

# An exploratory study of Special Educational Needs Co-ordinator's knowledge and experience of working with children who have sustained a brain injury

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An exploratory study of Special Educational Needs Co-ordinator's knowledge and experience of working with children who have sustained a brain injury.

## Abstract

This research aimed to measure Special Educational Needs Co-ordinators knowledge of the educational implications of acquired brain injury in children and young people and whether experience of working with pupils with a brain injury or additional training impacts upon this knowledge. Data was collected within one local authority in England using an online survey. The results indicated that the respondents had high levels of uncertainty regarding the impact of a brain injury though they were more confident in those areas which related most closely to their practice. The responses suggested that experience of working with a pupil with a brain injury promoted greater knowledge than receiving training; however the results showed that only a minority of SENCOs had received any training and those who had tended to have undertaken this independently. This suggests that there is a need for SENCOs to be provided with specialist training in order to increase their understanding of the impact of acquired brain injury in children and young people.

Key Words: Special Educational Needs Co-ordinator; Acquired Brain Injury; education, children, schools

## Introduction

Acquired brain injury (ABI) is defined as damage to living brain tissue which causes impairment of normal brain function and can be caused by either internal events such as a stroke or infection or external events such as a road traffic accident or a fall (Rehab UK, 2002). The term traumatic brain injury (TBI) is used to refer to damage caused by an external event, typically a road accident or fall. As the term ABI is often used as an umbrella term that encompasses all types of brain injuries it will be used throughout this paper as a term that encompasses both internal and external causes of brain injury.

There are no accurate figures to calculate the prevalence rate of ABI in children and young people, due to inconsistent systems of recording such injuries (Hawley et al., 2002). It has however been estimated that 280 in every 100,000 children under 14 years of age will suffer a traumatic head injury (Hawley et al., 2003). Children under the age of 2 years are more likely to have suffered a brain injury as a result of a fall, being dropped or non accidental injury whereas children and young people aged 10-15 years are more likely to have been involved in road traffic accidents. It is likely that the prevalence of ABI is underestimated, as parents may not in all cases seek medical advice through their doctor when the injury is less severe.

Head injury is the most common cause of death in childhood and is a major source of acquired disabilities (Hyde, Eddie and Langford, 2014) as there are increasing numbers of children and young people who survive a head injury due to improving road side care and intensive care in hospitals. It is therefore increasingly likely that educational professionals will encounter children and young people with an ABI.

## The impact of an ABI

The needs of children and young people with ABI can be complex and lifelong and have a significant impact on the family and community systems around them. It is well documented that children and young people who have had an ABI are more likely to have subsequent difficulties with memory (Lowther and Mayfield, 2004; Anderson and Catroppa 2007), attention (Allen et al, 2010), social adjustment (Dykeman, 2003), participation (Law, Anaby and DeMatteo, 2011) and externalising behaviour (Ryan et al, 2015). Children and young people with an ABI are a heterogeneous groups and their needs are influenced by a number of interacting factors, including the severity of their injury, their age at the time of injury, family functioning and the resources that they are able to access (Gordon and di Maggio, 2012). As a consequence, Arroyos-Jurado et al (2000) state that ‘school aged children with TBI require extraordinary effort and energy from individuals in their school, home and community’ (p. 571).

The long term effects of a brain injury in children and young people can often be misunderstood as there is often an assumption that childhood neuroplasticity in the brain will produce better outcomes for children compared to adults. Neuroplasticity refers to the structural and functional changes in the brain that are brought about through interactions with the environment and which is thought to be most important in childhood (Mundkur, 2005). The assumption of a greater degree of neuroplasticity for younger children has largely been demonstrated to be a myth, as the interaction between developmental stage and injury is much more complex than was previously assumed (Levin, 2011; Anderson, Spencer-Smith and Wood 2011; Gordon and di Maggio, 2012). A crucial factor influencing long term outcomes are the stages of neural and social developmental processes at the time of injury as

different regions of the brain have different degrees of plasticity (Dennis and Levin, 2004; Anderson, Spencer-Smith and Wood, 2011). Even where the brain has greater plasticity this can come at a cost, as areas of the brain which compensate for an injury may become 'crowded' causing difficulties to emerge over time (Anderson, Spencer-Smith and Wood 2011). These effects may be latent, only becoming apparent as the further neural development occurs particularly as the cognitive demands on the brain increase with age (Gioia and Isquith, 2004). This 'sleeper effect' is a common problem for children and young people with an acquired brain injury, whose physical recovery maybe complete but as they grow and develop other difficulties emerge over time. Difficulties often emerge during adolescence when development and the transfer to secondary education place greater demands upon the cognitive system (Gioia and Isquith, 2004; Appleton and Baldwin, 2006).

The complexity and heterogeneity of children and young people with ABI when they return to school presents a particular challenge for educational professionals. This is further complicated as there are a number of pathways in returning to school that children and young people may experience. In some cases, where a child has sustained a mild head injury, they may not have had any involvement from a medical professional and return to school as normal. While children and young people who have sustained a moderate or severe head injury are more likely to have been submitted to hospital and may then have time in the hospital or at home before returning to their previous school or, in some cases, a new school if the child is now deemed to require more specialised provision.

Ball & Howe (2013) found that one of the biggest barriers to supporting children transition to school following an ABI is a lack of communication between medical and educational professionals. In some cases a multi-disciplinary team meeting is held to support the planning and a shared understanding of the needs of the child and embed a collaborative active plan

that incorporates both medical and educational targets. The availability of professionals to attend and facilitate such meetings is variable. Furthermore medical reports are not always available to schools and often contain medical ‘jargon’ which school staff may find difficult to translate into meaningful information that will support them in differentiating the curriculum for the child (Ball and Howe, 2013).

Taken together, these factors may leave educators such as teachers and SENCOs feeling unprepared to support children who have had an ABI through the transition period from hospital to school and later in the classroom. In a systemic review of studies exploring the experience of parents of their child’s return to school following an ABI, parents identified the lack of knowledge amongst teachers of the effects of brain injuries was a major issue in the successful transition back into education (Andersson, Bellon and Walker, 2016).

This lack of knowledge amongst teachers regarding the effects of brain injury in children is reflected in research conducted with both healthcare professionals and the general public that has demonstrated the misconceptions regarding the complexity and long term effects of brain injury (Swift and Wilson, 2001; Chapman and Hudson, 2010; Linden and Boylan, 2010). It is therefore unsurprising that research conducted with educational professionals has produced similar results. A survey of teachers in Northern Ireland conducted by Linden, Braiden and Miller (2013), found that personal experience of an individual with a brain injury was more influential than training, in increasing the understanding that respondents had of the impact of a brain injury. They also found that in the absence of any formal training on the impact of brain injury teachers were likely to seek out information themselves in order to support their pupils. Linden, Braiden and Miller (2013) used the common misconceptions about brain injury questionnaire (CM-TBI) to measure teacher understanding of brain injury and

concluded that ‘...many misconceptions exist in their understanding of the condition which are likely to adversely impact on the treatment of children in their care.’ (p. 101).

## Rationale for present study

The aim of this research was to investigate SENCo knowledge of ABI in a local authority within England and to explore if this knowledge was influenced by experience working with children with an ABI and by any training that the professional may have received. As it is likely that children and young people who have experienced a moderate or severe brain injury will be identified as having a Special Educational Need upon their return to school, the role of the SENCo in co-ordinating resources in order to meet these needs is crucial. Therefore SENCo knowledge of the impact of a brain injury is of particular importance amongst the educational professionals working with the child or young person. It was predicted that the concept of brain plasticity would lead the respondents to expect the outcomes of a brain injury to be adversely affected by age. Linden, Braiden and Miller’s (2013) suggested that experience of working with children and young people increased professional understanding this was also explored as well as the impact that training had upon SENCo knowledge.

## Method

### Design

The research was conducted using a survey with data collected through an online questionnaire. The questionnaire was adapted from research conducted by Linton, Braiden and Miller (2013) in Northern Ireland which measured teacher knowledge of ABI. A questionnaire was designed containing questions with fixed choice answer which were used to gather information about the background of the respondent, for example the type of setting

in which they worked, their experience of working with pupils with an ABI and information about any training on ABI that they may have received. Then 13 questions using a rating scale of 1 – 5 were used in order to measure knowledge of ABI. These questions were counterbalanced in order to discourage a set response and were developed from the existing literature in the field of ABI in children and young people. In contrast to Linton, Braiden and Miller's (2013) research the questionnaire items were designed specifically to cover the knowledge that would be helpful for SENCOs working with children and young people with an ABI.

The survey was pretested with four SENCOs from a neighbouring local authority and any ambivalent questions were amended. The online survey was then piloted for accessibility and sense with 6 specialist teachers working in a local authority support service and some minor typographical changes were made to the questionnaire as a result of their feedback.

The survey was administered online using software provided by Bristol Online Surveys. The survey was closed and only respondents who received an invitation were able to access it online. The choice of an online survey was made largely for practical reasons as it allowed the researchers to access the respondents more easily and avoided the costs of postal questionnaire. Difficulties can also arise if respondents are not familiar or confident with the technology needed to access a survey online. In this research as all of the respondents were teachers who regularly accessed information from their local authority online, this was considered to be less likely to be a difficulty than may be the case for other populations. The respondents were also invited to contact the researchers should they experience any difficulties.

Respondents

A total of 108 SENCOs from one local authority within the West Midlands were invited to take part in the online survey. Permission from the local authority's special needs advisor was provided in order to access a database containing the email address of all of the SENCOs within the authority. 55 questionnaires were completed, a response rate of 50%.

### Procedure

One researcher attended SENCO cluster groups meetings within a local authority in the West Midlands in order to outline the purpose and procedure of the research including the ethical safeguards. Following these meetings, details of how to access the questionnaire were distributed to the 108 SENCOs via an email, which contained their unique username and password. Over the course of a six month period those SENCOs who had not completed the questionnaire were prompted to do so by email, a maximum of three times.

### Ethics

The researchers used the British Psychological Society (2013; 2014) guidelines to ensure that the respondents were protected from harm and ethical approval to complete the research was granted by the Ethical Review Board at the University of Birmingham. Information regarding the nature of the research, confidentiality and the right to withdraw data were provided at the beginning of the online survey. Respondents were asked indicate that they had understand this information and to provide consent before moving on to the survey questions.

### Data Analysis

The initial collation of the data was completed automatically by the online survey software and this allowed the data to be transposed directly into SPSS (ver 21) which was used to run all of the statistical analysis. Descriptive statistics were used to explore the background

information provided by the respondents and their knowledge of ABI. The Mann-Whitney U test was used to test for differences between groups of respondents.

## Results

### Background Information for Respondents

Table 1 shows that the majority of the respondents worked within mainstream primary schools (83.6%). Almost a third of respondents (30.9%) had some experience of working with a pupil with an ABI while the majority had no experience. Most of the respondents had no personal experience of an ABI (92.7%).

Table 1: Background Information for Respondents

<b>Background Information for Respondents</b>	<b>Number of Respondents</b>
<b>Role</b>	
SENCo	51 (92.7%)
Assistant Head Teacher	1 (1.8%)
Deputy Head Teacher	2 (3.6%)
Foundation Stage Manager	1 (1.8%)
<b>Type of school</b>	
Primary	46 (83.6%)
Secondary	7 (12.7%)
Special School	2 (3.6%)
<b>Involvement with a pupil with an ABI</b>	
Yes	17 (30.9%)
No	36 (65.4%)
Don't Know	2 (3.6%)
<b>Received training on the impact of an ABI</b>	
Yes	13 (23.6%)
No	42 (76.4%)

## Knowledge of ABI

Table 2 shows the frequency and percentages of responses that respondents gave to each of the 17 questions that were designed to measure their knowledge of ABI. The respondents were more confident in their responses that related most directly to their experience as SENCOs and teachers (questions 2,4,7,8).

Table 2: Frequency and percentage of responses for each item of the questionnaire by category.

		T/F	Strongly agree	Agree	Unsure	Disagree	Strongly disagree
1	Most acquired brain injuries are defined medically as mild	T	0	4 (7.5%)	25 (47.2%)	20 (37.7%)	4 (7.5%)
2	A child can appear to recover fully from an acquired brain injury and then experience difficulties with learning later in life	T	10 (18.9%)	31 (58.5%)	10 (18.9%)	2 (3.8%)	0
3	The head teacher of a school is always informed when one of their pupil's has had an acquired brain injury	F	4 (7.5%)	9 (17%)	23 (43.4%)	14 (26.4%)	3 (5.7%)
4	It is helpful for a child who has had an acquired brain injury to return to some form of education as part of their rehabilitation as soon as possible after injury	T	4 (7.5%)	30 (56.6%)	18 (34%)	1 (1.9%)	0
5	The amount of physical damage seen in the brain through scans in hospital determines if the brain injury is classed as severe, moderate or mild	F	2 (3.8%)	16 (30.2%)	27 (50.9%)	8 (15.1%)	0
6	The local authority keep a record of all children who have experienced an	F	0	7 (13.2%)	39 (73.6%)	6 (11.3%)	1 (1.9%)

	acquired brain injury						
7	A child who has had an acquired brain injury may be more likely to become tired more during the day	T	5 (9.4%)	35 (66%)	10 (18.9%)	3 (5.7%)	0
8	Learning new skills for the first time is likely to be more difficult for a child who has had an acquired brain injury than a child who has not	T	6 (11.3%)	28 (52.8%)	16 (30.2%)	3 (5.7%)	0
9	The younger a child is the better chance they have of a full recovery from an acquired brain injury	F	1 (1.9%)	12 (22.6%)	27 (50.9%)	12 (22.6%)	1 (1.9%)
10	A child must be unconscious after a head injury in order to be classed as an acquired brain injury	F	0	1 (1.9%)	24 (45.3%)	25 (47.2%)	3 (5.7%)
11	Children who have had an ABI (moderate or severe) are likely to experience cognitive difficulties throughout their school years	T	0	30 (56.6%)	22 (41.5%)	1 (1.9%)	0
12	An adult's brain is better able to recover from an acquired brain injury than a child's brain	T	0	1 (1.9%)	22 (41.5%)	28 (52.8%)	2 (3.8%)
13	If a child has been hospitalised as a result of an acquired brain injury, school staff will always be invited to a discharge meeting arranged by the hospital	F	1 (1.9%)	5 (9.4%)	25 (47.2%)	17 (32.1%)	5 (9.4%)
14	It is possible that a child may develop behavioural difficulties during their adolescence as a result of having an acquired brain injury during their primary years	T	1 (1.9%)	26 (49.1%)	21 (39.6%)	4 (7.5%)	1 (1.9%)
15	Once a child is walking and talking again after an acquired brain injury, there are few further effects that are seen in school	F	0	4 (7.5%)	16 (30.2%)	26 (49.1%)	7 (13.2%)

16	Most damage that is caused as a result of an acquired brain injury is apparent immediately after or within weeks of the injury occurring	F	0	3 (5.7%)	20 (37.7%)	25 (47.2%)	5 (9.4%)
17	The hospital provides the best environment for children during their cognitive rehabilitation after a brain injury	F	1 (1.9%)	4 (7.5%)	29 (54.7%)	18 (34%)	1 (1.9%)

For 7/17 questions the respondents were most likely to choose “unsure” as their response, suggesting a high level of uncertainty regarding the most accurate response (questions 1, 3, 5, 6, 9, 13, 17). In some cases this may be unsurprising as questions 1, 5 and 17 required more specific knowledge regarding medical processes, such as the use of scans and medical definitions of ABI. Perhaps more surprising is the number of respondents who were “unsure” about those questions which referred more specifically to the role of schools and the local authority, for example the recording and reporting of acquired brain injuries (questions 1 and 5). As at present there are no formal systems to record and report the numbers of pupils with acquired brain injuries to schools, it is possible that the respondents were uncertain if these processes were in place but that they had not encountered them.

One of the myths that has been identified in the literature surrounding acquired brain injury in children is that the brain’s plasticity during development supports recovery in children with an acquired brain injury. Question 9 was designed to test this assumption and again showed a high level of uncertainty amongst the respondents with 50% choosing the unsure option and even split between those who agree and disagreed with the statement. A corresponding question regarding the ability of adults to recover from brain injury (question 12) also showed

high levels of uncertainty (41.5%) however the respondents were much more likely to disagree with the statement that *An adult's brain is better able to recover from an acquired brain injury than a child's brain* than disagree (56.6%). Take together these questions indicate that the myth of neuroplasticity is likely to be influential in the thinking of SENCOs. The respondents demonstrated more confidence in their responses and greater knowledge for those questions which were more directly related to learning and the long term impact of an acquired brain injury on learning and behaviour (questions 2, 4, 7, 8, 14, 15 and 16). Here the majority of responses were skewed towards the 'correct' answer.

#### Comparisons between groups

Does SENCO experience of working with pupils with acquired brain injury significantly increase their knowledge of the condition?

The responses of respondents who had experience of working with a pupil with an ABI were compared with those who had no experience. It should be noted that two of the respondents did not know whether or not they had worked with a pupil with an ABI and their results are not considered here. Respondents who identified as having experience of working with a pupil with an ABI scored an average of 4 more points ( $M = 59.81$ ;  $SD = 2.81$ ; range = 55-64) than those who identified as having no such experience ( $M = 55.19$ ;  $SD = 4.04$ ; range = 46 – 65).

The Mann-Whitney U test was used to test for differences in the knowledge scores of respondents with experience working with a pupil with an ABI compared to those who had no such experience. The results showed that the knowledge for the respondents with experience were significantly higher than for those respondents without experience ( $p = <0.05$ ).

Does training for SENCOs on acquired brain injury significantly increase their knowledge of the condition?

The responses of respondents who had received some form of training on working with pupils with an ABI were compared to those who had received no training. A total of 13 (23.6%) respondents had received training in ABI, table 3 shows the range of training they had received.

Table 3: Training received by respondents

Type of training	Number of respondents
In school training from an outside professional	2
Off-site training with an outside professional	3
Own research, e.g. reading, internet	5
Information provided by the hospital	1
Former job working with children and adults with a brain injury	1
Other, not specified	1

Respondents who identified as received training scored an average of 2 more points ( $M = 56.1$ ;  $SD = 4.03$ ; range = 46-65) than those who identified as having no such experience ( $M = 58.6$ ;  $SD = 4.19$ ; range = 55-64).

The Mann-Whitney U test was used to test for difference in knowledge of ABI between those respondents who had receive some form of training in ABI compared to those who had received no training. The difference in knowledge scores between the two groups was not significant ( $p = 0.214$ ).

## Discussion

The aim of this research was to investigate SENCo knowledge of ABI in children and young people. The results show the tendency of the respondents to demonstrate a high level of uncertainty about the correct responses to the questions about knowledge of ABI. This is indicated in the tendency for the respondents to choose the “unsure” category and in the general weighting of responses to the centre of the rating scale. This is however some variation in the distribution of the responses and the respondents showed a greater level of knowledge on those questions which related to the impact of an ABI on educational factors such as learning, fatigue and behaviour. A majority of respondents understood that some of the effects of brain injury may not be immediately apparent (56.6%) and that due to the sleeper effect some difficulties may emerge over a longer time span (51%) (Appleton and Baldwin, 2006).

As predicated the concept of brain plasticity led to uncertainty from respondents regarding the outcomes expected with regard to young children with an ABI, with just over half of the respondents choosing the “unsure” option for this question (50.9%). For the corresponding question regarding recovery from brain injury for adults over half of the respondents felt that adults do not recover as easily as children from brain injury (56.6%). While the myth of plasticity has been widely questioned in brain injury research (Levin, 2011; Anderson, Spencer-Smith and Wood, 2011; Gordon and di Maggio, 2012) the rise in interest in neuroscience and what this may be able to offer can lead to simplifications when metaphors such as brain plasticity are employed (Sala and Anderson, 2012). This suggests that when younger children have an ABI there is a potential danger that the necessity for timely and structured support may not be apparent, if education professionals believe that the developing brain can compensate for any injuries. Thus there is a need for education professionals, and

SENCOs in particular, to have some understanding of how age and development stage interacts with the severity of the injury.

This research also highlights the limited access to training that SENCOs have when they are working with a pupil with an ABI. Although 13/17 respondents had received some form of training, 5 of these had conducted their own research on the internet. While many organisations working with families where the child has an acquired brain injury produce useful online resources for parents and teachers, relying solely upon these resources requires the ability to select those which provide the most accurate and relevant information. It is perhaps unsurprising therefore that the difference in knowledge between those SENCOs who had received training and those who had not was not significant. There was however a significant difference in the knowledge of the SENCO who had experience of working with a pupil with an ABI and those who had no such experience. This suggests that when SENCOs do encounter a pupil with an ABI they are 'learning on the job', which given the complexities involved in meeting the needs of many pupils with an ABI is not an ideal situation for either the SENCO or the pupil.

It is perhaps also worth noting that a similar proportion of respondents in this research (30.9%) indicated experience of working with a pupil with an ABI to that found in Linden, Braiden and Miller's (2013) research conducted in Northern Ireland. They comment that this proportion of their respondents seems smaller than would be expected, given the estimated numbers of children and young people who experience a brain injury. They suggest that some pupils with an ABI may remain hidden due to information not being passed on from parents and other professionals and this may also be a factor in this research.

## Limitations

While the survey had a higher response rate than many online surveys, the sample of respondents remains self-selected and it is unclear if the SENCOs who chose to respond to the survey had a greater interest in or knowledge of ABI than the respondents who did not complete the survey. There may therefore be a bias in the responses provided. An additional source of bias was the focus upon SENCOs with a single local authority in the U.K. who may not be representative and this limits the generalisability of this research. This is particularly the case regarding access to training which is variable across the U.K. At the time of this research there was no regular training provided for SENCOs in the borough where the research was conducted. While in a neighbouring local authority one of the researchers has been providing regular training for SENCOs on the educational implications of ABI over a number of years. It would therefore be expected that SENCO knowledge within this local authority would be higher than in the sample from this research. However the limited access to training in the local authority where the research is more typical of the situation elsewhere in the U.K. A further limitation is the nature of the statements contained in the question which were designed to measure SENCO knowledge of ABI. In order to make these statements unambiguous it was necessary to simplify them and so remove some of the complexity surrounding issues such as the impact and outcomes of an ABI.

## Conclusion

As has been found in previous research, this study suggests that SENCO knowledge of ABI in children and young people is inconsistent. In those areas where SENCOs have the most experience which relate to the impact of an ABI on education, the respondents demonstrated the most accurate knowledge and the most confidence in this knowledge. Elsewhere their

responses were characterised by uncertainty and, in the case of the brain plasticity in young children, some misconceptions which have the potential to adversely impact upon children with an ABI. Perhaps the most important finding is the limited access to training for most of the SENCOs who were reliant upon conducting their own research and learning from experience rather than being able to access training from a professional with expertise in this area. Given that children and young people with ABI are complex and require intervention over time this research suggests that there is a need for SENCOs to be able to access specialist training on the educational impact of an ABI.

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