ***(Page 9)***

   There is evidence of the usefulness of this tool in practice.

   Action:
   To produce a similar tool that works specifically to assist with Mental Capacity Act assessments for individuals with ABI. The new tool, like the BINI, would adhere to the already rooted legislation and any new changes put forward. The tool would be specifically developed for those involved in the process of assessing capacity but who do not have specialist knowledge of brain injury. The ABI/MCA interest group and BIRT are willing to work together on this project if the Department of Health backs it to ensure its effective use.

   This action will support meeting their Lordships' recommendations 1, 5, 6 and 11.

2. The emphasis on current social worker (and other professional) training relates to the completion of capacity assessments but is lacking in instruction around underpinning knowledge of specific disabilities and impairments that may lead to capacity being questioned.

   An absence of this knowledge impacts upon the ability for this to be undertaken adequately, leading to potential for unnecessary and often damaging outcomes which may put the individual at risk (***see case studies starting on page 10***). In the field of ABI this is more likely because the social worker or other professional often does not understand issues around lack of insight i.e. the difference between the individual with executive impairment saying what he believes he can and will do and actually being able to 'action' it.

   As ABI is a fundamental and integral part of all social work (and other professional) practice ***(see section 6 The impact of ABI on individuals families and communities, starting on page 18)***, not just specialist practice, this knowledge gap requires addressing during training and on an on-going basis. There is clear evidence of the danger and difficulties presented by this lack of knowledge, understanding and experience. To our knowledge, no present plans would appear to be set to address this.

Action:
Provide specific training to social workers and other professional groups to address the challenges of assessing the capacity of an individual with ABI. Currently our experience is that social work staff are trained to use a form to assess capacity but not trained to understand the nature of the impairment(s) that may affect capacity. This training will be most effectively carried out in conjunction with the use of the adapted BINI. Members of the ABI/MCA group can assist with the design and implementation of such programmes.

This action will support meeting their Lordships' recommendations 1, 5, 6 and 11.

3. Independent Mental Capacity Advocates (IMCA's) have precisely the same issues and difficulties as social workers and other professionals with regards knowledge and impact of ABI in functioning and this will need to be addressed if this potentially valuable resource is to be better used. ***(See examples 1 & 2 page 10 onwards)***

   There is clear evidence of the danger and difficulties presented by this lack of knowledge, understanding and experience. To our knowledge, no present plans would appear to be set to address this.

   Action:
   IMCA's require specific training on matters related to the nature of ABI to be able to fulfil their roles appropriately.

   This action will support meeting their Lordships recommendation 23.

4. We understand that decisions regarding how the MCA is managed and monitored on an on-going basis are still under discussion. However, at some stage, an "overseeing" type body or organisation of some form will be established. We would lobby strongly in favour of this body being directly informed of ABI, and that professionals with influence within said organisation have considerable ABI experience.

   With the exception of individuals who remain in vegetative states/low states of awareness, the majority of issues that relate to capacity and ABI will revolve around difficulties such as executive impairment, reduced insight, cognitive difficulties, impulsive/disinhibited behaviour, self neglect and the influence of the environment. As such these are "psycho-social" issues (or perhaps more accurately neuro-psycho-social) and not medical ones. Therefore we would argue that the brain injury-aware professionals who support and inform the MCA overseeing organisation would do so better if their ABI experience were reflective of these areas.

   The House of Lords report and evidence provided is testimony to the difficulties that present when a lack of ABI specific knowledge predominates. However it is decided that the MCA is monitored and managed in the longer term, direct ABI knowledge from specialists will reduce the well-evidenced difficulties that are currently apparent.

Action:
Enlist ABI-knowledgeable professionals within the MCA overseeing body to reduce this specific difficulty.

This action will support meeting their Lordships' recommendations 3, 4, 9, 12, 14, 19, 26, 30 and 31.

5. ABI-specific services have a track record of "creating" capacity or "supported decision making" that facilitates greater community engagement and involvement for people who may otherwise lose their place in the community or be placed at unnecessary risk by their actions/inactions or, as importantly, the actions/inactions of others in the community.

   The extension of DOLS to domestic settings as per the Judgment of the Supreme Court in the P v Cheshire West and Chester Council and P and Q v Surrey County Council is to be welcomed as a way of ensuring protection of individuals lacking in capacity and resident in the community. A number of extremely complex people with an ABI are managed in the community by managing the environment around them, a form of "*Antecedent Dependent Reflexive Operant Conditioning".* Such packages are often run by highly-trained support staff who are reacting, in the moment, to support brain injured people manage their behaviour. As such it will not be entirely possible to predict the exact nature of the liberty that an individual may be "deprived" of in order that their overall behaviour and functioning can be maintained. ***(For an example of this form of support package please see example 2, page 11)***

   Future work on the DOLS adaptation/replacement will need to take account of this in order that an unintended consequence of any new DOLS does not increase the risk of community placement failure/removal to inpatient settings with concomitant increased costs and, perversely, greater chance of liberty being deprived. Those undertaking work drafting documents in relation to future DOLS will benefit from being supported to gain a greater understanding of how such packages work and how they promote community engagement, creating capacity and supporting decision making.

   Specialist brain injury services report worrying and significant gaps in knowledge around the impact of acquired brain injury amongst Best Interest Assessors (BIA) and, disturbingly, potential conflicts of interest relating to the recommendations made by BIA's when these have a financial impact upon an authority. This conflict of interest, particularly but not exclusively if it crosses authority boundaries and normal residence is questioned, will need addressing. The role of BIA and commissioner needs to be clearly separated to ensure the spirit of the Act is upheld.

   Action:
   Members of the group that have informed the writing of this document are very well placed to support the team that undertakes the process of updating the DOLS.

   This action will support meeting their Lordships' recommendations 13, 14, 15 and 21.

6. Headway, the UK-wide brain injury charity is well placed to support non-specialist clinicians and others who come across brain-injured people who may or may not have issues pertaining to decision-making and capacity. Headway has a range of documentation and information that is user friendly and sign-posting of where further support can be obtained.

   In particular Headway has launched a campaign to support General Practitioners. Conversations with Headway staff would suggest that this well-received campaign would be far more effective if it received stronger backing from within the Department of Health.

   Other organisations such as the United Kingdom Acquired Brain Injury Forum (UKABIF), British Association of Brain Injury Case Managers (BABICM) etc. are also able to contribute to the essential training of General Practitioners and non-specialist health, care and other staff.

   Action:
   Department of Health to work with Headway, UKABIF, BABICM and others to promote greater knowledge and understanding of ABI and ABI/MCA issues dealt with by GP's.

   This action will support meeting their Lordships' recommendation 8.

4. BRAIN INJURY NEEDS INDICATOR (BINI)

The BINI was developed by the Brain Injury Rehabilitation Trust (BIRT) along with a stakeholder group of twenty-five local authorities and approximately the same number of specialist brain injury organisations. It was produced following a meeting with the Department of Health (Paul Woods, Social Care and Policy) as concerns had been expressed by local authorities about the difficulties in accurately assessing the needs of people with brain injury. The rarity of specialist brain injury social workers added to the argument that a tool that evidenced brain injury and highlighted specific deficits associated with these injuries should be developed for non-specialist staff to use during a formal care needs assessment under the Care Act. The draft BINI promotes an 'ABC' method, reminding the assessor to think about the use of an Advocate, using the BINI correctly and conversing with the individual's treating Clinician to form an accurate picture of social care need. The BINI then advises on the next steps for the assessor to take.

The resulting sixteen-part draft questionnaire is downloadable from the BIRT website and there will be no charge for local authorities to use it.

Following discussions with the Department of Health and the stakeholder group it was determined that one of the most difficult symptoms of brain injury to establish during a social care assessment is whether and how executive function has been impaired, how such deficits are impacting on the individual and whether individuals with an ABI can accurately state their needs.

The tool is designed to evidence if there is a lack of insight by using the 'ABC' method and a series of triangulated questions that will highlight any inconsistencies in answers given by the individual. Further, the tool is designed to work effectively in conjunction with the Care Act's Regulations and Guidance on assessments and advocacy so that local authorities can implement good practice when assessing individuals with brain injury.

The BINI is also undergoing trials with four separate local authorities. Social workers and assessors will use the BINI each time they assess an individual with suspected or established brain injury. After twelve weeks feedback will be gathered and this, along with the final Care Act regulations and guidance will be used to publish the final version of the BINI in April 2015.

If the MCA Steering Group give backing to this plan, MCA/ABI interest group and BIRT staff are happy to look at adapting the BINI to provide non-specialist staff with a tool that will support and assist them when issues relating to mental capacity and ABI.

A copy of the current draft of the BINI is available via the Disabilities Trust website ***(www.thedtgroup.org).***

5. EXAMPLES OF ISSUES OF ACQUIRED BRAIN INJURY AND CAPACITY IN PRACTICE

All names and identifying locations etc. have been changed to maintain anonymity however these are genuine examples not composites.

5.1 EXAMPLE 1: Mr Kamal – Assessing invisible difficulties

Mr Kamal acquired a severe injury to the brain aged 15 when he was a pedestrian hit by a car. After six weeks in hospital he was discharged home with outpatient neurology follow up. Mr Kamal had no physical impairment, no obvious loss of IQ and no insight into his on-going difficulties. Mr Kamal had significant problems with idea generation, problem solving and planning. This makes him very vulnerable to other people as he simply agrees with whomsoever he is talking. Mr Kamal was able to get himself up, washed and dressed but did not initiate making snacks for himself. He was very passive and was not engaged in any regular activities or structure.

Aged 20, Mr Kamal's family were aware that he had not developed as they would have expected, they met all of his needs with regards managing the household, providing him with meals, managing his finances etc. Following a chance conversation with a neighbour they contacted their local Headway, which recommended that they request an assessment from a local authority care manager. Mr Kamal's family initially experienced difficulties as the local helpline stated that as he had no physical impairment he was not entitled to an assessment. Eventually a one-off assessment was arranged and undertaken.

The assessment concluded that all of Mr Kamal's needs were met by his family, that Mr Kamal himself did not see the need for any input, that he failed to meet eligibility criteria for services and that he would benefit from going to college or finding employment. He was provided with leaflets.

Mr Kamal's family challenged the assessment and stated that they could no longer continue to meet all of his needs. The care manager stated that until there was evidence of increased risk, social services would not act. The family refused to place Mr Kamal in his own accommodation and leave him to fail to eat, take medication, manage his finances etc. simply to generate the evidence of risk that was reportedly required. The care manager said that if Mr Kamal lived in his own accommodation he may meet eligibility criteria and suggested that Mr Kamal manage this himself via a personal budget.

Via moneys accessed through a litigation claim, Mr Kamal's family purchased specialist services for their son and established him in his own accommodation. Significant disputes arose within his family regarding what his best interests were and how these should be met. Mr Kamal was referred to social services by his independent brain injury case manager as he was being very badly affected by these intractable disputes and had no capacity to resolve them owing to his brain injury. The social worker allocated did not speak to any members of the specialist brain injury team who had worked with him for over five years, undertook a capacity assessment for welfare decisions which did not mention anything to do with his cognitive and executive impairments (unsurprisingly and contra all previous assessments, she found capacity to be present), made allegations of abuse against the family and professionals involved and brought in an IMCA with no knowledge or experience of brain injury.

EXAMPLE 1 CONTINUED:

Despite best efforts to support the IMCA to learn about the impact of Mr Kamal's acquired brain injury he resolutely refused to take any of this knowledge on board as a stated point of ideological principle, saying that this would make him "medical model". The IMCA was unable to comprehend that the viewpoint he had obtained from Mr Kamal was one that the IMCA had generated himself. If he had made other suggestions to him, Mr Kamal would have agreed with those instead. It was even demonstrated to the IMCA that it was possible to make Mr Kamal state entirely contradictory viewpoints within a space of five minutes and this fact was openly acknowledged by all parties who had known him during the years since his acquired brain injury.

18 months and tens of thousands of pounds later this ended up in the Court of Protection where the specialist treating team were found to have been correct all along and allegations and investigations were finally dropped. Had the social worker and IMCA's view predominated this client would have been at extreme risk of self-neglect and abuse. There was clear evidence to support this fact as found by the Court.

5.2 EXAMPLE 2: Mr Jones – Confusing unwise decision-making with capacity to make welfare decisions.

Mr Jones had a long history of substance use, funded by petty criminal activity, when he suffered a very severe brain injury in road traffic accident aged 35. Mr Jones spent 18 months in hospital and an NHS rehabilitation unit before being discharged to a nursing home near his family. Mr Jones had no significant physical difficulties but suffered severe memory impairment, considerable executive difficulties and was irritable and very aggressive. Mr Jones did not eat or drink unless it was provided for him.

Mr Jones did not believe he had any difficulties and refused to return to the nursing home following a visit to family. Mr Jones, separately to his brain injury, had significant lung and heart conditions that required regular monitoring, medication and careful management. These conditions could be fatal.

After several years living with his elderly father, during which time Mr Jones began drinking very heavily, Mr Jones's aggression and lack of self care lead to frequent A&E visits and calls to the police. Mr Jones received virtually no services in the community as he rejected them, sometimes violently. The local CCG did fund a small package of non-specialist support work but the staff were unable to engage Mr Jones at all to participate in any activity. Instead they watched television with him. At this stage Mr Jones was noted to be drinking up to 50 cups of tea a day with large amounts of sugar, smoking heavily, drinking heavily but to eat on average around once a week.

Mr Jones's decision to not follow medical advice, to not take his medication as it was prescribed and to refuse virtually all input was repeatedly assessed by non-brain injury specialists to be acceptable as he was defined as having capacity. It is estimated that he saw over 30 different health and social care professionals over several years, each of whom did not question his capacity. Social Services stated that they could not be involved, as Mr Jones did not wish them to be. It was considered to be his "human right" to refuse to eat, wash and engage. At this stage Mr Jones was noted to be pulling out his own teeth with pliers, as they were so painful.

EXAMPLE 2 CONTINUED:

Assessment by brain injury specialists identified that Mr Jones lacked capacity with decisions relating to his health and welfare (and finances) and an application was made to the Court of Protection. The application was fought at length and great cost by local health and social services. An IMCA was requested by social services and they reported what Mr Jones told them, that he did not want any rehabilitation. The Court of Protection found in favour of the brain injury specialists and under a Declaration of Best Interests Mr Jones was taken to a specialist brain injury rehabilitation unit. At the time of his arrival all of his remaining teeth had to be removed and he was noted to have not showered for at least six months. Had local services and the IMCA's views prevailed there is good evidence that Mr Jones would have died.

Three years on and Mr Jones lives in the community with support (funded independently via litigation and managed by a team of brain injury specialist professionals), he is very engaged with his family, his health and wellbeing are well managed and he is very active and structured, he undertakes voluntary work helping other people.

Mr Jones has not intrinsically changed, the environment around him has changed and the biggest factor in his environment is his staff. To promote his placement in the community the team regularly and consistently reduce the choices Mr Jones has to make. This is a clinically agreed protocol and is a reflection of his impairments and needs as well as his reasonable goals. This requires staff to act in a uniform and sometimes counter-intuitive manner.

Staff action/words	**Mr Jones reaction**	**Underlying reason for Mr Jones reaction**	**Outcome**
"Have a shower"	Refusal	Mr Jones does not see the need to shower at the time of the request and consistently refuses to undertake any action he perceives as telling him what to do.	Mr Jones is un-showered, begins to smell and his family do not wish to visit. Maintaining good contact with his family is his main goal and is very supportive of his mental health.
"Would you like a shower?"	Either outright refusal or a statement that he will do so later although this never occurs.	Mr Jones does not have the executive skills to weigh up the decision as to whether to shower or not.	Mr Jones is un-showered, begins to smell and his family do not wish to visit. Maintaining good contact with his family is his main goal and is very supportive of his mental health.

Staff action/words	Mr Jones reaction	Underlying reason for Mr Jones reaction	Outcome
Written prompts, diary prompts or mobile telephone prompts to shower	Mr Jones is overwhelmed by written information and will not follow written instructions, sometimes stating he will do so later.	Mr Jones does not have the cognitive skills to turn written prompts into actions.	Mr Jones is un-showered, begins to smell and his family do not wish to visit. Maintaining good contact with his family is his main goal and is very supportive of his mental health.
"Would you like the blue shower gel or the green shower gel? (Staff have both shower gels in their hands and physically offer them towards Mr Jones, doing this in close proximity to the bathroom).	Mr Jones choses a shower gel and has a shower	None of Mr Jones' cognitive, behavioural or executive difficulties are challenged by this approach, he is able to go along with this without any form of confrontation or feeling loss of control.	Mr Jones has a shower, he receives positive reinforcement from family and staff about his appearance, his mood lifts and his aggression drops.

A naïve and non-brain injury-aware reading of the above would lead to questions as to whether Mr Jones "human right" to not shower is being abused.

Exactly the same approach is undertaken regarding food; Mr Jones will not eat if asked if he wants to eat or even if he is asked what he wants to eat. He cannot do so as a consequence of his impairments. He is unable to take these decisions despite being of average intelligence and able to communicate clearly. Providing him with choices reduces his capacity to remain in the community. Depriving him of this choice supports his liberty.

Supporting Mr Jones, in this very highly structured way creates a sense of "capacity", it supports Mr Jones to look, act and feel more capable than is accurate. An assessment undertaken when such an individual is well supported is more likely to find capacity when in fact, intrinsically, Mr Jones is not capacitous, it is his highly structured and managed environment that sustains this. Identifying this and being able to assess *intrinsic* capacity is essential to maintain Mr Jones (and others) safely in the community in highly structured support packages.

The updated DOLS process will need to be aware of the above style of work that promotes engagement, promotes goal attainment, "creates" capacity, supports decision making and reduces risk of community placement breakdown and subsequent long-term removal to non-community settings. Best interest assessors will need knowledge of the impairments and difficulties experienced by brain-injured people to be able to recognise why such a style of working with individuals is essential for their well-being.

5.3 EXAMPLE 3: Mr Taylor - Non-specialists disputing the findings of specialists.
Twenty years ago Mr Taylor suffered a very severe brain injury when aged seven. Litigation was undertaken on his behalf however the settlement achieved was never going to be able to meet his needs as a 50% discount was applied owing to contributory negligence.

Mr Taylor was defined as a Patient of the Court of Protection and his finances are managed by a professional Deputy.

The Deputy commissioned independent brain injury services to work with Mr Taylor however the relationship between the professional staff and family was complicated. It was necessary for the family to be regularly reported to social services as there was evidence of them assaulting and mistreating Mr Taylor. Family used his money and his possessions without his knowledge or permission. Mr Taylor is extremely easy to influence.

Mr Taylor's family removed him from a stable and specialist residential placement against the advice of all professional staff. Once home family quickly became aware that they could not cope with Mr Taylor's complex behaviour and requested support. Mr Taylor expressed clearly that he wished to live in his own accommodation and this was arranged on his behalf with a suitable 24-hour care package in place.

The care package quickly became untenable as:

- His father moved in with him.
- The family changed the door locks and came and went as they pleased.
- The family regularly sent carers home or threatened them until they left.
- Family members regular brought and consumed alcohol and drugs onto the property.
- Family regularly helped themselves to Mr Taylor's food, he was very upset about this in particular.
- The family used Mr Taylor's car as their vehicle.

Eventually, and as a result of Mr Taylor's increasing vulnerability and risks to himself and others, an application to the Court of Protection was made by the independent professionals involved, asking the judge to consider some restrictions on family access to Mr Taylor. It was assessed that Mr Taylor was unable to protect his own welfare with regards to matters involving his family and that this was a consequence of his very severe brain injury.

Local social services disputed the specialist assessment of capacity undertaken by a Consultant Clinical Neuropsychologist and arranged for a further assessment by a Consultant Psychiatrist. The Psychiatrist agreed with the Neuropsychologist that Mr Taylor lacked capacity to manage his interactions with his family and his own safety. Social Services then disputed this assessment too.

During this protracted and expensive process it became clear that social services did not understand the nature and consequences of Mr Taylor's cognitive and behavioural problems, and encouraged him in ill-thought out actions. Despite all of the evidence, generated over many years, social services felt that Mr Taylor's family should manage his care and support and advised that Mr Taylor should be allowed to spend his money as he saw fit, as such they had no concept of the duties and responsibilities of the financial Deputy.

EXAMPLE 3 CONTD:
The Court of Protection found in favour of the specialist professional input and made an order restricting when family could visit, preventing their involvement with care/support and prohibiting them from bringing alcohol or drugs into Mr Taylor's house.

5.4 EXAMPLE 4: Mr Portman- The difference between "saying" and 'doing"
The following excerpts relating to Mr Portman have been taken from an expert witness report in relation to a brain injured man who presents extremely well but, when third party evidence is included and time taken to examine his functioning not his stated intentions, it is clearly observable that he functions very poorly and is highly reliant upon family.

Mr Portman is very unlikely to meet eligibility criteria for the provision of social services support, does not see the need for an IMCA and is unable to use the knowledge he has repeatedly gained from past failure to make any predictions about his future abilities, which he consistently over-rates.

Insight, Denial and Realistic Goal setting
Mr Portman does not appear to set himself goals that are reasonable or achievable. Mr Portman wishes to return to work in his previous profession and to driving. The first of these goals would appear to be unlikely, at present at least, owing to his difficulties with cognitive and executive impairments set in a context of his fatigue, understandable low mood and tendency to have debilitating headaches.

Mr Portman purchases ten cigarettes a day, first thing in the morning, to limit his smoking habit. By 12:30PM on the day of my visit he had only 3 cigarettes left. He acknowledged that he would not be meeting his goal and would buy some more.

Despite having only attended the gym for 2 days, Mr Portman was unable to perceive that he would not continue to go to the gym on a daily basis. He was asked what would happen if his friend was not available to attend and he acknowledged that he might not go.

Mr Portman has a goal of being a property developer and landlord but has no notion of how he would get there from his present situation.

Dr Smith (treating psychologist) noted that Mr Portman did not have insight and that his goals were unrealistic.

When Mr Portman was externally supported to set goals and work towards them he made progress but, in the absence of this support, he quickly demonstrated that his progress was externally generated and maintained. He did not receive sufficient support (in terms of quantity or speciality of input) to establish routines that were able to exist in the absence of said support. Presently Mr Portman goals are both unachievable in the sense that he lacks the material resources to achieve them and he lacks the cognitive and executive abilities to plan and carry them out.

When discussed with him, Mr Portman is well aware of the nature of his difficulties with fatigue, headaches and memory (for example) and is somewhat aware, functionally, of the fact that he is

EXAMPLE 4 CONTD:

unable to plan (in the sense that he knows his mother would have to plan a train journey for him for example) but he is not able to extrapolate from this intellectual awareness and have genuine insight into his problems. This presence of intellectual awareness but absence of insight is particularly difficult for non-brain injury specialists to conceptualise and respond to, hence his needs will regularly be missed. This is particularly the case as Mr Portman is a particularly amenable, pleasant and seemingly motivated individual. In this instance, he seems to know his difficulties but this has no impact upon his plans/goals which, accordingly, are not achieved.

Despite his ability to verbally describe his difficulties, Mr Portman does not have insight in to his situation.

CAPACITY TO MANAGE FINANCES

There is a range of opinion regarding Mr Portman's capacity to manage his financial affairs.

In a structured and guided conversation lead by a well-intentioned and intelligent other, Mr Portman can demonstrate that he understands decisions relating to finances, can retain information for the period of the dialogue and can even be supported to weigh up the pros and cons of decisions. He is very clearly able to communicate.

The difficulty arises in the absence of the externally managed and structured discussion and when Mr Portman needs to use the information to make potentially complex and inter-related decisions that take place over time. Decisions often have an emotional content/driver and are not discrete, clinical and abstract ones undertaken in unreal settings.

There is a very real risk therefore that Mr Portman's capacity is measured in the abstract and extrinsically governed environment of an assessment and it is his stated intention that is assessed, one he is in fact supported to state, rather than his actual functioning. The process of assessment itself providing the compensatory strategy required to facilitate the generation of evidence of capacity and "good" decision making.

An alternative risk is the fact that rather than Mr Portman's capacity being assessed, it is the capacity of those who support him that is found to be present as currently Mr Portman is not dealing with his correspondence, others are. The fact that he has limited self-awareness of why this is the case, with regards to his cognitive and especially executive difficulties means that he will be a poor historian within the abstract assessment process, unintentionally under-playing his difficulties with decision making.

There are several factors that make me concerned in particular, these are:

- Mr Portman cannot make decisions regarding which film to watch but does not see that this difficulty with decision-making in real life may have an impact upon other decisions such as the purchase of property to renovate (in the abstract and in the future).
- Mr Portman presently absents himself from planning, even regarding such matters as a journey that will require change of train etc.
- Mr Portman's memory is such that he could not recall his parents being away for a week three months earlier. Real-life decisions can take place over time and not in the instant;

they are cumulative and require adjustment in the moment, responding to environmental cues and feedback.

- Mr Portman is easily overwhelmed by written information.
- Mr Portman considers buying his friends new vans is reasonable.
- Mr Portman is very indiscreet regarding the fact that he is undertaking a litigation claim.
- Mr Portman would appear to have significant difficulties dealing with his ex-partner and would currently appear to give her most of his money.
- Mr Portman wants to tell women that he is wealthy to attract them to him.
- Mr Portman lends money and forgets who to and how much.
- Mr Portman himself says that he cannot manage his money and needs help. Whilst this, paradoxically, may be viewed as a good example of recognising a deficit and seeking support, I do not believe that he would be able to initiate this process and take suitable decisions in actuality were, for example, the litigation claim to settle tomorrow. His recognition of needing help is an intellectual one, not one he may successfully follow if he is in the scenario where he needs to use this awareness. Again this is the difference between intellectual awareness and insight.
- Mr Portman does not deal with his own correspondence. Whilst deferring this to his parents may be viewed as a sensible decision I suspect that this is a "default" decision, in fact not a decision at all but based upon an absence of a decision. They have taken over because they have to, there is no alternative.
- The role of emotion in decision-making is not so easy to assess in the abstract. I draw to The Court's attention is drawn to a paper by Professor Brown:

> "The literature supported the study findings that decisions are not made in a linear way and identified the importance of history and memory, motivation and drive, mood and stability, and openness to influence when assessing the mental capacity of vulnerable people," (Brown, 2011)

- Working with brain-injured people over the very long term, leads me to have concerns regarding Mr Portman's vulnerability to others. He is vulnerable and has difficulty in being able to assess the motivation and intention of others. It is questioned whether Mr Portman has any difficulty, post brain-injury, with emotional prosody.
- Dr Smith (Treating Psychologist) stated that anything to do with Mr Portman's finances was "tricky" as he was so conversationally good but lacked insight and was not able to make realistic goals, thinking that the purchase of sports cars and vans for others from a settlement that is supposed to last him a lifetime would be a good idea.

The proposed rehabilitation and support plan outlined below, if properly enacted, should provide more concrete evidence of decision making and capacity "in action" thus being supportive of all experts who have been asked to comment

6. THE IMPACT OF ABI ON INDIVIDUALS FAMILIES AND COMMUNITIES:

The following section of this document identifies recognised and researched areas of difficulty following a brain injury that may lead an individual to have contact with a panoply of different services, most usually not specialist ones informed by an underlying understanding of the condition.

6.1 Summary:

- Brain injury has a "neuro-psycho-social" impact, affecting the individual, their family and wider community.
- The impact is long-standing.
- Prevalence is not straightforward to ascertain.
- Residual disability is high, even for those with mild brain injuries.
- Mortality/morbidity rates are high, even with mild brain injury. This is very recent evidence.
- Relationship breakdown rates are high with all the commensurate difficulties this creates for individuals, families and the state.
- Prevalence of ABI in UK prisons is high, as is recidivism for this specific group. Injury is frequently noted to pre-date incarceration.
- ABI appears related to homelessness, with the injury predating loss of accommodation.
- Unemployment and therefore dependency on welfare benefits is high.
- Quality of life for the injured, their children and families is noted to be affected deleteriously. Care burden increases not diminishes over time.
- Mental health service use is a predictor and an outcome of acquired brain injury.
- Suicide rates are three to four times community norms.
- Whilst substance use rates are noted to be lower following severe brain injury, problematic substance use is noted to be significant within dual diagnosis service use for people with a brain injury and mild brain injury in childhood is a predictive factor for both substance use and violent crime.

6.2 Prevalence of head injury admissions to hospital.

Department of Health estimates suggest that between 10 to 15 people per hundred thousand of the UK population suffer a severe or very severe injury to the brain every year (Headway, 2014). However several of the studies described below suggest this may be an under-estimate. Most common causes of injury include road traffic accidents, assaults, falls, loss of oxygen to the brain following a cardiac arrest, near drowning etc. and from conditions such as meningitis or encephalitis and stroke.

Numbers of people who have a brain injury, either via trauma or medical condition, each year within the UK are not completely clear therefore and would appear to vary depending upon location (Tennant, 2005) and suffer from under-recording via NHS coding (Thornhill et al., 2000). 20% of the Thornhill cohort of 769 people with an acquired brain injury that they followed up did not have a coding that reflected their injury and hence they would have been missed if recruitment to the research had been based solely on NHS coding to identify them.

Tennant reported:

> *"Head injury is common; there were 112,718 recorded admissions for English residents during the year April 2001 to March 2002, giving a hospitalised incidence rate of 229.4 per 100,000 all ages."* (Tennant, 2005)

McKinlay et al's prospective cohort study followed, for 25 years, 97% of all children born in Christchurch New Zealand in mid 1977. Over 30% of this cohort researched sustained a traumatic brain injury by the time they reached 25 years old. (McKinlay et al., 2008)

Not all people who report to hospital with a head injury will have a resultant and lasting acquired brain injury.

6.3 Residual disability

Thornhill et al's study, a prospective cohort study (Thornhill et al., 2000), identified that 154 people per 100,000 of the population were left as "disabled" as measured by the Glasgow Outcome Scale Extended, (GOSE) one-year post brain injury. (Wilson et al., 1998) This is a significantly higher prevalence of injury and rate of incidence of disability than had been anticipated. In particular, the rate of disability amongst those who had been assessed as having a "mild" brain injury, as measured by Glasgow Coma Scale upon admission was unexpectedly high. 47% of this population were classified as severely or moderately disabled one-year post injury.

Only 28% of those defined as moderately or severely disabled one-year post injury had received any form of rehabilitation. Only 15% had contact with social services, replicating precisely Murphy et al's findings from ten years earlier. (Murphy et al., 1990) In the fifteen years since the Thornhill study was undertaken (13 years since publication), eligibility criteria for services has risen further. (Roulstone and Morgan, 2009) Potentially even fewer people with a severe brain injury have contact with social services presently. The GOSE identified, for the cohort that were defined as having had a severe brain injury, 76% had cognitive difficulties and 76% reported difficulties with mood.

6.4 Impact upon relationships

An injury that causes personality and behavioural changes is one that is both common and experienced by the injured party and their relatives, most keenly felt perhaps by parents and partners/spouses. It is unsurprising therefore that relationship breakdown post acquired brain injury is a feature reported upon. Wood et al noted that, in their cohort, 49% of relationships broke down within a five to eight year period post injury. (Wood and Yurdakul, 1997)

6.5 Prevalence of Acquired Brain Injury in UK Prison Populations

Research into prevalence of acquired brain injury rates in UK male prisoner populations shows similar and concerning levels of injury (Williams et al., 2010) at around 60% and a meta-analysis of previous studies indicating a prevalence rate of 52%. (Shiroma et al., 2012).

Preliminary findings from the largest UK study undertaken to date, on behalf of the Disabilities Trust Foundation, indicated a prevalence rate of 47% amongst a prisoner population and that of these brain injured prisoners:

- 73% reported that the brain injury predated their first offence

- 71% had experienced more than one traumatic brain injury and 30% had experienced 5 or more traumatic brain injuries
- 43% had been in prison 5 or more times
- 80% had a history of drug use
- They were 3 times more likely than non-brain injured prisoners to have held only partly skilled, unskilled jobs or to have never been employed. (Pitman et al., 2012)

6.6 Acquired Brain Injury and Increased Rates of Homelessness

Acquired brain injury amongst homeless populations has been assessed at around 48% with 90% reporting acquiring a brain injury prior to becoming homeless. (Oddy et al., 2012)

6.7 Acquired Brain Injury and Unemployment

Return to work, post acquired brain injury, has been noted to be complex and an early study, (Brooks et al., 1987) demonstrated that employment rates dropped from 86% to 29% post injury and that "the presence of cognitive, behavioural, and personality changes was significantly related to a failure to return to work." Research into employers' attitudes towards applicants with a declared acquired brain injury rated similarly to those applicants who declared a history of schizophrenia. (Bricout and Bentley, 2000)

6.8 Quality of Life Post-Brain Injury

General quality of life post injury is subjectively and objectively deleteriously affected (Jacobsson et al., 2010) and is noted to be reported upon as lower even than for other groups with long term and life-changing health conditions. (Horneman et al., 2005)

6.9 Impact upon Family/Carers

A body of literature exists as to the specific burden felt and difficulties experienced by those who are the "carers" of people with an acquired brain injury, including the development of psychiatric and health difficulties by the carers. (Moules and Chandler, 1999) This is a sudden onset condition, acquired without warning, and the longer-term impact takes time to ascertain. As the majority of the impact of the injury is not visible (in relation to changes to cognition, executive functioning, mood, personality and behaviour) the non-injured party is often left unsupported and lacking information. (Powell, 1997, McPherson et al., 2000)

In a comparison study with the carers of people with dementia, carers of people with an acquired brain injury were shown to suffer greater carer burden, poorer mental health and reduced quality of life. (Jackson et al., 2009)

The intensity and complexity of caring for brain-injured relatives, without adequate support, is such that parents have been reported to wish their own brain-injured children to be dead. (Webb, 1998, Higham et al., 1996) Many writers have attempted to capture the very personal nature of acquired brain injury and the emotional impact upon family. (Crimmins, 2001, Swanson, 1999) Resolution or emotional closure for relatives being hard to achieve because of what is described as "ambiguous loss". The injured party is physically present but emotionally changed/absent and so grief is unresolved. (Boss, 1999) Carer burden is noted to increase over time. (Levor and Jansen, 2000)

Notwithstanding the position families are left in by brain injury, their incorporation and involvement in the process of rehabilitation is recognised as central to good recovery. (Kreutzer et al., 2010)

6.10 Prevalence of Acquired Brain Injury in Psychiatric Settings/Amongst People with a Psychiatric Diagnosis.

Prevalence of acquired brain injury within UK psychiatric settings/users of psychiatric services appears to have not been interrogated. Within the limited US studies available prevalence of traumatic brain injury in psychiatric settings notes increased rates of injury, compared to controls, increased severity of injury compared to control groups and increased likelihood of the presence of more than a single incident of brain injury. (Burg et al., 1996, McGuire et al., 1998)

A large study *(n=1,440)* by Fann et al identified that the relationship between acquired brain injury and psychiatric conditions can and does operate in both directions:

> *The main finding of our study was that patients with any indicator of psychiatric illness experienced an increased risk of subsequent TBI (relative risk 1.6) compared with those who had no indicator of psychiatric illness. This increase was seen with three different indicators of psychiatric illness: ICD-9-CM diagnoses, psychiatric medication prescription, and psychiatric service utilisation. (Fann et al., 2002) p618*

With specific reference to schizophrenia and traumatic brain injury Molloy et al undertook a meta-analysis of research available and found that there was an increased risk of developing (or of being diagnosed with) schizophrenia post-traumatic brain injury of 60%. They state:

> *This meta-analysis supports an increased risk of schizophrenia following TBI, with a larger effect in those with a genetic predisposition to psychosis. (Molloy et al., 2011) p1104*

A review of the literature into suicide post acquired brain injury indicated that this appears to run at approximately three times community controls. (Fleminger et al., 2003) Simpson et al estimated this to be at 3 to 4 times greater than for the general population. (Simpson and Tate, 2007)

As rates of acquired brain injury amongst UK-based psychiatric service users has not, to our knowledge, ever been established, it is not possible to state how many people are misdiagnosed/misplaced as having mental health problems with no reference made to their brain injury. Experience would lead to a belief that this is not unheard of at all, particularly in the case of brain injury in childhood/adolescence leading to an altered development by the young person concerned. (Fleminger, 2008) UK social workers, specialising in mental health settings, would be expected to come across people with an acquired brain injury but who may not self-identify as such and therefore their assessments and interventions will not be informed by the underlying nature of the presenting condition.

6.11 Impact on premature mortality

Prevalence of injured parties living in the community has therefore increased as advances in para-medicine, neurosurgery and intensive care management have taken place. (Higham and Phelps, 1998, Powell, 1997)

Once the initial acute phase of the condition has passed, the injury itself is not noted to foreshorten life expectancy except in the case of the impact of the development of unmanaged post-traumatic epilepsy. Life expectancy therefore had previously thought not to have been affected or at least not greatly affected. McMillan's work in Glasgow however, a 13-year prospective study, would appear to raise very significant doubts about the commonly held view that death rates, post acute phase, are similar to those of non-brain injured people with an increased likelihood of mortality being assessed as 2.8 times community controls. (McMillan et al., 2011) Cause of death was not noted to be directly related to the brain injury itself.

This significantly increased rate of mortality raises questions regarding why this should be the case when the explanation is not simply medical in nature, it would not appear to be the brain injury per se that is causing death but the impact of the brain injury upon day-to-day functioning. It is recognised that this cohort of injured people are potentially experiencing cognitive and executive difficulties and, as per the Thornhill cohort, may well be living without any formal or even informal support in the community. It is possible to question whether an absence of support or rehabilitation to compensate for cognitive, executive, behavioural and emotional difficulties foreshortens life. Most simple examples being a lack of ability to manage a balanced diet and/or note when medical treatment is required and comply with it. These are the very issues we support our clients with on a daily basis, issues that some of our clients do not manage themselves without input.

More recent work by McMillan on mortality following *mild* traumatic brain injury over a 15 year period post injury identified that younger adults (aged 15–54 years) who had suffered a mild brain injury had a 4.2-fold greater risk of death than matched community controls. This was a prospective case-controlled population study with an n= 2,428 brain injured adults. (McMillan et al., 2014)

6.12 Acquired Brain Injury and Substance Use

Work by Corrigan et al into prevalence of traumatic brain injury amongst service users at a dual diagnosis (substance use and severe mental illness) US treatment centre identified that 72% of their cohort were brain injured. Perhaps more importantly, it was noted that the participants with a brain injury had commenced drug use at a younger age, had worse functioning and had a more severe diagnosis of mental ill health. (Corrigan and Deutschle, 2008) Further work by Corrigan notes:

> *Early childhood injuries were also associated with slower speed of information processing and more cognitive complaints; in addition, these clusters were also associated with more complicated substance use disorders. (Corrigan et al., 2012)*

Research from a large birth cohort in New Zealand (McKinlay A, 2002) has identified that rates of problematic drug and alcohol use in early adulthood for those who suffered just a *mild* brain injury aged between 0 and 5 are three times that of their non-brain injured peers and they are also five times more likely to be arrested for crimes of violence.

6.13 Conclusion:

Acquired brain injury is noted therefore to have a significant impact for individuals, their families and the wider community. Decision-making and resultant action/inaction by the injured parties can lead to question being asked regarding Capacity and most certainly brings such individuals into contact with often costly services but not necessarily specialist brain injury ones or even non-specialist ones but with an awareness of the condition.

Whilst the above broadens the debate to beyond the MCA specifically, addressing or acknowledging the impact of ABI more widely will limit the current difficulties in the application of the MCA.

7. ASSESSMENT OF CAPACITY BY SOCIAL WORKERS:

7.1 The Impact of Executive Impairment and Loss of Insight.

Social workers are required, as part of their practice, to make assessments of capacity under the auspices of the Mental Capacity Act, or to identify when matters of capacity require assessment and by whom. (MCA, 2005)

To be able to carry out an assessment (or recognise that an assessment is required) a social worker will need to have knowledge of the Act and the guidance. We would argue that the social worker also needs knowledge of the specific nature of the brain injury related issues that may have an impact upon an individual's capacity to take decisions that are in their best interests and act upon these decisions. A social worker will also need enough knowledge of ABI to recognise when they need support to undertake assessments. An absence of such knowledge of the underlying impairments limits the ability of the social worker to recognise that a matter of capacity is potentially at issue, limits their ability to carry out the assessment and limits their ability to seek appropriate professional input from others.

In practice, in a structured and guided conversation led by a well-intentioned and intelligent other, such as a social worker, brain injured people with intellectual awareness and reasonably intact IQ can frequently demonstrate good understanding in relation to decisions relating to matters of finance or their personal health and welfare. They can frequently retain information for the period of this dialogue and can be supported to weigh up the pro's and cons of decisions and communicate this to the person undertaking the assessment of Capacity. (BPS, 2005) As noted, IQ is often not affected or not affected greatly. In doing so, the test for the assessment of capacity, according to the Mental Capacity Act and guidance, would appear to be met. (MCA, 2005)

Guidance generated for UK social workers notes the impact that cognitive difficulties such as poor memory or attention may have but fails to recognise that the support suggested in the checklist provided is compensatory "scaffolding". Rather than assessing decision-making skills the checklist supports decision-making in that moment alone. (Dawson and McDonald, 2000) Such support may of course be a useful approach when assisting adaptation and change but is not an assessment of independent decision making ability. Dunn notes that there is a tension between the legal and procedural notions behind Capacity assessments and the practicalities of supporting decision-making. (Dunn, 2013)

Difficulties arise in the absence of the externally managed and structured discussion and when it is necessary for the brain injured party to use the information to make potentially complex and inter-related decisions that take place over time and have an emotional content/driver (not discrete, clinical and abstract ones supported to be made in unreal settings). (Brown and Marchant, 2013)

Further complicating the assessment of capacity is that inaction, passivity and following instruction of others is, for some, an outcome of ABI. Such people, if they are well and benevolently supported, do not generate evidence of poor or irresponsible decision-making. This is not the same as having independent ability to take decisions, wise or otherwise. The self-same individuals are likely to be unable to distinguish between benevolent and malevolent

influences. As informal support networks change over time this particular difficulty can have significant and damaging outcomes.

There is a very real risk therefore that capacity is measured in the abstract and extrinsically governed environment of an assessment and it is therefore the stated intention that is assessed, one that the assessed party is in fact accidentally supported to state, rather than actual functioning that will follow outside of the assessment setting. The gap between the stated intention and the actual action in practice is precisely the gap identified by Crosson and others as the intellectual awareness necessary to sound competent and capable but this is in the context of poor genuine self-awareness in real-life and real-time settings. (Crosson et al., 1989)

The process of assessment therefore can provide the compensatory strategy required to facilitate the generation evidence of capacity and "good" decision-making. It is externally structured, it is a forum for problem solving (in the abstract) and it supports the very generation of ideas. The assessment is the compensation required to ameliorate for the executive impairment caused by the brain injury but only for the duration of that assessment. The assessment process mimics the approach taken to support engagement with rehabilitation and the very rehabilitative processes itself. (Medley and Powell, 2010, Oddy and Worthington, 2009) The assessor provides a context, generates the initial idea, supports problem solving, maintains focus on a specific issue, does so at the pace of the assessed, re-explains if anything is found not to be understood and does so from the basis that the assessed is assumed to have capacity until proven otherwise. This is clearly a fraught and contested field for social workers. (Johns, 2007)

7.2 Social Work Assessment: Safeguarding

Criticisms have been raised regarding the possible conflict between increased notions of personalisation and of safeguarding, another role of the social worker. Lymbery and Postle note that self-assessment, a service user defining their own needs, would "seem unlikely to facilitate accurate identification of levels of risk." (Lymbery and Postle, 2010)

In the case of brain injured potential service users, impairment to executive skills such as reasoning, idea generation and problem solving, often in the context of poor insight in to these impairments, means that self identification of risk may be considered extremely unlikely. Underestimating needs is common (Prigatano, 1996). The meta-cognitive skills required to identify risk and potential problems are the very ones that are impaired, unknowingly so. (Mantell, 2010)

In this context, a social worker may find themselves involved in Safeguarding procedures:

- Unaware that a party considered at risk (or a party in said person's milieu, potentially part of the risk/part of the perceived 'protection' of said individual) has an acquired brain injury. This includes undisclosed parental injury in child safeguarding investigations.
- Unaware of the impact and consequences of the acquired brain injury upon the individual's functioning, capacity to self-protect, to request support or parent adequately.
- Unaware of the nature and impact of present intellectual awareness in the absence of insight in relation to the validity of self-report during assessment.
- Unaware of the need to adjust the process of assessment to take account of acquired brain injury with regards actual functioning, variability, vulnerability and degree that an

individual is environmentally led and therefore gain a more accurate picture of the risks posed to them or by them.

This approach, when combined with what Fyson describes as a too dogmatic attitude towards promoting independence without recognising vulnerability and the impact of the wider community (Fyson and Kitson, 2010), would appear to leave both brain injured people and the wider public not safeguarded. (Fyson, 2009, Fyson and Cromby, 2012)

Further recent criticisms have been raised in the House of Lords during oral evidence given by Nicola Mackintosh Q.C. (Hons) to the committee investigating the implementation of the Mental Capacity Act. Ms Mackintosh identifies that the shift from "old style social work" to care management/brokerage does not adequately safeguard vulnerable people.

> *I have seen practice changing. We no longer have the old fashioned social work, the therapeutic work between social workers and families or individuals, which we were used to. We have a very different system of a single one-off assessment of needs followed by a brokering of a care package… In my experience where a social worker is allocated to the case and has ongoing involvement with that person, that involves a much greater degree of protection….. So it is about old fashioned social work going out of the window being replaced by a simple one off assessment. (Mackintosh, 2013)*

7.3 Social Work Assessment: Self Neglect and Safeguarding

Adults who appear not to be able to care for themselves, for reasons other than physical impairment alone, may come to the attention of a Local Authority owing to what is perceived to be self-neglect. How the social worker conceptualises the root causes of this self-neglect may define their assessment of the perceived "risks to independence" and "likelihood of risk" that are in themselves the gatekeepers of access to service. Braye et al identify that there is uncertainty amongst professionals regarding the causes and interventions that may best address concerns of self-neglect. (Braye et al., 2011) Indeed they go further than this and note that the social workers role is one of potentially conflicting doctrines:

> *Attention is given to the challenges when navigating in practice the potentially competing principles of empowerment, autonomy and well-being and imperatives of choice and control versus duty of care and protection. (Braye et al., 2011)*

7.4 Social Work Assessment and Acquired Brain Injury: Conclusion

Social workers therefore, most likely dependent upon self-report and guided by principles of self-autonomy and self-actualisation, externally driven to promote a "personalisation" agenda, may therefore be ill-placed to make adequate assessments and plans for intervention <u>without</u> knowledge of acquired brain injury, in particular of executive functioning and impairment and the impact of the loss of insight into this. Furthermore the increased reliance on brief structured assessments, in the absence of longer-term relationship development (Postle, 2001) and a lack of observation of functioning in practice, is contra-indicated particularly without third party corroborative evidence and time allowed to develop the complete picture. If a central aspect of the condition is variability of performance and abilities (Stuss, 1991), against a backdrop of reduced self-awareness (Prigatano, 2005), then it is the triangulation of evidence over time and from more than one source that generates accuracy in assessment (Manchester et al., 2004), leading to more effective plans and interventions.

The consequences of acquired brain injury are hard to comprehend, are variable, are mediated via environmental factors and change over time. A process of assessment that is prescriptive, with the prescriptive document/computer programme written by someone lacking brain injury knowledge and is implemented (inputted?) by a care manager also lacking knowledge in a context where creativity is not permitted is unlikely to be adequate.

Perhaps more importantly than all of the above is the notion that adaptation to acquired brain injury can be a lifetime process. (Carlton and Stephenson, 1990, Simpson et al., 2002) As such it is the therapeutic relationship with the injured party that may support rehabilitation, change and adaptation best. Such a relationship takes time to develop and becomes an iterative process, supporting future change and development. (Miller and Rollnick, 1991, Medley and Powell, 2010) A one off, brief and scripted assessment does not support such a relationship.

Post-traumatic growth following brain injury can occur (Powell et al., 2007) and the notion of "expert companions" to facilitate this has been raised. (Calhoun and Tedeschi, 2006) By bearing witness and being present to our brain injured clients' struggles and travails as they face a new and changed life, by providing positive reinforcement and knowledge, a social worker can be this expert companion. Service users and their families report positively regarding such an approach. (Hingley-Jones and Mandin, 2007, Gridley, 2013, Beresford et al., 2008)

Privileging notions of "independence" may possibly be unrealistic for those with cognitive, executive or behavioural difficulties following brain injury and removes notions of reintegration (Willer et al., 1993) or interdependence (Condeluci, 1995) that, it may be argued, are more accurate descriptors of the way non-brain injured people live and fails to take account of risks from the wider community. (Fyson, 2009)

> *"The balance between freedom and choice, and risk and protection, becomes ever more fragile as services seek to privilege the autonomy of the service user in discharging their responsibilities towards adults made vulnerable by age and frailty, mental health problems and physical and intellectual impairments. Sometimes, abuse stemming from both violence and neglect occurs." (Holloway and Lymbery, 2007)*

Being unaware of their own absence of knowledge of the basic understanding of the consequences of acquired brain injury places the social worker/care manager in the invidious position of both not knowing what they do not know and not knowing that they do not know it. Brain Injury specific training will support addressing this issue.

Appendix 1.
8. HOUSE OF LORDS EVIDENCE TO SUPPORT ABI/MCA's RECOMMENDATIONS 1 to 7:

8.1 What did House of Lords report say about Acquired Brain Injury?
The ABI/MCA interest group recognises that the MCA steering group is very familiar with the House of Lords report, its recommendations and the evidence that underpins it. The following excerpts are collated to draw together all of the written information as it pertains particularly to ABI.

Whilst much of their Lordships' report is universal, acquired brain injury was highlighted for a particular difficulty, that of *how* to undertake an assessment of capacity of people who may have high IQ but concurrently have impaired executive functioning and reduced insight into their needs or the likely outcome of their decisions.

The following excerpts have been chosen both for their universality but also for the specific nature of ABI in relation to the implementation of the MCA.

CHAPTER 1: INTRODUCTION:
16. The presumption of capacity as set out in the Act—a person must be assumed to have capacity unless it is established that he does not—is widely misunderstood. At times, it is used to justify non-intervention by health or social care services, either erroneously or, in some cases, deliberately.

Conclusions and recommendations:
3. The presumption of capacity, in particular, is widely misunderstood by those involved in care. It is sometimes used to support non-intervention or poor care, leaving vulnerable adults exposed to risk of harm. In some cases this is because professionals struggle to understand how to apply the principle in practice. In other cases, the evidence suggests the principle has been deliberately misappropriated to avoid taking responsibility for a vulnerable adult. (paragraph 105)

20. ***Recommendation 8***: The proposed fourth year of training for GPs provides an opportunity to embed and enhance understanding of the Mental Capacity Act with this group of practitioners. We recommend that the Government supports the proposal in light of the vital role which GPs play in providing health care in the community. (paragraph 140)

51. ***Recommendation 23***: Given the importance of the role of IMCAs in the lives of vulnerable adults we believe that the role requires further professionalisation to ensure consistency of service. This should be achieved through national standards and mandatory training in the Mental Capacity Act and the role of the IMCA within that. We recommend that responsibility for such standards and training be undertaken by the independent oversight body which we recommend in chapter 4, enabling peer support and consistency between IMCA services. (paragraph 177)

63. We were told of a worrying tendency among local authorities to use the presumption of capacity to avoid taking responsibility for a vulnerable person. Nicola Mackintosh, representing the Law Society, told us that she had seen "lots of cases where a person has been neglecting themselves, and the local authority or the relevant health agency has used the presumption of

capacity to allow that to continue".[79] This was echoed by the submission from Irwin Mitchell LLP, who suggested that the assumption of capacity was on occasion deliberately used by local authorities "as an excuse to do nothing on the basis of someone being a conscientious refuser of services, on the basis that P is expressing a view and 'they must be assumed to have capacity'".[80] The Law Society referred to the principles of the Act being "applied perversely", using the presumption of capacity to avoid assessing capacity, "with the implications for associated support and resources".[81] The British Association of Brain Injury Case Managers put it more starkly: "assessment of capacity is used as an economic tool to justify lack of provision, leaving the disabled person unprotected and those trying to protect them with no means to provide services".[82]

ASSESSING CAPACITY IN ADULTS WITH SPECIFIC CONDITIONS

71. Particular concern was expressed regarding the assessment of capacity in adults with specific conditions such as Down's syndrome, autism and brain injury. The Down's Syndrome Association questioned whether social workers had the ability to assess correctly the capacity of people with Down's syndrome, given that "young people with Down's syndrome often have quite good language skills and so they come across as being more able than they actually are because they have learnt lots of different social cues to use".[95] The National Autistic Society pointed out that assessments were carried out very quickly, and that environmental factors ("the language the person uses or even the colour jumper someone is wearing")[96] could have an impact on the assessment; they called for "better understanding of autism"[97] on the part of the assessors.

72. We received a number of submissions from those working with individuals who had experienced a brain injury, expressing concern about whether those without experience in this field were able correctly to assess capacity.[98] The British Association of Brain Injury Case Managers summarised the dilemma thus:

"Clients who have a good residual intellect, who present plausibly and articulate their thoughts well are very likely to be considered to have capacity to manage their own affairs, even despite a lengthy history of impulsivity, lack of social judgement, tangential thought processes, problems with attention and a lack of insight into how their cognitive deficits affect their decision making. Yet this is a client group who can still be extremely vulnerable to malign influence and coercion, particularly if they are in possession of a lump sum of money".[99]

73. Across the submissions concerning brain injury two factors appeared to collide: the difficulty for a non-specialist of assessing the nature of the impairment in a structured interview, and the application of the third principle—the right to make unwise decisions—by social workers, who sometimes interpreted as lifestyle choices what others with expertise in brain injury considered the actions of a vulnerable person suffering from a debilitating injury. One example concerned a local authority who had "found that a very vulnerable client who had sustained 2 brain injuries and was heavily influenced by her boyfriend, had capacity and was simply making a 'lifestyle choice' to partake in street prostitution to fund both their drug habits".[100]

92. We heard evidence that, especially in medical settings, the concept of best interests as defined by the Act was not well understood, in part because it was at odds with the concept of best interests as it is used in a medical or clinical sense. Headway, a charity for brain injury patients, reported feedback from one of their members whose sister was in a minimally

conscious state following a catastrophic brain injury:

"Staff defined a 'best interests' decision as a 'clinical decision'—and just saw it as a matter of clinical judgment. From the moment of my sister's accident it was as if she belonged to them, they were not interested in what we knew about her and her wishes. I can understand this in the immediate emergency but this went on for months and months, it was a constant battle".[141]

168. IMCAs were said to vary in their skills and knowledge and Sussex Partnership NHS Foundation Trust told us that this had an impact on how effectively they advocated on behalf of their clients.[275] Beverley Dawkins of Mencap called for greater investment in training of IMCAs whose clients had non-verbal communication, were in complex medical situations or who had challenging behaviour.[276] Headway suggested that the specific impact of acquired brain injury on capacity required an IMCA with an understanding of those issues in order to advocate effectively on the client's behalf.[277] The Standing Commission on Carers supported the call for IMCAs with expertise in specific areas.[278]

8.2 Brain injury specific evidence submitted to House of Lords:

The phrase "brain injury" is noted to appear precisely 200 times within the written evidence submitted to the House of Lords. There are 60 pages of written (or transcribed) ABI specific evidence. The following brief excerpts are indicative of the evidence provided to their Lordships although the full documents should be referred to for completeness.

The phrase "brain injury" is, highly unsurprisingly, repeatedly used within the evidence submitted by specialists. What is perhaps more telling is just how infrequently it is used by others, despite the fact that the impact of acquired brain injury pervades **all** health and social services. ***(See Section 6, page 18 onwards or evidence of this)***

1. *British Association of Brain Injury Case Managers Written Evidence:*

Summary of findings

Review of the information forwarded by the membership carried several common themes and concerns. These may be summarised as:

- Lack of understanding of brain injury by assessors and decision makers, in particular by local authority social workers.
- Poor practice in assessment and without consideration of the experiences of those that know the person well; i.e treating therapists, support staff, family and carers- either not exploring these or disregarding them.
- Face value acceptance of clients with executive difficulties and high level of intellectual abilities that present well in a structured assessment situation but are unable to carry out their decisions in "real life" situations.
- Social workers assessing clients on a "here and now" decision without considering wider perspectives and evidence that impacts on complex decisions.
- Decision making by assessors failing to understand the interaction of decisions.
- Failure to understand the impact of insight or fluctuating insight on decision making and to place decisions in context of the individual and factors that impact on that decision.

HOUSE OF LORDS EVIDENCE TO SUPPORT RECOMMENDATIONS CONTINUED:

- Failure to understand the impact of emotion and mood on decision making
- Failure to understand the impact of the assessors own biases and factors influencing their decision regarding capacity; including organisational pressures, pressures of the litigation process, financial constraints, cultural values, paternalism and management of risks
- Common use of the implication that a person has capacity as a means to remove accountability and responsibility and as a reason for non-provision of services.
- Use of advocates and IMCAs that have no understanding of the nuances and complexities of brain injury.
- Reluctance from Financial Deputies and others to challenge decisions as a consequence of cost, and variability in outcomes meaning that challenges are unpredictable.
- Concerns regarding risks and vulnerability of brain injured people and their families as a consequence of decision making by ill informed assessors of Capacity. *(p237 and 238)*

2. *Headway Oral Evidence:*

Peter McCabe: I think our view is that the Act has generally been well received but, as with all things, you can make it better. The specific suggestions that we would have there would be to simplify the guidance on best-interests decisions; to create brain injury-specific independent mental capacity advocates with a real understanding of brain injury—that is a very specific condition—to ensure that mental capacity assessments are performed by appropriately trained staff, particularly staff with an understanding of brain injury; to simplify the process for appointing deputies; and to require more regular supervision. We have a real concern about how that is going, and we think there is a need for further training and clarification for medical professionals because, although generally we feel it has been well received, there is a significant difference between best practice and what we hear about from service users, which is worst practice. *(p79)*

Peter McCabe: I think you mentioned frontline social workers having a good understanding of the Mental Capacity Act or being seen to. Our difficulty is that they do not seem to have a very good understanding of brain injury. We do not fit into the boxes, the silos within an adult social care department, so very often our service users are neglected and there are so few social workers. There is an excellent brain injury social worker group, but they are tiny. We constantly try to encourage local authorities to undertake training of their staff so that they do understand those issues. I think another issue with social workers is that a lot of our clients say they very rarely see them and have little support for adult social care from social workers, so there are big issues there. *(p84)*

Peter McCabe: With our service users there are all sorts of complexities; and one is that capacity can change over a period of time, and that presents some challenges. Then issues like lack of awareness and insight, impulsivity and inflexibility can create problems for people who are trying to make those assessments. One of the issues with survivors of a brain injury can be that they can be very good in terms of their presentation and giving you the answer that they think you want to hear, whereas the carers and their families would have a very different story. That is a difficulty we have to acknowledge and recognise. *(p89)*

HOUSE OF LORDS EVIDENCE TO SUPPORT RECOMMENDATIONS CONTINUED:

3. *Head First Written Evidence:*

Overview
I have significant concerns with the implementation of the Act, with particular reference to individuals with an acquired brain injury, especially in respect of:

1. Those brain injured clients, who have a lack of insight or fluctuating insight and are able to logically say what they should do but are unable to apply this into practice.
2. Poor working practices in preparation of capacity assessments –

- Social Workers in statutory services, who undertake assessments but have no knowledge of the 'invisible deficits' after brain injury and take everything from clients at 'face value' without liaising with others who have knowledge and experience of caring for or working with them (i.e. family members or other professionals).
- Social Workers in statutory services, who do not take account of the client's behavioural patterns relating to the capacity question (i.e. taking the 'here and now' of what clients say they will do rather than what they do).
- Social Workers in statutory services (from experience of working with clients in four different geographical areas), who override the outcomes of capacity assessments prepared by independent clinical specialists in brain injury. They have stated, in their view, the client has capacity and this is valid, as their assessment has been prepared more recently.

3. The use of "Capacity" as a way of statutory services avoiding the need to provide any form of service and input.
4. The use of IMCA's, who are also not aware of the 'invisible deficits' after brain injury.
5. The time-consuming and costly processes associated with challenges to Capacity/Best Interests.

Of most concern are the increased risks and vulnerability for severely brain-injured clients and their families, as a consequence of the above.

Our experience as an organisation that works over the longer-term with people with complex needs following an acquired brain injury is that the lack of condition-specific knowledge and experience by statutory staff, can sometimes make the Act a handicap to the well-being of brain-injured people. In particular there are serious issues with the assessment of brain-injured clients who have an intellectual awareness of their condition but do not have insight into it. These are the clients who sound competent and able, particularly in a structured or semi-structured assessment but fail to use their own knowledge and carry out their stated intentions in practice, because they cannot. This is a function of their condition but misunderstood by those who lack brain injury specific experience and knowledge. *(p 713 and 714)*

HOUSE OF LORDS EVIDENCE TO SUPPORT RECOMMENDATIONS CONTINUED:

4. *Head First supplementary written evidence (co-signed by 19 very experienced ABI specialist professionals) in response to BASW evidence.*

Ms Ribas-Gonzalez notes that social workers do not have to carry out capacity assessments in isolation. It is our shared view that in fact it is very important that such assessments are informed by a range of professionals as well as by family and the brain injured party themselves.

In practice however, we regret to say, this collegiate approach, seeking information and knowledge from those with a specialist interest in acquired brain injury often does not occur; in fact quite the reverse. Specialist knowledge and experience (often developed over decades of dedicated work with this client group) that provides a challenge to the social worker's "common-sense" view is regularly rejected and frequently actively fought against.

It is our shared experience that a lack of basic knowledge of the impact of cognitive and executive impairments, in particular if the brain injured party demonstrates intellectual awareness but not insight, means that assessments are carried out in a way that is contra-indicated by the condition itself. *(p718)*

There is a very real risk therefore that the capacity of brain-injured people is measured in the abstract and extrinsically governed environment of an assessment and it is the stated intention that is assessed, one that is in fact supported to made, rather than actual functioning. The process of assessment itself provides the compensatory strategy required to facilitate the generation of evidence of capacity and "good" decision-making. It is our shared experience that when this is highlighted to social workers, the absence of underlying background knowledge prevents this from either being understood or incorporated within the assessment or decision-making process. Sadly in fact highlighting this has caused conflict with the social worker viewing this as a challenge to be fought rather than support to undertake an accurate assessment as it is intended. *(p719)*

5. *The Brain Injury Rehabilitation Trust Written Evidence (collated from an evidence gathering exercise from a number of brain injury professionals):*

Loss of insight following acquired brain injury is common and is a confounding factor for assessment. This difficulty arises because this group often has high IQ, sound plausible and, in the context of a conversation lead by a third party, can often be supported to understand, retain and weigh up information. The issues arise however because this "good decision making" or even "unwise decision making" is extrinsically environmentally governed. The difficulty comes with the use of the information outside of this setting. The process of assessment creating a false sense of capacity, particularly where the assessor is reliant upon a snapshot or self-report, sometimes without corroborative evidence. *(p1684)*

Our experience is that local authority staff, usually social workers are not trained to make capacity assessments particularly when someone has cognitive deficit due to brain injury. We also find that social workers use “capacity,” as a means of avoiding responsibility for service users. We have examples where our clinicians assess a lack of capacity and social workers assess as having capacity. *(p1711 and 1722)*

HOUSE OF LORDS EVIDENCE TO SUPPORT RECOMMENDATIONS CONTINUED:

8.3 Non-brain injury specific evidence of note:

1. Association of Directors of Adult Social Services (ADASS) Written Evidence:

Greater clarity could be provided in the **Code of Practice** addressing the more complex areas which social care and health professionals encounter, rather than the very simplistic examples which are given. *(p154)*

2. Oral Evidence British Association of Social Workers

Q140 The Chairman: Could I ask all three of you how you think social workers are equipped to undertake assessments of capacity for the purposes of the Act, irrespective of the nature of the person's impairment? For instance, there is some evidence about brain-injury cases; there is some suggestion that social workers are not particularly equipped to make that assessment. Perhaps the Association of Social Workers would like to lead on that.

Anna Ribas Gonzalez: It is certain that, with certain individuals, social workers might not feel equipped to that, but they do not have to do it in isolation. The intention is for people to seek help from other professionals, who might be in a better position to understand the illness of the patient or the situation of the patient. *(p268)*

3. British Psychological Society Written Evidence:

Areas that are of particular concerns are:
1 General medical in patient services and
2 Third sector provision of 24 hour care services for older people and people with Learning Disability and with Acquired Brain Injury (ABI).

Which areas of the Act, if any, require amendment; and how?

1 Psychological factors impacting on capacity
Clarity around when emotional/mental health issues impact on decision making (e.g. someone who has a history of severe neglect, multiple abuses, difficulty in asserting their needs, despite having adequate financial knowledge, gives all of their money away). It would be valuable if any amendments to the Code of Practice should specifically address this. The Society has particular expertise in this area and is willing to contribute.

2 Undue Influence
There needs to be increased clarity around the concept of 'undue influence' and to what degree this would need to be at in order to render a person incapacitated. It also needs to be clear as to how 'undue influence' could be evidenced. It would be valuable if any amendments to the Code of Practice should specifically address this. The Society has particular expertise in this area and is willing to contribute.

HOUSE OF LORDS EVIDENCE TO SUPPORT RECOMMENDATIONS CONTINUED:

3 People with Dysexecutive problems/Serial poor decision makers
There are examples of people (for instance those with ABI) who are able to demonstrate capacity within an assessment but lack the capacity to maintain this in practice due to cognitive impairments. Problems with "executive functioning" are often not identified within routine capacity assessments but can lead to risky behaviours for self and others. It would be valuable if any amendments to the Code of Practice should specifically address this. The Society has particular expertise in this area and is willing to contribute. *(p 328 - 329)*

4. *Julia Lomas Court of Protection Approved Deputy, Oral Evidence:*

Julia Lomas: I think that the ethos of the Mental Capacity Act is correct, but there has to be a recognition that the whole thing slows down, particularly if you have a difficult client, as in my situation, where I have a number of acquired brain injury clients who actually have quite a high level of functioning but impaired cognitive ability and very little insight into their difficulties.

In that situation, if I sat a client in front of me, asked them a question and got the right answer, is that enough? No, not really, because if I then asked that client over a period of time and had evidence of a pattern of behaviour, that pattern of behaviour might demonstrate to me that actually that client did not have the capacity to make that decision in the way that perhaps that first conversation might have suggested. *(p1449)*

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10. Membership of the ABI and MCA interest group:

Name	***Role(s)***
Professor Mike Barnes	Consultant in Neuro-rehabilitation
Jane Bennett	Court of Protection appointed Deputy
Claire Booth	Occupational Therapist, Brain Injury Case Manager, Expert Witness and BABICM Council member
Kerry Bretherton	Barrister, Court of Protection specialist
Professor Hilary Brown	Emeritus Professor of Social Work
Ann Buckler	Acting Director, Brain Injury Rehabilitation Trust (BIRT)
Erin Rodgers	Policy and Campaigns Officer BIRT/The Disabilities Trust
Jo Clark Wilson	Occupational Therapist, Brain Injury Case Manager and Expert Witness
Sarah Clifford	Director of Communications BIRT/Disabilities Trust
Carol Collins	Occupational Therapist, Brain Injury Case Manager, Expert Witness and BABICM Council member
Jackie Dean	Occupational Therapist, Brain Injury Case Manager, Expert Witness and BABICM Council member
Dr Michael Dilley	Consultant Clinical Neuropsychiatrist, Expert Witness
Eddie Fardell	Court of Protection appointed Deputy, Expert Witness
Caroline Ferber	Occupational Therapist, Brain Injury Case Manager and Expert Witness
Dr Rachel Fyson	Associate Professor, School of Sociology and Social Policy
Fergus Gracey	Consultant Clinical Neuropsychologist
Luke Griggs	Director of Communications, Headway
Chloe Hayward	Administrator United Kingdom Acquired Brain Injury Forum
Mark Holloway	Social Worker, Brain Injury Case Manager, Expert Witness and BABICM council member
Howard Jackson	Consultant Clinical Neuropsychologist, Expert Witness
Cathy Johnson	Social Worker, Brain Injury Case Manager and Expert Witness
Alex Ruck Keene	Barrister, Court of Protection specialist
Julia Lomas	Court of Protection appointed Deputy, Partner, National Head of Court of Protection Department Irwin Mitchell and Expert Witness
Claire Norman	Mental Health Legislation Manager BIRT
Professor Michael Oddy	Consultant Clinical Neuropsychologist and former Clinical Director of BIRT/The Disabilities Trust, Expert Witness
Jacqueline Parker	Social Worker, Brain Injury Case Manager and Expert Witness
Alex Rook	Public Law Solicitor, partner Irwin Mitchell Solicitors.
Dr Martyn Rose	Consultant in Neuropsychiatric Rehabilitation, Expert Witness
Kim Russell	Social Worker, Brain Injury Case Manager and Treasurer Brain Injury Social Work Group
Dr Richard Seamark	Consultant Clinical Neuropsychiatrist
Dr Jacky Sheppard	Consultant Clinical Neuropsychologist
Patti Simonson	Social Worker, Brain Injury Case Manager and BABICM council member
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Lisa Turan	Chief Executive Officer Child Brain Injury Trust
Professor Huw Williams	Consultant Clinical Neuropsychologist

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