

BRAIN INJURY AUSTRALIA

Policy Paper: Inflicted Traumatic Brain Injury in Children

**Nick Rushworth
Executive Officer**

Prepared for the Australian Government
Department of Families, Housing,
Community Services and Indigenous Affairs

April 2010

1. executive summary:

...Q66: Why did you shake him?

A: I don't know, being a dickhead.

Q67: Was he playing up?

A: A little bit, yeah. He was crying.

Q68: How long had he been crying for?

A: Not that long, probably about 10 minutes and I changed him and done everything. My girlfriend was cooking and, yeah, I – I just shook him probably twice if – I don't know how – how that would have happened...I shook him a maximum of three times, not even... I can't remember how hard. It obviously must have been hard if he died from it...

Q99: Did he – was he a good baby? Did he cry normally at a different time of day or in the afternoon did he cry more?

A: ...Well, he never usually cries, that's what I mean, he barely cries. That's how he was good all the time, barely ever cried...but then once I'd done it I thought, "What I – what the fuck did I do?"

Q112: Why – why did you think that?

A: I thought, "He's too pure. I shouldn't have done it."... At the start it was alright but then it just got to me ... made me a bit pissed off, and I realised what I done after I shook him, and I shouldn't have done it. Now, I know what causes it, I shouldn't have done that...¹

Inflicted traumatic brain injury (ITBI) is the leading cause of death and disability in children who have been abused. Infants are at the greatest risk. The New South Wales Child Death Review Team's 10-year survey of 136 fatal assaults found that **children less than 1 year old were 16 times more likely to die than those aged between 5 and 15, 6 times more likely than those aged between 2 and 4 and 4 times more likely than those aged between 1 and 2 years.**²

Of those children who survive ITBI, as many as 2 in every 3 will live with profound and permanent disability.³ Because it is their brain that is injured, children will experience a range of disabilities that will affect them not only physically but also in the way they think, feel and behave. This paper details the outcomes for children who are abused in this way and the need for nationally consistent protocols for their rehabilitation and follow-up care.

In spite of the severity of such abuse and its consequences for the developing child, there is no reliable information - national, state or territory-based – on how often it occurs. **Over the last 5 years, more than 50 children with ITBI have been admitted to two of New South Wales' children's hospitals alone, and their numbers are increasing. Their average age was 10 months.**

This paper establishes the urgent need for research into the incidence and outcomes of this abuse, beginning with national agreement on terminology, and its incorporation into all hospital morbidity and mortality data collections.

As part of the paper's preparation, Brain Injury Australia consulted widely with professionals engaged in child health, welfare and protection. There was universal agreement that children whose ITBI is detected and diagnosed in hospital represent only a small fraction of those abused in this way. A number of clinicians referred to ITBI hospitalisations as simply "the tip of the iceberg". **This paper cites Australian child protection agency data and parent survey evidence indicating that for every child hospitalised with ITBI as many as 150 others experience abusive head trauma from their caregivers.**

Brain Injury Australia's paper has attempted to estimate the size of the "iceberg", citing the potential **association between ITBI, post-natally acquired cerebral palsy (CP), developmental delay⁴ and attention deficit hyperactivity disorder (ADHD).** **And as many as 1 in every 3 cases of ITBI may be missed even if they reach hospital. Many of those children will go on to be re-abused, and some will experience fatal abuse.**

While Brain Injury Australia's paper acknowledges the difficulties in the detection and diagnosis of ITBI, it also reveals a **clear and pressing need for education in ITBI for all professionals involved in child health, welfare and protection.** Brain Injury Australia also strongly believes that where ITBI is suspected, **children should receive a nationally consistent assessment protocol from health professionals trained in the detection of child abuse.** This includes access to the technology necessary for accurate diagnosis, including computed tomography (CT) and magnetic resonance imaging (MRI) scans.

Like other forms of child abuse and neglect, ITBI is potentially preventable. Brain Injury Australia welcomes the Council of Australian Government's "National Framework for Protecting Australia's Children, 2009-2020" and the shift in policy from statutory child protection responses to abuse prevention. Brain Injury Australia expects that such a shift in policy will be reflected in changed spending priorities. **This paper details programs of parent education and early intervention that have demonstrated their effectiveness at reducing child abuse, including ITBI. Brain Injury Australia also advocates a nationally consistent program of parent education, inclusive of information about child abuse and neglect, combined with secondary interventions targeting families "at risk" of child abuse.** The costs of such programs are negligible when compared to the lifetime costs of a severe ITBI – more than \$5 million – for just one child.

R E C O M M E N D A T I O N S :

Recommendation 1:

Brain Injury Australia recommends the Department of Families, Housing, Community Services and Indigenous Affairs (FaHCSIA) provides funding to Brain Injury Australia to convene a short-term working group - comprising professionals involved in child health, welfare and protection - to produce a nationally agreed descriptor for trauma to a child's head and brain as the result of abuse.

Recommendation 2:

Brain Injury Australia recommends that FaHCSIA, as part of the National Research Agenda for Child Protection, fund the first national incidence study of inflicted traumatic brain injury (ITBI).

Recommendation 3:

Brain Injury Australia recommends, as part of the National Research Agenda for Child Protection, that FaHCSIA and the Department of Health and Ageing (DOHA) direct all future Australian Modifications of the International Statistical Classification of Diseases and Related Health Problems (ICD-10-AM) to include classifications that will allow for the optimum identification of all child abuses, including ITBI.

Recommendation 4:

Brain Injury Australia recommends that FaHCSIA enjoin the Community and Disability Services Ministers' Conference, in implementing Strategy 4.4 of the National Framework for Protecting Australia's Children ("the Framework") – "support enhanced national consistency and continuous improvement in child protection services" – to develop and provide professional education and training in child abuse (inclusive of ITBI) through bodies such as The Royal Australian College of General Practitioners, the Paediatrics and Child Health Division of The Royal Australasian College of Physicians, the Australian Medical Association and the Australian Nursing Federation.

Recommendation 5:

Best practice radiology is key to the diagnosis of ITBI. Brain Injury Australia recommends that FaHCSIA, in implementing Outcome 4.4 of the Framework - "support enhanced national consistency and continuous improvement in child protection services" – to direct production of national standards of practice for radiology relating to the detection of child abuse. Brain Injury Australia also recommends that FaHCSIA, through DOHA, include the development of such national standards in the latter's Diagnostic Imaging Quality Program.

Recommendation 6:

The majority of victim-survivors of inflicted traumatic brain injury are placed in Out Of Home Care. Brain Injury Australia recommends the "National Standards in Out of Home Care" being prepared by FaHCSIA should include regular and ongoing comprehensive assessments conducted only by medical and other professionals with relevant qualifications in child health and development.

Recommendation 7:

Brain Injury Australia recommends that FaHCSIA propose to the Community and Disability Services Ministers' Conference, in its implementation of Strategy 2.4 of the Framework – to "enhance services and supports for children and families to target the most vulnerable and protect children 'at risk'" – that both intensive (secondary) prevention and early intervention services receive dedicated education and training in child abuse and neglect inclusive of ITBI.

Recommendation 8:

Brain Injury Australia recommends that FaHCSIA urge the Community and Disability Services Ministers' Conference, in implementing Strategy 1.2 of the Framework – “educate and engage the community about child abuse and neglect and strategies for protecting children” – to fund a universally available, evidence-based, child abuse and neglect prevention campaign inclusive of information relating to ITBI.

Recommendation 9:

Brain Injury Australia believes that *parent* education should be no different from any other – nationally consistent. Brain Injury Australia recommends that FaHCSIA propose to the Community and Disability Services Ministers' Conference, in its implementation of Outcome 1.2 of the National Framework – “educate and engage the community about child abuse and neglect and strategies for protecting children” – that a nationally consistent curriculum for parent education be developed and implemented, inclusive of information about child abuse and neglect.

B R A I N I N J U R Y A U S T R A L I A

Brain Injury Australia is the national peak ABI advocacy organization representing, through its State and Territory member organizations and network relationships, the needs of people with an ABI, their families and carers. The major components of Brain Injury Australia's role are:

- advocacy for Australian Government program allocations and policies that reflect the needs and priorities of people with an ABI and their families, and
- the provision of effective and timely input into policy, legislation and program development through active contact with Australian Government ministers, parliamentary representatives, Australian Government departments and agencies, and national disability organizations.

2. background:

Inflicted traumatic brain injury (ITBI) is as old as any other abuse of children. The “syndrome” manifest in one form of ITBI - “shaken baby syndrome” (SBS) - is a more recent discovery. In 1946 John Caffey, the “father of paediatric radiology”, was the first to question the presence of bleeding in the brain in 6 infants, where none had long bone fractures or a history of head trauma. A 1971 report by a British neurosurgeon, on another 2 infants with bleeding in the brain but no sign of head trauma, was the first to propose that their brain injuries may have been caused by shaking alone.⁵

Caffey's 1974 paper coined “Whiplash Shaken Infant Syndrome”: “our evidence, both direct and circumstantial, indicates that manual whiplash shaking of infants is a common primary type of trauma in the so-called battered infant syndrome.” And he called for a “nationwide educational campaign against the shaking, slapping, jerking, and jolting of infants' heads.”⁶ **Infants have weak neck muscles but large, heavy heads. Shaking results in the brain bouncing back and forth inside the skull, tearing blood vessels and potentially damaging the brain resulting in disability or death.** However, the “clinical presentation is often nonspecific with symptoms of irritability, excessive crying, vomiting, drowsiness and seizures. The lack of history of trauma makes the diagnosis of intracranial haemorrhage difficult.”⁷

The United States' lead SBS prevention body, the National Center on Shaken Baby Syndrome states: “Shaken baby syndrome is the leading cause of death in abusive head trauma cases. **An estimated 1,200 to 1,400 children are injured or killed by shaking every year in the United States. Actual numbers may be much higher as many likely go undetected. Over 300 babies a year die from being shaken in the United States...**Of those who survive 80% suffer permanent disability such as severe brain damage, cerebral palsy, mental retardation, behavioral disorders and impaired motor and cognitive skills.”⁸

But like most child abuse, it occurs in private. Ordinarily the only eyewitness is the perpetrator. “Short of a confession or video documentation of an injury, the diagnosis of child abuse is circumstantial.”⁹ And that diagnosis “can result in children being removed from their homes, parents losing their parental rights, and adults being imprisoned for their actions.”¹⁰ One study “conservatively assumes” **1,500 convictions “for SBS” have been recorded in the United States since 1990, perhaps as many as 200 per year.**¹¹ “If, across the country over the years, defendants have been proven guilty of shaking babies to death based on the presence of retinal hemorrhages [bleeding in the eye], subdural hematomas [bleeding on the brain] and cerebral edemas [swelling], then the presence of these symptoms must mean that someone is guilty of shaking a baby to death. All that remains is to identify the last person with the conscious child. That person becomes the suspect, who can then be confidently pursued.”¹² Such sentiments are part of a legal and scientific “backlash” against the diagnosis. In the United States, **the number of appeals to overturn convictions involving SBS has grown from 74 during the period 1990-1995 to 259 between 2005 and 2008.**¹³

After some highly publicised appeals against convictions involving SBS in the United Kingdom, the Attorney-General, Lord Goldsmith, reviewed 88 cases and found 85 “do not give cause for concern.” Furthermore, the “triad” of injuries, above – “retinal and subdural haemorrhaging with encephalopathy (a form of brain damage)” – “is consistent with the unlawful application of force” and “a strong pointer” to SBS.¹⁴ Other debate surrounds whether “short falls” are capable of producing such injuries and whether impact to the child’s head, not shaking alone, is necessary. Because of the immediacy of the effects of violent shaking, the last person known to have been with the victim often emerges as the chief suspect. Some skeptics of SBS have pointed to studies where children have been reported to display a “lucid interval” for more than 72 hours before death.¹⁵ The use of expert witnesses in these cases has also been questioned: “the expert *is* the case: there is no victim who can provide an account, no eyewitness, no corroborative physical evidence, and no apparent motive to kill.”¹⁶

Brain Injury Australia is not in a position to debate the legal or bio-mechanical questions implicit in SBS. But its starting position conforms with the 2001 joint statement prepared by the Canadian Paediatric Society, the Canadian Institute of Child Health, the Canadian Public Health Association, the Child Welfare League of Canada, Health Canada, the Canadian Bar Association and the Canadian Association of Chiefs of Police, that; **“the severity of the shaking force required to produce injury is such that it cannot occur in any normal activity such as play, the motions of daily living or a resuscitation attempt. The act of shaking that results in injury to the child is so violent that untrained observers would immediately recognize it as dangerous.”** And potentially harmful. And it is not the only ITBI that children, of any age, suffer.

Brain Injury Australia has timed this paper to acknowledge both the first year of operation of the Council of Australian Government’s (COAG) National Framework for Protecting Australia’s Children (“the Framework”) – which aims to address child abuse as a problem of the public health rather than statutory protection – and the twentieth anniversary of the Australian Government’s ratification of the United Nations Convention on the Rights of the Child, specifically Article 19; “states Parties shall take all appropriate legislative, administrative, social and educational measures to protect the child from all forms of physical or mental violence, injury or abuse, neglect or negligent treatment, maltreatment or exploitation, including sexual abuse, while in the care of parent(s), legal guardian(s) or any other person who has the care of the child.”

This paper relies heavily on the results of international research. ITBI is not under-studied. 242 papers relating to it were published in 2007 alone. Very few, if any, of them would have derived from Australian research.

This paper is also meant to accompany Brain Injury Australia’s 2007-2008 policy paper on “Children, Young People and Acquired Brain Injury”, which is available at: www.braininjuryaustralia.org.au

3. terminology:

i. acquired brain injury (ABI), traumatic brain injury (TBI)

Acquired brain injury (ABI) refers to any damage to the brain that occurs after birth. Common causes of ABI include accidents, stroke, infection, alcohol and other drug abuse and degenerative neurological disease. **Traumatic brain injury (TBI) is an ABI caused by a traumatic event, from an external force applied to the head from an assault, a fall a motor vehicle accident. ABI is common in Australia. In 2003, 432,700 people (2.2% of the population) had an ABI with “activity limitations” or “participation restrictions”¹⁷ due to their disability.¹⁸ 317,900 Australian children were living with a disability, about 1 in 12 of all Australian children. 162,800 children had “physical/diverse disabilities” - an estimated 22,800 of whom were children with an ABI.**¹⁹

ii. inflicted traumatic brain injury (ITBI), inflicted head injury (IHI) abusive head trauma (AHT), non-accidental head injury (NAHI), shaken baby syndrome (SBS)

“When is a case of inflicted TBI appropriate to be counted? As a part of assessing incidence, an important task is defining what constitutes a case. Do all children need to have evidence of intracranial injury? How should the presence or absence of skull fractures be included? What about children with retinal hemorrhages...in the absence of intracranial injury?...The inherent difficulty is that the injuring of young children by an adult shaking them is likely to be a private act, experienced in a childcare setting in which the caregiver and the child are alone. While this private act can have devastating consequences, the child cannot report and the caregiver may hesitate to admit for fear of family and/or legal ramifications.”²⁰

As part of the preparation of this paper, Brain Injury Australia consulted widely with professionals engaged in child health, welfare and protection.²¹ There was mixed agreement on a preferred descriptor for trauma applied to the head the result of abuse. There was some strong feeling that SBS captured the specific circumstances, such as those described above, of some physical abuse of infants. **There was also, however, near-unanimity that, while “shaken baby syndrome” (SBS) might have the highest level of public recognition – and thus make it the most serviceable for parent education and abuse prevention campaigns – SBS has outlived its usefulness in clinical or forensic/legal settings.** Firstly, SBS fails to capture other forms of abusive head trauma apart from shaking. Secondly, SBS carries the suggestion that infants alone are at risk of such abuse when it is clear older children experience ITBI from being shaken as well.²² Thirdly, many felt that SBS’ currency had been degraded by the ongoing debates, described above and the choice of another descriptor avoided “the whole pointless courtroom controversy as to whether this was shaking alone, impact alone, or a combination of both.”²³ Lastly, it also sidesteps concerns over “syndrome evidence”²⁴ – that the presence of a so-called “triad” of clinical findings (bleeding in the eye and on the brain, with damage to the brain) is ordinarily the result of violent shaking.

While Brain Injury Australia accepts that SBS is irretrievably problematic, it is equally unsettled by abusive head trauma (AHT) - the preferred descriptor in the United States – because, when the crucial question of the intent behind injury is considered, “some carers did not set out to be *abusive*, but they did inflict an injury.”²⁵ Thus, AHT “may prejudice medical and legal responses.”²⁶ While ITBI should always be a diagnosis of exclusion²⁷ – that all potential explanations for a child’s head injury should be sought and examined before arriving at one indicative of abuse – Brain Injury Australia believes the same potential for prejudice arises with “non-accidental head injury” (NAHI), the preferred descriptor in the United Kingdom. One paediatrician resisted NAHI because it “covers the situations when neglect and stupidity result in head trauma. I find nothing good about the whole matter of intent: a bit like culpable driving - there is no need to assess intent to drive like an idiot, just the result.”²⁸

Brain Injury Australia believes that the use of “inflicted” – in the sense of to *cause* to bear, to feel, to suffer²⁹ - avoids the problem of intent and the potential for prejudice. But Brain Injury Australia generally considers the term “head injury”, whether inflicted or not, so non-specific as to be unhelpful. “Head injury” can include everything from abrasions to the face to an “open” head injury where an object penetrates the skull and enters the brain.³⁰ Brain Injury Australia’s other general objection to the use of “head injury” as a term inclusive of traumatic brain injury is that only a minority of the former result in the latter. Except, perhaps, in young children. In the absence of compelling bio-mechanical evidence - that the application of a certain amount of force, from impact, from acceleration or rotation of a child’s head results in a certain amount of injury to the brain - “any injury to the child’s head has the potential to cause brain damage even if it is not apparent, radiologically or clinically, at the time of the injury.”³¹ “We simply don’t know what the injury thresholds are for infant brains undergoing repetitive accelerational movements [from shaking].”³² Moreover, where community awareness about brain injury is low the other benefit from the use of inflicted traumatic *brain* injury as the descriptor, in parent education for example, is its directness in naming the most serious consequences of *head* injury in young children.

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Brain Injury Australia recommends the Department of Families, Housing, Community Services and Indigenous Affairs (FaHCSIA) provides funding to Brain Injury Australia to convene a short-term working group - comprising professionals involved in child health, welfare and protection - to produce a nationally agreed descriptor for trauma to a child's head and brain as a result of abuse.

4. incidence: **i. hospitalisations**

“...3 months old; fractured skull, facial bruising, non-accidental injury...
2 ys 9 months; hit around head multiple times by mother, witnessed by ambulance officers, bruising/marks...
7 months; punched in face during DV incident, bruising...
8 yo; severe disability (developmentally less than 1yr) serious inflicted head injury...
2 yo; assaulted by mother's partner, facial/eye bruising...
2 yrs 8 months; thrown into wall by father in psychotic episode. Bruising to head...”

Given the challenges to the detection and diagnosis of ITBI described throughout this paper, it is unsurprising that there is no reliable national, state or territory incidence data – reflected in the number of hospitalisations in a given year – currently available on ITBI in children. What follows is a collection of local datasets and rough approximations to incidence. As part of the preparation of this paper, Brain Injury Australia sought admissions information from the major referring hospitals for children in each State and Territory. Some hospitals were unable to produce such information. Others were unwilling - out of concern that the often very small numbers involved might identify a child victim.³³ In some of those cases, Brain Injury Australia had reason to believe that the numbers were so low as to defy credibility.

4. i. a) traumatic brain injury, 1999-2005

Australia's National Hospital Morbidity Database is an annual compilation of episode-level hospital records indicating diagnosis, external causes of injury and procedures performed. The compilation consists in; the extraction of patient details from hospital records, their assignment by clinical coders according to the International Statistical Classification of Diseases and Related Health Problems, 10th Edition, Australian Modification (ICD-10-AM), who submit their codings to State and Territory health departments for aggregation of the data and supply to the Australian Institute of Health and Welfare (AIHW).

There is no discrete ICD-10-AM code for any of the descriptors mentioned above – ITBI, IHI, NAHI or SBS. While the ninth revision of the ICD (ICD-9) used in the United States included a code specifically for “shaken infant syndrome”, there is no equivalent coding in the ICD-10-AM. The closest approximation is “T74.1 Maltreatment syndrome, physical abuse. Battered: baby or child syndrome NOS [“Not Otherwise Specified”], spouse syndrome NOS.” T74.1 “includes children and adults, and is a very non-specific code.”³⁴

The interpretation of ITBI hospitalisations information as an index of incidence needs to come with the following cautions. Firstly, it may exclude deaths prior to hospitalisation (i.e. at the scene of the abuse) or that occur after discharge. Secondly, “identification of inflicted injury in children in a clinical setting can be complex and confronting for medical and nursing staff. Some cases of child maltreatment are not identified and/or documented adequately and therefore may not be represented in morbidity or mortality statistics. Without standardized definitions of maltreatment and methods of capturing maltreatment in datasets it is difficult to gain a reliable estimate of the true magnitude of child abuse in the community.”³⁵ Where medical and other professionals remain uncertain about the cause of child's head injury, it will be unlikely that hospital records will yield information sufficient for clinical coders to determine whether the injury was inflicted or not, let alone whether it constituted “maltreatment”. A 2008 Access Economics report into the costs of child abuse found **“hospitalisation data under-report child abuse. Only 14 hospitalisations were directly recorded for child abuse and neglect between 1998-99 and 2004-05.”**³⁶ Given the difficulties in detection and diagnosis specific to ITBI, it is likely that this kind of abuse is even more likely to go unrecognised in coding. Thirdly, given the often non-specific nature of the symptoms many children who have experienced ITBI

present with – vomiting, fever, irritability, and lethargy – some, perhaps many, instances of ITBI will be missed in hospital.

The AIHW has produced the most recent national survey of traumatic brain injury (TBI) hospitalizations, for the year 2004-2005. Brain Injury Australia has been able to obtain some additional information in relation to assault-related TBI from the Institute's National Injury Surveillance Unit. **Between 1999 and 2005, 385 children aged 0-14 were hospitalised with TBI as the "Principal Diagnosis"³⁷ where "assault" was the cause. During the same period, 93 children were hospitalised with assault-related TBI as an "Additional Diagnosis."³⁸ Though these hospitalisations will include some peer-on-peer violence, of the 22 hospitalisations for assault-related TBI as "Principal Diagnosis" during 2004-05 where the "relationship of the victim of assault to perpetrator" was specified, the perpetrator was a "parent/ family member" in 8 cases.**

During 2007-08, there were 194 hospital separations³⁹ for infants - less than 12 months old - and 218 for children aged 1- 4 years due to assault.⁴⁰ During 2006-2007, separations for assault were more common among infants – at rates of 68.4 per 100,000 boys and 43.9 for girls - than for any other childhood age group. In almost half of those cases, the perpetrator was either a parent, carer or other family member.⁴¹

4. i. b) New South Wales

Brain Injury Australia has obtained admissions information from New South Wales' three statewide children's hospitals - The Children's Hospital at Westmead, Sydney Children's Hospital and John Hunter Hospital in Newcastle. **25 children were admitted to The Children's Hospital at Westmead with ITBI between 2001 and 2008.⁴² Their average age was 10 months.⁴³ 34 children were admitted to the Sydney Children's Hospital with ITBI between 2004 and 2008. Their average age was also 10 months.⁴⁴ 16 children with ITBI were admitted to John Hunter Hospital between 2007 and 2009. Their average age was 16 months.⁴⁵**

There have also been two studies of ITBI admissions to New South Wales hospitals. A survey of admissions to The Children's Hospital at Westmead between 1995 and 2002 revealed 65 cases of ITBI. The average age of victims was 8 months.⁴⁶ The most common cause of subdural haematoma in infants (the collection of blood between the outer and middle layers of the covering of the brain, caused by force applied to the head sufficient to rupture veins) and effusion (the resulting leakage of cerebrospinal fluid) is abuse. A review of admissions to The Royal Alexandra Hospital for Children/ The Children's Hospital at Westmead between 1987 and 1996 found 38 children with subdural haematoma/ effusion (SDH/E), the commonest cause for which (in 55% of cases) was inflicted Traumatic Brain Injury. The average age of the children was 5 months.⁴⁷

New South Wales' Brain Injury Rehabilitation Program provides services to people with a severe TBI and other sudden onset ABI. Of the 261 new admissions of children aged 0-14 years to the NSW BIRP during 2006-07, 7% were due to "assault/non-accidental - largely the result of child abuse or domestic violence"⁴⁸

4. i. c) Victoria

As far as Brain Injury Australia is aware the only attempt by *government* to determine the extent of ITBI was undertaken in Victoria, "following a Ministerial request for an information campaign regarding the dangers of shaking a baby or infant"⁴⁹. The Office of the Child Safety Commissioner's (OCSC) found "data on the instances of babies and children being harmed by shaking in Victoria is limited. Variation in the level of awareness, diagnosis difficulties and inconsistencies in coding practices makes extraction and comparative analysis problematic. This results in the data being unreliable, likely underestimating the number of children harmed by shaking."⁵⁰ Monash University's Accident Research Centre examined all Victorian hospital admissions between 2001 and 2005 that reflected the "triad" of diagnoses traditionally associated with "shaken baby syndrome" - traumatic subdural haemorrhage [SDH], retinal haemorrhage and encephalopathy. The search identified 73 cases. Of the 73 cases identified: "no cases met the full triad diagnoses indicative of SBS"; "22 cases were coded as child maltreatment" and 11 cases met 2 of the 3 criteria and 9 of the 11 were noted to be associated with child maltreatment."⁵¹

The OCSC also searched data maintained by the Victorian Forensic Paediatric Medical Service for the period 1 July 2006 to 20 June 2007 and examined records for six children admitted to Melbourne's Royal Children's Hospital and assessed by the Service. "All six infants were under 3 months of age and presented with injuries consistent with being shaken." During 2009, the VFPMS "assessed 11 inpatients at Royal Children's Hospital for suspected non-accidental head injury" and 5 children admitted to Monash Medical Centre.⁵² Another review of the 1115 "head injury" presentations to the Royal Children's Hospital emergency department during 2004, found only 3 had been inflicted.

4. i. d) Queensland

A recent study of admissions to Brisbane's Royal Children's Hospital between 2004 and 2008 found 18 cases of children "suffering identified or presumed abusive head trauma" received from Brisbane's northern suburbs.⁵³ Their average age was 8 months.

4. i. e) South Australia

Brain Injury Australia has been able to obtain the results of two audits of hospital admissions in South Australia. The first, for potentially statewide admissions between 2008 and 2010, found 7 cases of inflicted head injury. All the children presented with subdural and retinal haemorrhages, 6 of the 7 had skull fractures, 4 of the 7 evidenced "brain injury". The children's average age was 5 months. The second, a review of all injury admissions of children aged less than 12 months to Flinders Medical Centre between 2001 and 2002 identified only 1 out of the 74 children as a "shaken infant".

4. i. f) Western Australia

An unpublished analysis of admissions to Perth's Princess Margaret Hospital between 2001 and 2006 identified 24 children with "abusive head injuries or a history of having been shaken. Of these 16 were classified as having [shaken baby syndrome], the remaining 8 infants having been shaken without ensuing intracranial head injury." The study arrived at an incidence rate of 10.9 per 100,000 children aged less than 1 year.⁵⁴

An array of international surveys of hospital admissions has produced estimates of the rates of ITBI on a population basis. They vary between 5.1 and 33.8 cases of ITBI per 100,000 children aged between 0 and 2 years, depending on: the number of children studied; what kinds of injuries indicative of ITBI were included, whether cases were consolidated for both ages (children aged less than 1 year generally experience much higher rates of ITBI); and whether the studies were prospective or retrospective (the latter approach likely to yield fewer cases). As far as Brain Injury Australia is aware, the only Australian studies to attempt population projections are the Brisbane and Perth surveys referred to above, which arrived at incidence rates of 9.7 and 10.9 cases of ITBI per 100,000 children, respectively, "with a rate of 14.5 cases [of ITBI] per 100,000 births evident upon inclusion of those cases identified as presumed [ITBI]...utilising dual combinations of inconsistent or lack of history, and the presence of one or more of either parental risk factors, retinal haemorrhages, and/or other child abuse related injuries to identify presumed [ITBI] cases."⁵⁵

Applying the range of incidence rates, above, to the population of Australian children aged less than 1 year at June 2007 (276,469) produces an estimate of between 14 and 93 ITBI hospitalisations per year in that age group. It should be noted that the most conservative estimate for ITBI hospitalisations in Australia is still markedly higher than those arrived at by Access Economics - across all ages and external causes - for the *incidence* of moderate TBI (7 per 100,000 population) and severe TBI (4.7 per 100,000).⁵⁶ A group comprising paediatricians specialising in child protection, paediatric neurosurgeons, ophthalmologists and researchers have attempted to apply some of the international survey evidence, above, to the Australian population. They have conservatively estimated that 65 cases of SDH/E occur each year nationwide. The majority of these would be the result of ITBI. The group has proposed a national surveillance study of SDH/E in children aged less than 2 years through the Australian Paediatric Surveillance Unit. The study would also assess outcomes for these children at discharge from hospital and at six months. While ethics approval has been obtained, the group has been unable to raise the small amount of funding - \$11,000 per annum - necessary to run the study.⁵⁷

Recommendation 2:

Brain Injury Australia recommends that FaHCSIA, as part of the National Research Agenda for Child Protection, fund the first national incidence study of inflicted traumatic brain injury (ITBI).

The accuracy of any ITBI incidence study will be greatly enhanced if child abuse-related codes were built into all future editions of the International Statistical Classification of Diseases and Related Health Problems (ICD). Australian researchers occupy key positions in the revisions prepared for the 11th edition of the ICD, as members of the World Health Organisation's Injury and External Causes Topic Advisory Group (TAG). The TAG's work – on “non-medical based issues which can be difficult to determine or classify at the point of hospital admission or death, such as intent to cause harm”⁵⁸ - could directly address many of the challenges facing the identification and classification of child abuse-related hospitalisations, by including a range of agreed descriptors. Alongside one for ITBI, Brain Injury Australia agrees with an Australian study that the inclusion of codes in the ICD for “possible abuse’ to indicate that there was a suspicion or investigation of child abuse in the medical record may circumvent issues where a determination of abuse does not occur until after the child is discharged and may flag concerns for future medical investigations.” Future editions of the ICD-10 should also include a code for childhood injuries “under review’... where there remains a question over the intent...to diminish some of the misclassification issues surrounding abuse.”⁵⁹ It is anticipated that the ICD-11 will be released in 2014. The Australian Modification (ICD-10-AM) is updated every second year by the National Centre for Classification in Health (NCCCH). Brain Injury Australia understands that NCCCH's contract ends in June, and the work on future revisions is subject to tender.

Recommendation 3:

Brain Injury Australia recommends, as part of the National Research Agenda for Child Protection, that FaHCSIA and the Department of Health and Ageing (DOHA) direct all future Australian Modifications of the International Statistical Classification of Diseases and Related Health Problems (ICD-10-AM) to include classifications that will allow for the optimum identification of all child abuses, including ITBI.

4. incidence: **ii. “community”**

Brain Injury Australia believes that its advocacy should come from a base of evidence. Relative to other ABI or TBI, the number of children *hospitalised* with a detected and diagnosed ITBI is small, and certainly smaller than the number hospitalised as a result of other forms of abuse or neglect. But clinicians and professionals working in child welfare and protection have long suspected that those ITBIs detected and diagnosed in hospital represent “only the tip of a much bigger iceberg of infants who are shaken and never come to medical attention”.⁶⁰ When Brain Injury Australia combines the local child protection agency data it has been able to obtain with the results from the limited international survey literature of parental physical discipline, it suggests frequencies of head trauma far in excess of hospital admissions. What follows is a detailed assembly of research evidence suggestive of the size of that “iceberg”.

A 2002 survey of 1435 households in the North and South Carolinas of the United States found an “overall incidence of harsh physical discipline was 43 cases *per 1000 children*.”⁶¹ [italics added] For children aged less than two years of age, “shaking was most prevalent, with a rate of 26 cases per 1000 children.”⁶² The survey's authors compared their estimates with the US' National Child Abuse and Neglect Data System, 1995 Gallup Poll survey data from 1000 US families - where 4.4% of parents of children aged less than 2 years reported having shaken their child as a means of discipline - and a study of the incidence of hospitalised ITBI in North Carolina over a two-year period. They concluded “**for every 1 child less than 2 years of age who sustains a serious or life-threatening injury, another 152 children may be shaken by their caregivers and sustain sub-clinical brain trauma that goes undetected.**”⁶³ Significantly, Carolina *mothers* were surveyed “about potentially abusive behaviors used by either themselves or their husbands or partners in the context of other disciplinary practices.”⁶⁴ Given the age group of the children at the greatest risk of ITBI, given the clandestine circumstances in which such abuse ordinarily occurs, that fathers/ male partners are overwhelmingly the perpetrators of severe ITBI, and a pervasive reluctance to disclose child abuse, it is likely the study's alarmingly high estimates of the community incidence of ITBI remain an underestimate.

One of the co-authors of the Carolinas study, above, sought to check its results for potential ITBI against survey evidence from other countries. When samples of between 400 and 1,000 mothers from India, Chile, the Philippines, Egypt, and Brazil were surveyed as part of the World Health Organization's World Report on Violence and Health (WorldSAFE) **"the frequency of shaking...of children aged less than 3 years ranged from 6.6% of mothers in the Manila, Philippines, neighborhood of Paco to 42% of mothers in the urban slums of India."**⁶⁵ The same study compared the Carolinas' results with those from the United Nations Children's Fund's (UNICEF) "Multiple Indicator Cluster Survey" - an survey of households monitoring the health and wellbeing of women and children. "Survey data, anonymised as to the specific countries providing the data, have been shared with the author for two eastern European countries, three central Asian countries, and one West African country. **With sample sizes of over 3000 parents in each country, self-reported shaking of children as discipline in the last month ranged from 18% to 36%."**⁶⁶ Significantly, fathers/ male partners – who constitute the overwhelming majority of perpetrators – were not surveyed. The author's more recent surveys "are getting 88% of fathers now...Interestingly, the data on shaking as discipline suggests that 1.6% of mothers and 1% of fathers shake kids under 2. We think the reason men show up as perpetrators in hospital samples has more to do with [the] strength [of their shaking] than rates of perpetration or intent."⁶⁷ **Brain Injury Australia was unable to identify any local surveys of parental abuse/ discipline of children that might arrive at potential rates of ITBI.**

There is also some evidence from victim-survivors of child abuse that the community "incidence" of ITBI may radically exceed hospitalisations. In 2001 the United Nations General Assembly called for a global study on violence against children, acting on a recommendation of the United Nations' Committee on the Rights of the Child. The International Society for the Prevention of Child Abuse and Neglect (IPSCAN) responded by convening a group of academics, health care professionals and community-based advocates to work on developing a set of internationally relevant instruments for the measurement of child maltreatment. **The use of one of the resulting tools, "IPSCAN Child Abuse Screening Tool-Retrospective" (ICAST-R) with 842 young adults from Colombia, Egypt, India, Kyrgyzstan, Lebanon, Malaysia, and Russia found rates of recollection of having been "shaken hard" ranged between 4.2% (Lebanon) and 20.8% (Colombia).**⁶⁸ The fact that the overwhelming majority of victims of ITBI are aged between 0 and 24 months, and the little likelihood of either explicit memory prior to 18 months or of such memories being available to adult recall, suggests these results are also bound to be conservative.

Brain Injury Australia understands that ITBI can result from a range of head trauma apart from shaking. But in order to check these international reckonings of community "incidence" relative to hospitalizations (that result in the detection and diagnosis of ITBI) it approached each State and Territory child protection agency requesting information regarding notifications⁶⁹ - as well as substantiations⁷⁰ of notifications – relating to reports of "shaking" of children aged between 0 and 2 years over the last 3 years. Of those states that responded, the majority only collected data in the broad classifications of physical, sexual, emotional abuse and neglect required for annual reporting to the Productivity Commission and the AIHW. Brain Injury Australia was able to obtain some data from New South Wales Department of Community Services and "Families SA" - the division of South Australia's Department for Families and Communities whose "primary area of concern is the protection of children".

4. ii. a) New South Wales

Between 2005 and 2009, NSW Community Services received 514 "Child Protection Reports relating to shaking of children aged 0-2 years".⁷¹ In 236 instances, "secondary assessment determined actual harm or risk of harm relating to shaking of children".

4. ii. b) South Australia

Between 2004 and 2009 in South Australia, of the 7973 "children in Notifications" of child abuse less than 2 years of age, **there were 2089 "children in Substantiations [of those Notifications]", of which there were 23 "Substantiations involving Shaking" and 7 "Substantiations involving Skull Fracture".**

4. ii. c) Western Australia

Between 1999 and 2006, the Department for Child Protection recorded 46 substantiations of notifications relating to "shaken baby syndrome."⁷² The 14 May, 2003 statement by the then Community Development Minister for Western Australia, Sheila McHale, announcing an SBS prevention campaign "Babies Break If You Shake Them", recorded; **"last year the Department for Community Development reported 15 children under the age of three were injured from being shaken or thrown."**⁷³

It is important to reiterate that, even though these numbers are considerably higher (especially those from New South Wales) than ITBI *hospitalisations* that, given the circumstances in which this abuse ordinarily occurs – safely away from eyewitnesses – the community “incidence” of ITBI is bound to be higher than numbers of notifications or substantiations of notifications suggest. **During 2008-2009, Australian child protection agencies made 11,789 substantiations in relation to notifications of physical abuse involving 7,801 children. A 2008 report by Access Economics argues that ‘it is likely that for every child officially identified as abused or neglected (by State or Territory child protection systems), there may well be almost five times as many who are not identified. Indeed, it could be as high as 18 times more children who have been abused or neglected who are not identified as the number of those who are.’**⁷⁴

5. outcomes:

As with incidence studies, the local literature on the outcomes of ITBI is scant. A 2007 survey of international research found **“the short-term outcome in infants with [ITBI] is poor and the associated mortality ranges from 11% to 36%; in surviving children, long-term morbidity is usual and ranges from mild learning difficulties to severe physical and cognitive impairment.”**⁷⁵ Of the 65 children with ITBI admitted to The Childrens’ Hospital at Westmead 4 died, 7 remained in a vegetative state, 17 were discharged with “severe disability”, 12 with “moderate disability” and 25 with “good” outcome. When 56 of them were followed up between 1 and 73 months later, 17 were experiencing “severe disability”, 12 “moderate disability” and 19 had a “good” outcome.⁷⁶ A study comparing the outcomes for 25 children with ITBI with 20 children with non-inflicted brain injury admitted to the Royal Children’s Hospital, Brisbane found the inflicted group “had more severe head and peripheral injuries with significantly higher proportions of diffuse [brain] injury...The two groups had comparable proportions of normal outcome at discharge with 64% of the inflicted group having good recovery and 75% in the non-inflicted group. However, post-follow-up, only 33% in the inflicted group had good recovery compared with 82% in the non-inflicted.”⁷⁷ Five of the children with ITBI died. A number of studies have compared outcomes for these two groups with broadly similar results.⁷⁸ The reasons are not clear but hypotheses point to the mechanism of injury (that shaking results in more diffuse, but deeper, brain injury than blunt trauma from impact) and to the greater degree of force often involved in ITBI.

As many as two-thirds of children with severe ITBI will experience physical disability, including vision and hearing impairment, epilepsy, paralysis, difficulties with speech and with muscle co-ordination. Some will develop cerebral palsy (CP). Between 10% and 18% of all CP in Australia is acquired post-neonatally - after 30 days of age and up to 2 years of age - accounting for 60-100 new cases each year. Of these, approximately 10% are the result of ITBI. **The most recent information from the nation’s CP registries indicates “the non-accidental group is slightly rising.”**⁷⁹

While the Brisbane study, above, found no significant differences in cognitive function between the ITBI and non-inflicted groups, other research has found a greater level of impairment in those children with ITBI. A Virginia study comparing 27 children with ITBI with another 27 with non-inflicted scored “significantly and markedly lower” on measures of mental development and gross motor skills 6 months after injury.⁸⁰ A recent review of 28 studies of children’s cognitive outcome from TBI found a direct relationship between injury severity and resulting function. **Children with severe TBI demonstrated significant impairment from IQ scores and tests of executive functioning (processing speed, attention) and verbal memory within months of injury. After two or more years, all areas tested were still affected.**⁸¹

A study of 25 Scottish children with ITBI found more than half of them experienced “behavioural abnormalities” including “self-injurious and self-stimulatory behaviors, hyperactivity, impulsivity, temper tantrums, and rage reactions. Psychological testing mirrored the parental reports as 47% of children scored in or below the ‘moderately low’ category of the socialization domain.”⁸² (For 2 in 3 *adults* with TBI, the effects of injury on behaviour are described as being the most disabling.) Of all the consequences of ITBI, the parents in the Scottish study reported having “the most difficulty in dealing with” their child’s “challenging behaviours”. When combined with cognitive impairment, the potential impacts on school entry, integration and performance as well as friendship formation can be immense. “Special educational needs are identified in a large proportion of children with inflicted brain injury. In a study of school age children, five of 18 children attending mainstream school had a statement of special educational needs. In addition, seven children attended special schools.”⁸³

6. costs:

Brain Injury Australia is unaware of any local attempts to cost ITBI. 1998's National Conference on Shaken Baby Syndrome in the United States estimated the initial hospitalisation costs at as much as US\$70,000, health care costs over the next 5 years at US\$300,000 and US\$1 million over a lifetime.⁸⁴ "Additional costs associated with loss of societal productivity and occupational revenue and with prosecution and incarceration of a perpetrator are unknown."⁸⁵ A 2009 report by Access Economics estimated the **"lifetime costs per incident case of TBI...to be \$2.5 million and \$4.8 million for moderate TBI and severe TBI respectively."**⁸⁶ **The estimated total economic cost to Australia of TBI was \$8.6 billion**, which "appears to be much higher than all neurological conditions previously assessed by Access Economics including dementia, bipolar disorder, multiple sclerosis, muscular dystrophy and cerebral palsy."⁸⁷

PricewaterhouseCoopers' 2005 **costings for care of a person with a TBI the result of a motor vehicle accident ranged between \$8,819 ("community living") to 282,992 ("24 surveillance/care") per annum.**⁸⁸ Victims of ITBI may be entitled to crime compensation to a maximum of \$75,000 in Queensland, \$60,000 in Victoria, \$50,000 in New South Wales and South Australia, \$40,000 in the Northern Territory and \$30,000 in Tasmania. Access Economics has reported separately on the costs of child abuse, estimating the **"annual cost of child abuse and neglect that occurred in 2007" at nearly \$4.0 billion. "On an incidence basis, the lifetime cost of children abused for the first time in 2007 was estimated as \$6.0 billion... In addition, the value of the burden of disease represents a further \$7.7 billion."**⁸⁹

7. incidence:

i) trend?

Given the general uncertainty surrounding the detection and diagnosis of ITBI, and the very small numbers of hospitalisations indicative of ITBI incidence, Brain Injury Australia is hesitant to speculate about trends. Moreover, any interpretation of an increase in ITBI is subject to the perennial question of whether it is indicative of more abuse or more abuse awareness, with better detection. Insofar as ITBI admissions to the two largest statewide children's hospitals in New South Wales - when combined with that state's child protection agency data - are reflected in other jurisdictions, there is some evidence to indicate that ITBIs are increasing. Whether that increase exceeds the increase in the *number of children* - 301,000 births were recorded during 2008-2009, the highest fertility rate since 1977 - it is perhaps impossible to judge. However, if any recent increase in ITBI suggests more *abuse*, then recent rises in fertility may offer an explanation. Some stakeholders contacted by Brain Injury Australia wondered (privately) whether the Australian Government's \$5,185 "baby bonus" might have acted as perverse incentive to bear children, especially in those communities of economic disadvantage where the apparent rates of abuse are higher. Media reports of parents having children "for" the bonus abound. A retired police officer advised Brain Injury Australia of "parents at the (suspicious) death of their newborn recently who asked the police whether they would still be getting the bonus."

There is, however, emerging evidence of a relationship between economic hardship and increases in ITBI. Results from a study of admissions to 4 United States' children's hospitals for "unequivocal AHT"⁹⁰ have found "a tremendous increase in the number of cases in both Pittsburgh and Seattle" since the recession began in late 2007. "There were also increases in both Cincinnati and Columbus, but the increase was not as large. We are still looking for reasons other than the recession why the rate may have increased."⁹¹

7. incidence:

ii. "missed" cases

"...we evaluated a 14 month-old child who had sustained an abusive head injury 4 months previously. Shortly after his initial injury, he had been examined by his physician and his new-onset seizures were attributed to his history of prematurity. During the next 4 months, the child had 7 physician visits and 2 [head] imaging studies. At each visit, the diagnosis of abusive head trauma was not recognized. When we examined him 4 months later, he had multiple old and new fractures and healing brain injuries, including extensive brain atrophy and healing brain infarctions."⁹²

This case, above, is taken from a landmark study of 173 young children admitted with head injuries to The Children's Hospital in Denver, Colorado. **As many as 1 in every 3 of the children had been seen by physicians after experiencing ITBI and the diagnosis had not been made.** Twenty-two of the children experienced medical complications related to the missed diagnosis. The number of additional visits made to physicians before the child's ITBI was detected ranged between 2 and 9. **Of the 54 children whose ITBI had gone unrecognised, 15 were re-abused, 5 of those dying as a result.** Brain Injury Australia has contacted the study's lead author. Even though her study involved cases now between 15 and 20 years old, a similar review has not been undertaken since.⁹³

When asked by Brain Injury Australia whether current local practice might produce results similar to those above, the responses of paediatricians were mixed. Brain Injury Australia suspects that some of the variance could be explained by differences in the culture of individual hospitals. For instance, clinicians' awareness of, and education in, child abuse varies between individual hospitals. Some have readier access to diagnostic technologies like CT and MRI machines (see below, p.16). The following, however, reflects a consensus view: **"significant head injury leading to unconsciousness or seizures, as a result of abuse, is not likely to be missed. Less serious head injury in infants, leading to a brief period of decreased consciousness, but accompanied by intracranial haemorrhage and, possibly, retinal haemorrhage, with a subsequent return to normal consciousness, is much more likely to be missed."**⁹⁴ Brain Injury Australia understands that the diagnosis of "mild" ITBI can be problematic. Infants may present with none of the classical features of head injury but instead a constellation of non-specific symptoms suggestive of common early childhood illness – irritability, vomiting, poor appetite, lethargy etc. **"The fact that 60% of children present to hospital with symptoms that would be consistent with many childhood illnesses seen in this age group suggests that [ITBI] may never be considered in many cases."**⁹⁵ And "unless there are other signs to alert one to the possibility that there is underlying intracranial abnormality, such as facial or other bruising, then this presentation is likely to ascribed to another disorder, such as a viral illness, gastroenteritis etc."⁹⁶

7. iii. detection bias⁹⁷

While a substantial heritage of research has clearly identified population subgroups of children at the greatest risk of abuse – from backgrounds of economic disadvantage, family disruption, parental substance abuse, mental illness - Brain Injury Australia is concerned that, given the challenges to ITBI detection and diagnosis, an education in child abuse might result in medical and other professionals viewing ITBI through a lens of stereotype.⁹⁸

The Denver hospital "missed cases" study, above, found "striking differences...in the race and family composition of infants with missed and recognized injuries. **Infants with recognized [ITBI] were more likely to be minority children or children whose mothers and fathers were not living together...A physician examining a white child from an intact family may be less likely to think about the possibility of child abuse.**"⁹⁹ A study of 659 cases of childhood injury in the United States found that physicians were more likely to have "some suspicion" of abuse for those children who were Hispanic or African-American, whose mothers had no higher education, or whose visit was funded under Medicaid – the government health program for individuals and families on low incomes.¹⁰⁰ A 6-year survey of admissions to hospitals in the South West of England and South Wales of 90 infants with SDH found that suspicion of ITBI was "significantly more likely to be reported" to child protection services if the child's mother was unmarried and her "occupational status was unskilled or partly skilled than if it was professional or managerial."¹⁰¹ Conversely, nearly 1 in 3 of the ITBIs came from backgrounds with "no known social risk factors."¹⁰²

A 2004 report from the Longitudinal Study of Australian Children's found 883 (17.7%) of a sample of 4,976 four year-olds had sustained injuries in the previous 12 months. The injury households were 28% more likely to be public housing and 40% more likely to be in "poor condition". The injured children's primary caregivers "had lower education levels and were less likely to report being married", had "greater experience of medical conditions, including post-natal depression" and "higher BMI [Body Mass Index] scores."¹⁰³

One paediatrician wanted to challenge the “widely held belief that ‘bad’ people shake their babies. Nice people don’t. I suspect most services (including health and child protection) have similar ‘gut’ beliefs. I recall seeing several infants over the years with articulate, professional parents and a clear diagnosis of ITBI where the infant, apparently recovered, has gone home with the parents, who have promised to attend the required follow-up appointments and services, but have done nothing. And there has been no response from the services, or requirement for any action from the parents, who seem to have a remarkable capacity to deny the seriousness of the situation and then have their beliefs confirmed by the lack of statutory action.”¹⁰⁴

Brain Injury Australia believes that this paper makes the case for the inclusion of information about ITBI in all parent education and child abuse prevention programs, as well as continuing medical and other child protection and welfare education. At the same time, Brain Injury Australia would be equally concerned that, under COAG’s Framework, either universal programs may not identify those children most at risk of ITBI or that programs targeting children or families “at risk” might perpetuate stereotypes of abusive parents and skew the suspicions of medical and other professionals involved in child welfare and protection.

7. iv. continuing medical education

“Unfortunately, there remains considerable difficulty for some doctors to accept that children are abused.”¹⁰⁵

It was clear from Brain Injury Australia’s consultations with paediatricians that rates of ITBI detection and diagnosis are at least partly a function of local cultures of “vigilance”¹⁰⁶ in hospitals and the “index of suspicion”¹⁰⁷ of child abuse fostered by medical and other professionals working with children. “I have considered the awareness and manner of working with children in the medical services mainly involved – General Practitioners [GPs], Early Childhood Nurses, the Emergency Department, paediatric wards and outpatient departments. The awareness and focus of all these services has fluctuated hugely over this time and certainly has not steadily improved. The most effective situation has been that where the senior staff have been knowledgeable and proactive in considering the possibility of a diagnosis of inflicted head injury. This consideration is then reflected in the response and awareness at all levels, from reception staff, nursing and medical staff and other “support” people involved with the family.”

All of the paediatricians Brain Injury Australia consulted with advocated for more and better training in child protection, including education in ITBI; for its inclusion in the curricula of universities’ schools of medicine, and for continuing medical education (CME) for clinicians working with children, especially GPs. **One unpublished Australian review of 68 cases of suspected IBTI identified GPs, community nurses and other doctors in general (non-paediatric) hospitals as being most likely to miss or misdiagnose ITBI in children.**¹⁰⁸ “It would be possible - with, for example, the support of the Australian Medical Association - to hold regular training sessions to which doctors from a particular area could be invited to attend. If these sessions are accredited, as counting towards CME (for the purposes of ongoing registration with their State or Territory medical board), the chances of success of such a program are improved. Basic training in [ITBI] could be made compulsory for all doctors prior to their commencement of work with children in non-specialist hospitals...The concerns therefore also need to be addressed at an undergraduate stage, that is, during university. The only way to ensure universal education would be to make it a pre-condition of registration; this would be difficult but not impossible.”¹⁰⁹

Brain Injury Australia knows of two states that offer ITBI training for clinicians and other health professionals. Queensland Health and Brisbane’s Mater Children’s Hospital has just commenced a “Queensland Child Protection Medical Training Project”. Its draft “Project Overview” promises to “develop expertise for doctors involved in child protection matters”, specifically in “AHT” (separately from “physical abuse”). Though the training will begin in Queensland, its developers intend to make it available to clinicians nationwide.¹¹⁰ Paediatricians from South Australia’s Child Protection Services currently offer child abuse training to medical students as well as conducting “regular audit meetings with our Emergency Departments to review all cases referred to child protections services including those situations where a diagnosis was missed. Country GPs and hospitals are still an area where these cases can be misdiagnosed and we are currently undergoing training of senior nursing staff in the country hospitals to improve their recognition of injuries which are potentially inflicted and have developed a clear method of consultation for them.”¹¹¹

Brain Injury Australia has viewed draft NSW Health “Clinical Practice Guidelines” for the “Management of Infants and Children with Acute Head Injury” (including a detailed appendix “Recognition of Abusive Head Trauma (Non-accidental Head Injury)”, which notes; “children with abusive head injury (child abuse) present

to Emergency Departments. Much of this may go unrecognised unless a high index of suspicion is maintained.”¹¹² NSW Health is also developing a “forensic protocol to assist medical staff in assessing children who have been or are suspected of being physically abused or neglected.” It aims to: “standardise the information gathered; create a comprehensive checklist of issues to be covered during medical history taking; and facilitate an accurate and complete recording of history, injuries and other relevant results of the physical examination.”¹¹³ Any child abuse screening protocol can only ever be as accurate as the clinicians using it. Access to both paediatricians specialising in child abuse as well as relevant training are therefore crucial to detection.

Recommendation 4:

Brain Injury Australia recommends that FaHCSIA enjoin the Community and Disability Services Ministers’ Conference, in implementing Strategy 4.4 of the National Framework for Protecting Australia’s Children (the Framework) – “support enhanced national consistency and continuous improvement in child protection services” – to develop and provide professional education and training in child abuse (inclusive of ITBI) through bodies such as The Royal Australian College of General Practitioners, the Paediatrics and Child Health Division of The Royal Australasian College of Physicians, the Australian Medical Association and the Australian Nursing Federation.

7. v. diagnostics

Subdural and retinal haemorrhages in children aged less than 2 years are strongly associated with ITBI. A review of 65 children admitted to The Children’s Hospital at Westmead with ITBI found subdural hematomas in 53 (81.5%) and retinal haemorrhages in 34 (59%).¹¹⁴ The study of 25 children with ITBI admitted to the Royal Children’s Hospital Brisbane, referred to above, found subdural haematomas in 79% of the ITBI group and 35% of the non-inflicted TBI group and retinal haemorrhages in 59% of the ITBI group and 12.5% of the non-inflicted TBI group.¹¹⁵ A review of 38 children admitted to Sydney’s Royal Alexandra Hospital for Children with subdural haematomas found ITBI to be the cause in 55% of cases, accidents in 39% and non-traumatic causes in 6%.¹¹⁶ **A 2009 analysis of 320 studies comparing the clinical indicators for ITBI and non-inflicted TBI - representing 1,655 children – found that retinal haemorrhages were “strongly associated” with ITBI, with a positive predictive value¹¹⁷ of 71%.**¹¹⁸ In cases where abuse is suspected, the (draft) NSW Health “Clinical Practice Guidelines” for the “Management of Infants and Children with Acute Head Injury” “require...ophthalmological examination by a paediatric ophthalmologist, as early as possible...even if retinal exam is carried out in peripheral hospital.”¹¹⁹

Best practice detection of SDH requires computed tomography (CT) scans – x-rays that create cross-sectional pictures of the body – combined with access to magnetic resonance imaging (MRI) – which uses a large magnet and radio waves to generate images of bodily organs and structures. Brain Injury Australia’s consultations returned general agreement that **CT was the “initial investigation of choice”¹²⁰ but MRI was the “gold standard”¹²¹ for more sophisticated investigation of ITBI.** While CT scanners are more widely available (there are currently 889 Medicare-eligible CT scanners in Australia compared to only 124 MRI scanners) MRI produces superior images of soft tissue like the brain. It is able to detect smaller haemorrhages and can provide some indication of their age (as evidence of prior abuse). CT relies on radiation. MRI is more expensive. NSW Health’s draft “Clinical Practice Guidelines” describe the use of CT in children as “relatively safe...Although CT involves larger radiation doses than conventional x-ray, the long term cancer risk is small.”¹²² Because the child must remain still for both procedures, sedation or general anaesthesia is usually required. Both NSW Health’s draft “Clinical Practice Guidelines” for “Tertiary Hospital Investigation by Child Protection Consultant” and draft Queensland “Guidelines for Neuroimaging Investigations in Suspected Abusive Head Trauma” recommend an initial CT followed by MRI between 3 and 5 days after admission for the detection of both smaller haemorrhages and those that may have occurred after the initial CT.

Insofar as these two sets of draft guidelines, above, demonstrate consistency in planning for best practice in the **brain imaging of child abuse, local practices remain *ad hoc***; “there is a lack of experience and expertise in this area, a lack of a cohesive approach and a lack of standardised guidelines.”¹²³ A survey of Queensland “Child Protection Advisers” offered the following scenarios. In the first, “a well infant with normal examination...presents with a history of being allegedly shaken”. Where both MRI and CT were available there were “divided responses” on which should be used. In the absence of MRI “most would do CT”, one respondent would have ordered a CT only if child was aged 12 months, two would not have conducted any radiological investigation. In the second, “a child under 2 years of age...presents with an injury such as a suspicious burn or fracture with an otherwise normal examination and normal skeletal survey.” Where MRI was available, some would have sought a scan, some not. Where MRI wasn’t available “most said nil investigations”.

The range of responses, particularly to the second scenario, gives additional clues to the size of the “iceberg”. A survey of all admissions over 4 years to the Children’s Hospital of Philadelphia of children aged less than 2 with injuries suspicious for child abuse found that more than 1 in every 3 classified as “high-risk” – with rib fractures, multiple fractures, or aged less than 6 months were - had “occult” (hidden) head injuries despite displaying no clinical signs of same. Conducting a skeletal survey alone - a series of x-rays of all the bones in the body, including the skull – failed to detect head injuries in 1 in every 4 children, including scalp swelling (74%), skull fracture (74%), and intracranial injury (53%).¹²⁴ The authors lament that: “despite the universal recommendation of screening abused children less than 2 years of age with a skeletal survey for occult fractures, no comparable guidelines exist for detecting occult head injury in the same population... Based on our results, we would recommend screening with CT or MRI all children under 6 months of age with any evidence of physical maltreatment, and children under 1 year of age with high-risk injuries, including rib fractures, multiple fractures, and facial injury.”¹²⁵ However, the American College of Radiology’s 2005 “Appropriateness Criteria” for imaging “Suspected Physical Abuse” - where the child is “2 years or less” with “no focal signs or symptoms” – rates CT at 2 on a scale from 1 (for “least appropriate”) to 9 (“most appropriate”) – and MRI at 5, but “for evidentiary purposes only”, should the case end up in court.¹²⁶

There is good, though anecdotal, evidence that the same potential for missing occult head injury and ITBI exists locally. “I think that it is clinically likely that we miss cases of inflicted head injury especially in peripheral settings where there is less access to imaging and perhaps a lower index of suspicion. A recent case highlights the fact that a young baby may not demonstrate much in the way of clinical signs and yet on MRI scan demonstrate considerable evidence of acute brain injury. The clinical significance of which may not emerge till as late as school age.”¹²⁷ Brain Injury Australia is disappointed that the relevant professional bodies, such as The Royal Australian and New Zealand College of Radiologists, seem content to leave the challenge of ITBI detection and diagnosis to “individual jurisdictions and hospitals” because they “will usually have standardised protocols to investigate clinical symptoms that might be related to child abuse.”¹²⁸ Of perhaps greater concern is that the College considers the American College of Radiology’s “Appropriateness Criteria” “overly ‘aggressive’...when an alternative approach based on careful clinical examination and multidisciplinary consultation as to the most effective imaging to be carried out for an individual patient may be more useful.”¹²⁹

Brain Injury Australia cannot demand an MRI (or CT) scanner for every public hospital even though “there is no doubt...that a greater availability of MRI would make clinicians more willing to routinely investigate [ITBI.]”¹³⁰ And while Brain Injury Australia accepts that the Australia Government’s current review of funding arrangements for diagnostic imaging “will not focus on issues around the requesting of and demand for diagnostic imaging services”,¹³¹ the findings of an independent report commissioned by the review are revealing. International comparisons of the availability of CT scanners “would place Australia well on top of the list of OECD [Organization for Economic Cooperation and Development] countries” but **similar comparisons for MRI placed Australia 20 out of 24, behind Turkey and the Slovak Republic.**¹³²

Between 2000 and 2006, Medicare spending for imaging services more than doubled, to about \$14 billion per year. Brain Injury Australia cannot advocate mandatory brain imaging for every child with symptoms suggestive of ITBI. It would bankrupt government: “during flu season many young infants can present looking glassy-eyed and vomiting. While part of the problem may be lack of recognition due to inadequate professional education, the bigger part of the problem is poor clinical tools.”¹³³ While access to the necessary technology remains patchy and the risks associated with brain imaging in young children – of radiation, of sedation – remains insuperable, trials in the United States using biomarkers in serum¹³⁴ and cerebrospinal fluid¹³⁵ as a screening tool for TBI in children look promising.¹³⁶ In the meantime, Brain Injury Australia recommends that government policy relating to the detection and diagnosis of ITBI go back to taws, informed by the Framework’s commitment to abuse *prevention*. Along with an education and training in child abuse generally, and ITBI specifically, the medical and other professionals involved with child welfare and protection

are given the greatest possible access to the technologies that will detect abuse (and prevent re-abuse) as well as the guidelines necessary to ensure their best practice use.

Recommendation 5:

Best practice radiology is key to the diagnosis of ITBI. Brain Injury Australia recommends that FaHCSIA, in implementing Outcome 4.4 of the Framework - “support enhanced national consistency and continuous improvement in child protection services” – to direct production of national standards of practice for radiology relating to the detection of child abuse. Brain Injury Australia also recommends that FaHCSIA, through DOHA, include the development of such national standards in the latter’s Diagnostic Imaging Quality Program.

8. the “iceberg”?

“I would agree...that it would be at least a third, if not more, of all children who have been abused, or presented to the hospital when abuse has occurred, are missed. We are only seeing the tip of the iceberg and the serious end of the spectrum of abuse. A similar analysis of “missed cases” conducted in Australia would yield at least similar results.... In my 30 years of practice there has been an explosion in the number of children who have significant developmental problems. My partner is a school teacher and reports a similar impression. One has to question why this is occurring and some of it, I suspect, is due to a greater exposure of children to abusive head trauma.”¹³⁷

As early as 1972, the then lead proponent of ITBI speculated that cases detected and diagnosed in hospital may constitute a small fraction of the abuse occurring in the community: “habitual, prolonged, casual whiplash shakings may produce an insidious progressive clinical picture...which is often inapparent to both parents and physicians. It usually first becomes evident at school age when minor cerebral motor defects are first detected along with mild mental retardation...The actual number of such cases is incalculable from current evidence but it appears to be substantial.”¹³⁸ The obverse question to how many potential ITBIs do not result in hospitalisation or are “missed” while there is; what are the long-term consequences for those children?

For some the consequences involve repeat abuse, sometimes resulting in death. A review of 55 head injury deaths in children younger than 2 years in New York City identified 46 homicides, 10 of which “had no contact injury (impact) at autopsy (i.e. no...skull fracture, cerebral contusion/ laceration, or scalp or facial injury).”¹³⁹ Three of those 10 children “were dead on arrival and had acute and chronic subdural haematomas at autopsy. These acute (and chronic) bleeds were small, without mass effect, which confirms that there were at least 2 traumatic events, with the more recent causing the fatal neurologic injury.”¹⁴⁰ Brain imaging of victim-survivors of ITBI show similar results: a Texas study comparing 40 children - 20 with ITBI, 20 with non-inflicted TBI – found “evidence of preexisting brain injury” only in the ITBI group. More than 2 in every 5 demonstrated the softening or loss of brain tissue consistent with previous injury. None of the 40 had a history of previous head trauma.¹⁴¹ The review of 65 cases of ITBI admitted The Children’s Hospital at Westmead, referred to above, found haematomas in 16 suggestive of previous head trauma.¹⁴²

The important questions surrounding evidence of repeated ITBI are manifold. Firstly, none of studies referred to above recorded whether the earlier injuries received medical attention and, if so, whether ITBI was detected. **Brain Injury Australia is convinced that the key to the prevention of re-abuse is, alongside ready access to imaging technologies, national protocols for the medical assessment of child abuse combined with the education and training necessary for their implementation.** Secondly, the severity of re-abuses can increase quickly. A qualitative study of 3 ITBI deaths in Iowa found the fatal re-abuse occurred within 1 day, 12 days and 6 weeks of a “missed diagnosis” of “milder forms of abusive trauma.”¹⁴³ An Australian paediatrician noted: “less severe head injury may present quite non-specifically with vomiting, lethargy, irritability, seizures etc...If they are not carefully examined including checking eyes for retinal haemorrhages these cases can be and are still relatively frequently missed by medical staff (I can recall a few from last year). It is often discovered when they come back with more serious injury that there has been a previous presentation in this manner.”¹⁴⁴ Thirdly, if it is accepted “that significant symptoms will occur at the time of head injury, but these can improve very rapidly, and the baby may have non-specific symptoms (or, indeed, no symptoms at all) when they subsequently present to medical attention”¹⁴⁵, then it is not only feasible but likely that some children sustain ITBI without ever coming to medical attention.

Brain Injury Australia understands the challenges in the diagnosis of a single ITBI. The diagnosis of *earlier* injuries is perhaps beyond the reach of medical science. And while the strong association between

intracranial bleeding and shaking abuse remains - especially in very young children, and in the absence of both external signs of impact injury and a compatible explanation - there is uncertainty about what, if anything, subdural haematomas (of different apparent ages) may suggest of previous abuse. Moreover, just as there is no established linear relationship between the force of shaking and the severity of subsequent brain injury, neither is it clear whether all intracranial bleeding results in *brain* injury. "The difficulty is in knowing whether there was an associated brain injury or not, particularly if they did not have imaging with MRI, if they were misdiagnosed, or not brought to the attention of a doctor. In our experience it does seem possible that subdural [haematomas] can be caused with minimal symptoms evident to the carer and presumably without brain injury."¹⁴⁶

Given all these uncertainties, just as hospitals can never certifiably account for their number of "missed cases", the size of the ITBI "iceberg" can only be imagined. Mass screening of young children for occult ITBI would be costly, justifiably resisted by parents, and probably futile: "we see a number of babies where parents admit to shaking but unless symptomatic our yield from scanning and eye reviews and skeletal surveys is very low."¹⁴⁷ The lead author of the international survey of parental discipline (referred to above) hypothesises that ITBI "**inflicted by shaking, may be an occult but leading cause of infant mortality and mental retardation in the developing world...Apparently, many shaken children escape detection and perhaps even significant health consequences. It is unknown whether shaking of these young infants in a more mild fashion can be linked to the development of mental retardation, learning difficulties, or behavioral problems. Mental retardation and behavioral problems have been shown for children whose TBI does come to medical attention.**"¹⁴⁸ Furthermore, "we have data showing very high rates of shaking of young children for discipline in India, Egypt, the Philippines, Brazil, and Bangladesh. In these countries there are also reports of high rates of mental retardation among the poor without explanation."¹⁴⁹

Brain Injury Australia notes the recent results of the first national report of the Australian Early Development Index (AEDI). Of the 261,203 five year-olds surveyed (97.5 per cent of the estimated five-year-old population): 21,800 were found to be "developmentally vulnerable"¹⁵⁰, 34,300 "developmentally at risk,¹⁵¹ in the "language and cognitive (school-based) domain"; 21,700 "vulnerable" and 37,900 "at risk" in the "emotional maturity" domain; 23,200 "vulnerable" and 37,300 "at risk" in the "social competence" domain; and 22,600 "vulnerable" and 38,800 "at risk" in the "communications skills and general knowledge" domain. 11,486 (4.4%) of children were reported to have "chronic physical, intellectual and medical needs". The results of a 2006 "Strengths and Difficulties Questionnaire" conducted with New South Wales and Victorian children aged between 4 and 12 years, found 9% of New South Wales and 8.6% of Victorian children had "conduct problems", 10.6% and 7.8% respectively had "emotional problems" and 1.2% and 1.8% had difficulties with "prosocial behaviour."¹⁵²

Brain Injury Australia acknowledges that an "**established association exists between attention deficit hyperactivity disorder (ADHD) and head injury...**Studies have suggested both that injury is more common in children with ADHD and that moderate to severe traumatic brain injury in school age children results in the development of ADHD."¹⁵³ **ADHD is reported to occur in 20% to 50% of children following brain injury.**¹⁵⁴ **In 1998, 355,600 Australian children and adolescents (11.2% of those aged between 4 and 17) were estimated to have ADHD.**¹⁵⁵ Brain Injury Australia welcomes the draft guidelines on ADHD recently prepared by The Royal Australasian College of Physicians, specifically that "a thorough medical history and examination are required to identify any acquired brain injury or other neurological condition that may contribute to the presenting symptoms."¹⁵⁶

Some sudden unexpected deaths in infancy (SUDI – inclusive of Sudden Infant Death Syndrome, SIDS) may form part of the ITBI "iceberg." A 1991 study examined the deaths of nine infants "who had been previously the subject of hospital inquiry regarding possible abuse. All deaths had been initially ascribed to Sudden Infant Death Syndrome (SIDS), but autopsy findings in six suggested death was not accidental and in the other three significant doubt was raised by the history. The investigators conclude that 'inappropriate death recording procedures may result in some sudden deaths being recorded as SIDS when in fact they are caused by child abuse.' In addition, a number of children reportedly the victims of accidental falls or other misfortunes may also have been the victims of intentional injury."¹⁵⁷ Brain Injury Australia has no reason to believe that, over the last 20 years, health professionals' awareness of, and ability to identify, child abuse would not have risen markedly.

And the same would be true of coronial practices. In 2007, at the request of Victoria's Office of the Child Safety Commissioner, "the National Coroners Information System (NCIS) was searched for the terms 'shaken baby' and 'infant and shake' for the 0-2 years of age cohort over the period 2000-2007. **The results identified 11 deaths nationally where the cause of death was confirmed to have been as a result of**

shaking...The NCIS report notes the limitations of the dataset and states the figures may be an under-representation of relevant deaths.”¹⁵⁸ And in light of the “significant change in the knowledge within the field of forensic paediatrics and forensic pathology surrounding injuries considered to be diagnostic of shaken baby syndrome”, the NCIS now considers “it would not be appropriate to rely on previous forensic determinations made surrounding ‘shaken baby syndrome’ as they are “no longer considered a reliable representation of deaths.”¹⁵⁹

SIDS deaths have undergone recent revision, after this national definition was agreed in 2004: “the sudden and unexpected death of an infant under 1 year of age, with onset of the lethal episode apparently occurring during sleep, that remains unexplained after a thorough investigation including performance of a complete autopsy, and review of the circumstances of death and the clinical history.”¹⁶⁰ When the NCIS applied the new definition to 805 infant deaths between July 2000 and May 2007, “where the medical cause of death was SIDS or unexplained (including terminology such as unascertained or undetermined)”¹⁶¹, 489 retained SIDS as the cause of death and 246 of the remaining 316 deaths were classified as simply “undetermined” or “unascertained”. The report does not indicate how many deaths were reclassified after the new definition was applied. Neither does it explain the marked differences between jurisdictions in apparent rates of infant deaths that are “undetermined” or “unascertained”. Brain Injury Australia notes the following, from NSW Health’s Policy Directive “Death - Management of Sudden Unexpected Death in Infancy [SUDI]”, that; **“a small percentage of SUDIs are the result of non-accidental injury. Thus child protection issues should be borne in mind by health professionals assessing SUDIs.”**¹⁶² Brain Injury Australia understands that a competent and complete autopsy, undertaken ideally by a forensic pathologist with paediatric experience, will correctly identify ITBI.

9. rehabilitation and follow-up

Baby “A” was born prematurely as a result of a “domestic violence incident” involving his parents. The year before his two older siblings - aged 3 and 5 - were placed in out-of-home care after the parents left them unsupervised to pursue their “joint alcohol misuse” and “gambling problems” and the house caught fire. At 4 months “A” was admitted to hospital with acute (and chronic) subdural haemorrhages, retinal haemorrhages and seizures. While the parents were unable to offer any explanation for “A”’s injuries, clinicians judged they were the result of ITBI. “A” was discharged from hospital with a comprehensive rehabilitation plan and placed in foster care – a “responsibility of the Minister” [for community services]. “A” has “global developmental delay”¹⁶³, is blind and unable to eat. He was described by a foster carer as “no trouble, he just lies there” and was often left in a beanbag in front of the television. Neither of “A”’s parents have applied for access visits. One of his doctors said “A”’s parents took him home after he was born “against our better judgment”.

This paper is not the place to catalogue systemic failures in Australian child protection (official reports on them are legion) except to note the following. Firstly, the age group at the greatest risk of ITBI is at also at the greatest risk of any abuse and abuse death – children aged less than 1 year. Secondly, child protection agencies are overloaded. The majority (53%) of notifications to child protection services are not investigated. At the same time, the majority (82%) of those that are investigated are not substantiated. Thirdly, Brain Injury Australia understands that child protection agencies are regular punching bags for pundits seeking to lay blame for the ills of society. Fourthly, while no one will ever be able to establish whether – even in the presence of an array of “risk factors” – “A”’s abuses could have been prevented, Brain Injury Australia is bewildered that only a minority of jurisdictions are able to accept notifications in regards to an *unborn* child.¹⁶⁴ Aside from the range of “abuses” to which a child may be exposed before birth, an approach to child protection that is serious about abuse prevention needs to address all the potential for abuses in the first days, weeks, months of a child’s life.

Brain Injury Australia’s real interests lie elsewhere. Given the very young ages at which ITBI ordinarily occurs, given the severity of injury *and* disability occurring at a crucial stage of child development, access to appropriate rehabilitation services is vital. That “A”’s rehabilitation plan was not pursued for many months after his discharge, and opportunities for functional improvement lost - until his foster care placement changed - is partly explained by his falling into the gap between health and community services. The lack of interagency coordination in child protection has been well documented, most notably by NSW’s Special Commission of Inquiry into Child Protection Services. It recommended “legislation governing each human services and justice agency should be amended by the insertion of a provision obliging that agency to take reasonable steps to coordinate with other agencies any necessary decision making or delivery of services to

children, young persons and families, in order to appropriately and effectively meet the protection and care needs of children and young persons.”¹⁶⁵

The majority of victim-survivors of ITBI are placed in Out of Home Care¹⁶⁶ (OOHC). Half of the victim-survivors of ITBI in the Westmead survey and almost a third of those from Brisbane’s Royal Children’s Hospital were in foster care at follow-up.¹⁶⁷ Both the number and rate of children in OOHC have more than doubled since 1997.¹⁶⁸ Even with the abuse *prevention* overhaul of child protection policy promised by COAG’s Framework, pressures on foster care places will remain; of both cost (in New South Wales, projected to rise from \$589 million to \$900 million over the next three years¹⁶⁹) and carer numbers. Brain Injury Australia is worried that the very high levels of skill and dedication required to care for victim-survivors of ITBI, like “A”, will be in even shorter supply.

Brain Injury Australia is concerned at some responses received from paediatric rehabilitation services; that “didn’t see” victims of ITBI, either because they were thought to be “too severely injured” or “too young” for rehabilitation. In the latter case, it was argued that the child’s disability would not manifest until “later”. Brain Injury Australia considers such views not only represent lost opportunities for a child to exercise their right to the fullest recovery, but they are also uninformed by the research evidence. For example, in the Scottish cohort, above, the ITBI-related behavioral problems present in over half of the victim-survivors were clinically obvious as early as their second or third year. **Brain Injury Australia feels strongly that every paediatric rehabilitation service should have clearly defined, evidence-based, “pathways” – especially for very young children with brain injury.** Such as those developed by Sydney Children’s Hospital’s Brain Injury Rehabilitation Program: “multidisciplinary clinic reviews will be completed at 4, 8, 12 and 18 months and 2, 2 ½, 3, 4, 5 and 6 years of age. Specialist support and advice will be provided by our Doctor, Physiotherapist, Occupational Therapist, Speech Pathologist, Clinical Psychologist and Social Worker. Results of our assessments will ensure timely provision of guidance and referrals to appropriate intervention services in the child’s community.”¹⁷⁰

Most of the children’s hospitals contacted by Brain Injury Australia prepared comprehensive care plans for follow-up and rehabilitation of victim-survivors of ITBI at discharge. But such planning was often both complicated by the availability of qualified foster care within reasonable proximity of specialist rehabilitation services and frustrated by short-term foster placements. The following reflections were typical: “many times the plan for the long-term follow up of these children is not able to be done because community services change foster carers, we are not informed and the new carers are not told of appointments. If the child is restored to the family often there is a reluctance to attend the hospital again...My secretary spends many hours talking to community services chasing up children and getting them to relevant appointments. A lot of children are lost to follow-up and may well be struggling in the education system with inappropriate diagnostic labels and management.”¹⁷¹

Local and international evidence on staff turnover in statutory child protection agencies put the churn rate at between 15% and 30% per year, double the rate of the rest of the labour force and much higher than that of other professions. Many of the paediatricians singled out **caseworker change in community services and non-government organisations involved in OOHC as the greatest impediment to continuity of care for victim-survivors of ITBI.** The New South Wales government’s response to the findings of “Special Commission of Inquiry into Child Protection Services” – a five-year “action plan” called “Keep Them Safe” – aims to correct this by appointing “out-of-home care coordinators” within both the Department of Education and Training and each Area Health Service of NSW Health to “ensure that children in out of home care are given priority access to health services wherever possible” and provide “better co-ordination of health services for them.”¹⁷²

Brain Injury Australia welcomes the Australian Government’s commitment to developing “national standards” for OOHC as a “key part” of the Framework. The January 2010 “Consultation Paper” included, as two of the “factors in OOHC that may form the basis of standards...stability of placements and relationships” and “regular health and well-being checks.”¹⁷³

In the advance of whatever “national standards” might emerge from the consultations, **Brain Injury Australia endorses the approach recommended by The Royal Australasian College of Physicians, namely that “all children entering care...have a comprehensive assessment within 30 days of placement.”** It would comprise: “a general health assessment including a health history of the child and family, physical examination, growth assessment, vision, hearing and dental screening, and an immunisation register check; a “developmental assessment incorporating standardised screening tools”; and “mental health screening using accessible and validated tools.” The College’s policy recommends that the checks be conducted at “a specialised clinic, by an individual Paediatrician, a General Practitioner, or Nurse Practitioners or by Aboriginal Health workers...depending on local resources.” **The child’s first assessment will result in “an individual health management plan”, including a “follow-up health review to occur within three months of assessment and subsequently at least on an annual basis.”**¹⁷⁴

R e c o m m e n d a t i o n 6 :

The majority of victim-survivors of inflicted traumatic brain injury are placed in Out Of Home Care. Brain Injury Australia recommends the “National Standards in Out of Home Care” being prepared by FaHCSIA should include regular and ongoing comprehensive assessments conducted only by medical and other professionals with relevant qualifications in child health and development.

10. prevention

A neighbour, Ms Kelly Campbell, said that she had visited the offender... At that time the offender complained about ML crying, saying, "He just doesn't fucking stop crying. He just doesn't fucking shut up." In addition, Ms Campbell observed the offender pick ML up, putting her hands under his arms, and violently shaking him shouting out, "I should buy you a fucking skirt". Ms Campbell described the offender as being, "very, very angry" when she shook ML. By way of replication, she demonstrated a corkscrew motion with the offender holding the baby in front of her, about 20cms from her face, and screaming at him, while shaking him very violently. She said she could not count the number of shakes, because, "it was happening so fast". Ms Campbell also said that the offender, "was on methylamphetamine at the time and that Mr G had injected her." On examination on his admission ML had extensive bruising consistent with injuries having been inflicted on him over a period of time. He had bruising to the face, the scalp, the trunk, arms, legs and his groin area. He had a fractured skull. He had fractures of the ribs, a collapsed right lung, and widespread hypoxic encephalopathy (brain damage in the nature of a stroke). He also suffered haemorrhages behind both eyes and retinal detachment in the left eye.¹⁷⁵

Stakeholders contacted by Brain Injury Australia disagreed about what ITBI prevention strategies would work. Some felt specific programs addressing ITBI in infants the result of shaking were called for. Others thought a combination of universal supports for families with secondary interventions targeting those “at risk” may help to prevent abuse generally, inclusive of ITBI. Two distinct ITBIs seemed to emerge from the consultations. The first: “a significant amount of inflicted traumatic brain injury is not necessarily deliberately inflicted, that is; premeditated. A lot of it occurs in the heat of the moment, in the middle of the night.”¹⁷⁶ And in response to the prolonged, often inconsolable bouts of crying common in infancy.

One dominant line in ITBI prevention argues that such crying “is the only child-specific variable consistently identified as important in the cycle of escalation to shaking.”¹⁷⁷ A United States study found the timing of 273 hospitalisations for ITBI from shaking followed the “curve” of such crying, increasing in the first month after birth, peaking between 10 and 13 weeks, and then decreasing to “baseline by about 36 weeks of age.”¹⁷⁸ The National Center on Shaken Baby Syndrome then developed a parent education program called “PURPLE Crying”¹⁷⁹ which “suggests 3 guidelines when caring for a crying infant. First, parents are encouraged to use typical calming responses (carry, comfort, walk and talk) with their infants. Second, if the crying is too frustrating, it is okay to put the baby down in a safe place, walk away, calm yourself and then return to check on the baby. Third, never shake a baby.”

The program has been adapted and implemented in a variety of settings in Australia. Trials of the program in the United States and Canada found mothers who received the PURPLE Crying materials scored higher than the comparison groups on knowledge about infant crying and on sharing information with other caregivers about walking away from a crying infant if frustrated. Mothers in the United States trial who received the PURPLE Crying materials scored higher on knowledge of the dangers of shaking an infant than the comparison group. The self-report of “walking away during inconsolable crying was significantly higher” in mothers in the Canadian trial who received the PURPLE Crying materials than in the comparison group.¹⁸⁰ Results of a study in North Carolina of the statewide use of PURPLE Crying measured against ITBI hospitalisations will be available later this year.¹⁸¹

In another program of SBS prevention, nurses in the maternity services of 16 hospitals in New York state distributed written and video materials that “discussed the dangers of violent infant shaking (but not striking, slamming, or other mechanisms of abuse) and suggested ways to handle persistent infant crying.” During the first 5 years of the program 65,205 parents signed “Commitment Statements...affirming their receipt and understanding of the materials”. This represented 69% of the 94,409 children born in the region during that time. 96% of the mothers signed Commitment Statements and 76% of fathers/father figures. **The incidence of “abusive head injuries” decreased by 47% during the program - from 41.5 to 22.2 cases per 100,000 live births - while rates in neighbouring Pennsylvania remained unchanged.** “We chose a hospital-based, primary prevention program targeting parents of newborn infants for several reasons. First, parents are the most common perpetrators of abusive infant head injuries. Second, the period of greatest risk is during the months after the infant’s birth. Third, childbirth is a time of almost universal contact between parents and the medical community. Fourth, educated parents might be advocates in disseminating this information to others. Finally, research on adult learning suggests that adults learn best when practical and contextually significant information is provided to help them cope with specific life-changing events, such as marriage, a new job, or the birth of a child.”¹⁸² The “Dias Model” (referring to the program’s originator) of ITBI prevention is being trialled throughout Pennsylvania and is used by several hospitals in Australia. **18 of the United States have passed laws mandating that shaken baby syndrome prevention information be made available through their hospitals.**

“...The parents of the infant victim (a female baby aged 4 months) were engaged in a domestic dispute. As the dispute unfolded, the infant was being held by the father and crying audibly. The infant’s father then threw her in a ‘rugby pass’ fashion across the room, in the direction of the mother. The child struck the ground, whereupon according to the mother’s statement she stopped breathing and began foaming at the mouth. An ambulance was immediately called. Upon arrival, paramedics found the infant to be unconscious. She was transported to hospital... Subsequent examinations revealed diffuse cerebral oedema, acute and chronic subdural bleeding and bilateral retinal haemorrhages. The infant’s father later admitted to the events as outlined by the mother, although he contended that he had ‘dropped’ rather than thrown her. He was subsequently convicted of grievous bodily harm assault.”¹⁸³

The second “type” of ITBI is one of an array of, often escalating, abuses. **A study of 52 cases of ITBI in infants investigated by the Queensland Police Service found “victims were shaken, thrown, punched, head-butted, and attacked with objects such as lumps of wood.”**¹⁸⁴ The backgrounds to such abuse commonly involve domestic violence, parental alcohol and drug abuse and mental health problems. Most of the paediatricians Brain Injury Australia consulted with thought that, even if ITBI was “preventable” in such circumstances, it demanded a different order of response from universal parent education: “prevention involves the recognition of adversity in families, assessing its level of activity, supporting those who are managing the adversity themselves and actively intervening in those families where the adversity is active. This will prevent harm, perhaps prevent inflicted head injury or other physical assaults in infants and older children. I don’t believe that programs targeted towards particular types of physical assault are, or will be, effective unless the underlying active adversity is recognized and therapeutic intervention occurs.”¹⁸⁵

Brain Injury Australia applauds the shift in government thinking demonstrated in the Framework, towards a “public health model”¹⁸⁶ for child protection. It also expects that “inverting the pyramid”¹⁸⁷ to make universal supports and intensive secondary interventions for at-risk families - rather than statutory child protection responses - the base for abuse prevention will be matched by a corresponding shift in spending. **In 2007-2008, governments spent approximately \$1.897 billion on services to remedy the impacts of abuse, but only \$1.16 billion on its prevention.**¹⁸⁸ Parent education and home visits are the most widely used child abuse prevention programs in Australia. A recent review into their effectiveness found parent education that combined “parent skills training, cognitive retraining, child development information, and concrete services, were generally more effective than programs that had a more narrow focus. Programs that focused exclusively on improving parental content knowledge were not as effective as programs that offered a combination of interventions.”¹⁸⁹ Home visiting programs targeted at “families that were 'at risk' of child maltreatment and/or were most socio-economically disadvantaged, were more likely to have positive results than those that targeted a universal population. Programs that targeted an 'at risk' population showed some positive results in improving parenting skills and reducing incidents of child maltreatment.”¹⁹⁰

A recent World Health Organisation “systematic review of reviews” of 298 studies in the child abuse prevention literature found some evidence of “small and medium effect sizes” for parent education in direct measures of the reduction child abuse. “The only home visiting programme whose effectiveness has been unambiguously demonstrated”¹⁹¹ is the Nurse Family Partnership program in the United States. A randomised controlled trial conducted in New York state showed a 48% reduction in the incidence of child abuse at a 15-year follow-up. The program now operates in 28 states with 20,000 families enrolled. An additional US\$2.25 billion in expansion funding is embedded in the health care reform bill recently passed by Congress. Brain Injury Australia congratulates the Australian Government for making Australia only the second country to receive approval from program’s originator to run it outside of the United States, with 1,900 Indigenous families across 10 sites. During 2008-2009 Indigenous children were 7.5 times as likely to the subject of substantiations of child abuse and neglect as non-Indigenous children.¹⁹²

R e c o m m e n d a t i o n 7 :

Brain Injury Australia recommends that FaHCSIA propose to the Community and Disability Services Ministers’ Conference, in its implementation of Strategy 2.4 of the Framework – to “enhance services and supports for children and families to target the most vulnerable and protect children ‘at risk’” – that both intensive (secondary) prevention and early intervention services receive dedicated education and training in child abuse and neglect inclusive of ITBI.

Brain Injury Australia is unaware of a local home visiting program claiming success specifically in the reduction of incidence of ITBI. Brain Injury Australia has examined evaluations of parent education programs in New South Wales and Queensland. The Shaken Baby Prevention Project, based at The Children’s Hospital at Westmead, interviewed 51 of 116 parents and carers who viewed a 3-minute animated DVD, “Shaking Your Baby is Just Not the Deal”. Participants reported increased knowledge of “key learning messages” relating to understanding of infant crying as well as knowledge of the adverse effects of shaking. They also reported increased use of “alternative management strategies” for infant crying.¹⁹³ Ipswich’s Project Safehands was a “social marketing and education campaign to raise awareness of physical abuse of children in the 0 to 4 years age group and the resources available in terms of harm minimization, prevention strategies and reporting”. One of the Project’s performance indicators was a reduction in “the number of victims of homicide and assault, aged between 0 and 4 years, for the 6-month period in 2007 during which the project was introduced into the Ipswich Police District.” “Police advised” that there were “no instances of homicide and assault” during the period of the Project.¹⁹⁴ Western Australia’s “Babies Break if you Shake Them” media and social marketing campaign was developed in response to 2 ITBI deaths and 8 serious injuries in the first 6 months of 2001. Between July 2003 and September 2004, 2,757 babies had “participated” in the program. An (unpublished) analysis found “the incidence of SBS in Western Australia between 2001 and 2006 was overall 10.9 per 100,000 infants under the age of 1 year. There was a decrease in incidence the year after the launch of the campaign from 12.4 to 4.1...However this trend was unsustainable and may indicate requirement for alternative education methods.”¹⁹⁵ One of developers of the campaign noted it was “cheap. **When one considers that the cost over the life of a child injured by being shaken or severely traumatised runs into millions of dollars; the prevention of one such child’s fate is worth the entire cost of the prevention campaign.**”

R e c o m m e n d a t i o n 8 :

Brain Injury Australia recommends that FaHCSIA urge the Community and Disability Services Ministers' Conference, in implementing Strategy 1.2 of the Framework – “educate and engage the community about child abuse and neglect and strategies for protecting children” – to fund a universally available, evidence-based, child abuse and neglect prevention campaign inclusive of information relating to ITBI.

In keeping with the “public health model” of child protection, **Brain Injury Australia advocates a strategy for ITBI prevention that combines universal parent education with early intervention and targeted services for “at-risk” families.** This derives from a range of considerations. Firstly, child protection policies that prefer universal services over targeted interventions may fail to capture chronic abuse environments like those described above. Conversely, policies that focus on targeted interventions at the expense of universal services run the risk of playing into stereotypes of abusive families, and missing cases of ITBI in those deemed “low risk”. Secondly, there is evidence to suggest that many American parents “have never heard about the dangers of shaking an infant.”¹⁹⁶ Without the survey evidence, nobody knows how many Australian parents don't know either. “In some cases of abuse, the perpetrators admitted to shaking the infant violently but confessed that they were unaware of the dangers of doing so.”¹⁹⁷ **Brain Injury Australia believes that information about the dangers of shaking a child should be incorporated into all parent education programs, but as part of a larger curriculum relating to child abuse and neglect.** Brain Injury Australia is also concerned that a focus on “babies” overlooks the potential for abuse of older children.

One paediatrician feared that education about SBS would “get ‘lost’ in a general program...SBS is probably different because (1) it is the only form of child abuse for which there is a positive feedback for the abuse (i.e. if you shake hard enough, you get a mild concussion and the crying stops, whereas if you punch the baby, the crying increases) and (2) [the data is only suggestive and not good on this] that it is likely that SBS is not as ‘enmeshed’ in difficult-to-change risk factors (like single parents, depressed, etc.) as other forms of child abuse. Bottom line; in this respect, SBS may be “more” preventable than other forms of child abuse.”¹⁹⁸ In whatever way ITBI were to be included, Brain Injury Australia notes there is no set curriculum for parent education programs in Australia. “It is very much up to the establishment (hospital, community-based education programs, and people who run private classes).”¹⁹⁹

R e c o m m e n d a t i o n 9 :

Brain Injury Australia believes that *parent* education should be no different from any other – nationally consistent. Brain Injury Australia recommends that FaHCSIA propose to the Community and Disability Services Ministers' Conference, in its implementation of Outcome 1.2 of the National Framework – “educate and engage the community about child abuse and neglect and strategies for protecting children” – that a nationally consistent curriculum for parent education be developed and implemented, inclusive of information about child abuse and neglect.

Thirdly, a number of correspondents suggested that parent education programs are likely to appeal to those people who would need them the least: “the ‘Never Shake a Baby’ campaign is well recalled by people, but likely by those people who would never be violent to an infant.”²⁰⁰ The programs can also be expensive. Course costs at Sydney's St. George, Sutherland, Royal North Shore, Nepean, Westmead, Blacktown, Campbelltown, Camden, Liverpool Hospitals and The Royal Hospital for Women ranged between \$40 and \$270. Given governments' interests in “mutual obligation” arrangements, Brain Injury Australia suggests the Australian Government tie payment of the “baby bonus” to Australian Government-subsidised attendance of *both* first-time parents at such programs.

Fourthly, Brain Injury Australia is concerned at the apparent lack of engagement of fathers/ male partners in ante-natal programs – and perhaps *vice versa* – since they constitute the majority of perpetrators of severe ITBI; in more than 2 out of every 3 of the Westmead cases referred to above.²⁰¹ This may be crucial in the case of unrelated male partners (1 in 3 perpetrators of the Westmead cases). A study comparing the abuse deaths of 149 children with deaths from natural causes found children living in households with adults unrelated to them 50 times as likely to die of inflicted injuries than children living with their 2 biological parents.²⁰² One social worker noted “fathers are generally left out of the model of care because they are not the ‘patient’, are not given the psychosocial screening and are therefore not referred for any intervention.”²⁰³

ENDNOTES:

- ¹ R v Klamo [2008], Supreme Court of Victoria Court of Appeal: "The applicant said that he had shaken the baby some days earlier. He at first said he thought this was about a week before, but later said it could have been two weeks."
- ² "...For those children aged 1 year old death is 6 times more likely; and for those children aged 2 to 4 years old death is 4 times more likely." Trends in the fatal assault of children in NSW: 1996-2005, NSW Child Death Review Team, p.3. Cf. "The rate of homicide among infants aged less than 1 year is higher than rates among older children and adults", "Child homicide in New South Wales from 1991 to 2005", Olav B Nielsens et al., Medical Journal of Australia, 2009,190, p.7
- ³ "The morbidity from shaken baby syndrome is serious: 12–30% of victims die, and 60–70% of the survivors suffer from significant neurological handicap.", "Investigating subdural haemorrhage in infants", A M Kemp, Archives of Disease in Childhood, 2002;86, p.99
- ⁴ When a child does not reach developmental milestones at the expected times: an ongoing major or minor delay in the process of development. Delay can occur in one or many areas—for example, gross or fine motor, language, social, or thinking skills.
- ⁵ "Infantile Subdural Haematoma and its Relationship to Whiplash Injuries", A. N. Guthkelch, British Medical Journal , 1971, 2, p. 430-431
- ⁶ "The Whiplash Shaken Infant Syndrome: Manual Shaking by the Extremities With Whiplash-Induced Intracranial and Intraocular Bleedings, Linked With Residual Permanent Brain Damage and Mental Retardation", John Caffey, Pediatrics, Vol. 54 No. 4, October 1974, pp. 396-403
- ⁷ "Subdural Hematomas in Children Under 2 Years. Accidental or Inflicted? A 10-Year Experience" Dimitra Tzioumi The Royal Alexandra Hospital for Children, Westmead, Australia, R. Kim Oates, The University of Sydney and The Royal Alexandra Hospital for Children, Westmead, Australia, Child Abuse and Neglect, vol. 22, no. 11, pp. 1106
- ⁸ www.dontshake.org
- ⁹ "Inflicted Traumatic Brain Injury: Advances in Evaluation and Collaborative Diagnosis", Jill C. Glick, Kelley Staley, Pediatric Neurosurgery, 2007, 43, p.437
- ¹⁰ "Abusive Head Trauma in Infants and Children", Cindy W. Christian, Robert Block and the Committee on Child Abuse and Neglect, American Academy of Pediatrics, Pediatrics, Volume 123, Number 5, May 2009, p.1410
- ¹¹ "The Next Innocence Project: Shaken Baby Syndrome And The Criminal Courts", Deborah Tuerkheimer, Washington University Law Review, Volume 87, Number 1 2009, p.31
- ¹² ibid., p.32
- ¹³ The rates of prosecution and conviction are much lower in Australia. One study showed that charges were laid in 40% of cases and the majority of those charged were convicted. (Stephens, A "‘Truth’ and Uncertainty, Law and Science: The Legal Outcomes in Suspected ‘Shaken Baby Syndrome’ Cases" Paper presented at the 8th ISPCAN Asia Pacific Regional Conference on Child Abuse and Neglect, 2009.) "This is compared with 72% prosecuted and 89% - or 64% of the original 75 cases - resulting in convictions in a large USA study (Keenan, H. T., Nocera, M., and Runyan, D. K., 2008", Personal communication e-mail with Dr. Amanda Stephens.
- ¹⁴ "Review Of Infant Death Cases: Addendum To Report Shaken Baby Syndrome", Lord Goldsmith, Her Majesty's Attorney General ,14 February 2006
- ¹⁵ "Interval Duration Between Injury and Severe Symptoms in Nonaccidental Head Trauma in Infants and Young Children", M.G.F. Gilliland, Journal of Forensic Science, 723, 1998 and " In Reply to Letter to Editor, Initial Neurologic Presentation in Young Children Sustaining Inflicted and Unintentional Fatal Head Injuries", Kristy B. Arbogast et al., Pediatrics 1608 (2005). Cited in Tuerkheimer, op.cit., p.18
- ¹⁶ Tuerkheimer, op.cit., p.27
- ¹⁷ Participation restrictions are "problems an individual may experience in involvement in life situations" such as attending school or participating in recreation. (Australian Bureau of Statistics' 2003 Survey of Disability, Ageing and Carers)
- ¹⁸ Brain Injury Australia considers the Australian Bureau of Statistics' 2003 Survey of Disability, Ageing and Carers significantly underestimates the real number of Australians with an ABI. The survey's sample comprised "14,000 private dwellings and 300 non-private dwelling units", covering "people in both urban and rural areas in all states and territories, except for those living in remote and sparsely settled parts of Australia. The exclusion of these people will have only a minor impact on any aggregate estimates that are produced for individual states and territories, with the exception of the Northern Territory where they account for over 20% of the population." Estimates of the prevalence of ABI in Indigenous communities generally, and in the Northern Territory specifically (where Indigenous Australians comprise 30% of the population) indicate rates up to three times that of non-Indigenous communities. The survey had no capture of the criminal justice system or the homeless where estimates of the prevalence of ABI range between 40%-80% and 10%-30% respectively. The survey's results were "based, wherever possible, on the personal response given by the respondent. However, in cases where information was provided by another person, some answers may differ from those the selected person would have provided." Brain Injury Australia considers that, given the circumstances in which many ABIs occur – especially in the young, disclosure of the nature and level of impairment, let alone ABI itself, to a government-appointed surveyor may be difficult. The survey recognises this: "A number of people may not have reported certain conditions because of: the sensitive nature of the condition...[and] a lack of awareness of the presence of the condition on the part of the person reporting..." Also, "The need for help may have been underestimated, as some people may not have admitted needing help because of such things as a desire to remain independent..." Given the multiplicity and complexity of disability that many people with an ABI experience, cited above, the following statements of survey are also noteworthy: "as certain conditions may not have been reported, data collected from the survey may have underestimated the

number of people with one or more disabilities” and “as certain conditions may not have been reported, data collected from the survey may have underestimated the number of people with one or more disabilities.” Brain Injury Australia is grateful that the July, 2008 Community and Disability Services Ministers’ Conference agreed to inject \$6.5 million to enhance the next iteration of ABS Survey of Disability, Ageing and Carers, including doubling the sample size, due for release in 2010.

¹⁹ Australian Institute of Health and Welfare (AIHW), Children with disabilities in Australia, Canberra, 2004, Bulletin 55 and Disability Updates: Children with Disabilities (Bulletin no.42), Australian Institute of Health and Welfare, Canberra, 2006.

²⁰ “The Challenges of Assessing the Incidence of Inflicted Traumatic Brain Injury: A World Perspective”, Desmond Runyan, American Journal of Preventative Medicine, 2008, 34, p.114/115.

²¹ National Association for the Prevention of Child Abuse and Neglect (NAPCAN), “childprotect” discussion group (Australian Institute of Family Studies), National Association of Childhood Educators (NACE), membership of the Child Protection Special Interest Group of the Royal Australasian College of Physicians etc.

²² “Age-Related Mortality and Injury Characteristics of Abusive Head Trauma in Children: Implications for Prevention Programs”, Makoroff K et al., “Inflicted Traumatic Brain Injury (ITBI) in Children >1yr of Age: An Emerging Concern”, Rachel Berger et al., “Findings in Older Children With Abusive Head: Injury: Does Shaken-Child Syndrome Exist?” Hani Salehi-Had et al. Papers delivered to the 137th APHA Annual Meeting, November 7-11, 2009

²³ Author correspondence with Dr. Patrick Kelly, Paediatrician, Starship Childrens Hospital, Auckland New Zealand

²⁴ Brain Injury Australia is grateful to Dean Biron for providing his unpublished manuscript “Syndrome Terminology in Child Abuse: The Example of Shaken Baby Syndrome”

²⁵ Personal communication e-mail with Dr. Sue Packer.

²⁶ Personal communication e-mail with Dr. Amanda Stephens.

²⁷ American Academy Of Pediatrics, Committee on Child Abuse and Neglect, Shaken Baby Syndrome: Rotational Cranial Injuries—Technical Report “...Physical abuse is the leading cause of serious head injury in infants. Although physical abuse in the past has been a diagnosis of exclusion, data regarding the nature and frequency of head trauma consistently support the need for a presumption of child abuse when a child younger than 1 year has suffered an intracranial injury.”, p. 206

²⁸ Personal communication e-mail.

²⁹ “We use the term inflicted head injury to indicate that the injury has not been found to have been caused by the child under their own steam (i.e. self-inflicted) Infants who are not independently mobile are not capable of self inflicting serious injuries however once they can move even slightly if they are placed in a precarious position if on a kitchen counter they can fall off and sustain a head injury this would not be an inflicted head injury but there would certainly be concerns about neglect etc. The Police and Statutory agency investigation will determine who is responsible and therefore whether it is an abusive injury. For example a bruise to a baby’s head with no explanation from the parents would be considered inflicted if at a later date it is determined that a 3year old sibling dropped a heavy toy on the baby this would still be an *inflicted* injury but not an *abusive* one.” Italics added. Personal communication e-mail.

³⁰ “Head injury...is a non-specific and antiquated term, which includes clinically evident external injuries to the face, scalp, and calvarium, such as lacerations, contusions, abrasions, and fractures, and may or may not be associated with TBI. TBI injury is more properly defined as an alteration in brain function manifest as confusion, altered level of consciousness, seizure, coma, or focal sensory or motor neurologic deficit resulting from blunt or penetrating force to the head.”, Bruns J and Hauser A, “The epidemiology of traumatic brain injury: a review”, Epilepsia, 44:10, 2003, p. 2–10.

³¹ Personal communication e-mail.

³² “Abusive Head Trauma: Concepts and Controversies”, Mark S. Dias, Department of Neurosurgery, presentation to the Second International Conference on Abusive Head Trauma, June 25-26, 2009, Jackson Hole, Wyoming

³³ “The publication of small numbers presents challenges firstly because of the risk to confidentiality, and second because of statistical uncertainty. As a general principle, I caution against publishing numbers where the numerator is 3 or less, nor publishing rates where the numerator is less than 10 or the denominator less than 300. Other institutions have similar guidelines, for example ABS avoids publishing numbers where numerators are less than 5, and the [Australian Institute of Health and Welfare] recommends a minimum denominator of 1000.” Personal communication e-mail from Steven Guthridge, Director, Health Gains Planning, Department of Health and Families, Northern Territory

³⁴ Yvonne Helps, Geoff Henley and James Harrison, “Hospital separations due to traumatic brain injury, Australia 2004–05”, Australian Institute of Health and Welfare, 2008, p.6

³⁵ “The utility and challenges of using ICD codes in child maltreatment research: A review of existing literature”, Debbie Scott et al., Child Abuse & Neglect (in press)

³⁶ The Cost of Child Abuse in Australia, Report by Access Economics, Australian Childhood Foundation and Child Abuse Prevention Research Australia at Monash University, November 2008, p.v

³⁷ “...Principal Diagnosis is the condition considered to most completely explain the episode in hospital, these cases can be regarded, with some confidence, as being ones where hospitalisation has occurred because of TBI.” Helps, Henley and Harrison, op.cit., p.9.

³⁸ “TBI cases in which an injury other than TBI was recorded as the Principal Diagnosis. Injury was the main explanation for these episodes of in-hospital care, and TBI was recorded as being present. TBI alone might not account for the admission, although an injury to the head was the Principal Diagnosis for a little over half of these cases.” Ibid., p. 58.

³⁹ Ex Australian Institute of Health and Welfare: “Separation is the process by which an episode of care for an admitted patient ceases.” One patient may be “separated” more than once in a given year. Inter-hospital transfers (for the one patient) will include more than one separation.

- ⁴⁰ The ICD-10 codings for assault include - alongside “injuries inflicted by another person with intent to injure or kill, by any means”, “assault by bodily force”, “assault by unspecified means” including “homicide (attempt)”, “manslaughter (nonaccidental)” and murder “(attempt)”⁴⁰ and “other maltreatment syndromes”, including “physical abuse” and “torture”. “Australian hospital statistics 2007–08”, Australian Institute of Health and Welfare, Canberra, 2009
- ⁴¹ Picture of Australia’s Children, Australian Institute of Health and Welfare, Canberra, 2009, p.105.
- ⁴² Admissions for “NAI” – ‘non-accidental [brain] injury.’ Brain Injury Australia is grateful to Professor Danny Cass, Patricia Manglick Research Officer/Data Manager, Dept. of Surgery, Centre for Trauma Care. Prevention, Education, and Research (CTCPR), Children’s Hospital at Westmead
- ⁴⁴ Sydney Children’s Hospital data may have included a small number of peer-on-peer violence/ ITBI.
- ⁴⁵ “There were many presentations that were allegations of Shaken baby and no medical evidence and I have put these and similarly not confirmed Non Accidental Injury under OTHER.”, Merrin Dimmock, Social Work Coordinator-Child Protection, John Hunter Children’s Hospital
- ⁴⁶ “Nonaccidental Head Injuries In Children: A Sydney Experience”, Ali Ghahreman et al., Neurosurgery (Pediatrics) ,3, 103, 2005, p. 217/18.
- ⁴⁷ “Subdural Hematomas in Children Under 2 Years. Accidental or Inflicted? A 10-Year Experience” Dimitra Tzioumi and R. Kim Oates, Child Abuse and Neglect, vol. 22, no. 11, 1998, p. 1105–1112
- ⁴⁸ “Although deaths from assault are relatively rare among children, fatal outcomes from intentionally inflicted injuries or homicide provide an indication of the nature and extent of extreme interpersonal violence in this age group. Interpersonal violence, including domestic violence and child abuse, is often associated with parental drug and alcohol misuse and mental health problems. Hospitalisation rates for assault capture serious incidents of intentional harm inflicted by other people. This group includes hospitalisations for injuries from domestic violence and child abuse.” “Key national indicators of children’s health, development and wellbeing: indicator framework for A picture of Australia’s children 2009”, Canberra, 2008. Moreover, “some children have brain injury as a result of domestic violence, which is unlikely to be disclosed by the family, and the child may never have their brain injury correctly diagnosed.” Fortune N and Wen X, The Definition, Incidence And Prevalence Of Acquired Brain Injury In Australia, Australian Institute of Health and Welfare, Canberra, 1999.
- ⁴⁹ Personal e-mail communication with Pam Boag, Office of the Child Safety Commissioner
- ⁵⁰ Ibid.
- ⁵¹ “It is important to note that at the point of presentation to hospital, information about the case can be captured in two ways – only one of the coding options is tracked through the injury surveillance system. Therefore, it is likely that the information available significantly under reports the numbers of children presenting with injuries that may have been caused by shaking.” Ibid.
- ⁵² Personal e-mail communication with the Victorian Forensic Paediatric Medical Service, Royal Children’s Hospital.
- ⁵³ “Brisbane North is the health district for the catchment zone of the Royal Children’s Hospital and the Royal Brisbane and Women’s Hospital. It includes suburbs from the north side of the Brisbane river, extending from the bay west to Moggill and north to Redcliffe. In brief, Brisbane generally classes suburbs as ‘north’ and ‘south’ in relation to the river”, Personal e-mail communication with Melissa Faulkner, Senior Research Officer, Child Advocacy Service
- ⁵⁴ “Shaken Baby Syndrome Prevention Campaign in Western Australia: a Collaborative Process”, Associate Professor Peter Winterton, Medical Director Child Protection Unit, Princess Margaret Hospital for Children, November 2009
- ⁵⁵ “Abusive Head Trauma: Incidence in a South-East Queensland Sample”, Melissa Kaltner, Child Advocacy Service Royal Children’s Hospital, Queensland [unpublished], p.2
- ⁵⁶ “The Economic Cost of Spinal Cord Injury and Traumatic Brain Injury in Australia”, Report by Access Economics for The Victorian Neurotrauma Initiative, June 2009, p.34
- ⁵⁷ Personal communication e-mail with Yvonne Zurinski, Australian Paediatric Surveillance Unit, The University of Sydney, The Children’s Hospital at Westmead.
- ⁵⁸ <http://sites.google.com/site/injectcauseicd11/>
- ⁵⁹ Scott et al., op.cit., p. 18
- ⁶⁰ Personal communication e-mail 10/1/09 with Dr. Alison Kemp, Reader in Child Health, Child Health Department, Cardiff
- ⁶¹ “These behaviors included...beating, burning, or kicking a child, or hitting a child with an object somewhere other than the buttocks. Being hit with an object somewhere on the body other than the buttocks accounted for the majority of harsh physical discipline. “Epidemiologic Features of the Physical and Sexual Maltreatment of Children in the Carolinas” Adrea Theodore et al., Pediatrics, 2005,115, p.335
- ⁶² Ibid., p.335
- ⁶³ Ibid., p.336
- ⁶⁴ Ibid., p.331
- ⁶⁵ “The Challenges of Assessing the Incidence of Inflicted Traumatic Brain Injury: A World Perspective” Desmond K. Runyan, American Journal of Preventive Medicine, 2008, 34, p. 113
- ⁶⁶ Ibid., p.113. “We have also heard about high rates of shaking in the Netherlands and in Bangladesh.” Personal communication e-mail with Desmond Runyan, National Program Director, Robert Wood Johnson Foundation Clinical Scholars, Professor of Social Medicine and Pediatrics, The University of North Carolina

⁶⁷ Personal communication e-mail with Desmond Runyan.

⁶⁸ “The major limitation is that parents may not reveal all that they have done. However, experience in five countries suggests that this approach can produce incidence rates as much as 40 times higher than rates calculated from official statistics kept by authorities, even in a country in which reporting laws have long been established.” “ISPCAN Child Abuse Screening Tools Retrospective version (ICAST-R): Delphi study and field testing in seven countries”, Michael Dunne et al. Child Abuse and Neglect, 33, 2009, p.820

⁶⁹ A “child protection notification...consist of reports made to an authorised department by persons or other bodies making allegations of child abuse or neglect, child maltreatment or harm to a child.” Australian Institute of Health and Welfare 2009. Child protection Australia 2007–08, Canberra, p.69

⁷⁰ A “substantiation of a notification...refers to child protection notifications made to relevant authorities...which were investigated and the investigation...and it was concluded that there was reasonable cause to believe that the child had been, was being or was likely to be abused or neglected or otherwise harmed.” Ibid., p. 69

⁷¹ New South Wales Department of Community Services; 4 January, 2010 correspondence. Brain Injury Australia is grateful to Linda Mallett, Divisional Director, Policy and Planning, New South Wales Department of Community Services for the provision of these figures. They are broadly comparable with those provided to the following “Question on Notice” asked in the Legislative Council of New South Wales on 31 May 2007: “How many reports of baby shaking has the Department received for the following periods; (a) 2004/2005?, (b) 2005/2006?, (c) 2006 to present? (4) Of the reports received, how many were investigated by the Department for the following periods: (a) 2004/2005? (b) 2005/2006? (c) 2006 to present? In answer, Department of Community Services responded to 327 “reports of baby shaking” between 2004 and 2006. 284 of the cases “required investigation”. (NSW Legislative Council Questions and Answers No. 6, Thursday 31 May 2007)

⁷² “Shaken Baby Syndrome Prevention Campaign in Western Australia: a Collaborative Process”, Clinical Associate Professor Peter Winterton, Medical Director Child Protection Unit, Princess Margaret Hospital for Children, November 2009

⁷³ Accessed by the author via mediastatements.wa.gov.au

⁷⁴ Foreword Dr Joe Tucci, Australian Childhood Foundation and Professor Chris Goddard, Child Abuse Prevention Research Australia, Monash University, “The cost of child abuse in Australia Report by Access Economics, November 2008 [np]

⁷⁵ Sandeep Jayawant and Jeremy Parr, “Outcome following subdural haemorrhages in infancy”, Archives Disease in Childhood, 2007, 92, p.344

⁷⁶ “Patients were categorized as having a poor outcome if their GOS was 3 or less and a good outcome if 4 or 5 (for statistical analysis)”, Ghahreman et al., op.cit., p. 216

⁷⁷ Dr S. Ashanthi Munasinghe, op.cit., p.27

⁷⁸ “Mechanisms, Clinical Presentations, Injuries, and Outcomes From Inflicted Versus Noninflicted Head Trauma During Infancy: Results of a Prospective Multicentered, Comparative Study”, Kent Hymel et al., Pediatrics, Vol. 114, No. 3 September 2004, pp. 633-639, “A Population-Based Comparison of Clinical and Outcome Characteristics of Young Children With Serious Inflicted and Noninflicted Traumatic Brain Injury”, Heather Keenan et al. ?????

⁷⁹ Personal communication e-mail with Sarah McIntyre, Research Fellow, NSW/ACT CP Register, Cerebral Palsy Institute University of Notre Dame

⁸⁰ Kent Hymel, op.cit., p.925

⁸¹ Babikian et al. Neurocognitive outcomes and recovery after pediatric TBI: Meta-analytic review of the literature.. Neuropsychology, 2009, 23, p. 283

⁸² “Late Neurologic and Cognitive Sequelae of Inflicted Traumatic Brain Injury in Infancy”, Karen M. Barlow et al., Pediatrics 2005, 116, p.183

⁸³ Sandeep Jayawant and Jeremy Parr op.cit., p.345

⁸⁴ The National Conference on Shaken Baby Syndrome: A Medical, Legal, and Prevention Challenge - National Association of Children’s Hospitals and Related Institutions, Executive Summary by Jacy Showers, 1998

⁸⁵ Dias et al., op.cit., p.470/471

⁸⁶ “The economic cost of spinal cord injury and traumatic brain injury in Australia”, Report by Access Economics for The Victorian Neurotrauma Initiative, June 2009, p.78

⁸⁷ Ibid., p.86

⁸⁸ “Levels and Cost of Catastrophic Injuries from Motor Vehicle Accidents in Australia”, PricewaterhouseCoopers, CTP Claims Management Symposium 16 June 2005, p.11

⁸⁹ “The Cost of Child Abuse in Australia” Access Economics, op.cit., p.vi

⁹⁰ “The Importance of Non-Biologic Caretakers as Perpetrators of Abusive Head Trauma in Children > 1 year of Age”, Philip Scribano, Medical Director, Center for Child and Family Advocacy, Nationwide Children’s Hospital, Columbus, Ohio (abstract of paper to be presented at Pediatric Academic Societies Annual Meeting, Vancouver, May 1-4)

⁹¹ Personal communication e-mail with Dr. Rachel Berger, Pediatrics, Nationwide Children’s Hospital, Columbus, Ohio

⁹² “Analysis of Missed Cases of Abusive Head Trauma”, Carole Jenny et al., Journal of the American Medical Association, February 17, 1999, Vol. 282, No. 7, p.621

⁹³ “I don’t know of anyone who has replicated our study.” Personal communication e-mail with Dr. Carole Jenny.

⁹⁴ Personal communication e-mail with Dr. Keiran Moran

- ⁹⁵ "The Role of Health Professionals in Preventing Non- Accidental Head Injury", Alison Kemp and Lisa Coles, Child Abuse Review, Vol. 12, 2003, p. 379.
- ⁹⁶ Ibid.
- ⁹⁷ Sometimes called surveillance bias, this occurs when one group is followed more closely than the other group, leading to a health outcome being diagnosed more often in the more closely followed group, but not because it truly occurred more often in that group.
- ⁹⁸ "Among the risk factors studied, family disruption and separation were the most prominent, affecting 48% of the children. Notably, there was a history of abuse of the child or other family member in 24% of cases. A history of premature birth was present in 16% of cases. A history of mental illness or drug and alcohol abuse was present in 14% of cases. Two patients had twin siblings." Ghahreman et al., op.cit., p.214
- ⁹⁹ "Abusive head trauma was more likely to be unrecognized in very young white children from intact families and in children without respiratory compromise or seizures. In 7 of the children with unrecognized AHT, misinterpretation of radiological studies contributed to the delay in diagnosis. Fifteen children (27.8%) were reinjured after the missed diagnosis." Jenny et al., op.cit., p.625.
- ¹⁰⁰ "Assessment of suspicion of abuse in the primary care setting", E. Flaherty et al., Ambulatory Pediatrics Vol. 2, No. 2, p. 120-126.
- ¹⁰¹ "Factors Affecting Clinical Referral of Young Children With a Subdural Haemorrhage to Child Protection Agencies", Tom Sanders et al., Child Abuse Review, Volume 12, Issue 6, 2003, p. 358 -373
- ¹⁰² Ibid., p.380
- ¹⁰³ "Examining potential risk factors, pathways and processes associated with childhood injury in the Longitudinal Study of Australian Children", Tamara Blakemore, Research and Analysis Branch, Australian Government Department of Families, Community Services and Indigenous Affairs, [undated], p. 38, 47. Peculiarly, even though the study accepts that "the cause of childhood injuries may be 'intentional' or 'unintentional'", it did not appear to seek information about the latter group. Neither did it appear to survey injury to the 5,104 infants in the Longitudinal Study of Australian Children's sample.
- ¹⁰⁴ Personal communication e-mail.
- ¹⁰⁵ "The Evidence Base for Shaken Baby Syndrome: Response to Editorial From 106 doctors", Robert M Reece, Clinical Professor of Paediatrics, British Medical Journal, 2004, 328.
- ¹⁰⁶ "In my view, every hospital needs child protection expertise, in proportion to the size of its paediatric workload. This must be multi-disciplinary (paediatrician, social worker, nurse at least), and work in close collaboration with statutory authorities under agreed protocols.", Personal communication e-mail Dr S. Ashanthi Munasinghe. "A "safety-first" approach requires a careful and vigilant approach. The establishment of such child protection teams within hospitals or healthcare organisations, provides not only a clinical workforce to see cases, but a skilled resource to teach (undergraduates and postgraduates), and to develop safe quality assurance systems (policies, guidelines, audit loops)." Personal communication e-mail with Dr. Patrick Kelly
- ¹⁰⁷ Personal communication e-mail with Dr. Paul Tait.
- ¹⁰⁸ Personal communication e-mail with Dr. Amanda Stephens.
- ¹⁰⁹ Ibid.
- ¹¹⁰ Brain Injury Australia acknowledges the assistance of Keith Rickart, Project Officer Child Protection Medical Training Project with the supply of these materials.
- ¹¹¹ Personal communication e-mail.
- ¹¹² "Clinical Practice Guidelines" for the "Management of Infants and Children with Acute Head Injury", NSW Health. Draft as at September, 2008
- ¹¹³ Personal communication e-mail from Mailin Suchting, A/Associate Director, Primary Health and Community Partnerships Branch, NSW Health
- ¹¹⁴ Ghahreman et al., op.cit.
- ¹¹⁵ "Neurodevelopmental outcome and prognostic indicators in Inflicted Traumatic Brain Injury sustained under the age of 2 years", (unpublished), Dr S. Ashanthi Munasinghe, Royal Children's Hospital, Brisbane.
- ¹¹⁶ "Subdural Hematomas in Children Under 2 Years. Accidental or Inflicted? A 10-Year Experience" Dimitra Tzioumi The Royal Alexandra Hospital for Children, Westmead, Australia, R. Kim Oates, The University of Sydney and The Royal Alexandra Hospital for Children, Westmead, Australia, Child Abuse and Neglect, Vol. 22, No. 11, 1998, pp. 1105–1112.
- ¹¹⁷ The proportion of patients with positive test results who are correctly diagnosed.
- ¹¹⁸ The review also found strong associations between rib fractures, apnoea – cessation of breathing, potentially resulting in hypoxia – and ITBI. The review, oddly, excluded subdural haemorrhage: "it is recognised that subdural haemorrhage can occur in infancy from other causes, and consideration must be given to possible organic disease, such as metabolic disorders (eg. glutaric aciduria), albeit this has characteristic MRI findings. While coagulopathy may cause intracerebral haemorrhage, it may also be secondary to an [ITBI], highlighting the need for thorough investigations in this group. It is recognised that SDH in particular, may occur as a consequence of birth, particularly following instrumental delivery, 48–50 although a neonatal SDH without skull fracture has also been described where the mother was assaulted ante-natally", "Which Clinical Features Distinguish Inflicted from Noninflicted Brain Injury? A Systematic Review" S Maguire et al., Archive of Disease in Childhood, 2009, 94, p.860–867
- ¹¹⁹ "Management Of Infants And Children With Acute Head Injury: Clinical Practice Guidelines - NSW Department of Health" [draft], 2008, p.29.

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- ¹²⁰ “The Forensic Medical Assessment of Head Injury Suspected of having being Inflicted”, Dr. Jane Edwards
- ¹²¹ Personal communication e-mail, Dr Amanda Stephens
- ¹²² Management Of Infants And Children With Acute Head Injury: Clinical Practice Guidelines - NSW Department of Health [draft], p. 17
- ¹²³ “Guidelines for neuroimaging investigations in suspected abusive head trauma (Final draft for consultation)”, Queensland, op.cit., p.1
- ¹²⁴ Occult Head Injury in High-Risk Abused Children David M. Rubin et al. *Pediatrics* 2003;111;1382-1386
- ¹²⁵ Ibid., p. 1384
- ¹²⁶ “ACR Appropriateness Criteria: Clinical Condition: Suspected Physical Abuse — Child”, (1995, “last review date: 2005”), American College of Radiology
- ¹²⁷ Personal communication e-mail.
- ¹²⁸ Personal communication e-mail Lisa Penlington, Manager, Quality & Accreditation, The Royal Australian and New Zealand College of Radiologists.
- ¹²⁹ Ibid.
- ¹³⁰ Personal communication e-mail.
- ¹³¹ Via www.health.gov.au
- ¹³² “Final Report: Funding Arrangements For Diagnostic Imaging Services; An International Literature Review”, Prepared for the Department of Health and Ageing by ACIL Tasman Pty Ltd, 21 January 2010
- ¹³³ Personal communication e-mail with Desmond Runyan.
- ¹³⁴ The clear liquid that separates from blood on clotting.
- ¹³⁵ The fluid contained within the ventricles of the brain and spinal cord to protect both from shock.
- ¹³⁶ “We have identified several novel biomarkers, which are either increased or decreased after mild pediatric ITBI compared with controls. The results support our hypothesis that there are differences in the serum concentrations of nonbrain specific biomarkers in children with ITBI compared with those without brain injury...A prospective validation using a larger patient population is essential to allow for potentially exciting classification analyses using a greater number of both brainspecific and nonbrain specific biomarkers.” Multiplex Assessment of Serum Biomarker Concentrations in Well-Appearing Children With Inflicted Traumatic Brain Injury”, Rachel P. Berger et al., *Pediatric Research*, Vol. 65, No. 1, 2009, p.101
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