Acquired Brain Injury, Social Work and the Challenges of Personalisation

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Abstract

Increasing numbers of adults in the UK are living with acquired brain injury (ABI), with those affected requiring immediate medical care and longer-term rehabilitative and social care. Despite their social needs, limited attention has been paid to people with ABI within the social work literature and their needs are also often overlooked in policy and guidance. As a means of highlighting the challenge that ABI presents to statutory social work, this paper will start by outlining the common characteristics of ABI and consider the (limited) relevant policy guidance. The particular difficulties of reconciling the needs of people with ABI with the prevailing orthodoxies of personalisation will then be explored, with a particular focus on the mismatch between systems which rest on pre-suppositions autonomy and the circumstances of individuals with ABI—typified by executive dysfunction and lack of insight into their own condition. Composite case studies, drawn from the first author's experiences as a case manager for individuals with ABI, will be used to illustrate the arguments being made. The paper will conclude by considering the knowledge and skills which social workers need in order to better support people with ABI.

Keywords: Acquired brain injury, social work, personalisation, executive dysfunction, autonomy

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Introduction

Increasing numbers of people in industrialised nations are living with acquired brain injury (ABI), which is the leading cause of disability in

people under forty (Fleminger and Ponsford, 2005). Although the immediate response to brain injury is the preserve of medical doctors and clinicians, social work has an important role to play in both rehabilitative and longer-term support of individuals with ABI. Despite this, both within the UK and internationally, there is limited literature on social work and ABI (Mantell *et al.*, 2012). A search of the ASSIA database for articles with ‘social work’ and ‘brain injury’ or ‘head injury’ in the abstract identified just four articles published within the past decade (Alston *et al.*, 2012; Vance *et al.*, 2010; Collings, 2008; Smith, 2007). Social work practitioners may therefore have little knowledge of how best to support individuals with ABI and their families (Simpson *et al.*, 2002). This article aims to rectify this knowledge deficit by providing information about ABI and discussing some of the challenges which social workers may face when working with this service user group, particularly in the context of personalisation.

A brief introduction to ABI

Whilst UK government data do not provide exact figures, it is estimated that more than one million adults in the UK are currently living with the long-term consequences of brain injuries (Headway, 2014b). Rates of ABI have increased considerably in recent years, with estimated increases over ten years ranging from 33 per cent (Headway, 2014b) to 95 per cent (HSCIC, 2012). This increase is due to a variety of factors including improved emergency response following injury (Powell, 2004); more cyclists interacting with heavier traffic flow; increased participation in dangerous sports; and larger numbers of very old people in the population. According to NICE (2014), the most common causes of ABI in the UK are falls (22–43 per cent), assaults (30–50 per cent) and road traffic accidents (circa 25 per cent), though the latter category accounts for a disproportionate number of more severe brain injuries; other causes of ABI include sports injuries and domestic violence. Brain injury is more common amongst men than women and shows peaks at ages fifteen to thirty and over eighty (NICE, 2014).

International data show similar patterns. For example, in the USA, the Centre for Disease Control estimates that ABI affects 1.7 million Americans each year; children aged from birth to four, older teenagers and adults aged over sixty-five have the highest rates of ABI, with men more susceptible than women across all age ranges (CDC, undated, *Traumatic Brain Injury in the United States: Fact Sheet*, available online at www.cdc.gov/traumaticbraininjury/get_the_facts.html, accessed December 2014). There is also increasing awareness and concern in the USA about ABI amongst military personnel (see, e.g. Okie, 2005), with ABI rates reported to exceed one-fifth of combatants (Okie, 2005; Terrio *et al.*, 2009). Whilst this article will focus on current UK policy and practice, the issues which it highlights are relevant to many national contexts.

If the causes of ABI are wide-ranging and unevenly distributed across age and gender, the impacts of ABI are similarly diverse. Some people make a good recovery from their brain injury, whilst others are left with significant ongoing difficulties. Furthermore, as [Headway \(2014b\)](#) cautions, the 'initial diagnosis of severity of injury is not a reliable indicator of long-term problems'. The potential impacts of ABI are well described both in (non-social work) academic literature (e.g. [Fleminger and Ponsford, 2005](#)) and in personal accounts (e.g. [Crimmins, 2001](#); [Perry, 1986](#)). However, given the limited attention to ABI in social work literature, it is worth listing some of the common after-effects: physical difficulties, cognitive difficulties, impairment of executive functioning, changes to a person's behaviour and changes to emotional regulation and 'personality'.

For many people with ABI, there will be no physical indicators of impairment, but some may experience a range of physical difficulties including 'loss of co-ordination, muscle rigidity, paralysis, epilepsy, difficulty in speaking, loss of sight, smell or taste, fatigue, and sexual problems' ([Headway, 2014b](#)), with fatigue and headaches being particularly common after cognitive activity. ABI may also cause cognitive difficulties such as problems with memory and reduced speed of information processing by the brain. These physical and cognitive aspects of ABI, whilst challenging for the individual concerned, are relatively easy for social workers and others to conceptualise and their functional impact comparatively straightforward to assess. Less easy to comprehend and assess are those common consequences of ABI linked to executive difficulties, behavioural and emotional changes or 'personality' issues.

'Executive functioning' is the term used to describe a set of mental skills that are controlled by the brain's frontal lobe and which help to connect past experience with present; it is 'the control or self-regulatory functions that organize and direct all cognitive activity, emotional response and overt behaviour' ([Gioia et al., 2008](#), pp. 179–80). Impairments of executive functioning are particularly common following injuries caused by blunt force trauma to the head or 'diffuse axonal injuries', where the brain is injured by rapid acceleration or deceleration, either of which often occurs during road accidents.

The impacts which impairments of executive function may have on day-to-day functioning are diverse and include, but are not limited to, 'planning and organisation; flexible thinking; monitoring performance; multi-tasking; solving unusual problems; self-awareness; learning rules; social behaviour; making decisions; motivation; initiating appropriate behaviour; inhibiting inappropriate behaviour; controlling emotions; concentrating and taking in information' ([Headway, 2014b](#)). In practice, this can manifest as the brain-injured person finding it harder (or impossible) to generate ideas, to plan and organise, to carry out plans, to stay on task, to change task, to be able to reason (or be reasoned with), to sequence tasks and activities, to prioritise actions, to be able to notice (in real time) when things are

going well or are not going well, and to be able to learn from experience and apply this in the future or in a different setting (to be able to *generalise* learning) (Barkley, 2012; Oddy and Worthington, 2009). All of these difficulties are invisible, can be very subtle and are not easily assessed by formal neuro-psychometric testing (Manchester *et al.*, 2004).

In addition to these difficulties, people with ABI are often noted to have a 'changed personality'. Loss of capacity for empathy, increased egocentricity, blunted emotional responses, emotional instability and perseveration (the endless repetition of a particular word or action) can create immense stress for family carers and make relationships difficult to sustain. Family and friends may grieve for the loss of the person as they were prior to brain injury (Collings, 2008; Simpson *et al.*, 2002) and higher rates of divorce are reported following ABI (Webster *et al.*, 1999). Impulsive, disinhibited and aggressive behaviour post ABI also contribute to negative impacts on families, relationships and the wider community: rates of offending and incarceration of people with ABI are high (Shiroma *et al.*, 2012) as are rates of homelessness (Oddy *et al.*, 2012), suicide (Fleminger *et al.*, 2003) and mental ill health (McGuire *et al.*, 1998).

The above difficulties are often further compounded by lack of insight on the part of the person with ABI; that is to say, they remain partially or wholly unaware of their changed abilities and emotional responses. Where the lack of insight is total, the individual may be described medically as suffering from *anosognosia*, namely having no recognition of the changes brought about by their brain injury. However, total loss of insight is rare: what is more common (and more difficult to assess) is an individual having only an 'intellectual awareness' of the impact of their injury (Crosson *et al.*, 1989). This means that the person with ABI may be able to describe their difficulties, sometimes extremely well, but this knowledge does not affect behaviour in real-life settings. In this situation, a brain-injured person may be able to state, for example, that they can never remember what they are supposed to be doing, and even to note that a diary is a useful compensatory strategy when experiencing difficulties with prospective memory, but will still fail to use a diary when required. The intellectual understanding of the impairment and even of the compensation required to ensure success in functional settings plays no part in actual behaviour.

Social work and ABI

The after-effects of ABI have significant implications for all social work tasks, including assessing need, assessing mental capacity, assessing risk and safeguarding (Mantell, 2010). Despite this, specialist teams to support people with ABI are virtually unheard of in the statutory sector, and many individuals struggle to get the services they need (Headway, 2014a). Accessing support may be difficult because the heterogeneous needs of people with

ABI do not fit easily into the social work specialisms which are commonly used to structure UK service provision (Higham, 2001).

There is a similar absence of recognition at government level: the ABI report aptly entitled *A Hidden Disability* was published almost twenty years ago (Department of Health and SSI, 1996). It reported on the use of case management to support the rehabilitation of people with ABI, noting that lack of knowledge about brain injury amongst professionals coupled with a lack of recognition of where such individuals 'sat' within social services was highly problematic, as brain-injured people often did not meet the eligibility criteria established for other service users. Five years later, a Health Select Committee report commented that 'The lack of community support and care networks to provide ongoing rehabilitative care is the problem area that has emerged most strongly in the written evidence' (Health Select Committee, 2000–01, para. 30) and made a number of recommendations for improved multidisciplinary provision. Notwithstanding these exhortations, in 2014, NICE noted that 'neurorehabilitation services in England and Wales do not have the capacity to provide the volume of services currently required' (NICE, 2014, p. 23).

In the absence of either coherent policy or adequate specialist provision for people with ABI, the most likely point of contact between social workers and brain-injured people is via what is varyingly known as the 'physical disability team'; this is despite the fact that physical impairment post ABI is often not the main difficulty. The support an individual with ABI receives is governed by the same eligibility criteria and the same assessment protocols as other recipients of adult social care, which at present means the application of the principles and bureaucratic practices of 'personalisation'. As the *Adult Social Care Outcomes Framework 2013/2014* clearly states:

The Department remains committed to the 2013 objective for personal budgets, meaning *everyone* eligible for long term community based care should be provided with a personal budget, preferably as a Direct Payment, by April 2013 (Department of Health, 2013, emphasis added).

However, it appears that the particular needs of adults with ABI have not been considered: the *Adult Social Care Outcomes Framework 2013/2014* contains no references to either 'brain injury' or 'head injury', though it does name other groups of adult social care service users. Issues relating to ABI in a social care context remain, accordingly, overlooked and under-resourced. The unspoken assumption would appear to be that this minority group is simply too small to warrant attention and that, as social care is now 'personalised', the needs of people with ABI will necessarily be met. However, as has been argued elsewhere (Fyson and Cromby, 2013), 'personalisation' rests on a particular notion of personhood—that of the autonomous, independent decision-making individual—which may be far from typical of people with ABI or, indeed, many other social care service users.

Guidance which has accompanied the 2014 Care Act ([Department of Health, 2014](#)) mentions brain injury, alongside other cognitive impairments, in relation to mental capacity. The guidance notes that people with ABI may have difficulties in communicating their ‘views, wishes and feelings’ ([Department of Health, 2014](#), p. 95) and reminds professionals that:

Both the Care Act and the Mental Capacity Act recognise the same areas of difficulty, and both require a person with these difficulties to be supported and represented, either by family or friends, or by an advocate in order to communicate their views, wishes and feelings ([Department of Health, 2014](#), p. 94).

However, whilst this recognition (however limited and partial) of the existence of people with ABI is welcome, neither the Care Act nor its guidance provides adequate consideration of the particular needs of people with ABI.

In the *lingua franca* of health and social care, and despite their frequent administrative categorisation as a ‘physical disability’, people with ABI fit most readily under the broad umbrella of ‘adults with cognitive impairments’. However, their particular needs and circumstances set them apart from people with other types of cognitive impairment: unlike learning disabilities, ABI does not necessarily affect intellectual ability; unlike mental health difficulties, ABI is permanent; unlike dementia, ABI is—or becomes in time—a stable condition; unlike any of these other forms of cognitive impairment, ABI can occur instantaneously, after a single traumatic event.

However, what people with ABI may share with other cognitively impaired people are difficulties with decision making ([Johns, 2007](#)), including problems with everyday applications of judgement ([Stanley and Manthorpe, 2009](#)), and vulnerability to abuses of power by those around them ([Mantell, 2010](#)). It is these aspects of ABI which may be a poor fit with the independent decision-making individual envisioned by proponents of ‘personalisation’ in the form of individual budgets and self-directed support. As various authors have noted (e.g. [Fyson and Cromby, 2013](#); [Barnes, 2011](#); [Lloyd, 2010](#); [Ferguson, 2007](#)), a model of support that may work well for cognitively able people with physical impairments is being applied to people for whom it is unlikely to work in the same way. For people with ABI, particularly those who lack insight into their own difficulties, the problems created by personalisation are compounded by the involvement of social work professionals who typically have little or no knowledge of complex impacts of executive impairment.

ABI and personalisation

There is little doubt that adult social care is currently under extreme financial pressure, with increasing demand and real-term cuts in budgets ([LGA, 2014](#)). At the same time, the personalisation agenda is changing the mechanisms of

care delivery in ways which may present particular difficulties for people with ABI. Personalisation has spread rapidly across English social care services, with support from sector-wide organisations and governments of all political persuasion (HM Government, 2007; TLAP, 2011). The idea is simple: that service users and those who know them well are best able to understand individual needs; that services should be fitted to the needs of each individual; and that each service user should control their own personal budget and, through this, control the support they receive. However, given the reality of reduced local authority budgets and increasing numbers of people needing social care (CfWI, 2012), the outcomes hoped for by advocates of personalisation (Duffy, 2006, 2007; Glasby and Littlechild, 2009) are not always achieved. Research evidence suggested that this way of delivering services has mixed results, with working-aged people with physical impairments likely to benefit most (IBSEN, 2008; Hatton and Waters, 2013). Notably, none of the major evaluations of personalisation has included people with ABI and so there is no evidence to support the effectiveness of self-directed support and individual budgets with this group.

Critiques of personalisation abound, arguing variously that personalisation shifts risk and responsibility for welfare away from the state and onto individuals (Ferguson, 2007); that its enthusiastic embrace by neo-liberal policy makers threatens the collectivism necessary for effective disability activism (Roulstone and Morgan, 2009); and that it has betrayed the service user movement, shifting from being 'the solution' to being 'the problem' (Beresford, 2014). Whilst these perspectives on personalisation are useful in understanding the broader socio-political context of social care, they have little to say about the specifics of how this policy is affecting people with ABI. In order to begin to address this oversight, Table 1 reproduces some of the claims made by advocates of individual budgets and self-directed support (Duffy, 2005, as cited in Glasby and Littlechild, 2009, p. 89), but adds to the original by offering an alternative to the dualisms suggested by Duffy and highlights some of the confounding factors relevant to people with ABI.

ABI: case study analyses

Abstract conceptualisations of social care support, as in Table 1, can at best provide only limited insights. In order to demonstrate more clearly the how the confounding factors identified in column 4 shape everyday social work practices with people with ABI, a series of 'constructed case studies' are now presented. These case studies have each been created by combining typical scenarios which the first author has experienced in his practice. None of the stories is that of a particular individual, but each reflects elements of the experiences of real people living with ABI.

Table 1 Social care and self-directed support: rhetoric, nuance and ABI

1: Beliefs for social care	2: Beliefs for self-directed support	3: An alternative perspective ...	4: Confounding factors for people with ABI
Disabled people are vulnerable and should be taken care of by trained professionals	Every adult should be in control of their life, even if they need help with decisions	Vulnerable people need safeguarding from abuses of power wherever these arise; any form of care or 'help' can create a power imbalance which has the potential to be abused. Self-directed support does not eliminate the risk of abuse	Executive impairments can give rise to a range of vulnerabilities; individuals with ABI may lack insight into their own vulnerabilities and may lack the ability to correctly assess the motivations and actions of others
Existing services suit people well—the challenge is to assess people and decide which service suits them	Everybody needs support that is tailored to their situation to help them sustain and build their place in the community	Self-directed support will work well for some people and not others; it is most likely to work well for those who are cognitively able and have strong social and community networks	Specialist, multidisciplinary ABI services are rare and a concerted effort is needed to develop a workforce with the skills and knowledge to meet the specific needs of people with ABI
Money is not abused if it is controlled by large organisations or statutory authorities	Money is most likely to be used well when it is controlled by the person or people who really care about the person	In any system there will be some misuse of money and resources; financial abuse by individuals becomes more likely when the distribution of wealth in society is inequitable	People with cognitive and executive difficulties are often poor at financial management. Some people with ABI will receive significant financial compensation for their injuries and this may increase their vulnerability to financial abuse
Family and friends are unreliable allies for disabled people and where possible should be replaced by independent professionals	Family and friends can be the most important allies for disabled people and make a positive contribution to their lives	Family and friends are important, but not everyone has well-resourced and supportive social networks; public services have a duty ensure equality for those with and without networks of support	ABI can have negative impacts on existing relationships and support networks, and executive impairments make it difficult for some people with ABI to make good judgements when letting new people into their lives. Those with least insight and greatest difficulties are most likely to be socially isolated. The psycho-social well-being of people with ABI often deteriorates over time as pre-existing friendships fade away

Source: Duffy, 2005, as cited in [Glasby and Littlechild, 2009](#), p. 89.

Case study one: Tony—assessment of need

Now in his early twenties, Tony acquired a severe brain injury at the age of sixteen when he was hit by a car. After six weeks in hospital, he was discharged home with outpatient neurology follow-up. Since the accident, Tony has had significant problems with idea generation, problem solving and planning. He is able to get himself up, washed and dressed, but does not initiate any other activities, including making food or drinks for himself. He is very passive and is not engaged in any regular activities. Tony has no physical impairment, no obvious loss of IQ and no insight into his ongoing difficulties.

As he entered adulthood, Tony's family were aware that he had not developed as they would have expected. They have met all his care needs, provided his meals, managed his finances, etc., but have found this an increasing strain. Following a chance conversation with a neighbour, they contacted their local Headway and were advised to request a care needs assessment from their local authority. There was initially difficulty getting Tony assessed, as staff on the telephone helpline stated that Tony was not entitled to an assessment because he had no physical impairment. However, with persistence, an assessment was made by a social worker from the physical disabilities team. The assessment concluded that, as all Tony's needs were being met by his family and Tony himself did not see the need for any input, he did not meet the eligibility criteria for social care. Tony was advised that he would benefit from going to college or finding employment and was given leaflets about local colleges.

Tony's family challenged the assessment, stating they could not continue to meet all of his needs. The social worker responded that until there was evidence of risk, social services would not act, but that, if Tony were living alone, then he might meet eligibility criteria, in which case Tony could manage his own support via a personal budget. Tony's family would like him to move out and begin a more adult, independent life but are adamant that support must be in place *before* any such move takes place because Tony is unable to manage his own support. They are unwilling to make him move into his own accommodation and leave him to fail to eat, take medication or manage his finances in order to generate the evidence of risk required for support to be forthcoming. As a result of this impasse, Tony continues to live at home and his family continue to struggle to care for him.

From Tony's perspective, a number of problems with the existing system are clearly evident. His difficulties start from the lack of services after discharge from hospital, but are compounded by the gate-keeping function of the call centre and the lack of skills and knowledge of the social worker. Because Tony does not show outward signs of disability, both the call centre worker and the social worker struggle to understand that he needs support. The person-centred approach of relying on the service user to identify his own needs is unsatisfactory because Tony lacks insight into his condition.

This problem with non-specialist social work assessments of ABI has been highlighted previously by Mantell, who writes that:

Often the person may have no physical impairment, but lack insight into their needs. Consequently, they do not look like they need any help and do not think that they need any help, so not surprisingly they often do not get any help (Mantell, 2010, p. 32).

The needs of people like Tony, who have impairments to their executive functioning, are best assessed over time, taking information from observation in real-life settings and incorporating evidence gained from family members and others as to the functional impact of the brain injury. By resting on a single assessment, the social worker in this case is unable to gain an adequate understanding of Tony's needs because, as [Dustin \(2006\)](#) evidences, such approaches devalue the relational aspects of social work practice.

Case study two: John—assessment of mental capacity

John already had a history of substance use when, aged thirty-five, he suffered a severe brain injury in a road traffic accident. John spent eighteen months in hospital and an NHS rehabilitation unit before being discharged to a nursing home near his family. John has no visible physical impairments but does have lung and heart conditions that require regular monitoring and careful management. John does not believe himself to have any difficulties, but shows signs of substantial executive difficulties: he is often irritable, can be very aggressive and does not eat or drink unless sustenance is provided for him.

One day, following a visit to his family, John refused to return to the nursing home. This resulted in John living with his elderly father for several years. During this time, John began drinking very heavily and his drunken aggression led to frequent calls to the police. John received no social care services as he rejected them, sometimes violently. Statutory services stated that they could not be involved, as John did not wish them to be—though they had offered a personal budget. Concurrently, John's lack of self-care led to frequent visits to A&E where his decision not to follow medical advice, not to take his prescribed medication and to refuse all offers of assistance were repeatedly assessed by non-brain-injury specialists to be acceptable, as he was defined as having capacity.

Eventually, after an act of serious violence against his father, a police officer called the mental health team and John was detained under the Mental Health Act. Staff on the inpatient mental health ward referred John for assessment by brain-injury specialists who identified that John lacked capacity with decisions relating to his health, welfare and finances. The Court of Protection agreed and, under a *Declaration of Best Interests*, John was taken to a specialist brain-injury unit. Three years on, John 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 well-being are well managed, and he leads an active and structured life.

John's story highlights the problematic nature of mental capacity assessments. John was able, on repeated occasions, to convince non-specialists that he had capacity and that his expressed wishes should therefore be upheld. This is in accordance with personalised approaches to social care. Whilst assessments of mental capacity are seldom straightforward, in a case such as John's, they are particularly problematic if undertaken by individuals without knowledge of ABI.

The difficulties with mental capacity assessments for people with ABI arise in part because IQ is often not affected or not greatly affected. This means

that, in practice, a structured and guided conversation led by a well-intentioned and intelligent other, such as a social worker, is likely to enable a brain-injured person with intellectual awareness and reasonably intact cognitive abilities to demonstrate adequate understanding: they can frequently retain information for the period of the conversation, can be supported to weigh up the pros and cons, and can communicate their decision. The test for the assessment of capacity, according to the Mental Capacity Act and guidance, would therefore be met. However, for people with ABI who lack insight into their condition, such an assessment is likely to be unreliable.

There is a very real risk that, if the capacity of someone with ABI is measured in the abstract and extrinsically governed environment of a capacity assessment, it will be incorrectly assessed. In such situations, it is frequently the stated intention that is assessed, rather than the actual functioning which occurs outside the assessment setting. Furthermore, and paradoxically, if the brain-injured person identifies that they require support with a decision, then this may be viewed—in the context of a capacity assessment—as a good example of recognising a deficit and therefore of insight. However, this recognition is, again, potentially an abstract that has been supported by the process of assessment (Crosson *et al.*, 1989) and may not be evident under the more intensive demands of real life.

Case study three: Yasmina—assessment of risk and need for safeguarding

Yasmina suffered a severe brain injury following a fall from height aged thirteen. After eighteen months in hospital and specialist rehabilitation, she was discharged home despite the fact that her family were known to children's social services for alleged neglect. Following the accident, Yasmina became a wheelchair user; she is very impulsive and disinhibited, has a severe impairment to attention, is dysexecutive and suffers periods of depression. As an adult, she has a history of not maintaining engagement with services: she repeatedly rejects input and then, within weeks, asks for support. Yasmina can describe, fairly clearly, all of her difficulties, though lacks insight and so cannot use this knowledge to change her behaviours or increase her functional independence.

In her late twenties, Yasmina met a long-term mental health service user, married him and became pregnant. Yasmina was very child-focused and, as the pregnancy progressed, maintained regular contact with health professionals. Despite being aware of the histories of both parents, the pre-birth midwifery team did not contact children's services, later stating this was because they did not wish to be prejudiced against disabled parents. However, Yasmina's GP alerted children's services to the potential problems and a pre-birth initial child-safeguarding meeting was convened, focusing on the possibility of removing the child at birth. However, upon face-to-face assessment, the social worker was reassured that Yasmina had insight into her challenges, as she was able to describe what she would do to limit the risks created by her brain-injury-related difficulties. No further action was recommended.

The hospital midwifery team were so alarmed by Yasmina and her husband's presentation during the birth that they again alerted social services.

They were told that an assessment had been undertaken and no intervention was required. Despite being able to agree that she could not carry her baby and walk at the same time, Yasmina repeatedly attempted to do so. Within the first forty-eight hours of her much-loved child's life, Yasmina fell twice—injuring both her child and herself. The injuries to the child were so serious that a second child-safeguarding meeting was convened and the child was removed into care. The local authority plans to apply for an adoption order. Yasmina has been referred for specialist support from a head-injury service, but has lost her child.

In Yasmina's case, her lack of insight has combined with professional lack of knowledge to create situations of risk for both herself and her child. Opportunities for effective specialist assessment which might have led to reduced risk for Yasmina were repeatedly missed. This occurred when she was returned as a vulnerable brain-injured child to a potentially neglectful home, again when engagement with services was not actively supported, again when the pre-birth midwifery team placed too strong an emphasis on abstract notions of disabled parents' rights, and yet again when the child protection social worker did not appreciate the distinction between Yasmina's intellectual ability to describe potential risk and her functional ability to avoid such risks.

Loss of insight will, by its very nature, prevent accurate self-identification of impairments and difficulties; or, where difficulties are correctly identified, loss of insight will preclude accurate attribution of the cause of the difficulty. These problems are an established function of loss of insight (Prigatano, 2005), yet, if professionals are unaware of the insight problems which may be created by ABI, they will be unable, as in Yasmina's case, to accurately assess the service user's understanding of risk. Furthermore, there may be little connection between how an individual is able to talk about risk and how they will actually behave.

Impairment to executive skills such as reasoning, idea generation and problem solving, often in the context of poor insight into these impairments, means that accurate self-identification of risk amongst people with ABI may be considered extremely unlikely: underestimating both needs and risks is common (Prigatano, 1996). This problem may be acute for many people with ABI, but is not limited to this group: one of the difficulties of reconciling the personalisation agenda with effective safeguarding is that self-assessment would 'seem unlikely to facilitate accurate identification of levels of risk' (Lymbery and Postle, 2010, p. 2515).

Discussion and conclusion

ABI is a complex, heterogeneous condition that can impact, albeit subtly, on many of the skills, abilities and attributes used to negotiate one's way through life, work and relationships. Brain-injured people do not leave hospital and return to their communities with a full, clear and rounded picture of how

the changes caused by their injury will affect them. It is only by endeavouring to return to pre-accident functioning that the impacts of ABI can be identified. Difficulties with cognitive and executive impairments, particularly reduced insight, may preclude people with ABI from easily developing and communicating knowledge of their own situation and needs. These impacts and resultant needs can be seen in all international contexts and negative impacts are likely to be exacerbated when people with ABI receive limited or non-specialist support.

Whilst the highly individual nature of ABI might at first glance appear to suggest a good fit with the English policy of personalisation, in reality, there are substantial barriers to achieving good outcomes using this approach. These difficulties stem from the unhappy confluence of social workers being largely ignorant of the impacts of loss of executive functioning (Holloway, 2014) and being under instruction to progress on the basis that service users are best placed to know their own needs. Effective and accurate assessments of need following brain injury are a skilled and complex task requiring specialist knowledge. Explaining the difference between intellectual awareness and insight is stock-in-trade for brain-injury case managers working with non-brain-injury specialists. An effective assessment needs to incorporate what is said by the brain-injured person, take account of third-party information and take place over time. Only when these conditions are met can the impacts of an injury be meaningfully identified, by generating knowledge regarding the gaps between what is said and what is done. One-off assessments of need by non-specialist social workers followed by an expectation to self-direct one's own services are unlikely to deliver good outcomes for people with ABI. And yet personalised *practice* is essential.

ABI highlights some of the inherent tensions and contradictions between personalisation as practice and personalisation as a bureaucratic process. Personalised practice remains essential to good outcomes: it ensures that the unique situation of each person with ABI is considered and that they are actively involved in deciding how any necessary support can most usefully be integrated into their lives. By contrast, personalisation as a bureaucratic process may be highly problematic: privileging notions of autonomy and self-determination, at least in the early stages of post-injury rehabilitation, is likely to be at best unrealistic and at worst dangerous. Other authors have noted how personal budgets and self-directed services 'should *not* be a "one-size fits all" approach' (Netten *et al.*, 2012, p. 1557, emphasis added), but current social work practice nevertheless appears bound by these bureaucratic processes. This rigid and bureaucratised interpretation of 'personalisation' affords limited opportunity for the long-term relationships which are needed to develop truly personalised practice with and for people with ABI.

A diagnosis of ABI should automatically trigger a specialist assessment of social care needs, which takes place over time rather than as a one-off event, and involves sufficient face-to-face contact to enable a relationship of trust to develop between the specialist social worker, the person with ABI and their

social networks. Social workers in non-specialist teams may not be able to challenge the prevailing hegemony of ‘personalisation as self-directed support’, but their practice with individuals with ABI can be improved by gaining a better understanding of some of the complex outcomes which may follow brain injury and how these impact on day-to-day functioning, emotion, decision making and (lack of) insight—all of which challenge the application of simplistic notions of autonomy. An absence of knowledge of their absence of knowledge of ABI places social workers in the invidious position of both not knowing what they do not know and not knowing that they do not know it. It is hoped that this article may go some small way towards increasing social workers’ awareness and understanding of ABI—and to achieving better outcomes for this often invisible group of service users.

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