Education as Rehabilitation After Acquired Brain Injury in Children and Young People

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Education as Rehabilitation

“The child’s return to school is not the end point of rehabilitation. Rather school is an extension of the rehabilitation process begun in the hospital...” (Larkin, 1992)

“Ultimately, schools end up being the largest provider of services to children with brain injuries.” (Savage, 1988; Ylvisaker, 1991)
ABI: potentially a lifelong condition

“Both clinical experience and research literature document residual deficits in a range of cognitive and behavioural domains, including academic achievement, attention, memory and executive function. In addition, recent investigations suggest that injury to the immature brain may also affect psychological and social development, and that problems in these domains may persist or increase as the child matures. Together, these deficits affect a child’s ability to function effectively at home, in school and in their social environment, resulting in impaired acquisition of knowledge, psychological and social problems, and overall reduced quality of life.”

Wilde et al. 2015
First session

■ What challenges are faced by young people with ABI on their return to education and then as they progress through future years?
■ Why are these difficulties often missed or misunderstood?
■ How does age at injury affect potential difficulties within education?
■ Are these difficulties different for those with ABI resulting from different causes and are they affected by gender?

Second session

■ Practical ideas/suggestions for meeting the educational needs of students with ABI
■ Discussion/questions
Some problems which may result from acquired brain injury

- Impaired attention/concentration
- Poor memory
- Slowed information processing and visuo-motor skills
- Language and communication deficits
- Perceptual problems and hypersensitivity
- High levels of fatigue
- Impaired executive skills
- Impaired interpersonal skills
- Inappropriate behaviour
Often relatively good recovery of physical ability and superficial conversational speech
(no ‘badge of disability’)

But
However

- Some weaknesses (and strengths) may not be apparent until later in development – ‘the sleeper effect’
- These children do make progress but the learning process is frequently effortful and inefficient.
- The demands of the education system (and social expectations) rely increasingly on characteristic areas of impairment and on progressive acquisition of knowledge and skills.
- So progress is often slow and the gap does often widen, particularly academically.
ABI and school achievement

Graph showing normal progress and progress after brain injury.
Studies also show that:

Skills that are developing or yet to be learnt at the time of the injury are most vulnerable to the effects of ABI (Goldstrohm et al, 2005; Anderson et al, 2010)

Cognitive abilities that children rely on to learn new information may be compromised.
ABI commonly provokes diffuse damage, causing a range of complex difficulties in unusual combinations, which can provoke unique profiles of learning and behaviour.

Crucially, it is the **processes for learning** which may be impaired and educators sometimes focus on the consequences while not understanding or acknowledging the disruption to the underlying brain functions affecting learning abilities and potential.
Teaching methodologies

Despite, providing very young children with a range of experiences and opportunities for exploration, as a result of their usual developmental capabilities, they are taught many skills and supervised:

• Explicitly
• Directly
We begin to teach (directly and by example):

- Academic skills
- Social skills
- Behavioural skills and boundaries

Once children begin to develop the ‘building blocks’, this accelerates their learning

e.g. they learn to read
    then read to learn
    then learn to learn (metacognition)
As children mature there is an increasing expectation for:

- Greater independence
- Increased self management and awareness
- Extraction of principles from exemplar situations
- Recognising parallels between a new problem and an old, solved problem
- Indirect and experiential learning
- Forward planning
But if ..

Young learners may:

- Not have established the ‘building blocks’ of basic skills

- Have impaired ability to take on new learning in conventional ways

- Struggle to progress from direct, explicit forms of instruction

The impact of ABI on development and learning will be accumulative.
Problems can be misinterpreted because ...

- Each individual areas of difficulty may be shared with other students and are not unique to ABI.
- Their physical and sensory difficulties may present in the same way as those of other children.
- Their learning, cognitive and language difficulties may appear the same or similar to many others at any one point in time.
- Their underlying difficulties can often be missed or misunderstood.
Potential for misinterpretation through assessment

Formal assessment may compensate for:

- Deficits in new learning
- Attention deficits
- Decreased endurance and persistence
- Poor task orientation and impaired flexibility
- Lack of initiation and spontaneous problem solving
- Weakness in speed and efficiency of information processing
You cannot accurately assess the educational needs of a young person with ABI if you just know about ABI and not child development.

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You need to understand both or to be part of an interdisciplinary team.
Education systems can be inflexible

- There can be a focus on conformity to expected norms
- But, as the needs of this group of students are different, they often do not fit within usual models of provision

These young people can be *square pegs in round holes*
Age at injury

As we know, young peoples’ brains continue to develop well into their third decade of life.

Their developmental stage and their previous bank of skills and knowledge is very important as a factor affecting the sequelae of a brain injury.

We must be aware of this developmental process.
Brain development
The implications of an acquired brain injury during different ages/developmental stages

With a focus on two major peaks of development, which also correspond with an increased risk of ABI:

- Early years
- Adolescence
Early years

Major time of accelerated development, not only physically but in key areas:

- Cognitive
- Social/behavioural
- Language/communication
Children under 3 years are at double the risk of sustaining a TBI compared with any other group through childhood (Anderson et al, 2012) and are at a heightened risk for some illnesses (e.g. meningitis).

Young children’s brains are particularly vulnerable, e.g. because of their immature network of neural connections.

However, for many years there were limited studies focussing on children injured at pre-school age (they include Tonks et al, 2009, Koskiniemi et al, 1995 & Eslinger et al, 1992).
Overall indications from those studies..

Were that children sustaining severe and diffuse ABI at a young age (particularly with pre-frontal involvement) subsequently showed permanent:

- Reduction in intellectual ability

- Behavioural problems, including hyperactivity, conduct problems and poor self-control

- Social problems, including isolation and poor theory of mind
Some more recent research, e.g. 10 year follow-up study (Anderson et al, 2012)

- Children injured between 2 & 7 years

- Initial follow-up studies showed protracted period of disrupted development post-injury (up to 3 years)

- 10 year follow-up showed opportunity for progression - not catch up but potential developmental gains.

- This supports the premise of effectiveness of intervention throughout development,

- as does...
Neuro-cognitive ‘stall’

(Chapman, 2007)
The development and establishment of all emerging skills at this time will be susceptible to the effects of ABI.

When the ‘mechanics’ of basic literacy skills are well established they are often resistant to the effects of ABI but children injured before these skills are established often face significant difficulties obtaining these.

Basic numeracy may also be affected, but sometimes less so as the acquisition of concepts and learning in Maths is established over a longer period.
Adolescence

The second highest risk group for ABI.

Although injury at this stage can affect developing skills, it is also a time when increased or evolving problems may become manifest following injuries sustained earlier.

As this is usually a time of accelerated development of the frontal and pre-frontal cortex, if this does not proceed normally, as a result of a current or previous injury, many apparently ‘new’ problems may emerge. The frontal lobes are extremely vulnerable to injury because of their location (McAllister, 2011)
Frontal lobes

The level of development of this area of the brain is exclusive to our species.

(Human evolution has been termed “the age of the frontal lobes”)

The frontal area is ‘the gatekeeper’ – strategic problem solving, personality control, planning and sequencing, expressive language, response inhibition etc.
Although older adolescents may show intellectual ability on a par with adults, there is often a lack of synchronicity between this and development of other brain systems: a gap between reason and emotion. (Steinberg, 2008)

**Adolescents may show adult reasoning but -**

Heightened need for short-term rewards compared with longer-term gains

Lowered capacity to avoid responses to immediate influences, e.g. from peers

= risky decision making

“Starting the engines without a skilled driver behind the wheel” (Dahl, 2001)

Injury at this age may impair this future skill development.
An additional comment:

In much of the UK, the age of criminal responsibility determined in law is 10 years old. Children over this age are expected to be able to take responsibility for their actions and to exercise self control.

The areas of the brain required for this are not fully developed until well over 20 years (e.g. Sowell et al, 1999)
Most reported problems in adolescence are with behaviour, particularly relating to social skills (Burke et al, 1990)

Other often reported difficulties are with planning and problem solving (Anderson et al, 2009)
As teenagers with ABI may often present with problems regulating their behaviour; impulsivity; poor social judgement; and decreased awareness of their own emotional state, they show a relatively high risk for offending behaviour. (Hughes et al, 2015)

Studies show an increased risk of offending and increased severity of crimes (with co-morbidity as risk taking individuals are more likely to sustain further injuries)
Different types of ABI

Every child and every injury is unique.

There is little documented evidence regarding different, characteristic presentations, but

- Those with conditions such as tumours (abscesses, cysts) that have undergone surgical resection may show predictable issues relating to that intervention. They may also be undergoing continuing treatment with consequential effects
- Some of the young people with whom I have worked with the most significant levels of cognitive and behavioural difficulties that have been the most difficult to address have been those with anoxic injuries
- Others with complex needs have been those who are presenting post-encephalitis
Gender issues

There is current interest in the effects of ABI in women and girls but most research conducted on males and very little comparing the two, particularly in children and young people.

• Some current research, particularly in Canada (Canadian Institutes of Health Research C.I.H.R.)

• There is evidence that females with TBI report more headaches/dizziness (e.g. Colantonio et al, 2010)

• There is evidence that in sports with similar rules, females sustain more concussions than males (e.g. Lincoln et al, 2012)
• There is evidence that a history of TBI puts females at greater risk of abuse (Harris et al, 2012)

• There is speculation that physiological factors (e.g. physical size/strength, hormones) may affect severity of/recovery from injury (e.g. Stein, 2001)

• There are reports from female survivors that healthcare providers may trivialise rehabilitation goals - e.g. regaining ability to walk in high heels (C.I.H.R.)
There are various theories, e.g. relating to:

- Hormonal levels at time of injury
- Neck-strength to head-size ratios

With lack of a sound evidence base to date there is also some controversy:

- Are females more likely to report symptoms? Research by Gioia et al showed that adolescent girls report more symptoms than boys but not younger children.
Some of my thoughts:

• Are there differences post-injury with same/similar symptoms because of differing expectations/stereotypical gender role perceptions etc?

• Do girls receive different treatment/rehabilitation?

• Do girls suffer more problems of psychological distress as a result of symptoms?

• As brain injury can affect future physical development and hormonal balance, what are the longer-term effects for females?

• Issues relating to size/strength and hormones will not be influential at time of injury for pre-pubescents
There is clearly a need for further research in this area.
Comments? Questions?
Educational interventions

There is a limited number of studies to provide evidence regarding educational interventions and there have been many recent calls for more of these. There are a few studies exploring some basic principles or learning (e.g. Glang et al, 1992; Ylvisaker et al, 2007; Braga et al, 2005)

However, it is often not possible to provide a standardised approach suitable for all and, therefore, for RCT studies. The measurement of outcomes for large groups of children based on set interventions can be problematic.

It is possible to set individual goals and to measure progress towards these when using interventions that have proved useful to others.
There are lists of teaching strategies in

Educating Children and Young People with Acquired Brain Injury. Walker & Wicks, 2018

Also in Effective Learning After Acquired Brain Injury – a practical guide to support adults with neurological conditions. Lowings & Wicks, 2016

Although the latter relates to adults, many of the strategies are still appropriate and also this publication includes freely downloadable resources
There are many free resources available in a new document recently produced by the International Paediatric Brain Injury Society (IPBIS). This is available at https://ipbis.org/toolbox.html

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The impact of ABI on development and learning is accumulative.

Regardless of the student’s overall cognitive ability and awareness of potential academic potential/targets, teachers may need to:

- Continue direct/explicit teaching (coaching) beyond the stage where it may be widely used
- Continue higher than usual levels of structure/routine
- Continue to provide information in smaller amounts (chunking)
- Consider use of errorless learning techniques (caution re. experiential learning or experimentation)
Think not so much about what the student can do but the ways in which s/he can achieve

and

The types of teaching and support necessary for him/her to achieve to potential

(It is sometimes necessary to utilise teaching methodology from an earlier phase, combined with later, age appropriate content)

It is also important to set goals with the child and with awareness of his or her world.
In order not to perpetuate the misinterpretations, educational assessments must:

- Include both formal (standardised) and functional aspects
- Involve information from all relevant sources
- Carefully consider strengths and weaknesses (including task analyses)
- Be considered with reference to known effects of ABI
Be considered in relation to the age at injury and with reference to normal development

Be considered in light of the place and time of the assessment, the preceding events etc.

Be considered with awareness of the demands of the specific test

Not be considered in respect of long term prognosis or recommendations, but be regularly reviewed
Accurate assessment and task analysis is vital in order to understand the issues and ensure accurate intervention.

Never make assumptions!
Literacy

Conventionally, reading skills are often taught by phonics-based methods. Young people need many skills for this, including:

• To be able to recognise and remember sounds made by individual and groups of letters
• To be able to identify and recall sequences of letters and sounds
• To be able to remember all the irregular words that do not follow phonic ‘rules’

Some young people post-ABI will never be able to demonstrate those skills efficiently. They may need direct teaching:

• Of a social sight and key word vocabulary
• Probably with repetition, rehearsal and errorless learning techniques
Literacy

Some young people with ABI may present with an acquired (as distinguished from a developmental) dyslexia – there are many forms of this.

NB Word recognition does not equate with reading comprehension. Beware of some reading tests.

Fluent reading can also be affected by many other issues, such as
• information processing impairments (when audio books or text to speech software may be helpful)
• Visuo-perceptual problems (when adapted text layout is indicated)
• Attention problems (when cuing, reduced expectations or ‘chunking’ may be indicated)
Numeracy

Basic computational ability does not equate with mathematical proficiency beyond a basic level.

Young people with ABI may not, for instance, be able to apply skills to a word-based problems because
• They cannot apply skills learnt in one context to another
• They cannot process the language
• Their general problem solving ability is not adequate for the task.

As with literacy, it is important to consider functionality for the individual (not what the curriculum dictates).

Once again, practice and rehearsal are vital.
Strategies used with others

Within the repertoire of strategies that can be used to benefit students with ABI, some can selectively be taken from those used with students with other conditions, e.g.

- SpLD
- ASD
- ADHD
- etc.
Some specific resources:

Understanding and awareness

Resources designed to help young people cope with changes in their lives and based on a life story principle (initially designed for young people during fostering/adoption) can be useful.

e.g.
• My Life and Me (Camis, 2001)
• Life Story Work: Why, What, How and When (Ryan & Walker, 2016)
• Digital Life Story Work (Hammond & Cooper, 2013)
Social skills

There are many social skills training packages available. With students with ABI, it is very important to adapt these to assist the young person to practise and rehearse generalising these skills and knowing when and how to use them. Useful tools could be:

- Video Interactive Guidance (VIG) (Kennedy et al, 2011). BUT only if the young person/people are comfortable with any changes to physical appearance, speech production or behaviour
- Promoting Alternative Thinking Strategies (PATHS) (Greenberg & Kusche, 1998)
- Circle of Friends (Pearpoint et al, 1996)
- Circle of Adults (Wilson & Newton, 2006)
- Nurture Groups (Boxall, 2002. Sanders, 2007)
Behaviour

A number of strategies used with young people with autism spectrum disorders can be usefully adapted for those with ABI, such as

Applied behaviour analysis (ABA)

(And one resource specifically for children with ABI - My Best Friend Buddy (Spibey, Talbot & Wicks, 2015. Child Brain Injury Trust)
Appropriate education for students with ABI should promote:

- Maximum cognitive development
- Maximum academic achievement
- Development of a positive self-image
- Assistance towards the development of strategies to maximise future potential (social, behavioural, interpersonal, employment)

NB the use and development of compensatory strategies is a key message for teachers
School provision

Must promote executive development but with realistic, evidence based expectations and safeguards.

“children with TBI have a very special need for an executive system focus in their rehabilitation and special education due to the vulnerability of their frontal lobes.

all therapists and teachers can and should help the children to understand how easy or difficult various tasks are for them, to plan how to accomplish the job, to pay attention to how well they are doing, and to think of clever ways to succeed if they are having a difficult time.” (Ylvisaker et al, 1998)
Must provide appropriate opportunities to model and practice appropriate behavioural and social skills in functional (‘real-life’) contexts

“it is critical to highlight social development and behavioural regulation in rehabilitation and special education programs for children with early TBI.” (Ylvisaker et al, 1998)
Must promote theory of mind and sense of identity but with understanding of the child’s brain injury and adaptations to usual programmes (e.g. in ‘emotional literacy’).

Must promote language skills, particularly specific expressive language as appropriate communication (rather than inappropriate behaviour)
Must recognise and allow for impairments (for instance, in attention; memory; planning and reasoning; or information processing) in the acquisition of new learning.

Must recognise potential difficulties with the generalisation and application of that learning.

Must acknowledge that these children will become ‘overloaded’ at times and need a quiet place without sensory stimuli and the need to process information.

Must allow for a slowed rate of progress to enable the child’s potential to be fulfilled.
But

If these young people have appropriate educational provision and support outside of school (for them and their families), both the literature and personal experience show that, despite frequently very poor presentations, initially with bleak prognoses, there may be the potential for these young people to show real improvements in presentation and quality of life later within the developmental process.
My recent recommendations for a parliamentary group considering ABI

Despite ‘pockets’ of excellent practice and generally much more awareness of the issues – particularly among ABI researchers and practitioners

There are still, reports of too many young people and their families encountering exactly the same problems as they did when I began work in this field over 30 years ago!
The problems haven’t changed but the potential solutions have because:

■ The health and education systems (in the UK) have changed significantly and regional differences are also pronounced
■ Teachers’ roles and responsibilities have changed
■ The student population in mainstream classrooms has changed
■ Technology and the ways in which training and professional development is delivered have changed
Suggested solutions

Pathways from hospital back in to education and, crucially, throughout education to support as many students with moderate/severe ABI as possible

- These are being introduced and evaluated in specific areas in the UK (evaluation should be standardised)
- They are currently reliant on interest by professionals within these areas
A ‘red flag’ system for those with mild injuries with a review protocol so they can be monitored.

- If no issues arise, this will be time limited
- If concerns are raised, this will continue or the student can be placed on a pathway

A checklist for all schools/colleges regarding sports’ concussions.
Web-based training and interventions for educators to complement the pathway, to support those working with students who slip through the pathway net and to support those working with students with mTBI and sports concussions.

Different ‘levels’ and content:

- Overviews of the brain and the effects of injuries (for as many educators as possible)
- More in-depth information (for a smaller number)
- Easily accessible practical suggestions for interventions
- Interactive element to ‘tailor’ to specific students
How should advice/training for educators be devised?

- Only by those with knowledge of the education system and the role of a teacher!
- It must be feasible and practical within any setting
- Whenever possible, it must utilise teachers’ own knowledge and experience and draw on useful strategies from other groups
- It must be respectful of teachers’ expertise
- It must be seen to be effective
Key individuals within regions to provide face to face support/advice when required to support those with complex needs but without the benefit of a pathway or for those who have long-standing unmet needs

This presents challenges:

- How can this be rolled out nationally?
- Who employs them?
- How do we ensure that teachers/educational facilities know when they need them?
In summary

- ‘Low key’ monitoring within education for all children and young people with ABI
- ‘Pathways’ for students with moderate/severe ABI and others who later present with difficulties
- Web-based awareness raising and training for educators (with interactive element)
- If possible, key individuals with expertise within regions who can be involved for support/advice
- Checklist and pathway for sports concussion
The parliamentary group report can be found at:

https://www.ukabif.org.uk/campaigns/appg-report/
Thank you

And questions?